

THE NATURE AND EXTENT OF FEEDING AND SWALLOWING
DISORDERS IN THE PAEDIATRIC POPULATION
WITH CEREBRAL PALSY: A PILOT STUDY

A REPORT ON A STUDY PRESENTED TO
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Abstract

The aim of this exploratory study was to document the nature and extent of feeding and swallowing disorders amongst 100 young children with CP, below 4-years of age. Questionnaires were completed by the researcher in a brief interview with the caregivers of these children at the CP Clinic, Red Cross War Memorial Children's Hospital, Cape Town. Results indicated that the prevalence of feeding disorders amongst children with CP was high, with 100% of the children presenting with some feeding or swallowing difficulty. Furthermore, 89% of the caregivers had noticed these difficulties when their child was still very young and prior to a medical diagnosis of CP. These findings indicate the need for SLP to provide caregivers with the skills they require to maximize feeding abilities of their child, as well as to assist other professionals in understanding the importance of feeding and swallowing therapy in the overall management of children with CP.

Key words: Feeding and swallowing disorders, cerebral palsy, early intervention

Abbreviations: CP = cerebral palsy, SLP = speech-language pathologists

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- My supportive family and friends
- The 100 caregivers and their children, who so eagerly gave up their time to answer my questions

Declaration

I, Judy Davison, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise), and that neither the whole work nor any part of it has been, is being, or has been submitted for another degree in this or any other university.

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Introduction

“Feeding encompasses the process of obtaining food, ingesting the food into the mouth and swallowing” (Rudolph, 1994, p.116). Disruption at any stage of this complex process might result in a feeding disorder or dysphagia. Children with cerebral palsy make up between 39-56% of all children who present with feeding and swallowing problems (Reilly, Skuse & Poblete, 1996). This finding has sparked recent interest into the documentation of the characteristics of feeding and swallowing in children with cerebral palsy, in an attempt to gain a more in-depth understanding of the problem. This new knowledge is useful in both the planning and implementation of therapy strategies to help reintegrate the child with cerebral palsy into a society that places great emphasis on food. According to Rudolph (1994), the acceptance of a child into society is inseparable from the process of learning to eat. Feeding disorders disrupt this process, alienating the child and the family from normal social activities. Furthermore, the inability to eat normally greatly interrupts the normal psychosocial development of the child (Rudolph, 1994).

Whilst many studies have documented the high incidence of feeding and swallowing difficulties in the CP population, literature describing the specific aspects of feeding and swallowing that are disrupted, such as milk running down the sides of the baby’s mouth, is relatively scarce. It is important for professionals to realize the nature and extent of the problem so as to provide optimal care to those children with CP, who are unable to enjoy the pleasures of food and the related social integration. Furthermore, one must not ignore the link between feeding skills and communication. There has been much debate in the literature regarding the effect early feeding skills have on later speech

development (Arvedson & Brodsky, 1993; Love, Hagerman & Taimi, 1980; Morris & Klein, 1987). According to Arvedson and Brodsky (1993), the relationship of oral motor development to feeding and speech seems logical as feeding therapy involves oral motor treatment where the primary goal is the development of co-ordinated movements of the oral structures, respiratory and phonatory systems. Therefore, based on the assumption that movements of the oropharyngeal musculature in feeding are directly related to speech movements in that they utilize the same oral structures, oral feeding is a by-product of oral-motor exercises, whereby communication is also enhanced. However, there is very little research to support or refute a causal relationship between the development of the sensori-motor control of feeding and early speech movement (Arvedson & Brodsky, 1993).

Love et al (1980) emphasize that prespeech oromotor training is common in children with CP. This training is usually aimed at reducing dysphagic characteristics by implementing feeding programs to improve chewing, the oral and pharyngeal stages of the swallow and sucking. It is believed that one effect of reducing these dysphagic symptoms will be a reduction in the probability and severity of future dysarthria or speech difficulties. "Feeding programs have almost become a universal prescription in the prespeech management of a dysphagic child with CP (Love et al, 1980). More recently, the connection between feeding and communication has been examined with regards to sensory integration and the co-ordination of sucking, swallowing and breathing (Glass & Wolf, 1994; Selley, Ellis, Flack & Brooks, 1990). Love et al (1980) states that although it cannot be stated with complete assurance that oro-motor activities will develop the specific movement patterns for intelligible speech in CP, feeding activities

will meet the needs of making eating easier as well as stimulate gross movements of the oral musculature. According to Hardy (1983), after speech has emerged, these movements can be adapted, refined and incorporated into the more precise movements involved with articulation. In conclusion, both adequate oral skills and an intricate coordination of sucking, swallowing and breathing is required for effective feeding abilities (Glass & Wolf, 1994; Selley, Ellis, Flack & Brooks, 1990). A disruption in any of these processes can lead to feeding difficulties. In addition, the systems required for feeding are the same as those systems required for speech, therefore difficulties with feeding may later be represented as difficulties with communication and speech development (Arvedson & Brodsky, 1993).

A research study (using an administered questionnaire) was conducted in an attempt to document the dysphagia characteristics of feeding and swallowing present in 100 children with cerebral palsy, under 4-years of age, attending the CP clinic at Red Cross War Memorial Children's Hospital, Cape Town.

It is hoped that documentation of these problems existing in young children with cerebral palsy, as reported by their primary caregivers, might emphasize the need for early management in an attempt to reduce the serious consequences, such as malnutrition, pneumonia and death, closely associated with disrupted feeding and swallowing. Gaining a thorough understanding of the underlying difficulties with feeding and swallowing has important implications for developing a comprehensive, multidisciplinary management plan for optimizing the life of a child with CP.

It is, after all, the ultimate aim of therapists to maximize the quality of life of their patients, which would be an impossible task without having access to information on the characteristics underlying feeding and swallowing disorders in this population.

University of Cape Town

Literature Review

Efficient eating and swallowing is crucial for sustaining human life. Prerequisites to safe, efficient feeding include intact anatomy and physiology, intact sensory and tactile systems, adequate muscle tone and postural support of the oral, pharyngeal and respiratory systems (Alexander, Bochme & Cupps, 1993).

Dodds, Stewart and Logemann (1990, p.7) describe the swallow as “an orderly physiologic process that transports ingested material and saliva from the mouth to the stomach”. Although this entire swallow activity is over in a few seconds, it involves a variety of complex movements. Disruption at any stage of this process can result in a disordered swallow, also known as dysphagia. Recognized complications of dysphagia include dehydration, aspiration pneumonia, inadequate nutrition and even death (Logemann, 1983; Roger, Arvedson, Buck, Smart & Msall, 1994).

Feeding can be described as the process that includes the gathering of and preparation for intake of food, sucking or chewing and swallowing (Arvedson & Brodsky, 1993). Arvedson and Brodsky (1993) also suggest that therapy, which has a major emphasis on feeding, can result in the failure to achieve certain important steps underlying the skills of swallowing. Feeding involves both communicating the desire to eat, as well as selecting suitable types and sizes of bolus to meet the individual’s needs and abilities. Efficient and safe feeding requires adequate cognition, motor ability and self-feeding skills.

Feeding and swallowing problems are serious health issues, which affect a significant number of individuals (Ott & Pikna, 1993; Perlman, 1991). According to Perlman (1991), attempts have been made to summarize the prevalence of dysphagia,

amongst a variety of populations, since 1983. Results range between 6% and 74% depending on the setting of the study and the population being examined. The only unanimous finding of previous research is the suggestion that there has not been an increase in the incidence of dysphagia over the past decade, but rather an increase in the diagnosis of feeding and swallowing problems (Groher & Bukatman, 1986; Mirro & Patey, 1991).

Children and infants make up a large part of the population with dysphagia. Bu'Lock, Woolridge & Baum (1990) stated that feeding difficulties make up a major proportion of the problems that arise in otherwise healthy term and preterm infants. Feeding and swallowing problems in infants and children are typically a result of a number of interrelated and complex factors (Arvedson & Lefton-Grief, 1996; Alper & Manno, 1996). Ultrasound studies have indicated that a suckling response is elicited in a fetus as young as 12 weeks gestation, when the lips are touched (Arvedson & Brodsky, 1993). True suckling is evident between 18-24 weeks gestation, when the fetus is capable of sucking and swallowing amniotic fluid in utero. Furthermore, the volume of amniotic fluid being swallowed increases with increasing gestational age (Comrie & Helm, 1997; Humphrey, 1964). The development of suck-swallow-breathe (SSB) coordination has been documented in preterm infants born as young as 32 weeks gestation. This is often not well coordinated at this age, but by 37 weeks gestation, complete SSB coordination is usually achieved (Hack, Estabrook & Robertson, 1985). According to Arvedson and Brodsky (1993) a healthy 34-week-old fetus is capable of suckling and swallowing to sustain nutritional needs.

A normal infant swallow differs from the normal adult swallow. These differences can be explained by the different anatomical structures of the infant and adult. The newborn infant is born with sucking pads, which reduce the size of the oral cavity (Arvedson & Brodsky, 1993). The tongue takes up most of the oral cavity and is thus confined and restricted in movement. As a protective mechanism, the infant's epiglottis and soft palate are in approximation and they are obligate nose breathers. In addition, the larynx in a newborn infant is situated higher than that of an older child or adult. This high positioning of the larynx reduces the need for sophisticated laryngeal closure for airway protection during the swallow, as not as much hyoid and laryngeal elevation is required with infants as with adults. (Morris & Klein, 1987; Rudolph, 1994). The anatomical structuring of the newborn allows the infant to breathe and suck at the same time, while reducing the risk of aspiration (Arvedson & Brodsky, 1993). Anatomical changes begin between four to six months and continue throughout the first year of life, until the infant's anatomy resembles that of an adult (Morris & Klein, 1987).

A normal infant's feeding and drinking skills develop through a number of key stages (Arvedson & Brodsky, 1993; Morris & Klein, 1987). From birth to three months the infant is only able to manage liquids, which they drink using a forward-backward suckling motion of the tongue. This motion results from the lack of differentiation between the tongue and jaw movements, evident at a young age (Arvedson & Brodsky, 1993). According to Morris and Klein (1987) semi-solids (e.g. puree) are normally introduced between three and six months. At this stage the forward-backward tongue motion, previously associated with suckling changes to an up-down tongue motion until the infant is able to suck the food from the spoon. By six to nine months, finger foods

(e.g. rusks) can be given to the child under supervision. The child should now be able to bite food that is placed on the sides of the mouth. Tongue movements then become more refined and differentiated from the jaw, resulting in greater jaw stability during feeding and swallowing (Arvedson & Brodsky, 1993).

Foods that are introduced between nine and twelve months have greater variety according to taste, texture and consistency. The child should be able to use their tongue to move the food from side to side and their upper lip is now able to remove food from a spoon. By 12 to 18 months the child should be able to eat and chew all food varieties efficiently (Winstock, 1994).

A number of methods, both subjective and objective, have been developed to accurately document feeding and swallowing difficulties in adults and children. The oral-motor aspects of feeding are best examined using subjective methods such as feeding assessment scales and checklists (Arvedson & Brodsky, 1993), whereas accurate assessment of the oral, pharyngeal and oesophageal areas are best examined using objective imaging techniques such as videofluoroscopy, barium swallows and endoscopy (Sonies, 1991).

Infant assessment scales generally consist of descriptive observations, which are compared to normal development. As a brief summary, these scales require the clinician to observe the child during nutritive and non-nutritive sucking in an attempt to determine the absence or presence of normal or abnormal oral motor skills and reflexes. The child's abilities are typically rated on a numerical scale, but these scales differ according to the checklist being used. Many of these scales also require an additional parental report of their experiences of mealtimes with their child.

Some widely used and accepted assessment scales include the **Schedule for Oral Motor Assessment (SOMA)** (Reilly, Skuse, Mathisen & Wolke, 1995), **Neonatal Oral-Motor Assessment Scale (NOMAS)** (Braun and Palmer, 1985), **Clinical Feeding Evaluation of Infants** (Wolf & Glass, 1992), **Multidisciplinary Feeding Profile (MFP)** (Kenny et al., 1989), **Oral motor/feeding Rating Scale** (Jelm, 1990) and the **Developmental Pre-feeding Checklist** (Morris & Klein, 1987) all of which are discussed in detail by Alper and Manno (1996) and Arvedson and Brodsky (1993).

