FUNCTIONAL OUTCOMES OF A FEEDING INTERVENTION PROGRAMME FOR INFANTS AND YOUNG CHILDREN WITH CEREBRAL PALSY

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DECLARATION

I, Diana Margaret Novotný, declare that this thesis embodies only my original work except where acknowledgement indicates otherwise and that no part of it has been or is being submitted for a degree at any other university.

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CONTENTS

APPENDICES:

LIST OF FIGURES & TABLES

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EXECUTIVE SUMMARY

This study was conducted at the Cerebral Palsy (CP) Clinic, Red Cross Hospital, Cape Town between May and September 2004. The sample population was a group of mothers/ caregivers and their infants and young children, who presented with evolving or severe cerebral palsy, persistent feeding difficulties and other multiple disabilities. The research was in the domain of treatment outcome, against a background of lack of evidence regarding the effectiveness of intervention programmes for children with CP, and, in particular, for very young dependent feeders with neurologically-based feeding disorders.

The study incorporated three distinct but complementary parts, namely: (1) identification of the fundamental issues that needed to be addressed in an effective feeding intervention programme for this population of children; (2) evaluation of the functional outcomes of a feeding intervention programme, based on the Neurodevelopmental therapy (NDT) approach and currently employed at the CP Clinic, Red Cross Hospital; and (3) determination of the acceptability and sustainability of the feeding intervention programme for the participating mothers /caregivers.

The research design was in three parts. Non-formal, descriptive methods were used in Parts 1 & 3. Part 2 employed a quasi-experimental before-after intervention study design with no random allocation of the intervention i.e. all participants received the intervention and the participants were their own controls. Convenience sampling was employed with minimal restriction on eligibility of participants. Over the 5 month period, 35 of the new patients who presented at the clinic were eligible for inclusion, consented to participation in the study and formed the sample for Part 1. Time restraints for completion of all post-intervention assessments for Part 2 of the study, within the determined cut-off date for data collection, resulted in the sample size for Parts 2 and 3 being restricted to 25. More than 50% of the sample children were Xhosa males between 1-3 years with a diagnosis of Spastic Quadriplegia. Dystonia was the other type of cerebral palsy represented. Major associated problems were microcephaly, seizures, cortical visual impairment, drooling, constipation and failure to thrive.

The Scale of Feeding Competence in Cerebral Palsy, developed by the researcher, was used in Parts 1 & 2 of the study, during observations of typical feeding sessions. Areas assessed included nutritive sucking, spoon feeding, cup drinking and chewing in children, and feeding competence in their mothers /caregivers. Data yielded by the scale were ordinal ratings of severity, and frequency of occurrence of 40 specific limiting behaviours recorded in the sample children, and of 10 inappropriate feeding practices observed in the mothers /caregivers.

Following a pre-intervention assessment of a feeding session, mothers /caregivers received training in a comprehensive feeding intervention programme that included: basic understanding of the influence of physical handling/positioning on the muscle tone and movements of the child; ideas for positioning the child so as to facilitate improved postural control; and specific techniques to counteract limiting behaviours in feeding skills as applicable to each child. Training was based on a participative, problem-solving approach.

In Part 1, detailed profiles were established showing the overall commonality of the limiting behaviours and inappropriate feeding practices identified by the scale. The finding that the 50 items on the scale occurred with a frequency of 80% to 100% in more than half the participants, suggested some confirmation of the validity of the observations and measurement tool employed. The marked trend of escalating frequency and severity in limiting behaviours, with the progressive developmental complexity or task demand of each specific feeding skill, appeared to support the motor learning theories on which the NDT approach is based. Analysis of predominating limiting behaviours and feeding practices, revealed that difficulties associated with oral motor control and co-ordination of swallowing were high in severity, as anticipated with feeding disorders. However, problems with body position, both in the children themselves and in the ways their mothers /caregivers positioned them for feeding, ranked highest in severity, thereby confirming not only that difficulties with postural control are closely linked to feeding difficulties in children with CP, but also that an effective intervention programme should target this area.

In Part 2, a normal distribution of pre- and post intervention severity ratings was confirmed (Shapiro-Wilk test). Significant post intervention changes in severity ratings, of limiting feeding behaviours and of inappropriate feeding practices, were confirmed by standard parametric (Matched-Pairs T-tests) and non-parametric (Wilcoxon Signed Rank Tests) statistics. In addition, for both limiting behaviours and inappropriate feeding practices, non-formal analysis revealed overall frequency decreases after the intervention, and a consistent shift in severity from the 'severe' category towards the 'no problem' category. Variations in apparent responsiveness of individual behaviours and feeding practices to the intervention were identified and interpreted in terms of their clinical implications.

Part 3 employed content analysis of a questionnaire completed by mothers /caregivers after training in the intervention techniques. The consistently high level of positive responses indicated strong acceptance of the feeding programme and a positive perception of mothers /caregivers regarding their ability to implement it at home. The positive attitudes of mothers /caregivers, supported by the significant improvement in their feeding practices found in Part 2, suggested that the intervention programme had succeeded in the transference of therapeutic feeding skills. In addition these findings indicated that the feeding intervention programme could be sustained in the daily life of mothers /caregivers and children.

The positive functional outcomes obtained in this study appear to have had a direct link to the feeding intervention programme, thereby endorsing the Neurodevelopmental Therapy approach and techniques on which the intervention was based. In addition, the main objectives of the study appear to have been met sufficiently to justify further promotion of this feeding intervention programme, with training of a wider spectrum of health professionals who routinely encounter feeding disorders in children with cerebral palsy.

CHAPTER 1: INTRODUCTION

BACKGROUND

Red Cross Children's Hospital, Cape Town, is an institution with teams of highly-skilled personnel and sophisticated equipment combining to provide treatment for a wide range of children's disorders. Occupying one half of the Physiotherapy Outpatients' Department is the Cerebral Palsy Clinic. The CP Clinic is unique in that it is managed by a non-governmental organisation, the Western Cape Cerebral Palsy Association (WCCPA), but enjoys a symbiotic relationship with the hospital which is managed by the Provincial Administration of the Western Cape.

Figure 1: The CP Clinic at Red Cross Hospital

The WCCPA employs a team of physiotherapists, occupational therapists, speech therapists, paediatricians, orthopaedic surgeon and interpreter – all of whom work on a sessional basis. A full-time social worker from the WCCPA is available both at the clinic and for home visits. The hospital, in turn, provides the services of additional paediatricians, paediatric registrars, nursing sisters and administration clerk. In addition, the CP Clinic has access to all the services and specialist clinics necessary in the management of cerebral palsy, including neurology, audiology, ear- nose and throat, gastro-intestinal tract, eyes, dentistry, dietetics, X-ray, pharmacy, orthopaedic appliances etc.

Red Cross Children's Hospital is situated in a relatively affluent part of the city, but the majority of the patients and caregivers attending the CP Clinic are from disadvantaged backgrounds. More than half are Xhosa-speaking, and many live in the informal settlements around Cape Town. A significant number of the mothers are single and have come to the city from impoverished rural parts of the Eastern Cape, in order to seek help in managing their child's disability. Just over half (57%) of the children attending the CP Clinic are male. The age range is from 3 months to above 12 years, with 22% below 2 years and 36 % aged between 2 and 4 years.

The WCCPA also runs a community outreach programme. Therapists and paediatricians visit a number of day-care centres catering for children with severely disabling cerebral palsy. A satellite clinic is held once a month in Kraaifontein, 35 km from Cape Town, and additional outreach clinics are now operating monthly at two day hospitals in the Khayelitsha area. In addition, a WCCPA physiotherapist assists at regular High Risk Clinics at 2 Cape Town hospitals.

Although cerebral palsy is in itself a highly heterogeneous disorder, the clinic population is in many demographic aspects relatively homogeneous. As the CP Clinic has an efficient referral network in place, the majority of children are young, showing early signs of severe disability (including seizures and cortical visual disorder), and are entering a formal intervention programme for the first time. Many of the mothers /caregivers are from disadvantaged communities, are unable to attend more than once a month, and are from a different language and cultural background than the professional health workers in the clinic. Consequently therapy approaches and home programmes have been adapted and tailored to meet the needs of both child and mother /caregiver.

Persistent feeding difficulties are often one of the earliest signs of severe disability (Arvedson & Brodsky 1993, Crane 1992, Davison 1999, Morris & Klein 1987, Reilly & Skuse 1992), and occupy a significant proportion of the speech therapy service at the CP Clinic. In developing a feeding intervention programme appropriate for the clinic population, it soon became evident that reliance on many years of clinical experience with accepted methods from standard treatment approaches did not, on its own, address all the feeding management issues confronting the mothers and children attending the CP Clinic. Evaluation and treatment techniques had to take cognisance of the age and severity of disability of the child, the disadvantaged and differing cultural background of the mother /caregiver, and irregularity in clinic attendance.

Based on the philosophy and techniques of the Neurodevelopmental Therapy approach, a feeding intervention programme was developed that concentrated on the abnormal feeding behaviours most commonly identified in this population and most readily accessible to modification through retraining. The primary feeder of the child receives training in the following areas: basic postural and movement difficulties associated with CP; feeding positions and techniques for presenting liquid, soft and solid foods so as to counteract these difficulties; and development of a problem-solving approach towards dealing with common difficulties.

MOTIVATION FOR THE RESEARCH

Unresolved feeding issues can become a source of extreme stress in the lives of children with cerebral palsy and those who care for them, impinging on a range of health and developmental issues (Lebeer & Rijke 2003, Mäntymaa et al. 2003, Parrish 1997, Reilly & Skuse 1992, Wilder & Granlund 2003). Experience has confirmed that there is widespread lack of expertise in dealing with the feeding difficulties associated with cerebral palsy, within the area and population served by the CP Clinic at Red Cross Hospital. As the feeding intervention programme at the CP Clinic has developed and reached greater numbers of children and their mothers /caregivers, an increasing number of requests for assistance have been received from non-government organisations, day care centres, and residential homes catering for children and adults with cerebral palsy, and from training institutions for students in the health sciences. If the feeding intervention programme developed at the CP Clinic were supported by reliable evidence-based data, it could be more widely promoted over a considerably greater area, to the benefit of many more individuals with feeding difficulties associated with cerebral palsy, and their caregivers. However, outcomes research in the general management of childhood disability has been described as falling within an 'evidence-free zone' (Brown 2000). Clinical effectiveness of therapeutic intervention for CP, based on the

Neurodevelopmental Therapy (NDT) or any other recognised approach, has not been convincingly demonstrated (Barry 1996, Bower 1996, Butler & Darrah 2001, Campbell 1998, Harris 1993, Leary 1997, Lebeer & Rijke 2003, Leonard 1998, Mayo 1991, Saloojee 2005, Turnbull 1993); and studies in the field of effective intervention for feeding difficulties associated with severe cerebral palsy in infants and young children are notably lacking.

The background for this study therefore revolved around the following issues: the challenge of implementing effective intervention for a population of mothers/caregivers and their infants/young children with evolving/severe cerebral palsy, persistent feeding disorders and other multiple disabilities; an NDT-based feeding intervention programme developed at the CP Clinic that appears to have been clinically effective for this population; and increasing pressure to promote the specific feeding intervention programme more widely despite the lack of treatment outcomes evidence.

CHAPTER 2: LITERATURE REVIEW

A review of the relevant literature was undertaken in order to highlight the complexities of cerebral palsy itself; the abnormalities of posture and motor control that affect the acquisition of appropriate feeding skills in the infant with cerebral palsy; other problems of health and development in infants and young children arising from inadequate feeding skills; recognised therapeutic approaches to the management of cerebral palsy, in particular Neurodevelopmental Therapy; and some of the issues surrounding both treatment outcomes research and models of service delivery in this field.

1. WHAT IS CEREBRAL PALSY?

The Washington Workshop, convened in 2004 with the goal of working towards international consensus regarding a definition of cerebral palsy, identified cerebral palsy (CP) as 'a well-recognized neurodevelopmental condition beginning in early childhood and persisting through the lifespan', but pointed out that the concept of 'cerebral palsy' has thus far eluded a universally accepted definition (United Cerebral Palsy Research Foundation 2004).

1.1 THE CHALLENGE OF DEFINING CEREBRAL PALSY

For more than a hundred years, since the first medical description of cerebral palsy in 1861, the focus has been on describing a movement disorder linked to brain damage, hence the coined term 'cerebral palsy'. Achieving a universally accepted definition has remained a challenge, however, as evidenced by the number of attempts made over the years (NIH Publication 1993, Stanley et al 2000, UCP Information document 2001). 'Cerebral palsy' is in fact a term of convenience, a symptom complex, not a specific disease, and not a diagnosis in the sense that it is not informative of aetiology, pathology or prognosis. The fact that the concept of cerebral palsy encompasses a wide variety of disorders with different aetiological and clinical features has engendered considerable controversy and difficulties in diagnosis, management, epidemiological research, and public health services (Badawi et al 1998, Bax 1993a, Cogher et al 1992, Harrison 2000, Leland Albright 1996, McCarthy 1992, Stanley et al 2000, UCP Research Foundation 2004).

The need for universally accepted clarification, together with increased availability of high-quality brain imaging, acknowledgement that developmental motor impairment is almost invariably associated with a range of other disabilities, and increased understanding about associated antecedents and correlates of CP, prompted recent reassessment of the definition. This most recently updated definition of CP, released in 2004 by the United Cerebral Palsy Research Foundation, reads as follows:

'Cerebral palsy describes a group of developmental disorders of movement and posture, causing activity restriction or disability, that are attributed to disturbances occurring in the fetal or infant brain. The motor impairment may be accompanied by a seizure disorder and by impairment of sensation, cognition, communication and/or behaviour'.

(www.castangfoundation.net/docs/washington_CPDefintion1.doc)

1.2 DETERMINING THE PREVALENCE OF CEREBRAL PALSY

Rising hopes, in the 1960's and 70's, that neonatal medicine would contribute significantly to the prevention of CP, were to prove too optimistic (Bax 1993a). Estimates of prevalence internationally have remained stable, generally between 1.5 to 2.5 per 1000 live births (Mutch et al 1992, Bax 1993a, Leland Albright 1996, McCarthy 1992, Mayston 2002, SCPE 2002). Thus, cerebral palsy is still the most common physical disability in childhood (Arvedson & Brodsky 1993, Leland Albright 1996, Siebes et al 2002).

What is emerging is a pattern of differences in the aetiology of CP in developed and developing countries. Developed countries report that CP due to damage incurred during the birth process occurs in about 20% of cases, whilst about 10% of children with CP acquire the disorder after birth. Brain injury during intra-uterine life therefore accounts for about 70% of cases, with a consistent association between prematurity and cerebral palsy (Bax 1993a, Carter 1998, Ens-Dokkum et al 1994, Mutch et al 1992, NIH Publication 1993, UCP 2001, SCPE 2002).

In developing countries, risk factors for perinatal and acquired brain damage play a larger contributory role (UCP 2001). Studies in the Giyani district of South Africa's Northern Province

(Potterton 1996), and Cape Town area (Arens & Molteno 1989), found a prevalence of acquired cerebral palsy among disadvantaged coloured and black children between 24% and 36%. In keeping with findings in other developing countries where poor socio-economic conditions prevail, tuberculosis meningitis and gastroenteritis account for many cases of acquired CP (Arens et al 1987, Arens & Molteno 1995, Potterton 1996).

1.3 CLASSIFICATION OF CEREBRAL PALSY

Mutch et al (1992) and Stanley et al (2000) point out that there is no definitive test for cerebral palsy. Traditionally the classification of CP is by clinical description according to the predominant movement abnormality, i.e. spasticity, dyskinesia, ataxia and mixed forms, and by the extremities affected, namely quadriplegia, diplegia, hemiplegia etc. (Cogher et al 1992, Levitt 1995, NIH Publication 1993, Stanley et al 2000, UCP 2001). The predominant movement abnormalities are generally defined as follows:

- SPASTICITY is characterized by persistently increased muscle tone, abnormal resistance to passive stretch with sudden release (clasp-knife effect), and exaggerated reflexes. Tone in the trunk may be reduced. About 80% of those with cerebral palsy are predominantly spastic (Cogher et al 1992, Leland Albright 1996, Levitt 1995, NIH Publication 1993, Stanley et al 2000, UCP 2001).
- DYSKINESIA is characterized by the presence of involuntary movements which may be of two types, athetosis or dystonia (McCarthy 1992). Leland Albright (1996) describes dystonia as identifiable by sustained muscle contractions that result in twisting and repetitive movements or abnormal postures and believes that dystonia may be misdiagnosed as spasticity or athetosis. Athetosis is characterized by distal, slow, writhing movements, most prominent in the hands, feet and face causing grimacing and/or drooling (NIH Publication 1993, Stanley et al 2000, UCP 2001), and is often associated with normal intellect (Leland Albright 1996, Levitt 1995).
- ATAXIA and HYPOTONIA are seldom explicitly described unless they are the predominant motor impairment, which is rare (McCarthy 1992, Levitt 1995). Ataxia is most frequently associated with acquired head injury, whilst hypotonia frequently accompanies intellectual

impairment and is not traditionally classified as CP (Badawi et al 1998, Stanley et al 2000).

The common feature of all classifications of CP, however, is a disorder in the regulation of muscle tone resulting in difficulties with postural adjustment and the acquisition of skilled co-ordinated movement such as grasp, hand-eye co-ordination, mobility, swallowing and speech (Bly 1991, Arvedson & Brodsky 1993, Levitt 1995, McCarthy 1992, UCP 2001).

1.4 ADDITIONAL PROBLEMS ASSOCIATED WITH CEREBRAL PALSY

Due to the vulnerability of the developing nervous system, disorders that involve the brain and impair its motor function can also cause other associated problems (NIH Publication 1993, Levitt 1995, McCarthy 1992). Associated disabilities, commonly but not necessarily accompanying cerebral palsy, include intellectual impairment, seizures or epilepsy, impaired vision or hearing, abnormal sensation and perception, and growth problems (Mutch et al 1992, NIH Publication 1993, Levitt 1995, SCPE 2002).

1.5 THE NATURAL HISTORY OF CEREBRAL PALSY

Although, by definition not a progressive disorder, the movement disorder associated with cerebral palsy has a natural history with observable clinical change – including deterioration as well as improvement (Mutch et al 1992). Levitt (1995) and McCarthy (1992) point out that since the brain, damaged early in its development, continues to develop in the presence of damage, interference with the normal integration of function is inevitable. The result is a complex situation of pathological symptoms within the context of a developing child and abnormal tone and movement deficits become more obvious as increased precision and complexity of movement is needed. In addition, over time, persistent abnormality in tone and posture, combined with restricted and abnormal movement, can result in muscle and tendon contractures and bone deformities. Such progressive contractures, in turn, cause further loss of mobility and function. If allowed to occur and progress, fixed deformities may have catastrophic effects in compromising an increasing number of abilities and impinging on ease of handling and basic comfort (NIH Publication 1993, Arvedson & Brodsky 1993, Levitt 1995, Leland Albright 1996, McCarthy 1992).

2. DEFINING FEEDING

The complexity of feeding for any developing child is captured by the following definition provided by Alexander, Boehme and Cupps (1993):

> Feeding is 'a process that refers to the child's environment, parent-child interactions, the medical, developmental, neuromotor, sensory-motor, and cognitive integrity of the child, feeding techniques, feeding utensils, positioning needs, swallowing, the interaction of swallowing with respiratory and gastrointestinal factors, and the child's nutritional requirements.'

Rudolph (1994) identifies three stages in the process of feeding. The first involves appetite, procurement of food and what Rudolph terms the mechanical process of bringing the food to the mouth for ingestion – all largely a function of interaction with the external environment. The second stage involves the preparation of the ingested food for swallowing. The final stage involves the passage of the food or liquid (known as the bolus) further through the internal system for digestion and absorption of nutrients. Rudolph observes that the first two stages of feeding entail skills that evolve in a sequence that parallels the development of other motor skills, such that the process of feeding becomes increasingly independent.

In a normal swallow process, motor activity of the tongue stimulates a series of subsequent sensorimotor patterns that prepare and transport a liquid or solid bolus safely from the oral cavity, through the pharynx – bypassing the airway – into the oesophagus and lower digestive tract (Buchholz 1997, Logemann 1998, Morris & Klein 1987, Myer et al 1995, Perkins & Kent 1986). With the development of instrumental diagnostic imaging and measurement techniques, such as videofluoroscopy, ultrasound, manometry, electromyography, etc, it has become possible to view the intrinsic physiology during swallowing, and there is an extensive body of literature on studies of the normal swallow (Garon et al 2002, Logemann 1998, Newman et al 1991, Rademaker et al 1994, Ruark et al 2002, Sonies 1991, Tasko et al 2002).

Sonies (1991) describes swallowing as a 'complex, dynamic neuromuscular activity that can be separated into three distinct stages: oral, pharyngeal, and esophageal'. Loughlin & Lefton-Greif

(1994) describe the infant swallow as more automatic than that of the adult, and observe that as central nervous system function matures, the oral phase becomes increasingly volitional and further differentiated into oral-preparatory and oral-transport phase skills. Logemann (1998) observes that sensory information is very important in guiding the efficiency of a swallow and that both reflex and voluntary components are involved until the final stage of peristalsis.

There is wide consensus amongst the acknowledged authorities (Arvedson & Brodsky 1993, Bass 1997, DiIorio & Price 1990, Kendall 1997, Logemann 1998, Loughlin & Lefton-Greif 1994, Perlman 1991, Sullivan & Rosenbloom 1996b) in the field of swallowing as to the motor events taking place within each phase, with a brief summary as follows:

~ ORAL PREPARATORY PHASE: Food is manipulated in the mouth and chewed if necessary, reducing it to a consistency and cohesiveness appropriate for swallowing

~ ORAL TRANSPORT PHASE: The tongue propels the food or bolus posteriorly until the pharyngeal swallow is triggered

~ PHARYNGEAL PHASE: The pharyngeal swallow is triggered and the bolus is moved through the pharynx

~ OESOPHAGEAL PHASE: Oesophageal peristalsis carries the bolus through the cervical and thoracic oesophagus and into the stomach.

3. THE ACQUISITION OF FEEDING SKILLS

Relevant literature on the acquisition of feeding skills, in both the normal child and the child with CP, will be reviewed from four distinct but interrelated aspects: the knowledge gained from the rapidly developing science of motor learning; a description of specific feeding skills; the role of psychosocial factors in feeding; and significant developmental sequelae associated with problems in the acquisition of appropriate feeding skills.

3.1 FEEDING AS MOTOR LEARNING

Feeding is a functional motor skill and as such its acquisition should be viewed within the framework of neurophysiology and current theories of motor learning (Alexander et al 1993, Bahr 2001, Stevenson & Allaire 1996). The acquisition of functional motor skills is no longer seen as a mere unfolding of innately determined behaviour patterns, but rather in terms of the interplay of many systems and subsystems both internal and external to the developing child (Alexander et al 1993, Crane 1992, Leonard 1998, Rudolph 1994, Winstock 1994).

(i) INTERNAL SYSTEMS CRITICAL FOR FEEDING

Alexander et al (1993) and Stevenson and Allaire (1996) identify three systems internal to the developing child as most critical in the motor learning underlying the acquisition of feeding skills:

- THE MUSCULO-SKELETAL SYSTEM components directly involved in feeding include the structures of the nose, mouth, pharynx, trachea and oesophagus which are also involved in stabilization and maintenance of structural position and form, and respiration (Bosma 1997, Morris & Klein 1987, Stevenson & Allaire 1996, Wolf & Glass 1992). Many authorities emphasize that significant differences in oral-pharyngeal anatomical relationships between the termborn infant and the adult (including a smaller oropharyngeal cavity, sucking pads in the cheeks, and higher position of the larynx) support early sucking patterns in a recumbent position whilst protecting the airway. Gradually, as the head and neck grow, the infant's oral and pharyngeal anatomy is significantly remodelled, and by 6 months the child is dependent on developing neurological co-ordination to ensure safe and efficient swallowing (Alexander et al 1993, Arvedson & Brodsky 1993, Bahr 2001, Logemann 1998, Morris & Klein 1987, Myer et al 1995, O'Connor 1995, Oetter et al 1995, Rudolph 1994, Stevenson & Allaire 1996, Wolf & Glass 1992).

- POSTURE AND MOVEMENT SYSTEMS, representing stability and mobility respectively, are co-ordinated for the performance of functional skills (Alexander et al 1993, Hadders-Algra 2000, Leonard 1998). An infant initially shows random uncontrolled gross movements, which gradually become more organized, specific and controlled as a means of stabilizing parts of the body is established (Levitt 1995, McCarthy 1992). A stable base is necessary before mobility and functional skills can develop. The external environment initially provides the support or stability that enables the child gradually to achieve internal, dynamic, postural stability (Green 1992). Just as general postural control or body stability develops from proximal to distal, so oral stability is dependent upon the development of neck and shoulder girdle stability which are, in turn, dependent upon trunk and pelvic stability (Arvedson & Brodsky 1993, Morris & Klein 1987). At any age the clinical picture of severe forms of CP is characterized by serious postural dysfunction, which will, by implication, limit the development of mobility and functional skills, including oral motor skills (Bahr 2001, Hadders-Algra 2000, Levitt 1995, Morris & Klein 1987).

The first motor patterns of infants tend to be in straight planes of movement, with lateral and rotational patterns developing later. As the extensor system generally develops before the flexor system, infants commonly show a tendency toward active movement of the extensor muscles of the neck and, later, the back. After three months of age, as better control of the counterbalancing flexor muscles is attained, more stability in head control is achieved (Alexander et al 1993, Morris & Klein 1987). Increased head control coincides with the change in anatomical relationships within the oro-pharynx between 3 to 6 months, making a more upright position for feeding not only possible but even essential. The posture of the young child with severe CP is dominated by the early extensor system, and stability in head control is achieved very late, or not at all (Levitt 1995, Morris & Klein 1987), making an upright position for feeding very difficult.

* THE SENSORY SYSTEM is described as playing a 'crucial and incredibly complex' role in motor control (Alexander et al 1993, p7). Sensory input can increase or decrease arousal states and can be the motivating force to initiate, guide, modify and organise motor activity (Hadders-Algra 2000, Leonard 1998). The role of sensory systems in guiding efficient motor function for specific situations can be seen in the child's selection of different oral movements depending on the sensory aspects of food (size, texture, temperature, taste etc) and on the speed and manner of presentation of food with a spoon (Bly 1996, Morris & Klein 1987).

In reviewing theories of motor learning that incorporate musculo-skeletal, posture and movement and sensory systems, Hadders-Algra (2000) suggests that the Neuronal Group Selection Theory (NGST) developed by Edelman, not only presents a 'perfect balance' (2000 p708) between existing theories of motor development but also offers an attractive framework for understanding and treating developmental motor disorders. According to NGST, motor activity in the early infant or primary phase of motor development is variable and not strictly tuned to environmental influences (more developmentally determined). However, the sensory information generated by all movement and experience gradually guides the dynamic organization of selectively determined neuronal networks within the brain. These selected neuronal groups in turn guide motor behaviour to the secondary phase motor activity which is function specific. Over time 'a variable movement repertoire is created with efficient motor function for each specific situation', until with maturity, individuals can 'generate a repertoire of motor solutions for a single motor task' (Hadders-Algra 2000: p708, Leonard 1998).

Hadders-Algra (2000) states that not only do children with CP have a limited repertoire of primary neuronal networks associated with postural control, but that it is becoming increasingly clear that they also have impairments in processing various forms of afferent information (e.g. proprioceptive, tactile and visual deficits). Hadders-Algra suggests further that such sensory deficits interfere with experience-dependent selection of effective neuronal networks, resulting in stereotyped responses expressed in a limited repertoire of general movements and failure to develop appropriate task-specific motor behaviour.

(ii) THE CONCEPT OF PERFORMANCE ANATOMY

The concept of performance anatomy, that early experience and movement patterns influence developing structure and function, appears to be in keeping with the theory of neuronal group selection (Hadders-Algra 2000, Leonard 1998). Thus, Bosma (1997) points out that the co-ordinated performance of suckle feeding with participation of the pharynx and larynx in respiration and the maintenance of the pharyngeal airway is the developmental prologue of postural control of the head and neck. Bosma describes a reciprocating mechanism of development – 'sensory inputs from the mouth and pharynx during feeding stimulate the development of brain regions representing the various feeding movements, which then generate more refined movements' (1997, p140). These, in turn, generate further performance-appropriate input. Conversely, Haberfellner et al

(2001) state that lack of age-appropriate variety of movement and posture in children with neurologically based motor problems, can impair development in oral structure and function.

(iii) CRITICAL OR SENSITIVE PERIODS FOR MOTOR LEARNING

Movement and sensory exploration are now generally accepted as vital to neurophysiological maturational processes, with significant clinical and educational implications. There is also growing acceptance of the associated concept of critical or sensitive periods for the acquisition of specific skills. This concept implies that it is more difficult to learn certain behaviour patterns after the critical or sensitive learning period has passed (Bahr 2001, Hadders-Algra 2000, Leonard 1998). Critical or sensitive time periods for the introduction of new tastes (4-6 months) and for solid foods (by 6-7 months) are acknowledged clinically, and normal children without this experience at the appropriate time tend to be persistently resistant to unfamiliar oral experiences (Arvedson & Brodsky 1993, Hawdon et al 2000, Skuse 1993, Stevenson & Allaire 1996).

3.2 SPECIFIC FEEDING SKILLS

The acquisition of the functional motor skills necessary for the ingestion, oral manipulation and swallowing of a food or liquid bolus occurs in a predictable developmental sequence: early suckling or sucking from the breast or bottle, spoon feeding of soft foods, cup drinking and finally chewing of hard consistency foods. There is, however, no rigid timetable of events (Alexander et al 1993, Winstock 1994, Bosma 1997). The following section includes a description of the normal acquisition of these four feeding functions, and the role of what Morris and Klein term the 'limiting movement patterns' (1987 p83) that restrict normal acquisition of these skills in children with CP.

(i) DEVELOPMENT OF NUTRITIVE SUCKING SKILLS

Alexander et al (1993 p243) define suckling as 'an early lick-type of sucking pattern characterized by rhythmical forward/backward tongue movements, large rhythmical up/down and forward/backward jaw movements, and minimal cheek and lip activity', whereas sucking is a more mature pattern, 'a rhythmical method of obtaining liquid and food using small up/down jaw movements, up/down tongue movements, lip approximation, and cheek activity that creates negative pressure in the oral cavity'. Mature sucking is a combination of suction and compression that induces the flow of milk, transfers it along a grooved, rippling tongue and swallows it in one rhythmical, efficient, co-ordinated continuous pattern involving lips, jaw, tongue, cheeks, palate and pharynx (Arvedson & Brodsky 1993, Crane 1992, Morris & Klein 1987, Wolf & Glass 1992, Winstock 1994).

Swallowing movements begin in utero with the frequency of these movements increasing as the infant approaches term (Loughlin & Lefton-Greif 1994). Studies by Gewolb et al (2001) and Qureshi et al (2002), on healthy preterm infants, showed that the basic rhythmic organization of suck-swallow is established by 40 weeks. The term newborn begins sucking with a rapid, efficient, and regular movement and optimal sucking performance is established by the third day (Ramsay & Gisel 1996). During normal suckle feeding, respiration is incorporated into the rhythmic sequence (Bosma 1997, Logemann 1998). Irregularities in sucking rhythm have been identified as one of the earliest indicators of brain dysfunction or damage in newborns (Gewolb et al 2001, Lau & Kusnierczyk 2001, Morris & Klein 1987, Qureshi et al 2002).

Many authorities have observed that the mouth and feeding is the centre of the infant's world, with the suck-swallow-breathe (SSB) synchrony as the most organized system of sensory integrative and neuromotor behaviours available to the infant (Oetter et al 1995, Ramsay & Gisel 1996). Oetter et al draw attention to the repercussions of early gross motor and oral-motor disorders, stating that an intact SSB synchrony 'is critical to many elements of sensorimotor and cognitive development including speech and language development, state regulation, postural control, feeding/eating behaviour, ego development and eye-hand co-ordination' (1995 p3).

Specific elements of the SSB synchrony are the early automatic or reflexive oral movement patterns that assist suckle feeding: the rooting reaction, the suck-swallow reflex, the phasic bite-release pattern, the gag reflex, the tongue protrusion reflex, and the transverse tongue reflex. In the normal termborn infant, all these oral reflexive movements, other than the gag, will have disappeared by 4 to 6 months (Alexander et al 1993, Arvedson & Brodsky 1993, Bahr 2001, Levitt 1995, Morris &

Klein 1987, Pitcher & Crandall 1997). With maturation, sucking skills become increasingly less dependent on oral reflexive patterns, and show greater integration of sensory input, postural stability and mobility, with progression from gross to more finely controlled movements (Levitt 1995, McCarthy 1992).

The child with CP lacks neurophysiological control of posture and movement, resulting in the domination of gross motor patterns of flexion in prone and extension in supine positions, which in turn block the development of active postural stability and the possibility of increasing mobility (Levitt 1995, McCarthy 1992, Morris & Klein 1987, Saloojee 2005). In the infant with severe neurological disorder, the customary recumbent position for feeding therefore tends to trigger strong extensor thrusting, accompanied by oral extensor patterns of excessively wide jaw opening, lip retraction and tongue alternately bunching and retracting or protruding. The resultant difficulty with latching, sealing, and the co-ordinated movement pattern of drawing-compressing to induce milk flow from either breast or bottle, inevitably leads to increased feeding time and reduced feeding intake (Morris & Klein 1987, Wolf & Glass 1992).

Early reports of difficulties with feeding are often one of the earliest signs of neurological dysfunction, and frequently precede a diagnosis of CP (Arvedson & Brodsky 1993, Bahr 2001, Crane 1992, Davison 1999, Hawdon et al 2000, Larnert & Ekberg 1995, McCarthy & Croft 1992, Morris & Klein 1987, Motion et al 2002, Reilly & Skuse 1992, Rudolph 1994). Children with severe gross motor and oral-motor disorders seldom progress beyond primitive suckling movements, which contain all the elements of early reflexive oral movement patterns. These early patterns become more and more fixed and abnormal in terms of increased tone and thrusting action (Bahr 2001, Morris & Klein 1987). Moreover, within the context of the changing oral-pharyngeal anatomy after 3 months of age and the difficulty with integration of posture and movement and synchrony of suck-swallow-breathe, the danger of aspiration for the child with CP is high (Arvedson & Brodsky 1993, Shaw 1996, Wolf & Glass 1992). Aspiration pneumonia is acknowledged as a significant cause of morbidity in severe CP (Morton et al 2002, Shaw 1996).

(ii) DEVELOPMENT OF SPOON FEEDING

In the normally developing infant, spoon feeding of puree-consistency foods, generally introduced between 4-6 months of age, signals a transitional feeding period. Primitive oral reflexes are disappearing and spoon feeding is a time of graduation from exclusive suckle-feeding of liquids to voluntary ingestion of physically varied foods (Alexander et al 1993, Arvedson & Brodsky 1993, Bosma 1997, Pitcher & Crandall 1997, Winstock 1994).

With increasing stability, symmetry and alignment of the neck and shoulders, more independent oral function is possible, so that the lower lip is increasingly able to position and close around the spoon. In addition the tongue now fills less space in the oral cavity, allowing for more mobility and increased manipulation of the bolus in the mouth (Pitcher & Crandall 1997, Rudolph 1994, Stevenson & Allaire 1996).

In the child with cerebral palsy, the neurological problems preclude the establishment of a variable movement repertoire (Hadders-Algra 2000). On the oral-motor level, early oral reflexive movement patterns may; persist beyond the time when they are functional (rooting, suck-swallow, tongue protrusion); become excessively exaggerated with consistent stimulation (gag); or be abnormal (tonic bite reflex). Oral motor patterns observed in the child with cerebral palsy may also be part of a larger response pattern, such as; jaw thrust as part of strong extension pattern or jaw clenching as part of strong flexor patterns in neck, shoulder girdle and arms (Bahr 2001, Morris & Klein 1987, Winstock 1994).

Severe gross motor and oral-motor disorders make spoon feeding extremely difficult. Increased extensor tone, exaggerated primitive suck-swallow and tongue protrusion patterns result in vertical-only jaw movements, strong in-out tongue thrusting and difficulty in achieving and/or maintaining lip closure, thus limiting the child's ability to take food off the spoon, to hold and manipulate a bolus in the mouth, and to initiate a co-ordinated swallow (Bahr 2001, Morris & Klein 1987, Wolf & Glass 1992).

Faced with these difficulties described, and the need to provide more substantial nourishment for the child than liquids can provide, the concerned mother or caregiver inevitably resorts to keeping the child in a semi-lying position and spoon feeding only purees or semi-solids, relying on gravity to counteract the thrusting movements of the child. However, maintaining the child's head in an abnormally retracted position compounds the difficulties by exacerbating abnormal extensor tone and reinforcing wide jaw/mouth excursion and tongue thrusting. This in turn further limits effective feeding, swallowing, and the development of oral-motor and head control (Crane 1992, Larnert & Ekberg 1995, Morris & Klein 1987, Mueller 1997, Winstock 1994), and increases the risk of aspiration (Bülow et al 2001, Larnert & Ekberg 1993, Lewin et al 2001, Morton et al 1993).

(iii) DEVELOPMENT OF CUP-DRINKING

In the normal child, drinking from a cup held by the caregiver is generally introduced at about 6-7 months. Initially some liquid loss from the mouth is noted as the child typically reverts to the more primitive anterior-posterior tongue movements with vertical jaw movements. By 18-24 months cup drinking is increasingly skilled with the attainment of more postural and jaw stability and more precise lip control of the liquid (Alexander et al 1993, Morris & Klein 1987, Pitcher & Crandall 1997, Winstock 1994).

Poor co-ordination of respiratory, oral and pharyngeal function hampers the acquisition of cup drinking for the child with CP. In the case of spasticity, the main limiting behaviours observed are lip retraction with limited cheek and lip movement, tongue thrust or alternatively a tongue that is bunched and retracted, and oral sensitivity. With athetosis, the excessive uncontrolled facial movements and grimacing in combination with wide jaw excursion and tongue thrust, make cup drinking difficult. The common outcome is therefore prolonged bottle drinking or giving of fluids by other means such as a spoon, syringe etc. (Morris & Klein 1987, Winstock 1994).

(iv) DEVELOPMENT OF CHEWING

The acquisition of chewing marks a significant transition in feeding skills to increased voluntary control with the possibility of more variation in texture and range of foods. In early chewing patterns (around 6 months) the mandibular movements are vertical ('munching') but from 7-9 months they gradually become principally rotary or transverse ('grinding') and increase in efficiency (Alexander et al 1993, Arvedson & Brodsky 1993, Levitt 1995, Pitcher & Crandall 1997, Winstock 1994, Wolf & Glass 1992). As children gain more stability of the jaw and use this new control to explore biting and chewing of more difficult foods, they begin to use the tongue independently to lick their lips or retrieve food that has slipped into the cheek cavity (Alexander et al 1993, Arvedson & Brodsky 1993, Morris & Klein 1987, Pitcher & Crandall 1997).

By 12 months, the tongue plays a major role in chewing as it shifts the oral content to the molar area and interacts with the buccal musculature to form and manipulate a bolus. At the completion of the chewing or mastication process the tongue transfers the food to the primary bolus accumulation area, centrally at the junction of the hard and soft palates. This sequence of actions is guided by subjective cues and is under voluntary control, as is the initiation of the swallow (Bosma 1997, Pitcher & Crandall 1997, Winstock 1994). It is emphasized in the literature that although the molar area is involved, the achievement of chewing is not dependent on the eruption of the molar teeth (Arvedson & Brodsky 1993, Bosma 1997).

Discrete voluntary biting is separate from chewing in its co-ordination pattern and is usually first noted as a part of oral play at the end of suckle feeding. The infant of 6 to 12 months may bite objects brought to the mouth as part of hand and mouth play, and this mouthing provides useful pre-chewing experience (Bosma 1997, Winstock 1994). Oetter et al (1995, p49) point out that the food and objects children normally put in their mouths offer 'an assortment of challenges to oral-motor skills (suck, blow, bite, crunch, chew, lick)' and that the motor requirements to accommodate different tastes, sizes, shapes, temperatures and textures drive oral-motor development.

The child with severe CP experiences serious problems in progressing beyond soft foods. Stereotyped and abnormal patterns of jaw and tongue thrusting together with lip retraction, seen in both spastic and dyskinetic CP, preclude mouth closure, fine tongue movements and co-ordinated chewing and swallowing. A limited repertoire of oral movement and a prolonged soft diet restrict oral exploration and oral sensory stimulation (Bahr 2001, Morris & Klein 1987, Sullivan &

Rosenbloom 1996b). Moreover, bypassing the critical or sensitive time periods for the introduction of new tastes and for solid foods increases the likelihood of an increasing intolerance of age-appropriate food textures (Arvedson & Brodsky 1993, Skuse 1993, Stevenson & Allaire 1996).

In addition, instead of the gag reflex receding to the posterior third of the tongue, as in normal development, the gag remains anterior, with concomitant hypersensitivity to oral sensory stimulation. An exaggerated gag may also trigger the abnormal withdrawal pattern that manifests in the child with CP as a tonic bite response. Gagging, tonic biting, and predisposition to aspiration due to abnormal head posture hamper the development of chewing and expose the child with CP to repeated negative experiences within the feeding situation (Bahr 2001, Carroll & Reilly 1996, Morris & Klein 1987, Stevenson & Allaire 1996, Sullivan & Rosenbloom 1996b).

3.3 PSYCHOSOCIAL FACTORS IN THE FEEDING PROCESS

Stevenson & Allaire observe that the basic physiologic complexity of feeding, which relies on structure and function, is further compounded by social and cultural aspects. Thus 'feeding development occurs in the context of a parent-child relationship within a larger family unit within a still larger culture' (Stevenson & Allaire 1996, p11).

The infant is entirely dependent on the caregiver to provide sustenance, and a trusting relationship is reinforced when the parent or caregiver succeeds in comforting the hungry infant by providing food (Ramsay et al 1993, Rudolph 1994, Winstock 1994, Wolf & Glass 1992). In addition to bonding, feeding and mealtimes for the developing child present a myriad of opportunities for learning social rules and integration and particularly language (Crane 1992, McCarthy et al 1992, Morris & Klein 1987, Sullivan & Rosenbloom 1996b, Winstock 1994). As one writer puts it, of all the everyday life experiences through which the normal infant develops essential skills, the recurring routine of feeding is 'a very significant time for the earliest communication between mother and baby, a time for tuning in to speech, making eye contact, and receiving close attention', (Crane 1992, p29).

Baradon et al (1999) observe that caregiver and child are 'beset with feelings and needs that they pass between each other' (p37) and highlight the period between 6 and 18 months as critical both in terms of the role of maternal behaviour as the external environment of the young infant, and the stress placed by the young dependant child on its caregivers. Parrish (1997) cites the emotional and social implications of nurturing, bonding, comfort, communication, disposition, growth, reinforcement, and reward for the parent-child relationship as integral aspects of feeding, and points out that 'feeding disorders may challenge factors that are interwoven into the very fabric of parent-child dyads' (p74).

Many researchers have highlighted the considerable stress for both child and caregiver associated with feeding disorders in children with severe CP (Crane 1992, Crowe 1993, King et al 1996, Morton et al 1993, Mueller 1997, Rudolph 1994, Sullivan et al 2000). One study comments that 'mealtimes can be quite unpleasant as carers labour to give sufficient nutrition while the child struggles to avoid aspiration' (Morton et al 1993 p388). The epidemiological study of Sullivan and co-workers found that, of the respondents who reported feeding as stressful, 61% were taking 3 hours each day in feeding their children. Other stress factors reported were the time and cost associated with special food preparation (mashing, blending etc), and the restrictions placed on the primary caregiver in terms of being the principal feeder for the child (Sullivan et al 2000). These findings concur with those of other researchers (Crowe 1993, McCarthy 1992, Winstock 1994).

The spiralling cycle of long difficult feeding times fraught with tension and anxiety, whilst the distressed child slips or pushes further into extension and the feeder resorts to additional compensatory feeding methods, can have serious long-term effects, both in terms of psychosocial development of the child and reinforcement of the abnormal feeding behaviours. The child's restricted movement repertoire, limited communication to express food desires and preferences, and a legacy of unpleasant feeding experiences, combined with the caregiver's feelings of stress, inadequacy and frustration can impose serious strains on the parent-child relationship, with mealtimes becoming a focus for the expression of all these unresolved issues (Carroll & Reilly 1996, Lebeer & Rijke 2003, Mäntymaa et al 2003, McConachie 1999, Parrish 1997, Reilly & Skuse 1992, Rudolph 1994, Scrutton 2000, Sullivan & Rosenbloom 1996a, Wilder & Granlund 2003).

3.4 ASSOCIATED DEVELOPMENTAL PROBLEMS

Within the context of the central role of the feeding process in the development of the infant and young child, it follows that persistent feeding difficulties may result in a number of associated developmental problems including: food aversion; issues of health, growth and nutrition; oral and dental development; drooling; constipation; and speech and communication delay.

* FOOD AVERSION: Many authorities have observed that in some children food refusal may develop on the basis of learned aversion to certain foods, or even the feeding situation as a whole, due to an association with unpleasant experiences (Babbitt & Williams 2001, Skuse 1993). In the child with severe CP, strongly negative feeding experiences may result in the child self-limiting food intake through extreme avoidance behaviour. Feeding aversion may be related to the caregiver's way of handling the ongoing feeding difficulties (eg: inadequate postural support for the child who thrusts and flails more in response, inappropriate pacing during feeding, force-feeding etc), and/or associations with negative intra-oral experiences such as naso-gastric tube feeding, choking, nasal regurgitation and vomiting, gastro-oesophageal reflux and the effects of the tonic bite reflex (Ceysens & Green 2000, Field et al 2003, Mathisen et al 1999, Morris & Klein 1987, Sheppard 2001, Wolf & Glass 1996).

* HEALTH, GROWTH AND NUTRITION: Early studies assumed that growth failure in CP was due to neurological factors linked to the CNS damage, as well as altered energy expenditure and lack of activity (which decreases bone formation and muscle development) (Cronk et al 2001, NIH Publication 1993). However, many authorities now postulate that poor nutrition is not a necessary or unalterable component of CP (Gisel et al 1995, McCarthy & Croft 1992, Samson-Fang & Stevenson 2000, Skuse 1993, Stallings & Zemel 1996, Stevenson & Meyers 2001, Sullivan & Rosenbloom 1996b). Reasons proposed by various investigators as to why children with CP have difficulty achieving a nutritional intake sufficient to sustain a normal rate of growth, include: slowness and inefficiency in feeding; aspiration; gastro-oesophageal reflux; constipation; communication difficulties that inhibit or distort requests for food; and drug-nutrient interactions.

(Ceysens & Green 2000, Puntis et al 2000, Reilly & Skuse 1992, Sullivan & Rosenbloom 1996b).

Cass et al (1999) found that apparent loss of appetite reported in CP children could frequently be linked to unresolved issues such as difficulties with postural management and feeding, silent aspiration, gastro-oesophageal reflux etc. and that these underlying management issues were the cause of discomfort, malnutrition, poor health, and lack of motivation. McPherson et al (1992) stress that it is important to investigate the relationship between respiration and swallowing in the paediatric CP population with the observation that caregivers have noted that when respiratory problems develop, feeding problems also develop or worsen. Oral-motor dysfunction predisposes to aspiration (Helfrich-Miller et al 1986, Buchholz 1997), which is probably underestimated clinically in CP children (Sullivan & Rosenbloom 1996a), and may lead to pneumonia, even death (Shaw 1996).

Caregiver stress is often associated in the literature with increased duration of mealtimes for children with severe feeding difficulties who are dependent feeders (Crowe 1993, Reilly et al 1996, Sullivan et al 2000). Reilly (2001) points out that, in her 1996 study, mealtimes, especially for children with the most severe oral-motor dysfunction, were in reality far shorter than perceived by caregivers, and suggests that this may have contributed to some of the chronic under-nourishment seen in these children. In a study of the diets of 100 children with CP and feeding problems, Sullivan and co-workers found what they described as qualitative adequacy but quantitative deficiency, namely appropriate variety of foods offered but insufficient intake (Sullivan et al 2002).

An epidemiological study of CP, in a rural district in Limpopo Province, by Potterton (1996), highlighted the additional burden of poverty on the feeding of children with severe CP. Mothers in this study expressed concern about the quality and quantity of food they were able to provide for the child with difficulty in chewing and swallowing. Children with neurologically-based feeding disorders will be particularly vulnerable in areas where protein malnutrition is still a problem (Khan et al 1998, Werner & Saunders 1997), and Potterton states that this was evident in many of the children in her study. All mal- or undernourished children show problems over a wide spectrum, including: decreased muscle strength (including respiratory musculature with resultant impaired cough and predisposition to pneumonia); increased circulation times & diminished cardiac work capacity; disturbances in immune function with predisposition to infection; and impaired cerebral growth and cognitive development (Hansen, Pettifor et al 1995, Samson-Fang & Stevenson 2000, Stevenson & Meyers 2001). Malnutrition in children with CP has been estimated to be above 40% (Samson-Fang & Stevenson 2000, Stallings et al 1993a, Stallings et al 1993b, Sullivan et al 2002, Troughton & Hill 2001). Many of the secondary problems of malnourishment (predisposition to pneumonia and other infections, impaired physical and cognitive development, etc.) are already problems associated with CP. Therefore the malnourished CP child is a child severely at risk (Bax 1993c, Sullivan & Rosenbloom 1996a). Bax urges against delaying feeding and dietary intervention for infants with the words: 'Our growing knowledge of the complexity and diversity of morphological changes in the brain after birth increases the importance of getting nutrition right in the early years of the baby's life' (1993c, p1035).

- ORAL AND DENTAL DEVELOPMENT: Because tongue and swallowing movements generate strong forces, the oral anatomy can be profoundly influenced, in fact moulded, by these actions. Thus secondary orthodontic problems such as malocclusion, overbite etc can develop in children with CP as a consequence of the strong abnormal thrusting forces of jaw and tongue, and contribute to feeding difficulties in their own right (Arvedson & Brodsky 1993, Morris & Klein 1987). In addition, disease of the teeth and gums may be associated with: prolonged soft diet; difficulty with dental hygiene due to oral hypersensitivity; mouth breathing and drooling; and/or certain medications such as antibiotics, anti-convulsants etc. (Morris & Klein 1987, Mueller 1997, Sullivan & Rosenbloom 1996b, Winstock 1994).

- DROOLING: Children with CP frequently have difficulty handling oral secretions due to inadequate lip and mouth closure associated with extensor spasm, and to inefficient and infrequent swallowing. Drooling leads to constant wetness of clothing, excoriation of the chin, may contribute to dental and gum problems, and can present problems for caregivers (Blasco 1996, Crysdale et al

2001, Heine et al 1996, Johnson 1996, Lespargot et al 1993, Sochaniwskyj et al 1986).

* CONSTIPATION: Elawad and Sullivan (2001) include slow intestinal transit and constipation in a number of neuro-muscular intestinal motility problems common in children with neurological impairment. Additional significant contributory factors are certain medications commonly administered to children with CP, and the effects of a prolonged soft diet associated with feeding problems. Low-fibre pureed or mashed foods coupled with relatively poor fluid intake (often because of excessive spillage, or fears of choking and aspiration) play a prominent role in chronic constipation (Baker et al 1999, Clayden 1996, Elawad & Sullivan 2001, McCarthy & Croft 1992, Sullivan & Rosenbloom 1996b). Morris & Klein (1987) point out that poor or inactive positioning during and after meals can also lead to crowding of the intestinal tract and inhibition of normal intestinal movement. Constipation can exacerbate the problem of under-nourishment due to early satiety and poor appetite (Clayden 1996, Sullivan & Rosenbloom 1996b, Winstock 1994).

* SPEECH AND COMMUNICATION DELAY: According to Rossetti (1998), anything that interferes with the child's ability to interact with the environment in a normal manner, is a potential source of or a contributing factor to the presence of a developmental delay. For the child with both gross motor and oral motor limitations, the acquisition of speech and communication skills is seriously compromised. The child's attempts at communication signals via body movement (such as arching and extending) are likely to be difficult to understand and misinterpreted by caregivers and others. If parents, already unsure of coping with a child with disabilities, find their child hypersensitive to touch, difficult to cuddle and exhibiting unexpected startle or distress, feelings of anxiety and rejection may inhibit their interaction with the child (Carroll & Reilly 1996, Crane 1992, Levitt 1995, Morris & Klein 1987, Winstock 1994, Wolf & Glass 1996). Observation of the interactive style of mothers with children with disabilities has shown that while some mothers become increasingly less responsive to the child with limited communicative ability, others tend to be more directive as the child takes fewer interactive turns (Levitt 1995). In either case there is inherent danger of the child developing a learned passivity that further retards interaction and

communication (Louw 2000).

4. MANAGEMENT OF FEEDING PROBLEMS IN CP

Wolf and Glass (1992) observe that feeding specialists encompass a variety of disciplines. Historically, occupational therapists modified utensils and provided adaptive equipment; physiotherapists concentrated on positioning and body alignment; speech/language therapists were involved with programmes to improve oral-motor function; medical specialists attended to the associated problems (nutrition, reflux, etc.) and nurses in inpatient and outpatient settings (or mothers at home) were involved with the day to day practice of feeding (Wolf & Glass 1992). Clinical intervention in feeding disorders in the paediatric population began evolving rapidly in the late 1980's and early 1990's (Bosma 1997). With this evolution, speech/language therapists have been increasingly involved in the evaluation and treatment of dysphagia, defined in its broadest sense as 'all of the behavioural, sensory, and preliminary motor acts in preparation for the swallow' (Logemann 1998).

4.1 OUTLINE OF COMMON THERAPY APPROACHES

As a background to specific feeding intervention programmes, a number of recognised approaches to the management of the complex and diverse problems associated with CP, will be reviewed in the context of their contribution to the treatment of feeding problems. The most common therapy approaches are Conductive Education, Vojta, Sensory Integration and Neurodevelopmental Therapy (Mayston 2002, Siebes et al 2002).

* CONDUCTIVE EDUCATION (PETÖ): Conductive Education originated in Hungary and approaches the management of CP through the integration of education and therapy. Conditioning techniques and group dynamics are fundamental principles. Conductive Education begins with the young school-going child and specially trained 'conductors' each work with a group of 15 to 20 children. Speech and active movement are used to reinforce each other (Irwin-Carruthers 1992, Levitt 1995). The Petö approach has functional goals but is aimed at the older child and does not

cover the critical period for oral-motor development from birth to 2 years.

- VOJTA: The Vojta approach is used in Europe, particularly Germany. The treatment plan is based on reflex locomotor patterns (creeping, rolling etc) that are facilitated at various trigger points. Proprioceptive input through sensory stimulation and resistance is incorporated. Parents are taught an exercise plan for their child which is monitored regularly by the therapist (Barry 1996, Jones et al 1992, Levitt 1995). As the Vojta approach is essentially a physiotherapy treatment it does not specifically address the problems of the infant with severe feeding problems.

- SENSORY INTEGRATION: Jean Ayres formulated her ideas of sensory integration in the 1970's as an alternate technique for the management of minimal neurological dysfunction in children. Her methods of treatment are based on neurophysiological principles proposed by Rood and others. The aim of SI is to improve functional abilities by altering neural integration. This approach has also been extended to other populations such as mentally impaired, psychiatric, geriatric etc. (Kotkin 1996, Roley 1996).

Certain adherents of SI have expanded Ayres' theories further and developed programmes with more direct bearing on the problems of CP. Wilbarger (1996) has done much to draw attention to the problem of sensory defensiveness, including tactile, oral and gravitational or postural defensiveness. Oetter et al (1995) have expanded the idea of the interactions and interdependence of the motor, oral, respiratory and visual systems, to form the concept of 'suck, swallow, breathe synchrony' (SSB) as a synergy. They have emphasised that it is the motor requirements to accommodate different tastes, sizes, shapes, temperatures and textures that drive oral-motor development; hence the importance of providing 'a diversity of oral-motor opportunities with a variety of options for sensory input and motoric response' (Oetter et al 1995 p49). Developing SSB synchrony in older children has been shown to enhance oral sensory-motor co-ordination (Pate & Pinkstone 1996). Identification and treatment routines for sensory defensiveness and oral-motor problems are now included in many management programmes for CP (Bahr 2001, Bly 1996, Levitt 1995).

* NEURODEVELOPMENTAL THERAPY (BOBATH): Neurodevelopmental therapy (NDT) developed by Karel and Berta Bobath, is the most common approach implemented in treating children with CP in the UK (Knox & Lloyd Evans 2002), United States (Butler & Darrah 2001), Australia (Barry 1996), and South Africa (Saloojee 2005). The Bobaths considered their approach a 'living concept' (Barry 1996 pS52) meaning that it was sufficiently fluid to evolve in line with advances in neuroscience and clinical experience (Capelovitch 2005).

In Berta Bobath's words: ".... it is a way of thinking, observing and handling, in order to interpret what the client is doing, then adjusting what we do in the way of techniques to see and feel what is necessary to make it possible for them to achieve functional goals" (Mayston 2001, SANDTA pamphlet 2003). Similarly, Sharkey et al (2002) emphasize that NDT is not a treatment but an approach aimed at assessing and assisting children with CP 'to perform functional tasks sooner and better and with minimal negative effect on future functional abilities' (p430).

The essential features and components of NDT include:

- Analysis of quality of postural tone and patterns of movement and how this interferes with function
- Identification of key problems and awareness of the possible progression of atypical posture and loss of functional skills
- Setting of realistic, appropriate, meaningful and measurable treatment goals
- Use of specific handling and positioning techniques that improve postural control and functional ability, including enrichment by other approaches
- Incorporation of active participation and practice of relevant, functional skills
- Partnership with parent/carer to ensure shared goal-setting and structuring of the daily environment and routine to promote and practice newly acquired skills
- Acknowledgement that intervention should be both interdisciplinary and transdisciplinary

(Bly 1991, Capelovitch 2005, Irwin-Carruthers 1992, Irwin-Carruthers 2005, Knox & Evans 2002, Mayston 2000, SANDTA pamphlet 2003, Saloojee 2005, Valvano & Long 1991)

By virtue of the flexibility of the NDT approach, ongoing modifications and the use of NDT-based techniques in combination with other treatments have made NDT difficult to define (Barry 1996). Nevertheless, because of its holistic approach to improve functional skills in all aspects of daily life, NDT is one approach that has developed a comprehensive programme of techniques specific to feeding problems (Möhr 1998, Mueller 1997).

4.2 FEEDING INTERVENTION AND THE NDT APPROACH

Early intervention for a neurodevelopmental disorder such as CP has been stressed as a fundamental principle (Bax 1993c, Levitt 1995, McCarthy et al 1992). The urgency for provision of early intervention programmes is further underscored by the growing awareness of the interdependence of developing systems (Alexander et al 1993, Stevenson & Allaire 1996), and the concept of neural plasticity underlined by theories of motor learning (Irwin-Carruthers 1992, Leonard 1998), particularly NGST (Hadders-Algra 2000). Hawdon et al (2000) make a plea for early identification of disorganised /dysfunctional feeding and stress the role of the experienced speech and language therapist and dietician in the early detection of aberrant feeding patterns, the application of recommended therapeutic interventions, and education of medical and nursing colleagues. Early intervention in feeding difficulties associated with CP is what Crane (1992 p45) terms 'a complex process' involving the infant, parents, the wider family and carers, and many professionals.

Logemann (1998) differentiates between therapy procedures designed to improve feeding, and methodologies for swallowing therapy. Feeding techniques are directed at influencing the oral preparatory and oral stages of the swallow, whereas procedures used in swallowing therapy also include techniques for influencing triggering of the pharyngeal swallow and improving pharyngeal transit times. Swallowing therapy techniques (eg. thermal stimulation of the anterior faucial arch) have been used with adults with CP (Helfrich-Miller et al 1986). However, intervention programmes for infants and young children need to be less direct and invasive and concentrate therefore on feeding techniques (Arvedson & Brodsky 1993, Bahr 2001, Morris & Klein 1987, Winstock 1994, Wolf & Glass 1992).

Morris and Klein (1987) and Winstock (1994) describe in detail how a feeding intervention programme based on the NDT approach begins with observation of the whole feeding environment. An analysis is made of all aspects (sensory, tactile, positional, social, emotional etc) that may influence postural tone and patterns of movement and the extent to which these interfere with components of the feeding process. Treatment strategies or techniques to achieve the appropriate goals are selected according to the needs of the particular child.

An early NDT-based feeding intervention programme should incorporate the following goals:

- ~ facilitating the development of sensorimotor oral skills and feeding patterns that promote effective and adequate nutritional intake
- ~ limiting or preventing the development of inappropriate oral motor patterns and secondary problems
- ~ facilitating bonding and the emotional and interactional social aspects of development associated with the feeding process
- ~ enhancing the potential for communication, language, and cognitive development during the feeding process

(Crane 1992, Morris & Klein 1987, Winstock 1994)

4.3 OTHER MANAGEMENT STRATEGIES FOR FEEDING PROBLEMS

Wolf and Glass (1992) emphasize the importance of oral feeding for babies 'to whatever degree is possible' (p266). Nevertheless, for some infants full oral feeding is not in their best interests both medically and for maintenance of adequate growth rate, and a decision may be made to introduce non-oral feeding methods. Adjunctive feeding may be parenteral (intravenous), generally used only as a temporary measure (eg prior to surgery in selected children) or enteral (Carroll & Reilly 1996, Lloyd & Pierro 1996, Wolf & Glass 1992).

Enteral feeding is the provision of liquid formula diets by tube (Lloyd & Pierro 1996). The most common forms of enteral feeding in children with CP are:

* NASOGASTRIC TUBE FEEDING: Nasogastric tubes enter the gastro-intestinal tract through the nose and are usually the method of first choice for enteral feeding. The tube is fixed to the cheek by adhesive tape and left in place after feeding so as to minimize trauma to the oropharynx, but needs replacement every 3-4 days. In some children where the danger of gastro-oesophageal reflux and/or aspiration is greater with fluids, solid foods may be given orally, and the NG tube used for liquids only. There are several disadvantages to nasogastric tube feeding, particularly if prolonged.

In addition to being unaesthetic, the tube can cause discomfort in the nasopharynx, and interferes with normal sensory feedback in swallowing (Lloyd & Pierro 1996, Sheppard 2001).

- FEEDING GASTROSTOMY: Insertion of a gastrostomy tube may be indicated in severely disabled children with a seriously disordered or unsafe swallow, recurrent aspiration, prolonged failure in establishing satisfactory oral feeding, and severe failure to thrive (Lloyd & Pierro 1996, Wolf & Glass 1992). The gastrostomy tube is usually inserted directly into the stomach via a laparotomy incision, and although the procedure can be performed under sedation and local anaesthetic, general anaesthetic is generally preferred. In an alternative procedure (percutaneous endoscopic gastrostomy or PEG) the gastrostomy tube is inserted under general anaesthetic with endoscopic guidance (Eltumi & Sullivan 1996). Medical complications may occur following gastrostomy insertion and can be life-threatening (Heine et al 1995). Onset of gastro-oesophageal reflux following gastrostomy has also been reported in neurologically impaired children, prompting a common routine anti-reflux procedure (usually Nissen fundoplication) at the time of gastrostomy placement. This is major abdominal surgery and carries a cost of high morbidity and recurrence rates, particularly in neurologically impaired patients (Lloyd & Pierro 1996, Sullivan & Rosenbloom 1996a). Other medical concerns involve the need for daily care to prevent infection and insure proper placement and the necessity of access to a medical facility should the tube dislodge (Lloyd & Pierro 1996, Wolf & Glass 1992).

Wolf & Glass (1992) emphasize the need for providing a programme of oral-motor therapy for a child on non-oral feedings, not only to address the primary area of dysfunction, but also for prevention of hypersensitivity and oral aversions due to lack of oral input, and to maintain oral-motor skills for future oral feeding and speech.

Carroll & Reilly (1996) quote from studies showing that the degree of oral motor dysfunction correlated with the severity of oral structural abnormalities found in older children with CP (especially overbite). Orthodontic and intra-oral devices (notably the ISMAR) have been recommended by some researchers (Gisel et al 1998, Gisel et al 2001, Haberfellner et al 2001) as a factor in stabilizing the jaw. However, this approach has been used only with older, compliant children, and has not been introduced to South Africa.

5. ASSESSING FUNCTIONAL OUTCOMES

In discussing therapeutic intervention in CP, Sussman (2001 p507) asks the very pertinent question: 'Why don't we know more about what we are doing?' and urges that we have a 'daunting but essential job in front of us to base the therapeutic interventions we recommend and provide, on sound scientific data'.

5.1 EVIDENCE-BASED PRACTICE & OUTCOMES RESEARCH

Procopis (2002) attributes the introduction of the term 'evidence-based practice' to Sackett, who defined it as 'the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients'. The promotion of evidence-based practice has increased the demand for data on the end result of clinical interventions or services, and given rise to a specific subdomain of research in clinical epidemiology, known as treatment outcomes research (Majnemer & Limperopoulos 2002).

Campbell (1998) observes that in the past, therapists, physicians and others paid scant attention to measuring and/or documenting outcomes of developmental therapy, and comments that 'What we subjectively observed and what our families told us about effects of developmental interventions were generally accepted as true and satisfying' (p1). Therapeutic intervention for CP is widely advocated and desired, but consistent pressure to evaluate the services provided is increasing (Majnemer & Limperopoulos 2002, Sussman 2001).

However, reviews of medical literature reveal insufficient reliable studies on therapeutic intervention in children with CP, and a lack of convincing evidence to prove unequivocally either that therapy is effective (including early intervention) or that one approach (eg NDT) is more beneficial than another (Barry 1996, Bower 1996, Butler & Darrah 2001, Campbell 1998, Harris 1993, Leary 1997, Lebeer & Rijke 2003, Leonard 1998, Mayo 1991, Pennington et al 2003, Saloojee 2005, Turnbull 1993). Criticism has been levelled at the design of many of the studies in terms of small numbers of subjects, poorly-controlled interventions, inadequate follow-up, lack of statistical analyses, and variability of study populations (Butler & Darrah 2001, Knox & Lloyd Evans 2002, Leland Albright 1996, Mayston 2002, Pennington et al 2003, Turnbull 1993).

In their review of possible changes in the scientific quality of therapeutic motor intervention studies on children with CP over the decade 1990 to 2001, Siebes and co-workers found that despite the application of good methodological quality, a lack of positive findings persisted. They identified the ethical reluctance of withholding treatment from a control group, the slow growth and development of children with CP, the lack of instruments sensitive enough to detect small changes in motor ability, and failure to involve parents in therapy programmes as significant factors (Siebes, Wijnroks & Vermeer 2002).

Many authorities have observed that, given the complexities of CP in terms of definition, diagnosis, and changes in the clinical picture over time, demonstrating clinical effectiveness in therapeutic services is perhaps more complex, difficult, and fraught with challenges, than in any other field of health care (Brown 2000, Cass & Kugler 1999, Leland Albright 1996, McConachie 1999, Ottenbacher et al 1986, Sussman 2001, Majnemer & Limperopoulos 2002). Other researchers have drawn attention to the nature of therapeutic intervention in CP itself as presenting inherent difficulties in evaluating effectiveness. NDT, in particular, is not a treatment but an approach (Sharkey et al 2002). In other words, it is mostly not possible to identify consistent, specific treatments delivered in a standardized manner (Butler & Darrah 2001, Sharkey et al 2002). Variables identified as difficult to control include: motivation and compliance (Majnemer & Limperopoulos 2002, McConachie 1999); the impact of clinical intervention that is often qualitative rather than quantitative (Cass & Kugler 1999, Sharkey et al 2002); the individuality of therapists' personal characteristics, skill level and specific aims (Barry 1996, Butler & Darrah 2001, Stanley et al 2000); and the interpersonal aspects of working in partnership with families (Butler & Darrah 2001, Majnemer & Limperopoulos 2002).

If the overall failure to demonstrate clinical effectiveness of therapeutic intervention for CP extends beyond poor methodology, then attention should possibly be directed towards how and what we are measuring. The effectiveness of a specific intervention is measured by whether, when deployed in the field, it does what it is intended to do (Stanley et al 2000). Monitoring and evaluating the efficacy of an intervention programme implies three areas of questioning:

- the subject of the intervention (Is the client responding to the intervention programme?)
- the outcome considered (Is significant, important change occurring?)
- the intervention itself (Is treatment responsible for the change?)

(McConachie 1999, Olswang & Bain 1994)

In addressing the three questions above, there is growing emphasis for those working in the field of developmental therapy to select meaningful, relevant goals or outcomes that are, moreover, measurable (Campbell 1998, Mayston 2000, Saloojee 2005). Moreover, the focus is changing from medical symptoms or disease, i.e. working on what is wrong with the child, to the consequences of disease or functional limitations, i.e. working on what the child will be able to achieve with appropriate assistance or intervention (Battaglia et al 2004, Buckon et al 2002, Campbell 1998, Majnemer & Limperopoulos 2002, Mayston 2000, Rosenbaum 1998, Saloojee 2005, Stanley et al 2000, WHO: International Classification of Functioning, Disability and Health, 2001).

However, as Bax (1993b) points out, the difficulty lies not only in selecting what to measure, but also in selecting appropriate measurement tools. Harris (1993, p13) queries whether there is a 'mismatch between process and product' and suggests that there has been a failure to provide a match between what we are trying to change in children with cerebral palsy, and what strategies we are choosing to measure those changes. Harris warns that 'Until we select outcome measures that are simple, clinically relevant, and ecologically valid, we are in danger of throwing the baby out with the bathwater' (p13). Thus demonstrating effectiveness requires measures of functional clinical significance (Turnbull 1993).

5.2 MEASURING FUNCTIONAL OUTCOMES OF FEEDING THERAPY

Monitoring and evaluating the efficacy of an intervention programme necessitates the collection of data, which can be either quantitative or qualitative. Quantitative data is objective and behaviours can be operationally defined for observation and measurement, whereas qualitative data is subjective, reflecting what the data collector sees or what participants report, i.e. behaviours in context (Katzenellenbogen et al 1997, Olswang & Bain 1994).