Although these assessment scales are quick and non-invasive, they require greater experience and skill as they rely on the clinician's perception of the child's difficulties (Arvedson & Brodsky, 1993). As a result, it is useful to also include objective assessments of the child's feeding abilities for greater reliability and a more in depth assessment. The most common method is videoflouroscopy. This x-ray technique provides a clear picture of the entire swallowing process (Mirrett, Riski, Glascott & Johnson, 1994), however the risks of radiographic procedures cannot be ignored (Sonies, 1991) and may constrain research. Other techniques involve milk studies (where radionuclide is added to the feed and regular images are recorded) and a pH probe test, both of which are useful for identifying gastro-oesophageal reflux (Feranchak, Orenstein & Cohn, 1994; Weber, Woolridge & Baum, 1986). Patient compliance must be considered together with the purpose, risks and discomfort inherent in any techniques currently used in dysphagia evaluations (Sonies, 1991).

Tcheremenska and Gisel (1994) in their study on the use of substitute food textures for eating assessments found that children with CP are more sensitive to subtle food changes than their normal peers. As a result, food textures and consistencies should

not be changed arbitrarily during standard feeding assessments. Mirrett et al. (1994), in their videofluoroscopic study of children with CP, report that routine and early assessment of dysphagia using videofluoroscopy is useful for determining the timing and goals of treatment for such children. Furthermore, videofluoroscopy clearly indicates the risk of aspiration and allows one to judge the efficacy of postural changes or alterations in textures or bolus sizes of the material being swallowed (Mirrett et al., 1994).

Lefton-Grief and Loughlin (1996) add that objective assessments are only one component of a comprehensive paediatric feeding and swallowing evaluation. As important is a careful, subjective observation of the child and caregiver interaction during mealtimes, as well as the characteristics of the food (Arvedson & Brodsky, 1993).

The successful oral feeding and growth of infants and children relies not only on functional swallowing, but also on a broad range of neurodevelopmental skills. These skills include the sensory systems, gross and fine motor abilities, cognition and communicating the desire to eat. Deficits in any of these areas may result in poor feeding and swallowing skills, often resulting in inefficient nutritional intake (Rogers, 1996).

Sensory deficits common in children with dysphagia include abnormalities of central sensory processing or integration (Rogers, 1996). Sensory integration refers to the ability to use the sensory organs, such as eyes, skin, nose, ears and tongue, to receive information (Rogers, 1996; Winstock, 1994), while perception is the ability of the brain to process and interpret the desired sensory message correctly (Winstock, 1994). Difficulties with sensory integration and perception can greatly affect the eating and drinking process (Rogers, 1996; Winstock, 1994).

Winstock (1994) identified four distinct difficulties with sensory perception (hypersensitivity, hyposensitivity, sensory defensiveness, sensory overload). Hypersensitivity involves a stronger reaction to sensory input than would normally be expected. Hypersensitive responses resulting from feeding include tightening of the lips, gagging, exaggerated mouth opening and pushing into extension. In contrast, hyposensitivity results in less of a reaction than would be expected. A common sign of oral hyposensitivity is when children are unaware of a bolus in their mouth and they do not attempt to deal with it appropriately. Sensory defensiveness occurs when the child is unable to respond appropriately to oral sensations, resulting in a protective reaction, such as the refusal of any touch in and around the mouth. This affects feeding and swallowing as the feeder is unable to place a bolus in the child's mouth (Winstock, 1994). Sensory overload occurs when children are unable to filter out irrelevant sensations in order to focus only on those sensations that are important. This causes the child to be easily distracted, resulting in the inability to concentrate on one particular task, such as feeding (Winstock, 1994).

Mealtimes involve both visual and auditory communication between the parent and child. Rogers (1996) suggests that in the early stages of life, children react consistently with an alerting response to voices and noises. Maturation results in this response diminishing with repetition, allowing the infant to focus on specific tasks at one time. Lack of this habituation to auditory input is often associated with CNS abnormalities. The excessive alerting to sound can result in a disordered state and frequent interruptions to feeding (Rogers, 1996), as the child is unable to focus their attention on a task such as feeding.

Light touch sensation to the face and oral cavity is essential for eliciting various oral reflexes in the first six months of life. These early reflexes include the sucking reflex (to suck an object placed in the mouth), the rooting reflex (to locate the source of food) and tonic bite reflex (a protective reflex) (Arvedson & Brodsky, 1993; Winstock, 1994). These primitive reflexes are important for early feeding. However, the infant is required to grow out of these reflexes to enable the development of more mature voluntary oral motor skills, such as the development of tongue lateralization, biting, chewing and the transfer of the bolus to the pharynx (Arvedson & Brosky, 1993; Morris & Klein, 1987; Rogers, 1996). Persistence of these premature reflexes beyond six months of age can therefore complicate the development of these more mature patterns, which in turn affects positioning and oral feeding of the infant.

Children with neuromotor dysfunction present with a variety of problems that may affect feeding and swallowing. These include the persistence of primitive reflexes, poor oral motor development, reduced mobility and poor posture (Reilly et al., 1996; Rogers, 1996). Previous research has demonstrated that these problems are a major cause of feeding and swallowing difficulties and thus many cases of paediatric dysphagia occur in children with neuromotor dysfunction (Arvedson & Lefton-Grief, 1996; Reilly & Skuse, 1992; Reilly et al, 1996; Rogers, 1996; Alper & Manno, 1996).

The major mechanism thought to be responsible for feeding and swallowing problems in children with neuromotor dysfunction is poor oral motor skills, typically resulting in food loss due to spillage and vomiting (Gisel, 1994). Campbell (1979 cited in Gisel, 1994) suggested that one of the earliest clinically diagnostic signs of a neurological disturbance is a child's feeding difficulties. Such early signs include difficulty sucking,

problems latching on, frequent coughing and choking and the need for non-oral feeds (Reilly et al., 1996).

It has been postulated that modern advances in neonatal care have resulted in a dramatically improved survival rate for those premature and low birth weight infants, who might have died in the past (Alper & Manno, 1996; Hack et al., 1985; Rossetti, 1996). The improved survival rate has coincided with an increased number of chronically ill children requiring special care and prolonged hospitalization (Rossetti, 1996).

In addition, premature infants are at a higher risk of developing problems with feeding because of neurological immaturity, abnormal muscle tone, weak oral reflexes and overall weak state (Comrie & Helm, 1997; Glass & Wolf, 1994; Stanley, 1992). Moreover, these premature and low birth weight infants are at a greater risk, than full term infants, for a diagnosis of CP (Cooke, 1990; Grether, Nelson, Emery & Cummins, 1996; Mutch, Alberman, Hagberg, Kodama & Perat, 1992). Children with a birthweight below 2500 grams are 25 times more likely to be diagnosed with CP, while 25-40 % of all children with CP have a history of low birthweight (Pharoah, Cooke, Cooke & Rosenbloom, 1990). According to Cooke (1990), CP is the most prevalent severe disability in very low birthweight survivors. Stanley (1992) examined two contrasting positions in an attempt to explain this phenomenon. Firstly, it has been suggested that as the number of surviving premature and low birth weight infants increases, they suffer brain damage due to postnatal complications related to their extreme immaturity. Secondly, it has been postulated that many of those CP and premature infants, who are compromised well before birth, are now surviving (Stanley, 1992).

CP has been defined as a disorder in which a non-progressive cerebral lesion results in significant motor delay, abnormal neuromotor findings and other central nervous system deficits in cognition and neurobehaviour during the developmental years (Arens, 1978; Hardy, 1983; Levitt, 1995; McDonald & Chance, 1964; Rogers, 1996).

Muscle weakness resulting from CP is not confined to specific areas. As a result, abnormal tone in the limbs will be associated with abnormal tone throughout the body, including the oral musculature. As previously mentioned, intact oral musculature is a prerequisite for safe and efficient feeding, and any disruption in muscle tone might result in coexisting feeding problems and dysphagia (Arvedson & Lefton-Grief, 1996; Gisel, 1994; Rogers, 1996).

The incidence of CP in South Africa is still unknown (Arens, 1978). Worldwide incidence figures reported by Pharoah et al. (1987) are estimated at about 1.5 per 1000 live births. Although past studies indicate that the incidence of CP in Europe and America appears to be dropping (Hagberg, Hagberg & Olow, 1975 cited in Arens, 1978) South African studies have shown a rising incidence of CP, at least amongst the Coloured population (Arens, Molteno, Marshall, Robertson & Rabkin, 1978; Molteno, Arens, Marshall & Robertson, 1980). Recent studies on the incidence of CP in South Africa are reportedly lacking (C.D. Molteno, personal communication, 23 July 1999). Statistics received from the Cerebral Palsy Association of the Western Cape estimate a prevalence of 2.5 per 1000 live births, which appears consistent across all the cultural groups of South Africa (C.D. Molteno, personal communication, 23 July 1999).

The acquisition of reliable health statistics is only one difficulty facing health professionals in South Africa. A possibly greater challenge is the provision of health care services to those individuals requiring intervention. According to McConkey (1994), early intervention is a challenging service, which is exacerbated in developing countries (such as South Africa) as a result of poverty, lack of education and language and culture differences. According to Tuomi (1994), in South Africa there is a situation of too many people requiring speech therapy services and not enough therapists. In addition, as a result of past political policies, the majority of speech therapists are from middle or upper class White families (Tuomi, 1994) and therefore do not speak the language or know the culture of the non-white population of South Africa. Thus, the services provided by a SLP are not accessible to the majority of the South African population.

Interventions will only be successful if therapists focus on the child as a whole and involves the child's family in the therapy (McConkey, 1994). As a result, it is essential that therapists in South Africa modify their therapy to suit the expectations, needs, culture and customs of their clients so that their services are valuable and necessary to the entire South African population (Tuomi, 1994). According to Van Rensburg, Fourie and Pretorius (1992) health care extends beyond health services to include aspects surrounding these services, such as planning and implementation of policy, the financing system, preventative medicine, health training and research and education of the population. As a result, there has been a shift in South Africa towards an emphasis on primary health and community care. Community care can generally be described as any care given outside large institutions, including both statutory and

voluntary services and personal social networks with special emphasis on family care (Compton & Ashwin, 1992).

Besides the universal problems facing health care systems throughout the world, the South African system has unique problems as a result of the distinctive socio-cultural, political-economic and geographic set-up of the country and its people (Van Rensburg et al., 1992). Thus, as a speech therapist working in South Africa, one has to adapt one's services to best meet the needs of the community.

“The professional has to adjust both its training and professional practices and therefore implement alternative service delivery models based on the community needs and resources” (Tuomi, 1994). Therefore, with regards to the management of children with CP in South Africa, therapists must incorporate family members in all aspects of therapy so that the services can be extended to areas presently out of reach to traditional service delivery systems. According to Tuomi (1994), such services need to rely greatly on counseling and home programmes due to large travelling distances and the need for interpreters. It is of particular importance to identify at risk children at a very young age, so that they are not “lost” in rural areas until they are older and their impairments more severe. One aim of community care must be to form parent groups, involve local people in therapies and indirectly to develop public policies and schemes to overcome poverty (McConkey, 1994).

Lesions to different parts of the brain produce different symptoms of motor dysfunction. A number of types of CP, classified according to neuromuscular characteristics, have been identified in the past (McDonald & Chance, 1964). The three most common types referred to as spastic, athetoid and ataxic.

Damage to the cerebral cortex results in spastic CP, which is associated with increased muscle tone, rigidity and abnormal postures. This is recognized as the most common type of CP. Damage to the cerebellum is most often associated with ataxic CP, characterized by low muscle tone and balance disturbances. Damage at the level of the basal ganglia results in fluctuating tone, which is referred to as athetosis. In the majority of cases the exact diagnosis of CP is not clearly defined. In such cases, the children are diagnosed as having a combination of two or more of the different types, referred to as mixed CP (Levitt, 1995).

Children with CP are not only diagnosed according to the type of CP they present with, but also according to the severity of limb involvement. Hemiplegia involves affected motor ability on one side of the body. Quadriplegia explains the involvement of all four limbs, as does diplegia, where the legs are more severely affected than the upper limbs (Levitt, 1995; McDonald & Chance, 1964).