Proponents of the quantitative and qualitative approaches to research methodology have ensured a lively debate in the literature (Aylwin 1988, Eastwood 1988), but ultimately, in the words of Eastwood (p176): 'We need to be able to choose an investigatory procedure or philosophy to match the type of research under consideration'. This sentiment is endorsed by Majnemer & Limperopoulos (2002 p774) with the statement that: 'Researchers must carefully select the best tools that accurately measure the constructs of interest or else develop new tools that are developmentally appropriate'. Studies measuring intervention outcomes in the field of feeding / swallowing difficulties have employed both quantitative and qualitative measures. The following section is a review of some of the available measurement tools.

(i) QUANTITATIVE MEASURES OF FEEDING SKILLS

Quantitative measures generally involve either follow-up growth and weight (Samson-Fang & Stevenson 2000, Stallings et al 1993a & b, Stallings & Zemel 1996, Stevenson 1996) or, alternatively, instrumental measurement of the actual deglutition process (Chen et al 2001, Kuhlemeier et al 2001, Morton et al 1993, Newman et al 1991, Perlman et al 1991, Rosenquist 1997, Selley et al 2000).

* MEASUREMENT OF WEIGHT GAIN AND GROWTH RATE: Measurement of weight and growth has been widely used for long term studies, as the high prevalence of failure to thrive and stunted growth in children with CP is well documented (Ceysens & Green 2000, Rudolph 1994, Stallings et al 1993a, Stallings et al 1993b, Stevenson 1996). However, as some researchers point out, there are inherent problems in using these measures, including:

- ~ The influence of other factors in patterns of growth in both healthy children and those with CP
- ~ The likelihood of both nutritional & non-nutritional factors in poor growth & weight gain in CP
- ~ The validity of comparing growth of children with CP with normally active children

~ The accuracy of measurement of either height or supine length in children with flexor spasm &

~ fixed joint contractures.

(Ceysens & Green 2000, Stallings et al 1993a, Stallings et al 1993b, Stevenson 1996)

Alternative measurements, namely the segmental measurements of upper-arm length, tibial length and knee height, and triceps skinfold thickness have also been investigated as applied to children with CP (Samson-Fang & Stevenson 2000, Stevenson 1996), but not considered applicable to this study due to their long term nature.

* INSTRUMENTAL MEASUREMENT: Because swallowing is a rapidly occurring complex sequential behaviour, instrumental measurement of the actual process of deglutition has been used increasingly by researchers in the field (Arvedson & Brodsky 1993, Chen et al 2001, Goodrich & Walker 1997, Helfrich-Miller et al 1986, Larnert & Ekberg 1995, Logemann 1998, Morton et al 1993, Perlman et al 1991, Sonies 1991). Sonies (1991) and Logemann (1998) discuss a number of imaging and non-imaging instrumentation procedures that have been used to study various aspects of normal and/or abnormal swallowing, and point out that each technique generates a different output with regard to time, clarity and flexibility.

Non-imaging procedures, including manometry, electromyography, cervical auscultation, electroglottography, respiratory responses etc, each provide very precise information on certain specific aspects of the swallow process (Arvedson & Brodsky 1993, Selley et al 2000, Sonies 1991, Tamura et al 1996 & 1998). However, these procedures would be of limited application in an evaluative study of a therapeutic intervention in infants, as a more comprehensive measure of change in feeding behaviour is required.

Some of the common imaging techniques available include ultrasound, videoendoscopy, the technetium scan (scintigraphy), and videofluoroscopy (Arvedson & Brodsky 1993, Helfrich-Miller et al 1986, Logemann 1998, Sonies 1991). Ultrasound and videoendoscopy are useful as biofeedback techniques with older patients, but have limited application for infants (Logemann 1998). The technetium scan or milk study is done routinely in the Department of Nuclear Medicine at Red Cross Hospital to assist in the diagnosis of gastro-oesophageal reflux, but does not yield information as to co-ordination and efficiency of oral stages of the swallow process (Logemann 1998, Sonies 1991).

Videofluoroscopy is also known as the modified barium swallow procedure, oral-pharyngeal motility study, or videofluoroscopic swallowing function study (Arvedson & Brodsky 1993, Helfrich-Miller et al 1986, Logemann 1998, Sonies 1991). It is the only technique that can view the flow of a bolus through the entire aerodigestive system while simultaneously displaying the anatomy of these areas. Videofluoroscopy also allows this portion of the swallow process to be captured, stored, studied and analysed in detail (Logemann 1993, Sonies 1991, Wooi et al 2001), and is accepted by most authorities as the 'gold standard' for quantitative assessment of feeding difficulties, in particular the efficiency of the swallow (Arvedson & Brodsky 1993, Ekberg 1997, Logemann 1998, McKenzie 1997, Wolf & Glass 1992).

Numerous studies in the field of dysphagia, based on videofluoroscopy, have explored the complexities of the normal swallow, and the effects of different intervention strategies such as seating position, head position, method of food presentation, bolus consistency, etc. with swallowing difficulties (Bülow et al 2001, Helfrich-Miller et al 1986, Johnson 1997, Kuhlemeier et al 2001, Larnert & Ekberg 1995, Morton et al 1993, Morton et al 2002, Rademaker et al 1994). Thus, a 1993 videofluoroscopy study by Morton et al, with children with CP, revealed the swallowing problems associated with neck extension during feeding, whilst a 1995 study by Larnet and Ekberg, also with children with CP, demonstrated that a position with flexed neck with 30° recline resulted in decreased aspiration. Studies by Lewin et al (2001) and Bülow et al (2001), both with adults with dysphagia found that the postural technique of chin tuck assisted swallowing efficiency and helped to eliminate aspiration.

Reilly et al (1995 p932) comment on the practical difficulties in performing videofluoroscopy on children with neurological problems stating that 'the children are often difficult to position, natural food textures are difficult to replicate and ensuring the co-operation of the child is often a problem'.

Children with CP in studies using videofluoroscopy were all older children or young adults in schools and centres (Helfrich-Miller et al 1986, Larnert & Ekberg 1995, Morton et al 1993, Reilly et al 1995). Furthermore, certain researchers have also warned against the indiscriminate use of videofluoroscopy, pointing out that, often obscured by the simplicity and clinical utility of the procedure, is the inescapable fact that it involves exposure of both operator and patient to irradiation (Beck & Gayler 1990, Chapple et al 1993, Dept. of Health 2000, Wright et al 1998).

Videofluoroscopy was originally selected as the outcome measure for this study. However, trials and a pilot study, conducted during 2002 and 2003, confirmed the observation of DeMatteo (2004) and Loveday (1996) that the capture of reliable data by videofluoroscopy with such young disabled children is rendered extremely difficult due to the inescapable stress induced in the participants. The strangeness of the environment, presence of clinical equipment, feeding of barium-impregnated food, and use of adapted seating as opposed to the warmth and familiarity of the child's usual surroundings and caregiver, combined to compromise the feeding situation to such an extent that in 14 of the 15 trial cases no actual swallow could be obtained.

(ii) QUALITATIVE MEASURES OF FEEDING SKILLS

The task of subjecting the feeding patterns of infants and young children to reliable, objective analysis is not a simple one due to the number of variables that may corrupt and confound the data collection process; e.g. hunger and/or emotional state of the child; familiarity or strangeness of the environment; type and texture of the food, etc. (Arvedson & Brodsky 1993, Selley et al 2000). In addition, Arvedson and Brodsky (1993) maintain that oral-motor function can be examined only in the context of the total child and that caregivers should be an integral part of both the assessment process and the treatment programme.

Qualitative information can be gathered using caregiver questionnaires, clinical observation, and/or rating on a variety of feeding efficiency scales ranging from basic checklists to more complex assessment protocols. The advantages and disadvantages of each measurement tool need to be weighed against the ultimate objective of collecting the information, ranging from pure problem identification for intervention planning to more complex analysis and quantifying of intervention outcomes (Campbell 1996, Eastwood 1988). For instance, Rudolph (1994) describes the wealth of qualitative information that can be obtained through observation of a feeding session during which the infant is fed by the usual primary feeder. On the other hand, where the goal is that of quantifying functional outcomes, Campbell (1996) advocates the use of simple rating scales, which although not always thoroughly evaluated for psychometric quality, nevertheless 'have the advantage of simplicity, can be adapted to highly specific circumstances or therapeutic goals, and can usually be completed rapidly' (pS65).

A review of some of the available qualitative measures of feeding behaviour, incorporating clinical observation, questionnaires, checklists and/or rating scales, may be found in Appendix A.

6. MODELS OF THERAPEUTIC SERVICES

In today's global health care environment it is essential not only to justify the need for services but also to ensure that the health care system provides high quality, effective care at the lowest possible cost (Campbell 1998, Hendry 1992, Majnemer & Limperopoulos 2002). Although the concepts and goals of Primary Health Care and Health for All by the year 2000 (Ebrahim 1993) are far from being realised (Werner & Sanders 1997), one legacy has been the increase in calls and pressure to respond to the needs of the receiver of health services with greater clarity and sensitivity (Crishna 1999, Law et al 2003, McConachie & Logan 2003, Stanley et al 2000). In the context of developmental disabilities, this implies that disability services should be parent /family-centred with a genuine partnership between parents and service providers (Dyer 1996, Law et al 2003, Majnemer & Limperopoulos 2002, McConachie & Logan 2003, Wilder & Granlund 2003).

Due to the very nature of the disability and the associated problems, management of the child with CP has traditionally been in large established centres, and has involved a team of medical and health professionals; paediatricians, neurologists, orthopaedic surgeons, ENT specialists, eye specialists, physiotherapists, occupational therapists, speech and language therapists etc. With the growing awareness of feeding difficulties in infants with evolving or severe CP, management teams in some centres have drawn in additional members eg. gastro-enterologists, radiologists, dieticians, nursing staff etc. (Arens & Molteno 1995, Bosma 1997, Couriel et al 1993).

Much has been written on the subject of teamwork in the management of CP and its interdisciplinary and transdisciplinary nature. Sharing of core skills has been promoted whilst acknowledging the expertise of each individual discipline (Saloojee 2005). However there has also been increasing concern that the familiar child-centred medical model does not fit newer concepts of appropriate models of service provision and does not promote effectiveness of the interventions (Campbell 1998, King et al 1996, Saloojee 2005, Woolfson 1999). In their review of studies on therapeutic outcomes, Siebes and co-workers (2002) observed that reaching parents and teaching them to cope with the abilities and limitations of their child may be just as valid a part of intervention. A study by Colodny (2001) showed that within a residential facility, it is also essential to reach caregivers as an integral part of the team.

Emerging trends in NDT philosophy and intervention, expressed in the emphasis on meaningful, relevant, functional therapy goals with ample provision for practising of new skills in activities of daily living, also reflect the shift to partnership between family and service providers (Bly 1996, Irwin-Carruthers 1992, Mapasa 2004, Saloojee 2005, Venter 1997). Anderson (2000), in discussing lessons learned from the application of the NDT concept in an under-resourced and disadvantaged area (Soweto, Gauteng) observes that empowering mothers as partners in the rehabilitation process and providing them with information about cerebral palsy and resources enables them not only to make informed choices and decisions but also to bring about changes in their own and their children's lives.

Sloper (1999) cites research which suggests that those successful models of service provision that meet parental needs have a number of features in common:

- an holistic approach
- relationship building between parents and professionals
- flexibility and a needs-led approach

- ~ recognition of parents' perception of the hierarchy of their needs
- ~ empowerment of parents rather than taking control away
- ~ recognition and acknowledgement of parents' own expertise

In discussing empowerment, Werner and Sanders (1997) maintain that one cannot empower someone else; empowerment is a dynamic process that comes about only when people shed the feelings of powerlessness and resignation that result, at least in part, from the lack of skills and confidence required to change their condition.

In a 1997 needs analysis of disability services in South Africa, McLaren & Philpott pointed out that the Primary Health Care approach is underpinned by a commitment to make services affordable, accessible and appropriate to all community members. They identified the priority areas where intervention and investment or resources would have the most impact as being early detection, early intervention, and strengthening of and support for home-based care. Therapists working in rural and /or disadvantaged areas have all commented on the limited services available to children with severe cerebral palsy, particularly in the area of access to professional advice regarding feeding difficulties (Levin 2000, SANDTA Journal 1994, Potterton 1996). Despite limited services and resources, several newly-qualified speech /language therapists, completing their community service in rural hospitals in different provinces, have reported to this researcher alone that CP is the most common problem presented by their paediatric patients.

Within the context of a growing demand for professional advice regarding feeding difficulties but limited services and resources, this researcher undertook a search, spanning several years, for materials appropriate for transferring basic skills in the management of feeding difficulties to mothers and caregivers who did not have access to a major service centre such as the CP Clinic at Red Cross Hospital. The search revealed a number of manuals and programmes covering aspects of CP as a whole (Dart 1994; Foden Centre Manuals 1999; University of Stellenbosch, CP: Guide for Parents; WHO 1993: Promoting the Development of Young Children with Cerebral Palsy). The few basic resources specific to feeding difficulties (McClannahan 1987; Mueller 1997; Winstock 1994) are not tailored to the practical needs of mothers /caregivers from disadvantaged backgrounds and possessing limited literacy skills, and their infants or young children with neurologically-based severe feeding disorders.

Anderson (2000) points out that a therapist working without the benefit of resources relies heavily on her ability to assess and identify the key problems very quickly and to problem solve around the situation in order to make a difference and enable the child to reach his or her potential. In a similar situation, this researcher sought to identify the key problems in the clinic population of infants and young children that interfered with efficient feeding, described as 'limiting' feeding behaviours (Morris & Klein 1987), and to problem solve around the challenge of transferring basic therapeutic feeding skills to mothers or caregivers. The result was the feeding intervention programme that has been evaluated in this study and the supplementary booklet that is reproduced in Appendix B.

CHAPTER 3: AIMS AND OBJECTIVES

1. PURPOSE OF THE RESEARCH

Early intervention and the adapted feeding intervention programme, as applied at the Western Cape Cerebral Palsy Association's Clinic at Red Cross Children's Hospital, Cape Town, appear to have brought about improvement in the feeding of infants or young children with neurologically-based severe feeding disorders, but in the light of current demands to determine effectiveness and best-practice, it is incumbent on those using and promoting intervention programmes to evaluate outcomes more rigorously (Leland Albright 1996, Majnemer & Limperopoulos 2002, McConachie 1999, Sussman 2001). The purpose of this study was, therefore, to address the lack of data regarding feeding interventions by evaluating the specific therapeutic feeding intervention programme, based on the Neurodevelopmental Therapy approach, currently employed in the CP Clinic at Red Cross Hospital.

A preliminary review of the literature on functional outcomes relative to feeding intervention programmes for infants and young children with cerebral palsy, revealed certain fundamental issues needing clarification through more specific research, namely:

- ~ Pertinent descriptive information regarding the feeding behaviour of infants and young children with severe feeding difficulties associated with cerebral palsy, and the compensatory strategies or inappropriate feeding practices adopted by their mothers /caregivers.
- ~ Convincing evidence of the clinical effectiveness of feeding intervention techniques for the very young child with severe feeding difficulties associated with cerebral palsy.
- ~ Data regarding the effectiveness of skills transference and how mothers/caregivers perceive and/or accept retraining in a feeding therapy programme.

2. AIMS AND OBJECTIVES OF THE STUDY

Accurate knowledge of the presenting problem is essential for the selection of appropriate measures in evidence-based research. The compilation of a comprehensive descriptive profile, both of the feeding problems observed in a sample of young children with severe CP and the limiting feeding practices of their caregivers, was undertaken as the initial step in this research. Secondly, the study set out to evaluate whether the goals of treatment of the specific feeding intervention programme, based on the Neurodevelopmental Therapy approach, were congruent with the practical difficulties encountered by both children and mothers/caregivers, and whether the treatment outcomes satisfied the requirements for clinical effectiveness and best-practice. Finally the study aimed to gather information on the attitudes of mothers /caregivers regarding the feeding intervention programme.

Objectives identified for each part of the study were as follows:

PART 1:

- ~ To describe, prior to the specific feeding intervention, the limiting behaviours observed within a typical feeding situation in a sample of young children with severe sucking, chewing and/or swallowing difficulties associated with cerebral palsy.
- ~ To describe inappropriate feeding practices employed by their mothers /caregivers, prior to the specific feeding intervention, in response to the feeding difficulties of these children.

PART 2:

To evaluate the functional outcomes and effectiveness of the specific feeding intervention programme based on the Neurodevelopmental Therapy approach, by measuring and analysing:

- ~ Post-intervention changes, if any, in the feeding behaviour of a sample of infants /children
- ~ Post-intervention changes, if any, in the feeding practices of their mothers /caregivers.

PART 3:

To evaluate the acceptability and sustainability of this specific feeding intervention programme for the participating mothers /caregivers.

3. THE IMPLEMENTATION OBJECTIVES OF THE STUDY

Should the feeding intervention programme meet the requirements for effectiveness and best-practice, the recommendation would be made to promote training in this specific feeding intervention programme. Such training would incorporate the early recognition and management of typical feeding behaviours associated with severe cerebral palsy, and not confined to mothers of infants and children with CP, but also extended to caregivers in day and residential centres, and other health professionals who may encounter early feeding difficulties (nurses, therapy assistants and Speech-Language therapists working in clinics and day hospitals, etc).

CHAPTER 4: METHODOLOGY

1. RESEARCH DESIGN

The research was in three parts. Descriptive methods were used in Parts 1 & 3. Part 2 employed a quasi-experimental pre- and post intervention study design with no random allocation of the intervention, i.e. all participants received the intervention and the participants were their own controls (Katzenellenbogen et al 1997, Oppenheim 1992). A randomised control trial is generally accepted as the most desirable method for measuring efficacy and effectiveness of an intervention (Altman 1991, Beaglehole et al 1993, Bland 2000). However, given the serious nature of swallowing and feeding difficulties, the withholding of therapeutic intervention from a control group was rejected on ethical grounds. In addition, with the participants as their own controls the pitfalls of reliable case-control matching were avoided (Bland 2000).

2. PARTICIPANTS

2.1 SELECTION CRITERIA

The target population was infants and children with a diagnosis of cerebral palsy (or evolving cerebral palsy) who presented with feeding and swallowing difficulties sufficiently pronounced to arouse the concern of the child's mother/ caregiver, or a referring agency such as a private doctor, day hospital, another department at Red Cross Hospital, etc.

(i) INCLUSION CRITERIA :

- A DIAGNOSIS OF CEREBRAL PALSY. Where a firm diagnosis had not been confirmed, especially with infants less than one year of age, an interim diagnosis of 'evolving cerebral palsy' was sufficient basis for inclusion (Stanley et al 2000).
- REPORTED DIFFICULTY IN FEEDING. Reports by mothers /caregivers or a referring agency citing all or any of the following feeding behaviours commonly associated with cerebral palsy:

- ~ 'extended time taken and pronounced leakage when feeding liquids'
- ~ 'tongue pushing the food out'
- ~ 'difficulty swallowing' or 'coughing /choking' during feeding
- ~ 'can't chew' and still on a soft diet when no longer age-appropriate

(Bahr 2001, Bosma 1997, Morris & Klein 1987, Reilly & Skuse 1992, Winstock 1992)

- * OBSERVATION OF AN EXTENDED HEAD POSITION DURING FEEDING. Commonly associated with extensor thrusting in the child with cerebral palsy, but also seen as a deliberate tipping back of the child's head by mothers /caregivers 'in order to keep the food in' (Morris & Klein 1987, Morton et al 1993, Sullivan & Rosenbloom 1996).

(ii) EXCLUSION CRITERIA

- * MATURATIONAL DELAY AFFECTING FEEDING PATTERNS. Where maturational delay (as opposed to neurological dysfunction) was considered the predominant factor, observed differences in pre- and post intervention ratings of feeding competence could be ascribed to developmental progress, not to the intervention alone (Majnemer & Limperopoulos 2002).
- * PREVIOUS EXPOSURE TO THE FEEDING INTERVENTION PROGRAMME, as pre-intervention assessment would not have reflected a true baseline of feeding patterns.

2.2 RECRUITMENT STRATEGY

Participants were confined to new patients referred to the Cerebral Palsy Clinic at Red Cross Hospital over a period of 5 months from May 2004 to September 2004.

(i) APPROACH

The mothers or caregivers of all new patients referred to the CP Clinic who met the inclusion criteria, were approached by the researcher and informed of the study. They were assured that non-participation would in no way prejudice the quality or duration of therapy offered their child, and only if they professed interest were they then presented with the informed consent form (Appendix C 1 – 3) and included in the study.

(ii) SAMPLING

Convenience sampling was the strategy employed as there was minimal restriction on eligibility of participants (Altman 1991, Katzenellenbogen et al 1997). In other words, all new patients presenting at the CP Clinic over the 5 month period, who were eligible in terms of the selection criteria, and whose mothers /caregivers consented to participation, were included in the study.

2.3 SAMPLE SIZE

A study based on measurement of treatment outcome requires a high chance of detecting, as statistically significant, a worthwhile effect, if it exists (Altman 1991). A power calculation was performed for this study. To detect a medium-sized effect, with an α (significant value) of 0.05 and a δ (effect size) of 0.75, a sample size of 30 – 50 was recommended.

Over the 5 month period, 35 of the new patients who presented at the clinic were eligible for inclusion and consented to participation in the study. However, limitations in completing all post-intervention assessments for Part 2 of the study within the determined cut-off date for completion of data collection, plus variation in ages and developmental stages of feeding of the participants, resulted in differing sample sizes for specific feeding skills. These differences will be discussed further in Chapter 5 (Results), but a summary of sample sizes is as follows:

PART 1: Total sample size 35

Nutritive sucking	18	Chewing	31
Spoon feeding	34	Caregiver competence	34
Cup drinking	31		

PART 2: Total sample size 25

Nutritive sucking	9	Chewing	20
Spoon feeding	24	Caregiver competence	24
Cup drinking	24		

PART 3: Total sample size 25

With the exception of nutritive sucking (Part 2), these sample sizes could be considered relatively powerful (Altman 1991, Bland 2000) in comparison with the generally smaller sample sizes in related studies of treatment outcome (Butler & Darrah 2001).

A full description of the participants is provided in Chapter 5 (Results) as it forms an essential part of the profile of feeding behaviours, which is one of the aims of the study.

3. MATERIALS

Materials used in this study included an information sheet and informed consent document, the Scale of Feeding Competence in Cerebral Palsy, food and equipment employed both in assessment and training, and a questionnaire completed by mothers or caregivers following training.

3.1 INFORMATION SHEET & INFORMED CONSENT DOCUMENT

The information sheet (Appendix C 1-3) outlined the aim of the study and what would be required of participants, and assured participants of autonomy, confidentiality and anonymity. The consent form (Appendix C 1-3) was drawn up according to the protocol for informed consent set by the Research Ethics Committee (REC), Faculty of Health Sciences, University of Cape Town. The research proposal, informed consent and information document were passed by the REC on 11 February 2004.

Before the study commenced, this document was given to natural English, Afrikaans and Xhosa speakers (2 per language group) for confirmation as to appropriateness of the grammar and clarity of the information conveyed. From their assessment it was determined that the contents of the information and informed consent document would be clearly understood by their intended readers.

The information document was presented in the language of choice (English, Afrikaans or Xhosa), to the mothers or legal guardians of children who met the inclusion criteria. Only after the mother /legal guardian had read it through and stated that the contents were fully understood, was consent for participation sought.

3.2 SCALE OF FEEDING COMPETENCE IN CEREBRAL PALSY

This scale, presented in full in Appendices D2 & E, and reproduced for reference on page 51, was designed by the researcher for the purposes of collecting data relevant to this study.

(i) DEVELOPMENT OF THE SCALE

Although a number of assessment protocols and measures of various aspects of feeding and swallowing currently exist (Arvedson & Brodsky 1993, Bahr 2001, Gisel & Patrick 1988, Jelm

1990, Morris & Klein 1987, Wolf & Glass 1992,), experience at the CP Clinic at Red Cross Hospital, over a period of 6 years had revealed that none were sufficiently specific to the clinic population of very young, dependent feeders with severe feeding difficulties. A review of a range of assessment protocols can be found in Appendix A.

Over and above a comprehensive feeding history (Appendix D1), the circumstances of this research required a measurement tool that could organise the wealth of descriptive information obtained through observations of feeding sessions, and provide a means of quantifying the functional outcomes of an intervention. With the knowledge of certain existing protocols (Gisel & Patrick 1988, Jelm 1990, Morris & Klein 1987) and the background of clinical experience, the researcher expanded and refined the feeding observation checklist already employed in the clinic, in order to provide a specific assessment protocol, The Scale of Feeding Competence in Cerebral Palsy.

The following objectives governed the development of this scale:

- ~ Provision of a feeding assessment protocol that would include a more comprehensive range of qualitative information than that provided by any existing protocols, regarding the feeding behaviour of the specific population on which this study was based (namely very young, dependent feeders with pronounced feeding difficulties associated with evolving /severe CP).
- ~ Facilitation of systematic identification and evaluation of limiting behaviours of children that hampered efficiency in feeding, and the feeding practices of those feeding them, in a population of totally dependent feeders.
- ~ Sampling of feeding behaviours and caregiver practices representative of the child's and caregiver's daily mealtime experiences (Bahr 2001, McCarthy 1992).
- ~ Relative ease and speed of administration to enable quick, accurate observations of feeding behaviour in a population of characteristically 'fussy', irritable, even aversive feeders (Couriel et al 1993, Groher 1997, Winstock 1994).
- ~ Facilitation of the measurement, on repeat administrations, of incremental changes in feeding behaviours of the child and feeding practices of the caregiver.

Figure 2: Assessment Form for Scale

SCALE OF FEEDING COMPETENCE IN CEREBRAL PALSY

To be completed during observation of a typical feeding session with regular caregiver and familiar seating arrangement, food and utensils

*** 0 = no problem 1 = mildly limiting 2 = moderately limiting 3 = severely limiting**

RATE 0-3* FOR EACH FEEDING BEHAVIOUR DESCRIBED BELOW		DATE	DATE	DATE	DATE
NUTRITIVE SUCKING	Inappropriate head/neck alignment				
	Stiffening/pushing back during feed				
	Poor lip seal / undue escape of liquid				
	Tongue unable to assist latching				
	Tongue thrust hindering sucking				
	No or inappropriate jaw movement				
	Abnormal ratio of suck : swallow				
	Disorganised sucking rhythm				
	Coughing /spluttering while sucking				
	Nasal regurgitation during /after feeds				
	Vomiting during / after feeds				
	Time relative to intake per feed				
SPOON-FEEDING 4mths +	Inappropriate head/neck alignment				
	Stiffening/pushing back while eating				
	Poor lip closure around the spoon				
	Biting down on the spoon				
	Unable to maintain lip closure				
	Tongue pushing the food out				
	Repeated swallows per mouthful				
	Frequent coughing whilst eating				
	Gagging or choking				
	Unable to cope with variety of textures				
	Significant vomiting after solids				
	Insufficient amount taken by spoon				
CUP DRINKING 6mths +	Inappropriate head/neck alignment				
	Stiffening/pushing back while drinking				
	Poor lip closure around the cup				
	Biting down on the cup				
	Tongue position inappropriate				
	Poor co-ordination of sip-swallow				
	Excessive spillage				
	Augmented fluid intake (bottle, spoon, etc.)				
CHEWING 7mths +	Inappropriate head/neck alignment				
	Stiffening/pushing back while chewing				
	Poor lip closure while chewing				
	Tongue pushing the food out				
	Limited tongue action to form bolus				
	Inefficient/inappropriate jaw movement				
	Residue retained after swallow				
	Gagging or choking				
CAREGIVER COMPETENCE	Inadequate general postural support				
	Permits head-neck extension				
	Inappropriate choice of spoon				
	Encourages wide mouth opening				
	Permits sucking on spoon				
	Scrapes food off upwards				
	Collects and reinserts drooled food				
	Repeated touching of circum-oral area				
	Inappropriate pacing of presentation				
	Limited interaction with child				

(ii) CONSTRUCTION OF THE SCALE

* GENERAL DESCRIPTION: The scale was constructed according to the developmental sequence of the normal acquisition of four feeding skills, namely nutritive sucking, spoon-feeding, cup-drinking and chewing (Alexander et al 1993, Arvedson & Brodsky 1993, Bahr 2001, Morris & Klein 1987). The purpose of the scale was to identify factors limiting efficiency of feeding in infants and children with CP and to provide a means of measuring possible reduction in these factors following an intervention. Therefore behaviours included in the scale were selected, on the basis of both clinical experience and descriptions in the literature, as those most readily and frequently observed in feeding patterns associated with CP (Arvedson & Brodsky 1993, Bahr 2001, Morris & Klein 1987, Mueller 1997). Furthermore, the children in this population were all dependent feeders. As the feeding practices of the mother or caregiver can play an important role in the feeding efficiency of the child (McCarthy 1992, Reilly & Skuse 1992, Sullivan & Rosenbloom 1996, Winstock 1994), and as training of each child's primary feeder in therapeutic feeding techniques was a fundamental part of the intervention, caregiver competence was considered essential for inclusion as a fifth function area for assessment (McCarthy 1992, Reilly & Skuse 1992, Sullivan & Rosenbloom 1996, Winstock 1994).

* THE 5 SUBSCALES: The full scale was made up of a total of 50 items, viz. 40 limiting feeding behaviour patterns in children and 10 feeding practices of mothers /caregivers. These 50 items were divided into 5 subscales or feeding function areas: nutritive sucking (12 items); spoon feeding (12 items); cup drinking (8 items); chewing (8 items); and caregiver competence (10 items).

Items identifying the effects of gross motor patterns of extensor thrusting (described as 'stiffening and pushing back' and 'inappropriate head-neck alignment') were included under all 5 subscales. Within the 4 areas of infant/child feeding skills, 32 of the 40 items were specific to each feeding skill, and identified common limiting behaviour patterns observed in children with CP that hamper efficient achievement of that skill. Thus the items described behaviours in context; in other words, how certain behaviour patterns limited oral-motor skills essential for nutritive sucking, spoon feeding, cup drinking and/or chewing, such as achieving and/or maintaining lip closure, effective tongue and jaw movements, and integration of respiratory, oral and pharyngeal function.

As the target population in this study were all young dependent feeders, the majority of items identified in the area of caregiver competence were related to spoon feeding. Two items were related to the caregivers' customary positioning of the child, and three items were related to how the caregiver initiated interaction with the child during feeding.

* RESPONSE MODE ON THE SCALE: A response mode was required that could reflect severity of the specific behaviours observed, and also provide a means of documenting and comparing incremental changes in these behaviours on test – retest administrations (Vaughan & Morrow 1989). Because observed differences in severity could not be measured discretely, an ordinal scale (0-3) was selected with categories of severity assigned rank orders as follows: 0 denoting the absence of a particular behaviour, 1 = mild, 2 = moderate and 3 = severe impact of that specific behaviour on the child's feeding adequacy (Beaglehole et al 1993). Prior to the study, the primary and secondary observers determined the severity ratings of behaviours in a series of trial feeding observations until a level of consensus above 90% was reached (McCullough et al 2001).

(i) VALIDITY AND RELIABILITY OF THE SCALE

In the simplest terms, validity refers to the truthfulness of data: that is whether the data accurately measure the phenomenon of interest, whilst reliability refers to the trustworthiness of data (Olswang & Bain 1994).

* VALIDITY: Validity has several aspects of which those most relevant to this study are content, internal and external validity.

CONTENT VALIDITY demands that the scale should include or account for all the elements of the issue being investigated (Beaglehole et al 1993, Stanley et al 2000, Vaughan & Morrow 1989); the issue in this case being the feeding behaviours of children with cerebral palsy and compensatory strategies adopted by those who feed them. The Scale of Feeding Competence in Cerebral Palsy was designed in its present form for the specific purpose of identifying factors limiting efficiency of feeding in a specific population of infants and children with CP, and of providing a means of measuring possible reduction in these factors following an intervention. In the absence of any other similar appropriate measurement tool, no comparison could be made in terms of content. However, the items selected for the scale were drawn from a comprehensive body of literature regarding both normal development of oral-motor and feeding skills (Alexander et al 1993, Arvedson & Brodsky 1993, Bosma `1997, Morris & Klein 1987, Logemann 1998) and the abnormal patterns and difficulties associated with cerebral palsy (Arvedson & Brodsky 1993, Bahr 2001, Bass 1997, Bly 1991 & 1996, McCarthy 1992, Morris & Klein 1987, Mueller 1997, Reilly & Skuse 1992, Wolf & Glass 1992). Selection of scale items was further guided by the researcher's training in the Neurodevelopmental Therapy approach and more than 30 years' clinical experience in the field. As this scale was developed for severely affected dependent feeders, it included the vital element of the role played by the feeder, omitted in all other scales and assessment protocols other than the rating scale of Gisel and Patrick (1988).

INTERNAL VALIDITY requires that the results of an observation must be correct for the particular group of individuals being studied (Beaglehole et al 1993). As stated earlier, the main rationale for the development of this scale was the provision of a feeding assessment protocol that would be more descriptive of the feeding behaviour of the specific population on which this study is based (namely young infants or children with evolving /severe cerebral palsy) than that provided by existing protocols. Accordingly, the 50 items selected as the variables assessed by the scale are those feeding behaviours quoted most frequently in the literature and reported or observed most regularly in clinical practice with this specific population.

EXTERNAL VALIDITY requires that the results obtained by the measure can be inferred as applicable to individuals not in the study sample (Beaglehole et al 1993). The Scale of Feeding Competence is intended specifically for infants and children with severe feeding difficulties associated with cerebral palsy. Although all the study participants were drawn from one clinic/ hospital, the CP Clinic serves children with cerebral palsy and their caregivers from all over the Western Cape, and even the Eastern Cape. In addition, as convenience sampling was employed with minimal restriction on eligibility of participants, the study sample was inherently as inclusive as possible. Therefore it could be assumed with relative confidence that sampling bias was minimised and that the study sample was representative of a broader population of infants and children with the diagnosis of severe feeding difficulties associated with cerebral palsy.

* RELIABILITY: In order to meet the requirements for consistency and repeatability of measurement (Beaglehole et al 1993, Vaughan & Morrow 1989), potential sources of variation between measures were addressed in the following ways:

THE ENVIRONMENT was kept as consistent and as familiar, in terms of the child's usual feeding session, as possible. Seating was arranged to duplicate that to which the primary feeder and child were accustomed, and the caregiver was asked to bring the child's familiar foods and utensils.

OBSERVER VARIATION was addressed both in terms of the construction of the scale and the procedure used in this study. It was assumed that most users of the scale would be Speech-Language therapists with clinical experience in feeding difficulties associated with CP, but the use of descriptive as opposed to technical language in the scale items, and the relatively simple 4-point scaling system were employed to minimise variations in interpretation. In this study observer variation was further controlled by the introduction of a second rater (see page 62).

3.3 FOOD & EQUIPMENT FOR ASSESSMENT & TRAINING

It was considered essential that all food and equipment should be easily accessible to both rural families and those from disadvantaged backgrounds.

(i) FOOD

Where a child was still bottle-fed, all mothers /caregivers, without exception provided the equipment and milk formula or juice. The majority routinely also brought the child's usual food such as cereal, vegetables, commercial baby foods, bananas etc. Where this was not available, the CP Clinic provided the following for both assessment and feeding training:

- Cerelac ® Regular cereal for spoon-feeding
- Boudoir ® (lady finger) biscuit pieces, softened in milk, for chewing

- Milk (only if requested by mothers) or semi-liquid custard for cup drinking.

(ii) FEEDING EQUIPMENT (See Appendix F for illustrations)

The mothers and/or caregivers were requested to bring their own feeding equipment, with which the child was familiar. However, a full range of typical utensils (both appropriate and inappropriate) was available so that the items most closely resembling those used at home could be selected.

BOWLS: As the children in this study were all dependent feeders, the features of the feeding bowl were not significant and a small standard bowl was provided if needed.

SPOONS: The characteristics of the spoon influence the efficiency with which the food can be cleared from the bowl of the spoon and into the mouth.

Appropriate spoons included those with the following features:

- ~ Small enough to discourage the child from opening the mouth too wide, triggering general body extension.
- ~ A flat bowl to facilitate removal of the food with the lips.
- ~ Non-flexible to provide tactile input and to facilitate pressure downwards on the tongue, thereby assisting in inhibition of a tongue-thrust.
- ~ Silicone-coated should the child demonstrate oral tactile sensitivity.

Inappropriate spoons were those that failed to meet the above criteria, namely:

- ~ Too big resulting in too wide mouth opening and triggering general body extension
- ~ Too deep making it difficult for the child to remove the food with the lips
- ~ Too flexible (eg soft plastic) and therefore providing insufficient tactile input
- ~ Hard or cold

(Arvedson & Brodsky 1993, Bahr 2001, Morris & Klein 1987, Mueller 1997, Winstock 1994)

MUGS: The mug used in training and provided for home use, was similar to that originally promoted by Helen Mueller (Mueller 1997). Inexpensive, made of flexible plastic, it could be squeezed and adapted to the size of the child's mouth, thereby inhibiting too wide mouth opening with triggering of general body extension. In addition, a semicircular opening cut from one side made it possible to tilt the mug to clear the contents without tipping the child's head back, thus further minimising the triggering of general body extension (Morris & Klein 1987, Mueller 1997, Winstock 1994).

(iii) TRAINING EQUIPMENT

As the fundamental principle guiding this intervention programme was that the mother /caregiver should be able to implement the new feeding techniques at home, the only equipment used comprised ordinary chairs, therapy blocks that could be arranged to simulate a bed or couch, pillows and cushions, blankets and telephone books (the latter for footrests).

Training was augmented by the use of simple drawings to illustrate body position, inappropriate head alignment, alternative ways of providing postural support for the child during feeding etc. These drawings were reproduced in the booklet given to mothers /caregivers for reference at home (Appendix B).

3.4 QUESTIONNAIRE (See Appendix G 1-3)

The purpose of the questionnaire was to determine how the participating mothers/caregivers perceived their training in the feeding therapy programme, so as to provide an indication of the acceptability and sustainability of this feeding intervention programme for mothers and/or caregivers.

(i) CONSTRUCTION OF THE QUESTIONNAIRE

The questionnaire was compiled specifically for use in this study. Cognisance was taken of the fact that the response of mothers /caregivers to the feeding programme was both subjective and abstract, and therefore construction of the questionnaire followed guidelines provided by Oppenheim (1992), Schuman and Presser (1996), Stanley et al (2000), Vaughan and Morrow (1989).

- ORDERING OF QUESTIONS: The questionnaire commenced with 12 structured questions. The first 2 of these questions were of a general nature intended to establish the effectiveness of training in the techniques. The next 4 questions were related to use of specific techniques at home followed by 4 questions dealing with any apparent changes in the child's feeding patterns in response to specific techniques. The last 2 structured questions were intended to establish the likelihood of future compliance with the feeding programme by the mother /caregiver. Two free-response questions were placed at the end of the questionnaire by which time the respondent was likely to feel less constraint in writing out a fuller response (Oppenheim 1992).

- TYPE OF QUESTIONS: In view of the limited literacy skills of many of the respondents, closed questions with pre-coded answer categories were selected for the main part of the questionnaire. Providing a choice of alternative replies was intended to make the questions less leading and facilitate analysis of the data (Schuman & Presser 1996). However, in order to provide a measure of freedom to those respondents who were able to express their impressions in their own way, two open or free-response questions were included (Oppenheim 1992).

- QUESTION WORDING: Pitfalls in question wording as described by Oppenheim (1992), Schuman and Presser (1996) and Vaughan & Morrow (1989) were addressed in the following ways:
  - To facilitate understanding, the wording throughout the questionnaire was kept as simple and familiar to the respondents as possible.
  - In order to minimise the influence of inner curbs on self-incriminating information, loaded words were not used.
  - Care was also taken to minimise response expectations by avoiding leading questions.

Schuman and Presser (1996, p6) state that the respondents most influenced by question form are generally not only those less educated, but also those less interested and involved in the particular issue. As the respondents in this study were both informed and involved, question effects related to wording ought not to have played a major role. Moreover, both the Afrikaans and Xhosa draft translations were given to uninformed natural speakers of these languages for confirmation of the appropriateness of the grammar and ease of understanding, and small modifications made where indicated (Vaughan & Morrow 1989).

- RESPONSE MODE ON THE QUESTIONNAIRE: The closed questions on the questionnaire had 4 pre-coded answer categories as follows:

Yes, definitely	Most of the time	Some of the time	No, not at all

In order to avoid the possibility of inviting evasion by presenting a middle option, 4 response options were provided ranging between strongly positive and strongly negative (Schuman & Presser

1996). To facilitate understanding, wording in the response categories was consistent with only a slight adaptation for the final closed question.

(ii) RELIABILITY AND VALIDITY OF THE QUESTIONNAIRE

Oppenheim (1992), Schuman & Presser (1996), Stanley and others (2000), and Vaughan and Morrow (1989) all caution against factors that could induce respondents to provide answers that might be inconsistent (reliability) or not factual (concurrent validity). Several controls were in place to limit such factors:

- ~ The questionnaires were self-administered in privacy to ensure minimum interviewer bias (Oppenheim 1992, Vaughan & Morrow 1989). Response bias in terms of a desire to please the researcher is less likely with anonymous self-completing questionnaires (Oppenheim 1992).
- ~ To reduce the likelihood of responses tending to satisfy outcome expectations of the study, respondents were informed that neither they nor the researcher were being 'tested', only the feeding techniques.
- ~ Anonymity was ensured by the absence of any identifying name or number on the questionnaire forms, and respondents were asked to place their completed forms randomly between others.
- ~ The respondents were informed and involved and would therefore more easily have grasped the focus of the questions and have also been more sensitive to the verbal distinctions in the four response categories provided (Schuman & Presser 1996).
- ~ The Xhosa-speaking interpreter and other clinic staff members, not the researcher, were on hand to assist any respondent requesting clarification of any items (Vaughan & Morrow 1989).

4. PROCEDURE

One aspect of the validity (truthfulness) and reliability (trustworthiness) of the data recorded in any study can be addressed by examining the rigorousness with which variables were controlled and standards of procedure adhered to (Altman 1991, Bain & Olswang 1994, Beaglehole et al 1993, Bland 2000, Katzenellenbogen et al 1997).

4.1 PRE-INTERVENTION ASSESSMENT

All pre-intervention assessments were conducted in the CP Clinic at Red Cross Hospital between May 2004 and September 2004.

(i) OBTAINING INFORMED CONSENT

The mothers /guardians of all new patients who met the inclusion criteria and agreed to participate in the study, were given a copy of the information and consent document in the language of their choice, English, Afrikaans, or Xhosa (Appendix C 1-3). Mothers /guardians were allowed time to read the information sheet and ask any questions, with the assistance of the Xhosa-speaking clinic interpreter if required, before completing the consent form in duplicate. One document was retained by the mother /guardian, the other filed for record purposes by the researcher. For reasons of security and confidentiality these documents were filed securely with access available to no-one but the researcher.

(ii) PRELIMINARY INTERVIEW

A full feeding history was obtained from the mother or caregiver including information on early methods of feeding, feeding milestones (introduction of solids, chewing, cup, etc), time spent feeding, typical daily diet, drooling, weight gain and constipation (Arvedson & Brodsky 1993, Morris & Klein 1987, Reilly & Skuse 1992). The information was obtained via a structured face-to-face interview with no identifying particulars appearing on the form other than the case number allocated randomly to each participant on their inclusion in the study. The feeding history format (Appendix D1) has been refined and used successfully over the past 6 years at the CP Clinic. Experience has shown that a considerable number of mothers /caregivers initially report no concern regarding feeding, and it is frequently only through more detailed, probing questioning that the difficulties are revealed.

(iii) OBSERVATION AND RATING OF A TYPICAL FEEDING SESSION

Whilst home-based observation of mealtime behaviour of children with CP and the feeding practices of their usual caregiver would be ideal (Reilly & Skuse 1992), this was not an option for this study in view of the socio-economic background of the clinic population and the practical implications. Observation and rating of feeding sessions were therefore clinic-based, but care was taken to ensure that these feeding sessions were a valid reflection of the mealtime situation at home. Throughout this study, the participants were fed by their usual primary feeder and care was taken to duplicate the both the feeder's and child's customary feeding position insofar as possible:

- At the time of making the appointment for observation of a feeding session, the mother /caregiver was asked to bring the child's customary food and to ensure that the child was sufficiently hungry to want to eat despite unfamiliar surroundings. It was explained that the rating would not be a 'test' but a way of gaining the necessary information on the child's feeding difficulties and any problems experienced.
- The mother /caregiver was asked to describe the setting in which the child was usually fed at home and this was reproduced as exactly as possible in a designated part of the clinic. Care was taken to match the height of the seating normally used, arm rests, cushions, position of table etc. Requests for any additions or adjustments were encouraged.
- The mother /caregiver was then required to select the most familiar foods and utensils, either those brought from home or from the clinic range as described, and to proceed with feeding as per the routine normally followed at home. The rater/s took up a position that was as unobtrusive as possible yet permitted adequate observation of the oral movements of the child.
- Rating for each feeding skill area applicable to the particular child was done on the Scale of Feeding Competence in Cerebral Palsy, in the developmental order in which the skills appear on the scale. The assessment forms (Appendix D2) carried no identifying information on the child other than a case number randomly allocated.
- For both cup drinking and chewing there were a number of cases where these skills were already age appropriate for the child, but where the mother /caregiver, due to past experiences, was afraid of choking and/or aspiration and insisted that the child was quite unable to manage the particular skill. If the researcher-clinician considered that there was an unacceptable probability of choking and/or aspiration, and that these skills were not at the given time

~ customary, practical or safe for this particular child-feeder dyad, the mother /caregiver was not forced to proceed. In such cases the maximum rating of 3 was allocated for each item within the function of cup drinking and/or chewing.

~ Once completed, the rating forms for each participant were stored separately from any identifying information, until required for analysis.

(iv) RELIABILITY OF RATING

Reliability can be influenced by a number of potential sources of variation, including the environment and both intra- and inter-observer variation (Katzenellenbogen et al 1997).

* ENVIRONMENT: Care was taken to ensure that the child was calm and relaxed and that the mealtime surroundings replicated those of the home situation as closely as possible (see page 61).

* INTRA-RATER RELIABILITY: The researcher has more than 30 years' experience in the field of cerebral palsy and this experience, together with an extensive literature review and familiarity with the Scale of Feeding Competence in Cerebral Palsy should have ensured a high level of intra-rater reliability.

* INTER-RATER RELIABILITY: The second rater was a speech - language therapist with 4 years experience in the treatment of feeding difficulties in severely ill, hospitalised infants and children. Inter-rater reliability was addressed in the following ways:

~ As discussed under Response Mode (page 53), an initial training period with the Scale of Feeding Competence in Cerebral Palsy was conducted, during which both raters observed and rated the feeding behaviours of a number of non-participants in the study. Independent ratings were compared and discussed until a level of consensus was reached (McCullough et al 2001).

~ In order to establish a pre-study level of confidence in inter-rater reliability, a further 5 feeding sessions were simultaneously but independently rated. A consistent agreement level between 90% and 97% was achieved, with no rating discrepancy more than one unit on the ordinal scale.

~ During the course of the study, 10% of all pre- and post-intervention feeding assessments were independently rated by both observers, with an agreement level ranging from 90% - 94%.

Table 1: Limiting Behaviours in Feeding Skills Addressed by the Feeding Intervention Programme

SKILL	LIMITING BEHAVIOURS	FEEDING INTERVENTION TECHNIQUES
NUTRITIVE SUCKING	Inappropriate head-neck alignment	Maintain upright head position + 'chin tuck' position
	Stiffening/pushing back into extension	Controlled upright postural support + hip & neck flexion
	Poor lip seal with escape of liquid	Chin tuck + facilitation of lip closure with feeder's finger
	Tongue thrust hindering latching and sucking	Chin tuck + pressure down on tongue to inhibit thrust
	No or inappropriate jaw movement	Stabilisation of shoulder girdle to reduce tone in jaw
	Disorganised rhythm and suck-swallow ratio	Postural & proximal stabilisation to facilitate oral function
	Coughing /spluttering while sucking	Stabilisation + 'chin tuck' position to facilitate swallow
SPOON FEEDING	Inappropriate head-neck alignment	Maintain upright head position + 'chin tuck' position
	Stiffening/pushing back into extension	Controlled upright postural support + hip & neck flexion
	Poor achievement & maintenance of lip closure	Chin tuck + facilitation of lip closure with feeder's finger
	Tongue thrust pushing food out	Chin tuck + pressure down on tongue to inhibit thrust
	Inability to cope with variety of textures	Promote ↑ oral experience through finger feeding
	Repeated swallows (tongue cannot control bolus)	Facilitate tongue control through finger feeding
	Biting down on spoon (tonic bite reflex)	Avoid tonic bite by eliciting normal phasic bite response
	Coughing and/or gagging	Stabilisation + 'chin tuck' position to facilitate swallow
CUP DRINKING	Inappropriate head-neck alignment	Maintain upright head position + 'chin tuck' position
	Stiffening/pushing back into extension	Controlled upright postural support + hip & neck flexion
	Excessive spillage	Stabilisation + maintenance of flexion using cut-out mug
	Poor lip closure around the cup	Facilitation of lip closure with chin tuck + feeder's finger
	Tongue position inappropriate	Reduce tongue tone by chin tuck + jaw stabilisation
	Poor co-ordination of sip-swallow	Facilitate control of bolus by thickening consistency
	Biting down on cup	Facilitate control by stabilisation, chin tuck + consistency
CHEWING	Inappropriate head-neck alignment	Maintain upright head position + 'chin tuck' position
	Stiffening/pushing back into extension	Controlled upright postural support + hip & neck flexion
	Poor lip closure	Chin tuck + facilitation of lip closure with feeder's finger
	Tongue thrust → food loss & poor control of bolus	Promote phasic bite by lateral placement of food pieces
	Inefficient /inappropriate jaw movement	Promote phasic bite by lateral placement of food pieces
	Problem controlling bolus → incomplete swallows	Assist tongue function by lateral placement of food pieces
	Gagging or choking	Facilitate swallow by stabilisation + 'chin tuck' position

4.2 FEEDING INTERVENTION PROGRAMME

The feeding intervention programme used was based on the Neurodevelopmental Therapy approach (Bahr 2001, Bly 1991 & 1996, Levitt 1995, Mayston 2000, Morris & Klein 1987, Mueller 1997, Winstock 1994). The focus of the intervention was on reducing the limiting feeding behaviours and inappropriate feeding practices as observed on pre-intervention assessment of the sample of infants /children and their mothers /caregivers. A summary, of how the feeding intervention programme was designed to address the limiting feeding behaviours and inappropriate feeding practices identified in the Scale of Feeding Competence in Cerebral Palsy, appears in Table 1 on page 63.

(i) POSITIONING AND FEEDING TECHNIQUES

Physical handling and positioning techniques that form the basis of postural control and facilitation of movement in the NDT approach were combined with specific feeding techniques in a single intervention programme.

* POSTURAL CONTROL AND POSITIONING: Problems with postural control are one of the most prominent characteristics of cerebral palsy (Levitt 1995, McCarthy 1992), whilst oral musculature needs postural control and stability for function (Möhr 1998, Morris & Klein 1987). The principle that handling (touching, placing and/or moving) the child with CP can either exacerbate or reduce the child's motor control difficulties is fundamental to the Neurodevelopmental Therapy approach (Bly 1991, Irwin-Carruthers 1992, Mayston 2001, SANDTA pamphlet 2003, Saloojee 2005) Consequently specific training in handling and positioning was basic to this feeding intervention programme.

- ~ Mothers and/or caregivers were instructed in a basic understanding of the influence of physical handling and positioning on the overall muscle tone and movements of the child. Simple pictures and demonstrations were used, often involving a doll, and suggestions given as to suitable methods for daily lifting, carrying and positioning of the particular child so as to minimise abnormal motor patterns and promote improved postural control and stability (Finnie 1997, Levitt 1995, WHO 1993). Examples of this training appear in the booklet (Appendix B).

- Mothers /caregivers were taught positioning of the child for all aspects of feeding as follows:
  - Maximum postural support in an appropriate upright position with ± 30° recline,
  - Ensuring hip flexion of more than 90° to limit abnormal extensor tone and thrusting,
  - Head-neck alignment with posterior neck elongation and slight chin tuck

  (Avery-Smith 1997, Carroll & Reilly 1996, Hulme et al 1987, Lewin et al 2001, McCarthy et al 1992, Morris & Klein 1987, Mueller 1997, Winstock 1994)

  Figure 3 shows a typical extended feeding position, whilst Figure 4 shows the controlled feeding position as described above and taught to mothers /caregivers.

- Mothers /caregivers were encouraged to develop a problem-solving approach by creating props and aids with items easily accessible to the mother /caregiver in the home: e.g. bags of sand to provide extra stability, bolsters made by rolling up towels or small blankets, telephone books to raise the leg of the feeder thereby increasing back support for the child, etc.

Figure 3: Inappropriate Position

Figure 4: Feeding Position as taught

* NUTRITIVE SUCKING: Where promotion of nutritive sucking was appropriate for the age of the child, mothers /caregivers were shown how to facilitate latching and lip seal as follows:

- Providing downward pressure with the teat/nipple on the tongue,
- Giving the sensory cue of slight traction on the teat/nipple,
- Assisting lip closure through pressure on the upper lip and/or chin, with the feeder's index and

middle fingers respectively.

(Arvedson & Brodsky 1993, Morris & Klein 1987, Wolf & Glass 1992)

- SPOON FEEDING: Mothers /caregivers were instructed in the following aspects –
  - Appropriate choice of spoon (see page 56).
  - Ensuring that food given with the spoon was of a firm consistency.
  - Maintaining the spoon horizontally on approach and withdrawal from the mouth (Fig 4).
  - Applying downward pressure with the spoon on the child's tongue so as to reduce the strength of the tongue-thrust.
  - Assisting removal of the food from the spoon with the lips by forward and downward pressure of the feeder's supporting arm, thus inducing additional flexion of the child's head.
  - Facilitation of lip closure until completion of the swallow, by an upward rolling pressure of the feeder's finger on the child's chin.
  - Avoiding repeated touching and cleaning of the area around the child's mouth – using a soft cloth to blot excess food instead.

(Arvedson & Brodsky 1993, Bahr 2001, Morris & Klein 1987, Mueller 1997, Winstock 1994)

- CUP-DRINKING: For all participants older than 6 months, cup-drinking was introduced with the special cut-out mug provided by the clinic, and the technique taught as follows:
  - Initial presentation of selected thickened semi-liquids such as yoghurt, custard, fruit puree etc. with gradual progression to normal liquids only once the child has mastered the sip-swallow sequence.
  - Facilitation of lip closure during drinking.
  - Maintaining slight downward pressure with the mug, keeping the mug between the lips and using a paced tilting motion to allow only a small amount of liquid to enter the mouth at a time, and waiting for completion of a swallow after each sipped bolus.

(Avery-Smith 1997, Mueller 1997, Winstock 1994)

- CHEWING: For all participants above the age of 7 months, chewing was introduced by training the mother /caregiver in the following technique for finger-feeding:
  - Selection of suitable food, and preparation into small bite-sized pieces.
  - Insertion of food pieces into the oral cavity between the cheek and teeth and placement posteriorly between the molars or gums.
  - Facilitation of lip closure until completion of chewing and a swallow.
  - Encouraging chewing alternately on both sides of the mouth.

(Mueller 1997, Winstock 1994)

(ii) ENHANCING THE MEALTIME ENVIRONMENT

Mothers /caregivers were taught to be sensitive to the child's non-verbal messages and to the learning and communication possibilities that accompany every meal, in the following ways:

- Watching the child's responses carefully and becoming sensitive to the child's messages of discomfort, 'enough', 'more' etc; and adjusting positioning, presentation of food, wiping spillage etc. accordingly.
- Interacting with the child by encouraging eye contact and attention, responding verbally to the child's communicative attempts, singing, soothing, rocking, commenting on what was happening etc.

(Morris & Klein 1987, Wilder & Granlund 2003, Winstock 1994)

(iii) ADDITIONAL FACTORS IN TRAINING

Throughout the intervention programme the emphasis was on relationship-building between clinician and caregiver, flexibility in terms of what was required of mothers /caregivers, and recognition of each mother's /caregiver's own perception of which issues should receive priority (Sloper 1999). Mothers /caregivers were encouraged to feel that the training sessions were their time and that the agenda was not set by the clinician. They were encouraged to ask questions, seek clarification, and discuss any difficulties they might be experiencing in applying the new feeding methods at home. As the clinician aimed to foster an environment in which clinician and caregiver worked together with a joint problem-solving approach, mothers /caregivers were not given instructions but suggestions and demonstrations, often on a doll or on the mothers themselves. Role playing was used, for example, in allowing caregivers to experience swallowing with the head in extension, to feel the amount of pressure to give with the spoon, etc.

The clinic interpreter played an invaluable role in conveying information to the Xhosa-speaking mothers and relaying their feedback. However, owing to the practical nature of the training sessions, it was possible to proceed in less than ideal circumstances (the clinic interpreter temporarily unavailable, the child ill or asleep).

(iv) FREQUENCY OF TRAINING

As this research was conducted within a normal clinic situation, the length and frequency of training sessions were an uncontrolled variable. Individual sessions varied from 30 minutes to more than an hour, and there was no set number of sessions or level of competency before the post intervention assessment. Specific details regarding number of sessions for each participant appear in Chapter 5.

(v) THE BOOKLET (See Appendix B)

The booklet, reproduced in Appendix B, was available in English, Afrikaans and Xhosa and provided reinforcement and suggestions for overcoming common difficulties encountered in applying the new methods at home. Once the mother /caregiver had received instruction in all aspects of the intervention programme relevant for her particular child, she was guided through the contents of the booklet (together with the clinic interpreter where indicated) and given the booklet for home reference.

4.3 POST-INTERVENTION ASSESSMENT

The post intervention assessments took place during November 2004, coinciding with the child's regular monthly appointment at the CP Clinic.

(i) OBSERVATION AND RATING OF A FEEDING SESSION

Appointments for the post-intervention assessment were made in advance following the usual clinic routine. As with the pre-intervention assessment and during training sessions, the mother /caregiver was asked to bring familiar food and utensils and ensure that the child would be relatively hungry. Before commencement of the post-intervention feeding session she was invited to select what was required in terms of additional food, utensils, and seating arrangements including 'props'.

Observation and rating of specific feeding behaviours on the Scale of Feeding Competence in Cerebral Palsy were carried out as before by the researcher with /without the second observer as specified. To eliminate bias in recording of responses a new rating form was used for the post intervention assessment with no reference to the earlier assessment.

(ii) RELIABILITY OF RATING

The same measures to control issues of reliability in the pre-intervention assessment, pertaining to the assessment environment and both intra-rater and inter-rater reliability, were applicable to the post-intervention assessment.

4.4 QUESTIONNAIRE

Completion of the questionnaire by the mother /caregiver took place immediately following the observation and rating of the final feeding session.

(i) COMPLETION BY MOTHER OR CAREGIVER

Following the feeding session, the mother /caregiver was asked to complete the questionnaire in the language of her choice (Appendix G1-3). Respondents were settled in a quiet adjoining room with total privacy and assured of as much time as required. The Xhosa-speaking clinic interpreter and other clinic staff members were on hand to assist with clarification of any of the items if requested.

To confirm anonymity, no name or coding appeared on the questionnaire and the mother /carer was asked to place her completed questionnaire randomly inside a folder with other completed questionnaires.

5. DATA ANALYSIS

The data collected in all three parts of the study were entered into a Microsoft Excel spreadsheet for subsequent collation and analysis.

PART 1: PROFILE OF FEEDING BEHAVIOURS AND PRACTICES

Descriptive analysis was used to provide a profile of the frequency and severity of specific feeding behaviours (of child participants) and feeding practices (of their mothers /caregivers) observed and evaluated in the pre-intervention feeding sessions. Ratings (0-3) for the 50 individual items on the Scale of Feeding Competence in Cerebral Palsy were analysed in the following ways:

- Individual items for each function area of feeding were ranked in terms of observed frequency.
- Individual items within each function area were ranked in terms of overall severity of ratings.
- Trends in frequency and severity of behaviours /practices within each function area were identified.
- In order to facilitate comparisons across function areas and reveal possible dominant patterns

in severity of feeding difficulties, individual feeding behaviour items were clustered in terms of common features regarding the motor skills and co-ordination involved. Five clusters were identified, namely: body position, oral-motor control, co-ordination of the swallow, overall efficiency of the feeding process (food intake v food loss orally) and reflux.

- Due to the range of ages in the sample, from very young infants to children above four years, all four feeding skills: nutritive sucking, spoon feeding, chewing and cup drinking, were not appropriate for all child participants. As this resulted in varying sample numbers across the four feeding functions, direct comparisons would not have been valid (Keller & Warrack 2003). To derive a common feature as basis for comparison, the ratings for each individual item within a cluster were summed to give a total severity rating for that cluster. Each cluster severity rating was divided by the highest possible severity rating for that cluster, depending on the number of participants rated, and then expressed as a percentage, referred to as the severity index.

This can be expressed in an algebraic equation based on simple mathematical induction (Bester et al 2003) as follows:

r … rating (0; 1; 2; 3)
n … number of participants
y … number of items

T … total
S … severity
S_i … severity index

$T_r = r \bullet n \bullet y$ … total severity rating (for cluster)
for $r = 3$ (maximum rating) $\rightarrow T_{max} = 3ny$
$S_i = (T_r / T_{max}) \bullet 100$ (%)

(Bester et al 2003)

PART 2: FUNCTIONAL OUTCOMES OF THE INTERVENTION

The data for this phase, from the final sample of 24 children, consisted of pre- and post-intervention ratings ranging from 0-3 on the 50 different items on the Scale of Feeding Competence in Cerebral Palsy, grouped into the same five function areas of feeding as in Part 1. In order to assess the functional outcomes of the feeding intervention programme, both statistical and non-statistical methods of analysis were employed. For the statistical analysis, Stata 8 was used to establish the level of significance of differences in severity in pre- and post intervention ratings.

The Shapiro-Wilk test for normality was used on the differences between the pre and post intervention severity data in order to validate the normality assumptions required for the parametric tests. Matched-Pairs T-tests and Wilcoxon Signed Rank Tests were used to determine whether differences in severity ratings after the intervention were significant (Keller & Warrack 2003). For all statistical analyses a p value of 0.05 was considered significant.

The pre- and post-intervention data was subjected to non-statistical analysis in the following ways:

- In order to establish which behaviours occurred most frequently, individual pre-intervention scale items were ranked from highest to lowest number of participants presenting with the particular problem. Post-intervention frequency totals were subtracted from pre-intervention totals with the difference (Δ) signifying the amount of change. For ease of comparison between the four feeding functions, all totals were also converted to percentages.
- Another important aspect of change is the assessment of how a skill or function has changed. Analysis of pre- and post intervention severity ratings of the limiting behaviours recorded for the study participants was used to assess what kind of changes had occurred in the skills measured. Pre- and post-intervention ratings on scale items were grouped according to the severity rating (0 to 3) and expressed as a percentage of the total number of participants in each feeding function in order to facilitate comparison between the four feeding functions.
- As in Part 1, different sample numbers in the four feeding functions meant that direct comparisons could not be made. Therefore, the severity index for each cluster of scale items, both pre- and post intervention was calculated as described on page 70. Where δ = difference or amount of change, calculation of the difference between pre- and post intervention severity indices provided a figure (δS_i) proportional to the magnitude of change.

  Three possibilities were identified:
  $\delta S_i < 0$ represented deterioration
  $\delta S_i = 0$ represented no change
  $\delta S_i > 0$ represented improvement

(Bester et al 2003)

PART 3: EVALUATION OF ACCEPTABILITY AND SUSTAINABILITY

The responses of mothers /caregivers to the questionnaires completed after the post intervention assessment were subjected to content analysis as opposed to statistical analysis and examined for trends and patterns (Katzenellenbogen et al 1997).

6. ETHICAL ISSUES

The ethical issues encountered in this study included acknowledged ethical principles of therapeutic practice in terms of the therapeutic intervention itself, and research ethics surrounding the participation of the mothers /caregivers:

NON-MALEFICENCE was a fundamental principle guiding this study. The research design was such that all participating children were included in the intervention programme. Through the use of a pre- and post intervention measure, the participating children served as their own controls thus precluding the use of a matched control group. In the light of the serious, even life-threatening, nature of feeding and swallowing problems, the necessity of withholding therapeutic intervention from a control group was considered a grave contravention of therapeutic ethics and thus totally unacceptable.

EQUAL OPPORTUNITY was assured by the use of convenience sampling. Thus all patients presenting for the first time at the CP Clinic within the prescribed period who met the study criteria, had an equal opportunity for inclusion in the study.

BENEFICENCE was considered to be of primary importance. As the therapeutic intervention per se was a programme of positional and feeding techniques that have been clinically employed in the treatment of feeding difficulties in the cerebral palsy population and well-reported in the literature, the participants were not subjected to any untried or experimental methods. Conversely, inclusion in the study was of benefit to the participants as they received the identical, routine intervention programme as all patients with similar problems attending the CP Clinic, implemented by the researcher, an experienced clinician.

AUTONOMY of the participating mothers /caregivers was respected by ensuring that they were fully informed of the goals of the study, the procedure to be followed, and what their participation would entail, before being required to sign consent. All were made aware that they could withdraw from the study at any stage without prejudicing further therapy options for the child.

CONFIDENTIALITY was respected and transparent in that the participants were allocated random numbers and only these numbers appeared on all documents relevant to the study. All documents relevant to the study were filed and stored securely, well away from general hospital and clinic files and other identifying information.

ANONYMITY of the mothers /caregivers regarding completion of the questionnaires was regarded as of prime importance, and was ensured by arranging for privacy, the use of unmarked forms, and by the placement of completed forms, by the mother /caregiver herself, randomly inside a closed folder. The photographs used in Figures 3 and 4 did not reveal the identity of the mother concerned and were used with her consent.

CHAPTER 5: RESULTS

The results of the research are presented separately for each of the three parts of the study:

1. PART 1: PROFILES OF FEEDING BEHAVIOURS

The limiting behaviours observed in the sample of 35 infants and children with severe feeding difficulties and the limiting feeding practices employed by their mothers /caregivers were rated prior to the specific feeding intervention programme, and analysed to provide a descriptive profile.

1.1 DESCRIPTION OF PARTICIPANTS

In the preliminary interview with the 35 mothers /caregivers, the main feeding difficulty cited was 'not getting enough food in / the tongue pushes everything out' followed by 'cannot chew / chokes / can only manage soft foods'. A total of 6 (17%) of the mothers /caregivers, however, initially reported no concern regarding feeding, despite describing a diet of soft foods only for their child. According to the Dietetics Department at Red Cross Hospital, the diets of all participants did not satisfy criteria in terms of age-appropriate quantity, variety and/or nutritional value. This discrepancy between maternal perception of a feeding problem, inadequate diet, and observed feeding behaviours, may result in delayed referral and will be discussed in the following chapter.

The identifying characteristics of all 35 children in the sample are presented in Table 2, on page 75. The summary table (Table 3) shows that more than 50% of the sample children were Xhosa males between 1-3 years of age, with a diagnosis of Spastic Quadriplegia. Major associated problems were microcephaly, seizures, cortical visual impairment, drooling, constipation and failure to thrive.

Table 3: Number of Participants in Each Diagnostic / Demographic Category (Part 1)

# PARTICIPANTS IN EACH DIAGNOSTIC CATEGORY					# PARTICIPANTS IN EACH DEMOGRAPHIC CATEGORY							
Evolving CP	Spastic Quad	Spastic Tri.	Evolving Dystonia	Sp/Dystonia	<1y	1-3y	4y +	M	F	Afr	Eng	Xho
3	24	1	2	5	11	21	3	19	16	6	9	20

# PARTICIPANTS WITH ASSOCIATED NEUROLOGICAL PROBLEMS								# WITH OTHER PROBLEMS		
Micro.	Hydro.	Seizures	CVI	Hear/Loss	GOR	Gastros.	G.Delay	FTT	Drooling	Const.
15	2	18	13	4	9	5	7	17	21	26

Table 2: Identifying Characteristics of all 35 Participants

#	DIAGNOSIS	AGE	SEX	LANG	ASSOCIATED NEUROLOGICAL PROBLEMS	OTHER PROBLEMS RELATED TO POOR ORAL-MOTOR FUNCTION
30	Evolving CP	<1	M	A	Microcephaly /Seizures /CVI	FTT /Constipation
12	Evolving CP	1	F	E	Microcephaly /Seizures /CVI	FTT / Drooling /Const
26	Evolving CP	1	M	E	*Microcephaly /CVI	FTT
3	Spastic Quad	<1	M	X	Microcephaly /CVI	FTT /Constipation
4	Spastic Quad	<1	F	E	Hydrocephaly /Seizures /CVI	Drooling /Constipation
8	Spastic Quad	<1	F	E	Microcephaly /Seizures /GOR	FTT /Drooling
15	Spastic Quad	<1	M	X	Microcephaly /Seizures /?CVI	FTT /Constipation
16	Spastic Quad	<1	M	X	Microcephaly/Seizures/CVI/GOR	Drooling /Constipation
22	Spastic Quad	<1	M	X	Microcephaly/Seizures/CVI/GOR	Constipation
32	Spastic Quad	<1	M	A	*Microcephaly /Seizures	FTT /Drooling /Const.
2	Spastic Quad	1	M	X	Microcephaly /Seizures	Drooling
6	Spastic Quad	1	M	E	Microcephaly /CVI /?HL	Drooling /Constipation
23	Spastic Quad	1	F	X	**MCA/GD/GOR+GT/Seizures	Drooling /Constipation
24	Spastic Quad	1	M	E	Microcephaly /CVI /Seizures	FTT /Drooling
33	Spastic Quad	1	F	X	TBM /Microcephaly /CVI	Drooling /Constipation
34	Spastic Quad	1	F	X	Micro. /Seizures /HL /GOR+GT	FTT /Drooling /Const.
35	Spastic Quad	1	M	X	Microcephaly	Drooling /Constipation
11	Spastic Quad	2	F	A	Global Delay	Drooling /Constipation
18	Spastic Quad	2	M	X	Hydrocephalus /GOR+GT	FTT
31	Spastic Quad	2	F	A	Microcephaly /Seizures	FTT /Constipation
17	Spastic Quad	3	F	A	Microcephaly /HL /GOR+GT	FTT /Drooling /Const.
19	Spastic Quad	3	F	X	?Global Delay	Drooling
21	Spastic Quad	3	F	X	Microcephaly	FTT /Drooling
28	Spastic Quad	3	M	X	Microcephaly /CVI	Constipation
1	Spastic Quad	4	F	X	Global Delay	Drooling /Constipation
25	Spastic Quad	4	M	X	Hydrocephalus	FTT /Drooling /Const.
27	Spastic Quad	12	M	X	Global Delay /Seizures	Constipation
13	Spastic Triplegia	1	M	X	Microcephaly /Seizures	Drooling /Constipation
9	Evolving Dystonia	<1	M	E	--------	Drooling /Constipation
20	Evolving Dystonia	<1	F	X	--------	FTT /Constipation
5	Spastic/Dystonic	<1	M	X	Seizures	Constipation
10	Spastic/Dystonic	1	F	E	Microcephaly /Seizures	FTT /Constipation
7	Spastic/Dystonic	2	M	E	Global Delay /CVI /GOR	Drooling /Constipation
14	Spastic/Dystonic	2	F	X	CVI /Seizures	FTT /Constipation
29	Spastic/Dystonic	3	F	A	TBM /GD /GOR+GT /?HL	

KEY:		
	CVI – Cortical Visual Impairment	GOR – Gastro-oesophageal Reflux
	TBM – Tubercular Meningitis	GT – Gastrostomy
	HL – Hearing Loss	FTT – Failure to Thrive (diagnosed by paediatrician)

* Congenital Brain Abnormality

** Multiple Congenital Abnormality including Cleft Palate (repaired)

1.2 LIMITING FEEDING BEHAVIOURS OF INFANTS / CHILDREN

The findings for each of the four function areas of feeding are presented initially in terms of the individual limiting behaviours observed, with profiles of the frequency and severity of ratings. This is followed by a comparison between clusters of limiting behaviours associated with each function area, and finally by a comparison of trends identified across the four function areas.