Although two thirds of all children with CP are born full term, the actual birth prevalence of CP amongst children who are born prematurely is up to three times higher (Pharoah et al., 1990). In examining the correlation between the types and severity of CP with low birthweight and prematurity (Cooke, 1990; Grether et al., 1996; Pharoah et al., 1987,1990; Stanley, 1992), in normal birthweight infants, the prevalence of quadriplegia and hemiplegia are similar, but consistently higher than the prevalence of diplegia (Pharoah et al.,1990). Diplegia, however, becomes significantly more prevalent in low birthweight and premature infants (Cooke, 1990).

As has been mentioned, children with CP make up a large proportion of the population who present with feeding and swallowing problems. Reilly et al. (1996) estimated that children with CP account for 39% to 56% of all children with feeding and swallowing problems. The prevalence of feeding and swallowing disorders in the population with CP could be as high as 90 % (Reilly et al., 1990; Reilly & Skuse, 1992). Inadequate nutrition, resulting from impaired self-feeding skills and oral motor involvement can further exacerbate the existing physical growth retardation of children with CP (Reilly & Skuse, 1992).

Boyle (1991), studied the nutritional management of developmentally disabled children and concluded that poor growth and development in the CP population is far too often ascribed to the neurological condition than to chronic malnutrition resulting from poor feeding skills and dysphagia. According to Reilly and Skuse (1992) the difficulty children with CP have in sustaining the normal rate of growth can be ascribed to the lack of self-feeding skills, communication difficulties for requesting food, severe oral motor dysfunction, and the inability to search for food when it is needed.

Reilly et al. (1996) have attempted to document the prevalence of feeding and swallowing disorders in the CP population. Of their sample of 49 children with CP, 91.5% presented with some degree of oral motor dysfunction, as scored on the *Schedule for Oral Motor Assessment (SOMA)* (Skuse, Stevenson & Reilly, 1995). In addition, 65 % had been fed non-orally during their first year of life and 71% were found to have frequent coughing and choking during mealtimes. The high prevalence of feeding and swallowing problems reported by Reilly et al. (1996) is supported by other research emphasizing the nature and extent of feeding and swallowing difficulties amongst

children with CP (Couriel, Bisset, Miller & Clarke, 1993; Gisel, 1994; Gisel & Alphonse, 1995; Mirret, Riski, Glascott & Johnson, 1994; Reilly & Skuse, 1992).

The Reilly et al. study (1996) also indicated that a large proportion of children with CP had significant problems with feeding and swallowing within the first year of life, and that the majority of these problems preceded their diagnosis of CP. These results are also supported by similar studies once more suggesting that feeding behaviour is a sensitive indicator of central nervous system integrity (Ingram, 1962; Caesar, Daniels, Devleiger, DeCock & Eggermont, 1982; Reilly & Skuse, 1992). Couriel et al. (1993) report that feeding and swallowing difficulties typically persist throughout the life of a child with CP. As a result, mealtimes continue to be a battle for the caregivers and many of the children are small and undernourished (Couriel et al., 1993; Reilly et al., 1996), many of them requiring alternative methods of feeding such as nasogastric tubes or a feeding gastrostomy. There have been a number of outcome studies examining the effects of low birth weight, prematurity and neurological disorders on young infants as they grow older and enter school or training centres (Amiel-Tison & Stewart, 1989; Cooper & Sandler, 1997; Kelleher, Casey, Bradley, Pope, Whiteside, Barrett, Swanson & Kirby, 1993 & Veen, Ens-Dokkum, Schreuder, Verloove-Vanhorick, Brand and Ruys, 1991). According to Amiel-Tison and Stewart (1989), CP was the most common developmental impairment reported in follow-up studies of low birth weight or very premature infants. Similar findings were reported by Cooper and Sandler (1997) in their longitudinal study of low birth weight infants in South Africa. In contrast, Veen et al. (1991) reported that most high risk children in their study survived without handicap or serious disability at preschool age. However, they noted that more subtle impairments, such as language,

reading and learning difficulties may only be identified at a later stage. This emphasizes the importance of re-assessing at risk children at the age of nine or ten years, where achievements at school can also be included (Veen et al., 1991).

Furthermore, there is an increased focus both in the literature and clinically for the early intervention of children presenting with a variety of developmental disorders (Rossetti, 1996). Although research on feeding and swallowing in CP is extensive, many prevalence studies have examined the feeding characteristics of the older child. (Gisel & Alphonse, 1995; Reilly et al., 1996; Rogers et al., 1994). This past research mentions the presence of poor oral-motor skills and general feeding difficulties, but there have been limited studies of the exact feeding and swallowing problems that are often evident from birth, such as difficulties latching onto the nipple or milk running down the sides of the infant's mouth.

Of all the dysphagia studies of children with CP, a limited number have relied solely on maternal reports of difficulty (Reilly & Skuse, 1992). The bond developed between a mother and the child she carries for nine months is immeasurable (Herzog, 1999). The close and intimate contact shared between mother and child places the mother at an increased advantage of recognizing any disruptions or abnormalities in her child. As mentioned by Herzog (1999), a mother and child are synchronized physically and mentally from birth and during the first few months of the infant's life. Feeding is the most basic need a mother is required to provide her infant, and it requires a close bond and shared physical contact. According to Graffy (1992), social pressures and advertising play a role in a woman's decision about feeding their children and the majority of women decide on their choice of feeding method whilst still pregnant.

For this reason, the mother is the first person who might identify a disruption to the complex process of feeding and swallowing in a young infant. As a result, although objective methods are typically employed in research, one should not underestimate the negative effects of exposure to radiographic studies as well as their high cost. In addition, time constraints were placed on the researcher's contact with the infants at the CP Clinic due to their appointment times with other professionals. As the caregivers involved in the study could not afford additional trips to the clinic solely for the purpose of research, it was not considered feasible to complete feeding assessment scales on the subjects. As a result, the use of maternal reports of their child's feeding and swallowing abilities would be time effective and beneficial for this study. Furthermore, in a country such as South Africa, the use of objective techniques that require greater skills and resources is often limited, especially in research. "Therapists must be less dependent on technical advancement and rely more on knowledge of linguistic, sociological and psychological characteristics of the population" (Tuomi, 1994: 7).

As previously mentioned, this study aims to document the aspects of feeding and swallowing disorders that are evident in 100 children, younger than four years of age, with cerebral palsy, attending the CP Clinic at Red Cross War Memorial Children's Hospital, Cape Town. In the past, few studies on CP in South Africa included the Black population, possibly related to the prevailing politics of the time, and to difficulties in obtaining birth history information as a result of language differences and differing medical care. While research has indicated an increase in the prevalence of CP amongst the Coloured population (Arens et al., 1978), comprehensive statistics on the prevalence of CP amongst the Black population are still lacking.

As this hospital is a government institution, which has a well-established CP Clinic receiving referrals from a number of other hospitals in the Western Cape, it is hoped that many of the cultural groups of South Africa will be included.

The severity of the feeding and swallowing disorders, based on the number of coexisting symptoms will also be documented. It is hoped that a description of the nature and extent of feeding and swallowing problems in the CP population will facilitate more equitable resource allocation and earlier intervention to maximize the management of children with CP.

Research has indicated differences in the type and severity of CP according to birth weight and gestation. However, to the best of this researchers' knowledge, no studies have examined different characteristics of feeding and swallowing difficulties according to the different types and severities of CP. As a result, the correlation between the characteristics of the dysphagia and feeding problems, as well as the type and severity of CP will also be noted in an attempt to examine how the feeding and swallowing disorders might differ according to the type and severity of the CP.

Unlike studies in the past that examined the characteristics of feeding and swallowing more generally, the researcher aims to document information on a number of individual characteristics of feeding and swallowing problems, such as coughing, falling asleep and milk dribbling down the sides of the mouth (Reilly et al., 1996).

By providing information on the characteristic features of dysphagia in children with CP, it is hoped that health professionals in the field will become more aware of the nature and extent of feeding and swallowing disorders that commonly exist in this population. In addition, early intervention might be promoted with the paediatric

population presenting with feeding and swallowing difficulties, including better distribution of staff, equipment and resources to maximize rehabilitation outcomes in this much needed and rapidly expanding area of health care.

As a result of the numerous challenges facing therapists in South Africa, it is important to determine exactly where intervention is required. Thus there is a need to document the types and severities of CP occurring across the cultural groups in South Africa, as well as the effects of birthweight and prematurity on the prevalence of CP. Hence this study will also describe biographical details of the sample, such as birthweight, gestation and age of diagnosis of CP according to the different races that were included in the study. In doing this, trends may emerge that might encourage further research in the area.

Rationale

1. Prevalence can be defined as the rate of a disorder existing in a defined population during a specific time (Lubker, 1997). By identifying and documenting the prevalence of feeding and swallowing disorders in the paediatric population with CP, the involved health professionals will have a better idea of the nature and extent of these problems
2. This knowledge will also allow for better allocation of resources and staff to aid with the early intervention of this at risk population.
3. Knowledge of the age at which the feeding and swallowing disorders are first identified in the CP population would facilitate early identification and referral to a speech therapist, in turn enabling early intervention for the feeding and swallowing disorders.
4. Appropriate management of feeding problems and dysphagia is essential to minimise the risk of malnutrition, dehydration, aspiration pneumonia and death.
5. Improvement of feeding and swallowing abilities early in life should result in better oral motor control and may be related to improved development of speech.
6. The age of onset of feeding disorders and the age of the initial diagnosis of CP will be compared and may be useful in providing caregivers with information, through education and counseling, which might empower the caregivers and reduce the negative sequelae of dysphagia.

Aims

1. To determine the general prevalence of feeding and swallowing problems present in children with Cerebral Palsy (CP), under four years of age, attending the CP Clinic at Red Cross War Memorial Children's Hospital, as determined by the entire questionnaire (see appendix A).
2. To emphasize the need for better staff and resource allocation for early intervention with children presenting with feeding and swallowing problems, who are at an above average risk for CP.
3. To document the reported frequencies of specific characteristics of feeding and swallowing reported in this paediatric population with CP (as determined by responses to the questionnaire-see Appendix A).
4. To document the biographical details of the sample in an attempt to examine the effect of race, gender, gestation or birthweight on the resulting type and severity of CP.

Research questions

1. What percentage of children with CP exhibit characteristics of feeding and swallowing disorders, as identified by a questionnaire? (see Appendix A)
2. At what age were these disruptions in feeding and swallowing first noticed?
3. Is there a correlation between the feeding and swallowing characteristics and the type and severity of the CP?
4. Is there a correlation between the biographical details (gender, race, gestation and birth weight) of the sample and the type of CP, severity of CP and the presenting feeding and swallowing problems?

Methodology

Research Design

A descriptive study in the form of a questionnaire, administered face-to-face, was conducted in an attempt to determine the nature and extent of feeding and swallowing problems amongst a sample of 100 children, between the ages of 0-4 years, with CP.

Subjects

Selection Criteria

The following subject selection criteria were used in this study.

Selection Criteria of caregivers

Biographical details.

The primary caregivers, who were interviewed about their children, could be of any age, race or socioeconomic background. Previous studies have indicated that the incidence of dysphagia and feeding problems in children with CP is not influenced by age, race and socioeconomic status (Kuhlemeier, 1994).

Language.

The informants were required to be first language speakers of English, Afrikaans or Xhosa. The interviews were conducted in any of these three languages, as required by the informant. A common understanding of the language of the interview would ensure that all questions were clearly understood by the informants and the answers accurately recorded by the interviewer (Bennett & Ritchie, 1975; Katzenellenbogen et al., 1997).

Memory.

All informants were required to answer questions pertaining to the early aspects of their child's feeding behaviours. Parents were asked whether they remembered characteristics of their child's feeding behaviours prior to the interview. Those parents who admitted that they were unable to remember much information were excluded from the study.

In addition, according to the flexible nature of an administered questionnaire (Bennett & Ritchie, 1975) the time taken to answer questions, hesitations, body language and missing answers were judged subjectively by the interviewer as a sign of poor memory, and such questionnaires were removed from the study. This only occurred in two cases, both where the father had brought the child.

Parental Consent.

The purpose of the study and content of the questionnaire was explained to all informants prior to the interview. Due to the personal and inquiring nature of many of the questions, consent was required from all informants. As a result of the large number of illiterate caregivers, verbal consent to participate in the research was obtained before questioning began. Exact wording of the consent, read to each informant before questioning, can be seen in appendix B. The informants were informed of their right not to participate in the study, or to withdraw at any stage of the interview (Katzenellenbogen et al., 1997).

Selection Criteria of the children with CP

Biographical details.

The children with CP could be of any race, gender or socioeconomic status. By their nature, unless otherwise specified, epidemiological studies do not reject any subjects on the basis of these factors (Katzenellenbogen, Joubert & Karim, 1999).

Age.

All children were under four years of age. With an older child, the caregiver may not accurately remember early characteristics of their child's feeding and swallowing. Accurate and reliable recall of facts is greatly reduced over time and is referred to as recall bias (Bennett & Richie, 1975; Katzenellenbogen et al., 1997).

Diagnosis.

All children with a diagnosis of CP were eligible (Badawi, Watson, Petterson, Blair, Slee, Haan & Stanley, 1998; Hardy, 1983), regardless of the type of CP (spastic, athetoid, ataxic, mixed) and severity of limb involvement (quadriplegia, hemiplegia, diplegia). A doctor specialized in CP had confirmed the diagnosis in all the children prior to the study.

Associated problems.

Children presenting with any other syndromes or neurological signs not directly related to their CP were excluded from the study. Additional problems frequently associated with CP such as mental retardation, epilepsy and hearing loss (Rogers, 1996) were noted as complicating factors.

Hospital patients.

All eligible children were required to be registered patients at Red Cross War Memorial Children's Hospital, with up to date and available hospital folders. Access to hospital folders was essential for accurate recording of birth history, background information and medical history of the children involved. By its nature, this government hospital is utilized by all cultural groups of South Africa and the CP Clinic is well established, receiving referrals from a number of surrounding hospitals and clinics.

Selection procedure

The researcher herself was present daily at the CP clinic for the duration of one month. On arrival at the clinic the hospital folders of the patients booked for that day were examined and those children matching the predetermined selection criteria were identified. The caregivers of these children were approached in the waiting room and were evaluated according to the above mentioned selection criteria. Verbal consent was obtained from those caregivers that were willing and able to participate in the study. In conclusion, a non-random sample of the first 100 caregivers and their children who met all the selection criteria were included in this study.

Sample size

As already mentioned, the caregivers of the first 100 children with CP, attending appointments at the CP Clinic in the Department of Physiotherapy at Red Cross War Memorial Children's Hospital, and meeting the previously specified selection criteria, were selected as informants for this study.

A sample size of 100 was decided upon based on statistical calculations (STATCALC on EPI INFO 6) at a confidence interval of 95 %. The prevalence of CP in South Africa, which is estimated at about 2,5 per 1000 (Cerebral Palsy Association of the Western Cape, 1999) was included in the calculation to determine a representative sample size.

Summary of selected subjects

This study comprised 100 children with CP attending the CP clinic at Red Cross War Memorial Children's Hospital. Race, gender, birthweight and gestation are documented in Table I, which shows a summary of the biographical details of the subjects involved in the study. According to the widely accepted norm (Cooke, 1990; Grether et al., 1996; Kelleher et al., 1993; Pharoah et al., 1990; Rossetti, 1996; Stanley, 1992) children below 2500 grams were judged as low birth weight. A premature infant was described as one born before 37 weeks gestation (Rossetti, 1996; Stanley, 1992).

Table I

Biographical details of subjects

RACE		GENDER		BIRTHWEIGHT		GESTATION	
Coloured	Black	Male	Female	Low	Normal	Preterm	Normal
49	51	52	48	42	58	41	59

Note. N = 100

The age distribution of the children being studied, as well as a summary of the age of diagnosis of the CP are summarized in table II below.

Table II

Average age and age of diagnosis of CP

	Age distribution of the sample	Age of CP diagnosis
Average age (months)	\bar{M} = 25.9	\bar{M} = 12.3
	\bar{Mdn} = 25	\bar{Mdn} = 10
	\bar{SD} =12.6	\bar{SD} =8.5



Figure 1

Characteristics of the type and severity of the CP

Figure 1 above indicates the distributions of the type and severity of the CP amongst the sample of children in the study (N=100).

Hospital Permission

Permission to conduct the study was sought and obtained from the Senior Medical Superintendent of Red Cross War Memorial Children's Hospital (see Appendix C). Once permission was obtained, the nature and purpose of the study was briefly explained to the head of the Physiotherapist department and to all professionals involved in the CP Clinic.

Materials

Questionnaire

A questionnaire, including questions of past and present feeding practices, was compiled for use during a semi-structured interview, with 100 caregivers of children with CP. The content of the questions was based on those features identified during a comprehensive literature review and as discussed by other researchers, such as Couriel et al, (1993), Reilly and Skuse, (1992), Reilly et al., (1996) and Alper and Manno, (1996). This was to ensure that the questionnaire captured the aspects of feeding and swallowing that were already identified as questions that are relevant to feeding and swallowing abilities. These characteristics were formatted into a selection of open- and closed-ended questions. The questions were designed to be simple, concise and specific according to the wording and ease of answering (Katzenellenbogen, 1997). The majority of questions were closed-ended (74%) where the caregivers were given a limited choice of options to select. According to Maccoby and Maccoby (in Bennett & Ritchie, 1975), as more information is recognized than recalled, it is generally more useful to rely on closed questions in a questionnaire survey.

The wording of the questionnaire was designed to be user-friendly with lay terms being used, such as *coughing and choking* for *penetration and aspiration*, as identified during the pilot study explained below in further detail. The questionnaire was constructed to elicit yes/no answers for 72% ($n=25$) of the questions, and one-word answers for the remaining 28% ($n=10$) (see Appendix A).

This design was useful for meeting the time constraints, to compensate for language differences, to minimize misunderstandings due to cultural differences and for ease of analysis (Bennett & Ritchie, 1975).

An administered questionnaire entails a method whereby questions are read out by the interviewer, answered orally by the interviewee and recorded by the interviewer in writing (Bennett & Ritchie, 1975). This interviewing method was selected by the researcher in an attempt to best overcome the large cost and time influences evident in other methods of assessing feeding and swallowing. Furthermore, as a result of the reliance on mother's recall and opinions, it was crucial for the researcher to develop a situation of trust, honesty and openness with the caregivers involved in the study (Bennett & Ritchie, 1975). This was best attained during a personal face-to-face interview as was employed in this study and by providing a description of the study and its aims, by providing the caregivers with a chance to ask questions and giving them the option to participate in the study or not. Furthermore, population-based surveys have gained acceptance as basic tools for the study of health in developing countries over the past several years (Fisher, Pappas & Limb, 1996).

Translation of the questionnaire.

A competent bilingual speaker of Afrikaans and English translated the questionnaire into Afrikaans *verbatim*. It is essential for the initial translation of a questionnaire to be done by a fluent speaker, who can judge whether certain phrases are both understandable and acceptable (Katzenellenbogen et al., 1997). This translated questionnaire was used as a template for all subsequent Afrikaans interviews (see appendix D).

A Xhosa interpreter, employed at the CP clinic, was available at all times during the data collection process. She was briefed about the study's aims and objectives, and conducted all interviews with native speakers of Xhosa. She translated the questions asked by the researcher, as well as the answers of the informants. In those cases where first language Xhosa informant was able to understand either English or Afrikaans, the interview was conducted in the informant's second language. The interpreter was also available in these situations for clarification or interpreting the responses as required by the informant or researcher.

Pilot Study

A pilot study was conducted with the aim of fine tuning the structure of the questions to ensure that they elicited valid responses, as well as to determine the best protocol for interviewing the mothers. It involved an in-depth look at the questionnaire with the aim of improving its quality (Katzenellenbogen, 1997).

Validity

Validity can be referred to as "the efficiency with which a questionnaire measures what it is supposed to measure according to its relevance, completeness and accuracy" (Bennett & Ritchie, 1975:28). Validity is typically divided into face validity, construct validity and content validity (Katzenellenbogen, 1997).

The face validity of the questionnaire was first evaluated according to whether the questions "made sense" (Katzenellenbogen et al., 1999). The questionnaire was administered to two mothers, acquainted with the researcher, who were not involved with the subsequent study and who had no more than a layperson's knowledge of feeding and

swallowing. These mothers, in discussion with the researcher, were asked what they understood from each question and how they might have answered them. Those questions that were identified as ambiguous or unclear were refined until all the questions were clearly understood and the answers remained consistent on multiple repetitions of the questionnaire. From the original draft of the questionnaire, two questions were re-worded and two were completely omitted (see Appendix A for the final questionnaire).

The content validity refers to how the questions probe the areas it should probe. This was judged in consideration of past literature in the area (Couriel et al, 1993; Reilly & Skuse, 1992; Reilly et al., 1996; Alper & Manno, 1996) as well as during discussions with qualified SLP's knowledgeable in the area of paediatric dysphagia (Personal communication, D. Novotny and S. Singh, 1999). Furthermore, as certain questions tapped the same areas, consistency of the caregivers' answers between these questions added to the reliability of the questionnaire.

The construct validity of the questions was confirmed *post-hoc* by plotting the data using the statistical test Principal Components and Alternating Last Squares (PRINCALS). The clustering of answers and their agreement with past literature indicates good construct validity of the questionnaire (Bennett & Ritchie, 1975; Gifi, 1990).

Feasibility

The questionnaire was then administered to five caregivers attending the CP Clinic at Red Cross War Memorial Children's Hospital. The entire procedure was judged according to ease of questioning, time taken and attitudes of the informants during the interview. The time for recording the answers and obtaining necessary information from

the hospital folders was estimated to account for feasibility of the researcher interviewing all 100 caregivers herself. The procedure was refined until an optimal method of identifying eligible candidates, obtaining consent, filling in medical information and conducting the interview was obtained.

Procedure

Selection of informants

Between 10 and 15 patients were booked for the CP Clinic each day. However, as a result of the strict selection criteria of both the children with CP and their caregivers accompanying them to their appointments, on average only 5 were eligible for the study each day.

The caregivers of all these children with CP (attending the CP Clinic and who were identified as eligible candidates to participate in this study) were examined according to the previously specified criteria. Those children, who had been brought by distant family members or adults who were unaware of their early feeding and swallowing status, were excluded from the study.

The researcher then informed the caregivers about the procedure, content and purpose of the study and asked whether they would be willing to participate. Participation was entirely voluntary. Verbal consent was obtained from all of the selected informants.

The interview

The questionnaires were completed during individual face-to-face, semi-structured interviews with each of the selected informants (Bennett & Ritchie, 1975). By their nature, these interviews allow the researcher to change the wording of the questions at her discretion, provided that certain standards are still adhered to during each interview (Bennett & Ritchie, 1975). As a result, the respondents answered every question and clarification was provided as necessary. A protocol for the clarifications was identified prior to interviewing to ensure that no bias or leading questions contaminated the results (Bennett & Ritchie, 1975; Katzenellenbogen et al.; 1997). As a result of the nature of the questions, the use of gesture was greatly used for clarification. For example, the researcher could indicate milk running out of the mouth with her fingers. The word undernourished was clarified with additional words such as too thin or small or not eating enough food. Finally, examples of textures were provided such as rough, smooth, soft and hard. Such clarifications were only necessary where the caregivers were competent second language speakers of English and where an interpreter was not required.

The interviews were conducted in a quiet area of the clinic for privacy. The procedure was reviewed with the informants before commencing with the interview and they were once more given the opportunity to withdraw from the study.

The interview was conducted in the informant's preferred language of English, Afrikaans or Xhosa. An interpreter, who was knowledgeable about the nature of the study, translated the questions for those informants not speaking English or Afrikaans. An interpreter was only required for 25 of the 100 interviews.

Following completion of the questionnaire, the informants were thanked for their time and cooperation and the confidentiality of their responses was once more reiterated.

Medical information

On completion of the interview, background medical history (such as the birthweight, gestation period, age and diagnosis of CP) was obtained from the patient's hospital folder. It was hoped that by obtaining this information only upon completion of the interview that possible bias, based on prior medical knowledge of the child, would not influence the researcher's interpretation and recording of the informants' responses.

The method of data collection was random, in that interviews were conducted during the month of May, until the first 100 informants who met the selection specifications had been interviewed.