(i) NUTRITIVE SUCKING

Nutritive sucking includes both breast-feeding and bottle-feeding. Two participants were fed with both breast and bottle at the time of the assessment. However, as a breast-feeding sample of 2 was considered too small for inclusion on the profile, ratings for bottle feeding only were included under nutritive sucking.

Of the total sample of 35 participants, 18 were assessed for nutritive sucking (age range 3 months – 1 year 11 months) with the remaining 17 participants excluded for the following reasons:

- PROBLEMS WITH SUCKING TOO SEVERE: For 5 participants, fluids were currently being given solely by alternative means such as a spoon, syringe, gastrostomy tube, etc.
- BOTTLE-FEEDING NOT AGE APPROPRIATE: An additional 4 participants, ranging from 1 year 11 months to 3 years 10 months of age, were still given all liquids from a bottle. However, as one of the goals of the intervention programme was to promote cup drinking in preference to bottle drinking where age-appropriate, pre-intervention ratings for bottle drinking were not taken for these 4 participants.
- ALREADY WEANED FROM BOTTLE TO CUP: A further 8 participants fell into this category.

Table 4 shows the behaviours observed during nutritive sucking in the order of their frequency of occurrence, the number of participants presenting with each behaviour, and the severity ratings.

As can be seen from Table 4, 83% (10 of 12) of the limiting behaviours associated with nutritive sucking, identified by the Scale of Feeding Competence in Cerebral Palsy, were observed in at least 61% (11 of 18) of the participants. Vomiting and regurgitation behaviours occurred with markedly less frequency, despite being reported regularly in the case histories.

Table 4: Profile of Behaviours associated with Nutritive Sucking

NUTRITIVE SUCKING Behaviours in order of frequency	Analysis of behaviours during sucking				
	Frequency		Severity		
	Total		Severe (%)	Moderate (%)	Mild (%)
	n = 18	(%)			
Inappropriate head/neck alignment	18	100	45	33	22
Poor lip seal / undue escape of liquid	17	94	33	22	39
Tongue thrust hindering sucking	16	84	22	45	22
Stiffening/pushing back during feed	15	83	17	28	38
Tongue unable to assist latching	15	83	33	33	17
No or inappropriate jaw movement	15	83	6	44	33
Time relative to intake per feed	15	83	39	28	16
Abnormal ratio of suck : swallow	14	78	17	44	17
Disorganised sucking rhythm	14	78	22	28	28
Coughing /spluttering while sucking	11	61	11	17	33
Vomiting during / after feeds	8	45	11	28	6
Nasal regurgitation during /after feeds	1	6	0	0	6

The findings regarding severity ratings of limiting behaviours associated with nutritive sucking suggest that those skills most severely affected in this sample included head/neck alignment, time relative to intake per feed, and tongue latching. Generally, the severity ratings showed a fairly even distribution across the 3 rating categories. In other words, the range between the mild, moderate and severe categories was relatively small, with average percentages ranging from 21% to 29%.

Table 5 shows how limiting behaviours associated with nutritive sucking were clustered in groups and the severity index for each cluster calculated according to the formula given on page 70.

Table 5: Behaviour Clusters for Nutritive Sucking ranked in terms of Severity Indices

CLUSTERS	Body Position	Efficiency	Oral-motor control	Co-ordination of Suck-Swallow-Breathe	Reflux
SEVERITY INDEX	58%	57%	56%	43%	15%
INDIVIDUAL BEHAVIOURS	Inappropriate head/neck alignment	Time relative to intake per feed	Poor lip seal / undue escape of liquid	Abnormal ratio of suck : swallow	Vomiting during / after feeds
	Stiffening/pushing back during feed	-	Tongue thrust hindering sucking	Disorganised sucking rhythm	Nasal regurgitation during /after feeds
	-	-	Tongue unable to assist latching	Coughing / spluttering while sucking	-
	-	-	No or inappropriate jaw movement	-	-

Table 5 shows that the range in severity index (S_i) values for the behaviour clusters involving body position, oral-motor control and overall efficiency of sucking was small, whilst the reflux cluster S_i was notably lower.

(ii) SPOON FEEDING

As the 3-month old infant in the sample was not yet fed solids at the commencement of the study, assessments of spoon feeding competency were obtained on a total of 34 participants, ranging in age from 6 months to 12 years and 10 months.

Table 6 presents the limiting behaviours observed during spoon feeding in the order of their frequency of occurrence, the number of participants presenting with each of the behaviours, and the severity ratings of each.

Table 6: Profile of Behaviours associated with Spoon Feeding

SPOON FEEDING Behaviours in order of frequency	Analysis of behaviours during spoon feeding				
	Frequency		Severity		
	Total n=34	(%)	Severe (%)	Moderate (%)	Mild (%)
Unable to maintain lip closure	34	100	23	62	15
Inappropriate head/neck alignment	33	97	44	47	6
Poor lip closure around the spoon	33	97	29	53	15
Tongue pushing the food out	33	97	38	44	15
Stiffening/pushing back while eating	31	91	24	47	20
Unable to cope with variety of textures	31	91	53	29	9
Repeated swallows per mouthful	27	79	26	35	18
Biting down on the spoon	22	65	9	26	29
Insufficient amount taken by spoon	22	65	15	26	24
Frequent coughing whilst eating	21	62	3	27	32
Gagging or choking	19	56	3	21	32
Significant vomiting after solids	6	18	0	12	6

The limiting behaviours recorded for spoon feeding reflect the increased task demand of this skill compared to sucking, with an overall trend of increasing frequency and severity of specific behaviours observed. Of those limiting behaviours associated with spoon feeding, 92% (11 of 12) were observed in more than half the participants, with 50% (6 of 12) observed in 91% to 100% of the sample of 34. Only vomiting occurred with low frequency.

In terms of severity ratings, those skills most severely affected in this sample included head/neck alignment, achieving and maintaining lip closure, and the ability to manage a variety of textures.

Tongue thrusting presented as a moderate to severe limiting behaviour in 82% of the participants. In comparison with the severity ratings for limiting behaviours associated with nutritive sucking, there was a wider distribution of ratings across the 3 rating categories. The average percentages in the mild, moderate and severe categories for limiting behaviours associated with spoon feeding were 18%, 36% and 22% respectively.

Clusters of limiting behaviours associated with spoon feeding and the severity index calculated for each cluster are presented in Table 7, showing that the range in severity index (S_i) values for the behaviour clusters was relatively wide, with limiting behaviours involving body position prominent, whilst the severity index for vomiting/reflux was notably lower than others.

Table 7: Behaviour Clusters for Spoon Feeding ranked in terms of Severity Indices

CLUSTERS	Body Position	Oral motor control	Efficiency	Co-ordination of swallow	Reflux
SEVERITY INDEX	70%	60%	58%	38%	10%
INDIVIDUAL BEHAVIOURS	Inappropriate head/neck alignment	Poor lip closure around the spoon	Unable to cope with variety of textures	Repeated swallows per mouthful	Significant vomiting after solids
	Stiffening/pushing back while eating	Biting down on the spoon	Insufficient amount taken by spoon	Frequent coughing whilst eating	-
	-	Unable to maintain lip closure	-	Gagging or choking	-
	-	Tongue pushing the food out	-	-	-

(iii) CUP DRINKING

Assessments of cup drinking competency were obtained for 31 participants, as only those older than 8 months were assessed for this skill. Of these 31 participants, 18 (58%) were described in the case histories as 'totally unable to drink from a cup or mug'. As noted earlier, 5 participants had such severe problems with taking in fluids via either bottle or cup that alternative means were used. Of these 5, 1 was fed fluids exclusively via a syringe, 2 received all fluids with a spoon, 1 through a gastrostomy tube or occasionally with a spoon, and 1 via a gastrostomy tube only. The remaining

13 participants in this group of 18 were all still drinking exclusively from a bottle.

As stated in the Procedure section (page 61), where the clinician estimated that there was an unacceptable probability of choking and/or aspiration, and that cup drinking was not customary, practical or safe for this particular child-feeder dyad, the mother/caregiver was not obliged to attempt this feeding function. On this basis, a maximum rating of 3 was allocated for each limiting feeding behaviour in cup drinking for 14 of the sample of 31 participants.

Table 8 presents the behaviours observed during cup drinking in the order of their frequency of occurrence, the number of participants displaying each of the behaviours, and their severity ratings.

Table 8: Profile of Behaviours associated with Cup Drinking

CUP DRINKING Behaviours in order of frequency	**Analysis of behaviours during cup drinking**				
	Frequency		**Severity**		
	Total n=31	(%)	**Severe** (%)	**Moderate** (%)	**Mild** (%)
Excessive spillage	31	100	71	26	3
Inappropriate head/neck alignment	31	100	68	19	13
Stiffening/pushing back while drinking	30	97	65	23	9
Poor lip closure around the cup	30	97	71	23	3
Tongue position inappropriate	30	97	68	19	10
Poor co-ordination of sip-swallow	30	97	75	16	6
Augmented fluid intake (bottle, spoon, etc)	27	87	81	3	3
Biting down on the cup	20	65	52	13	0

Cup drinking is a more advanced skill in the developmental sequence than sucking and spoon feeding, and the increased task demand was reflected not only in the greater frequency of all 8 limiting behaviours observed (ranging from 65% to 100% frequency of individual behaviours), but also in the higher percentage of ratings in the severe category for all 8 behaviours (ranging between 52% and 81%). There was a wide range in distribution of severity ratings, with average percentages of 6% in the mild category, 18% moderate, and 69% severe. All limiting behaviours identified on the Scale of Feeding Competence in CP occurred with comparatively equally high frequency and severity.

Four behaviour clusters were identified for cup drinking, and their severity indices calculated as before. The results are presented in Table 9.

Table 9: Behaviour Clusters for Cup Drinking ranked in terms of Severity Indices

CLUSTERS	Co-ordination of swallow	Efficiency	Body Position	Oral motor control
SEVERITY INDEX	87%	87%	84%	77%
INDIVIDUAL BEHAVIOURS	Poor co-ordination of sip-swallow	Excessive spillage	Inappropriate head/neck alignment	Poor lip closure around the cup
	-	Augmented fluid intake (bottle, spoon, etc)	Stiffening/pushing back while drinking	Biting down on the cup
	-	-	-	Tongue position inappropriate

Table 9 illustrates the uniformly high severity indices of all four behaviour clusters for cup drinking relative to sucking and spoon feeding.

(iv) CHEWING

Of the sample of 35 participants, a total of 31 were above the age of 9 months by which stage early munching patterns would normally have progressed to more mature and complex rotary grinding movements. In this group of 31 participants, on whom the profile for behaviours limiting chewing was based, 25 (81%) ranging in age from 9 months to 12 years, were described by their mothers /caregivers as being ‘unable to chew’ and all were still exclusively on a ‘soft diet’ of cereal and finely mashed or pureed foods. On the basis of the observation of the child’s feeding difficulties in the preceding part of this assessment and of the competence and/or anxiety of the mother /caregiver, the clinician judged whether it was acceptable, practical or safe to request a demonstration of chewing. Accordingly, objective assessment of this feeding function was not completed for 25 of the 31 participants and a maximum rating of 3 was allocated for each of the 8 limiting behaviours identified with chewing.

Table 10 presents the behaviours limiting chewing in the order of their frequency of occurrence, the number of participants presenting with each behaviour, and severity ratings for each behaviour. These results were in keeping with the trend already identified of a marked increase in frequency and severity of limiting behaviours matching the increase in developmental complexity of each feeding skill.

Table 10: Profile of Behaviours associated with Chewing

CHEWING Behaviours in order of frequency	Analysis of behaviours during chewing				
	Frequency		Severity		
	Total n=31	(%)	Severe (%)	Moderate (%)	Mild (%)
Poor lip closure while chewing	31	100	84	13	3
Limited tongue action to form bolus	31	100	94	6	0
Inefficient /inappropriate jaw movement	31	100	87	10	3
Tongue pushing the food out	30	97	84	7	6
Stiffening/pushing back while chewing	30	97	81	13	3
Inappropriate head/neck alignment	30	97	81	13	3
Residue retained after swallow	30	97	81	6	10
Gagging or choking	29	94	81	3	10

The increased task demand of chewing was confirmed by the frequency of 94% to 100% of all 8 limiting behaviours observed, and in the increased percentage of ratings in the severe category for all 8 behaviours (81% to 94%), with few ratings in either the moderate (average 9%) or mild categories (average 5%).

The behaviour clusters identified for chewing and their severity indices are presented in Table 11. The severity indices for all three behaviour clusters, as shown in Table 11, were uniformly high, also with little variation in range, thus confirming the extreme difficulty that chewing presented to all 31 participants.

Table 11: Behaviour Clusters for Chewing ranked in terms of Severity Indices

CLUSTERS	Oral motor control	Body Position	Co-ordination of swallow
SEVERITY INDEX	94%	90%	87%
INDIVIDUAL BEHAVIOURS	Poor lip closure while chewing	Inappropriate head/neck alignment	Residue retained after swallow
	Tongue pushing the food out	Stiffening/pushing back while chewing	Gagging or choking
	Limited tongue action to form bolus	-	-
	Inefficient / inappropriate jaw movement	-	-

(v) COMPARATIVE SEVERITY OF BEHAVIOUR CLUSTERS IN FEEDING SKILLS

Many of the individual limiting behaviours identified for each feeding function were specific to that particular skill thus precluding direct comparison between the four feeding functions. However, the severity indices of behaviour clusters were compared across all four feeding skills so as to reveal any trends and these results are presented in Table 12.

Table 12: Severity Indices of Behaviour Clusters for all Four Feeding Functions

Behaviour Cluster	Severity indices – S_I (%)			
	Sucking	Spoon Feeding	Cup Drinking	Chewing
Body Position	58	70	84	90
Oral motor control	56	60	77	94
Efficiency	57	58	87	-
Co-ordination of swallow	43	38	87	87
Reflux	15	10	-	-

It can be seen from Table 12 that the trend for increasing severity with increasing developmental complexity of the specific feeding skill, was manifested for all behaviour clusters except reflux. It is also apparent that whilst the severity indices for body position rose uniformly with the developmental level of each feeding skill, the severity index for oral motor control rose more steeply for chewing, and that for co-ordination of the swallow rose most steeply for cup drinking and chewing.

1.3 PROFILE OF FEEDING PRACTICES OF CAREGIVERS

The function area of Caregiver Competence on the Scale of Feeding Competence in Cerebral Palsy identified 10 limiting feeding practices commonly employed by mothers /caregivers. Of these 10 feeding practices, 5 related to spoon feeding. The 3 month old infant in the sample was still entirely bottle-fed and consequently 5 of the 10 caregiver behaviours assessed on the scale could not be observed or rated for this participant's mother/caregiver. Consequently data from which the profile of feeding practices employed by mothers /caregivers was compiled was based on a sample of 34.

The specific practices observed during a feeding session in the order of their frequency of occurrence, the number of participants presenting with each of the practices, and the total severity ratings for each practice identified, are presented in Table 13.

Table 13: Profile of Feeding Practices of Caregivers

LIMITING FEEDING PRACTICES in order of frequency	Analysis of Feeding Practices				
	Frequency		Severity		
	Total		Severe (%)	Moderate (%)	Mild (%)
	n=34	(%)			
Scrapes food off upwards	34	100	35	59	6
Permits head-neck extension	33	97	41	47	9
Inadequate general postural support	32	94	23	62	9
Collects and reinserts drooled food	32	94	35	53	6
Repeated touching of circum-oral area	29	85	12	50	23
Encourages wide mouth opening	28	82	18	20	44
Inappropriate choice of spoon	19	56	26	21	9
Permits sucking on spoon	18	53	3	29	21
Inappropriate pacing of presentation	16	47	3	26	18
Limited interaction with child	13	38	6	12	20

These findings indicate that 80% (8 of 10) of the feeding practices identified by the Scale of Feeding Competence in Cerebral Palsy were observed in more than half (ranging from 53% to 100%) of the participating mothers/caregivers. The 2 interactive behaviours, involving rate of presentation of food and interaction with the child, occurred less frequently.

The 3 feeding practices with the highest severity ratings were the permitting of head-neck extension, scraping the food off with the spoon against the child's palate, and collecting and reinserting drooled food. The majority of feeding practices were recorded in the moderate category with an average of 38%, followed by severe (20%) and then mild (17%).

1.4 SUMMARY OF FINDINGS IN PART 1

The main findings in Part 1 of the study are presented in summary form as follows:

(i) COMMONALITY OF BEHAVIOURS AND PRACTICES

Of the 50 behaviours and practices identified by the Scale of Feeding Competence in CP, 45 of these occurred in 50% to 100% of all the participants. Table 14 presents the percentage of frequencies and combined severe and moderate ratings, observed in at least half the participants, for each feeding skill and for caregiver competence (derived from Tables 4, 6, 8, 10, 13). The common levels of frequency and severity confirm that these feeding behaviours and practices were shared by and/or common to the majority of sample children and participating mothers /caregivers.

Table 14: Frequency & Severity Levels recorded in Majority of Participants

FEEDING FUNCTION AREA	FREQUENCY	SEVERE-MODERATE
	Behaviours recorded in 50% or more of sample	Behaviours rated in these categories in 50% or more of sample
Nutritive Sucking	83%	67%
Spoon Feeding	92%	58%
Cup Drinking	100%	100%
Chewing	100%	100%
Caregiver Competence	80%	50%

(ii) FREQUENCY & SEVERITY INCREASED WITH DEVELOPMENTAL LEVEL

The predominant trend across all 4 feeding skills in the participating children was the marked escalation in frequency and severity of limiting behaviours, and in the calculated severity indices of behaviour clusters, in direct relation to the increasing developmental complexity of each skill (Tables 4, 6, 8, 10, 12).

(iii) PREDOMINANCE OF CERTAIN BEHAVIOUR CLUSTERS

Table 15 compares the total severity indices of behaviour clusters for all four feeding skills combined, and shows that body position was predominant overall, followed by oral motor control, efficiency and co-ordination of the swallow. Behaviours associated with reflux, measured only for nutritive sucking and spoon feeding, were low in frequency (Tables 4 & 6) and severity.

Table 15: Average Severity Indices for all Feeding Skills

BEHAVIOUR CLUSTER	AVERAGE SEVERITY INDICES
Body Position	76%
Oral Motor Control	72%
Efficiency	67%
Co-ordination of Swallow	64%
Reflux	13%

(iv) PREDOMINANCE OF CERTAIN FEEDING PRACTICES

The 5 most predominant inappropriate feeding practices observed in mothers /caregivers, in terms of both frequency and severity, were those related to body position, namely permitting head-neck extension and inadequate postural support, and the 3 compensatory practices of scraping the food off with the spoon against the child's palate, collecting and reinserting drooled food, and repeatedly touching or mopping around the child's oral area.

2. PART 2: FEEDING INTERVENTION OUTCOMES

The second part of the study was designed to evaluate the effectiveness of the feeding intervention programme based on the NDT approach. Pre- and post intervention ratings of feeding behaviours and feeding practices in a sample of 25 infants/children and their mothers/caregivers were analysed and compared.

2.1 DESCRIPTION OF PARTICIPANTS

With reference to the description of participants in Table 2 (page 75), those highlighted are the 25 participants who made up the final sample for Part 2 of the study. A summary description of these 25 participants is presented in Table 16.

Table 16: Numbers of Participants in each Diagnostic / Demographic Category (Part 2)

# PARTICIPANTS IN EACH DIAGNOSTIC CATEGORY					# PARTICIPANTS IN EACH DEMOGRAPHIC CATEGORY							
Evolving CP	Spastic Quad	Spastic Tri.	Evolving Dystonia	Sp/Dystonia	<1y	1-3y	4y +	M	F	Afr	Eng	Xho
2	15	1	2	5	9	15	1	14	11	5	7	13

# PARTICIPANTS WITH ASSOCIATED NEUROLOGICAL PROBLEMS								# WITH OTHER PROBLEMS		
Micro.	Hydro.	Seizures	CVI	Hear/Loss	GOR	Gastros.	G.Delay	FTT	Drooling	Const.
14	1	13	11	3	6	3	6	10	14	21

As with the larger sample in Part 1 (Table 3), more than 50% of the participants in Part 2 were Xhosa males between 1-3 years of age, with a diagnosis of Spastic Quadriplegia. Major associated problems were microcephaly, seizures, cortical visual impairment, drooling, constipation and failure to thrive.

2.2 TRAINING SESSIONS

As noted earlier, the length and frequency of training sessions were not predetermined. Within the normal clinic situation, time allotted to any one mother /caregiver and child could vary from 30 minutes to 1hour or more, depending on many extraneous factors: the number of patients attending clinic; how many other appointments the child had that day (neurology, eyes, audiology, etc); and the physical /emotional state of the child (asleep, ill, fitting etc) and mother. Similarly, there was no set number of sessions or level of competency before the post intervention assessment, and training sessions attended by each mother /caregiver and child between the pre- and post intervention feeding assessments varied as shown in Table 17. Number of sessions refers to training sessions for each feeder-child dyad only, and does not include pre- and post intervention feeding assessments. The mother and child who attended one training session only were recalled suddenly to the Eastern Cape, and returned for the post intervention assessment after 2 months of home practice. The average number of training sessions attended was 4.

Table 17: Frequency of Training Sessions

NUMBER OF TRAINING SESSIONS ATTENDED BY PARTICPANTS					
1 session	2 sessions	3 sessions	4 sessions	5 sessions	6 sessions
1	6	7	6	4	1

2.3 CHANGES IN PRE- AND POST INTERVENTION SEVERITY

On the Shapiro-Wilk Test for normality, the differences in pre- and post intervention rating of severity for all 5 of the feeding functions were found to be normally distributed, with all values of $p > 0.3$. With normal distribution of differences, the use of standard parametric tests was indicated. Nevertheless, due to the limitations of tests for normality for small sample sizes, non-parametric tests were used for additional confirmation (Altman 1991, Bland 2000, Keller & Warrack 2003). The results of both the parametric (Matched-Pairs T-tests) and the non-parametric (Wilcoxon Signed Rank Tests) tests confirmed significant post intervention changes in the severity of limiting feeding behaviours in the participants during nutritive sucking, spoon feeding, cup drinking and chewing, and in the severity of inappropriate feeding practices of their mothers/caregivers. The statistical analyses are summarised in Table 18.

Table 18: Differences in Pre- and Post Intervention Ratings of Severity

Variable	Sample size	Matched-Pairs T-tests		Wilcoxon Signed Rank Tests	
		Test stat	p value	Test stat	p value
Nutritive sucking	9	6.86	0.0001	2.67	0.008
Spoon-feeding	24	12.3	0.00001	4.29	0.00001
Chewing	20	13.19	0.00001	3.92	0.0001
Cup drinking	24	14.22	0.00001	4.3	0.00001
Caregiver competence	24	10.83	0.00001	4.29	0.00001

2.4 FUNCTIONAL OUTCOMES IN LIMITING FEEDING BEHAVIOURS

A descriptive analysis of intervention outcomes measured in the limiting behaviours of the 25 participating infants/children is presented in terms of general trends for each of the four feeding skills, followed by comparisons between behaviour clusters – both within specific skills and across the different feeding skills.

(i) NUTRITIVE SUCKING

Due to differences in developmental stages of feeding, only 15 participants, out of the final sample of 25, had been assessed for pre-intervention nutritive sucking. Over the course of the intervention however, 6 of these 15 participants were weaned from bottle to cup. The sample for outcomes measurement in nutritive sucking was therefore reduced to 9 participants, with an age range from 3 months to 1 year 3 months.

Table 19 presents the frequency of pre-and post-intervention limiting behaviours recorded during nutritive sucking, with δf = the difference between pre- and post intervention frequencies. The greater the post intervention reduction in frequency, the greater the improvement signified. In Table 19 the decrease in post intervention frequency of limiting behaviours is shown by the positive δf values, ranging from 22% to 78% in all behaviours except nasal regurgitation, which was not observed at all in either the pre- or post intervention assessments. Five of the 12 behaviours (42%) showed a post intervention frequency decrease of above 50%.

Table 19: Frequency of Behaviours during Nutritive Sucking: Pre- & Post Intervention

NUTRITIVE SUCKING Behaviours in order of decreased frequency post-intervention	Participants with this behaviour					
	n = 9			(%)		
	Pre	Post	δf	Pre	Post	δf
Stiffening/pushing back during feed	7	0	7	78	0	78
Poor lip seal / undue escape of liquid	8	1	7	89	11	78
No or inappropriate jaw movement	7	1	6	78	11	69
Inappropriate head/neck alignment	9	3	6	100	33	67
Time relative to amount taken per feed	6	1	5	67	11	56
Abnormal ratio of suck : swallow	7	3	4	78	33	45
Tongue thrust hindering sucking	7	4	3	78	45	33
Disorganised sucking rhythm	7	4	3	78	45	33
Vomiting during / after feeds	3	0	3	33	0	33
Coughing /spluttering while sucking	5	3	2	56	33	23
Tongue unable to assist latching	7	5	2	78	56	22
Nasal regurgitation during /after feeds	0	0	0	0	0	0
					Average δf	45

Table 20 presents the pre- and post-intervention severity ratings for each limiting behaviour recorded during nutritive sucking.

Table 20: Severity Ratings of Behaviours during Nutritive Sucking: Pre- & Post intervention

NUTRITIVE SUCKING Behaviours in order of pre-intervention frequency	Ratings for individual limiting behaviours n = 9							
	Severe (%)		Moderate (%)		Mild (%)		No problem (%)	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Inappropriate head/neck alignment	33	0	22	11	45	22	0	66
Poor lip seal / undue escape of liquid	11	0	33	0	45	11	11	89
Tongue thrust hindering sucking	22	0	45	22	11	23	22	55
Stiffening/pushing back during feed	11	0	22	0	45	0	22	100
Tongue unable to assist latching	11	0	56	23	11	33	22	44
No or inappropriate jaw movement	0	0	45	0	33	11	22	89
Abnormal ratio of suck : swallow	12	0	33	0	33	33	22	67
Disorganised sucking rhythm	22	0	23	0	33	45	22	55
Time relative to amount taken per feed	33	0	23	11	11	0	23	89
Coughing /spluttering while sucking	0	0	11	0	45	33	44	67
Vomiting during / after feeds	0	0	33	0	0	0	67	100
Nasal regurgitation during /after feeds	0	0	0	0	0	0	100	100
Average %	**13**	**0**	**29**	**5**	**26**	**18**	**31**	77

The finding that the average percentage of participants with severe, moderate or mild ratings for limiting behaviours decreased post-intervention, with no ratings in the severe category, suggests that the severity of the behaviours had decreased as a result of the intervention. This interpretation is supported by the finding that the average percentage of behaviours recorded in the no problem category more than doubled after the intervention.

The post intervention shift of behaviours from the severe, moderate or mild categories to the no problem category is further illustrated in Table 21, where the average of decreases in severity (all ratings in the severe, moderate and mild categories) for each of the behaviours (-x%) is compared to the average increase in the no problem category for that behaviour (+x%).

With reference to Tables 19 and 21, it can be seen that all limiting behaviours, other than nasal regurgitation which was not observed either pre- or post intervention in this sample, showed change (i.e. improvement) after the intervention. Those behaviours showing the most change in frequency and severity were 'stiffening/pushing back during a feed' and 'poor lip seal with undue escape of liquid'. The behaviours ranked lowest for amount of change were 'tongue unable to assist latching' and 'coughing /spluttering while sucking' (the latter suggesting poor co-ordination of the swallow with possible aspiration).

Table 21: Percentage Change in the Severity of Nutritive Sucking Behaviours

NUTRITIVE SUCKING Behaviours ranked in order of overall percentage change		**Severity** % decrease	**No problem** % increase
Poor lip seal	1	-26	+78
Stiffening/pushing back during a feed	2	-23	+78
No or inappropriate jaw movement		-34	+67
Inappropriate head/neck alignment	3	-22	+66
Time relative to amount taken per feed	4	-19	+66
Abnormal ratio of suck : swallow	5	-15	+45
Disorganised sucking rhythm	6	-19	+38
Tongue thrust hindering sucking	7	-11	+33
Vomiting during / after feeds		-11	+33
Coughing /spluttering while sucking	8	-8	+23
Tongue unable to assist latching	9	-7	+22
Nasal regurgitation during /after feeds	10	N/A	N/A
Average %		**18**	**50**

(ii) SPOON FEEDING

Spoon feeding was not yet age appropriate for the 3 month old infant in the final sample of 25, with the result that 24 participants were assessed for spoon feeding both pre- and post-intervention. Their ages ranged from 6 months to 12 years, with the majority (more than 70%) below 2 years of age.

Table 22 presents the frequency of limiting behaviours recorded during spoon feeding, both pre-and post-intervention, with δf = the difference between pre- and post intervention frequencies. The greater the post intervention reduction in frequency, the greater the improvement signified. It is evident from the positive δf values shown in Table 22, that there was a decrease in post intervention frequency of all the limiting behaviours observed during spoon feeding, ranging from 4% to 55%, with 2 of the 12 behaviours (17%) showing a post intervention frequency decrease of above 50%. Prior to the intervention, 11 of the 12 limiting behaviours were recorded in more than half the participants (54% to 100%). Post intervention, only 6 of these behaviours occurred in 50% or more of the participants.

Table 22: Frequency of Behaviours during Spoon Feeding: Pre- & Post Intervention

SPOON FEEDING **Behaviours in order of decreased frequency post intervention**	**Participants with this behaviour**					
	n = 24			**(%)**		
	Pre	**Post**	**δf**	**Pre**	**Post**	**δf**
Stiffening/pushing back while eating	21	8	13	88	33	55
Insufficient amount taken by spoon	15	2	13	63	9	54
Unable to cope with variety of textures	23	12	11	96	50	46
Gagging or choking	14	4	10	58	17	41
Inappropriate head/neck alignment	23	15	8	96	63	33
Biting down on the spoon	14	9	5	58	38	20
Poor lip closure around the spoon	24	20	4	100	83	17
Tongue pushing the food out	24	20	4	100	83	17
Frequent coughing whilst eating	13	10	3	54	41	13
Significant vomiting after solids	5	2	3	21	8	13
Repeated swallows per mouthful	18	16	2	75	67	8
Unable to maintain lip closure	24	23	1	100	96	4
					Average δf	**27**

The pre- and post-intervention severity ratings of limiting behaviours associated with spoon feeding for the sample of 24 participants are presented in Table 23. The post intervention results for spoon feeding show a 21% decrease in ratings recorded in the severe category, a small decrease of 4% in moderate ratings, an increase of 9% in mild ratings, and a 28% increase in no problem ratings. This shift across the rating categories, from severe towards no problem, confirms the interpretation of the findings for nutritive sucking that the severity of the behaviours had decreased as a result of the intervention.

Table 23: Severity Ratings of Behaviours during Spoon Feeding - Pre- & Post intervention

SPOON FEEDING Behaviours in order of pre-intervention frequency	**Ratings for individual limiting behaviours n = 24**							
	Severe (%)		**Moderate (%)**		**Mild (%)**		**No problem (%)**	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Unable to maintain lip closure	33	0	50	42	17	46	0	12
Poor lip closure around the spoon	33	4	50	54	17	29	0	13
Tongue pushing the food out	42	8	42	50	16	29	0	13
Unable to cope with variety of textures	59	8	29	33	8	9	4	50
Inappropriate head/neck alignment	50	4	42	17	4	42	4	37
Stiffening/pushing back while eating	29	4	46	4	13	25	12	66
Repeated swallows per mouthful	29	0	33	38	13	29	25	33
Insufficient amount taken by spoon	17	4	25	4	21	0	37	92
Biting down on the spoon	12	0	17	4	29	29	42	67
Gagging or choking	4	0	29	0	25	17	42	83
Frequent coughing whilst eating	4	0	29	4	21	33	46	63
Significant vomiting after solids	0	0	13	0	8	8	79	92
Average %	**24**	**3**	**25**	**21**	**16**	**25**	**24**	**52**

The post intervention shift of severity of behaviours is further illustrated in Table 24, where the average of decreases in severity (ratings in all 3 severity categories) for each of the behaviours in spoon feeding is compared to the average increase in the no problem category for that behaviour.

Table 24: Percentage Change in the Severity of Spoon Feeding Behaviours

SPOON FEEDING Behaviours ranked in order of overall percentage change		**Severity** % decreased	**No problem** % increased
Insufficient amount taken by spoon	1	-18	+55
Stiffening/pushing back while eating	2	-18	+54
Unable to cope with variety of textures	3	-15	+46
Gagging or choking	4	-14	+41
Inappropriate head/neck alignment	5	-11	+29
Biting down on the spoon	6	-8	+25
Frequent coughing whilst eating	7	-6	+17
Poor lip closure around the spoon	8	-4	+13
Tongue pushing the food out		-4	+13
Significant vomiting after solids		-4	+13
Unable to maintain lip closure	9	-4	+12
Repeated swallows per mouthful	10	-3	+8
Average %		**9**	**27**

With reference to Tables 22 and 24, it can be seen that all limiting behaviours showed change (i.e. improvement) after the intervention. Those behaviours showing the most change in frequency and severity were 'stiffening/pushing back while eating' and 'insufficient amount taken by spoon'. The behaviours ranked lowest for amount of change were 'unable to maintain lip closure' and 'repeated swallows per mouthful'.

(iii) CUP DRINKING

Both pre- and post-intervention cup drinking assessments were completed on 24 participants, their ages ranging from 6 months to 12 years, with the majority (more than 70%) below 2 years of age.

Table 25 presents the frequency of limiting behaviours recorded during cup drinking, both pre-and post-intervention, with δf = the difference between pre- and post intervention frequencies. The greater the post intervention reduction in frequency, the greater the improvement signified. As with the results for the previous two feeding functions, it is evident from the positive δf values shown in Table 25 that there was a decrease in post intervention frequency of all the limiting behaviours observed during cup drinking, ranging from 8% to 58%. Three of the 8 behaviours (38%) showed a post intervention frequency decrease of above 50%.

Table 25: Frequency of Behaviours during Cup Drinking: Pre- & Post Intervention

CUP DRINKING Behaviours in order of decreased frequency post intervention	Participants with this behaviour					
	n = 24			(%)		
	Pre	Post	δf	Pre	Post	δf
Stiffening/pushing back while drinking	23	9	14	96	38	58
Augmented fluid intake (bottle, spoon, etc)	22	10	12	92	41	51
Biting down on the cup	18	6	12	75	25	50
Inappropriate head/neck alignment	24	15	9	100	63	37
Tongue position inappropriate	24	18	6	100	75	25
Poor co-ordination of sip-swallow	23	20	3	96	83	13
Excessive spillage	24	21	3	100	88	12
Poor lip closure around the cup	23	21	2	96	88	8
					Average δf	32

Table 26 presents the pre- and post-intervention severity ratings for each limiting behaviour recorded during cup drinking. The results for cup drinking, set out in Table 26, show a 73% post intervention decrease in ratings recorded in the severe category, with post intervention increases of 16% in the moderate category, 24% in the mild category and 32% in the no problem category. This pronounced post intervention shift, from higher to lower severity or no problem ratings, confirms the trend found in nutritive sucking and spoon feeding.

Table 26: Severity Ratings of Behaviours during Cup Drinking: Pre- & Post intervention

CUP DRINKING Behaviours in order of pre-intervention frequency	Ratings for individual limiting behaviours n = 24							
	Severe (%)		Moderate (%)		Mild (%)		No problem (%)	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Excessive spillage	75	4	21	37	4	46	0	13
Inappropriate head/neck alignment	75	0	17	25	8	37	0	38
Tongue position inappropriate	79	4	8	29	13	42	0	25
Stiffening/pushing back while drinking	63	0	25	21	8	17	4	62
Poor lip closure around the cup	75	0	17	62	4	25	4	13
Poor co-ordination of sip-swallow	75	0	17	54	4	29	4	17
Augmented fluid intake (bottle, spoon, etc)	84	0	4	8	4	33	8	59
Biting down on the cup	63	0	12	12	0	13	25	75
Total %	74	1	15	31	6	30	6	38

The post intervention shift of severity of behaviours is again illustrated in Table 27, where the average of decreases in severity (ratings in all 3 severity categories) for each of the behaviours in cup drinking is compared to the average increase in the no problem category for that behaviour.

Table 27: Percentage Change in the Severity of Cup Drinking Behaviours

CUP DRINKING Behaviours ranked in order of overall percentage change		Severity % decreased	No problem % increased
Stiffening/pushing back while drinking	1	-19	+58
Augmented fluid intake (bottle, spoon, etc)	2	-17	+51
Biting down on the cup	3	-17	+50
Inappropriate head/neck alignment	4	-14	+38
Tongue position inappropriate	5	-12	+25
Excessive spillage	6	-4	+13
Poor co-ordination of sip-swallow		-4	+13
Poor lip closure around the cup	7	-3	+9
Average %		11	32

With reference to Tables 25 and 27, it can be seen that all limiting behaviours showed change (i.e. improvement) after the intervention. Those behaviours showing the most change in frequency and severity were ‘stiffening/pushing back while drinking’, ‘augmented fluid intake’ and ‘biting down on the cup’. The behaviours ranked lowest for amount of change were ‘excessive spillage’, ‘poor co-ordination of sip-swallow’ and ‘poor lip closure around the cup’.

(iv) CHEWING

Chewing was considered age appropriate for 20 of the final sample of 24 children who ranged in age from 9 months to 12 years 10 months. The frequency of limiting behaviours recorded during chewing, both pre-and post-intervention, with δf = the difference between pre- and post intervention frequencies is presented in Table 28. The greater the post intervention reduction in frequency, the greater the improvement signified.

Table 28: Frequency of Behaviours during Chewing: Pre- & Post Intervention

CHEWING Behaviours in order of decreased frequency post intervention	Participants with this behaviour					
	n = 20			(%)		
	Pre	Post	δf	Pre	Post	δf
Gagging or choking	19	3	16	95	15	80
Stiffening/pushing back while chewing	19	8	11	95	40	55
Tongue pushing the food out	20	14	6	100	70	30
Inefficient /inappropriate jaw movement	20	15	5	100	75	25
Residue retained after swallow	19	14	5	95	70	25
Inappropriate head/neck alignment	19	15	4	95	75	20
Poor lip closure while chewing	20	19	1	100	95	5
Limited tongue action to form bolus	20	20	0	100	100	0
					Average δf	30

The trend of a decrease in post intervention frequency of limiting behaviours recorded was maintained for 7 of the 8 behaviours associated with chewing, with 1 behaviour (limited tongue action to form a bolus) showing no change in frequency. Two of the 8 behaviours showed a post intervention frequency decrease of above 50%, whilst 4 showed decreases in the 20% to 30% range.

The pre- and post-intervention severity ratings for each limiting behaviour recorded during chewing are presented in Table 29.

Table 29: Severity Ratings of Behaviours during Chewing: Pre- & Post Intervention

CHEWING Behaviours in order of pre-intervention frequency	Ratings for individual limiting behaviours n = 20							
	Severe (%)		Moderate (%)		Mild (%)		No problem (%)	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Poor lip closure while chewing	80	5	15	30	5	55	0	10
Limited tongue action to form bolus	90	10	10	50	0	40	0	0
Inefficient /inappropriate jaw movement	85	0	10	15	5	60	0	25
Tongue pushing the food out	85	5	5	15	10	50	0	30
Stiffening/pushing back while chewing	80	0	10	15	5	25	5	60
Inappropriate head/neck alignment	80	5	10	25	5	40	5	30
Residue retained after swallow	80	0	10	20	5	50	5	30
Gagging or choking	80	0	5	0	10	15	5	85
Total %	**82**	**3**	**9**	**21**	**6**	**42**	**3**	**34**

The results for chewing, as seen in Table 29, show a 79% post intervention decrease in ratings recorded in the severe category, with post intervention increases of 12% in the moderate category, 36% in the mild category and 31% in the no problem category. The differences in pre- and post intervention severity category ratings for chewing also reveal that the only behaviour (limited tongue action to form a bolus) showing no change in frequency, nevertheless showed considerable change in severity ratings, namely an 80% post intervention decrease in the severe category, and 40% increases in both the moderate and mild categories.

Table 30, where the average of decreases in severity (all ratings in the severe, moderate and mild categories) for each of the behaviours in chewing is compared to the average increase in the no problem category for that behaviour, further illustrates the post intervention shift of behaviours.

Table 30: Percentage Change in the Severity of Chewing Behaviours

Behaviours ranked in order of overall percentage change		Severity % decreased	No problem % increased
Gagging or choking	1	-27	+80
Stiffening/pushing back while chewing	2	-18	+55
Tongue pushing the food out	3	-10	+30
Inefficient /inappropriate jaw movement	4	-8	+25
Inappropriate head/neck alignment		-8	+25
Residue retained after swallow		-8	+25
Poor lip closure while chewing	5	-3	+10
Limited tongue action to form bolus	6	0	0
Average %		**10**	**31**

With reference to Tables 28, 29 and 30, it can be seen that all limiting behaviours showed change (i.e. improvement) after the intervention. Those behaviours showing the most change in frequency and severity were 'gagging or choking' and 'stiffening/pushing back while drinking'. The behaviours ranked lowest for amount of change were 'poor lip closure while chewing' and 'limited tongue action to form a bolus'.

(v) FUNCTIONAL OUTCOMES IN CLUSTERS OF FEEDING BEHAVIOURS

In the previous section the emphasis was on intervention outcomes within each feeding function. This section presents the results of a comparison of changes in severity calculated for the behaviour clusters for each feeding function.

The pre- and post intervention severity indices, and differences between them (δS_i), for the clusters of limiting behaviours identified in the four feeding skills, are set out in Table 31. A positive δS_i value indicates that the difference measured was an improvement; the higher the value the greater the improvement indicated.

Table 31: Severity Ratings of Behaviour Clusters: Pre- & Post Intervention

Clusters of Limiting Feeding Behaviours	Severity Indices (%)											
	Sucking			Spoon Feeding			Cup Drinking			Chewing		
	Pre	Post	δS_i	Pre	Post	δS_i	Pre	Post	δS_i	Pre	Post	δS_i
Body Position	52	7	**45**	72	22	**50**	85	24	**61**	88	27	**61**
Efficiency	52	7	**45**	60	20	**40**	89	30	**59**	-	-	-
Oral Motor Control	49	14	**35**	63	40	**23**	82	35	**47**	93	40	**53**
Co-ordination of swallow	38	12	**26**	39	18	**21**	88	47	**41**	88	17	**71**
Reflux	11	0	**11**	11	3	**8**	-	-	-	-	-	-
Average	40	8	**32**	49	21	**28**	86	34	**52**	90	28	**62**

With reference to Table 31, it can be seen that the average pre-intervention severity indices rose according to the developmental level of each feeding function, confirming the trend found in the profile established in Part 1 of the study. The matching rising values in the average post intervention severity differences (δS_i), shown in Table 31, reveal a trend of escalating positive change (i.e. improvement) according to the developmental level of each feeding function. The implication of this finding that skills with a higher task demand appear to have been more responsive to the intervention, (and the exception of the lower change in severity difference for spoon feeding), will be discussed in the following chapter.

* BODY POSITION: Behaviours associated with body position (inappropriate head-neck alignment and pushing back into extension), rated consistently highly in severity in all four feeding skill areas before the intervention, showed the most modification after the intervention in nutritive sucking, spoon feeding and cup drinking. In chewing, the body position cluster ranked second highest for post intervention change in severity.

- EFFICIENCY: Behaviours associated with limited efficiency ranked second in terms of reduced severity after the intervention for the three feeding skills in which severity indices for efficiency were measured, namely nutritive sucking, spoon feeding and cup drinking.

- ORAL MOTOR CONTROL: Post intervention reduction in severity, of those limiting behaviours associated with oral motor control in all four feeding skills, ranked third in comparison with other clusters. However, the change in severity measured in spoon feeding was relatively lower than changes recorded for this cluster in nutritive sucking, cup drinking and chewing, indicating that difficulties in oral motor control affecting spoon feeding were less responsive to the intervention.

- CO-ORDINATION OF THE SWALLOW: Positive change, in terms of lower severity in all four feeding skills after the intervention, was also shown in this behaviour cluster. As in oral motor control, the change in severity, measured for behaviours related to co-ordination of the swallow in spoon feeding, was lower than changes recorded for this cluster in the other three feeding skills. Improvement in co-ordination of the swallow for chewing showed the highest level of change recorded for all clusters in the four feeding skill areas.

- REFLUX: This cluster of behaviours, measured in nutritive sucking and spoon feeding, did not feature prominently in this study but the changes in severity nevertheless showed an improvement.

2.5 OUTCOMES IN FEEDING PRACTICES OF CAREGIVERS

Pre- and post intervention assessments of caregiver competence were analysed in terms of changes in both frequency and severity of ratings of inappropriate feeding practices. The frequency of inappropriate feeding practices observed during assessment of caregiver competence in the sample of 24 participants, with δf = the difference between pre- and post intervention frequency is presented in Table 32. It can be seen from Table 32 that of the 10 inappropriate feeding practices assessed, all showed post intervention decreases in frequency. The 8 practices with the highest pre-intervention incidence showed the greater decreases (33% - 50%).

Table 32: Frequency of Inappropriate Feeding Practices: Pre- & Post Intervention

CAREGIVER COMPETENCE Practices in order of decreased frequency post intervention	Caregivers with this practice					
	n = 24			(%)		
	Pre	Post	δf	Pre	Post	δf
Inadequate general postural support	22	10	12	92	42	50
Encourages wide mouth opening	22	11	11	92	46	46
Collects and reinserts drooled food	22	12	10	92	50	42
Inappropriate choice of spoon	14	4	10	58	16	42
Scrapes food off spoon upwards	24	16	8	100	67	33
Permits head-neck extension	23	15	8	96	63	33
Repeated touching of circum-oral area	20	12	8	83	50	33
Permits sucking on spoon	14	6	8	58	25	33
Inappropriate pacing of presentation	10	6	4	42	25	17
Limited interaction with child	8	6	2	33	25	8
					Average δf	34

The pre- and post intervention severity ratings for inappropriate feeding practices, recorded in the sample of 24 participants, are presented in Table 33 and show that the ratings decreased in all 3 severity categories following the intervention, with a consequent increase in the 'no problem' ratings. This finding matched the overall trend of a pronounced shift from higher to lower severity ratings found in the feeding behaviours of the participating children following the intervention.

Table 33: Severity Ratings of Inappropriate Feeding Practices: Pre- & Post Intervention

CAREGIVER COMPETENCE Practices in order of pre-intervention frequency	Ratings for individual caregiver practices n = 24							
	Severe (%)		Moderate (%)		Mild (%)		No problem (%)	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Scrapes food off spoon upwards	38	8	58	29	4	29	0	34
Permits head-neck extension	46	4	46	25	4	33	4	38
Inadequate general postural support	21	0	63	17	8	25	8	58
Collects and reinserts drooled food	38	12	50	13	4	25	8	50
Encourages wide mouth opening	17	4	21	13	54	29	8	54
Repeated touching of circum-oral area	8	8	54	21	21	21	17	50
Inappropriate choice of spoon	25	4	21	0	12	13	42	83
Permits sucking on spoon	4	0	33	12	21	13	42	75
Inappropriate pacing of presentation	0	0	29	8	13	17	58	75
Limited interaction with child	0	4	8	4	25	17	67	75
Total %	**20**	**4**	**38**	**14**	**17**	**22**	**25**	**59**

The post intervention shift of severity ratings from the severe, moderate or mild categories to the no problem category is further illustrated in Table 34, where the average decrease in severity (all ratings in the severe, moderate and mild categories) for all participants in each of the feeding practices is compared to the average increase of ratings in the no problem category.

Table 34: Percentage Change in the Severity of Inappropriate Feeding Practices

Practices ranked in order of overall percentage change		Severity % decreased	No problem % increased
Inadequate general postural support	1	-17	+50
Encourages wide mouth opening	2	-15	+46
Collects and reinserts drooled food	3	-14	+42
Inappropriate choice of spoon	4	-14	+41
Permits head-neck extension	5	-8	+34
Scrapes food off spoon upwards	6	-11	+34
Repeated touching of circum-oral area		-11	+34
Permits sucking on spoon	7	-11	+33
Inappropriate pacing of presentation	8	-6	+17
Limited interaction with child	9	-3	+8
	Average %	**11**	**34**

The 2 practices of inappropriate pacing in presenting food to the child, and limited interaction with the child during the feeding session, rated notably lower than the remaining 8 practices for frequency and severity. Nevertheless both practices showed positive post intervention change, as shown by the % decrease in severity ratings and the complementary % increase in no problem ratings .

2.6 SUMMARY OF FINDINGS IN PART 2

The main findings in Part 2 of the study, in terms of post intervention changes in limiting feeding behaviours in the sample of infants /children and the inappropriate feeding practices of their mothers /caregivers, are summarized as follows:

(i) SIGNIFICANT POST INTERVENTION IMPROVEMENT

Significant changes in severity ratings, of both limiting feeding behaviours and inappropriate feeding practices, were confirmed by standard parametric and non-parametric tests (Table 18).

(ii) OVERALL DECREASES IN FREQUENCY

Overall decreases of both limiting behaviours and inappropriate feeding practices were observed after the intervention. The average decreases, derived from Tables 19, 22, 25, 28, and 32 are shown in Table 35.

Table 35: Average Decreases in Frequency of Behaviours & Practices

FEEDING SKILLS & PRACTICES	Average δf
Nutritive Sucking	45%
Spoon Feeding	27%
Cup Drinking	32%
Chewing	30%
Caregiver Competence	34%

(iii) A SHIFT IN CATEGORIES OF SEVERITY from severe towards no problem was observed after the intervention in both limiting feeding behaviours and inappropriate feeding practices. The average percentage decreases in severity and increases in no problem ratings for all feeding skills and practices, derived from Tables 21, 24, 27, 30 and 34, are shown in Table 36.

Table 36: Average Severity Changes in Behaviours & Practices

FEEDING SKILLS & PRACTICES	AVERAGE CHANGE	
	Severity % decreased	No problem % increased
Nutritive Sucking	18%	50%
Spoon Feeding	9%	27%
Cup Drinking	11%	32%
Chewing	10%	31%
Caregiver Competence	11%	34%

(iv) VARIATIONS IN INTERVENTION OUTCOMES were noted insofar as certain specific behaviours appeared to have been more responsive than others to the intervention (Tables 19, 21, 22, 24, 25, 27, 28, 30, 32 & 34). Throughout all 4 feeding skills and the feeding practices of mothers /caregivers, greater change was recorded in stiffening /pushing back into extension (children) and providing postural support (caregivers), than in the related positional pattern of head-neck alignment (capital extension). Variations in changes recorded for individual behaviours and practices will be elaborated on in the following chapter.

(v) **MOST IMPROVED SKILLS** were cup drinking & chewing, as indicated by the averages of pre- and post intervention differences in severity indices for behaviour clusters (Table 31). These skills showed the greatest post intervention change (i.e. improvement), despite being of a higher developmental and task demand level than either nutritive sucking or spoon feeding (Alexander et al 1993).

3. PART 3: ATTITUDES & PERCEPTIONS OF CAREGIVERS

The responses of the 25 participating mothers/caregivers to the questionnaire were analysed to determine their attitudes and level of endorsement of the training received in the feeding therapy programme. The responses were also evaluated in terms of forming a prognosis as to the long term sustainability of the intervention.

3.1 ATTITUDES TO IMPLEMENTATION OF THE PROGRAMME

The responses of the 25 mothers/caregivers regarding their perceived success in implementing the therapeutic feeding methods at home are presented in Table 37.

Table 37: Caregivers' Rating of Success in Implementation of the Feeding Programme

Success in implementation of the feeding programme	Responses of Caregivers (%)			
	Strongly positive	Moderately positive	Mildly positive	Negative
1. Able to follow explanations easily	60	20	16	4
2. Using new feeding methods at home	60	32	8	0
3. Able to use new position	56	32	12	0
4. New method of spoon feeding	68	12	16	4
5. New method of cup drinking	72	8	12	4
6. New method of finger feeding	64	8	24	0
7. General improvement in drinking	60	16	20	0
8. Less spilling with drinking	44	4	40	8
9. General improvement in eating	64	20	12	4
10. Greater food variety	76	8	12	4
11. New methods helping mother & child	92	4	0	0
12. Likely to keep on using new methods	84	12	4	0
Average	**67**	**15**	**15**	**2**

The high level of positive responses, particularly in the strongly positive category, indicated overall acceptance of the feeding programme, and that mothers /caregivers felt able to implement it at home. In particular, mothers /caregivers reported that the new methods of feeding had definitely benefited both them and their child, and that they intended persisting with the programme.

To further highlight attitudes to different aspects of the intervention, responses in the strongly and moderately positive categories were combined, and the items ranked as to level of endorsement. These findings are presented in Table 38.

Table 38: Ranking of Caregivers' Endorsement re Implementation of the Feeding Programme

Ranking of Individual Items	Strongly positive + moderately positive (%)
New methods helping mother & child	96
Likely to keep on using new methods	96
Using new feeding methods at home	92
Able to use new position	88
Greater food variety	84
General improvement in eating	84
New method of cup drinking	80
New method of spoon feeding	80
Able to follow explanations easily	80
General improvement in drinking	76
New method of finger feeding	72
Less spilling with drinking	48

The highly positive attitudes expressed towards the items ranked in the first three places, and the report that mothers /caregivers had been able to follow explanations easily during training, suggest a positive prognosis for sustainability of the programme at home. The scores and rankings in Table 38 indicate that mothers /caregivers felt able to manage specific techniques related to positioning, spoon feeding and cup drinking, and that this was reflected in general improvement in eating and the child's ability to cope with greater variety of foods. Mothers /caregivers were not as positive about finger feeding, although this aspect did not receive any negative endorsements (Table 37).

The item regarding less spilling with drinking received the lowest ranking but this did not accord with the responses regarding success with the new method of cup drinking, or the attitudes of the mothers /caregivers regarding general improvement in drinking, (Items 5 & 7, Table 37). However, in discussions with mothers / caregivers during training sessions, it was apparent that many mothers did not grade the transition from thickened to normal fluids as recommended. Whilst giving some semi-fluids (porridge, custard, yoghurt) in the cut-out cup as suggested, many presented normal fluids (juice, water, tea) more often.

3.2 THEMES EMERGING FROM RESPONSES OF CAREGIVERS

The open-ended questions were analysed in terms of themes regarding endorsement of the programme and/or difficulties encountered in implementation of any aspects. Responses were also evaluated in terms of providing a prognosis of sustainability of the programme.

(i) ENDORSEMENT OF THE INTERVENTION PROGRAMME

Responses of the 25 mothers /caregivers reflected a positive endorsement of the new feeding methods and the intervention programme as a whole. Content analysis of these responses led to the emergence of two main themes:

* PERSONAL BENEFIT FROM TRAINING: Of the 25 mothers/caregivers, 19 (76%) expressed direct satisfaction with the level of information sharing and demonstrations of feeding techniques that had facilitated their implementation of the feeding methods at home. Their comments ranged from moderate to more positive:

> *"I don't have any other problems. I am satisfied with the way you showed me"* (Translated from Xhosa)
>
> *"... I am satisfied with what I was taught, because before I struggled a lot with his bottle feeding and swallowing problems, and I really appreciate it, because how would I ever have known this on my own"* (Translated from Afrikaans)

* EXPERIENCE OF POSITIVE CHANGES WITHIN THE CHILD: All 25 (100%) of mothers/caregivers commented favourably on their experience of the positive effect of the new feeding methods on their child's overall feeding ability, with responses such as:

> *"I can see the difference - ever since she started these new methods she feeds well"*

> *"I think the feeding method was the best thing that could have ever happened to my child. He is able to do things now that I never thought he'd be able to do. It's just so wonderful."*

Most mothers/caregivers also singled out certain aspects of the feeding programme for specific positive comment, including chewing/finger feeding (36%), increased food intake (24%), cup drinking (24%), spoon feeding (16%), physical improvement and increased responsiveness (16%), feeding position (8%). A further 16% commented on the individual aspects of no more choking or vomiting, decreased constipation and weight gain. A sample of these responses follows:

> *"... before he could not chew, but now ever since you showed me finger feeding things are much better"* (Translated from Xhosa)
>
> *"My child eats better and more than before"* (Translated from Afrikaans)
>
> *"She always struggled terribly with drinking, but it has really improved with the new feeding methods"* (Translated from Afrikaans)
>
> *"I am not even having any difficulties feeding him with the spoon"* (Translated from Xhosa)
>
> *"...more relaxed than before"* (Translated from Xhosa)
>
> *"...he can open his mouth when I feed him"* (Translated from Xhosa)
>
> *"He is more pleasant and responds to his feeding equipment, eg. spoon, bowl"*
>
> *"...he is more alert and I'm so happy that my son is more lively now"* (Translated from Afrikaans)
>
> *"...before he pulled very stiff when I fed him and then I was shown the right position and now it improves a little more each day"* (Translated from Afrikaans)
>
> *"He has also picked up lots of weight. Our clinic always used to shout at me because he was so underweight, but last time I took him to them for his 9-month injection, they got such a shock at how nicely he had gained."* (Translated from Afrikaans)

(ii) DIFFICULTIES WITH THE INTERVENTION PROGRAMME

Comments regarding the experience of difficulties or issues with any aspects of implementation of the intervention programme could signify poor sustainability and future non-adherence. However, only 6 mothers/caregivers (24%) identified any specific concerns with implementation of the feeding programme at home. Once again two themes emerged:

- CONTINUING DIFFICULTIES WITH SPECIFIC FEEDING TECHNIQUES: Two mothers /caregivers reported difficulty with finger feeding and a further 2 with cup drinking. A sample of these responses follows:

> *"Sometimes I find it difficult to close her mouth with my finger and to feed her with my finger"* .
>
> *"She still messes a lot with the mug"* (Translated from Afrikaans)

* NEED FOR ONGOING THERAPEUTIC SUPPORT: The following two comments express the importance for mothers /caregivers of children with a multiple handicap, such as severe cerebral palsy, to know that therapeutic support on many levels will continue to be there for them when needed:

> *"The only problem I have is when my child pulls stiff.. I start to panic and do not know what to do."* (Modified for grammar from the original English text)
>
> *"If only I could come more regularly to the hospital. But I live far away and there is not always the money to come"* (Translated from Afrikaans)

3.3 SUMMARY OF FINDINGS IN PART 3

The main findings in Part 1 of the study are presented in summary form as follows:

(i) OVERALL ACCEPTANCE

A high level of endorsement (67% strongly positive) indicated overall acceptance of the feeding intervention programme as presented at the CP Clinic. Responses regarding the use of the new feeding methods at home and benefit to both the mother /caregiver and child were particularly positive. The only comments regarding ongoing difficulties with implementation involved spilling with cup drinking and finger feeding.

(ii) INDICATIONS FOR SUSTAINABILITY

Positive responses, regarding the implementation of the feeding methods and likelihood of continuing with their use at home (Tables 37, 38), supplemented by the improvements in feeding practices found in Part 2 of this study (Tables 32, 33, 34), implied that the intervention programme had succeeded in training mothers /caregivers in therapeutic feeding techniques. A positive outcome in skills transference to the mothers /caregivers suggested an optimistic prognosis for sustainability of the feeding intervention programme in the daily life of mothers /caregivers and children.

CHAPTER 6: DISCUSSION

In this chapter the main research results will be interpreted in relation to the stated aims of each part of the study, linked to similar research, and discussed in terms of the theoretical, research and clinical implications.

1. PART 1: PROFILES OF FEEDING BEHAVIOURS

The aim of Part 1 of this research was to identify the fundamental issues that need to be addressed in a feeding intervention programme for a population of young children, presenting with severe sucking, chewing and/or swallowing difficulties, associated with cerebral palsy. The extent to which this aim was achieved will be discussed firstly in terms of the fundamental issues associated with the profiles, and secondly in relation to the more specific findings of this part of the study, as summarised on pages 84 to 86.

1.1 FUNDAMENTAL ISSUES

There is a considerable body of literature describing general feeding disorders in children with cerebral palsy (Bahr 2001, Carroll & Reilly 1996, Crane 1992, Morris & Klein 1987, Mueller 1997, Winstock 1994) and early sucking difficulties in infants (Arvedson & Brodsky 1993, Wolf & Glass 1992). However, as noted in the literature review, the pattern of causation and prevalence of CP in developing countries is different from developed countries, whence the literature has originated (Arens et al 1987, Arens & Molteno 1995, Potterton 1996). Consequently, the clinician in South Africa, faced with implementing effective intervention for severe feeding disorders, in a population of young children with multiple disabilities (cerebral palsy, seizures, developmental delay, cortical visual impairment, failure to thrive etc.), has found very little information specific enough to this particular group.

In Part 1 of this study, the researcher set out to fill this gap in available information by profiling feeding behaviours observed in a sample of 35 infants /children with severe feeding difficulties, associated with cerebral palsy. Moreover, in acknowledgement of growing awareness of the paramount role of the feeder-child dyad in the understanding and management of feeding difficulties in dependent children ((Baradon et al 1999, Carroll & Reilly 1996, Mäntymaa et al 2003, Parrish 1997, Stevenson & Allaire 1996, Wilder & Granlund 2003), a description of the feeding practices of mothers /caregivers was an integral part of the composite profile. The clinical implications of implementing effective intervention for severe feeding disorders, in a population of young children with multiple disabilities (cerebral palsy, seizures, developmental delay, cortical visual impairment, failure to thrive etc.), will be discussed more fully later in this chapter.

Conventionally, most assessments of motor function in CP children measure the degree of skill in selected functions, thereby rating the motor ability of the child with CP against normal expectations (Siebes et al 2002, Knox & Lloyd Evans 2002). The current NDT approach, to understanding the effects of CP on motor learning, is that the disorder in regulation of muscle tone with persistence of primitive motor patterns, operates as a limiting factor in the development of mobility and functional skills, including oral motor skills (Bahr 2001, Hadders-Algra 2000, Levitt 1995, Morris & Klein 1987, Saloojee 2005). Consequently, this study did not focus on the presence/absence of particular feeding and/or oral motor skills. Instead, the researcher believes that the identification, measurement, and description of behaviour patterns that limit the child's further acquisition or refinement of oral movement for feeding, has provided information of greater functional clinical significance in determining aspects that need to be addressed in an effective intervention.

1.2 COMMONALITY OF BEHAVIOURS AND PRACTICES

The finding that the 40 feeding behaviours, measured in the sample of 35 participating infants /children, and the 10 feeding practices of their mothers /caregivers, were shared by and/or common to the majority of the sample, indicates that these behaviours were representative of this group. The composite profiles of limiting behaviours, observed in the sample children, during nutritive sucking, spoon feeding, cup drinking and chewing, provide a detailed, comprehensive set of information on which to base a feeding intervention programme. The extent to which the feeding intervention programme, featured in this research, attempted to address the behaviours profiled was shown in Table 1. As stated previously, the description of the feeding practices of mothers /caregivers was an integral part of the composite profile, drawing attention to the interplay between feeder and child during feeding. In addition, the levels of frequency and severity of the individual behaviours assessed in each of the 4 feeding skills, and the feeding practices assessed in caregiver competence (Table 14), occurring in 50% or more participants, highlighted the need for an early effective intervention programme. Early intervention is essential in order to reduce or minimise the possibility of aspiration and aspiration pneumonia (Arvedson & Brodsky 1993, Wolf & Glass 1996), and the effects of secondary developmental problems (such as food aversion, failure to thrive, oral and dental problems etc.) associated with persistent feeding difficulties, as discussed fully in the literature review.

The common levels of frequency and severity also provide some confirmation regarding the validity of the observations and the measurement tool employed. The Scale of Feeding Competence in CP was compiled, for the purposes of this research, on the basis of clinical experience and descriptions in the literature of the feeding difficulties associated with CP (Bahr 2001, Crane 1992, Larnert & Ekberg 1995, Morris & Klein 1987, Mueller 1998, Pitcher & Crandall 1997, Winstock 1994, Wolf & Glass 1992). Ideally, additional verification of the data collected in this study would have been sought through a comparison with results obtained on similar feeding evaluation protocols, but the absence of appropriate measurement tools for the particular population represented in the study sample has already been discussed. In view of such absence, the Scale of Feeding Competence served the purpose of identifying, describing and rating the limiting feeding behaviours of the sample children, and the feeding practices of their mothers /caregivers.

As discussed previously, a review of relevant literature did not reveal any studies dedicated to observation of competence in the feeder. Most studies and articles dealing with mothers /caregivers are in the field of social work or psychology, and are not confined to feeding difficulties, but incorporate a wide spectrum of developmental disorders with bonding and stress issues as the central theme (Babbitt & Williams 2001, Baradon et al 1999, Crowe 1993, Field et al 2003, King et al 1996, Mäntymaa et al 2003, Wilder & Granlund 2003). The 1992 study of Reilly and Skuse assessed the characteristics and home management of feeding difficulties in 12 infants with CP, and reported both on bonding difficulties and stress for mothers and the lack of appropriate management advice. However, research specific to *how* mothers /caregivers feed children with feeding difficulties associated with CP, is lacking. NDT literature explores both general and specific effects of positioning and physical contact on tone and motor responses in the child with CP (for example, the influence of the spoon touching the dental arch in triggering the tonic bite response; Bahr 2001, Morris & Klein 1987, Winstock 1994), but the only assessment of compensatory feeding practices in caregivers is that of Gisel and Patrick (1988), described in Appendix A. Gisel and Patrick state that their assessment was intended as a basis for early identification of children in need of non-oral feeding. Observation of caregiver feeding practice was therefore included purely as an additional indicator of the severity of the child's feeding difficulty.

An apparent lack of awareness or concern regarding feeding difficulties, indicated by the initial reporting of some participating mothers /caregivers that they did not experience any difficulties with feeding their child, confirmed this researcher's clinical experience. A possible explanation may be that all the children in this study had histories that included multiple medical complexities that not only provoke stress and anxiety for both caregiver and child, but also entail frequent medical interventions, hospitalization and clinic visits, typical of the life experiences of many children with neurologically based feeding disorders (Parrish 1997). Winstock (1994 p2) includes the testimony of one mother who states that in the early stages of establishing a diagnosis for her child, when there were countless new challenges to face, 'feeding problems were the last thing on our minds'. In addition, many parents do not realise that, beyond early infant suckling, the acquisition of feeding skills is largely learned and that should difficulties persist, intervention is both possible and desirable (Stevenson & Allaire 1996). As nurture, nourish and nutrition are closely allied concepts (Rosenbloom & Sullivan 1996b), difficulty in providing adequate nutrition for her child can be perceived as failure and contribute to feelings of inadequacy, depression and denial in mothers (Baradon et al 1999, Carroll & Reilly 1996, Reilly & Skuse 1992, Parrish 1997).

It has been established that early reports of difficulties with feeding are often one of the earliest signs of neurological dysfunction, and frequently precede a diagnosis of CP (Arvedson & Brodsky 1993, Bahr 2001, Crane 1992, Davison 1999, Hawdon et al 2000, Larnet & Ekberg 1995, McCarthy & Croft 1992, Morris & Klein 1987, Motion et al 2002, Reilly & Skuse 1992, Rudolph 1994). The commonality of feeding behaviours and practices revealed on assessment with the Scale of Feeding Competence in CP, suggests that this scale would be a useful tool for early identification of the pattern of feeding difficulties associated with cerebral palsy. Moreover, the finding of non-reporting of feeding difficulties by some mothers /caregivers implies that this scale could provide more empirical evidence than can be relied upon by basic interviewing and case histories.

In view of the common levels of frequency and severity in the majority of participants, for 45 out of 50 of the limiting feeding behaviours and practices, an interpretation of the lower levels of observation of the remaining 5 behaviours /practices may be beneficial. Regurgitation and vomiting were included in 3 items on the Scale of Feeding Competence, on the basis of descriptions in the literature (Arvedson & Brodsky 1993, Morris & Klein 1987, Wolf & Glass 1992) but were recorded rarely if at all in this study. The problem of vomiting, regurgitation and reflux is complex (Arvedson & Brodsky 1993, Eltumi & Sullivan 1996, Mathisen et al 1999, Morris & Klein 1987), with many components beyond the scope of this discussion, but some relevant aspects may be highlighted here. Although poor body position, especially upper trunk flexion combined with a prolonged supine position, may exacerbate vomiting by increasing intra-abdominal pressure, the problem of vomiting or gastro-oesophageal reflux (GOR) in neurologically impaired children is regarded as even more directly linked to the impact of central nervous system dysfunction on gastrointestinal motility (Bosma 1997, Sullivan & Rosenbloom 1996a, Lloyd & Pierro 1996). When compounded by oral-tactile aversive responses, strong emotions (fear, anxiety, frustration, helplessness etc) can be aroused with mealtimes becoming dominated by negative elements, conducive to even more vomiting etc. (Bahr 2001, Parrish 1997, Reilly & Skuse 1992, Winstock 1994). As these behaviours were reported by mothers /caregivers of the sample children in the preliminary interviews, no explanation can be offered for the low incidence of vomiting and regurgitation in this study, other than to postulate a link with the relative calm in the clinic feeding assessment situation and unrestricted time given to mothers and children.