Data Analysis

Entering data

The researcher developed a database for each of the questions on a statistical package EPI INFO 6 (see appendix E). All data from the 100 questionnaires was entered twice, on two different occasions and by two separate individuals for ensuring reliability and consistency of the entries. Frequencies for all 45 variables identified by the questionnaire were computed and the same frequencies were obtained across entries.

As a result of the explorative nature of this study, a number of different stages of analysis were identified and undertaken. Firstly, frequencies were calculated for each of the variables being studied.

The statistical analysis that followed consisted of two distinct stages. The data was analyzed using Principal Component Analysis and Alternating Last Squares (PRINCALS) to examine the underlying relationships between the different variables.

Post hoc 1-way analysis of variances (ANOVAS) were then conducted to test certain trends for statistical significance (Personal consultation, Prof. Herman Kruijse, Statistician)

Statistical analysis

The data was then converted for use on the statistical programme SSPS for Mackintosh computers. A PRINCALS was performed on the biographical and physiological variables. The PRINCALS is a non-linear scaling technique that aims to identify the relationship amongst a set of variables with different levels of scale-measurement (e.g. nominal, ordinal, numerical) in such a way that underlying constructs are identified (Gifi, 1990). As in Principal Component Analysis (PCA), PRINCALS generates principal components, which are referred to as dimensions, component loadings and commonality (h^2). The component loading of each variable represents the contribution of that variable to a dimension. The sum of the squared component loadings indicates the amount of explained variance each variable represents, which is regarded as the commonality (h^2) of a variable (Gifi, 1990).

Results

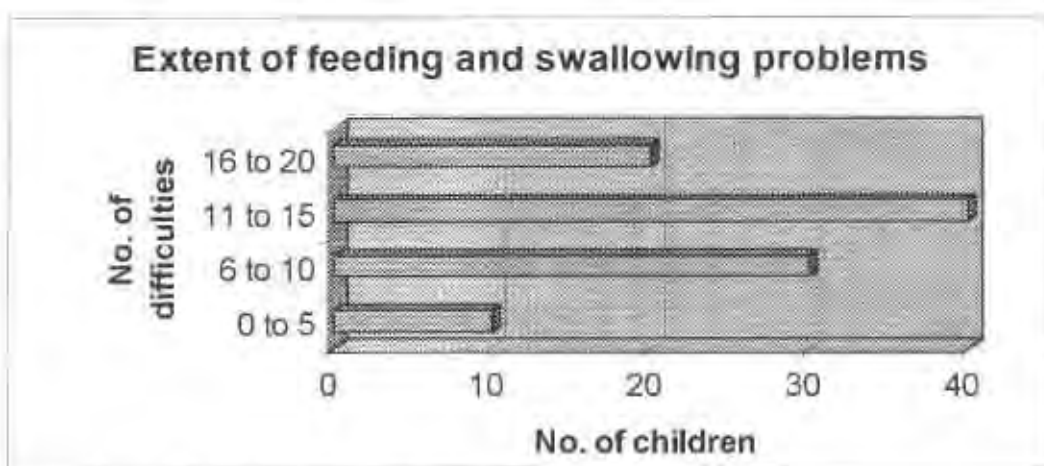
The results are presented in a number of stages as indicated above. The first stage consisted of a descriptive analysis. In the second stage, the relationship between the variables was examined using PRINCALS. Since the data consisted of both physiological and biographical variables, three PRINCALS analyses were conducted. These three stages were the physiological variables, containing the characteristics of feeding and swallowing; the biographical variables, such as age, gender, race, type and severity of CP and a combination of the physiological and biographical variables respectively. The latter analysis aimed to reveal insight into unique combinations of the biographical and physiological variables.

Finally, as a result of certain relationships suggested by PRINCALS analyses, a number of post hoc 1-way ANOVAS were conducted to test trends for statistical significance.

Stage 1: Descriptive analysis

Extent of feeding and swallowing problems in children with CP.

All of the children with CP ($N = 100$) were reported to have had at least one feeding or swallowing difficulty, but none were reported to have more than 20 (of the 25 predetermined characteristics). Nonetheless, almost half of the children ($n = 46$) were reported to have had half ($n = 13$) of the possible twenty-five characteristics of feeding or swallowing difficulties. The number of children and the characteristics they present with are clearly indicated by Figure 2 below



Note: Total possible difficulties = 25; $N = 100$

Figure 2

Number of feeding problems reported in 100 children with CP

Problems reported with liquids

Of all the infants, 64 % had been fed non-orally at least once, all via naso-gastric tubes (NGT). Furthermore, 42 % of the children had not been breast-fed, which caregivers attributed to difficulties with sucking or prolonged hospitalization.

There were many reported difficulties with sucking and swallowing of liquids and these are summarized in Table III below.

Table III

Feeding and swallowing difficulties reported with liquids

Feeding/swallowing characteristic	n
Problems with bottle-feeding (e.g. weak suck, coughing/choking)	82
Loud swallowing noises during drinking	69
Falling asleep during feeding	57
Loss of milk out the sides of mouth	51
History of chest infections	50
Coughing/choking	49
Difficulty sucking on the nipple/teat	47
Increased time to complete a feed	47
Tongue pushing nipple/teat out of mouth	40
Slow, weak suck	39
Frequent vomiting during/after feeds	35

Note: Total number of children with CP (N = 100)

Problems reported with solids

The mean age for the introduction of solid foods was $M = 10.09$ months ($SD = 5.83$ months). As a result of the young age of some of the children, as well as feeding and swallowing difficulties, only 78% of the children were receiving a diet of solid food, the remaining 22% of the children were still on a liquid diet. Reported difficulties with solids are summarized in Table IV below.

Table IV

Feeding and swallowing difficulties reported with solids

Feeding/swallowing characteristic	n
Difficulty biting/chewing	55
Loss of solid bolus anteriorly	47
Rejection of certain textures	37
Coughing/choking	35

Note. N = 78 (22 children not yet receiving solid diet)

The number of children reported to have feeding and swallowing difficulties varied on three consistencies of food, liquids (such as milk), semi-solids (such as puree) and solids (such as bread). The majority of children were reported to have difficulties with liquids (82%), 58% of the children were reported to have difficulties with solids and the least number of children (19%) were reported to have difficulties with semi-solids. This finding suggests that children with CP can handle semi-solid consistencies better than either liquids or solids.

Early identification and management of reported feeding and swallowing difficulties.

Eighty-nine percent of the caregivers reported problems with their child's feeding and swallowing, which were evident before a diagnosis of CP had been made. They had identified problems with sucking (n=47), difficulties with positioning (n=37) and coughing and choking on liquids (n=49) by one month of age in all cases.

Thirty-four percent of the caregivers had been given information about the management of feeding and swallowing difficulties in their child from a speech therapist, paediatrician or dietician at the hospital at the time of delivery. While 65% of caregivers expressed ongoing concern about feeding and swallowing difficulties, only 24% of the cases were currently receiving feeding and swallowing therapy from a speech therapist employed at Red Cross War Memorial Children's Hospital.

The effect of birthweight and gestation on the severity of CP.

Of the three degrees of limb involvement or severity of CP examined in this study, viz. diplegia, quadriplegia and hemiplegia, the incidence of low birthweight (<2500g) and prematurity (<40 weeks gestation) was highest for diplegia. Frequencies for each of these groups are shown in Table V below.

Table V

Birthweight and gestation according to severity of CP

Severity of the CP	Low birthweight & premature	Normal birthweight & Full term
	%	%
Diplegia	31	18
Quadriplegia	48	60
Hemiplegia	21	22

Note. Of **N** = 100, **n** =29 were both low birthweight and premature

Nature and extent of reported feeding and swallowing problems.

Table VI summarizes the characteristics of feeding and swallowing difficulties reported by the caregivers in descending order according to the combined frequencies (N=100).

Table VI

Reported feeding and swallowing difficulties in the 100 children with CP

Feeding/swallowing characteristic	n
Problems with bottle-feeding	73 ^a
Loud swallowing noises while drinking	69
Fed non-orally at least once	64
Difficulty biting and chewing solids	55 ^a
Falling asleep while drinking	57
Frequent drooling	54
Loss of milk out the sides of mouth	51
History of chest infections	50
Coughing/choking on liquids	49
Loss of solid bolus anteriorly	47 ^a
Difficulty latching on to the nipple	47
Increased feeding time	47
Tongue pushing nipple/teat out the mouth	40
Slow, weak suck	39
Rejection of certain textures/tastes	37 ^a
Difficulties positioning	37
Coughing/choking on solid food	35 ^a
Frequent vomiting during/after feeds	35
Problems with semi-solids	19
Concerns about malnutrition	17

Note. ^an = 78 (22 children never bottle fed and 22 children not yet on solid diet)

Stage 2: PRINCALS Analysis

Physiological variables (characteristics of feeding and swallowing).

The relationship between the physiological variables (characteristics of feeding and swallowing) was calculated using PRINCALS. Results indicated a two-dimensional solution with a total fit of .29, indicating that only 29% of the variance could be explained by the two dimensions. This was a result of the low contribution of a number of variables, whose explained variance (h^2) was lower than 20 % (0.20). These variables were excluded from further analysis and are listed in Table VII below.

Table VII

Rejected variables

Feeding/swallowing characteristics	h^2
Frequent drooling	.06
Tongue pushing nipple/teat out the mouth	.17
Falling asleep while drinking	.05
Loud swallowing noises while drinking	.07
History of chest infections	.04
Rejects certain textures/tastes	.07

The remaining physiological variables were once more analyzed by PRINCALS. This resulted in a two-dimensional solution with Eigenvalues of .23 and .13 for dimensions 1 and 2 respectively, indicating a total fit of 36%.

Table VIII summarizes the component loadings per dimension for each variable. Dimension 1 is dominated (relative high loadings) by the variables that were related to the feeding and swallowing of solids, while dimension 2 is dominated by variables related to liquids.

Table VIII

Component loadings for physiological variables

Feeding and swallowing characteristics	Component loadings	
	Dimension 1	Dimension 2
Caregiver concerned about child's nourishment	.42*	.21
Child still presenting with feeding/swallowing difficulties	.76*	.18
Coughing/choking on solids	.62*	.08
Difficulty biting and chewing	.70*	.08
Difficulty positioning the child during feeding	.56*	.07
Food falling out of the mouth during feeding	.71*	.11
Problems with semi-solids	.40*	.23
Received information about feeding their child	.36*	.19
Infant never breast fed	.09	.61*
Problems noticed before an official diagnosis of CP	.24	.44*
Problems with bottle-feeding	.30	.54*
Difficulty latching on to the nipple/teat	.17	.60*
Fed non-orally at least once (via NGT)	.08	.56*
Slow, weak suck	.38	.41*
Frequent vomiting during/after feeds	.26	.43*
Milk dribbling out the sides of the child's mouth	.23	.44*

Note. * = variables dominating each dimension

Figure 3 below is a graphical representation of these component loadings and clearly reveals how the variables are related. The angle between the vectors indicates the strength of the association of the variables, whereas the length of the vector indicates the importance of the variable to the study. Two clusters of variables can be identified, the bottom left quadrant represents the variables related to solids (dominating dimension 1) and the top left quadrant represents those variables related to liquids (dominating dimension 2). Directly opposite this quadrant (in the bottom right quadrant) is the variable *infant never breast fed*. This equal, but opposite relationship to the difficulties with liquids in dimension 2 indicates that those children who were never breast fed are more likely to have feeding and swallowing difficulties with liquids.

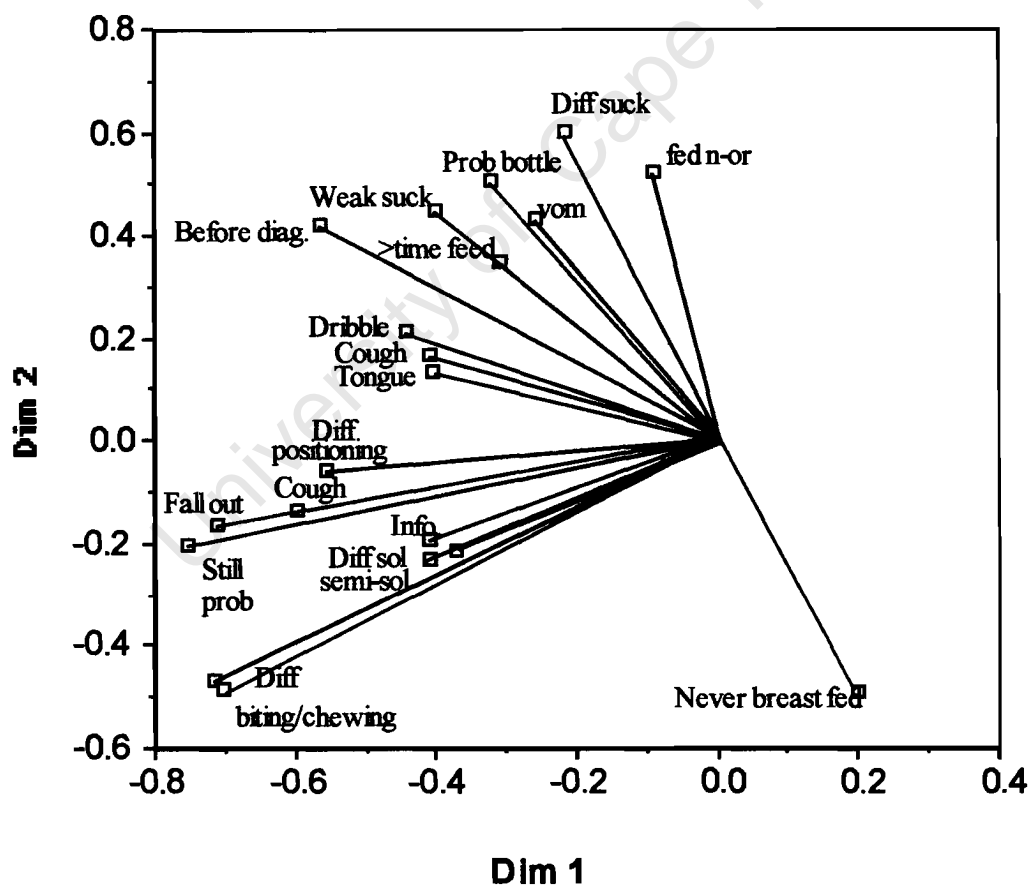


Figure 3. Graphical representation of component loadings

The variables *increased time to feed, having been fed non-orally* and *problems noticed before a diagnosis of CP* clustered with the variables associated with liquid feeds. This suggests that problems with liquids are noticed before a diagnosis of CP and are also associated with being fed non-orally, which is to be expected as an infant begins with liquid feeds from birth.

The remaining variables, viz. *still presenting with feeding and swallowing problems, difficult to position, concern about the child's nourishment* and *received information on how best to feed their children* clustered with the variables associated with solid feeds. The suggestion is that children who have feeding and swallowing difficulties with solid food are more likely those who are still presenting with problems, who are difficult to position and about whose nourishment the caregiver expresses concern.

Biographical variables.

Relationships between the biographical details of race, language, gender, birthweight, gestation, age of diagnosis, type and severity of CP were analyzed using PRINCALS. The results indicated a three-dimensional solution, with an Eigenvalue of .32, .24 and .18 for each dimension respectively, indicating a total fit of 74%.

The contribution of each variable to the dimensions, referred to as the component loadings, is summarized in Table IX below.

Table IX

Component loadings for the biographical variables

Biographical variables	Component loadings		
	Dimension 1	Dimension 2	Dimension 3
Gestation	.53	.70*	.13
Birthweight	.56	.67*	.13
Age diagnosis	.19	.17	.80*
Severity	.22	.28	.81*
Race	.88*	.45	.10
Language	.88*	.45	.09

Note. * = variables dominating each dimension

Dimension 1 involved the variables of race and language, dimension 2 involved the variables of gestation and birthweight and dimension 3 involved the age of diagnosis and severity of CP. The contribution of gender and type of CP was less than 20% and these variables were therefore not considered important to the findings of the study.

Two levels of birthweight (normal birthweight and low birthweight) and two levels of gestation (full term and preterm) were evident. There was an inverse relationship between the variables low birthweight and premature, as well as with the variables normal birthweight and full term, indicated by almost equal, but opposite variances ($h^2 = .57$ & $-.61$ and $h^2 = .55$ & $-.58$ respectively). This finding suggests that birthweight decreases as the gestation of the infant decreases.

Combination of biographical and physiological variables.

A third PRINCALS was conducted to determine the relationship of gestation, birthweight, age of diagnosis, severity of CP and race to the physiological variables. Results indicated a three-dimensional solution, with an Eigenvalue of .21, .13 and .12 for each dimension respectively. This indicates that 46% of the variance was explained by the analysis.

Dimension 1 was determined by the physiological variables associated with feeding and swallowing of solids. None of the biographical variables contributed to this group, suggesting that problems with the feeding and swallowing of solids are independent of birthweight, gestation, age of diagnosis and severity of CP.

Similarly, the variables associated with feeding and swallowing of liquids dominated dimension 2. The two biographical variables of *gestation* and *birthweight* have their highest contribution to this group (component loadings = .62 and .63 respectively). This finding suggests that *gestation* and *birthweight* are more strongly related to feeding and swallowing difficulties with liquids, including being fed non-orally, as compared with solids.

Dimension 3 consisted of the remaining biographical variables viz. *race*, *severity* and *age of diagnosis of CP*. The variable of *difficulties positioning the child for feeds* clustered with these biographical variables, indicating that *age of diagnosis*, *severity of CP* and *race* are related to maternal reports of *positioning difficulties*. This remains logical, as the older the child and the greater the limb involvement, the more difficult it might be for the caregiver to position the child for feeding. The component loadings each variable contributes to the dimensions are summarized in Table X below.

Table X

Component loadings for the biographical and physiological variables combined

Biographical/Physiological Variables	Component loadings		
	Dimension 1	Dimension 2	Dimension 3
Coughing/choking on solids	.64*	.07	.30
Difficulty chewing solids	.84*	.04	.43
Difficulty biting solids	.85*	.05	.44
Food falling out the mouth	.70*	.17	.06
Still presenting with problems	.75*	.15	.01
Gender	.54*	.18	.20
Gestation	.40	.62*	.34
Birthweight	.39	.63*	.36
Problems with bottle-feeding	.10	.51*	.20
Difficulty sucking on the nipple	.01	.55*	.30
Infant never breast fed	.01	.65*	.01
Fed non-orally at least once	.09	.49*	.27
Age of diagnosis of CP	.01	.03	.58*
Severity of CP	.08	.02	.62*
Difficulty positioning the child	.20	.02	.52*

Note. *= variables with the highest contribution to each group

It appears that the biographical variables of the sample had little to do with the resulting feeding and swallowing problems. Besides the effect of birthweight and gestation on difficulties with liquids, the remaining biographical details do not appear to result in any particular feeding and swallowing difficulties. Rather, there are general feeding and swallowing difficulties, spread across the sample, independent of their biographical information.

Stage 3: Post hoc analysis

The results of the PRINCALS analyses suggested relationships amongst the biographical variables of *birthweight* and *race* and the variables *severity* and *age of diagnosis* respectively. In order to test the statistical significance of these relationships, two 1-way ANOVAS were conducted on the original data. The null hypothesis to test the homogeneity of the variances in the ANOVAS, conducted using Cochran's C test, could not be rejected ($p > 10\%$).

The birthweight of Coloured children ($M = 2471.94$ grams, $SD = 749.8$) was found to be significantly lower than the birthweight of Black children ($M = 2784.41$ grams, $SD = 767.9$) as indicated by a 1-way ANOVA, $F(1, 98) = 4.27$, $p = .04$.

Similarly, the average age of diagnosis of CP was significantly younger for children with quadriplegia or hemiplegia ($M = 11.24$ months, $SD = 8.76$) than for diplegia ($M = 18.06$ months, $SD = 9.74$) as indicated by a 1-way ANOVA, $F(1, 98) = 9.55$, $p = .003$.

Discussion

All of the children in this study were reported to have experienced some feeding and swallowing difficulties, which is in agreement with other studies on the high prevalence of feeding and swallowing disorders amongst the paediatric population with CP (Reilly et al., 1996; Reilly & Skuse, 1992). Disruptions to feeding and swallowing place a child at risk for decreased food consumption, often resulting in poor growth and nutrition, as well as other consequences such as dehydration, aspiration pneumonia or even death. Finnie (1974) stresses that adequate food intake is essential for a child's physical, emotional, social and dental development. Results indicated that 60% of all the children have at least half of the feeding and swallowing difficulties examined in this study. The high number of feeding and swallowing difficulties suggested by this research stresses the importance of adequate management of children with CP so as to reduce the negative sequelae that may occur. It does not need to be emphasized just how crucial adequate feeding ability is for integration into society. The results of this study therefore indicate that there are a number of children with CP at risk for social exclusion, based largely on their poor feeding and swallowing abilities. Furthermore, as has already been mentioned, one must not ignore the effect adequate feeding skills have on later communication development. Oral-motor stimulation, which is important for encouraging coordinated timing and sufficient muscle strength, not only assists with safe swallowing, but also helps with the improvement of the coordination of the respiratory and phonatory systems for later speech and communication (Arvedson & Brodsky, 1993). Thus the children with CP in this study, who are reported to have many feeding and swallowing difficulties, may be at risk for later speech and communication development.

Of the 100 children with CP, all of whom presented with feeding and swallowing difficulties requiring intervention of some form, only 24% of children were currently receiving feeding or swallowing therapy. A large number of additional caregivers (41%) reported that they were concerned about their child's feeding and swallowing and required assistance. All 100 were receiving physiotherapy regularly, with a minimum of two sessions a month. The skewed allocation of therapists found at the clinic in this study (8 physiotherapists for 1 speech therapist) can possibly be explained by a lack of knowledge of health professionals on the need of a multidisciplinary team managing children with CP. Secondly, it could be as a result of a paucity of knowledge on the nature and extent of feeding problems and ignorance of the negative consequences that may occur as a result of disruptions to feeding and swallowing. In addition, the lack of availability of medical services in South Africa may have resulted in poor allocation of staff and resources. This is confounded by the many different cultural and language groups that exist in South Africa and the challenges faced by SLPs in meeting the needs of the entire population (Tuomi, 1994). According to Tuomi (1994) there is a shortage of SLPs in South Africa in general, but particularly amongst the non-English speaking population. This shortage of SLPs occurs impacts on all children presenting with disorders requiring speech therapy, including those children with CP. Therefore, not only is there a lack of knowledge amongst caregivers on the role of SLPs in the management of their child with CP, there is also a need for greater education of other team members on the abilities and roles of SLPs. Many of the caregivers added that they not only required feeding therapy for the general development of their child, but also to enable them to once more experience the joy of mealtime.

As stated by Rudolph (1994, p.S123), “it is essential that the nutritional requirements of every patient be met by either an oral or alternate route. Similarly, the development of social skills and interactions, achieved during mealtimes, must be incorporated into the patient’s life, despite the lack of oral intake”. Therefore, management of a CP child by a multidisciplinary team, including a SLP is essential. A SLP has the skills to judge whether alternative methods of feeding are required as well as to provide caregivers with the skills and knowledge they require to better cope with the strains of mealtimes.

According to maternal reports, besides *difficulties latching on to the nipple* (which may be simply overcome by adjusting the teat size or shape), the two earliest problems most often reported were the *loss of liquid anteriorly during drinking* and *coughing and choking on liquids*. The *loss of liquid anteriorly* suggests poor lip closure, which assists in holding the bolus in the oral cavity (Arvedson & Brodsky, 1993; Logemann, 1983). Thus parent training in habilitation should focus on adaptation of the teat, according to shape and diameter of the hole of the teat. This would help to control milk flow rate and the sucking strength required for expressing the milk. Furthermore, the provision of oral control, for example placing one’s fingers under the chin to provide the necessary jaw and mouth stability assist with adequate feeding and swallowing (Winstock, 1994). These techniques can be taught to the mother and may assist in minimizing feeding and swallowing difficulties.

The reports of *coughing and choking* on liquids indicate that the children are at risk for aspiration pneumonia. The early signs and symptoms of aspiration pneumonia should be explained to caregivers in an attempt to diagnose it early and prevent any

serious complications. A *history of chest infections* was not often reported by the caregivers in this study. This finding is crucial, as it appears that although there are a number of feeding and swallowing difficulties reported in the sample, serious medical complications, such as aspiration pneumonia, appear rare. It is possible that many of the children experienced oral phase dysphagia with little or no pharyngeal involvement, thereby reducing the risk of penetration and aspiration. However, modified barium swallows (MBS) studies have indicated problems occurring almost equally in both the oral and pharyngeal stages of the swallow (Mirret et al., 1994; Rogers et al., 1994). Thus this finding might also indicate that, as a result of lack of knowledge and poor medical facilities, many infants who present with initial signs of aspiration pneumonia are being missed, and treated in day hospitals for general cold and flu symptoms. Rogers et al. (1994) performed modified barium swallows (MBS) on a sample of 90 children with CP and reported that of the 38% of the sample who were aspirating, the aspiration was silent in 97% of the cases. There is a concern that early signs and symptoms of aspiration pneumonia are being overlooked, especially as the researcher noticed a large majority of the children were coughing, wheezing or had reportedly elevated temperatures (according to the caregivers), but caregivers still maintained that there was no history of chest infections. Wording of the question might not have fully encapsulated the information the researcher was trying to obtain. It may be important for future studies to routinely include a more objective evaluation of the swallowing function (such as MBS) as well as include a review of the medical records for a history of chest infections and increases in temperature, so as to document the exact nature of the problem for prevention purposes

With solid consistencies, the two main reported difficulties were with *biting or chewing* and with *food falling anteriorly out of the mouth*. This finding suggests that reduced oral motor skills may be a major cause of feeding and swallowing difficulties in a child with CP. This allows the therapist a focus for therapy, such as incorporating exercises for developing oral control, techniques for improving oral sensory awareness, improved placement of the bolus for ease of chewing and swallowing, improved lingual coordination and the incorporation of bolus management exercises to aid with the formation and propulsion of the bolus, to improve lip closure and to reduce anterior loss of the bolus.

Many of the caregivers (89%) could identify that something was wrong with their child virtually from birth, which was well before their child was diagnosed with CP. According to Rudolph (1994), feeding is probably the most complicated challenge a newborn infant faces. Deficits in feeding are often early indicators of an underlying neurological deficit (Gisel, 1994; Reilly et al., 1996). It is important for health professionals to accept that mothers are very cued in to the early feeding patterns of their children. Thus SLPs need to consider the parent-child relationship and foster it in the management of children presenting with early developmental difficulties.

A number of implications emerge from the ability of the caregivers to identify feeding and swallowing difficulties when their child is still very young. Firstly, it is important for a bond to develop between a mother and her newborn infant (Morris & Klein, 1987). The interaction between mother and infant during the act of feeding, and the comfort and pleasure experienced by the child, is the base of this developing mother-child bond (Morris & Klein, 1987). When the mother experiences difficulty feeding her

child, this bonding process is interrupted causing anxiety and stress for both the mother and child (Reilly & Skuse, 1992). According to Rudolph (1994), feeding difficulties can frustrate even highly educated, experienced parents, thereby altering the parent-child relationship. Secondly, adequate growth and nutrition in an infant is a prerequisite to discharge from hospital. Failure to meet the criteria of growth and nutrition, as a result of disrupted feeding and swallowing, may result in prolonged hospitalization and non-oral feeding with additional financial costs. Thus, mothers should be questioned about the feeding patterns of her child before post-partum discharge from hospital, and at the routine follow-up visits to well baby clinics. There are existing factors, such as maternal illness, hereditary factors, maternal drug or alcohol dependence, very low birthweight, low APGAR scores, limited prenatal care, severe pre- or perinatal complications and asphyxia, which place an infant at risk for later disease, illness or developmental delay. It might be beneficial to include feeding and swallowing difficulties together with these factors for placing an infant at risk for delay. Although, not 100% indicative of later disorders, the importance of maternal reports of feeding and swallowing difficulties is crucial for early identification and management of these difficulties.

The need for in-service training of relevant health professionals in this regard is emphasized. Not only will this early identification of feeding and swallowing difficulties promote better team management and care of the child, but it might reduce the negative sequelae of and the financial costs to society, such as prolonged hospitalization and increased medical needs. This is of particular importance in a developing country such as South Africa, where therapists are working against challenging odds including poverty, language and cultural differences (McConkey, 1994). In order for our services to reach

those individuals who require therapy, it is essential for SLPs in South Africa to find out what the families and communities need, nurture their feelings and plan interventions accordingly (Tuomi, 1994). There is also a need to train more linguistically and culturally diverse SLPs who match the demographics of South Africa and lobby the government to motivate for more SLP posts so that needs of general population, as well as the population with CP can be adequately addressed. The primary care approach aims to empower the communities by training health-care workers and significant members of the community (Compton & Ashwin, 1992; Van Rensburg et al., 1992), thus allowing services to extend to those communities which were previously excluded due to past political policies and language and cultural differences.

The early identification of feeding and swallowing problems by caregivers and relevant health care professionals, including speech-language pathologists (SLP), can result in timely and efficient management and development of suitable oral feeding strategies. This may consequently reduce the length of time children might require non-oral feeds and so reduce the costs and negative consequences of tube feeding. The diagnostic importance of early feeding and swallowing ability further strengthens the need for early intervention by all professionals, including speech-language pathologists (SLP). Until recently, especially in South Africa, SLP's role was seen to be with the older child. However, their input with children in the 0-3 year age group is also indicated, especially with regard to feeding and swallowing difficulties.

Sixty-four percent of the children in this study had been fed non-orally at least once and this agrees with the Reilly et al. (1996) finding. Premature and low birthweight infants are not only at an increased risk for CP (Pharoah et al., 1990), but are also more

likely to have been fed non-orally as a result of their extreme immaturity. The large number of children with CP who have been fed non-orally is critical as infants who have experienced long periods of intubation and tube feeding have a learned aversive response to oral stimulation and it can often be difficult to introduce subsequent oral feeds to these infants. Early management is recommended and, according to Comrie and Helm (1997), providing opportunities for non-nutritive sucking during non-oral feeds has been shown to improve respiratory and gastrointestinal function, decrease energy expenditure, increase absorption, decrease irritability, enhance growth, maturation and weight gain and allows for the earlier introduction of nipple feeds.

Although 89% of the caregivers reported difficulties with their child's feeding and swallowing, only one-third had received any information about strategies to improve the feeding process from a paediatrician, nurse or dietician. The mothers reported that they "taught them how and when to breast-feed" and "how much food the child needs". This is general information typically given to new mothers, even though these mothers experienced additional difficulties with feeding their babies. Anecdotally, nearly half of the caregivers asked the researcher for information on how to 'feed their child properly' and were referred to the SLP based at the CP clinic. These reports indicate the need for SLPs to provide parents with necessary skills training to maximize feeding strategies, as well as to train other professionals to provide parents with more relevant information on feeding strategies that might aid feeding, swallowing, nutritional intake and later speech development.

Caregivers reported that their children had fewer feeding and swallowing difficulties with semi-solids in this study (18%) than with either liquids or solids. While

Reilly et al. (1992) reported no such differences between the three consistencies, Gisel and Alphonse (1995) reported that children with CP took less time to manipulate semi-solid consistency, than liquids and solids. Finnie (1974) also stated that if a child with CP is offered semi-solids, the child is more likely to manage swallowing it adequately than he/she might manage with liquids. Whereas this study relied on maternal reports of feeding and swallowing, the others incorporated a variety of objective methods, such as the MBS and feeding and swallowing checklists, and may account for contrasting findings. Different methodologies and the need for objective assessments might be indicated for future studies in an attempt to avoid contrasting results.

Of the characteristics of feeding and swallowing examined in this study, caregivers reported being least concerned that their child was undernourished. As half of the children were less than 2-years old (and all were below 4-years of age), malnutrition might not be so obvious. Disrupted physical growth is frequently more evident in the older child, when the variations between children with CP and their peers becomes more pronounced. Thus responses to this question might have varied with an older sample.

Drooling was also not considered a major source of concern in this study and could be due to the fact that most of the children were still quite young (below 2-years), where drooling during teething is common. This variable may have been more relevant to an older sample, where the persistence of drooling might suggest CP or other neurological deficits.

Limitations

There were certain limitations in this study, which might have affected the results. Although it was the researcher's intention to examine feeding and swallowing in children with CP across all race groups, the sample was representative of only two groups viz. Coloureds and Blacks. The CP Clinic where the data collection took place was situated in a government teaching hospital and is accessible to all races. However, during the month of data collection, no White children attended the clinic. In later discussion with the staff of the clinic, they acknowledged seeing very few White children with CP, possibly suggesting that private professionals are providing therapy to those White children with CP. Conversely, the presumed prevalence of CP being equal across all race groups in South Africa may in fact be incorrect, indicating the need for more in depth investigations to correct the existing statistics.

Cultural differences between the researcher and her subjects may also have affected the results of this study. Certain questions were relatively probing, such as whether the child had difficulty sucking on the nipple. Black caregivers may not have been as willing to admit this as White or Coloured caregivers. One suggestion might be for fear of failure as a mother in not being able to "provide" for their child. Secondly, because of financial constraints and the high costs of milk formula, breast-feeding may have been the only option, regardless of the difficulties experienced. Future studies ought to consider developing a questionnaire in conjunction with representatives from each cultural group, to develop questions that are sensitive to cultural issues.

Future research implications

As a result of the exploratory nature of the study, a number of interesting trends emerged, which should prompt further research. Firstly, there was a strong trend for diplegics to have a greater history of low birthweight and prematurity than quadriplegics and hemiplegics, which supports similar findings worldwide. Unfortunately, probably as a result of the unequal representation of these three severities of CP amongst this sample, this trend was not significant. A study involving equal representations of diplegia, quadriplegia and hemiplegia would be useful to determine whether this trend is also significant on a South African population with CP and whether it relates differentially to feeding and swallowing difficulties.

In addition, there was a significant difference between the birthweight of the Coloured and Black children examined in this study, with the Coloured children being significantly lower birthweight. This birthweight was on average below 2500 grams, which is the currently accepted definition of a medically low birthweight infant. Previous research in South Africa (Arens et al., 1978) indicated a rising incidence of CP amongst the Coloured population. As CP is closely related to low birthweight, this finding might indicate the need for education to Coloured mothers about appropriate pre-natal care (such as diet, no smoking and alcohol). Such studies might also motivate for funding for projects aimed at facilitating adequate pre-natal care. After all, according to Rossetti (1996), complications of low birth weight or prematurity involve a variety of developmental pathologies, including communication impairments. The education of mothers in the different cultural subgroups comprising the South African population may need to consider language and cultural differences as well as time and travel expenses.

Thus it is important that we adjust our service delivery models to meet the needs of the people of South Africa, including the training of more linguistically and culturally diverse SLPs, for our services to be successful (Tuomi, 1994). According to McConkey (1994) this is best achieved by involving the caregivers in therapy using home programmes and including sufficient counseling and parent discussion groups. The primary care approach is hindered in South Africa by a number of issues including a variety of shortages, fragmentation and deficient co-ordination of the health care supply, inequality in the provision of health care, lack of synchronization between the supply of and need for health care, escalating costs and the unaffordability of health care (Van Rensburg et al., 1992). It is important for health professionals to discuss these issues with the actual community members. In this way it is hoped that the needs of the people in the community will be met and the provision of health services will be more usefully allocated to include all the required professionals, including SLPs.

A significant difference between the severity of the CP and the age of diagnosis was also evident. As previously mentioned, quadriplegia and hemiplegia were diagnosed at a significantly younger age than diplegia. While quadriplegia and diplegia both entail involvement of all four limbs, diplegia, with greater lower limb involvement, will only be evident once the child is beginning to attempt to crawl or walk. Therefore, it is only at this later stage, that it might be identified that the legs are more severely affected than the upper limbs. In addition, previous research has indicated a strong connection between low birthweight, prematurity and diplegia (Cooke, 1990; Pharoah et al. 1987, 1990). As a result, education that focuses on pre-natal care might reduce the number of CP children

with diplegia, which is diagnosed later and is more severe than quadriplegia or hemiplegia.

The relationship of the type of CP (spastic, athetoid, mixed) on the resultant feeding and swallowing problems, as well as the age of diagnosis, could not be accurately examined in the study as a result of the differences in representation of these groups by the sample studied. The fact that more than 80% of the sample fell into the category “spastic CP” can be explained by the fact that spastic CP is reportedly the most common type. It would be beneficial for future studies to examine feeding and swallowing difficulties with equal representation of spastic, athetoid, ataxic or mixed CP. This might help determine whether the type of CP influences the characteristics of feeding and swallowing difficulties that might occur, such as greater difficulties with liquids and solids.

The findings of this study stress the importance of the need for appropriate management of the children with CP who present with associated feeding and swallowing difficulties. In agreement with Reilly and Skuse (1992), the need for a multidisciplinary approach in evaluating the feeding and swallowing of children with CP is indicated, including a paediatrician, speech-language pathologist, radiologist, dietician, occupational therapist, physiotherapist and social worker, who can work together to develop a comprehensive management plan for these children and their families.

The earlier intervention is introduced, the more effective it is likely to be, with reduced negative sequelae and financial implications. Early management of feeding and swallowing difficulties is of particular importance when one considers the severe

consequences that can result from dysphagia, such as aspiration pneumonia or death (Rossetti, 1996).

This study has indicated that feeding and swallowing difficulties can be identified within the first month of life, thus emphasizing the importance of better staff and resource allocation to aid the early identification and management of feeding and swallowing disorders.

Conclusion

In conclusion, all children with CP in this study appear to experience some degree of disruption to their feeding and swallowing skills. As a result, the nature and extent of feeding and swallowing problems in the paediatric population with cerebral palsy should not be underestimated. Firstly, knowledge of the young age at which feeding and swallowing difficulties can be identified must be made known and emphasized. In turn, this might allow for early intervention and management thereby reducing the negative consequences that frequently result. Feeding and swallowing therapy must be incorporated into overall rehabilitation programmes for children with CP so as to reintegrate these children into society and to promote adequate nutrition, hydration and growth (Levitt, 1995, Reilly & Skuse, 1992, Rudolph, 1994).

Such therapy is important to both improve the child's safety and to promote a normal mother-child interaction. Thus there is a need for better resource and staff allocation to create the opportunity for SLPs to provide caregivers with the skills they require to maximize feeding strategies, as well as to assist other professionals in understanding the importance of including aspects of feeding and swallowing in the multidisciplinary management of children with CP.

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University of Cape Town

Appendix A

Parental Questionnaire (English)

Background Information: (obtained from hospital folder)

- Date of birth _____ Age (in months) _____ Gender _____
- Race _____ Caregiver's first language _____
- Gestation (in weeks) _____ Birthweight (in grams) _____
- Birth complications/APGAR scores _____
- Type of CP (spastic, athetoid, ataxic, mixed) _____
- Degree of limb involvement / severity (quad, hemi. etc) _____
- Age of diagnosis of CP (in months) _____

Questions pertaining to the early feeding/swallowing abilities of the children with CP:

1. Did you breast feed your child? _____ Yes _____ No

If yes, for how long?

_____ 0-2w _____ 2-4w _____ 1-2m _____ >2m

2. Was it difficult for your baby to suck on your nipple? _____ Yes _____ No

If yes, at what age did you first notice this?

_____ 0-2w _____ 2-4w _____ 1-2m _____ >2m

3. Did you notice any of the following when breast (or bottle) feeding your baby?

Slow, weak suck

Your nipple (or teat) being pushed out of your baby's mouth with his/her tongue

Milk dribbling out the sides of your baby's mouth

Baby falling asleep during feeding

Loud swallowing noises heard during feeding

4. Did you find it difficult to position your baby during feeding? Yes No

If yes, at what age did you first notice this?

0-2w 2-4w 1-2m >2m

5. Does/did your baby often cough or choke during feeding? Yes No

If yes, at what age did you first notice this?

0-2w 2-4w 1-2m >2m

6. Does/did your baby often vomit during or after feeding? Yes No

If yes, at what age did you first notice this?

0-2w 2-4w 1-2m >2m

7. Does your child suffer from lots of chest infections?

Yes No If yes, please specify _____

8. Does/did it take a long time to feed your child?

Yes No If yes, please specify _____

9. Has your child ever been fed non-orally (e.g. tube fed)?

Yes No If yes, please specify _____

10. Are you worried that your child could be undernourished because of feeding difficulties?

Yes No If yes, please specify _____

11. At what age did you start bottle feeding your child? _____

12. Did you notice any of the above problems during bottle feeding?

Yes No If yes, please specify _____

13. At what age did you start feeding your child semi-solids (e.g. puree)? _____

14. Did you notice any of the above problems during semi-solid feeds?

Yes No If yes, please specify _____

15. At what age did you start feeding your child solid food (e.g. rusks)? _____

16. Did you notice any of the following during solid feeds?

Coughing or choking

Difficulty chewing

Difficulty biting

Food falling out your child's mouth

Other, please specify _____

17. Did/does your child reject certain textures/tastes of food? Yes No

18. Does your child drool frequently? Yes No

If yes, at what age did you first notice this?

0-2w 2-4w 1-2m >2m

19. Have you ever received any information about feeding problems and ways you can help your child to eat and drink more efficiently?

Yes No If yes, please specify _____

20. Did you notice these feeding problems before you were told that your child has CP?

Yes No If yes, please specify _____

21. Does your child still present with any feeding and swallowing difficulties?

Yes No If yes, please specify _____

Appendix B

Verbal consent

My name is Judy Davison. I am a speech therapist, who is doing a study on the feeding and swallowing abilities of the children with CP who attend this clinic. I would like to ask you some questions about your experiences of feeding your child.

It is entirely up to you whether you wish to participate in my study. If you do, I will be asking you about 30 questions relating to the feeding and swallowing abilities of your child. The interview will not take more than 10 minutes. Your answers will be entirely confidential and no names will be reported in my study.

You may refuse to answer any of the questions or withdraw from the interview at any stage, should you wish to for any reason. Now that you have heard about my study, are you willing to answer my questions about your child?

Dr K R Ramiah

Appendix C

658-5068

22 April 1999

**Ms J Davison
13 Prideaux Road
RONDEBOSCH
7700**

Dear Ms Davison

RESEARCH PAEDIATRIC DYSPHAGIA

Thank you for your application to conduct your research at Red Cross Children's Hospital.

Permission is granted for you to go ahead with this project. Please inform the departmental head of your project.

A copy of your findings will be appreciated.

With best wishes for a successful outcome.

Yours sincerely



**DR K R RAMIAH
SENIOR MEDICAL SUPERINTENDENT
KR/cd**

RED CROSS WAR MEMORIAL ROOIKRUIS OORLOGSGEDENK
CHILDREN'S HOSPITAL HOSPITAAL VIR KINDERS
PRIVATE BAG PRIVAATSAK
RONDEBOSCH RONDEBOSCH
7701 7701

Telephone/Telefoon 658-5111
Fax/Faks 685-3891

T - "Hosfil"



Appendix D

Parental Questionnaire (Afrikaans)

Background Information: (obtained from hospital folder)

- Date of birth _____ Age (in months) _____ Gender _____
- Race _____ Caregiver's first language _____
- Gestation (in weeks) _____ Birthweight (in grams) _____
- Birth complications/APGAR scores _____
- Type of CP (spastic, athetoid, ataxic, mixed) _____
- Degree of limb involvement / severity (quad, hemi. etc) _____
- Age of diagnosis of CP (in months) _____

Questions pertaining to the early feeding/swallowing abilities of the children with CP:

1. Het u jou kind geborsvoed? ____ Ja ____ Nee

Indien ja, vir hoe lank?

____ 0-2 w ____ 2-4w ____ 1-2m ____ >2m

2. Was dit vir u kind moeilik om aan jou tepel te suig? ____ Ja ____ Nee

Indien ja, op watter ouderdom het jy dit vir die eerste keer opgemerk?

____ 0-2 w ____ 2-4w ____ 1-2m ____ >2m

3. Het jy enige van die volgende opgemerk tydens die borsvoeding (of bottel) van u baba?

___ Stadige, swak suig

___ Jou tepel wat uit u baba se mond gedruk word met sy/haar tong

___ Hoes en verstikking gedurende voeding

___ Melk wat kwyl uit u baba se mond

___ Baba wat aan die slaap raak gedurende voeding

___ Harde sluk geluide tydens voeding

4. Het jy dit moeilik gevind om u baba te posisioneer tydens voeding? ___ Ja ___ Nee

Indien ja, op watter ouderdom het jy dit vir die eerste keer opgemerk?

___ 0-2 w ___ 2-4w ___ 1-2m ___ >2m

5. Het u baba dikwels gehoos of verstik tydens voeding? ___ Ja ___ Nee

Indien ja, op watter ouderdom het jy dit vir die eerste keer opgemerk?

___ 0-2 w ___ 2-4w ___ 1-2m ___ >2m

6. Het u baba dikwels opgegooi tydens voeding? ___ Ja ___ Nee

Indien ja, op watter ouderdom het jy dit vir die eerste keer opgemerk?

___ 0-2 w ___ 2-4w ___ 1-2m ___ >2m

7. Het u kind 'n geskiedenis van borsinfeksies?

___ Ja ___ Nee Indien ja, spesifiseer _____

8. Neem dit 'n lang tyd om u kind te voed?

Ja Nee Indien ja, spesifiseer _____

9. Is u kind ooit nie-oraal gevoed? (bv. Buisvoeding)

Ja Nee Indien ja, spesifiseer _____

10. Is u besorg dat u kind moontlik ondervoed kan wees as 'n gevolg van hierdie voedingsprobleme?

Ja Nee Indien ja, spesifiseer _____

11. Op watter ouderdom het u bottelvoeding begin met u kind? _____

12. Het u enige van die voorafgaande probleme opgelet gedurende bottelvoeding?

Ja Nee

13. Op watter ouderdom het u begin om u kind semi-soliede kos te voer? _____

14. Het u enige van die voorafgaande probleme opgelet gedurende semi-soliede voeding?

Ja Nee

15. Op watter ouderdom het u begin om u kind soliede kos te voer? _____

16. Het jy enige van die volgende opgemerk tydens die voeding van soliede kos?

Hoes en verstikking gedurende voeding

Probleme om te kou

Probleme om gedeeltes van die kos af te byt

Kos wat by u kind se mond uitval

Iets anders, spesifiseer _____

17. Het u kind sekere teksture of smake van kos verwerp? Ja Nee

18. Het u kind gereeld gekwyl? Ja Nee

Indien ja, op watter ouderdom het jy dit vir die eerste keer opgemerk?

0-2 w 2-4w 1-2m >2m

19. Het u ooit inligting ontvang rakende voedingsprobleme en maniere waarop jy u kind kan help om meer effektief te eet en te drink?

Ja Nee Indien ja, spesifiseer _____

20. Het u hierdie voedingsprobleme opgelet voordat die inisiële CP diagnose gemaak is?

Ja Nee Indien ja, spesifiseer _____

21. Presenteer u kind nogsteeds met enige van hierdie voedingsprobleme?

Ja Nee Indien ja, spesifiseer _____

Appendix E

CEREBRAL PALSY DATA:

AGE ##
GENDER _
GESTATION ##
APGAR #
BIRTHWEIGHT ####
TYPE CP _ (S=Spastic, A=Athetoid, M=Mixed)
SEVERITY _ (Q=Quad, H=Hemi, D=Diplegic)
AGE DIAGNOSIS ##
RACE _ (B=Black, C=Coloured, W=White)
1st LANG _ (E=English, A=Afrikaans, X=Xhosa)

Q1 <Y>
Q1t #
Q2 <Y>
Q2t #
Q3 <Y>
Q3 <Y>
Q3 <Y>
Q3 <Y>
Q3 <Y>
Q3 <Y>
Q4 <Y>
Q4t #
Q5 <Y>
Q5t #
Q6 <Y>
Q6t #
Q7 <Y>
Q8 <Y>
Q9 <Y>
Q10 <Y>
Q11 ##
Q12 <Y>
Q13 ##
Q14 <Y>
Q15 ##
Q16 <Y>
Q16 <Y>
Q16 <Y>
Q16 <Y>
Q16 <Y>
Q16 <Y>
Q17 <Y>
Q18 <Y>
Q18t ##
Q19 <Y>
Q20 <Y>
Q21 <Y>