Two feeding practices, namely inappropriate pacing of presentation of food and limited interaction with the child during feeding, were also observed with lower frequency and severity during pre-intervention assessments than anticipated from clinical experience and descriptions in the literature (Crane 1992, Reilly & Skuse 1992, Reilly 2001). Reilly and Skuse's 1992 study compared videotaped mealtime observations of a case group of young children with CP with a control group of normal children. This comparison could, on the one hand, have highlighted a contrast in interaction levels. However, specific mention was made of a 'remarkable change' (p382) taking place in the mother's behaviour on conclusion of the meal, with increased attention paid to the child. If mothers /caregivers in the current study showed a similar change in attention, this could have inflated ratings of interactive behaviour, resulting in lower frequency and severity recordings.

1.3 FREQUENCY & SEVERITY INCREASED WITH SKILL LEVEL

The marked trend escalating frequency and severity of limiting behaviours in direct relation to the increasing developmental complexity and task demand of each successive feeding skill, as revealed in this research, is in accord with theories of motor learning advanced by proponents of the Neuronal Group Selection Theory (Hadders-Algra 2000) and the NDT approach (Bly 1991, Irwin-Carruthers 1992, Mayston 2000, Saloojee 2005). According to both these approaches, the neurological problems of CP (namely the persistence and domination of gross motor patterns) are seen as blocking the development of active postural stability and the possibility of increasing mobility, thus hampering the establishment of more advanced motor skills (Hadders-Algra 2000, Levitt 1995, McCarthy 1998, Morris & Klein 1987, Saloojee 2005).

The interpretation of limiting behaviours increasingly blocking higher levels of function in feeding skills is also supported by the concept of restricted sensory experience interfering with the development of more advanced motor skills (Hadders-Algra 2000, Leonard 1998). Thus, a diet confined to soft or pureed foods hampers the sensory-dependent development of brain regions representing the various feeding movements, and blocks the acquisition of more refined movements required in the advanced feeding skills of cup drinking and chewing (Bahr 2001, Bosma 1997, Morris & Klein 1987).

The clinical implications of limiting behaviours increasingly blocking higher levels of function in feeding skills becomes even more apparent when linked to a further two concepts in motor learning. The concept of performance anatomy states that early experience and movement patterns do not only influence developing function, but also structure (Bosma 1997), whilst the concept of critical or sensitive periods implies that it is more difficult for an individual to learn a particular behaviour pattern after the critical or sensitive period has passed (Bahr 2001, Hadders-Algra 2000, Leonard 1998). When applied to the acquisition of appropriate feeding skills, the clinical implication for this study population is the need for early effective intervention to achieve appropriate higher level feeding skills and that, without intervention, the children in this study were all at risk for serious long term outcomes in terms of issues of health, growth and nutrition, food aversion, oral and dental development, etc. (Bax 1993c, Ceysens & Green 2000, Morris & Klein 1987, Sullivan & Rosenbloom 1996a). Many authorities stress the need for intervention to promote appropriate oral-motor development within the critical period from birth to 2 years (Arvedson & Brodsky 1993, Bahr 2001, Skuse 1993, Stevenson & Allaire 1996).

1.4 PREDOMINANT LIMITING BEHAVIOUR CLUSTERS

The finding that the behaviour cluster associated with body position had the highest average severity index (Table 15), and was prominent in all four feeding skills (Table 12), appears to confirm that difficulties with postural control are closely linked to feeding difficulties in children with CP. This relationship, between body position and oral-motor difficulties, is in keeping with the accepted definition of CP, as a disorder in the regulation of muscle tone resulting in difficulties with postural adjustment and acquisition of skilled co-ordinated movement including feeding and swallowing (Bly 1991, Arvedson & Brodsky 1993, Levitt 1995, McCarthy 1992, UCP Research Foundation 2004). As oral motor control and co-ordination of the swallow are unequivocally fundamental aspects of feeding skills (Alexander et al 1993, Morris & Klein 1987), the finding of high average severity indices for these behaviour clusters in a sample of children with feeding difficulties associated with cerebral palsy (Table 15), was foreseeable and supported both clinical experience and descriptions in the relevant literature (Crane 1992, Morris & Klein 1987, Mueller 1997, Winstock 1994).

The predominance of these 3 behaviour clusters implies clinically that these should be the areas targeted by intervention. This conclusion is in accord with the NDT principle that a feeding therapy programme, aimed at improving the efficiency of any or all of the 4 feeding skills in infants and children with CP, should include not only techniques to facilitate oral motor control and co-ordination of swallowing specific to each skill, but also the means of addressing the problems of postural control underlying acquisition of finer skills (Crane 1992, Morris & Klein 1987, Mueller 1997, Winstock 1994)

1.5 PREDOMINANT FEEDING PRACTICES

Much of the literature related to the NDT approach includes descriptions of the responses of the child with CP to sensory stimulation and physical handling /positioning (Crane 1992, Finnie 1997, Levitt 1995, McCarthy et al 1992, Morris & Klein 1987, Mueller 1997, Winstock 1994). If the 5 most predominant inappropriate feeding practices observed in mothers /caregivers (Table 13), are viewed within the context of the predominant limiting behaviours of the participating children (profiled in Tables 4, 6, 8, & 10), the following typical picture emerges:

~ 'Inadequate general postural support': Confronted with the child's gross motor difficulties, particularly in postural adjustment and head control, the caregiver was unable to provide sufficient postural support and stability (Table 13). Insufficient postural support and instability caused the child to respond with excessive movement, especially extensor thrusting with head-neck (capital) extension (Bahr 2001, Morris & Klein 1987).

- 'Permits head-neck extension': Without the knowledge of how (or the need) to counteract the extensor thrusting, the caregiver allowed the child's head to tip back – even capitalizing on the associated wide jaw excursion to introduce food into the child's open mouth.
- 'Scrapes food off upwards': As the extended position of the child restricted lip and jaw closure, the caregiver scraped the food off against the upper teeth or gums, quickly to avoid triggering the tonic bite.
- 'Collects and reinserts drooled food': The child's poor oral motor control, exacerbated by increased extensor tone with anticipation, sensation of the food entering the mouth, and effort to form / control the bolus, resulted in tongue thrusting with expulsion of a quantity of food. The caregiver acted swiftly to replace the food in the mouth as before.
- 'Repeated touching of circum-oral area': As the child's chin and area around the mouth became increasingly covered with expelled food, the caregiver repeatedly used the spoon or a cloth to mop, wipe and clean, inadvertently stimulating more oral-tactile aversive behaviour in the child.

The above scenario illustrates the interplay between typical feeding practices of caregivers and the gross and oral motor patterns associated with severe cerebral palsy, and highlights the need for an effective intervention to address both components of the child-feeder dyad.

2. PART 2: FEEDING INTERVENTION OUTCOMES

The aim of part 2 of this research was to determine whether the functional outcomes of the feeding intervention programme could provide evidence for the effectiveness of the NDT-based approach and techniques. The extent to which this aim was achieved will be discussed in relation to the main findings of this part of the study (as summarised on pages 100 to 102), together with an evaluation of the strategies and techniques introduced to address individual behaviours and feeding practices (as presented in Table 1).

2.1 SIGNIFICANT POST INTERVENTION IMPROVEMENT

The finding that the positive changes in both the feeding behaviours of the sample children and feeding practices of their caregivers were statistically significant, implies that the feeding intervention was clinically effective, providing that the gains could not be attributed to any other causes (Siebes et al 2002). The conclusion that the favourable outcomes determined were linked to the intervention is based on confidence in the rigour of the research methods employed in this study. The finding of significant post intervention improvement is in marked contrast with the inconclusive results of the majority of studies on therapeutic interventions in children with CP. Most studies have failed to produce convincing evidence to prove unequivocally either that therapy is effective or that one approach (eg. NDT) is more beneficial than another (Barry 1996, Bower 1996, Butler & Darrah 2001, Campbell 1998, Harris 1993, Leary 1997, Lebeer & Rijke 2003, Leonard 1998, Mayo 1991, Saloojee 2005). The differences between the current research and most other studies reported in the literature appear to centre on the following aspects:

(i) HOMOGENEITY OF PARTICIPANTS

Due to the heterogeneous nature of CP itself (in terms of type and severity of motor disorder and associated disabilities), many studies have been criticised on the basis that the lack of homogeneity in the sample limited the power of the results (Butler & Darrah 2001, Knox & Lloyd Evans 2002, Siebes et al 2002). In the current study sample, all except one participant were below 4 years of age, all were diagnosed with severe forms of CP, most had similar associated problems (seizures, cortical visual impairment etc.) and all had severely disordered feeding. The participants in this study therefore represented a specific sub-group within a population of children with CP, thus reducing the diversity of population characteristics common to many other studies.

(ii) SAMPLE SIZE

Sample sizes in most studies on therapeutic interventions in children with CP have been criticised for being too small (Butler & Darrah 2001, Siebes et al 2002), with an average sample size of 22 in the 21 studies reviewed by Butler and Darrah (2001). Although the sample size in the current study was not large, the homogeneity of the sample reduced the number of variables (Butler & Darrah 2001), thus offsetting to a degree the limitation of a relatively small sample size.

(iii) MEASURABLE FUNCTIONAL GOALS

As outcomes can occur at a variety of levels (Campbell 1998), some of the criticisms levelled at many studies of therapeutic intervention in CP, have been the choice of insufficiently defined general effects of treatment, the use of measurement tools that are not sufficiently sensitive to detect small changes in motor ability, and lack of emphasis on the clinical significance of change observed (Butler & Darrah 2001, Knox & Lloyd Evans 2002, Majnemer & Limperopoulos 2002, Siebes et al 2002). This current study was designed to fulfil the need for measures of functional clinical significance (Campbell 1998, Mayston 2000, Saloojee 2005, Turnbull 1993), insofar as it set out to measure qualitative changes in identified feeding behaviours of children with CP and feeding practices of their caregivers, following an intervention that specifically targeted these behaviours and practices.

(iv) CONSISTENCY OF INTERVENTION

A further criticism of many studies has been the inconsistency in delivery of therapeutic interventions in terms of variability in individual therapists' techniques, skill level and specific aims (Barry 1996, Butler & Darrah 2001, Stanley et al 2000). As only this researcher was involved in the training of the mothers /caregivers, the limitation of inconsistency of intervention did not play any role in the current study.

(v) CAREGIVER INVOLVEMENT

Knox and Lloyd Evans (2002) quote a number of studies/articles in stating that 'treatment strategies involving both parents and children have been shown to be most effective in achieving an enhanced developmental outcome' (p447), and parent-carer education is one of the main elements of the NDT approach (Bly 1991, Knox & Evans 2002, Mayston 2000, SANDTA pamphlet 2003, Saloojee 2005, Valvano & Long 1991). In an evaluation of behaviour style and interaction between children with multiple disabilities and their caregivers, Wilder and Granlund (2003) conclude that it is essential to direct interventions to the everyday interaction in caregiver-child dyads. Nevertheless, in their evaluation of 50 studies of different therapeutic interventions for children with CP, Siebes and co-workers found that only 20 studies mentioned parent involvement (Siebes et al 2002). Of 21 studies on the effects of NDT for CP, reviewed by Butler and Darrah (2001), only 2 were directed at mother-child dyads, whilst a further 3 specifically stated that a home programme was included in the intervention. Thus the majority of studies yielding inconclusive results involved one-on-one physical therapy, with the attendant difficulties in controlling many of the variables discussed earlier (choice of appropriate functional goals and methods of measurement, consistency of intervention etc.), in addition to an apparently low level of direct caregiver involvement.

2.2 OVERALL DECREASES IN FREQUENCY

It appears that this study was sufficiently methodologically robust to support the assumption that the 27% to 45% average decreases in frequency, of limiting behaviours in all 4 feeding skills of participating children and of inappropriate feeding practices of their mothers /caregivers (Table 35), were directly linked to the effects of the intervention. This research was unusual in that it was designed to measure changes in specific behaviours in children with CP identified as limiting or blocking the acquisition of more efficient refined levels of a functional skill (feeding). In contrast, the majority of studies evaluated to establish best evidence for therapeutic interventions in CP, have employed measures of various aspects of motoric response that reflect the extent to which the specific aspect selected is impaired compared with normal. The lack of convincing results in these studies overall has been attributed in part to uncertain validity and/or sensitivity of the measures to detect changes that may have occurred (Butler & Darrah 2001, Siebes et al 2002).

CP is a disorder in the regulation of muscle tone resulting in difficulties with postural adjustment and the acquisition of skilled co-ordinated movement (Bly 1991, Arvedson & Brodsky 1993, Levitt 1995, McCarthy 1992, UCP 2001). This research was designed on the premiss that measuring a reduction in abnormal motor responses that limit or block adequate postural adjustment and acquisition of specific motor skills, was of greater functional clinical significance in evaluating the effects of an intervention, than seeking to compare levels of achievement of those skills to established standards of normal development. Furthermore, this approach was able to measure the effects of specific therapy techniques more directly, as behaviours were observed and measured in context (i.e. within the everyday interaction of a typical feeding session) both prior to and with application of these techniques.

2.3 SHIFT IN CATEGORIES OF SEVERITY

The finding of an overall decrease in severity of limiting behaviours and inappropriate feeding practices, with a post intervention shift, from higher to lower severity or no problem ratings, was pronounced and consistent for all feeding functions assessed (nutritive sucking, spoon feeding, cup drinking, chewing and caregiver competence). This qualitative change signified a positive change in both participating children and their caregivers following the intervention, and confirms the research implication stated previously; namely that measuring incremental and/or qualitative changes in limiting or inappropriate behaviours may be more valid for evaluating effectiveness of an intervention than attempting to measure changes in levels of motor skills.

2.4 VARIATIONS IN INTERVENTION OUTCOMES

Some variation in frequency and severity outcomes suggested that certain limiting behaviours of the sample children and inappropriate feeding practices of their mothers /caregivers were more responsive to the intervention than others. The specific intervention techniques included to bring about desired change in limiting feeding behaviours were described under procedures in Chapter 4, and summarised in Table 1. The functional outcomes of specific techniques will be discussed in terms of those behaviours and practices showing the most change, and those showing the least change in the areas of general postural control, each of the 4 feeding skills, and caregiver competence.

(i) GENERAL POSTURAL CONTROL

Within each of the 4 feeding skills, stiffening /pushing back into extension, ranked in the first 2 behaviours for the most post intervention change. Stiffening or pushing into extension by the child should be considered together with the caregiver practice of providing inadequate general postural support which also showed the most change (in both frequency and severity). In terms of NDT theory, the interpretation is that providing increased stability was instrumental in reducing hypertonicity with increased comfort for the child (Levitt 1995, Morris & Klein 1987, Winstock 1994), and also the possibility of more complex co-ordinated motor activity eg more distal mobility in lips, tongue and cheeks (Alexander et al 1993, Bahr 2001, Bly 1991, Levitt 1995). The techniques for promoting increased general stability and postural control during feeding were outlined on page 65 and illustrated in Figure 4.

The other aspect of postural control, head-neck alignment, did not show the same level of improvement for either children or caregivers. Clinical observation of pronounced backward tipping of the head (capital extension), particularly in Xhosa children, may be related to the custom of carrying infants and non-ambulant children on the caregiver's back, sometimes for prolonged periods of the day. Such reinforcement of capital extension makes it more difficult for both caregiver and child to achieve the appropriate head-neck alignment (posterior neck elongation and 'chin tuck') as taught in this feeding intervention. Maintaining appropriate head-neck alignment has important clinical implications for children with severe CP, in terms of reducing the risk of aspiration (Bülow et al 2001, Larnert & Ekberg 1993, Lewin et al 2001, Morton et al 1993). Provision by the Provincial Health Department of modular seating systems for children with severe CP is now standard procedure. With correct monitoring, these seating systems should contribute to alleviating severe capital extension.

(ii) NUTRITIVE SUCKING

Poor lip seal with undue escape of liquid showed the most improvement (decreased frequency and severity) in nutritive sucking, implying decreased extensor tone thus allowing for the necessary lip closure and pursing to achieve a seal (Morris & Klein 1987, Wolf & Glass 1992). Due to the severity of the motor disorder in the sample children, decreased extensor tone (achieved through appropriate postural control) was not always sufficient to facilitate lip closure and pursing. The supplementary technique of pressure on the child's chin and/or upper lip was an important part of feeding training. The broader clinical implication of achieving better lip seal in nutritive sucking is that less oral escape means more efficient intake of fluid, with improved prospects for health and nutrition (Bax 1993c, Ceysens & Green 1999).

Despite positive change, the 2 behaviours with the least gain were tongue thrust hindering latching and sucking, and coughing /spluttering while sucking. With reference to tongue-thrusting, once the critical period for acquiring mature sucking has passed, the established primitive suckling response pattern in the child with CP (wide jaw excursion and tongue-thrusting movements) may be resistant to change (Bahr 2001, Hadders-Algra 2000, Leonard 1998). In this study sample, the technique of downward pressure of the teat on the child's tongue was not always sufficient to inhibit a strong tongue thrust. Over time tongue thrusting behaviour appears to be reinforced by the action of bottle drinking (Arvedson & Brodsky 1993, Morris & Klein 1987, Wolf & Glass 1992), with the clinical implication, supported by this research, that gradual weaning from bottle to cup, in all children with CP from 8 to 9 months of age, should be a functional goal of feeding intervention.

Coughing /spluttering while sucking is associated with inadequate integration of suck-swallow-breathe synchrony (Alexander et al 1993, Oetter et al 1995). Not only is difficulty with integration of motor activities an inevitable result of disordered muscle tone (Levitt 1995, McCarthy 1992), but due to the changes in oro-pharyngeal anatomical relationships from 3 months of age onwards, a more upright head-neck position becomes increasingly important to ensure safe and efficient swallowing (Alexander et al 1993, Arvedson & Brodsky 1993, Bahr 2001, Logemann 1998, Morris & Klein 1987, O'Connor 1995, Stevenson & Allaire 1996, Wolf & Glass 1992).

(iii) SPOON FEEDING

In spoon feeding, the most improvement following the intervention was in the amount of food taken by spoon. A reduction in food loss during spoon feeding suggests greater postural support and more efficient spoon feeding techniques of the mother /caregiver, with possible increased satisfaction and comfort for the child (Bahr 2001, Morris & Klein 1987, Wolf & Glass 1992). Improvement in the amount of food taken by spoon may further have been associated with the marked reduction in the inappropriate caregiver practice of encouraging wide mouth opening (Table 34). Wide jaw excursion /mouth opening, due to head tipped back (capital extension) and/or too large a spoon, is part of a generalised extensor pattern and is counterproductive for taking food off the spoon with the lips and retaining a bolus in mouth (Bahr 2001, Morris & Klein 1987, Mueller 1997, Winstock 1994).

The lower gains made by the limiting behaviour of repeated swallows per mouthful suggests that difficulty with control of the bolus persisted due to hypertonicity and restricted lateral movement of the tongue (Bahr 2001, Morris & Klein 1987, Wolf & Glass 1992). Some authorities have observed, and clinical experience confirmed, that spoon feeding may actually trigger and reinforce limiting behaviours in the child with CP, specifically wide jaw excursion, tongue thrusting and tonic bite (Bahr 2001, Morris & Klein 1987, Wolf & Glass 1992). This strong link between spoon feeding and primitive /abnormal motor patterns in the child with CP supports the functional goal in this intervention programme of promoting finger feeding for children showing persistently abnormal patterns in spoon feeding.

(iv) CUP DRINKING

Augmented fluid intake (by means of bottle, spoon, syringe etc.) and biting down on the cup showed the most improvement. Reduced need for augmented fluid intake by alternative methods confirmed that the introduction of cup drinking in this intervention, employing positional strategies, use of thickened fluids and the adapted mug, was effective. The improvement achieved underscores the NDT philosophy of working for what the child needs and is able to do with assistance, sooner and better (Saloojee 2005, Sharkey et al 2002).

Biting down on the cup is associated most frequently with the tonic bite reaction (Arvedson & Brodsky 1993, Morris & Klein 1987, Wolf & Glass 1992) and less frequently with general instability – observed even in normal development, as the infant first learning to take fluids from a cup tries to stabilise lips and jaw on the cup (Alexander et al 1993). The techniques to address biting down behaviour in this intervention, (feeding posture, the 'chin tuck' position, downward pressure with the cup and thicker consistency), appear to have been effective in assisting stability and reducing the tonic bite reaction.

The less favourable gains achieved with excessive spillage, poor co-ordination of sip-swallow, and poor lip closure around the cup, suggest persisting limiting oral motor patterns that are part of a larger strong extension response pattern, described as lip retraction with limited cheek and lip movement, and exaggerated primitive suck-swallow (Bahr 2001, Morris & Klein 1987, Winstock 1994). Thickening the fluid consistency was recommended to reduce spillage, facilitate control of the bolus and improve the integration of sip-swallow (Carroll & Reilly 1996, Morris & Klein 1987, Winstock 1994), with very gradual transition to normal fluids. However, the fact that many mothers were not compliant with presenting thickened fluids consistently at home would have reduced the opportunities for appropriate practice of new patterns, thus allowing familiar limiting patterns to persist (Irwin Carruthers 1992, Saloojee 2005). The clinical lesson learned was that it is essential not to assume understanding of a concept, particularly in cross-cultural environments (Venter 1997), to take into account custom and habit, and beware of convincing clients of procedures which professionals think are appropriate. Additional dedicated practice in the clinic training situation, comparing the child's efficiency of drinking with both normal and thickened fluids, and more precise suggestions regarding timing and manner of grading consistencies, might have resulted in greater success.

(v) CHEWING

Gagging or choking, observed in all but one participant in the sample, showed the most improvement of all behaviours identified as limiting in efficiency of chewing. Placement of small firm pieces of food directly between the molars (or posterior gums prior to eruption of the teeth) was employed to trigger the phasic bite and reduce the limiting effect of persisting restricted lateral jaw and tongue movements (Bahr 2001, Carroll & Reilly 1996, Morris & Klein 1987, Winstock

1994). The effectiveness of the technique of lateral placement of food pieces, so as to facilitate munching action and assist control of the bolus, was highlighted in view of the persistence of restricted tongue action. Despite limited tongue action to form a bolus showing the lowest amount of change after the intervention, the sample children nevertheless showed significant overall gains in chewing skill.

In this study, the focus was on functional outcomes of the feeding intervention programme. No formal record was made as to whether mothers /caregivers actually employed specific therapeutic techniques included in the training. Significant post intervention improvement in feeding behaviours and practices was accepted as evidence of effectiveness of the intervention. However, when compared to improvement in other behaviours in chewing, the finding of low levels of change in lip closure may be linked to the informal observation that many mothers /caregivers did not assist lip closure with pressure on the child's chin during chewing. From clinical experience, most mothers /caregivers have experienced bitten fingers as a result of their child's uncontrolled tonic bite reaction and are consequently wary of the new method of introducing chewing. A longer period of training and practice, than was possible within the time restraints of this research, might have allowed for greater consolidation of all aspects of assisting chewing.

(vi) CAREGIVER COMPETENCE

Notable improvements made by participating mothers /caregivers regarding inadequate postural support have already been discussed under general postural control, in relation to associated changes in their children. For this research, the time frame for training of the mothers /caregivers was limited, with 4 sessions the average number attended. As reported previously, if the child was ill, fitting, distressed etc., training sessions proceeded with use of a doll or role playing. Despite these handicaps in training, the improvement shown by mothers /caregivers in positioning and stabilizing their children was one of the most successful functional outcomes in this study. Facilitation of postural stability in children with feeding disorders associated with CP is basic to the development of improved oral motor skills (Bahr 2001, Hadders-Algra 2000, Levitt 1995, Morris &

Klein 1987). Mothers were taught successfully to provide external support and stability, especially in the shoulder girdle and head-neck, in order to facilitate more mobility in the oral structures (lips, tongue, cheeks, jaw etc). Given the improvement shown over the time frame of this study, it seems reasonable to postulate that continued, consistent use of appropriate external postural control for these sample children would facilitate gradual achievement of their own internal postural stability and improved oral motor skills (Arvedson & Brodsky 1993, Green 1992, Morris & Klein 1987).

However, significant functional outcomes achieved in all 4 feeding skills in the sample children, and in other feeding practices of their mothers /caregivers, also demonstrated the importance of additional techniques designed to target specific limiting behaviours. Mothers /caregivers showed marked improvement in the practices of using an overly large spoon, encouraging wide mouth opening and collecting and reinserting drooled food. These were predominant practices prior to the intervention and their effect on the child with heightened oral sensitivity was described earlier in this chapter under Part 1. Once again the importance of the feeder-child dyad and how facilitating change in one promotes reciprocal change in the other (Woolfson 1999) has been demonstrated.

2.5 MOST IMPROVED SKILLS

When the average pre- and post intervention differences in the severity indices, for behaviour clusters identified in each of the 4 feeding skills, were compared, the greatest improvement shown was in cup drinking and chewing (Table 31). Within the framework of predictable developmental sequence, more positive gains in skills of a higher developmental and task demand level than in the lower developmental skills of nutritive sucking and spoon feeding (Alexander et al 1993) may appear contradictory. However, in terms of the theoretical concepts of NGST (Hadders-Algra 2000, Leonard 1998) and NDT (Capelovitch 2005), this apparent contradiction may be interpreted as the greater effectiveness of the intervention techniques in facilitating new task-specific motor behaviour than in re-organizing familiar more stable motor patterns. Capelovitch emphasizes that understanding the development of normal components and sequences of movement in the treatment of children with CP is important, but 'the application of normal development to treatment has been reviewed and changed, so that developmental sequences are no longer adhered to and some are skipped and not used at all' (2005, p7). The clinical implication of this approach in terms of feeding intervention, together with the relatively greater improvement of cup drinking and chewing skills in this research, seems to be an endorsement of early introduction of these skills.

3. PART 3: ATTITUDES & PERCEPTIONS OF CAREGIVERS

The aim of part 3 of this research was to evaluate the acceptability and sustainability of the feeding intervention programme for the participating mothers /caregivers. The extent to which this aim was achieved will be discussed in relation to the main findings of this part of the study, which were summarised on page 106.

3.1 OVERALL ACCEPTANCE

Mothers' /caregivers' reporting of experiencing both positive change in their children and benefit to themselves; of satisfaction with the training received; and their intention of continuing with the feeding programme suggest a strong endorsement of the intervention. However, there are certain caveats against an unqualified acceptance of this interpretation. Whilst the accepted limitations of the questionnaire method (Oppenheim 1992, Schuman & Presser 1996, Stanley et al 2000, Vaughan & Morrow 1989) were controlled as far as possible, the possibility of responses tending to satisfy outcome expectations of the study, despite anonymity of the respondents, was indeterminable. Nevertheless, this limitation should be viewed within the context of Part 2 of the study. In other words, the statements of mothers /caregivers in Part 3, regarding both positive change in their children and benefit to themselves were supported by the positive outcomes of mother /caregiver training revealed in Part 2.

Variations in how mothers /caregivers perceived their success with specific techniques /aspects of programme (e.g. comments regarding some ongoing difficulties with finger feeding and spilling during cup drinking) highlighted a number of vital factors in working towards skills transference: establishing shared goals (Sloper 1999); creating a balance between goals that fill a specific need and that which it is possible to attain (Saloojee 2005); identifying key problems quickly and problem-solving around them, thus facilitating experience of success (Anderson 2000, Woolfson 1999); and regular affirmation (Parrish 1997).

3.2 INDICATIONS FOR SUSTAINABILITY

Positive indications for sustainability of the feeding intervention programme appeared to have been provided by the personal endorsement of mothers /caregivers in response to the questionnaire, and by the improvements in feeding practices found in Part 2 of this study. However, an optimistic prognosis should be tempered by the acknowledgement that the time span of this research was restricted and that long term forecasts should not be made on the basis of short term findings (Siebes et al 2002). Focus groups with mothers /caregivers were beyond the remit of the current study, but could provide a dual role by providing adjunctive ongoing support (Woolfson 1999) and by giving group members the opportunity to provide more in-depth feedback, reveal facts and opinions they might not otherwise have done, and clarify their attitudes and perceptions (Katzenellenbogen et al 1997).

4. LIMITATIONS OF THE STUDY

Any proposed follow-up of this study could address the following issues: standardization of the Scale of Feeding Competence in CP; extension of the research over a longer period so as to include data from a larger sample; inclusion of additional experienced Speech/Language therapists (although the issue of skill level would need to be addressed); the setting of a prescribed training period or level of competency for mothers /caregivers; and the use of focus groups for mothers /caregivers so as to provide more comprehensive feedback.

5. CONCLUSIONS

This research focussed on the challenge of implementing effective intervention for severe feeding disorders in a population of young children with multiple disabilities (cerebral palsy, seizures, developmental delay, cortical visual impairment, failure to thrive etc.). The study incorporated 3 distinct but complementary parts, namely: identification of the fundamental issues that needed to be addressed in an effective feeding intervention programme for this population of children; evaluation of the functional outcomes of an NDT-based feeding intervention programme currently employed at the CP Clinic, Red Cross Hospital; and determination of the acceptability and sustainability of the feeding intervention programme for the participating mothers /caregivers.

Through use of the Scale of Feeding Competence, designed by the researcher, Part 1 of the research provided composite profiles of limiting behaviours, observed in the sample children, in the feeding skills of nutritive sucking, spoon feeding, cup drinking and chewing. The incorporation of the feeder-child dyad, by assessing the typical feeding practices of each child's primary feeder, was an integral part of providing a detailed, comprehensive set of information on which to base a feeding intervention programme. The profiles established in Part 1 of the study highlighted the frequency and severity, not only of limiting feeding behaviours in the sample children, but also of the inappropriate feeding practices of their mothers /caregivers. The profiles also demonstrated the need for early effective intervention in order to minimise the effects of associated and secondary developmental problems associated with persistent feeding disorders.

Following implementation of the feeding intervention programme in Part 2 of the study, marked improvements were found in reduced frequency and a significant reduction in severity of limiting behaviours exhibited by the sample children, and in inappropriate feeding practices of their mothers /caregivers. The conclusion that the favourable outcomes were linked to the intervention is based on confidence in the rigour of the research methods employed. The main impact provided by the positive functional outcomes of the feeding intervention programme included: endorsement of the NDT approach and techniques on which the intervention was based; active involvement of mothers /caregivers as an essential part of the feeder-child dyad; the selection of functional, meaningful goals; and use of an instrument that could measure incremental changes in feeding behaviours and practices.

Part 3 revealed a positive endorsement by participating mothers /caregivers, within the limited time span of this research, of the new feeding methods and of the training programme as a whole. Positive indications for sustainability of the feeding intervention programme were provided by the statements of mothers /caregivers regarding both positive change in their children and benefit to themselves, and supported by the positive outcomes of mother /caregiver training found in Part 2 of the study.

On initiation of this study, the motivation for research was described as: the need to meet the challenge of implementing effective intervention for a population of mothers/caregivers and their infants/young children with evolving/severe cerebral palsy, persistent feeding disorders and other multiple disabilities; an NDT-based feeding intervention programme developed at the CP Clinic that appears to have been clinically effective for this population; and increasing pressure to promote the specific feeding intervention programme more widely despite the lack of treatment outcomes evidence. The positive functional outcomes obtained in the study would seem to justify implementation of the secondary objectives of the research, namely, promotion and training in this feeding intervention programme to reach a wider spectrum of health professionals who routinely encounter early neurologically-based feeding difficulties.

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APPENDIX A

SELECTED AVAILABLE FEEDING QUESTIONNAIRES /SCALES

(i) QUESTIONNAIRES AND CLINICAL OBSERVATION

Caregiver questionnaires (in the form of a feeding history) and clinical observation of feeding are usually combined as two sections of one protocol. They are generally intended to provide a clinical description of specified areas of feeding behaviour prior to formulating a therapy plan.

* BAHR & MILLER (2001): ORAL MOTOR CASE HISTORY

Very general form encompassing a wide range of possible disabilities. Intended for gathering information prior to observation of feeding behaviour.

* MORRIS & KLEIN (1987): PARENT QUESTIONNAIRE & FEEDING ASSESSMENT

Combines a feeding history obtained from the caregiver and assessment of issues and concerns related to oral-motor skills.

* WOLF & GLASS (1992): CLINICAL FEEDING EVALUATION OF INFANTS (CFEI)

Provides a comprehensive structure for organizing observations related to infant feeding but designed for very young infants therefore restricted to the developmental level of sucking.

(ii) CHECKLISTS

* ARVEDSON & BRODSKY (1993): ORAL-MOTOR AND FEEDING EVALUATION

Comprehensive history and physical examination plus feeding assessment. Presence or absence of items noted with tick or 'not applicable'.

* BOCHELKAMP ET AL (1997): ORAL MOTOR ASSESSMENT CHECKLIST

Age range 6 months – adult. Very general with no distinction of developmentally appropriate skills. Not intended as a measurement tool.

(iii) RATING SCALES

* BRAUN & PALMER (1986): NEONATAL ORAL-MOTOR ASSESSMENT SCALE

Tongue and jaw function evaluated during nutritive and non-nutritive sucking. Contains 42 items scored on a 4-point scale. Sucking is the only feeding function assessed.

* GISEL & PATRICK (1988): ASSESSMENT OF A TYPICAL FEEDING SESSION

A numerical rating scale combining observations made by the caregiver and direct observation of the child feeding. Lists 20 negative actions; 14 factors in the child related to inadequate lip and tongue function, drooling, gagging, regurgitation, food retention, and risk for aspiration, and 6 compensatory behaviours in the caregiver (eg collecting and reinserting drooled food). Intended as a basis for early identification of children in need of non-oral feeding. The only scale that assesses caregiver behaviour, but summary scores of normal / marginal / inadequate feeding skills not sensitive for measurement of small changes in quality of function.

- JELM (1990): ORAL-MOTOR/FEEDING RATING SCALE

Age range 12 months – adult. Uses a 6-point scale to examine 3 specific oral-motor movements (lip/cheek, tongue, jaw) in 8 function areas of feeding (breast, bottle, spoon, cup drinking, biting (soft cookie), biting (hard cookie), chewing and straw drinking. Also provides an overview of abilities in related areas such as self-feeding, adaptive equipment, diet adaptations, position, sensitivity, food retention, swallowing, and oro-facial structure. Very comprehensive and detailed at the higher levels of function, but not a sensitive measure at the level of severe feeding difficulties in infants from 0-4 years. No summary scores or information on interpretation of findings.

- KENNY ET AL (1989): THE MULTIDISCIPLINARY FEEDING PROFILE (MFP)

Can be used for children with neurological deficits who are dependent feeders. Provides scaled numerical ratings for a variety of components including physical/neurologic factors (posture, tone, reflexes, and motor control), oral-facial structure, oral-facial sensory inputs, oral-facial motor function, ventilation/phonation, and a functional feeding assessment. However, the scaled numerical ratings do not lead to a definition of the level of severity of feeding problems.

- MORRIS SE (1982): THE PRE-SPEECH ASSESSMENT SCALE

Described as a rating scale for the measurement of pre-speech behaviours and includes a rating and scoring system but the age range is limited from birth to 2 years.

APPENDIX B

BOOKLET FOR MOTHERS /CAREGIVERS

PRACTISING THE NEW WAYS OF FEEDING YOUR CHILD AT HOME

Diana Novotný
Speech, Language & Feeding Therapist

Cerebral Palsy Clinic – Red Cross Hospital
Western Cape Cerebral Palsy Association

Before we even begin to talk about feeding, remember all you have been shown about handling your child –

how to pick up
how to hold and carry
positions for sleep and play
positions for dressing and undressing

We need to change some of your child's patterns of moving and make it possible for him or her to feel more and better ways of moving

REMEMBER: THIS IS A 24 HOUR PROGRAMME!

FOR FEEDING: Begin by making sure that your child is firmly positioned in the way you were shown

Remember to play with your child in this position before using it for feeding. Both you and your child must be comfortable this way, so take time for both of you to get used to it.

This is the best sitting posture for your child:

The back is straight, not round.
The hips, knees and feet are bent.
The arms are forward.
The head is upright.

Always look carefully at the position of the head:

wrong

right

Remember: 'Shoulders down & back and chest stretched open'

Sitting on a chair, couch or bed to feed:

Make sure that you are comfortable, with a cushion behind your back and another under your supporting elbow.
Hold the child's bottom firmly between your legs so that he cannot push back.
Raise the leg that is supporting your child's knees by putting a box under your foot.
Keep your upper arm firmly against the top of the child's head – *not behind his neck*. Make sure you can see your elbow!

If the child's back is very rounded, it may help if you raise your leg that is behind his back even higher than the other leg.

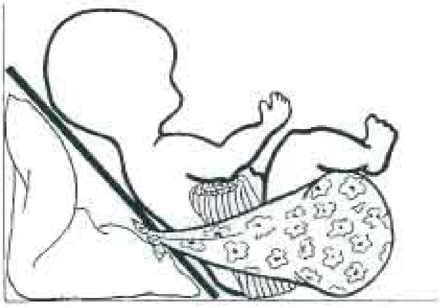
Sitting on the floor to feed

A corner is best so that you can rest your back and your supporting arm.
Put a cushion under your raised knee to keep yourself comfortable.
Make sure the child's bottom is well between your legs so that you can keep his hips firmly bent.
Keep your upper arm firmly against the top of the child's head – *not behind his neck.* Make sure you can see your elbow!

For the bigger child, or the child who pushes back very strongly try resting his bottom firmly on the floor and then push his legs up towards his chest. Place your leg firmly across his feet to hold them flat on the floor.

Positioning for the child who moves and thrusts back a lot

You will need:
- firm board or large kitchen tray
- sheet folded over into a triangle-shape
- large towel / small blanket folded & rolled tightly
- firm pillow
- two small soft cushions or small rolled towels
- extra pillows for side support if needed



PROBLEM-SOLVING

If you are finding it too difficult to control your child's position, do not give up. Some of the following suggestions might help:

- Make sure that your child's shoulders are really well back and supported. Remember his back must be straight, not rounded.
- If your child is sinking down too far between your legs, it might help to put a firm, folded towel or small blanket under his bottom.
- If your child is still too rounded in the back, try putting a folded towel over a tray or small piece of board and slipping it in behind his back to give him something to lean against.
- If it is difficult to keep your child from stiffening and pushing back, make the little 'nest' from a small rolled towel and triangle of cloth as shown in the picture.
- If your child continues to thrust his legs out, make a small bag filled with sand, lentils or dried beans and rest it across his lower legs.
- Remember that your child will sense if you are tense and anxious, so keep calm, sing softly, talk gently and when you first change the way of feeding, make sure that you give your child food that he enjoys.

If you are having difficulty with spoon-feeding:

- Make sure that the food is not too sloppy – it should be easier for your child to take a small amount of firm food on the front of the spoon.
- Remember to keep the spoon flat and press down firmly on the tongue.
- Remove the spoon quickly, still keeping it flat.
- Remember to press down gently against the top of your child's head to help the lips close over the spoon.
- Help with keeping your child's lips closed as you were shown.

If you are having difficulty with finger-feeding:

- Make sure it is a small, firm piece of food.
- Do not push the food into the child's mouth – pull the corner of the lip out, work your finger gently along the child's cheek first, and then only slide the food in with your thumb.
- Help with keeping your child's lips closed as you were shown.

If you are having difficulty with drinking:

- Don't be in a hurry to give your child normal liquids in the mug – first get him/her used to thick semi-liquids like yoghurt, custard, sloppy jelly, fruit puree, etc.
- Hold the mug firmly in place, but make sure you give time for a swallow between sips.

APPENDIX C 1

AN EVALUATION OF SELECTED FEEDING INTERVENTIONS FOR CEREBRAL PALSIED INFANTS AND YOUNG CHILDREN

INFORMATION FOR PARENTS/CAREGIVERS OF CHILDREN PARTICIPATING IN THE STUDY

- The aim of this study is to assess if, and how, the feeding methods taught in the Cerebral Palsy Clinic at Red Cross Hospital change the feeding patterns of children with feeding difficulties.
- We are planning to study the feeding patterns of all babies and young children with feeding difficulties referred to our clinic for the first time from May – September 2004.
- If you, as the parent or caregiver of the child, agree to take part in the study you will be asked to do the following:
    1. Attend an initial session in which you will be asked about the diet of the child and how he/she is fed at home. At this session you will also be asked to feed your child at the clinic. The speech therapist and one other observer will watch the feeding pattern of the child and mark off items on a list.
    2. Attend a number of treatment sessions in which you will be shown what we feel would be the best position and ways of feeding your child. You will be helped until you feel confident using the new methods.
    3. Feed your child at the clinic while the speech therapist and one other observer again watch and assess the feeding pattern of the child.
    4. Fill in a questionnaire in which you will be asked how you feel about the new feeding methods.
- All parents/ caregivers of those children referred to our clinic for feeding difficulties are taught these same feeding methods as part of our normal treatment. What we are asking of you is permission to include you and your child in a special group so that we can assess as effectively as possible what difference these methods make.
- To make sure that all information remains confidential, the assessment and questionnaires forms will be kept locked away in the Cerebral Palsy Clinic at the hospital and there will be no names on any of the forms.
- You may decide whether or not you wish to take part. If you do not wish your child to be in this study, it will not prevent him /her from receiving treatment at our clinic.

DECLARATION BY PARTICIPANTS

I, the undersigned, ...

(ID no................................)

in my capacity as parent /caregiver of ....

(Date of birth...................................)

declare that:

- I am satisfied that information regarding the above project being undertaken by Mrs Diana Novotný of the Cerebral Palsy Clinic at Red Cross Hospital, has been given and explained to me, in the language of my choice (Afrikaans, English, Xhosa), with/without the assistance of an interpreter.
- I am willing to take part in the project.
- I understand that I am not under any obligation and may withdraw from the project at any time.

Signed at .... on 2004

....
Mother/ Caregiver

....
Researcher

....
Witness

APPENDIX C 2

EVALUASIE VAN SPESIFIEKE VOEDINGSINTERVENSIES VIR SEREBRAAL-VERLAMDE BABAS EN JONG KINDERS

INFORMASIE VIR OUERS /VERSORGERS VAN KINDERS WAT IN DIE PROJEK DEELNEEM

- Die doel van hierdie studie is om te evalueer *of*, en *hoe* die voedingspatrone van kinders met voedingsprobleme verander met die voedingsmetodes wat ons gebruik in die Kliniek vir Serebraal Verlamdes by Rooi Kruis Hospitaal,.

- Ons beplan om die voedingspatrone te evalueer van al die babas en jong kinders met voedingsprobleme wat vir die eerste keer vanaf Mei – September 2004 na ons kliniek verwys word.

- As u, as ouer of versorger van die kind, saamstem om deel te neem aan die studie sal dit die volgende behels:
  1. 'n Eerste sessie waar die ouer of versorger van die kind gevra sal word oor die dieët van die kind en hoe hy/sy tuis gevoer word. U sal ook gevra word om die kind by die kliniek te voer terwyl die spraak-terapeut en moontlik nog een persoon die eetpatroon van die kind waarneem.
  2. 'n Aantal terapiesessies waarin u sekere posisies en metodes vir voeding gewys sal word. Die leerperiode sal duur totdat u tuisvoel met die nuwe metodes.
  3. 'n Tweede formele observasiesessie waar u weer die kind by die kliniek voer, terwyl die spraakterapeut en moontlik nog een persoon waarneem en die eetpatroon van u kind her-evalueer.
  4. 'n Vraelys waarin u opinie van die nuwe voedingsmetodes gevra sal word.

- Alle ouers/versorgers van kinders met voedingsprobleme, wat verwys word na ons kliniek, word diesede voedingsmetodes geleer as deel van ons gewone behandelingsprogram. Wat ons wel van u vra is toestemming om u en u kind by 'n spesiale groep in te sluit, sodat ons meer effektief kan evalueer watter verskil hierdie voedingsmetodes aan hy/sy slukpatroon maak.

- Om seker te maak dat alle informasie vertroulik bly, sal die evalueeringsvorms en vraelyste toegesluit word in die Kliniek vir Serebraal Verlamdes by die hospital, en daar sal verder geen name op enige van die vorms wees nie.

- U mag besluit of u wil deelneem of nie. As u nie toestemming gee vir u kind om deel te wees van hierdie projek nie, sal dit hom /haar geensins uitsluit van die gewone behandelingsprogram by ons kliniek.

VERKLARING DEUR DEELNEMERS

Ek, die ondergetekende ....

(ID nr.................................)

in my hoedanigheid as ouer/ versorger van ....

(Geboortedatum...................................)

verklaar dat:

- Ek is tevrede dat informasie aangaande bogenoemde projek, wat onderneem word deur Mev Diana Novotný van die Kliniek vir Serebraal Verlamdes by Rooi Kruis Hospitaal, aan my verduidelik is in die taal van my keuse (Afrikaans, English, Xhosa), met/ sonder die behulp van 'n tolk.
- Ek is bereid om deel te neem aan die projek.
- Ek verstaan dat ek onder geen verpligting staan en mag teen enige tyd onttrek uit die projek.

Geteken te .... op 2004

....
Ouer /Versorger

....
Navorser

....
Getuienis

APPENDIX C 3

UKUHLUZWA KOKHETHO LOKULAMLA INDLELA ZOKUTYISWA KWENTSANA NABANTWANA ABANCINCI ABAKHUBAZEKE NGOKWASEMALUNGWINI

INKCAZELO YA BAZALI / ABAGCINI BABANTWANA ABATHATHA INXAXHEBA KWEZIZIFUNDO

- Injongo yesisifundo kukulinganisa ukuba, indlela ekufundiswa ngayo ukutyiswa kwikliniki yabakhubazekileyo ngokwasemalungwini kwisibhedlele sase Red Cross itshintshe indlela abaginya ngayo abantwana abanengxaki zokuginya.

- Siceba ukwenza umlinganiselo wendlela zokutya kubo bonke abantwana abancinci abanengxaki zokutya abathe bathunyelwa kule kliniki okoku okokuqala ukusukela ngo May – September 2004.

- Ukuba wena, njengomzali okanye umgcini womntwana, uyavuma ukuthatha inxaxheba kwesisifundo uzakubuzwa ukuba wenze ezizinto zilandelayo:
    1. Uze kumhlangano apho uzakubuzwa ngendlela umntwana atya ngayo ekhaya. Uyakhuti ucelwe umtyise umntwana apha ekliniki ingcali kwezothetha nomnye umhloli bazebe bejonge indlela atya ngayo umntwana bahlabe apho babone khona.
    2. Uyakuza amatyeli kunyango apho uyakuthi uboniswe indlela eyakuthi ikholise wena yokuhlala nendlela yokutyisa umntwana wakho. Uyakuncedwa ude uzive ukhululekile ukusebenzisa lendlela intsha.
    3. Uyakutyisa umntwana wakho apha ekliniki ngalomzuzu speech therapist nomnye wabahloli bekujongile bahlole nendlela omtyisa ngayo umntwana.
    4. Uyakuphendula imibuzo ozakuthi ubuzwe ukuba uziva njani kulendlela intsha yokutyisa.

- Bonke abazali / abagcini babantwana abathunyelwe kulekliniki abanengxaki zokutya bafundiswa ezindlela zokutya nje ngonyango lwabo lwesiqhelo. Eyonanto siyicelayo kuni yimvume ezakunkxulumana ngayo nomntwana kwigroup ukwenzela sijongisise kakhuhle ukuba umohluko ezindlela eziyenzayo.

- Ukuqinisekisa ukuba lenkcazelo ihlala ilihlebo, unyango nemibuzo ebhaliweyo iyakugciwna itshixelwe kwikliniki yabakhu bazekileyo esibhedlele akuyakubakho magama kweziforms.

- Uyakuzigqibela ukuba uyafuna okanye akufuni ukuthatha inkxaxheba. Ukuba awunqweneli umntwana wakho ukuba abe kwezizifundo lonto ayunqandi ukuba angalufumani unyayo ekliniki.

ISIBHENGEZO NGABATHATHINXAXHEBA

Mna, otyikityayo ....

(Nombolo yesazisi ....)

egameni lam njengomzali / umgcini ka ....

(Umhla wokuzalwa ....)

ndazisa ukuba:

- Ndanelisekile yinkcazelo enkulumene nombandela weprojekti engasentla ethatyathwe ngu Nkosikazi Diana Novotný wekliniki yabakhebazeke ngamalungu kwisibhedlele sase Red Cross, enikiweyo yachazwa kum, ngolwimi endizikhetheleyo (Afrikaans, English, Xhosa), ngaphandle / ngoncedo kwencedo lwetoliki.
- Ndiyavuma ukuthatha inxaxheba kule projekti.
- Ndiyaqonda ukuba andibophelekanga ndingarhoxa kule projekti naninina.

Ityikitywe e .... nge 2004

....
Mama / umgcini womntwana

....
Umphandi

....
Ingqina

APPENDIX D 1

FEEDING EVALUATION

NAME: ______________________ **DATE:** ____________ **AGE:** __________

PHYSICAL DIAGNOSIS: ______________________________

INFORMANT: ______________________ **REFERRED BY:** ____________________

FEEDING PROBLEM (According to informant): ______________________

FEEDING HISTORY & ORAL MOTOR DEVELOPMENT:

Any tube-feeding:	Chewing:
Breastfeeding:	Cup drinking:
Bottle-drinking:	Time per feed:
Introduction of solids:	Oral sensitivity:

DAILY FEEDING ROUTINE ON INITIAL ASSESSMENT:

Breakfast ______________________________

Lunch ______________________________

Supper ______________________________

In-between snacks ______________________________

Daily liquids ______________________________

FEEDING POSITION USED BY MOTHER /CAREGIVER ON INITIAL ASSESSMENT:

____

____

OBSERVATION OF RELEVANT GROSS MOTOR PATTERNS IN FEEDING:

____

____

SUCCESSIVE ASSESSMENTS:

DATE OF ASSESSMENT					
ADEQUACY OF DIET re:	Variety				
	Amount				
	Nourishment				
WEIGHT GAIN					
CONSTIPATION					

APPENDIX D 2

SCALE OF FEEDING COMPETENCE IN CEREBRAL PALSY

To be completed during observation of a typical feeding session with regular caregiver and familiar seating arrangement, food and utensils

*** 0 = no problem 1 = mildly limiting 2 = moderately limiting 3 = severely limiting**

RATE 0-3 * FOR EACH FEEDING BEHAVIOUR DESCRIBED BELOW		DATE	DATE	DATE	DATE
NUTRITIVE SUCKING	Inappropriate head/neck alignment				
	Stiffening/pushing back during feed				
	Poor lip seal / undue escape of liquid				
	Tongue unable to assist latching				
	Tongue thrust hindering sucking				
	No or inappropriate jaw movement				
	Abnormal ratio of suck : swallow				
	Disorganised sucking rhythm				
	Coughing /spluttering while sucking				
	Nasal regurgitation during /after feeds				
	Vomiting during / after feeds				
	Time relative to intake per feed				
SPOON-FEEDING 4mths +	Inappropriate head/neck alignment				
	Stiffening/pushing back while eating				
	Poor lip closure around the spoon				
	Biting down on the spoon				
	Unable to maintain lip closure				
	Tongue pushing the food out				
	Repeated swallows per mouthful				
	Frequent coughing whilst eating				
	Gagging or choking				
	Unable to cope with variety of textures				
	Significant vomiting after solids				
	Insufficient amount taken by spoon				
CUP DRINKING 6mths +	Inappropriate head/neck alignment				
	Stiffening/pushing back while drinking				
	Poor lip closure around the cup				
	Biting down on the cup				
	Tongue position inappropriate				
	Poor co-ordination of sip-swallow				
	Excessive spillage				
	Augmented fluid intake (bottle, spoon, etc.)				
CHEWING 7mths +	Inappropriate head/neck alignment				
	Stiffening/pushing back while chewing				
	Poor lip closure while chewing				
	Tongue pushing the food out				
	Limited tongue action to form bolus				
	Inefficient/inappropriate jaw movement				
	Residue retained after swallow				
	Gagging or choking				
CAREGIVER COMPETENCE	Inadequate general postural support				
	Permits head-neck extension				
	Inappropriate choice of spoon				
	Encourages wide mouth opening				
	Permits sucking on spoon				
	Scrapes food off upwards				
	Collects and reinserts drooled food				
	Repeated touching of circum-oral area				
	Inappropriate pacing of presentation				
	Limited interaction with child				

APPENDIX E

THE 50 ITEMS IN THE SCALE OF FEEDING COMPETENCE IN CP

(i) NUTRITIVE SUCKING

- INAPPROPRIATE HEAD/NECK ALIGNMENT

Seen consistently in association with cerebral palsy as a result of increased tone or abnormal fixation in the shoulder girdle and cervical area (Morris & Klein 1987, Arvedson & Brodsky 1993, Morton et al 1993, Winstock 1994, Bahr 2001).

- STIFFENING AND PUSHING BACK

Caused by general increase in tone and is a common response associated with tactile sensitivity, discomfort, anxiety, aversion etc (Sullivan & Rosenbloom 1996, Bahr 2001).

The above two behaviours are so typical of the feeding behaviour in this population that they were included under each of the four feeding function areas and, in modified form, under caregiver competence.

- POOR LIP SEAL

Evident as undue escape of liquid, poor lip seal is the most prevalent observation of abnormal lip function (Wolf & Glass 1992, Lau & Kusnierczyk 2001). Difficulty with lip seal is often related to the open mouth posture that accompanies hyperextension of the head-neck (Lespargot et al 1993).

- TONGUE UNABLE TO ASSIST LATCHING

Identified by Alexander et al (1993) as one of the earliest signs of feeding disorder. The tongue of the normal termborn is able to cup around the nipple immediately. In the infant or older child with cerebral palsy, the inability of the tongue to groove is associated with hypertonicity and the tongue thrust pattern (Morris & Klein 1987, Wolf & Glass 1992, Arvedson & Brodsky 1993, Winstock 1994, Bahr 2001).

- TONGUE THRUST HINDERING SUCKING

Tongue thrust may be confused with sucking and a child may exhibit both patterns, but tongue thrusting is an abnormal pattern associated with increased muscle tone and general hyperextension, and as such interferes with the development of normal sucking skill (Winstock 1994).

- NO / INAPPROPRIATE JAW MOVEMENT

Jaw opening may be described as either too much, too soon, or too little (Morris & Klein 1987, Winstock 1994), and is typically associated with triggering of the jaw thrust in anticipation of food (Morris & Klein 1987, Lespargot et al 1993) and/or the tonic bite reflex that occurs when the teeth or gums are stimulated (Morris & Klein 1987, Wolf & Glass 1992, Arvedson & Brodsky 1993).

- ABNORMAL RATIO OF SUCK : SWALLOW

  Delayed triggering of the swallow reflex is a common characteristic of the sucking difficulties of the infant with neurological problems, associated with difficulty in normal bolus formation and propulsion (Couriel et al 1993, Wolf & Glass 1992 Qureshi et al 2002).

- DISORGANISED SUCKING RHYTHM

  A common symptom of difficulty in the timing of swallowing within the respiratory cycle (Wolf & Glass 1992, Lau & Kusnierczyk 2001).

- COUGHING OR SPLUTTERING WHILE SUCKING

  Typically indicates that that some fluid has entered or nearly entered the larynx and if strong or frequent often reflects ongoing aspiration (Wolf & Glass 1992).

- NASAL REGURGITATION DURING / AFTER FEEDS

  Commonly related to inco-ordination in swallowing and/or a feeding position with neck hyperextension (Morris & Klein 1987).

- VOMITING DURING / AFTER FEEDS

  May be associated with difficulties in postural control characteristic of the infant with neurological problems, with gastro-oesophageal reflux or even with severe oral-tactile aversive responses (Wolf & Glass 1992).

- TIME TAKEN RELATIVE TO AMOUNT TAKEN PER FEED

  Included as an item as it is commonly reported by the mothers and carers of children with early feeding difficulties (Crowe 1993, Winstock 1994, McCarthy 1998).

(ii) SPOON-FEEDING

- POOR LIP CLOSURE AROUND THE SPOON

  Frequently reported and observed. It is associated, as in sucking, with the open mouth posture that accompanies hyperextension of the head-neck (Lespargot et al 1993) but may also occur in anticipation of the unpleasant consequences for the child of the tonic bite reflex (Morris & Klein 1987, Winstock 1994).

- BITING DOWN ON THE SPOON

  Typically observed as part of the tonic bite reflex that occurs when the teeth or gums are stimulated. It may, in turn build up anxiety and even aversion to eating (Morris & Klein 1987, Wolf & Glass 1992, Arvedson & Brodsky 1993).

- INABILITY TO MAINTAIN LIP CLOSURE

  Another common problem during spoon-feeding. Related to the open mouth posture that accompanies hyperextension of the head-neck (Lespargot et al 1993), and/or the presence of a strong tongue thrust pattern (Morris & Klein 1987, Wolf & Glass 1992).

- TONGUE PUSHING THE FOOD OUT

  Part of the abnormal tongue thrust pattern associated with cerebral palsy. A repetitive protraction-retraction movement of the tongue is employed to try and manage the food, as opposed to the more controlled pattern of bolus formation (Morris & Klein 1987, Alexander et al 1993, Bahr 2001).

- REPEATED SWALLOWS PER MOUTHFUL

  Characteristic of poor bolus formation occurring in association with oral motor difficulties (Wolf & Glass 1992, Logemann 1998).

- FREQUENT COUGHING WHILST EATING

  Signals penetration of food into the larynx triggering the cough reflex in order to protect the airway (Buccholz 1997, Winstock 1994).

GAGGING OR CHOKING

Common in neurologically impaired children with increased tone in the head-neck area, and is associated with a hyperactive gag reflex (Arvedson & Brodsky 1993)

INABILITY TO COPE WITH A VARIETY OF TEXTURES

Characteristic of individuals with feeding and swallowing difficulties, with or without associated oral tactile hypersensitivity, and results in prolonged maintenance on a diet of soft pureed foods (Morris & Klein 1987, Winstock 1994, Mueller 1997).

SIGNIFICANT VOMITING AFTER SOLIDS

Frequently reported and may be associated with difficulties in postural control characteristic of the individual with neurologically-based feeding difficulties, or with gastro-oesophageal reflux (Morris & Klein 1987, Winstock 1994).

INSUFFICIENT AMOUNT TAKEN BY SPOON

Regularly observed in association with poor feeding skills and is a major factor in the poor nutritional status of many children with cerebral palsy (Stallings et al 1993, Bosma 1997, Stevenson & Meyers 2001, Troughton & Hill 2001).

(iii) CUP-DRINKING

- POOR LIP CLOSURE AROUND THE CUP

  A prevalent observation that often precludes cup drinking altogether (Winstock 1994, Mueller 1997). This problem with lip function is related, as in the case of other feeding functions, to a combination of associated problems such as hyperextension of the head-neck, tongue-thrust, sensory defensiveness, effect of the tonic bite reflex, etc. (Morris & Klein 1987, Winstock 1994).

- BITING DOWN ON THE CUP

  Reported frequently. Triggered by the tonic bite reflex that occurs when the teeth or gums are stimulated (Morris & Klein 1987, Wolf & Glass 1992, Arvedson & Brodsky 1993). Less frequently associated with effort to stabilise lips and jaw on the cup and promote more organised sip-swallow (Alexander et al 1993).

- TONGUE POSITION INAPPROPRIATE

  The tongue often protrudes under the rim of the cup due to the abnormal tongue-thrust pattern and presents a serious barrier to effective cup drinking (Mueller 1997, Bahr 2001).

- POOR CO-ORDINATION OF SIP-SWALLOW

  Abnormal beyond the age of 9 months (Alexander et al 1993) but is seen regularly in individuals with neurologically-based drinking difficulties (Wolf & Glass 1992, Arvedson & Brodsky 1993, Couriel et al 1993).

- EXCESSIVE SPILLAGE

  A natural result of the fact that liquid moves more quickly than solid food (Winstock 1994). It is unpleasant for both child and feeder, and makes it extremely difficult for the feeder to estimate the amount of fluid actually consumed by the child.

- AUGMENTED FLUID INTAKE

  Giving fluids by means of syringe or spoon, or continued bottle-drinking long after it is no longer age-appropriate, is an inevitable sequel of the difficulties experienced by feeders of children with severe drinking problems, as they attempt to ensure adequate fluid intake.

(iv) CHEWING

- POOR LIP CLOSURE WHILE CHEWING

  Occurs as part of the open mouth posture that accompanies hyperextension of the head-neck (Lespargot et al 1993), but can also be exacerbated by tactile sensitivity to textured foods and the increased complexity of oral motor co-ordination demanded by chewing (Morris & Klein 1987, Winstock 1994).

TONGUE PUSHING THE FOOD OUT

Part of the abnormal tongue thrust pattern, as observed in spoon feeding (Morris & Klein 1987, Alexander et al 1993, Bahr 2001).

LIMITED ACTION TO FORM BOLUS

A major factor hindering the development of chewing skills in children with cerebral palsy. Results from a combination of increased muscle tone with hyperextension, open mouth posture, tongue thrust etc. (Morris & Klein 1987, Winstock 1994).

INEFFICIENT /INAPPROPRIATE JAW MOVEMENT

Typically associated with triggering of the jaw thrust in anticipation of food (Morris & Klein 1987, Lespargot et al 1993) and/or the tonic bite reflex that occurs when the teeth or gums are stimulated (Morris & Klein 1987, Wolf & Glass 1992, Arvedson & Brodsky 1993).

RESIDUE RETAINED AFTER SWALLOW

Characteristic of poor bolus formation occurring in association with the oral motor difficulties described above (Morris & Klein 1987, Logemann 1998).

GAGGING OR CHOKING

Frequently reported as a seriously limiting factor in the development of chewing skills, and is directly associated with the inability to form and control the bolus in the mouth and consequent delayed triggering of the pharyngeal swallow (Sullivan 1992).

(v) CAREGIVER COMPETENCE

- INADEQUATE GENERAL POSTURAL SUPPORT

  A frequent observation as the mother /carer struggles to feed a child who is thrusting backwards, sliding, moving and flailing (McCarthy 1988).

- PERMITTING HEAD-NECK EXTENSION

  Commonly employed as a strategy by the feeder of a child who moves and thrusts back. Allowing the head to tilt back utilises the effects of gravity to direct the food or liquid to the back of the mouth, but presents a serious threat for aspiration (Bahr 2001).

- INAPPROPRIATE CHOICE OF SPOON

  Observed regularly as a compensatory strategy by an anxious mother /carer who has felt obliged to push as much food as possible into the child's mouth in order to try and meet nutritional requirements. Most frequently a large spoon is used and this tends to trigger the jaw thrust and/or tonic bite reflex (Morris & Klein 1987, Winstock 1994).

- ENCOURAGING WIDE MOUTH OPENING

  An attempt by the feeder both to introduce as much food as possible and as a strategy to avoid triggering the tonic bite reflex (Morris & Klein 1987, Winstock 1994).

- PERMITTING SUCKING ON THE SPOON

  A strategy not routinely employed, as most feeders of a child with cerebral palsy have had experience of the consequences of a strong bite reflex (Morris & Klein 1987, Bahr 2001). However, when sucking is encouraged as part of spoon feeding, it reinforces the abnormal tongue-thrust pattern and seriously hampers the acquisition of more mature spoon feeding skills (Alexander et al 1993, Winstock 1994).

- SCRAPING FOOD OFF UPWARDS

  Possibly the most common strategy when the feeder is confronted with a child who is unable to use the upper lip actively to assist in the removal of food from the spoon (Gisel & Patrick 1988, Winstock 1994, Mueller 1997). This is a skill normally achieved by a seven-month-old infant (Alexander et al 1993).

- COLLECTING AND REINSERTING DROOLED FOOD

  Observed regularly as the feeder attempts to retrieve as much as possible of the food expelled due to an open mouth and tongue thrust pattern (Gisel & Patrick 1988).

- REPEATED TOUCHING OF THE CIRCUM-ORAL AREA

  Observed as the caregiver mops and wipes in an attempt to maintain social acceptability for the child (Gisel & Patrick 1988). This inevitably has the effect of increasing the child's sensory defensiveness, hyperextension, mouth opening, etc. (Wolf & Glass 1992).

- INAPPROPRIATE PACING OF PRESENTATION

  Typically observed when the caregiver responds to the child's feeding difficulties with anxious and dogged persistence (Sullivan & Rosenbloom 1996a).

- LIMITED INTERACTION WITH THE CHILD

  Frequently observed where mealtimes are fraught with anxiety for both child and feeder (Reilly & Skuse 1992, Sullivan & Rosenbloom 1996a).

APPENDIX F

EQUIPMENT FOR FEEDING TRAINING

APPENDIX G 1

QUESTIONNAIRE FOR MOTHERS and/or CAREGIVERS

1. Could you follow the demonstrations and explanations at the clinic easily enough?

Yes, definitely	Most of the time	Some of the time	No, not at all

2. Are you using the new feeding methods at home?

Yes, all of them	Most of them	Some of them	No, none of them

3. Are you able to use the feeding position as shown to you?

Yes, definitely	Most of the time	Some of the time	No, not at all

4. Are you able to use the way of spoon-feeding as shown to you?

Yes, definitely	Most of the time	Some of the time	No, not at all

5. If you were given the special mug for drinking, have you used it? (Not given)

Yes, definitely	Most of the time	Some of the time	No, not at all

6. If you were shown finger-feeding, have you been able to use it? (Not shown)

Yes, definitely	Most of the time	Some of the time	No, not at all

7. Is your child able to drink any more / better than before?

Yes, definitely	Most of the time	Some of the time	No, not at all

8. When he/she drinks, is there any less spilling than before?

Yes, definitely	Most of the time	Some of the time	No, not at all

9. Is your child able to eat any more / better than before?

Yes, definitely	Most of the time	Some of the time	No, not at all

10. Is your child now eating foods he or she was not able to eat before?

Yes, definitely	Most of the time	Some of the time	No, not at all

11. Do you think these feeding methods have helped you and your child?

Yes, definitely	Most of the time	Some of the time	No, not at all

12. Will you keep on using all these feeding methods at home?

Yes, all of them	Most of them	Some of them	No, none of them

If you would like to add any comments that might help us to understand any problems you may have been experiencing please do so here:

If you have noticed any other changes in your child since starting the new feeding methods, please tell us about them here:

APPENDIX G 2

VRAELYS vir MOEDERS en/of OPPASSERS

1. Kon u die verduidelikings en demonstrasies by die kliniek maklik genoeg volg?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

2. Gebruik u wel die nuwe voedingsmetodes by die huis?

Ja, almal	Meeste van hulle	Party van hulle	Nee, geen

3. Gebruik u wel die voedings posisie wat aan u gewys is?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

4. Gebruik u wel die metode vir lepelvoeding wat aan u gewys is?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

5. As die spesiale beker aan u gegee is, gebruik u dit wel? (Nie gegee nie)

Ja, definitief	Meestal	Partykeer	Nee, glad nie

6. As vingervoeding aan u gewys is, gebruik u dit wel? (Nie gewys nie)

Ja, definitief	Meestal	Partykeer	Nee, glad nie

7. Drink u kind enigsins meer of beter as vantevore?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

8. As u kind drink, mors hy/sy enigsins minder?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

9. Eet u kind enigsins meer of beter as vantevore?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

10. Eet u kind nou kossoorte wat hy of sy nie voorheen kon eet nie?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

11. Dink u dat hierdie voedingsmetodes wel u en u kind gehelp het?

Ja, definitief	Meestal	Partykeer	Nee, glad nie

12. Sal u aanhou om hierdie voedingsmetodes by die huis te gebruik?

Ja, almal	Meeste van hulle	Party van hulle	Nee, geen

As u enige aanmerkings wil byvoeg wat ons miskien sal help om enige probleme wat u ondervind het, te verstaan, skryf hulle asseblief hier:

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As u enige ander veranderinge in u kind opgemerk het, sedert u met die nuwe voedingsmetodes begin het, beskryf hulle asseblief hier:

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APPENDIX G 3

QUESTIONNAIRE FOR MOTHERS and/or CAREGIVERS

1. Ungakwazi ukulandela umboniso uwucacise ekliniki ngokweneleyo?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

2. Uyayi sebenzisa lendlela intsha ekhaya?

Ewe, zonke	Uninzi lwazo	Ezinye zazo	Hayi, nanye kuzo zonke

3. Uyakwazi ukusebenzisa indlela yokutyisa ngoluhlobo ububoniswe ngayo?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

4. Uyakwazi ukumtyisa ngecephe ngohlobo ububoniswe ngayo?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

5. Ukuba ubunikwe imagi oluhlobo olulodwa lokusela, ubuyisebenzisa? (Not given)

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

6. Ukuba ububoniswe ukutyisa ngeninwe, ukwazile ukwyisebenzisa? (Not shown)

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

7. Umntwana wakho uyakwazi ukusela / ngcono kunangaphambili?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

8. Xa esela usachitha ngokufanayo kunangaphambili?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

9. Umntwana wakho uyakwazi ukutya kunangaphambili?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

10. Umntwana wakho uyakwazi ukutya ebengakwezi ukutya kunangaphambili?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

11. Ucinga ukuba ezindlela zokutya umncedile umntwana wakho?

Ewe, ngokuqinisekileyo	Amaxesha amaninzi	Ngomanye amaxesha	Hayi, konke konke

12. Uyakuhlala usebenzisa enzindlela zokumtyisa ekhaya?

Ewe, zonke	Uninzi lwazo	Ezinye zazo	Hayi, nanye kuzo zonke

Ukuba ufuna ukongeza ezinye izinto ezinokuthi zisincede ukuqonda ezinye ingxaki othe wazifumana nceda yenza oko aphe:

Ukuba uyewaqaphela ezinye indlela ezintsha emntwaneni wakho oko waqala ezindlela zintsha, nceda sixelele ngazo aphe: