

Feeding intervention in children with cerebral palsy over an 18-month period in rural Eastern Cape.

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Abstract

The incidence of cerebral palsy (CP) is significantly higher in South Africa compared to international statistics. Feeding and swallowing difficulties associated with CP are of great concern in impoverished communities. There is a dearth of research regarding appropriate feeding interventions for children with CP in South Africa.

The aims of this study were to (i) determine if there was a change in the anthropometric measurements of children with CP, (ii) in the feeding performance of children with CP and (iii) in the caregiver awareness of and concerns about their children's feeding difficulties and weight over an 18-month period, following intervention and caregiver training, in a rural South African community.

A simple time-series experiment was employed. An intensive five-day intervention block of neurodevelopmental therapy (NDT) and caregiver training was provided in August 2007 and August 2008. Pre-intervention, post-intervention and follow-up data were collected. Participants were purposively selected. Children (aged one to 18 years) with a confirmed diagnosis of CP and their caregivers were included. Data collected included anthropometric measurements of the child participants, and extracted questions from the Pediatric Evaluation of Disability Inventory (PEDI) and the Feeding Profile (Kenny et al. 1989).

Statistically significant differences were observed in the mean weight, length/height and mid-upper arm circumference measurements of the child participants over the

18-month period. There was also a significant increase in the number of child participants able to tolerate ground/lumpy foods, instead of pureed foods, over the 18-month period. Individual participants demonstrated improvement in and maintenance of certain feeding skills over time. No significant differences were observed in the number of caregivers aware of and concerned about their children's feeding difficulties and weight over the 18-month period.

Although not classified as an effective intervention in the systematic review by Novak et al. (2013), NDT appeared to be a cost-effective and easily accessible approach for the purposes of the current study. As the caregivers, who lived far from healthcare facilities and services, received training, they could continue suggested activities at home. As no control group was used in the current study, it is not possible to say whether individual improvements in anthropometric measurements and feeding performance were as a result of intervention and caregiver training.

KEY WORDS: Cerebral palsy (CP), feeding, swallowing, neurogenic dysphagia, neurodevelopmental therapy (NDT) nutrition, anthropometry, caregiver concerns, rural South Africa, poverty, CP intervention.

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List of Abbreviations

AAC: Augmentative and alternative communication

AST: Adeli suit treatment

BMI: Body Mass Index

CIMT: Constraint-induced movement therapy

CP: Cerebral palsy

CPVS: Cervical perivascular sympathectomy

EI: Early intervention

FSS: Feeding Support Scale

GMFCS: Gross Motor Function Classification System

GMFM: Gross Motor Function Measure

HIV: Human immunodeficiency virus

MUAC: Mid-upper arm circumference

NDT: Neurodevelopmental therapy

PEDI: Pediatric Evaluation of Disability Inventory

PSI: Parenting Stress Index

RCT: Randomized controlled trial

SD: Standard deviation

SI: Sensory Integration

SPSS: Statistical Package for the Social Sciences

TB: Tuberculosis

WHO: World Health Organization

Chapter 1

INTRODUCTION

The aim of this chapter is to introduce the research topic and its relevance to the South African context; to critically discuss current literature that leads to the problem statement; and to present the rationale for the current study, the terminology used in the dissertation, as well as an outline of the chapters of the dissertation.

1.1 Problem Statement

According to Moreno-De-Luca, Ledbetter and Martin (2012), the most frequently reported cause of physical disability in children is cerebral palsy (CP). CP may be caused by a number of pre-, peri- and postnatal influences. In developing countries such as South Africa, the etiology of the disorder is most commonly associated with the perinatal or postnatal period, whilst the etiology of CP in developed countries is found to be during the antenatal period (Van Toorn, Laughton, van Zyl, Doets, & Elsinger, 2007). In a systematic review conducted by Donald, Samia, Kakooza-Mwesige and Bearden (2014), the most frequently described causes of CP in Africa were birth asphyxia, kernicterus and neonatal infections, while research conducted in North America and Europe names prematurity or low birth weight as the most prominent causes of CP.

Statistics regarding the prevalence of CP in South Africa are scarce due to insufficient resources to develop some form of official recording system. However, government reports show that the prevalence of CP is very high (Donald et al., 2014). A study that attempted to measure the incidence of children with disabilities in rural KwaZulu-Natal produced results that showed 10:1000 children below ten years of age present with some form of disability (Levin, 2006). This figure is significantly higher than the number

(2-3:1000 live births) that international statistics demonstrate (Moreno-De-Luca et al., 2012). In a study conducted on the incidence of intellectual disability in rural Bushbuckridge, the researchers found that of the 35.6 out of 1000 children that had an intellectual disorder, 8.4% of those children presented with CP (Levin, 2006). Due to the presumably high prevalence of CP in South Africa, research is required to find effective intervention solutions.

CP is a permanent neurological disorder caused by damage to the brain before it is completely developed (Kriger, 2006). The disorder results in motor impairment which may include physical and intellectual dysfunction. Symptoms associated with CP include spasticity and contractures, feeding complications, drooling, intellectual and communication impairments, osteoporosis, pain and functional gastrointestinal defects which may result in intestinal blockage, vomiting and constipation. Vomiting and aspiration pneumonia can be related to gastroesophageal reflux or a delayed swallow reflex (Clawson, Kuchinski, & Bach, 2007; Gates, Hartnell, & Gramigna, 2006). Motor development in children with CP is slow and atypical. Children with CP also present with atypical muscle tone, abnormal posture and persistent infantile reflexes which can interfere with eating and swallowing (Gates, Hartnell, & Gramigna, 2006; Kriger, 2006). The atypical tone that children with CP present with makes controlling their hands and arms for self-feeding a challenge (Clawson et al., 2007). Feeding, as it relates to CP, is used as a broad term to describe difficulties in a number of aspects of food consumption, including collecting, preparing and ingesting the bolus, as well as swallowing and digestion (Snider, Majnemer, & Darsaklis, 2011).

In contrast, swallowing is a sensorimotor event that involves both voluntary and involuntary movements of the oropharyngeal structures, esophagus and laryngeal and respiratory muscles (Aydogdu et al., 2014). Dysphagia can be caused by damage to any point along the neuromuscular pathway extending from the cerebral cortex to the muscles involved in swallowing. The atypical muscle tone that children with CP present with causes feeding and swallowing difficulties which are classified as neurogenic dysphagia (Arvedson & Brodsky, 2002). The authors state that neurogenic dysphagia

can result in reduced bolus movement or incorrect movement of the bolus into the nasal cavity, larynx and/or trachea. Poor control of the tongue and swallowing muscles may result in jaw deviation, problems with graded mouth opening, tongue movement, swallowing and pharyngeal motility, causing stressful and prolonged mealtimes, lethargy during meals, food refusal, prolonged malnutrition, respiratory disease, diminished quality of life for the caregiver and child, as well as premature death (Adams et al., 2011; Arvedson & Brodsky, 2002; Clawson et al., 2007). One of the foremost complications resulting from neurogenic dysphagia is aspiration, frequently causing pneumonia, malnutrition and dehydration that can be fatal for patients with neurological disorders, such as CP (Aydogdu et al., 2014).

Clawson et al. (2007) state that one of the earliest indicators of a neurological disorder is difficulty taking in oral feeds which occurs mainly as a result of diminished oral motor and physical functioning, as well as impaired cognition (Dahlseng, et al., 2011). Research has shown that 90% of children with CP also experience poor nutrition and growth (Clawson et al., 2007). After conducting a study on the anthropometric measurements and body composition of individuals with CP, Tomoum, Badawy, Hassan and Alian (2010) state that the significantly reduced anthropometric measurements in the adult and child participants may have been due to feeding difficulties and nutritional influences.

It is not only the children with CP that experience numerous difficulties as a result of the disability. Studies have shown that the parents of children with CP have a high tendency towards anxiety and depression, diminished health and continuing grief (Whittingham, Wee, Sanders, & Boyd, 2012). It is recognized that children with CP often present with behavioural and emotional difficulties (Carlsson, Olsson, Hagberg, & Beckung, 2008) which are related to a high level of parental stress (Ketelaar, Volman, Gorter, & Vermeer, 2008; Plant & Sanders, 2007).

The African Child Policy Forum conducted a study on children with disabilities in Africa. The results of this study highlighted the significant impact that reduced financial

circumstances have on the caregiver's capacity to support the basic necessities of their children (Donald et al., 2014). Caregivers stated that the expense involved in medical and rehabilitative services, assistive devices, and transport is a substantial problem in obtaining the necessary healthcare for their children. In addition, as pregnant mothers often do not receive appropriate pre-natal care or adequate nutrition, live in unhygienic environments and are more susceptible to contracting contagious illnesses, their children are at greater risk of presenting with a disability (Levin, 2006).

The living circumstances of children with CP in South Africa may also contribute to their poor nutrition. According to the South African constitution, children with disabilities have the right to basic healthcare and education. A study conducted by Saloojee, Phohole, Saloojee and Ijsselmuiden (2006) investigated the rehabilitative, educational and welfare needs of children with disabilities living in a peri-urban township in South Africa and to what extent those needs were being addressed. The authors found that the needs and rights that children living in a rural area are entitled to, were not being adequately addressed. A description of a typical rural or peri-urban South African situation was provided by the researchers:

“Living in an impoverished environment where unemployment rates are high, where many children live in single-parent families with little or no support from fathers, and where household incomes are very low, adversely affects a caregiver's ability to prioritize the care that a child with a disability needed” (Saloojee et al., 2006: 234).

The researchers also state that, in order to address the needs of these children, novel and coordinated service delivery approaches, trained caregivers as well as community awareness of these needs is necessary. The involvement of parents and caregivers in intervention is essential as they are the most informed individuals regarding the capabilities and requirements of their children (Hanna & Roger, 2002).

Research has demonstrated a tendency among parents (of children without a disability) to view their children's weight inaccurately. Bossink-Tuna, L'Hoir, Beltman and Boere-Boonekamp (2009) showed that 62% of the parents of overweight children and 46% of the parents of underweight children between the ages of two and four years, had the incorrect impression of their child's weight. However, there is a lack of research that examines whether the caregivers of children with CP in South Africa are aware or appropriately concerned about their children's feeding difficulties and weight gain. There is also a dearth of research regarding caregiver awareness of dysphagia in their children with CP and the effectiveness of intervention strategies for these difficulties in rural South Africa. It is, therefore, important that effective and sustainable intervention approaches targeting the feeding difficulties in children with CP, are investigated.

1.2 Rationale and research questions

As there is a high prevalence of CP in South Africa (Donald et al., 2014), with many children with the disability presenting with dysphagia and nutritional challenges, research is required to find effective intervention solutions.

Although dysphagia in children with CP may have serious implications, there is evidence that nutrition intervention can result in weight gain and, consequently, growth. It has been shown that positive results, such as reduced irritability and spasticity, improved alertness and substantial developmental progress, stem from successfully targeting nutrition in children with CP (Clawson et al., 2007). Dysphagia in children with CP has traditionally been targeted by means of two different kinds of intervention. Gisel (2008) states that the first of these interventions involves increasing the number and/or duration of meals in order to achieve weight gain and, consequently, growth. Tube feeding may become necessary when the quantity of food required by the child is more than the child is able to tolerate orally. The second type of intervention for dysphagia in children with CP is the use of sensorimotor stimulation in order to improve oral-motor

skills, or the use of intra-oral appliances to make the intake of food more efficient and, therefore, enable a larger caloric intake (Gisel, 2008). The two approaches are often used together in order to lessen invasive techniques and to maximize weight gain. According to Gisel (2008), the effectiveness of oral sensorimotor interventions in children with CP presenting with a moderate eating disorder, has been shown to be only approximately 15% above the normal maturation level and, therefore, is limited to maintaining growth. This type of intervention does not allow for catch-up growth (Gisel, 2008). García-Contreras et al. (2014) conducted a study on moderately/severely undernourished children with CP using nutritional support intervention via naso-enteral tube-feeding or gastrostomy. Their results indicated an average weight increase of 2700g following a four week period of nutritional recovery. There were also significant increases in anthropometric indicators such as Body Mass Index (BMI) and weight/length ($p < 0.01$) (García-Contreras et al., 2014).

The previous discussion largely reports on research in developed countries where a wide range of interventions, such as different types of tube feeding and caregiver education and training, are accessible to individuals of low, medium or high socioeconomic status. However, in developing countries, tube feeding may not always be a feasible option due to insufficiently developed healthcare systems for children with CP in the public sector, as well as financial difficulties that occur as a result of resources being taken up by the huge burden of human immunodeficiency virus (HIV), tuberculosis (TB) and malnutrition (Levin, 2006). In addition, although caregiver training may be conducted, its efficacy is not reported in the literature (Adams et al., 2011). Clawson et al. (2007) also mention that, as the mortality rate due to gastrostomies is substantial and the discomfort associated with nasogastric tubes (NG) tubes significant, a less invasive, lasting solution must be discovered.

In a systematic review conducted by Donald et al. (2014), caregivers stated that community-based rehabilitation programs substantially improved access to schooling and assistive devices for their children with CP. However, these rehabilitative programs have yet to be systematically assessed in South Africa. It is acknowledged that home-

or community-based interventions are more appropriate for areas that are poorly resourced as they make little use of infrastructure and resources in comparison to center-based rehabilitation. Another advantage of home- or community-based rehabilitation is that it improves parent-child bonding (Donald et al., 2014).

Malamulele Onward is a non-profit organization dedicated to offering specialized intervention skills, training and services to children with CP living in under-resourced areas of South Africa and other African countries. Many children with CP have little or no access to rehabilitative intervention in these areas. The mission of Malamulele Onward is to identify and reach children with CP in remote rural regions and to assist them in reaching their full potential in a supportive context. Malamulele Onward's mission is also to improve the children's quality of life by addressing their physical and emotional needs, as well as to assist and enable those involved in their intervention and care, including their parents and caregivers (www.malamuleleonward.org).

Information regarding the nutritional status of children with CP and caregiver perceptions of their children's feeding difficulties in low-resourced communities is lacking. A study conducted by the Malamulele Onward Rehabilitation Team (Daniel & Davisson, 2012) examined the caregiver perceptions, feeding profiles and nutritional status of children with CP in the Mquma health sub-district in rural Eastern Cape, South Africa. More specifically, the researchers investigated the differences between those caregivers who were concerned about their children's feeding difficulties and nutritional status and those caregivers who were not concerned. They also aimed to determine whether there was a significant difference between the two groups of participants and their children's actual nutritional status, as determined by the anthropometric measurements of the children. The results of the study indicated that all but one of the child participants presented with feeding difficulties and that most of the caregivers were aware of their children's actual feeding difficulties. Low length-for-age z-scores were an indication of chronic malnourishment in the participants, while weight-for-height scores and BMI were mostly appropriate. Since the participants were shorter than expected for their age, the weight-for-height z-score confirmed their

malnourishment (Daniel & Davisson, 2012). The study highlighted the need for nutrition and feeding intervention, as well as caregivers' information needs regarding their children's disability. A longitudinal study on the same sample was conducted and pre-intervention, post-intervention and follow-up data collected in order to determine how intervention influenced the anthropometric status and feeding performance of the children with CP, as well as the caregivers' awareness of and concerns about their children's feeding difficulties and weight. The current study aimed to analyze the retrospective data, relevant to feeding, dysphagia and nutrition, collected over 18 months by the Malamulele Onward Rehabilitation Team.

It is evident that CP is a disorder that affects the lives of a vast number of children and their caregivers in developing communities, particularly in South Africa. There is a dearth of research regarding children with CP in rural South Africa. The language barriers between caregivers requiring training and professionals, and low literacy rates in communities, present a significant challenge to researchers conducting studies in these specific locations. Despite the challenges faced, it is important that such studies be conducted in order for local research findings to inform services provided.

The study, therefore, addressed the following questions:

- 1) Is there a change over time in the anthropometric measurements of children with CP following NDT feeding intervention and caregiver training?
- 2) Is there a change over time in the feeding performance of children with CP (as reported by their caregivers) following NDT feeding intervention and caregiver training?
- 3) Is there a change over time in the caregivers' awareness of and concerns about their children's feeding difficulties and weight following NDT feeding intervention and caregiver training?

1.3 Terminology as used in this study

Anthropometry

Anthropometry is broadly defined as the scientific study of the measurements and proportions of the human body, particularly for comparative purposes (Merriam-Webster's online dictionary, n.d). Anthropometric measurements reflect physical growth and body composition in children, which provides important information regarding the children's nutritional status (Aroor et al., 2014). In this study, the following anthropometric measurements of the children with CP were measured over time: weight (kg), length/height (cm), tibial length (cm), half-span (cm), mid-upper arm circumference (MUAC) (cm) and triceps skinfold thickness (mm).

Concern

The term concern refers to the importance an individual places on someone or something (Cambridge Dictionaries Online, n.d.). In this study, caregiver concerns refer to the importance with which the caregivers (in this study, mothers and grandmothers) of the children with CP view their children's disability and the associated difficulties.

Cerebral palsy (CP)

CP is a permanent neurological disorder caused by damage to the brain before it is completely developed (Kriger, 2006; Rosenbaum et al., 2002). The most frequently described causes of CP in Africa are birth asphyxia, kernicterus and neonatal infections, while research conducted in North America and Europe names prematurity and low birth weight as the most prominent causes of CP (Donald et al., 2014). Symptoms associated with CP include spasticity and contractures, feeding complications, drooling, intellectual and communication impairments, osteoporosis, pain and functional gastrointestinal defects which may result in intestinal blockage, vomiting and constipation. Vomiting and aspiration pneumonia can be related to gastroesophageal reflux or a delayed swallow reflex (Clawson et al., 2007; Gates, Hartnell, & Gramigna, 2006). CP subtypes, according to which the participants of the

current study were classified, include spastic quadriplegia (moderate/severe), spastic hemiplegia, dystonic quadriplegia, ataxic, athetoid, mixed (dystonic athetoid) and mixed (dystonic spastic quadriplegia), the most severe subtype in terms of function being spastic quadriplegia (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007).

Feeding difficulties

Feeding difficulties, as it relates to CP, is used to describe difficulties in a number of aspects of food consumption, including collecting, preparing and ingesting the bolus, as well as swallowing and digestion (Snider et al., 2011).

Malnutrition

Diminished growth and poor nutritional status are well-recognized in children with CP (Bell et al., 2010). Malnutrition refers to either a deficiency or an excess of nutrients or vitamins in the body.

Neuro-developmental therapy

Novak et al. (2013) conducted a systematic review which indicated that there is limited evidence in the effectiveness of available CP interventions. The intervention provided to the children with CP in the current study was based on the NDT approach. NDT is an active approach that focuses on the child with CP as a whole. Intervention involves constraint or enablement of posture and the process of moving is used in order to help the child attain certain outcomes (Kim, Lee, & Park, 2016).

Rural South Africa

Saloojee et al. (2006) describe a typical rural South African situation as an impoverished environment where unemployment rates are high, where many children live in single-parent families with little or no support from their fathers, and where household incomes are very low (Saloojee et al., 2006). Due to the remote location of rural areas in South Africa, the people living in these areas have limited access to

healthcare facilities and services. The Amathole health district is an example of such an atypical rural South African context.

Swallowing

Swallowing is a sensorimotor event that involves both voluntary and involuntary movements of the oropharyngeal structures, esophagus and laryngeal and respiratory muscles (Aydogdu et al., 2014). The atypical muscle tone that children with CP present with causes feeding and swallowing difficulties which are classified as neurogenic dysphagia (Arvedson & Brodsky, 2002).

Undernutrition

Undernutrition is a form of malnutrition. It occurs when caloric intake is below the minimum dietary energy requirement (Sharma, 2015) and is associated with low weight-for-age, height-for-age and weight-for-height z-scores (Day et al., 2007).

1.4 Outline of chapters

CHAPTER 1: Introduction

The aim of this chapter is to introduce the research topic and its relevance to the South African context; to critically discuss current literature that leads to the problem statement; and to present the rationale for the current study, the terminology used in the dissertation, as well as an outline of the chapters of the dissertation.

CHAPTER 2: Literature overview on cerebral palsy interventions

The aim of this chapter is to critically discuss the effectiveness of existing interventions in children with CP with a focus on feeding and swallowing interventions.

CHAPTER 3: Methodology

The aim of this chapter is to describe the aims and research design employed in the current study. It also provides a detailed description of the study participants, data collection procedures, data analysis procedures and the ethical considerations taken into account throughout the study. It will be indicated that the research was conducted using valid outcome measures and that reliable procedures were employed.

CHAPTER 4: Results

The aim of this chapter is to present the results according to the sub-aims of the study. This includes statistical analysis of the anthropometric measurements obtained from each child participant as well as analysis of the raw data obtained from the PEDI (on caregiver reports of their children's feeding performance) and the Feeding Profile (on caregiver awareness of and concerns about their children's feeding difficulties and weight).

CHAPTER 5: Discussion

The aim of this chapter is to examine and interpret the results obtained in the current study by comparing the findings to the relevant literature. This chapter also aims to answer the study questions regarding the anthropometric measurements and feeding performance of the child participants with CP (as reported by their caregivers) and the caregiver participants' awareness of and concerns about their children's feeding difficulties and weight.

CHAPTER 6: Conclusion and recommendations

The aim of this chapter is to discuss the implications of the results obtained in the current study. It also aims to describe the strengths and limitations of the study as well as provide suggestions for the direction of further research.

Chapter 2

LITERATURE OVERVIEW ON CEREBRAL PALSY INTERVENTIONS

The aim of this chapter is to critically discuss the effectiveness of existing interventions in children with CP with a focus on feeding and swallowing interventions.

2.1 Introduction

Thirty to 40% of interventions for a wide range of disabilities are not based on evidence, while 20% of interventions are reported to be ineffective, redundant or detrimental to the recipients of the interventions (Novak et al., 2013). In a comprehensive systematic review conducted by Novak et al. (2013), the authors showed that there is a significant breach between research and practice in terms of CP intervention. Despite the research conducted on the effectiveness of intervention techniques, clinicians are implementing interventions that have not been adequately researched or interventions which have been found to be ineffective. This breach remains despite the availability of a substantial amount of research regarding which interventions work and which do not, in terms of children with CP.

There are a number of difficulties that children with CP may encounter and require treatment for. The discipline of CP intervention has moved away from solely focusing on treating the physical disabilities the children present with, to making the best use of the children's surroundings, assisting them in becoming more independent in their everyday tasks, and improving their involvement in society. Therapists, who make use of goal-directed therapy, now choose treatments that would be most appropriate for the family of the child with CP to reach their targets (Novak et al., 2013). As a result, this, along with the obstacles therapists face, such as a lack of time, minimal access to

books and articles containing the latest research, inadequate skills to critically evaluate research, and negativity towards studies conducted, there can be no guarantee that children with CP will be provided with treatment based on evidence (Novak et al., 2013).

Novak et al. (2013) describe the following levels of evidence into which they categorize current CP interventions:

- High level of evidence: it is highly improbable that future research will alter the assurance the researchers have in their appraisal of the effect of a particular CP intervention.
- Moderate level of evidence: it is probable that future research will have a significant influence on the assurance the researchers have in their appraisal of the effect of a particular CP intervention and may change their appraisal.
- Low level of evidence: it is highly probable that future research will have a significant influence on the assurance the researchers have in their appraisal of the effect of a particular CP intervention and is likely to change their appraisal.
- Very low level of evidence: any appraisal of effect of a particular CP intervention is unsure.

Although a vast amount of research has been conducted on CP interventions and a significant number of systematic reviews on the effectiveness of these interventions are available, the breach between research and practice remains. The following information aims to provide a critical discussion of recent evidence for interventions directed at the complexity of impairments associated with CP.

2.2 Intervention in children with CP

Direct medical approaches

It appears that medications such as valium, baclofen, artane and botox (botulinum toxin) manage to some degree, the abnormal muscle tone experienced by children with

CP (Workinger, 2005). In cases where contractures and disfigurements are present due to abnormal muscle tone, surgery is often required in order to prevent the deformity from becoming more severe, to reestablish function and to encourage constant improvement (Workinger, 2005). According to the systematic review conducted by Novak et al. (2013), botulinum toxin and diazepam are the only medications shown to be effective in lessening the spasticity of the individual's muscles. This finding was supported in a systematic review conducted by Tilton (2015), who stated that botulinum toxin is an appropriate and effective means of lessening spasticity in the upper and lower limbs of individuals with CP.

Assistive technology

Assistive technology (including wheelchairs, walking frames and structures that support posture) was used in the original research study. Assistive technology refers to the apparatus that assists a person in attaining or increasing independent living (Huang, Sugden, & Beveridge, 2009). Examples of assistive technology include wheelchairs, structures that support posture, augmentative and alternative communication (AAC) systems, computers and electronic devices that assist the individual on a day-to-day basis (Workinger, 2005). AAC involves the use of physical signing and/or symbol methods within a complete communication system, where all means of communication are viewed as beneficial (Clarke & Price, 2012). Novak et al. (2013) state that assistive technology, including AAC, falls into a low evidence category. The researchers also state that assistive technology has not been well-researched, possibly because the advantages of using such technology and devices are obvious. In other words, assistive devices such as wheelchairs assist children with CP in overcoming the physical obstacle of being unable to walk, while AAC devices assist them in overcoming, to some extent, the communication barrier they experience.

Therapeutic habilitative approaches

Sensory Integration (SI) intervention includes “activities that are believed to organize the sensory system by providing vestibular, proprioceptive, auditory and tactile inputs”

(Zimmer & Desch, 2012: 1187). Novak et al. (2013) demonstrate that SI interventions are ineffectual treatment approaches for children with CP as they have little effect on improving motor skills compared to alternative treatments.

Adeli suit treatment (AST) is a rigorous physical activity program that uses a suit designed to retain muscle tone in a weightless atmosphere, as in the case of an astronaut (Kim, Lee, & Park, 2016). AST is founded on three concepts, namely, resistance against loads, rigorous daily exercise intervention, and dynamic muscle movement involvement on the part of the patient with CP (Bar-Haim et al., 2006).

The neurodevelopmental therapy (NDT) approach was the approach used in the research study. It is an active approach that focuses on the child with CP as a whole. The primary goals of NDT are to decrease spasticity and to improve movement patterns and everyday functioning (Kim et al., 2016). Therapy involves constraint or enablement of posture and the process of moving is used in order to help the child attain certain outcomes (Kim et al., 2016). In terms of regulating movement, NDT is not classified as an effective intervention approach as it does not result in improvements above those of other interventions (Novak et al., 2013). NDT is also not viewed as effective in inhibiting contractures as the improvements achieved directly following intervention are not maintained or carried over. Finally, in terms of improving function, recent research has shown that the provision of NDT more frequently and for longer periods of time is beneficial, but that the approach should still be used with caution (Tsorlakis, Christina, George, & Charalambos, 2004). Kim et al. (2016) found that, when combined with the AST approach, NDT was a more effective intervention approach than when it was used on its own. Unfortunately, AST is a costly approach and the authors recommend further research to warrant the expense thereof.

The NDT approach was used in this study as it appeared to be the most cost effective and easily accessible approach to the participants who were living dispersed in a remote rural area. As the aim of this study was to determine the effectiveness of NDT intervention and caregiver training on the nutritional status and feeding behaviours of children with CP, as well as on the awareness and concerns of their caregivers, the

findings of this study will add to the body of research regarding the effectiveness of NDT with regard to the feeding behaviours of children with CP.

Treatment of language disorders

Greenspan and Wieder (2007) developed a language intervention program for children with autism that attempts to develop six areas: the ability of the child to regulate his/herself and his/her curiosity in the world, closeness, turn-taking in conversation, higher order communication, and emotive notions and thoughts. It has been suggested that this program is effective for children with CP in the early stages of life whose communicative abilities are emerging (Workinger, 2005). According to Novak et al. (2013), there is a low level of evidence for communication training in children with CP in general, as there is an insufficient amount of research available on these interventions. However, early intervention (EI) for infants and young children promises effectiveness as a result of neuroplasticity (Rossetti, 2001).

Alternative treatments

Electrical stimulation, strength training and counseling are all treatments that were found to be ineffectual in the systematic review conducted by Novak et al. (2013). An exercise program that included activities to increase fitness levels, parent guidance, and treatment provided in the home environment, did not produce the desired results in children with CP (Van Wely, Balemans, Becher, & Dallmeijer, 2014). The authors believe this to have been due to the intervention period being too short to bring about changes in such an intricate component as physical exercise. These results support the findings of Novak et al. (2013). A systematic review conducted by Dewar, Love and Johnston (2014) also showed that treatments involving exercise present with moderate (such as hippotherapy, trunk-targeted training and gross motor task training), low (such as hippotherapy simulators, NDT and virtual reality) or ineffective (such as visual biofeedback) levels of evidence. However, Xu, He, Mai, Yan and Chen (2015) conducted a study using constraint-induced movement therapy (CIMT) along with electrical stimulation, which was shown to improve muscle recruitment and

coordination in children with hemiplegic CP. CIMT involves rigorous training of the affected hand of the child with CP, whilst the wrist extensors of the same hand receive electrical stimulation and the unaffected hand is constrained. According to Novak et al. (2013), there is a high level of evidence for the CIMT approach.

Treatment of feeding and swallowing disorders

The main targets of dysphagia intervention are to support sufficient nutritional and water intake and promote feeding abilities that are on par with the child's age. The purpose of intervention is mainly to teach, coach and work together with the caregivers of the child in his/her family setup (Hall, 2001).

Snider et al. (2011) adapted the well-known Sackett levels of evidence for their literature review on evidence of feeding interventions for children with CP. They present the levels of evidence as follows:

- Level 1a (strong): a well-designed meta-analysis or two or more “high-quality” randomized controlled trials (RCT's) that demonstrate results that are alike.
- Level 1b (moderate): one RCT of “high-quality”.
- Level 2a (limited): at least one “fair-quality” RCT.
- Level 2b (limited): at least one “poor-quality” RCT.
- Level 3 (consensus): agreement between a number of individuals in the profession.
- Level 4 (conflict): contradictory evidence of two or more well-designed research designs.
- Level 5 (no evidence): no well-designed studies.

According to Snider et al. (2011), feeding therapy for children with CP can be divided into two categories: (i) impairment-based, which involves targeting sensorimotor aspects as well as adjusting the child's position in order to improve feeding and (ii) adaptive, which refers to appliances inserted into the mouth during feeding or adjusting the thickness of the food. The purpose of using sensorimotor strategies is to reduce or

improve muscle tone and prevent infantile reflexes which affect feeding. There is currently contradictory evidence (level 4) that sensorimotor strategies have a higher level of effectiveness than unconventional intervention or no intervention in increasing safe and productive feeding (Arvedson, 2013; Snider et al., 2011). The reason that oral sensorimotor interventions are labeled as presenting with 'contradictory evidence' is because two studies that used sensorimotor strategies used different approaches and the interventions were administered for varying lengths of time and intensities. It was, therefore, impossible to compare the studies. However, in a study conducted by Baghbadorani, Soleymani, Dadgar and Salehi (2014), sensorimotor stimulation substantially improved lip closure, control of food and liquids during swallowing, and chewing in children with spastic CP after eight weeks of intervention. Strategies that improve position may be used to encourage improved and more efficient feeding performance. There is currently limited evidence (level 2b) that adjusting the child's posture enhances safe and effective feeding by minimizing the chance of aspiration and decreasing the amount of time spent on meals. Oral appliances are, at first, used to stabilize the jaw before targeting initiation and movement of the structures of the mouth and pharynx. There is moderate (level 1b) evidence that using oral appliances has a higher level of effectiveness than no or unconventional treatments with regard to improving sensorimotor abilities. An RCT of high quality was described by Gisel (2008); the Innsbruck sensorimotor activator and regulator was used over a 12-month period in children who presented with dysphagia. Significant improvements in cup drinking, spoon feeding, biting, chewing and swallowing were shown. According to Snider et al. (2011), adjusting the thickness of the food the child eats may impact his/her chewing and swallowing skills. There is currently limited evidence (level 2b) that giving foods with a thinner consistency to children with CP facilitates safe and effective feeding. In general, Novak et al. (2013) found dysphagia therapy to be supported by inconclusive evidence due to the research studies conducted on dysphagia intervention in children with CP being of low quality.

Research has shown that gastrostomies considerably improve weight in children with CP and are related to a decrease in the length of mealtimes, drooling, choking, vomiting and respiratory difficulties (Sullivan, 2013). The reason for the decrease in

feeding difficulties is due to the food that the children receive not being taken in orally. The food, therefore, bypasses the mechanisms that may result in drooling, choking and vomiting, if the child experiences feeding difficulties, and enters the stomach directly. In a study conducted by McSweeney et al. (2015), it was found that the total number of hospitalizations in children who were aspirating with gastrostomies was less than the number of hospital admissions in children who were aspirating and fed orally. Based on the current literature, it would appear that the use of gastrostomies is an appropriate intervention strategy to improve weight gain and decrease aspiration, drooling, choking and vomiting (Sullivan, 2013). However, each case should be considered individually and the benefits to the child should be extensively examined.

Duan, Gao, Luo and Sun (2015) examined the effectiveness of cervical perivascular sympathectomy (CPVS) on drooling in children with athetoid CP and discovered that, although it reduced the drooling in a small number of their participants, the procedure yielded inadequate outcomes. CPVS involves making a small incision along the inner edge of the sternocleidomastoid muscle and, after the carotid artery has been exposed, the carotid adventitia is removed. This procedure is performed on both the left and the right side (Duan et al., 2015). The younger participants in the study, who had better neural plasticity and who presented with moderate drooling, demonstrated less drooling after the study period. However, the children with a low intelligence level and poor oral-motor function demonstrated minimal improvement.

Families of children with CP naturally want their children to receive the most appropriate and beneficial treatment possible, while healthcare services rely on intervention that is economical. Therefore, it is important to provide treatment and services that are effective and cost-efficient (Novak et al., 2013). However, this remains a constant challenge with such a heterogeneous disability as CP.

In summary, the literature overview confirms that much research is still required to improve the level of evidence for different CP interventions. However, evidence is slowly emerging as an increasing number of well-designed studies and RCT's are being conducted. Due to the limited number of studies conducted on feeding

intervention in children with CP, evidence therein is often labeled 'inconclusive'. However, research on the effectiveness of gastrostomies and sensorimotor interventions is increasing and demonstrating positive results in children with CP. Even though evidence is emerging, it is unclear whether these interventions would be effective for children with CP living in rural areas in South Africa, as their environmental circumstances may act as barriers. It is important, therefore, to determine which feeding interventions would be effective in improving the feeding performance in children with CP in a rural area in South Africa, and which would be carried over and maintained over time.

Chapter 3

METHODOLOGY

The aim of this chapter is to describe the aims and research design employed in the current study. It also provides a detailed description of the study participants, data collection procedures, data analysis procedures and the ethical considerations taken into account throughout the study. It will be indicated that the research was conducted using valid outcome measures and that reliable procedures were employed.

3.1 Aim of the study

3.1.1 Main Aim

The aim of this study was to determine if there was a change in the anthropometric measurements and feeding performance (as reported by caregivers) of children with CP over an 18-month period, following NDT feeding intervention and caregiver training, and if there was a change in the caregivers' awareness of and concerns about their children's feeding difficulties and weight over the specific time period in a rural South African community.

3.1.2 Sub-aims

1. To determine if there was a change over time in the anthropometric measurements of children with CP following NDT feeding intervention and caregiver training.
2. To determine if there was a change over time in the feeding performance of children with CP (as reported by their caregivers) following NDT feeding intervention and caregiver training.

3. To determine if there was a change over time in the caregivers' awareness of and concerns about their children's feeding difficulties and weight following NDT feeding intervention and caregiver training.

3.2 Research Design

The current study was retrospective in nature. Secondary data analysis was conducted using selected data collected prospectively by the Malamulele Onward Rehabilitation Team from August 2007 to January 2009 for a larger study.

The design employed was quasi-experimental. In such designs, it is not possible to control for all the confounding variables and, therefore, alternate explanations for the results of the study cannot be completely disregarded (Leedy & Ormrod, 2014). The type of quasi-experimental design used was a simple time-series experiment. Pre-intervention data were collected from each adult (caregiver) and child participant. Intensive NDT was then introduced for five consecutive days, after which post-intervention data were collected. Follow-up data were collected three months post-intervention. The pre-intervention, post-intervention and follow-up data collection procedures were performed in August 2007 to January 2008 (Period 1) and again in August 2008 to January 2009 (Period 2) to the same group of children. A disadvantage of this type of design is the chance that some outside event that has not been controlled for occurs at the same time that intervention is being administered and, therefore, results in change in the dependent variable (Leedy & Ormrod, 2014).

The participants in this study comprised children with a confirmed diagnosis of CP and their caregivers. Data pertaining to the anthropometric measurements of the children with CP were collected. Data were also obtained from each caregiver regarding their perceptions of their child's feeding performance and their awareness of and concerns about their child's feeding difficulties and weight. Table 1 depicts the assessment (A1, A2, and A3) dates in each period of data collection.

Table 1 Data collection periods

| Assessment Area | Pre-intervention assessment (A1) | | INTERVENTION BLOCK | | Post-intervention assessment (A2) | | Follow-up assessment (A3) | |
|-----------------|----------------------------------|---------------------|---------------------|---------------------|-----------------------------------|---------------------|---------------------------|---------------------|
| | Period 1 (Aug 2007) | Period 2 (Aug 2008) | Period 1 (Oct 2007) | Period 2 (Oct 2008) | Period 1 (Oct 2007) | Period 2 (Oct 2008) | Period 1 (Jan 2008) | Period 2 (Jan 2009) |
| PEDI | √ | √ | INTERVENTION BLOCK | INTERVENTION BLOCK | √ | √ | √ | √ |
| Feeding Profile | √ | √ | | | x | √ | √ | √ |
| Anthropometry | √ | √ | | | x | x | √ | √ |

x: refers to no data collected.

3.3 Ethical considerations

Ethical clearance was granted to Malamulele Onward, a non-profit organization, by the University of the Witwatersrand Human Research Ethics committee (Clearance Certificate R14/49) (see Appendix C) as well as the Department of Health in the Eastern Cape prior to the commencement of data collection in August 2007. Permission to conduct the study was obtained from the hospital CEO of the Butterworth/Tafalofefe Hospital Complex, as well as the Eastern Cape Provincial Health Research Committee. Dr Gillian Saloojee, the head of Malamulele Onward, in turn, gave permission to the current researcher to analyze the data which concerns the anthropometric measurements and caregiver perceptions of feeding in the children with CP and which was collected over an 18-month period (see Appendix B). Ethical clearance for the current study was obtained by the Faculty of Humanities Research Ethics Committee at the University of Pretoria (see Appendix A). The following ethical principles were taken into account during this research study:

3.3.1 Protection from harm

It is unethical to place research participants in harm's way, whether it be physical or psychological harm (Leedy & Ormrod, 2014). A standard rule to remember and follow when conducting research that involves human participants, is that the risks involved in participating in the study should not exceed the risks encountered in everyday living (Leedy & Ormrod, 2014). The researchers and fieldworkers of Malamulele Onward ensured that they did not inflict any form of harm on the participants and acted only in their best interests for the duration of the study. Caregiver reports were collected by four trained interviewers via a structured interview in the participants' first language, isiXhosa. First language communication reduced misunderstandings between the participants and interviewers.

As the researcher only used the data which was collected by the Malamulele Onward organization, there was no direct contact between the current researcher and the research participants.

3.3.2 Voluntary and informed participation

Lawrence (2011) states that, when individuals are asked to participate in a particular study, they should be informed of all aspects of the study. They should also be given the choice of whether or not they wish to participate and their consent should not be obtained by intimidation. All participants in the current study were informed of the nature of the study procedure in isiXhosa and were given the opportunity to withdraw their participation at any given time.

Informed consent refers to the necessity of participants or legal guardians (in the case of children and other specific populations) being informed of the nature of the study and providing their written or verbal permission to participate therein (Leedy & Ormrod, 2014). Before the speech-language therapists, physiotherapists and fieldworkers (employed by Dr Saloojee for data collection) began the research procedures (the

fieldworkers conducting the interviews for the Pediatric Evaluation of Disability Inventory (PEDI) and Feeding Profile, the physiotherapists collecting the anthropometric measurements and the speech-language therapists, occupational therapists and physiotherapists providing intervention and caregiver training), a Caregiver Information Sheet (see Appendices D and E) was provided to each participant. This form, provided in both English and isiXhosa, explained the purpose of the study as well as what participation in the study entailed. To ensure true informed consent, all aspects of the study were explained to the participants in isiXhosa, their first language. Written consent was obtained from each caregiver who was able to write (see Appendix F) and verbal informed consent was obtained from the caregivers who were unable to write (see Appendix G). Written informed assent was acquired from children who were able to read and understand (see Appendix H), while verbal informed assent was obtained from children who were able to understand, but unable to write (see Appendix I).

3.3.3 Right to privacy

“In general, a researcher must keep the nature and quality of individual participants’ performance strictly confidential” (Leedy & Ormrod, 2014: 109). This means that only the researchers and the staff assisting them in the research process are entitled to know the participants’ identities (De Vos, Strydom, Fouché, & Delport, 2005).

During the current study, each participant was allocated a number on a Microsoft Excel spreadsheet to ensure that all information obtained from the participants would be kept strictly confidential. No individual, aside from the data collectors, was aware of the identity of any of the participants. The raw data for this study had been securely stored at Malamulele Onward and was entered into an Excel file in a password protected computer by the current researcher.

3.3.4 Honesty with professional colleagues

Gass (2009) urges researchers to convey their findings in an honest, clear and unbiased manner. Misrepresentation or fabrication of results or the intentional misleading of others regarding the nature of results is not allowed under any circumstance. In this study, no deceptive procedures were used and the process of data collection was described to all participants in a truthful and accurate manner in the Caregiver Information Sheet. Furthermore, the analysis and results of this study are presented in an honest and precise fashion, avoiding plagiarism (see Declaration of Plagiarism).

3.4 Participants

3.4.1 Criteria for participant selection

Original study

In the original study, no sampling was conducted at the time of data collection. All children with a confirmed diagnosis of CP, and their primary caregivers, who were attending a CP clinic (namely, the Butterworth or Tafalofefe Hospitals or Nqamakwe Clinic) in the Mnquma sub-district of the Amathole health district in the Eastern Cape at the time of data collection were eligible to take part in the study. The following inclusion and exclusion criteria were followed in the purposive participant selection process:

Original inclusion criteria:

- The child must have had a confirmed diagnosis of CP, made by a medical doctor.
- He/she must have been 18 years and younger.
- The child must have received intervention at either the Butterworth or Tafalofefe Hospital or Nqamakwe Clinic at least twice during the six months preceding the

pre-intervention assessment of Period 1, to provide some proof of the caregiver's intent to adhere to intervention during the long-term study.

- He/she must have attended therapy with his/her primary caregiver.
- He/she must present with some form of feeding difficulty, as reported by the caregiver.

Original exclusion criteria:

- Children whose caregivers were unable to attend a five-day course of intervention.
- Children in poor health or who presented with acute infections (for example, children with upper respiratory tract or urinary tract infections, who would have been unable to tolerate five days of therapy).
- Children who experienced uncontrolled seizures.

Rehabilitation therapists in the Mquma health sub-district provided assistance in identifying caregivers and their children who complied with the inclusion criteria for participant selection in the original study. The children and caregivers were then invited to participate in the study.

Current study

In the current study, the following criteria were adhered to during the process of data cleaning.

Current inclusion criteria:

- All participants from the original study that had complete data sets over the 18-month period.

Current exclusion criteria:

- Participants from the original study that had incomplete data sets were excluded from the study.

A total of 61 children with CP and their caregivers participated in the original study over the 18-month period. Although no comparative population data are available, this number indicates a significant number of children presenting with CP in the sub-district. However, due to a significant number of incomplete and missing data collection instruments, the data sets of only 16 participants and their caregivers could be used in this study. Possible reasons for the limited number of complete data sets out of a potential 61 data sets include the following:

- The longitudinal study design meant that participants were required to attend six assessments over the 18-month period. This was in addition to attending the full five-day intervention blocks that occurred once a year over the 18-month period. A higher attrition rate can be expected when a study period is long. If a child participant missed only one assessment, that participant had to be excluded from the study.
- Eight participants joined the study at the beginning of Period 2, but could not be included in the study as they were not present during Period 1.
- Three participants passed away over the course of the 18-month study period.
- The treatment team phoned caregivers to remind them of follow-up appointments. However, the contact details of some of the caregivers changed over the course of the study period and the caregivers, therefore, could not be contacted.
- Some of the caregivers did not own cell phones and, in such cases, the treatment team attempted to contact the caregivers through the community members. The messages did not always reach the caregivers.
- Some child participants and/or their caregivers were ill at the time of the assessments and were, therefore, unable to attend the assessment sessions.

- Some caregiver participants were unable to bring their children on the day of the assessment as they had family responsibilities to attend to.
- Some caregiver participants and their children were away over the time of one or more of the assessments (for example, visiting relatives in the urban areas).

Participants who resided a significant distance from the Butterworth or Tafalofefe Hospitals or the Nqamakwe Clinic resided at the hospital or clinic over the five-day intervention period. Participants who resided close enough to the study sites travelled to the hospitals or clinic every day. In this case, the transport costs were paid by Malamulele Onward.

The 16 participants utilized in this study attended all the data collection sessions. The study reports on a total of ten intervention sessions and six assessment sessions. All participants resided in a rural area in the Eastern Cape Province. The child participant characteristics are presented in Table 2 and the caregiver participant characteristics are presented in Table 3.

3.4.2 Participant description

All the participants resided in the Eastern Cape Province in rural areas comprising villages or single homesteads.

Table 2 Participant description of the children with CP (n=16)

| Participant Description | | Frequency | Percentage (%) |
|--|--|-----------|----------------|
| Child's age | 1-3 years | 7 | 43.75 |
| | 4-6 years | 4 | 25 |
| | 7-9 years | 3 | 18.75 |
| | 10-12 years | 1 | 6.25 |
| | 13-15 years | 0 | 0 |
| | 16-18 years | 1 | 6.25 |
| Child's gender | Male | 10 | 62.5 |
| | Female | 6 | 37.5 |
| CP classification (as described by Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2009) | Spastic quadriplegia (moderate/severe) | 6 | 37.5 |

| | | | |
|--|--|---|-------|
| | Spastic hemiplegia | 2 | 12.5 |
| | Dystonic quadriplegia | 2 | 12.5 |
| | Ataxic | 1 | 6.25 |
| | Athetoid | 2 | 12.5 |
| | Mixed-dystonic athetoid | 2 | 12.5 |
| | Mixed-dystonic spastic quadriplegia | 1 | 6.25 |
| GMFCS (Gross Motor Function Classification System) level (as described by Palisano, Rosenbaum, Bartlett, & Livingston, 2007) | I (Walks without limitations) | 0 | 0 |
| | II (Walks with limitations) | 1 | 6.25 |
| | III (Walks using a hand-held mobility device) | 4 | 25 |
| | IV (Self-mobility with limitations) | 5 | 31.25 |
| | V (Transported in a manual wheelchair) | 6 | 37.5 |

* Mixed: a mixed CP classification refers to the child presenting with two types of CP

According to Table 2, the majority of the child participants were in the one to three years and four to six years age categories, therefore, in the pre-school years. Most of the children with CP were male which supports current statistics. The male-to-female ratio of individuals with CP is approximately 4:1 (Chounti, Hägglund, Wagner, & Westbom, 2013).

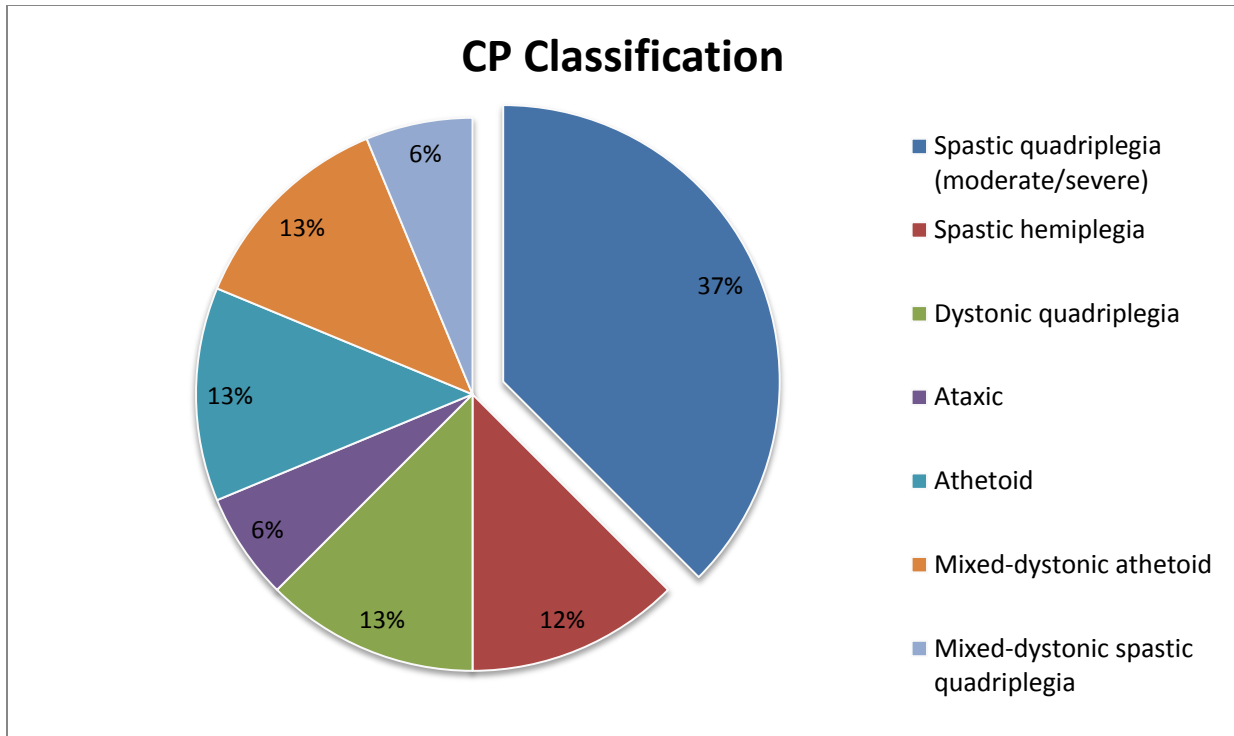


Figure 1 CP classification of child participants (n=16)

As depicted in Figure 1, the CP classification group with the highest number of children (37%) was the moderate/severe spastic quadriplegic category, with the least common classifications being ataxic CP and a mixed (dystonic spastic quadriplegia) subtype. This highlights the severity of the disorder that most of the children presented with. Van Toorn et al. (2007) conducted a study on children with CP in the Western Cape, South Africa. Their study indicated that the most commonly occurring subtype of CP was spastic quadriplegia (40%), which is a similar value to the percentage of children with spastic quadriplegia in the current study.

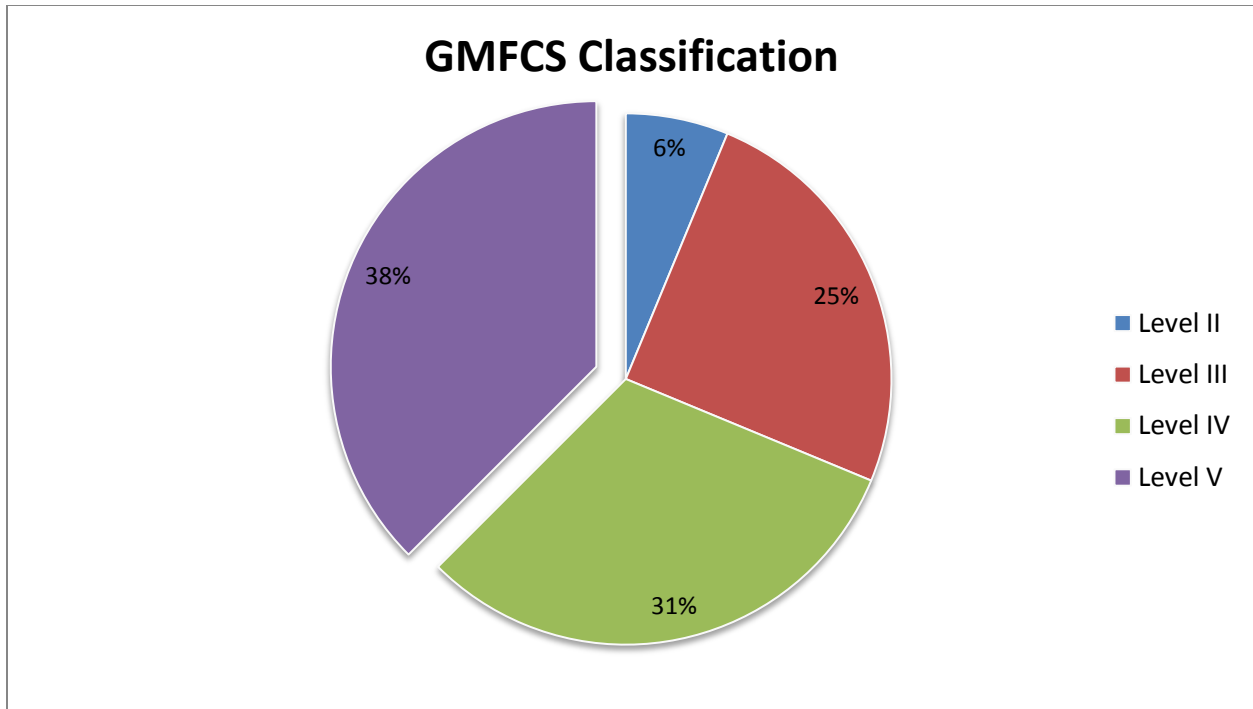


Figure 2 GMFCS classification of child participants (n=16)

As shown in Figure 2, the majority of the children were functioning on the GMFCS Level V (transported in a manual wheelchair) (38%), with the second most common level being Level IV (self-mobility with limitations). This demonstrates that the majority of the children were classified according to the two most dependent levels in terms of motor function, once again highlighting the severity of CP with which the children presented.

Table 3 Participant description of the caregivers of the children with CP (n=16)

| Participant Description | | Frequency | Percentage (%) |
|-------------------------------------|------------------------------|-----------|----------------|
| Person interviewed | Mother | 11 | 68.75 |
| | Grandmother | 5 | 31.25 |
| Responsible for child's care | All the time (night and day) | 15 | 93.75 |
| | Day only | 0 | 0 |
| | After school | 1 | 6.25 |
| Caregiver's age | 20-30 years | 5 | 31.25 |
| | 31-40 years | 4 | 25 |
| | 41-50 years | 4 | 25 |
| | 51-60 years | 1 | 6.25 |
| | >60 years | 1 | 6.25 |
| | Unknown | 1 | 6.25 |

| | | | |
|---|--------------------------------|----|-------|
| Caregiver's current marital status | Married | 7 | 43.75 |
| | Living together | 1 | 6.25 |
| | Divorced | 0 | 0 |
| | Separated | 1 | 6.25 |
| | Widowed | 1 | 6.25 |
| | Never married | 6 | 37.5 |
| Attended school | Yes | 15 | 93.75 |
| | No | 1 | 6.25 |
| Highest grade completed | Grade 1-3 | 0 | 0 |
| | Grade 4-7 | 4 | 25 |
| | Grade 8-9 | 6 | 37.5 |
| | Grade 10-12 | 5 | 31.25 |
| | Not applicable | 1 | 6.25 |
| Employment status | Full-time | 2 | 12.5 |
| | Part-time | 0 | 0 |
| | Piece jobs | 1 | 6.25 |
| | Unemployed | 13 | 81.25 |
| Source of income | Regular income from working | 1 | 6.25 |
| | Occasional income from working | 3 | 18.75 |
| | Pension | 6 | 37.5 |
| | Child support grant | 1 | 6.25 |
| | Care dependency grant | 4 | 25 |
| | Selling sweets and vegetables | 1 | 6.25 |

According to Table 3, the majority of the caregivers that participated in the current study were mothers of the children with CP (68.75%), while 31.25% were the children's grandmothers. In addition, most of the caregivers were responsible for the full-time care of their child with CP (93.75%). Only one of the caregivers was only responsible for the child's care after school. This was beneficial to the study as caregivers (who were mostly mothers in the current study) are the individuals that spend the most time with the children and who are most familiar with the children's strengths and difficulties (Hanna & Roger, 2002). Table 3 indicates that the majority of the caregivers were 20 to 30 years old (32%) when the study was conducted, while only two of the caregivers, presumably grandmothers of the children, were 51 years and older. All of the caregiver participants, but one, had received some form of schooling. However, only five participants (31.25%) had received schooling beyond Grade 9. The following participant characteristics will be interpreted further: caregiver's current marital status (see Figure 3) and employment status (see Figure 4).

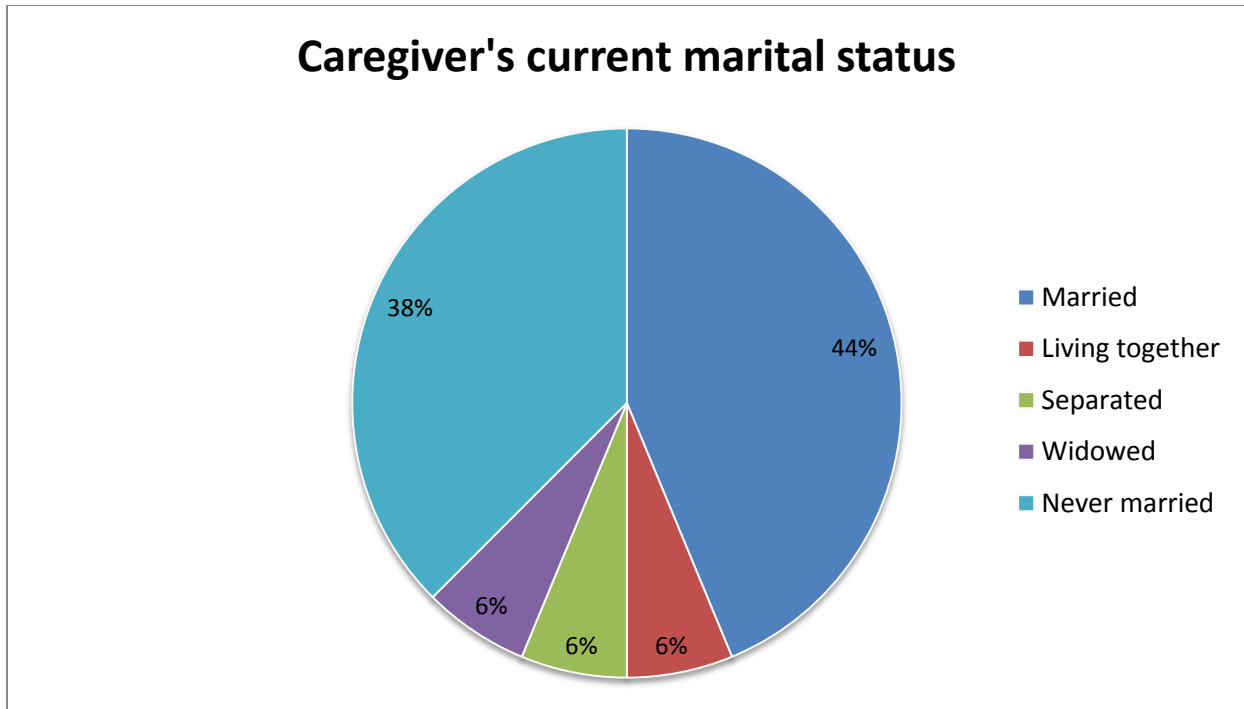


Figure 3 Current marital status of caregiver participants (n=16)

According to Figure 3, eight (50%) of the caregivers were married or living with a partner. The remaining eight (50%) participants had never been married, were separated or widowed. This needs to be considered in light of the high rate of unemployment amongst the caregiver participants (see Figure 4). It would not be unusual if the women who were married were also unemployed, as it is likely their husbands were the breadwinners of the family. However, with 13 caregivers (81%) being unemployed, among those caregivers had to also be those who were single. The financial, physical and emotional burden on these single caregivers would have been significant.

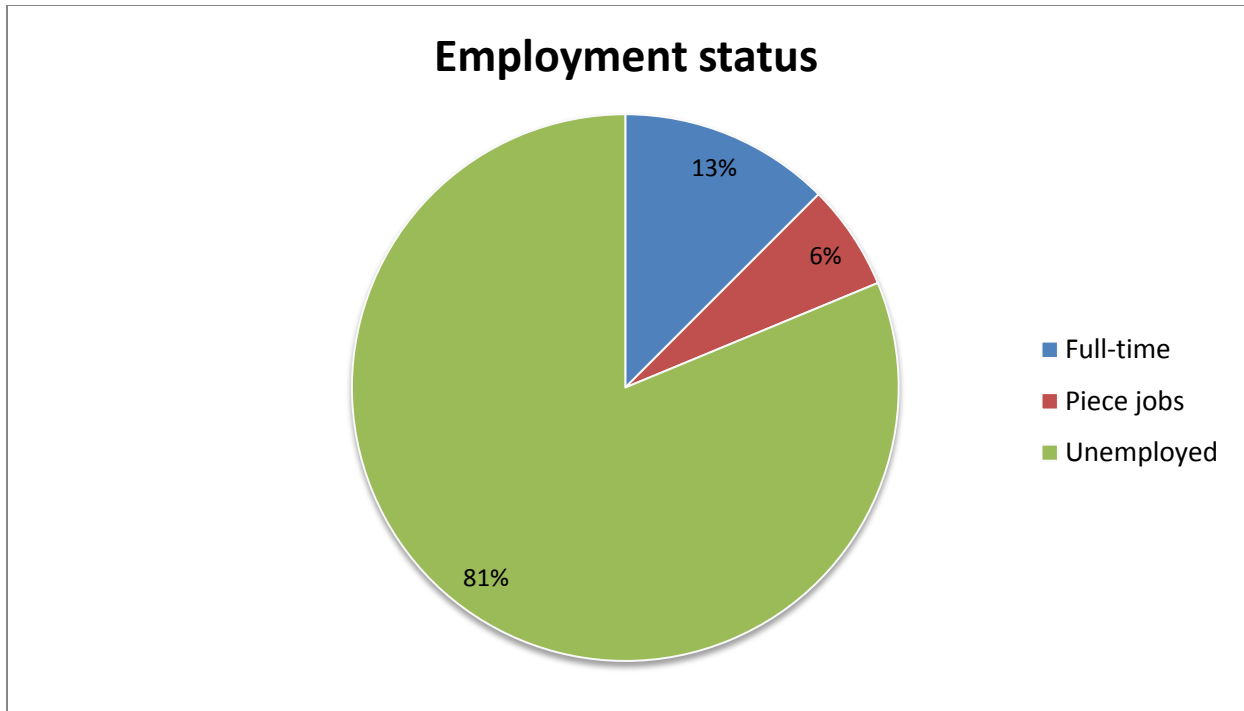


Figure 4 Employment status of caregiver participants (n=16)

Figure 4 shows that the majority of the caregiver participants were unemployed (81%). As eight (50%) of the caregivers were never married, had been separated or widowed, it needs to be considered that many of the single parents/caregivers were providing for their children with pensions, care dependency grants and support grants. The high rate of unemployment and low income level of the caregiver participants highlights the poverty experienced by the caregivers. Recent statistics show that 55.2% of rural households in South Africa are living in poverty (www.statssa.gov.za). Levin (2006) states that the primary responsibility of caring for children with CP befalls women, many of whom are not employed, have not been educated and, as a result thereof, are unable to read or write. The low literacy levels of women in rural areas is demonstrated in the current study, in that only five of the caregiver participants had received schooling beyond Grade 9.

3.4.3 Study sites for original data collection

Study sites included hospitals and clinics in the Mquma sub-district of the Amathole health district that provided a CP clinic, namely, Butterworth Hospital, Tafalofefe Hospital and Nqamakwe Clinic.

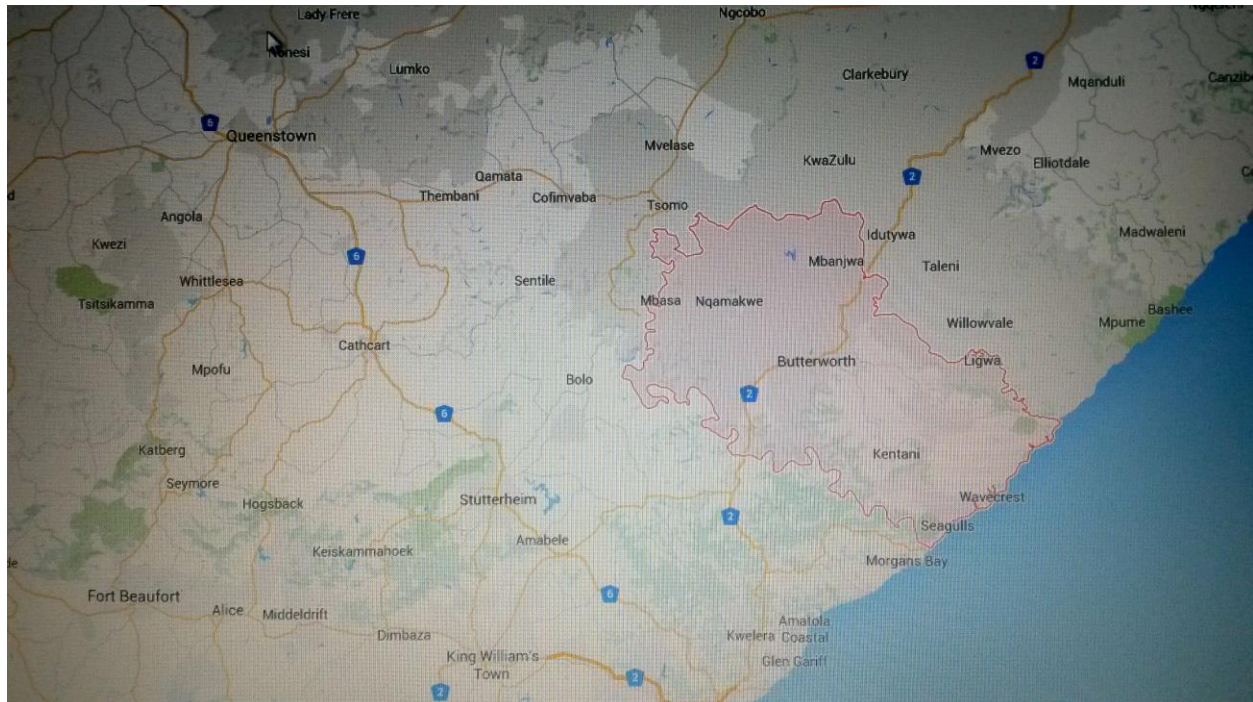


Figure 5 Map depicting the Mquma sub-district of the Amathole district in the Eastern Cape (Source: Google Maps)

According to Statistics South Africa (www.statssa.gov.za), the Mquma sub-district in rural Eastern Cape is approximately 32 995 240 square kilometers in size and mainly consists of small, traditional homesteads situated on the hillsides. Butterworth is the largest town in this area and contains two hospitals, namely Butterworth Hospital and Tafalofefe Hospital. Nqamakwe clinic is located in the small town of Nqamakwe which is 25.3km from Butterworth.

The Butterworth and Tafalofefe Hospitals are the only two hospitals in the Mquma sub-district of Amathole. Butterworth Hospital houses 350 beds and serves the rural

Amathole population of 286 000 people. Tafalofefe Hospital is the smaller hospital of the two, providing 280 beds.

This particular district was selected for this study due to its already established monthly CP clinics as well as the large number of children attending these clinics (www.malamuleleonward.org).

3.5 Materials used for data collection

Original study

- The fieldworkers from Malamulele Onward acquired informed consent via the following: Caregiver Information Sheet in English and isiXhosa (see Appendices D and E), Written and Verbal Caregiver Informed Consent Forms (see Appendices F and G), and Written and Verbal Informed Assent Forms for children (see Appendices H and I).
- A translated version of The Pediatric Evaluation of Disability Inventory (PEDI) (Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992) (see Appendix K). The PEDI assesses caregiver reports of the child's mobility, self-care (including feeding) and social function. The questionnaire is completed by means of caregiver interview and has been shown to be sensitive to changes following intervention.
- A Feeding Profile (see Appendices L and M), based on a translated version of the Multidisciplinary Feeding Profile (Kenny et al. 1989) as well as the ICF and the work of Gisel and Patrick (1988) was developed specifically for this study. The Feeding Profile sought information on difficulties the child experiences during feeding, self-feeding skills, food textures tolerated by the child, average length of mealtimes and types of food consumed by the child.
- Anthropometric measurements of each child participant were also collected using standardized methods as described by Palisano et al. (1997). Table 4 shows the measures included:

Table 4 Anthropometric measurements and instruments used in original study

| Measurement | Accuracy | Procedure and instruments used |
|---|---|---|
| 1) Child's weight (kg) | Measured to the nearest 0.1kg. | Electric load cell scale (UC-321 from Masskott Scales) |
| 2) Child's length/ height (cm) | Measured to the nearest 0.1cm. | Measured using a measuring board, either standing or recumbent depending on the child. |
| 3) Child's half-span (cm) | Measured from the tip of the middle finger to the mid-sternal notch (to the nearest 0.1cm). | A metal tape was used while the children were lying on their backs with their left arms extended to 90 degrees. |
| 4) Child's tibial length (cm) | Knee-heel length measured to the nearest 0.1cm. | A metal tape was used while the children were lying on their backs. |
| 5) Child's mid-upper arm circumference (MUAC) (cm) | Recorded to the nearest 0.1cm. | Measurements were made with the child in sitting position. The left arm was used for all measurements unless he/she had a left hemiplegia or paralysis. |
| 6) Child's triceps skinfold thickness (mm) | Recorded to the nearest 0.1mm | Skinfold thickness caliper. |

The half-span and tibial length measurements were used as proxies for the length/height measurement of children who were unable to stand as a result of contractures.

- The Gross Motor Function Measure (GMFM) (Russell et al., 1989, 1993).
- The Parent Questionnaire (Knox and Evans, 2002).
- Family Support Scale (FSS).
- Parenting Stress Index (PSI).
- Mental Health sub-scale of the SF20.

Current study

- Data specifically pertaining to feeding and dysphagia were extracted from the comprehensive PEDI (Haley et al., 1992). Only questions 1 to 14 were used in the current study as these are the only questions that refer to feeding performance of

the child. The remaining questions of the PEDI were not applicable to the current study. Table 5 presents the questions from the PEDI that were used in the current study.

Table 5 Questions extracted from the PEDI for the purposes of this study

| Question number | Question | Category Feeding performance |
|-----------------|--------------------------------------|--|
| 1 | Eats pureed/blended/strained foods | Food textures |
| 2 | Eats ground/ lumpy foods | Food textures |
| 3 | Eats cut up/chunky foods | Food textures |
| 4 | Eats all textures | Food textures |
| 5 | Finger feeds | Use of utensils |
| 6 | Scoops with spoon, bring to mouth | Use of utensils |
| 7 | Uses a spoon well | Use of utensils |
| 8 | Uses a fork well | Use of utensils |
| 9 | Uses a knife to cut food | Use of utensils |
| 10 | Holds bottle or cup | Use of drinking containers |
| 11 | Lifts cup to drink (cup may tip) | Use of drinking containers |
| 12 | Lifts open cup securely with 2 hands | Use of drinking containers |
| 13 | Lifts open cup securely with 1 hand | Use of drinking containers |
| 14 | Pours liquid from a carton or bottle | Use of drinking containers |

- Data were also extracted from the Feeding Profile (see Appendices L and M). Only questions that were relevant to the current study were used, namely questions 1 to 3 (see Table 6). These questions examined whether or not the caregivers were aware of and concerned about their children's feeding difficulties and weight. The current researcher recognizes that the terms 'feeding' and 'eating' cannot be used synonymously, as 'eating' refers to the taking in of food, whereas 'feeding' refers to the process involved in the taking in of food (Oxford Dictionaries online, n.d.).

However, due to the low literacy levels and limited schooling of the majority of the caregiver participants, the terms ‘eating’ and ‘drinking’ were used as they were the more understandable and accepted terms amongst the participants. During the interview, the interviewer explained to the caregiver participants that the terms ‘eating’ and ‘drinking’ may refer to any feeding difficulties experienced by their children. Thus, the caregiver participants’ awareness of and concern about their children’s eating and drinking was classified as their awareness of and concern about their children’s feeding difficulties, for the purposes of this study.

Table 6 Questions extracted from the Feeding Profile for the purposes of this study

| Question number | Question | Category |
|-----------------|---|---|
| 1 | My child has difficulty eating & drinking | Caregiver awareness of child’s feeding difficulties |
| 2 | I am worried about my child’s eating & drinking | Caregiver concerns about child’s feeding difficulties |
| 3 | I am concerned that my child is underweight | Caregiver concerns about child’s weight |

- Anthropometric measurements of the child participants were collected using standardized methods as described by Palisano et al. (1997) (see Table 4). Half-span and tibial length measurements were also calculated to use as proxies for length/height in children of whom accurate length/height measurements could not be obtained due to contractures of their limbs. Yousafzai, Filteau, Wirz and Cole (2003) found that armspan (half-span x 2), arm length and tibia length could be used to obtain an accurate height measurement in children with a physical disability.

3.6 Procedures

3.6.1 Data collection and recording

Original Study

Data were collected by the Malamulele Onward researchers and fieldworkers using the same participants over an 18-month period (August 2007 to January 2009).

In the first period (Period 1) and second period (Period 2) of data collection, pre-intervention, post-intervention and follow-up data were collected. Follow-up data were collected three months after intervention was provided. During the 7-month period between the follow-up assessment of Period 1 and the pre-intervention assessment of Period 2, no intervention or food supplementation was provided. As indicated in Table 1, no data were collected for the Feeding Profile during the post-intervention assessment of Period 1. Anthropometric data were also not collected for the post-intervention assessments of Period 1 and 2. The original researcher deemed it unnecessary to collect anthropometric data and data pertaining to caregiver concerns about feeding difficulties and weight (Feeding Profile) directly after intervention due to the short period of time between the collection of pre-intervention and post-intervention data. However, in Period 2, the original researcher concluded that data should be collected post-intervention for the Feeding Profile.

During the intervention blocks, each child participant received daily 90 minute long NDT sessions for a period of five consecutive days. The NDT approach is an active approach that focuses on the child with CP as a whole. Intervention involves constraint or enablement of posture and the process of moving is used in order to help the child attain certain outcomes (Kim et al., 2016). Speech-language therapy, physiotherapy and occupational therapy professionals together proposed that the intervention of a child with CP would be most effective if the aim of intervention is to assist the child in becoming as functional as possible and to develop the child's skills to the maximum (Workinger, 2005).

The two five-day intervention blocks were carried out by volunteer therapists (physiotherapists, occupational therapists and speech-language therapists) who were trained in NDT and who had a minimum of two years' experience in working with children with CP. The intervention blocks were led by the primary researcher who acted as team leader and who was responsible for overseeing the quality of the service provided. To ensure that the participants received the best possible course of treatment over the five consecutive days, the following procedures were followed:

- The intervention team was provided with a written outline of the proposed procedure for the intervention block from the assessment carried out previously on each participant, during the weeks preceding intervention.
- Each child was assigned a treating therapy team, consisting of two therapists (of different disciplines) who were chosen according to the main goals identified for the child. The treating teams were expected to practice transdisciplinary skills in order to achieve the intervention goals.
- As a transdisciplinary approach is based on the premise that one person may perform various professional roles by providing services under the supervision of other therapists from the other disciplines involved (King et al., 2009), specific disciplines were assigned, where possible, as follows:
 - Children with specific feeding and communication deficits were assigned a speech-language therapist;
 - Children with specific upper limb and fine motor deficits were assigned an occupational therapist;
 - Children with specific sensory issues or visual deficits were assigned an occupational therapist; and
 - All the children were assigned a physiotherapist.
- Each treating team was provided with a summary of each child's intervention goals for the week, the day before the intervention block began.
- A full team introduction and short training was conducted at the beginning of the week in order to:

- Introduce all team members – therapists, other volunteers and interpreters;
 - Outline the proceedings for the week;
 - Establish a high standard of work ethic amongst team members; and
 - Familiarize the team with the available equipment, materials and resources.
- Daily team meetings were held at the end of each day in order to discuss cases, problem solve difficulties and assist where required.
 - The team leader and identified senior therapists were available for specific periods during each day to mentor and assist younger therapists as required.

All participants were requested to attend the Butterworth Hospital or Tafalofefe Hospital two months after the pre-intervention assessment for daily NDT sessions. Each of the children was allocated two NDT trained therapists; a physiotherapist, and either an occupational therapist or speech-language therapist, depending on the children's individual primary goals. At the beginning of the intervention block, the treating therapists were asked to set a minimum of three short-term goals in agreement with the caregiver and taking into account the primary problems identified by the team leader. The short-term treatment goals are listed in Appendix N. Typically each NDT treatment session consisted of an analysis of each child's occupational performance and movement abilities pertaining to the identified areas of impairment, the agreed short-term goals and their participation in daily living activities. Thereafter, the child was positioned appropriately and received hands-on treatment and facilitation in order to participate more effectively in the individually chosen functional activities. During the intervention, each child participant was fitted for and received an appropriate piece of adaptive equipment that was individually chosen or designed to facilitate normal movement and participation in their occupational performance activities. The treating therapists, who were assisted by local community service therapists and mid-level rehabilitation workers who assisted with interpretation, were responsible for the design, fitting and use of the adaptive equipment. Most of the adaptation and fitting of

equipment was performed by the local community service therapists when the children were not receiving intervention.

Caregiver training was specific to the goals identified for their child. Caregivers were present throughout the therapy sessions during which they were trained to assist their children more effectively, and in the use and maintenance of the adaptive equipment, by the treating therapists (with the assistance of midlevel rehabilitation workers and volunteer community service therapists where necessary). During the week, caregivers were encouraged to practise the skills they had learned with their children, outside the therapy environment. These practice sessions were supervised by volunteer community service therapists. As a result, by the end of the five-day intervention block, each caregiver had been trained to continue a program of suggested activities at home and had been instructed in the use and care of their equipment. Each caregiver was issued with a basic set of pictures as a reminder of home-based activities that could be repeated following the intervention. Pictures were used instead of written instructions to accommodate those caregivers with low literacy skills.

The PEDI, Feeding Profile, Parent Questionnaire, Mental Health sub-scale of the SF20, FSS as well as the PSI were completed by interview (as previously indicated, not all data collection instruments were used in the current study). Each interview was conducted by a team of trained interviewers, some of whom were also the mothers of children with CP, thereby increasing their familiarity with the topics in the questionnaires. The interviewers were all literate and able to speak English and isiXhosa fluently (Saloojee, 2007).

The GMFM was conducted by four assessors (two teams of two assessors) who were not involved in the treatment phase. The assessors were physiotherapists who had already received training and practice in the use of the GMFM. Each team of assessors was assisted by a mid-level rehabilitation worker who acted as an interpreter (Saloojee, 2007).

The process of obtaining anthropometric measurements of the child participants was carried out by a single physiotherapist trained in anthropometry. Each measurement was taken three times and an average calculated in order to ensure reliability of the results (Saloojee, 2007).

Each assessment and interview was conducted before the five-day intervention block, directly after the intervention block and three months post-intervention. The same interviewers and physiotherapists were utilized throughout the 18 months of the study, thus ensuring consistency in data collection.

Participants who resided a significant distance from the Butterworth or Tafalofefe Hospitals or the Nqamakwe Clinic resided at the hospital or clinic over the five-day intervention period. Participants who resided close enough to the study sites travelled to the hospitals or clinic every day. In this case, the transport costs were paid by Malamulele Onward. It was not possible for the hospitals to provide rooms for the participants, or for Malamulele Onward to pay transport costs in order to conduct more frequent intervention blocks or one long intervention block. For this reason, only two five-day intervention blocks were selected for the purposes of the study.

Current Study

The current researcher extracted the portion of data from the PEDI, Feeding Profile and anthropometry that had already been entered into Microsoft Excel spreadsheets in order to provide sufficient data to achieve the aims of the study. Any outstanding raw data was then entered into the relevant spreadsheets and data cleaning commenced. This involved determining the reason for missing data values and completing where data values were available. Only participants with complete data sets for each assessment over the 18-month period were utilized in the current study.

3.6.2 Data processing and analyzing

Current study

With regard to the anthropometry of the child participants, three measurements were taken for each anthropometric factor (weight, length/height, MUAC and triceps skinfold thickness). An average of the three was then calculated in order to obtain the most accurate value. The z-score classification system, recommended by the World Health Organization (WHO), describes the nutritional status of a child. The calculation of z-scores (weight-for-age, height-for-age and weight-for height) for the child participants in the current study was attempted. However, when using the anthropometric calculator, z-scores appear as not available (NA) if a child's age is above 60 completed months (WHO, 2011). In the current study, 8 of the 16 participants were older than 60 months. Therefore, z-scores were not calculated for the participants.

One of the 16 participants presented with contractures making it impossible to obtain an accurate length/height measurement for the participant. Correlation analysis was performed in order to determine whether the tibial length or half-span measurement would serve as the most accurate proxy for length/height. According to Leedy and Ormrod (2014), correlation analysis is performed when it is necessary to determine whether there is some form of association between two or more variables. In this study, the degree of association between length/height and tibial length and between length/height and half-span was determined and compared. On average, the tibial length measurement produced a higher correlation coefficient than the half-span measurement. Based on these results, a regression equation ($Y = a + bX$, where Y = average length/height and X = average tibial length) was used to estimate the missing values for the participant that presented with contractures, thus resulting in the inability to obtain an accurate average length/height measurement. Regression is a parametric statistical test which allows one to determine how well one or multiple variables are able to predict the value of another (Leedy & Ormrod, 2014). The following regression equations were used for each assessment:

Period 1 (Assessment 1): $Y = 23,072 + 3,828X$

Period 1 (Assessment 3): $Y = 26,944 + 3,417X$

Period 2 (Assessment 1): $Y = 22,110 + 4,021X$

Period 2 (Assessment 3): $Y = 26,113 + 3,690X$

Y = average length/height X = average tibial length

Figure 6 Regression equations for Period 1 and 2

With regard to the PEDI, a score of 1 was allocated if the caregiver indicated their child was “capable” of performing the feeding skill stated in the question and 0 if their child was “unable” to perform the skill. To obtain an indication of the caregivers’ awareness of and concerns about their children’s feeding difficulties and weight, caregivers’ responses received a score of 1 if they indicated that they were aware of and concerned about their child’s feeding difficulties and weight, and a score of 0 if they were not concerned.

Raw data from the two data collection instruments as well as the anthropometric data, which were collected over a period of 18 months, were entered into a Microsoft Excel spreadsheet as frequencies. The data from the participants with complete data sets (n=16) were then transferred into the SPSS (Statistical Package for the Social Sciences, Version 22) program for analyzing purposes.

Using the SPSS program, descriptive statistics including the mean, median and standard deviation were calculated for each anthropometric measurement for Period 1 [assessment 1 and 3] and Period 2 [assessment 1 and 3]. In order to determine the p-value (level of significance) between Period 1 [pre-intervention] and Period 1 [follow-up] and between Period 1 [pre-intervention] and Period 2 [follow-up], the t-test was used. The t-test evaluates the means of two groups and determines whether there is a statistically significant difference between them (Trochim, 2006). In the case of the current study, the same group was compared to itself over time. Although it is not often used as a means of evaluating the differences between groups of a small sample size,

a study conducted by De Winter (2013) found that the t-test was an appropriate test to use in the case of a small sample size.

Proportional testing was used in order to determine the percentage of child participants able to perform a particular feeding skill (measured by the questions extracted from the PEDI) over Periods 1 and 2. The absolute difference (%) refers to the difference between the values of two random variables (www.stats.oecd.org). In this case, the difference between the percentage of participants able to perform a specific feeding skill in Period 1 [pre-intervention] and Period 1 [follow-up] as well as the difference between the percentage of participants able to perform a specific feeding skill between Period 1 [pre-intervention] and Period 2 [follow-up]. A critical value was then obtained for the differences between Period 1 [pre-intervention] and Period 1 [follow-up] and between Period 1 [pre-intervention] and Period 2 [follow-up] in terms of reported feeding performance. In hypothesis testing, a critical value is a position on the test distribution that is contrasted to the test statistic in order to decide whether to reject the null hypothesis. If the absolute value of the test statistic is larger than the critical value, statistical significance is confirmed and the null hypothesis is, therefore, rejected (Minitab, 2016).

Variables

Quantitative variables were used in this study. The variables were recorded in the *demographics questionnaire* provided to each caregiver (verbally or in writing) at the start of data collection. The child participant characteristics obtained from the demographic information included the gender, age and CP classification of the participants as well as the GMFCS level the participants were functioning on. The caregiver participant characteristics obtained from the demographic information included the age, marital status, level of education achieved, employment status and source of income of the primary caregiver.

Quantitative variables were examined in the PEDI (eats pureed/blended/strained foods, eats ground/lumpy foods, eats cut up/chunky foods, eats all food textures, finger feeds,

scoops with spoon (brings to mouth), uses a spoon well, uses a fork well, uses a knife to cut food, holds bottle or cup, lifts cup to drink (cup may tip), lifts open cup securely with two hands, lifts open cup securely with one hand, and pours liquid from a carton or bottle). They were also examined in the Feeding Profile (caregiver awareness of child's feeding difficulties, caregiver concerns about child's feeding difficulties and caregiver concerns about child's weight), as well as the anthropometric measurements (weight, length/height, MUAC and triceps skinfold thickness) taken of each child participant.

3.7 Reliability, validity and trustworthiness

According to Leedy and Ormrod (2014), reliability is the consistency with which a measuring tool produces a particular, constant result when the entity being measured has not altered. The PEDI (Haley et al., 1992) is a standardized assessment tool that was tested for reliability in a study conducted by Nichols and Case-Smith (1996). Their results found the PEDI to be a reliable and valid assessment of functional performance in children with disabilities. For the purposes of this study, the PEDI was translated into isiXhosa by a trained translator. Although the translation detracts somewhat from the reliability and validity of the assessment tool, it would have been impossible to conduct the interviews in a language unfamiliar to the participants of the study.

Both the PEDI and the Feeding Profile rely on caregiver responses to questions posed to them in a face-to-face interview. Participants may have been more honest in their responses to the questionnaires if they had completed them themselves and not been required to answer the questions in an interview (Leedy & Ormrod, 2014). Although the reliability of the data would have been increased in the case of self-completed questionnaires, this was not an option in the study as many of the caregivers presented with low literacy skills.

The anthropometric measurements of the child participants were taken by the same physiotherapist each time. This physiotherapist had received training in anthropometry. These measurements were objective, thus adding to the internal validity of the data.

Three scores were obtained for each measurement and an average score was calculated. This increased the reliability of the measurements obtained.

Chapter 4

RESULTS

The aim of this chapter is to present the results according to the sub-aims of the study. This includes statistical analysis of the anthropometric measurements obtained from each child participant as well as analysis of the raw data obtained from the PEDI (on caregiver reports of their children's feeding performance) and the Feeding Profile (on caregiver awareness of and concerns about their children's feeding difficulties and weight).

4.1 Introduction

The main aims of this study were to determine if there was a change in the anthropometric measurements and feeding performance (as reported by caregivers) in children with CP over 18 months, following NDT feeding intervention and caregiver training, and if there was a change in the caregivers' awareness of and concerns about their children's feeding difficulties and weight over the specific time period in a rural South African community.

The ages of the child participants ranged from one to 18 years with the majority of the participants being in the one to three years and four to six years age categories (see Table 2). The CP classification group with the highest number of child participants (37.5%) was the moderate/severe spastic quadriplegic subtype. This highlights the severity of the disorder that most of the child participants presented with. The most common GMFCS level according to which the child participants were categorized was level V (transported in a manual wheelchair), with the second most common level being level IV (self-mobility with limitations). This demonstrates that the majority of the

child participants were classified within the two most dependent levels in terms of motor function, once again highlighting the severity of CP that the child participants presented with.

The majority of the caregiver participants were 20 to 30 years old (32%) when the study was conducted, while only two of the caregiver participants, presumably grandmothers of the children, were 51 years and older (see Table 3). All of the caregiver participants, but one, had received some form of schooling. However, only five participants (31.25%) had received schooling beyond Grade 9. Half of the caregiver participants were single and 13 (81%) of the participants were unemployed. The results are presented in relation to the sub-aims of this study.

4.2 Results

Figure 7 depicts the periods and assessments (A1, A2, and A3) that will be referred to in the presentation of the results:

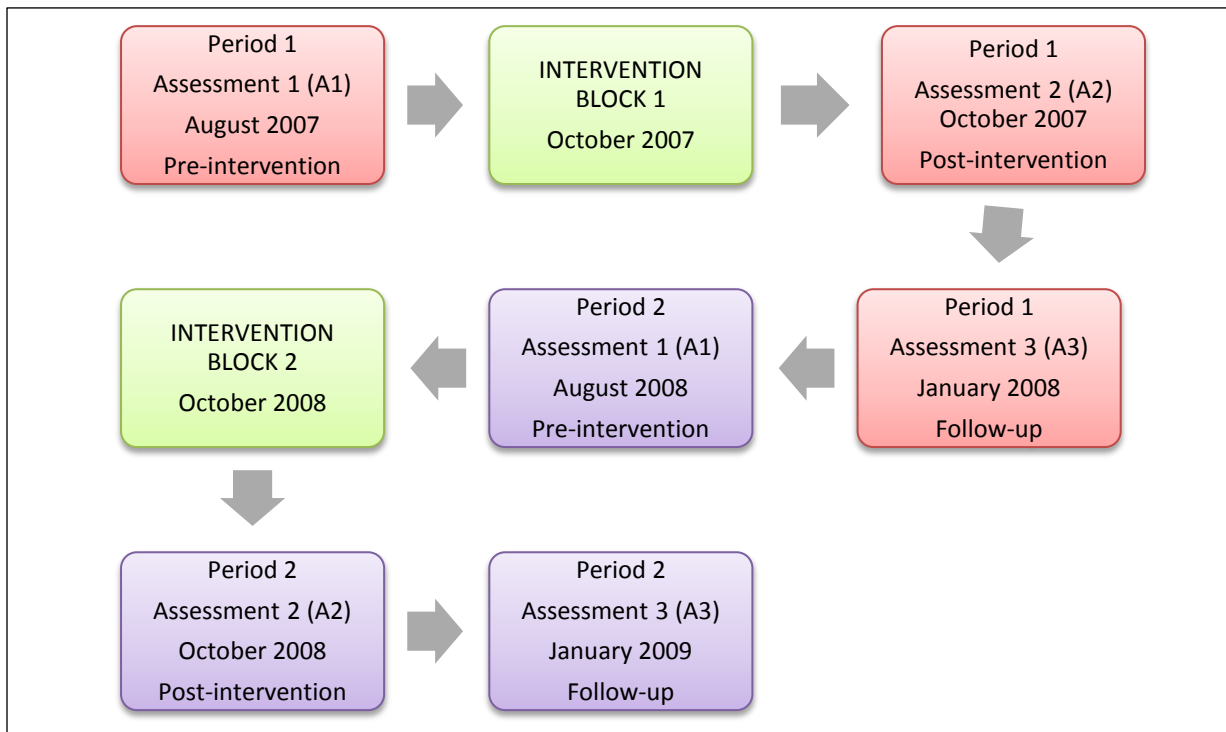


Figure 7 Data collection periods and individual assessments over the 18-month period

4.2.1 The anthropometric measurements of the child participants with CP over time following NDT feeding intervention and caregiver training

With regard to the anthropometric measurements, data was not collected in Period 1 [post-intervention] and Period 2 [post-intervention] as the original researcher deemed it unnecessary as the time between pre- and post-intervention data collection was short and minimal or no change in the measurements was expected (see Table 1). The results are presented in Tables 7, 8 and 9 and Figures 8 to 11. The tibial length and half-span measurements obtained from the child participants are not reported on in the results as they were used primarily as proxies to obtain a predicted length/height measurement for the child participant who presented with contractures. The average length/height (predicted) measurements indicated in Tables 7, 8 and 9 are the length/height measurements obtained through using the tibial length measurement as a proxy.

As the age range of the child participants was so wide (one to 18 years), it was not possible to compare the mean anthropometric measurements of the group of child participants to those of their typically developing peers. The results will, therefore, be presented solely in terms of change over time in the anthropometric measurements of the group of child participants.

Table 7 Significance between average anthropometric measurements of the child participants from Period 1 [pre-intervention] to Period 1 [follow-up] and from Period 1 [pre-intervention] to Period 2 [follow-up] (n=16)

| Anthropometric measurements | Period 1 [pre-intervention] to Period 1 [follow-up] | | Period 1 [pre-intervention] to Period 2 [follow-up] | |
|--|---|---------------------------------|---|---------------------------------|
| | Significance (2-tailed) (p-value) | Significant difference (Yes/No) | Significance (2-tailed) (p-value) | Significant difference (Yes/No) |
| Average weight (kg) | 0.013 | Yes | 0.001 | Yes |
| Average length/height (predicted) (cm) | 0.167 | No | 0.000 | Yes |
| Average mid-upper arm circumference (MUAC) (cm) | 0.323 | No | 0.014 | Yes |
| Average triceps skinfold thickness (mm) | 0.064 | No | 0.074 | No |

If $p < 0.05$, then differences are significant

Table 7 indicates whether there was a significant change ($p < 0.05$) in the average anthropometric measurements of the group of child participants from Period 1 [pre-intervention] to Period 1 [follow-up] as well as from Period 1 [pre-intervention] to Period 2 [follow-up].

Table 8 Anthropometric measurements of child participants for Period 1 (n=16)

| Measurements | Pre-intervention (A1) (August 2007) | | | Follow-up (A3) (January 2008) | | |
|--|--|----------|--------------------|----------------------------------|---------|--------------------|
| | Mean | Median | Standard deviation | Mean | Median | Standard deviation |
| Average weight (kg) | 16.0117 | 15.5250 | 3.99719 | 16.5967 | 16.0333 | 3.92619 |
| Average length/height (predicted) (cm) | 101.9195 | 100.5877 | 15.23647 | 103.3930 | 98.3599 | 14.42724 |
| Average MUAC (cm) | 17.4667 | 17.7667 | 1.64839 | 17.2313 | 17.4000 | 1.36009 |
| Average triceps skinfold thickness (mm) | 7.7083 | 7.3333 | 3.03346 | 6.6604 | 5.8000 | 2.34714 |

Table 9 Anthropometric measurements of child participants for Period 2 (n=16)

| Measurements | Pre-intervention (A1) (August 2008) | | | Follow-up (A3) (January 2009) | | |
|--|--|----------|--------------------|----------------------------------|----------|--------------------|
| | Mean | Median | Standard deviation | Mean | Median | Standard deviation |
| Average weight (kg) | 17.8656 | 17.0667 | 4.67251 | 18.3313 | 17.8083 | 5.10047 |
| Average length/height (predicted) (cm) | 106.5115 | 105.0202 | 14.67194 | 106.7367 | 105.1453 | 13.51944 |
| Average MUAC (cm) | 17.9167 | 17.6000 | 1.87122 | 18.2625 | 18.0833 | 2.11548 |
| Average triceps skinfold thickness (mm) | 7.4021 | 6.5833 | 2.77335 | 8.6371 | 7.8467 | 3.68235 |

Tables 8 and 9 depict the descriptive statistics regarding the average anthropometric measurements of the group of child participants for Period 1 and 2. Table 8 presents the change in the child participants' anthropometric measurements between Period 1 [pre-intervention] and Period 1 [follow-up], while Table 9 presents the change in the participants' anthropometric measurements between Period 2 [pre-intervention] and Period 2 [follow-up]. The change in the mean value of each anthropometric measurement will be presented and described individually.

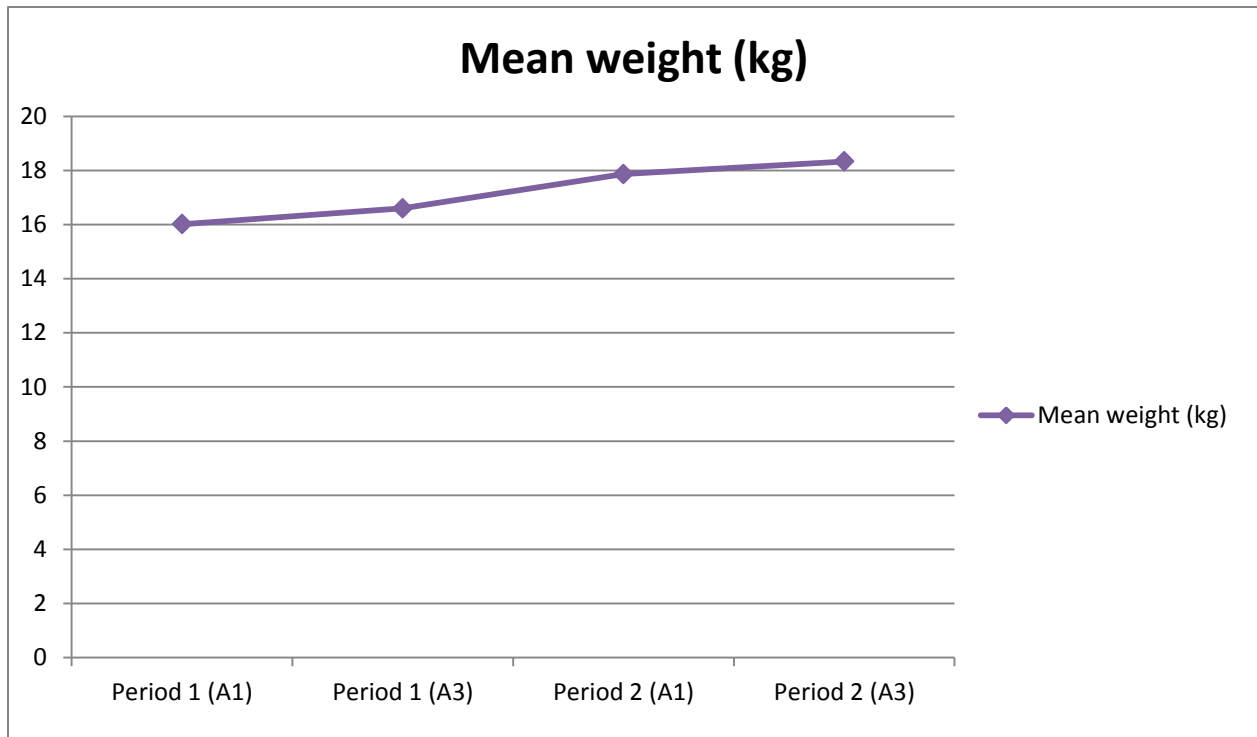


Figure 8 Mean weight (kg) of child participants over an 18-month period (n=16)

Table 7 indicates a significant difference in the average weight of the child participants between Period 1 [pre-intervention] and Period 1 [follow-up] as well as between Period 1 [pre-intervention] and Period 2 [follow-up]. According to Figure 8, the child participants gained an average of 2.32kg over the 18-month period, with the most notable increase in weight occurring between Period 1 [follow-up] and Period 2 [pre-intervention]. This can be expected due to the longer period of time (seven months) between these two assessment periods. However, it should also be noted that intervention did not take place between Period 1 [follow-up] and Period 2 [pre-intervention] and that neither food parcels nor feeding supplements were provided during this period. Despite no intervention and supplementation of food during this period of time, there was a significant increase in the child participants' weight. As the age of the child participants ranges from one to 18 years, it was not possible to calculate the expected natural weight increase for the group. Although there was a significant increase in the average weight of the group over the 18-month period, it is not possible to say how much was due to natural growth or, possibly, due to intervention and caregiver training. An age-matched control group of typically

developing children could have assisted in further interpretation of the results, as confounding factors could have been controlled for to a certain extent. The standard deviation (SD) decreased slightly from Period 1 [pre-intervention] (SD=4.00) to Period 1 [follow-up] (SD=3.93), followed by an increase to Period 2 [pre-intervention] (SD=4.67) and Period 2 [follow-up] (SD=5.10), indicating the variability in individual participants' weight over the 18-month period.

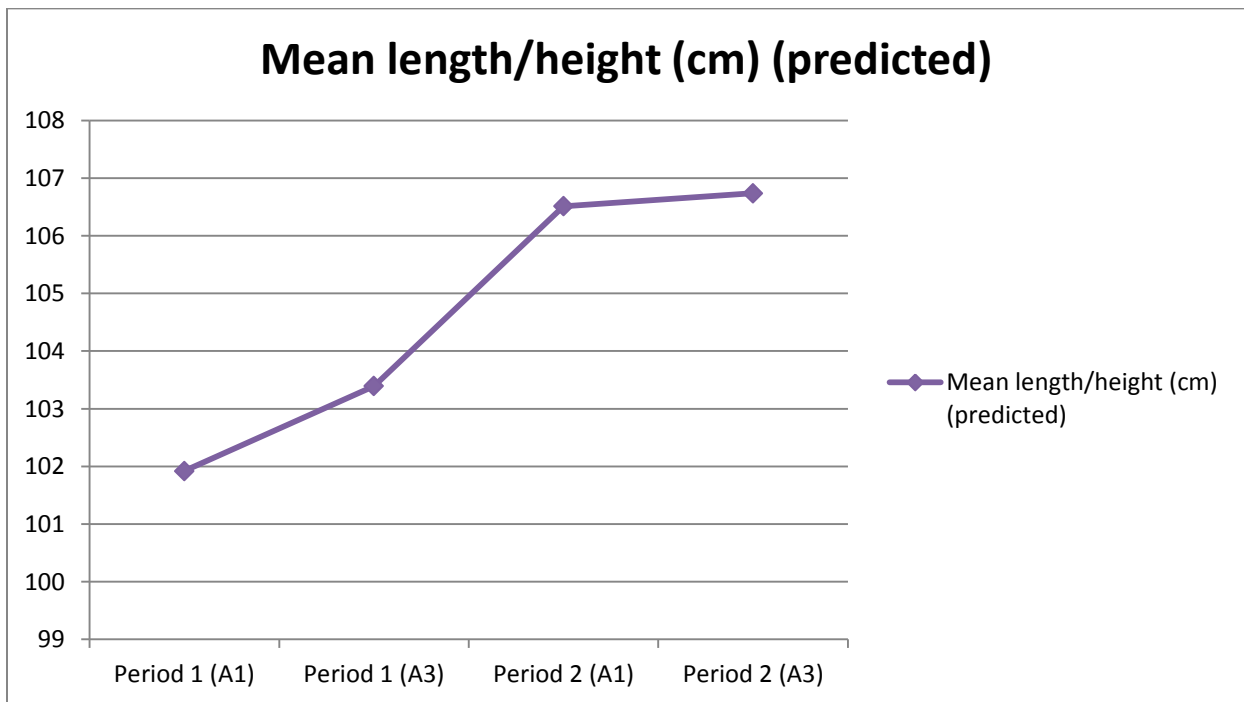


Figure 9 Mean length/height (cm) of child participants over an 18-month period (n=16)

According to Table 7, no statistically significant difference could be observed in the mean length/height of the child participants from Period 1 [pre-intervention] to Period 1 [follow-up]. However, there was a statistically significant difference in the mean length/height of the child participants over the 18-month period (Period 1 [pre-intervention] to Period 2 [follow-up]). Figure 9 shows a slight increase in the mean length/height of the child participants from Period 1 [pre-intervention] to Period 1 [follow-up], a more notable increase between Period 1 [follow-up] and Period 2 [pre-intervention], when the participants were not receiving intervention and/or food supplementation and, finally, a minimal increase over Period 2. A decrease in the SD

can be observed from Period 1 [pre-intervention] (SD=4.00) to Period 1 [follow-up] (SD=3.93), followed by an increase to Period 2 [pre-intervention] (SD=4.67) and then to Period 2 [follow-up] (SD=5.10), indicating the variability in individual participants' growth over the 18-month period. The total average increase in length/height in the child participants over the 18-month period was 4.82cm. It would have, once again, been expected that the increase over the 18-month period would have been more notable, given intervention, caregiver training and the wide age range of the child participants (one to 18 years).

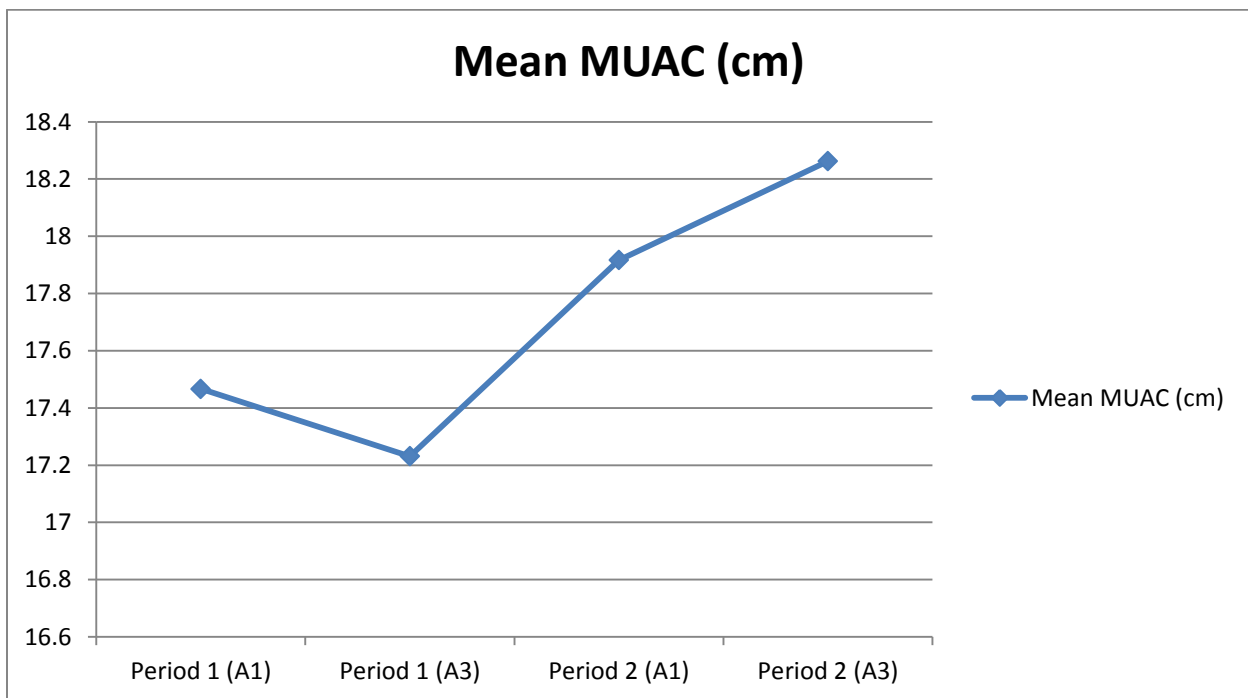


Figure 10 Mean mid-upper arm circumference (MUAC) (cm) of child participants over an 18-month period (n=16)

According to Table 7, no significant difference could be observed in the mean MUAC measurement of the child participants across Period 1, but a statistically significant difference was present between Period 1 [pre-intervention] and Period 2 [follow-up]. Figure 10 depicts a slight decrease in the mean mid-upper arm circumference (MUAC) measurement of the child participants from Period 1 [pre-intervention] to Period 1 [follow-up]. There is a more substantial increase in the mean MUAC measurement from the end of Period 1 to the beginning of Period 2, which can be expected given the

longer period of time (seven months) between the two assessments. However, it should also be noted that intervention did not take place between Period 1 [follow-up] and Period 2 [pre-intervention] and that neither food parcels nor feeding supplements were provided during this period. Finally the mean MUAC of the child participants increased slightly from the beginning of Period 2 to the point of follow-up data collection at the end of Period 2. The SD of the MUAC measurements showed a similar pattern to the mean MUAC measurements, decreasing from Period 1 [pre-intervention] (SD=1.65) to Period 1 [follow-up] (SD=1.36), indicating less variation in the group for the period. The SD then increased from Period 2 [pre-intervention] (SD=1.87) to Period 2 [follow-up] (SD=2.12). The mean MUAC measurements of the child participants' decreased by 0.24cm from Period 1 [pre-intervention] to Period 1 [follow-up] and then increased by 1.03cm from Period 1 [follow-up] to Period 2 [follow-up].

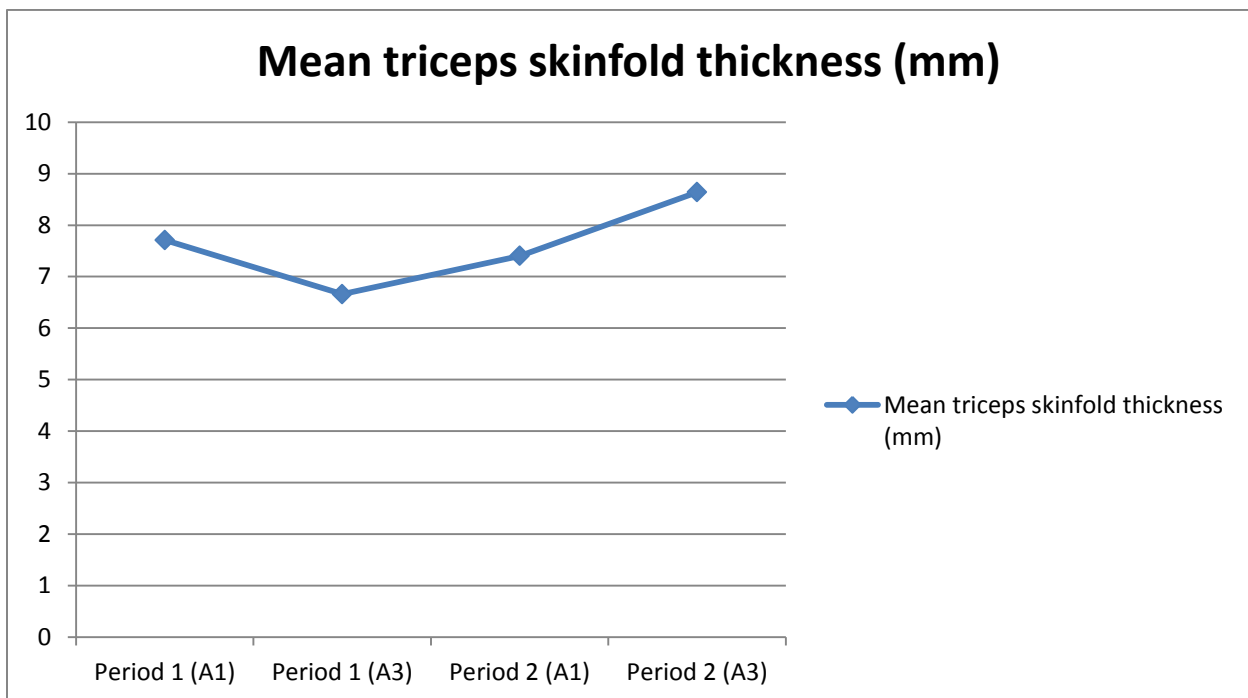


Figure 11 Mean triceps skinfold thickness (mm) of child participants over an 18-month period (n=16)

The mean triceps skinfold thickness of the child participants displayed a similar pattern to that of the mean MUAC measurement. Figure 11 depicts a slight decrease in the

mean triceps skinfold thickness of the child participants from Period 1 [pre-intervention] to Period 1 [follow-up]. However, a slight increase in the mean triceps skinfold thickness (0.93mm) occurred from Period 1 [follow-up] to Period 2 [follow-up], during which no intervention or food supplementation was provided. The SD also showed a decrease from Period 1 [pre-intervention] (SD=3.03) to Period 1 [follow-up] (SD=2.35) and a further decrease to Period 2 [pre-intervention] (SD=1.87), followed by an increase to the follow-up data collection point of Period 2 (SD=2.12). According to Table 7, no statistically significant differences were observed in the participants' mean triceps skinfold thickness over Period 1 or across the 18-month period (Period 1 [pre-intervention] to Period 2 [follow-up]). This indicates that the group of child participants did not show a significant increase in body fat over the 18-month period.

In conclusion, the anthropometric measurement of the child participants that showed a statistically significant difference between Period 1 [pre-intervention] and Period 1 [follow-up] was mean weight (kg), whilst mean length/height (cm) (predicted), MUAC (cm) and triceps skinfold thickness (mm) did not display a significant difference across Period 1. However, all the anthropometric measurements of the child participants, excluding triceps skinfold thickness, demonstrated statistically significant differences across the 18-month period (Period 1 [pre-intervention] to Period 2 [follow-up]). The significant increase in the anthropometric measurements of the child participants may have been due to natural growth and weight gain, but intervention could also have contributed to this increase. From a different perspective, a greater increase in growth could have been expected over the 18-month period, but it is possible that the child participants presented with stunted growth, as is common in children with severe forms of CP (Kuperminc & Stevenson, 2008). However, as no control group was used in the study, the results cannot be interpreted further.

4.2.2 The feeding performance of the child participants with CP (as reported by their caregivers) over time following NDT feeding intervention and caregiver training

Proportional testing was used in order to determine the percentage of child participants able to perform a particular feeding skill (measured by the questions extracted from the PEDI) over Periods 1 and 2. The absolute difference (%) refers to the difference between the values of two random variables (www.stats.oecd.org). In this case, the difference between the percentage of participants able to perform a specific feeding skill in Period 1 [pre-intervention] and Period 1 [post-intervention] as well as the difference between the percentage of participants able to perform a specific feeding skill between Period 1 [pre-intervention] and Period 2 [follow-up]. A critical value was then obtained for the differences between Period 1 [pre-intervention] and Period 1 [follow-up] as well as between Period 1 [pre-intervention] and Period 2 [follow-up] in terms of feeding performance. In hypothesis testing, a critical value is a position on the test distribution that is contrasted to the test statistic in order to decide whether to reject the null hypothesis. If the absolute value of the test statistic is larger than the critical value, statistical significance is confirmed and the null hypothesis is, therefore, rejected (Minitab, 2016). The results are presented in Tables 10 and 11.

Table 10 Differences in feeding performance calculated between Period 1 [pre-intervention] and Period 1 [follow-up] (n=16)

| Questions (PEDI) | % Absolute Difference | Critical value | Significant Difference |
|---|-----------------------|----------------|------------------------|
| Q1: Eats pureed/blended/strained foods | No difference | No difference | No |
| Q2: Eats ground/ lumpy foods | 43.8% | 0.340 | Yes |
| Q3: Eats cut up/chunky foods | 43.7% | 0.365 | Yes |
| Q4: Eats all textures | No difference | No difference | No |
| Q5: Finger feeds | 18.8% | 0.403 | No |
| Q6: Scoops with spoon, brings to mouth | 18.8% | 0.349 | No |
| Q7: Uses a spoon well | No difference | No difference | No |
| Q8: Uses a fork well | 6.3% | 0.149 | No |
| Q9: Uses a knife to cut food | No difference | No difference | No |
| Q10: Holds bottle or cup | 25.0% | 0.416 | No |
| Q11: Lifts cup to drink (cup may tip) | 18.7% | 0.381 | No |

| | | | |
|--|-------|-------|----|
| Q12: Lifts open cup securely with 2 hands | 6.3% | 0.313 | No |
| Q13: Lifts open cup securely with 1 hand | 25.0% | 0.386 | No |
| Q14: Pours liquid from a carton or bottle | 6.2% | 0.251 | No |

Table 10 shows the differences calculated between pre-intervention and follow-up data collection in Period 1. According to Table 10, a significant difference was observed in the caregiver reports of their children's ability to eat ground/lumpy and cut up/chunky foods from Period 1 [pre-intervention] to Period 1 [follow-up]. This indicates an improvement in the variety of textures tolerated. It needs to be taken into account that the CP classification group with the highest number of participants (37%) was the moderate/severe spastic quadriplegic subtype, with the most common GMFCS level within which the child participants were categorized being level V (transported in a manual wheelchair) (38%) (see Figures 1 and 2). This demonstrates that the majority of the child participants were classified within the most dependent levels in terms of motor functioning, once again highlighting the severity of CP that the child participants presented with. Questions 4 to 14 report on hand function and control which did not show a statistically significant difference from Period 1 [pre-intervention] to Period 1 [follow-up]. However, it needs to be considered that, although the caregiver reports of the remaining feeding performance variables may not have shown a significant difference statistically, the absolute difference (%) between the two periods with regard to the child participants' ability to hold a bottle or cup and lift an open cup securely with one hand, was notable from a clinical perspective. This implies that individual participants may have demonstrated improvement across Period 1.

Table 11 Differences in feeding performance calculated between Period 1 [pre-intervention] and Period 2 [follow-up (n=16)]

| Questions (PEDI) | % Absolute Difference | Critical value | Significant Difference |
|---|-----------------------|----------------|------------------------|
| Q1: Eats pureed/blended/strained foods | No difference | No difference | No |
| Q2: Eats ground/ lumpy foods | 43.8% | 0.340 | Yes |
| Q3: Eats cut up/chunky foods | 12.5% | 0.429 | No |
| Q4: Eats all textures | 6.3% | 0.424 | No |
| Q5: Finger feeds | 18.8% | 0.403 | No |
| Q6: Scoops with spoon, brings to mouth | No difference | No difference | No |

| | | | |
|--|-------|-------|----|
| Q7: Uses a spoon well | 6.2% | 0.251 | No |
| Q8: Uses a fork well | 12.5% | 0.202 | No |
| Q9: Uses a knife to cut food | 6.3% | 0.149 | No |
| Q10: Holds bottle or cup | 12.5% | 0.416 | No |
| Q11: Lifts cup to drink (cup may tip) | 18.7% | 0.381 | No |
| Q12: Lifts open cup securely with 2 hands | 12.5% | 0.282 | No |
| Q13: Lifts open cup securely with 1 hand | 12.5% | 0.371 | No |
| Q14: Pours liquid from a carton or bottle | 6.2% | 0.251 | No |

Table 11 depicts the differences calculated between Period 1 [pre-intervention] and follow-up data collection at the end of Period 2. According to Table 11, caregiver reports of their children's ability to eat ground/lumpy foods depicted a significant difference from Period 1 [pre-intervention] to Period 2 [follow-up], indicating that this skill was maintained over the 18-month period. In general, the absolute difference (%) between the feeding performance variables of Period 1 [pre-intervention] and the feeding performance variables of Period 2 [follow-up], either produced the same or a lower value than the difference between the variables over Period 1. This indicates that the participants demonstrated greater improvement in terms of feeding performance in the short-term than over the 18-month period. Interestingly, these results do not show a similar pattern to those obtained for the anthropometric measurements of the child participants over time (see Figures 8, 9, 10, and 11). With regard to the anthropometric measurements of the child participants, there were more statistically significant differences over the 18-month period than over Period 1 (five months). The results indicate that an increase in growth does not necessarily reflect an increase in functional ability.

The order of questions presented in Table 12 follows a logical sequence of increased difficulty of feeding skills, as well as increased hand control in the use of utensils and drinking containers. The % symbol refers to the percentage of child participants.

Table 12 Feeding performance (as reported by caregivers) in child participants with CP over an 18-month period (n=16)

| Questions (PEDI) | Period 1 (%) (August 2007-January 2008) | | | Period 2 (%) (August 2008-January 2009) | | |
|--|--|------|------|--|------|------|
| | A1 | A2 | A3 | A1 | A2 | A3 |
| Q1: Eats pureed/blended/strained foods | 100 | 93.8 | 100 | 100 | 100 | 100 |
| Q2: Eats ground/ lumpy foods | 50 | 56.3 | 93.8 | 100 | 100 | 93.8 |
| Q3: Eats cut up/chunky foods | 43.8 | 50 | 87.5 | 56.3 | 62.5 | 56.3 |
| Q4: Eats all textures | 37.5 | 37.5 | 37.5 | 56.3 | 50 | 43.8 |
| Q5: Finger feeds | 25 | 31.3 | 43.8 | 37.5 | 43.8 | 43.8 |
| Q6: Scoops with spoon, brings to mouth | 12.5 | 18.8 | 31.3 | 25 | 18.8 | 12.5 |
| Q7: Uses a spoon well | 6.3 | 6.3 | 6.3 | 12.5 | 12.5 | 12.5 |
| Q8: Uses a fork well | 0 | 0 | 6.3 | 0 | 0 | 12.5 |
| Q9: Uses a knife to cut food | 0 | 0 | 0 | 6.3 | 6.3 | 6.3 |
| Q10: Holds bottle or cup | 31.3 | 25 | 56.3 | 50 | 50 | 43.8 |
| Q11: Lifts cup to drink (cup may tip) | 18.8 | 18.8 | 37.5 | 37.5 | 25 | 37.5 |
| Q12: Lifts open cup securely with 2 hands | 18.8 | 12.5 | 12.5 | 12.5 | 18.8 | 6.3 |
| Q13: Lifts open cup securely with 1 hand | 18.8 | 12.5 | 43.8 | 25 | 25 | 31.3 |
| Q14: Pours liquid from a carton or bottle | 12.5 | 12.5 | 6.3 | 12.5 | 0 | 6.3 |

The following results relate to *food textures*:

Question 1: Eats pureed/blended/strained foods (as reported by caregivers)

According to Table 12, all the child participants were eating pureed/blended/strained foods across Periods 1 and 2, except in Period 1 [post-intervention]. As this is the only assessment that indicates that not all the participants were able to eat the pureed/blended/strained foods, it may be possible that one of the caregivers (6.2%) did not provide an accurate answer to Question 1 during the second assessment as there were no missing values indicated.

Question 2: Eats ground/lumpy foods (as reported by caregivers)

Ground/lumpy textured foods is the next level of food textures that children who are currently only tolerating pureed, blended or strained foods should progress to eating. According to Table 12, a notable increase in the percentage of child participants that

were able to eat ground/lumpy foods is observed from Period 1 [pre-intervention] to Period 2 [post-intervention]. However, the percentage of child participants that were able to perform this skill decreased in the follow-up assessment of Period 2, indicating that the increase was not maintained over time.

Question 3: Eats cut up/chunky foods (as reported by caregivers)

Table 12 shows a significant increase in the percentage of child participants that were able to eat cut up/chunky foods from the pre-intervention to the follow-up assessment of Period 1. However, this number of participants decreased at the start of Period 2 [pre-intervention] showing an increase directly following intervention and then again when follow-up data was collected. This indicates that, although there was an increase in the percentage of participants who were able to eat cup-up/chunky foods during Period 1, this skill was not maintained from Period 1 to Period 2. A similar trend was observed in the skill of eating ground/lumpy foods.

Question 4: Eats all textures (as reported by caregivers)

According to Table 12, there was no change in the percentage of child participants able to eat all textures from the pre-intervention assessment to the follow-up assessment of Period 1. Only six participants (37.5%) were able to eat all textures throughout Period 1. The pre-intervention assessment of Period 2 depicts an increase in the number of participants who are able to eat all textures, followed by a decrease after intervention was administered and when follow-up data was collected. However, at the end of the 18-month period, seven participants (43.8%) were able to tolerate all food textures.

In summary, with regard to food textures, significant differences in caregiver reports on their children's feeding performance were only observed in the ability to eat ground/lumpy foods as well as cut up/chunky foods from Period 1 [pre-intervention] to Period 1 [follow-up]. The only feeding skill that demonstrated a significant difference over the 18-month period was the ability to tolerate ground/lumpy foods, indicating that

this skill was maintained over time. Based on these results, it is apparent that the child participants progressed more in the short-term (five months) than over the 18-month period. Although the differences in feeding performance over time were not all significant in the group of child participants, individual participants in the group progressed over time, in terms of ability to tolerate a larger variety of food textures.

The following results relate to the *use of utensils*:

Question 5: Finger feeds (as reported by caregivers)

At the point of pre-intervention data collection in Period 1, four (25%) of the child participants were able to finger feed. Table 12 indicates a steady increase in the percentage of participants who were able to finger feed from the pre-intervention assessment to the follow-up assessment in Period 1. Despite a slight decrease in the percentage of participants able to perform this skill at the beginning of Period 2, the percentage increased following intervention and was maintained during the follow-up assessment of Period 2. At the end of the 18-month period, seven (43.8%) of the child participants were able to finger feed. The reason for the maintenance of this skill could be due to finger feeding being an easier skill to acquire and retain than using a utensil. The ability to finger feed provides a child with a higher degree of independence and his/her motivation to maintain the skill may, therefore, be greater.

Question 6: Scoops with spoon, brings to mouth (as reported by caregivers)

The ability to scoop with a spoon and bring it to the mouth is a difficult skill to acquire and maintain due to the complex hand function and coordination required. According to Table 12, only two (12.5%) of the child participants were able to perform this skill at the point of pre-intervention data collection in Period 1. The percentage of participants who were able to scoop with a spoon and bring it to their mouth increased steadily from the pre-intervention assessment to the follow-up assessment of Period 1, followed by a decrease from the pre-intervention assessment to the follow-up assessment of Period

2. By the end of the 18-month period, only two (12.5%) participants were able to perform the skill (the same number as was observed at pre-intervention data collection), indicating no carry-over or maintenance of the skill. This trend was also observed in the skills of eating ground/lumpy foods and cut up/chunky foods.

Question 7: Uses a spoon well and Question 9: Uses a knife to cut food (as reported by caregivers)

The number of child participants able to use a spoon well and the number of participants able to use a knife to cut food displays a similar pattern across Period 1 and Period 2. Only one participant (6.3%) was able to use a spoon well and no participants were able to use a knife to cut food at the point of pre-intervention data collection in Period 1. The percentage of child participants able to use a spoon well and a knife to cut food remained the same for all three assessments in Period 1 and then increased at the beginning of Period 2. The number of participants able to perform these two skills again remained constant over all the assessments in Period 2. By the end of the 18-month period, two participants (12.5%) were able to use a spoon well and one participant (6.3%) was able to use a knife to cut food. These results indicate that, although few participants acquired the skills of using a spoon well and using a knife to cut food, these skills were maintained over time.

Question 8: Uses a fork well (as reported by caregivers)

According to Table 12, no child participants were able to use a fork well before and directly after intervention in Period 1. However, one participant was able to use a fork by the follow-up assessment in Period 1. Table 12 shows that no participants were using a fork well during the pre-intervention assessment of Period 2 and directly following intervention in Period 2. This indicates that this skill, achieved by one participant (6.3%), was not maintained over the period of time (seven months) between the follow-up assessment of Period 1 and the pre-intervention assessment of Period 2.

However, two participants (12.5%) were able to use a fork well by the end of the 18-month period.

In summary, although differences over time were not significant in this category (use of utensils), individual participants progressed in terms of the ability to finger feed, use a spoon well, use a fork well and use a knife to cut food. With regard to the ability to scoop with a spoon and bring it to the mouth, no carry-over or maintenance was observed. The results again confirm that the child participants presented with severe disability, greatly affecting their functioning during feeding.

The following results relate to the *use of drinking containers*:

Question 10: Holds bottle or cup (as reported by caregivers)

Table 12 shows a decrease in the percentage of child participants that were able to hold a bottle or cup from the pre-intervention assessment to the post-intervention assessment of Period 1. However, a notable increase in the percentage of children able to hold a bottle or cup can be observed in Period 1 [follow-up]. This may be due to the caregivers making appropriate use of the techniques learned in the caregiver training during the seven-month period between Period 1 [follow-up] to Period 2 [pre-intervention], during which no intervention was provided. Period 2 in Table 12, however, shows a decrease in the percentage of child participants able to hold a bottle or cup from the post-intervention assessment to the follow-up assessment.

Question 11: Lifts cup to drink (cup may tip) (as reported by caregivers)

Although no change can be observed in the percentage of child participants able to lift a cup to drink from the pre-intervention assessment to the post-intervention assessment in Period 1, three participants (18.8%) acquired the skill of lifting a cup to drink during the seven-month period between Period 1 [follow-up] and Period 2 [pre-intervention], when no intervention was provided. This may indicate carry-over of the

techniques the caregivers learned during caregiver training. The percentage of participants able to lift a cup to drink was maintained from the follow-up assessment of Period 1 to the first assessment of Period 2. This percentage decreased following intervention in Period 2, but increased again during the period in which intervention was not provided.

Question 12: Lifts open cup securely with two hands (as reported by caregivers)

According to Table 12, three (18.8%) child participants were able to lift an open cup securely with two hands in the pre-intervention assessment of Period 1. Only two (12.5%) children were able to perform this skill during the post-intervention and follow-up assessments of Period 1 and the pre-intervention assessment of Period 2. Despite the increase in the number of participants able to perform the skill of lifting an open cup securely with two hands directly following intervention in Period 2, only 1 (6.3%) participant was able to perform this skill during the follow-up assessment of Period 2. This may indicate that caregivers were reporting fewer children being able to lift a cup with two hands as more children were able to lift an open cup securely with one hand. Lifting an open cup securely with one hand is an advanced skill in terms of hand function and independence during feeding.

Question 13: Lifts open cup securely with one hand

Table 12 depicts a decrease in the number of child participants able to lift an open cup securely with one hand from the pre-intervention assessment to the post-intervention assessment of Period 1. However, there was a notable increase in the number of participants able to perform this skill during the follow-up assessment of Period 1. Only four (25%) of the seven (43.8%) participants who were able to lift an open cup securely with one hand by the end of Period 2 maintained this skill to the pre- and post-intervention assessment of Period 2. However, by the end of the 18-month period, five (31.3%) participants in total were able to perform this skill.

Question 14: Pours liquid from a carton or bottle

According to Table 12, two (12.5%) child participants were able to pour liquid from a carton or bottle in the pre-intervention assessment of Period 1. This number remained unchanged after intervention was provided and decreased to one (6.3%) participant in the follow-up assessment. Once again, two (12.5%) participants were able to pour liquid from a carton or bottle during the pre-intervention assessment of Period 2, but this number also decreased to only one (6.3%) participant by the follow-up assessment of Period 2. This skill was not maintained across the 18-month period. A reason for this skill not being maintained may be due to the difficulty in performing the skill as it requires postural and hand control, skills that would be a significant challenge for children with severe spastic quadriplegia and a GMFCS level V classification.

In summary, the following skills saw an increase from Period 1 [pre-intervention] to Period 2 [follow-up] in the percentage of child participants able to perform them: *eats ground/lumpy foods* (statistically significant), *eats cut up/chunky foods*, *eats all textures*, *finger feeds*, *uses a spoon well*, *uses a fork well*, *uses a knife to cut food*, *holds bottle or cup*, *lifts cup to drink (cup may tip)* and *lifts open cup securely with one hand*. No change was observed across the 18-month period in the number of participants able to perform the following skill: *scoops with spoon, brings to mouth*. A decrease was observed across the 18-month period in the number of participants who were able to perform the following skills: *lifts open cup securely with two hands* and *pours liquid from a carton or bottle*. It is clear that there were more statistically significant differences in certain feeding skills in the short-term (five months) than over the 18-month period.

It is evident from Table 12 that the number of child participants able to perform the feeding skills fluctuates considerably across questions and assessments. The results are based on caregiver reports and not on direct observations of the participants' feeding performance. The findings also depend on the caregiver's ability to continuously assist the child in order to increase independent eating and drinking. There was a statistically significant increase in the number of child participants able to

tolerate ground/lumpy foods over the 18-month period. Although no statistically significant differences in the remaining reported feeding skills of the group of child participants were observed, individual participants demonstrated improvement in and maintenance of certain feeding skills, including the ability to eat cut-up chunky foods, finger feed, use a spoon and a knife to cut food, lift a cup to drink and lift a cup securely with one hand, over time. Fluctuation in the results may be due to certain child participants marginally being able to perform a specific feeding skill, but losing the skill over time as a result of it being too time consuming. The results, once again, illustrate the wide-ranging nature and heterogeneity of the child participants with CP. CP is a permanent disability and, considering most of the child participants presented with spastic quadriplegia/hemiplegia and were functioning on a GMFCS level V, progress would be marginal (Rosenbaum et al., 2002).

4.2.3 Caregiver participants' awareness of and concerns about their children's feeding difficulties and weight over time following NDT feeding intervention and caregiver training

Proportional testing was used in order to determine the percentage of caregiver participants aware of and concerned about their children's feeding difficulties and weight (determined by the questions extracted from the Feeding Profile) over Periods 1 and 2. The absolute difference (%) refers to the difference between the values of two random variables (www.stats.oecd.org). In this case, the difference between the percentage of concerned caregiver participants in Period 1 [pre-intervention] and Period 1 [follow-up] as well as the difference between the percentage of concerned caregivers participants between Period 1 [pre-intervention] and Period 2 [follow-up]. A critical value was then obtained for the differences over Period 1, as well as between Period 1 [pre-intervention] and Period 2 [follow-up] in terms of caregiver participants' awareness of and concerns about their children's feeding difficulties and weight. In hypothesis testing, a critical value is a position on the test distribution that is contrasted to the test statistic in order to decide whether to reject the null hypothesis. If the

absolute value of the test statistic is larger than the critical value, statistical significance is confirmed and the null hypothesis is, therefore, rejected (Minitab, 2016).

The current researcher recognizes that the terms ‘feeding’ and ‘eating’ cannot be used synonymously, as ‘eating’ refers to the taking in of food, whereas ‘feeding’ refers to the process involved in the taking in of food (Oxford Dictionaries online, n.d.). However, due to the low literacy skills and low levels of schooling achieved by the majority of the caregiver participants, the terms ‘eating’ and ‘drinking’ were used as they were the more understandable and accepted terms amongst the participants. During the interviews in isiXhosa, the interviewer explained to the caregiver participants that the terms ‘eating’ and ‘drinking’ may refer to any feeding difficulties experienced by their children. Thus, the caregiver participants’ awareness of and concern about their children’s eating and drinking was classified as their awareness of and concern about their children’s feeding difficulties, for the purposes of this study. The results are presented in Tables 13 and 14.

Table 13 Differences in the number of caregivers concerned calculated between Period 1 [pre-intervention] and Period 1 [follow-up]

| Questions (Feeding Profile) | % Absolute Difference | Critical value | Significant Difference |
|---|--------------------------|-------------------|---------------------------|
| Q1: My child has difficulty eating and drinking (awareness of feeding difficulties) | 43.7% | 0.388 | Yes |
| Q2: I am worried about my child’s eating and drinking (concern about feeding difficulties) | 37.5% | 0.397 | No |
| Q3: I am concerned that my child is underweight (concern about weight) | (-6.2%) | 0.313 | No |

According to Table 13, there was a statistically significant difference in the percentage of caregiver participants aware of their children’s feeding difficulties from Period 1 [pre-intervention] to Period 1 [follow-up], indicating that the caregiver participants became more aware of their children’s feeding difficulties following intervention and caregiver training. However, despite there being no statistically significant difference in the percentage of caregiver participants concerned about their children’s feeding difficulties between Period 1 [pre-intervention] and Period 1 [follow-up], the difference is still notable from a clinical perspective. The absolute difference (%) in terms of caregiver

concerns about their children’s weight was negative. In other words, there was a decrease in the percentage of caregiver participants who were concerned about their children’s weight from the pre-intervention assessment to the follow-up assessment of Period 1. This could indicate that, as a result of the statistically significant increase in the mean weight of the child participants over Period 1 (see Figure 8), the caregiver participants became less concerned about their children’s weight over the short-term period. A different result was, however, obtained when the entire 18-month study period was considered.

Table 14 Differences in the number of caregivers concerned calculated between Period 1 [pre-intervention] and Period 2 [follow-up]

| Questions (Feeding Profile) | % Absolute Difference | Critical value | Significant Difference |
|---|--------------------------|-------------------|---------------------------|
| Q1: My child has difficulty eating and drinking (awareness of feeding difficulties) | 37.5% | 0.401 | No |
| Q2: I am worried about my child’s eating and drinking (concern about feeding difficulties) | 25.0% | 0.419 | No |
| Q3: I am concerned that my child is underweight (concern about weight) | 6.3% | 0.250 | No |

According to Table 14, no significant differences could be observed between Period 1 [pre-intervention] and Period 2 [follow-up] in terms of the percentage of caregiver participants aware of and concerned about their children’s feeding difficulties and weight. The absolute differences (%) between the number of caregiver participants aware of and concerned about their children’s feeding difficulties from Period 1 [pre-intervention] to Period 2 [follow-up] was smaller than the absolute difference between the pre-intervention and follow-up assessments of Period 1. This indicates that, although there was an increase in the number of caregiver participants who were concerned about their children’s feeding performance throughout Period 1, fewer caregivers were concerned in the long-term (over the 18-month period). However, the absolute difference (%) in the number of caregiver participants concerned about their children’s weight also demonstrates an increase over the 18-month period. This is interesting as the mean weight of the child participants displayed a significant increase over the 18-month period. From a different perspective, the child participants’ significant increase in weight may have reflected the increased number of caregiver

participants concerned about their children’s weight. In other words, with increased time, the more concerned the caregivers were about their children’s weight, the more the child participants’ weight increased. However, as no statistical association could be made, a trend was simply observed.

In summary, the caregiver participants became more aware of and concerned about their children’s feeding difficulties and weight over the 18-month period as the feeding performance (Questions 1 to 14 of the PEDI) in individual child participants (as reported by caregivers) improved. Initially, the caregiver participants became less concerned during Period 1, but could have gained increased insight over the 18-month period regarding the longstanding difficulties that their children faced. Although there were not sufficient participants to determine statistical associations in this regard, a trend was observed. This could be as a result of the caregivers becoming more knowledgeable of their children’s feeding difficulties after receiving training. This could also indicate that, as the caregiver participants became more aware of and concerned about their children’s feeding difficulties and weight, they became more rigorous in using the appropriate feeding strategies and skills they had acquired during intervention and caregiver training, resulting in improved feeding performance in individual child participants.

The % symbol in Table 15 refers to the percentage of caregivers.

Table 15 Caregiver participants’ awareness of and concerns about their children’s feeding difficulties and weight over an 18-month period (n=16)

| Questions (Feeding Profile) | Period 1 (%) | | | Period 2 (%) | | |
|---|--------------|----|------|--------------|------|------|
| | A1 | A2 | A3 | A1 | A2 | A3 |
| Q1: My child has difficulty eating & drinking (awareness of feeding difficulties) | 31.3 | x | 75 | 43.8 | 75 | 68.8 |
| Q2: I am worried about my child’s eating & drinking (concern about feeding difficulties) | 37.5 | x | 75 | 56.3 | 81.3 | 62.5 |
| Q3: I am concerned that my child is underweight (concern about weight) | 87.5 | x | 81.3 | 75 | 93.8 | 93.8 |

x: No data (see Table 1)

Caregiver awareness of and concerns about their children's feeding difficulties (Questions 1 and 2)

According to Table 15, there is a notable increase in the percentage of caregiver participants aware of and concerned about their children's feeding performance from the pre-intervention assessment to the follow-up assessment of Period 1. The increase in the number of caregiver participants aware of their children's feeding difficulties over Period 1 was statistically significant. This percentage decreased over the time between Period 1 [follow-up] and the Period 2 [pre-intervention]. However, the percentage once again increased in the post-intervention assessment of Period 2. Although the percentage of concerned caregiver participants was not maintained from Period 1 to Period 2 [pre-intervention], the increase in the number of concerned caregiver participants directly following intervention and caregiver training in Period 2 should be noted. Table 15 depicts a decrease in the percentage of aware and concerned caregiver participants between the post-intervention and follow-up assessments in Period 2. This could indicate that, as the child participants' feeding performance improved, the caregiver participants became less concerned about their children's feeding difficulties.

Caregiver concerns about their children's weight (Question 3)

A different pattern was observed with regard to Question 3. Table 15 depicts a decrease in the percentage of caregiver participants concerned about their children's weight from Period 1 [pre-intervention] to Period 2 [pre-intervention]. However, following intervention and caregiver training in Period 2, an increased percentage of caregiver participants were concerned about their children's weight. This percentage was maintained across the period of time when no intervention or training was provided to the follow-up assessment of Period 2.

In conclusion, the results depicted in Tables 13, 14 and 15 indicate that there was a more notable increase in the percentage of caregiver participants aware of and concerned about their children's feeding difficulties and weight from the pre-

intervention assessment to the post-intervention assessment of Period 1 and the pre-intervention assessment to post-intervention assessment of Period 2 than across the 18-month period. Based on these results, it appears that the caregiver participants were more aware of and concerned about their children's feeding difficulties and weight directly following intervention and training in each period than over the 18-month period. However, in Period 2, the percentage of caregiver participants concerned about their children's weight increased following intervention and training and this percentage was maintained to the point of follow-up data collection in Period 2.

Chapter 5

DISCUSSION

The aim of this chapter is to examine and interpret the results obtained in the current study by comparing the findings to the relevant literature. This chapter also aims to answer the study questions regarding the anthropometric measurements and feeding performance of the child participants with CP (as reported by their caregivers) and the caregiver participants' awareness of and concerns about their children's feeding difficulties and weight.

5.1 Introduction

The results obtained from this study will be examined and interpreted according to the way the results were structured in Chapter 4, in other words, in relation to the sub-aims of this study. Firstly, the anthropometric measurements of the children with CP across the 18-month period will be discussed. Thereafter, the feeding performance of the children with CP (as reported by their caregivers) over the 18-month period will be discussed, followed by the caregiver awareness of and concerns about their children's feeding difficulties and weight over the 18-month period.

5.2 Discussion

5.2.1 The anthropometric measurements of the child participants with CP over time following NDT feeding intervention and caregiver training

There are certain challenges involved in measuring growth in children with CP. It is particularly challenging to accurately measure length/height in children with CP due to

contractures and spasticity (Cronk & Stallings, 1997). It is also difficult to make use of standard reference data to interpret growth data in children with CP as the reference data may not be suitable due to the heterogeneity of the disability (Tomoum et al., 2010). Growth in typically developing children can be evaluated simply by making use of weight and height measurements. In contrast, growth in children with CP needs to be evaluated by taking body composition factors into account in order to accurately examine their nutritional status (Kuperminc & Stevenson, 2008). Table 16 indicates the factors that are determined by each anthropometric measurement.

Table 16 Description of the factors determined by anthropometric measurements

| Anthropometric measurement | Factor determined |
|---|--|
| Weight (kg) | Indication of nutritional status (Kuperminc & Stevenson, 2008) |
| Length/height (cm) | Indication of growth patterns (Oeffinger, Conaway, Stevenson, Hall, Shapiro, & Tylkowski, 2010) |
| Mid-upper arm circumference (MUAC) (cm) | Not an accurate predictor for malnutrition, but appropriate measure to evaluate variations in body composition (Tomoum et al., 2009) |
| Triceps skinfold thickness (mm) | Measures body fat and nutritional status (Tomoum et al., 2009) |

Irregular growth, body composition, physical activity and feeding are factors commonly associated with CP (Cronk & Stallings, 1997). The mean weight of the child participants in the current study, which was determined at the point of pre-intervention data collection, was 16.01kg. The group of participants, on average, gained 2.32kg over the 18-month period. The pattern for mean length/height in the 16 participants over the 18-month period approximately parallels those for weight. Although there are statistically significant differences in the mean weight of the child participants from Period 1 [pre-intervention] to Period 1 [follow-up] as well as in the mean weight, length/height and MUAC of the child participants over the 18-month period, this difference appears minimal from a clinical perspective. The difference appears clinically minimal when considering the age range of the child participants, which was one to 18 years. Growth charts developed by Day et al. (2007), showed that children and adolescents with CP who present with a mild form of the disability are able to

attain weight and height measurements similar to those of their typically developing peers. However, in the current study, the CP classification subtype that contained the highest number of participants was spastic quadriplegia. Day et al. (2007) report that the height and weight of children and adolescents with the most severe forms of CP differs substantially from their typically developing peers. A possible reason for the lower weight gain than expected and minimal increase in length/height in the child participants may be, as children with CP increase in age, their growth pattern deviates further from the growth pattern of typically developing children. According to growth references for children with CP, children who present with moderate to severe CP do not undergo a significant growth increase during the time of puberty (Kuperminc & Stevenson, 2008). As a significant amount of adult height is dependent on the rapid increase in growth during puberty, it is necessary to consider hormonal changes as a factor that may contribute to reduced growth in children with CP (Kuperminc & Stevenson, 2008). However, this could only account for the growth of two participants as only two participants were in, or had already passed the starting age of puberty (approximately 11 to 12 years of age).

The graphs depicting the mean mid-upper arm circumference (MUAC) and triceps skinfold thickness of the 16 child participants display similar patterns. According to Tomoum et al. (2010), MUAC is not as effective as other anthropometric measurements in terms of determining the presence of undernourishment in children with CP. However, skinfold thickness is used as an indication of body fat and is a reliable indication of a child's nutritional status. Triceps skinfold thickness, in particular, is used in examining short-term variations in total body fat. The mean triceps skinfold thickness of the participants in the current study decreased from Period 1 [pre-intervention] to Period 1 [follow-up]. Although it may seem unusual that the body fat of the child participants decreased for a time while their weight increased, it needs to be taken into account that there is a difference between body weight and body fat. Body weight is defined as the amount that a person weighs, while body fat refers to the fat stored in the body (Oxford Dictionaries online, n.d.). The child participants' average body fat may have decreased between the pre-intervention and follow-up assessments

of Period 1 due to the initial adjustment to the intervention and altered interaction during feeding between the caregivers and their children following caregiver training. However, across the 18-month period, the child participants displayed an average increase of 0.80cm in terms of their MUAC measurements and an average increase of 0.93mm in terms of triceps skinfold thickness. Triceps skinfold thickness, which is an indication of body fat, was the only anthropometric measurement that did not show a statistically significant difference across Period 1 or over the 18-month period. This may be because body fat takes longer to show change than body weight does. In other words, weight can change over time, while body fat remains constant or displays minimal change (Stevens, Truesdale, McClain, & Cai, 2006).

It remains a challenge to understand data and diagnose poor nutrition or growth in children with CP, even when reliable anthropometric data are obtained (Kuperminc & Stevenson, 2008). Anthropometric measurements of children and adolescents with the most severe forms of CP and who present with substantial feeding complications are so different to those of their typically developing peers that standard growth curves are of minimal use in studying their growth (Day et al., 2007). Growth curves specific to conditions such as Down syndrome and Turner syndrome are available. However, in these conditions, genetic irregularity has a direct impact on growth (Kuperminc & Stevenson, 2008). Although it would be advantageous to professionals working with children with CP to have comparative growth charts, any sample of children with moderate to severe CP would be substantially diverse involving children with various levels and types of undernourishment. Due to this lack of data concerning what can be labeled suitable growth and nutrition in children with CP, professionals are required to come to conclusions and make decisions based on clinical judgment (Kuperminc & Stevenson, 2008).

It is clear from the graphs depicting the means of each anthropometric measurement, that the child participants demonstrated a statistically significant improvement in their mean weight, length/height and mid-upper arm circumference measurements over the 18-month period. No statistically significant differences were observed over time in the

triceps skinfold thickness measurement of the child participants. Due to the lack of reliable growth standards for children with CP, it is difficult to say whether this improvement was as a result of intervention and caregiver training or whether the change was due to standard growth and development in the child participants over time. A confounding factor that could not be controlled for during the seven months between the end of Period 1 and the start of Period 2 (when no intervention was provided), was the type of food the child participants were receiving at home. According to Bell et al. (2010), one of the causes of poor growth and nutrition in children with CP is insufficient dietary intake. Considering the unemployment rate and overall socioeconomic status of the caregiver participants (see Table 2), it would be difficult for them to provide their children with the nutrition and balanced diet they required. From a clinical perspective, a greater increase in growth could have been expected over the 18-month period, but it is possible that the child participants presented with stunted growth, as is common in children with severe forms of CP (Kuperminc & Stevenson, 2008). However, as no control group was used in this study, the results cannot be interpreted further.

5.2.2 The feeding performance of the child participants with CP (as reported by their caregivers) over time following NDT feeding intervention and caregiver training

The results obtained from the caregiver reports of their children's feeding performance will be discussed according to the three categories already described in Table 5.

Food textures (as reported by caregivers)

In order to obtain a better understanding of the results obtained with regard to the food textures tolerated by the child participants, it is necessary to examine typical feeding development in terms of food textures. Table 17 shows typical feeding development with regard to food textures as described by Delaney and Arvedson (2008).

Table 17 Typical feeding development with regard to food textures

| Feeding skill (PEDI Questions) | Age achieved in typically developing children |
|---|---|
| Q1: Eats pureed/blended/strained foods | 6 months |
| Q2: Eats ground/lumpy foods | 6-9 months |
| Q3: Eats cut up/chunky foods | 9-12 months |
| Q4: Eats all textures | 12-18 months |

The atypical muscle tone that children with CP present with causes feeding difficulties which are classified as neurogenic dysphagia (Arvedson & Brodsky, 2002). The authors state that neurogenic dysphagia can result in reduced bolus movement or incorrect movement of the bolus into the nasal cavity, larynx and/or trachea. One of the foremost complications resulting from neurogenic dysphagia is aspiration, frequently causing pneumonia, malnutrition and dehydration that can be fatal for patients with neurological disorders, such as CP (Aydogdu et al., 2014). Due to difficulties with regard to pharyngeal movement, children with CP frequently experience complications with ground, lumpy or mashed foods as it results in some of the food remaining in the pharynx and then entering the trachea after swallowing, resulting in aspiration. Children with CP may be able to tolerate thicker food consistencies such as cut up/chunky foods better as the food remains in the mouth for a longer period of time before they are required to swallow, but not in all cases (Arvedson, 2013).

According to the results of the current study, all the child participants were eating pureed, blended or strained foods at the time of pre-intervention data collection in Period 1 and at the time of follow-up data collection at the end of Period 2. Pureed, blended or strained foods are the first solid food textures that an infant is able to tolerate after consuming only liquids. The child participants were, therefore, mostly functioning on the most basic level of eating at the start of the 18-month period. This is not surprising as thinner food consistencies are the easiest consistencies to tolerate. The change over time in the number of children able to eat ground/lumpy foods and cut up/chunky foods showed a similar trend across Period 1. Eight children (50%) were able to eat ground/lumpy foods and seven children (43.8%) were able to eat cut

up/chunky foods at the point of pre-intervention data collection (Period 1). This number increased slightly after intervention was provided, but the most notable increase took place at the point of follow-up data collection in Period 1. During the follow-up assessment, it was noted that 15 children (93.8%) were able to eat ground/lumpy foods and 14 children (87.5%) were able to eat cut up/chunky foods, indicating that the skill was acquired by some of the child participants and maintained during the three months spent at home between the intervention block and the follow-up assessment of Period 1. The difference between Period 1 [pre-intervention] and Period 1 [follow-up] in terms of the number of participants able to tolerate ground/lumpy and cut up/chunky foods was statistically significant. However, although the number of participants able to tolerate ground/lumpy foods was maintained, the number of participants able to eat cut up/chunky foods had decreased by the end of the 18-month period. This may be due to the difficulty children with the most severe forms of CP (such as the child participants in the current study) experience with chewing, which is required in eating cut up/chunky foods. Children who experience difficulties with chewing will either force the food out of their mouth or push the food firmly against their palate, causing the food to become compressed, but not chewed. The bolus that forms as a result, is not effective and causes the child to gag and choke when swallowed (Arvedson & Brodsky, 2002). Some of the caregivers of the child participants may have observed this and stopped feeding their children cut up/chunky foods in order to avoid any discomfort their children were experiencing. Six (37.5%) participants were able to consume all food textures at the start of Period 1. This number did not change over Period 1 [pre-intervention to follow-up]. Despite an increase in that number at the start of Period 2 (three more participants were able to tolerate all food textures in Period 2 [pre-intervention]), by the end of the 18-month period, only one participant had gained and maintained the ability to tolerate all food textures. This decrease in the number of participants able to tolerate all food textures may be for the same reasons as the decrease in the number of participants able to tolerate cut up/chunky foods. A total of seven of the 16 participants were able to tolerate all food textures by the end of the 18-month period. This, once again, confirms the severity of CP that the child participants presented with as typically developing children are able to tolerate all food textures by

18 months of age (see Table 17). At least nine of the child participants with CP were above the age of 18 months (see Table 2).

Use of utensils (as reported by caregivers)

In order to understand the results obtained from the PEDI in terms of the participants' ability to use utensils, typical development in the use of utensils for independent feeding needs to be considered. Table 18 shows typical feeding development with regard to the use of utensils as described by Barclay and Weaver (2006).

Table 18 Typical feeding development with regard to use of utensils

| Feeding skill (PEDI Questions) | Age achieved in typically developing children |
|---|---|
| Q5: Finger feeds | Approximately 1 year |
| Q6: Scoops with spoon, brings to mouth | Approximately 2 years |
| Q7: Uses a spoon well | Approximately 3 years |
| Q8: Uses a fork well | Approximately 3 years |
| Q9: Uses a knife to cut food | Approximately 5 years |

Motor development in children with CP is slow and atypical. Children with CP also present with atypical muscle tone, abnormal posture and persistent infantile reflexes which can interfere with eating and swallowing (Gates et al., 2006; Krigger, 2006). The atypical tone that children with CP experience makes controlling their hands and arms for self-feeding a challenge (Clawson et al., 2007).

According to the results obtained regarding the use of utensils in the child participants over Period 1 as well as over the 18-month period, no statistically significant differences were observed, despite intervention and caregiver training. However, individual differences were observed in the child participants. Only four (25%) participants were able to finger feed at the start of Period 1. By the end of Period 1, seven (43.75%) participants were able to finger feed and had maintained this skill by the end of the 18-month period. A possible reason for the maintenance thereof may be due to finger feeding providing an increased level of independence in the participants

with CP without the complexity of using a utensil. Hall (2001) states that, as children become more independent feeders, their mealtimes involve taking part in a social occasion with the family and are no longer simply a one-to-one interaction with the caregiver. The enjoyment of this experience may have led to an increase in the participants' motivation to maintain the skill of finger feeding. With regard to the ability to scoop with a spoon and bring it to the mouth, only two participants (12.5%) were able to perform this skill at the start of Period 1 and, despite a slight increase in the number of participants by the end of Period 1, only two participants (12.5%) had maintained the skill by the end of the 18-month period. Only 1 participant (6.3%) was able to use a spoon well at the beginning of Period 1 and only one participant (6.3%) had acquired the skill at the start of Period 2. These two participants had maintained the skill by the end of the 18-month period. No participants were able to use a fork well until the last assessment of the 18-month period, by which time two participants (12.5%) had acquired the skill. No participants were able to use a knife to cut food at the start of Period 1, but by the start of Period 2, one participant (6.3%) had acquired the skill and maintained it to the end of Period 2. Taking into account that typically developing children should be able to use all types of cutlery well by the age of five years (see Table 18), it is clear that the child participants with CP in the current study, at least six of whom were over the age of five years, experienced substantial difficulty in terms of using utensils during feeding. The limited number of child participants able to use utensils during feeding may be due to the level of difficulty required in the execution of these skills. Workinger (2005) states that if a child with CP spends a significant amount of effort on attempting to bring a utensil to the mouth, irregular oral behaviours such as jaw or tongue thrust, may occur. In this case, deterioration in oral skills for feeding may be observed, increasing the length of mealtimes (Adams et al., 2011). In such cases, the caregivers of the child participants may have found it easier to feed their children themselves, despite the decrease in feeding independence for the child participants. Snider et al. (2011) state that longer mealtimes, that occur as a result of the feeding difficulties children with CP present with, increase the burden of responsibility on the caregiver. Taking into account that studies have shown that the caregivers of children with CP have a high tendency towards anxiety and depression,

diminished health and continuing grief (Whittingham, Wee, Sanders, & Boyd, 2012), it may be that the caregivers wanted to make mealtimes as manageable as possible, for both themselves and their children.

Use of drinking containers (as reported by caregivers)

In order to understand the results obtained from the PEDI in terms of the participants' ability to use drinking containers, typical development in the use of drinking containers for independent feeding needs to be considered. Table 19 shows typical feeding development with regard to the use of drinking containers as described by McCarthy (2008).

Table 19 Typical feeding development with regard to use of drinking containers

| Feeding skill (PEDI Questions) | Age achieved in typically developing children |
|--|---|
| Q10: Holds bottle or cup | 5-6 months |
| Q11: Lifts cup to drink (cup may tip) | 12-18 months |
| Q12: Lifts open cup securely with 2 hands | 12-18 months |
| Q13: Lifts open cup securely with 1 hand | 24-36 months |
| Q14: Pours liquid from a carton or bottle | 36 months-5 years |

As in the case of the use of utensils for feeding, it needs to be considered that independent drinking is also significantly difficult in the case of children with severe forms of CP, as their gross motor function is affected. The atypical muscle tone, poor coordination and control of movements, level of dependency and persistence of reflexes that children with CP present with, all affect the their ability to eat and drink independently (Andrew, Parr, & Sullivan, 2012).

According to the results obtained regarding the use of drinking containers in the child participants over Period 1 as well as over the 18-month period, no statistically significant differences were observed, despite intervention and caregiver training. However, individual differences were observed in the child participants. Only five

participants (31.3%) were able to hold a bottle or cup at the beginning of Period 1. This number had increased to nine participants (56.3%) by the end of Period 1. This skill, however, was not maintained over Period 2 by all nine participants and, by the end of the 18-month period, only seven of the 16 participants had retained the skill. Considering the skill of being able to hold a bottle or cup is developed by six months of age in typically developing children and that all of the child participants were over six months of age, this is not a substantial number. The next skill to develop, in terms of the use of drinking containers, is being able to lift a cup to drink. Interestingly, although only three more participants (18.8%) had acquired the skill of being able to lift a cup to drink by the end of Period 1, these participants maintained the skill to the end of the 18-month period, despite the skill being more challenging than holding a bottle or cup. When comparing the skills of being able to lift an open cup securely with two hands and the skill of being able to lift an open cup securely with one hand, Table 12 shows that three participants (18.8%) were able to perform each skill, respectively, at the start of Period 1. However, as the number of participants able to perform the skill of lifting an open cup securely with two hands largely decreased over the 18-month period (from three participants (18.8%) to one participant (6.3%)), so the number of participants able to perform the skill of lifting an open cup securely with one hand increased over the period of 18-months (from three participants (18.8%) to five participants (31.3%)), with some fluctuations between assessments. Although it may seem unusual that the number of participants able to perform the less challenging skill would decrease while the number of participants able to perform the slightly more challenging skill would increase, a possible explanation can be offered. A reason for this discrepancy could be that, as some of the participants became more skilled in lifting an open cup securely with only one hand, the caregivers reporting on their performance indicated that their children were lifting an open cup with only one hand more frequently than they were lifting an open cup with two hands. This does not necessarily mean that the participants were no longer able to perform the skill of lifting an open cup securely with two hands. However, with regard to the skill of being able to pour liquid from a carton or bottle, only two participants (12.5%) were able to perform the skill at the start of Period 1. This number decreased to only one participant (6.3%) by the end of Period 1.

and the end of Period 2. Despite this being the most advanced skill in terms of gross motor skill and coordination, typically developing children achieve this skill by five years of age. As at least six participants were over the age of five years, the severity of CP the child participants presented with was, once again, confirmed. According to Arvedson and Brodsky (2002), children with CP that exhibit atypical muscle tone, such as spasticity (as was the case with the majority of the child participants in the current study), display a higher level of resistance to passive joint movement, and restrictions in joint range of motion are observed. Children who present with spasticity may also display atypical movement patterns and persistent reflexes with regard to posture (Andrew et al., 2012). Taking into account the atypical muscle tone, abnormal movements and contractures children with severe CP present with, it could be expected that the child participants in the current study would have experienced significant difficulty in the maneuvering of their upper extremities for the independent use of drinking containers.

With regard to the food textures category of feeding performance, there was a statistically significant increase in the number of child participants able to eat ground/lumpy foods over Period 1 and over the 18-month period, as well as in the number of participants able to eat cut up/chunky foods over Period 1. Although there were no statistically significant differences in the skills of using utensils during feeding or the use of drinking containers, individual differences and improvements over time were observed. Taking typical development of food textures, the use of utensils and the use of drinking containers into account, it is evident that the child participants experienced significant difficulties in terms of being able to perform the feeding skills. The number of participants able to perform the various feeding skills fluctuated significantly over the six assessments. This could be attributed to the atypical muscle tone, abnormal posture and persistent infantile reflexes that children with CP often present with. This, in turn, can interfere with eating and swallowing (Gates et al., 2006; Krigger, 2006). The atypical tone that children with CP experience makes controlling their hands and arms for self-feeding a challenge (Clawson et al., 2007). The majority of the participants in the current study presented with the most severe form of CP

(spastic quadriplegia/hemiplegia), and a GMFCS level V. The heterogeneity of the group of child participants with CP in the current study may have also been a contributing factor to the fluctuation in results across the 18-month period. Certain feeding skills were maintained over time by individual child participants, while some participants were reported to have acquired a skill only to lose the ability to perform that skill soon thereafter. This may be as a result of the execution of the skill being too time consuming for the child participant.

Although no statistical association could be made, the trends observed in the change in the child participants' anthropometric measurements and feeding performance (based on caregiver reports) over time could be compared. It is interesting to note that, while statistically significant differences were demonstrated in the mean weight, length/height and MUAC measurements of the child participants over the 18-month period, mostly only individual differences were observed in terms of reported feeding performance, with some participants acquiring and maintaining certain feeding skills and others acquiring and losing certain skills, over the 18-month period. The results indicate that an increase in growth does not necessarily reflect an increase in functional ability.

5.2.3 Caregiver participants' awareness of and concerns about their children's feeding difficulties and weight over time following NDT feeding intervention and caregiver training

Caregiver awareness of and concerns about their children's feeding difficulties

The number of caregiver participants aware of their children's feeding difficulties and the number of participants concerned about their children's feeding difficulties displayed a similar trend over the 18-month period. Five caregiver participants (31.3%) were aware of their children's feeding difficulties and six caregiver participants (37.5%) were concerned about their children's feeding difficulties at the start of Period 1. At the point of follow-up data collection in Period 1, the number of caregiver participants aware of and concerned about their children's feeding performance had increased to 12 participants. Although the sample size was too small to determine any statistical

association, a trend was observed, in that the increase in the number of caregiver participants aware of and concerned about their children's feeding performance over Period 1 shows a similar pattern to the increase in the number of child participants able to perform the skills of eating ground/lumpy foods, eating cut up/chunky foods, finger feeding, scooping with a spoon and bringing it to the mouth, using a fork well, holding a bottle or cup, lifting a cup to drink, and lifting an open cup securely with one hand over Period 1. The increase in the number of child participants able to perform the feeding skills could be a reflection of the increased number of caregiver participants aware of and concerned about their children's feeding difficulties over Period 1. Fewer caregiver participants were aware of and concerned about their children's feeding difficulties after the seven-month interval between the end of Period 1 and the start of Period 2. This may be due to the caregiver participants becoming more comfortable with and used to the feeding routine at home and noticing that their children were experiencing fewer feeding difficulties. However, directly following intervention and caregiver training in Period 2, there was a notable increase in the number of caregivers aware of (seven (43.8%) participants in Period 2 [pre-intervention] to 12 (75%) participants in Period 2 [post-intervention]) and concerned about (nine (56.3%) participants in Period 2 [pre-intervention] to 13 (81.25%) participants in Period 2 [post-intervention]) their children's feeding difficulties. A possible reason for this increase may be that, as the caregivers employed the feeding techniques they had learned during caregiver training, in expecting their children to acquire a higher level skill in terms of food textures, use of utensils and use of drinking containers, their children responded negatively to the level of difficulty of that skill. For example, children who experience difficulties with chewing will either force the food out of their mouth or push the food firmly against their palate, causing the food to become compressed, but not chewed. The bolus that forms as a result, is not effective and causes the child to gag and choke when swallowed (Arvedson & Brodsky, 2002). The negative reactions that some of the child participants may have experienced might have caused an increased number of caregivers to become aware of and concerned about their children's feeding difficulties. During the follow-up assessment of Period 2, it was noted that one less participant was aware of her child's feeding difficulties and four less caregiver participants were concerned

about their children's feeding difficulties. It could be argued that some of the caregiver participants became less concerned about their children's feeding performance due to their children acquiring and maintaining certain feeding skills from the post-intervention assessment to the follow-up assessment of Period 2. However, the results obtained from the PEDI with regard to reported feeding performance only indicate an increase in the number of child participants being able to perform the skills of using a fork well, lifting a cup to drink, lifting an open cup securely with one hand and pouring liquid from a carton or bottle from the post-intervention assessment to the follow-up assessment of Period 2. Once again, although no statistical association could be made, a trend could be observed. As the number of caregivers aware of or concerned about their children's feeding difficulties decreased from the post-intervention assessment to the follow-up assessment of Period 2, so the number of child participants able to perform the skills of eating ground/lumpy foods, eating cut up/chunky foods, eating all textures, finger feeding, scooping with a spoon and bringing it to the mouth, using a spoon well, using a knife to cut food, holding a bottle or cup, and lifting a cup securely with two hands, decreased. A possible reason for the reduced number of caregivers concerned about their children's feeding performance may be due to the significant impact that reduced financial circumstances had on the caregivers' capacity to support the basic needs of their children (Donald et al., 2014). In a study conducted by Levin (2006), caregivers stated that the expense involved in medical and rehabilitative services, assistive devices, and transport is a substantial problem in obtaining the necessary healthcare for their children with CP. Studies have also shown that the caregivers of children with CP have a high tendency towards anxiety and depression, diminished health and continuing grief (Whittingham et al., 2012). With the majority of the caregiver participants being unemployed and unmarried (see Table 2), the level of stress and burden of care for their children with CP would be even greater. This could possibly have resulted in a shift in focus from their children's feeding performance to the financial difficulties and emotional stresses causing substantial concern.

Caregiver concerns about their children's weight

Fourteen (87.5%) caregiver participants were concerned about their children's weight at the start of Period 1. By the post-intervention assessment of Period 2, 15 (93.75%) of the 16 caregiver participants were concerned about their children's weight. Although no statistical association could be made, the increase in the number of caregiver participants concerned about their children's weight showed a similar pattern to that of the increased weight in the child participants over the 18-month period (see Figure 8). This could indicate that the more concerned the caregiver participants were about their children's weight, the more rigorous they became in using the appropriate feeding strategies and skills they had acquired during intervention and caregiver training, resulting in improved weight in the group of child participants.

In summary, although fluctuation in the results occurred between assessments, Table 15 demonstrated that there was an overall increase in the number of caregiver participants aware of and concerned about their children's feeding difficulties and weight over the 18-month period. Interestingly, although no statistical association could be made to the feeding performance of the child participants due to the small sample size, a similar trend was observed between the number of caregiver participants concerned about their children's feeding difficulties and the number of child participants able to perform a specific feeding skill, including the ability to eat cut-up chunky foods, finger feed, use a spoon well and a knife to cut food, lift a cup to drink, and lift a cup securely with one hand, over time. In other words, as the number of caregiver participants aware of and concerned about their children's feeding difficulties and weight increased, so did the mean weight of the child participants as well as the number of child participants able to perform certain feeding skills. Likewise, as the number of caregiver participants aware of and concerned about their children's feeding performance decreased, so did the number of child participants able to perform certain feeding skills.

Chapter 6

CONCLUSION AND RECOMMENDATIONS

The aim of this chapter is to discuss the implications of the results obtained in the current study. It also aims to describe the strengths and limitations of the study as well as provide suggestions for the direction of further research.

6.1 Introduction

Statistics regarding the prevalence of CP in South Africa are scarce due to insufficient resources to develop some form of official recording system. However, government reports show that the prevalence of CP is very high (Donald et al., 2014). Clawson et al. (2007) state that one of the earliest indicators of a neurological disorder is difficulty taking in oral feeds. The atypical muscle tone that children with CP present with causes feeding and swallowing difficulties which are classified as neurogenic dysphagia (Arvedson & Brodsky, 2002). However, much research is still required to improve the level of evidence for different CP interventions, as indicated by the systematic review on CP interventions conducted by Novak et al. (2013). Due to the limited number of studies conducted on feeding intervention in children with CP, evidence therein is often labeled 'inconclusive'. Even though evidence is slowly emerging, it is unclear whether these interventions would be effective for children with CP living in rural areas in South Africa, as their environmental circumstances, such as limited access to therapy, living in remote areas that are far from healthcare facilities and low literacy skills in caregivers (as described in the current study), may act as barriers to effective feeding intervention. It is important, therefore, to determine which feeding interventions would

be effective in improving the feeding performance in children with CP in a rural area in South Africa, and which would be carried over and maintained over time.

The current study aimed to determine if there was a change in anthropometric measurements and feeding performance of children with CP over an 18-month period following NDT feeding intervention and caregiver training, and if there was a change in caregiver awareness of and concerns about their children's feeding difficulties and weight over the same period in a rural South African community. The conclusions to the results obtained in the current study are presented according to the sub-aims of the study.

6.2 Conclusion of the results

6.2.1 Conclusion to sub-aim 1: The anthropometric measurements of children with CP over time following NDT feeding intervention and caregiver training

The results from the current study indicate that the child participants demonstrated a statistically significant improvement in their mean weight, length/height and mid-upper arm circumference measurements over the 18-month period. No statistically significant differences were observed over time in the triceps skinfold thickness measurement of the child participants. Due to the lack of reliable growth standards for children with CP, it is difficult to say whether this improvement was as a result of intervention and caregiver training or whether the change was due to standard growth and development in the child participants over time. From a clinical perspective, a greater increase in growth could have been expected over the 18-month period, but it is possible that the child participants presented with stunted growth, as is common in children with severe forms of CP (Kuperminc & Stevenson, 2008). However, as no control group was used in this study, the results cannot be interpreted further.

6.2.2 Conclusion to sub-aim 2: The feeding performance of children with CP (as reported by their caregivers) over time following NDT feeding intervention and caregiver training

With regard to the food textures category of feeding performance, there was a statistically significant increase in the number of child participants able to eat ground/lumpy foods over Period 1 and over the 18-month period, as well as in the number of participants able to eat cut up/chunky foods over Period 1. Although there were no statistically significant differences in the skills of using utensils during feeding as well as the use of drinking containers, individual differences and improvements over time were observed. Taking typical development of food textures, use of utensils and use of drinking containers into account, it is evident that the child participants experienced significant difficulties in terms of being able to perform the feeding skills. The number of participants able to perform the various feeding skills fluctuated significantly over the six assessments. This could be attributed to the atypical muscle tone, abnormal posture and persistent infantile reflexes that children with CP often present with. Certain feeding skills were maintained over the 18-month period by individual child participants, while some participants were reported to have acquired a skill only to lose the ability to perform that skill soon thereafter. Although no statistical association could be made, the trends observed in the change in the child participants' anthropometric measurements and feeding performance (based on caregiver reports) over time could be compared. It is interesting to note that, while statistically significant differences were demonstrated in the mean weight, length/height and MUAC measurements of the child participants over the 18-month period, mostly only individual differences were observed in terms of reported feeding performance, with some participants acquiring and maintaining certain feeding skills and others acquiring and losing certain skills, over the 18-month period. The results indicate that an increase in growth does not necessarily reflect an increase in functional ability.

6.2.3. Conclusion to sub-aim 3: Caregiver awareness of and concerns about their children's feeding difficulties and weight over time following NDT feeding intervention and caregiver training

Although fluctuation in the results occurred between assessments, there was an overall increase in the number of caregiver participants aware of and concerned about their children's feeding difficulties and weight over the 18-month period. Interestingly, although no statistical association could be made to the feeding performance of the child participants due to the small sample size, a similar trend was observed between the number of caregiver participants concerned about their children's feeding difficulties and the number of child participants able to perform a specific feeding skill, including the ability to eat cut-up chunky foods, finger feed, use a spoon well and a knife to cut food, lift a cup to drink, and lift a cup securely with one hand, over time. In other words, as the number of caregiver participants aware of and concerned about their children's feeding difficulties and weight increased, so did the mean weight of the child participants, as well as the number of participants able to perform certain feeding skills. This could indicate that, as the caregiver participants became more concerned about their children's feeding difficulties and weight, they became more rigorous in using the appropriate feeding strategies they had learned during intervention and caregiver training, resulting in improved feeding performance and weight in individual child participants. Likewise, as the number of caregiver participants aware of and concerned about their children's feeding performance decreased, so did the number of child participants able to perform certain feeding skills.

6.3 Critical evaluation of the study

6.3.1 Limitations of the study

A number of limitations were present in the current study. Firstly, in order to complete the PEDI questionnaire, the original researcher was dependent on the respondents' ability to recall and give a judgment based on perception. In the PEDI, each caregiver

was asked to state whether their child was unable or capable of performing a specific feeding skill. If the caregiver was not able to accurately recall their child's capabilities or feeding difficulties, he/she would have provided inaccurate answers to the questionnaire, thus affecting the reliability of the results. Questionnaires are inherently subjective (Leedy & Ormrod, 2014), but the fact that the questions could be posed and answered in the caregiver participants' first language (isiXhosa) could have contributed to increased reliability of this form of data collection.

The z-score classification system, recommended by the World Health Organization (WHO), describes the nutritional status of a child. The calculation of z-scores (weight-for-age, height-for-age and weight-for height) for the child participants in the current study was attempted. However, when using the anthropometric calculator, z-scores appear as not available (NA) if a child's age is above 60 completed months (WHO, 2011). In the current study, 8 of the 16 participants were older than 60 months. Therefore, z-scores could not be calculated for the participants.

Due to the small number of participants, the results obtained in the current study could not be generalized to the general population of children with CP. However, this is a limitation that has been experienced in many research studies conducted on children with CP. Gisel (2008) examined some of the difficulties incurred in research in children with CP. The review indicated that, due to the heterogeneity of CP, sample sizes are restricted, making it difficult to generalize the results obtained from small studies.

As the age range of the participants was broad (one to 18 years), the current researcher was unable to compare the results from the anthropometric measurements of the child participants to those of typically developing children. However, according to Day et al. (2007), anthropometric measurements of children and adolescents with the most severe forms of CP and who present with substantial feeding complications are so different to those of their typically developing peers that standard growth curves are of minimal use in studying their growth. Also, a lack of comparative growth charts for children with CP made it difficult to compare the anthropometric data obtained in the current study to the population of children with CP.

Finally, the lack of a control group also limited the researcher in terms of being able to make a comparison between a group of children with CP that did not receive any intervention and the group of children with CP that received intervention, thus more accurately determining the effect of the intervention. However, the use of a control group that does not receive intervention may not be feasible when intervention services are a scarce commodity in an impoverished rural community. A stronger research design may increase the validity of the results.

6.3.2 Strengths of the study

The PEDI (Hayley et al., 1992) is a standardized assessment tool that was tested for reliability in a study conducted by Nichols and Case-Smith (1996). Their results found the PEDI to be a reliable and valid assessment of functional performance in children with disabilities. For the purposes of this study, the PEDI was translated into isiXhosa by a trained translator. Although the translation detracts somewhat from the reliability and validity of the assessment tool, it would have been impossible to conduct the interviews in a language unfamiliar to the participants of the study.

The anthropometric measurements of the child participants were taken by the same physiotherapist each time. This physiotherapist had received training in anthropometry. The anthropometric measurements were objective, thus adding to the internal validity of the data. Each measurement was taken three times and an average score was calculated. This increased the reliability of the measurements obtained.

Through statistical analysis and the use of the regression equation, the tibial length measurement was found to be the most accurate predictor for the length/height measurement of the participant that presented with contractures. The tibial length measurement was found to be the more accurate proxy for length/height than the half-span measurement. This could be beneficial information for future researchers conducting research that involves obtaining anthropometric measurements of children with CP.

6.4 Recommendations

6.4.1 Recommendations for clinical practice

Based on the results of the current study, it remains a challenge to recommend a single intervention approach that would be effective in treating the population of children with CP, particularly in light of the barriers that exist in a rural area. However, considering the improvements that were made in individual child participants in terms of feeding performance, it is recommended that intervention be individualized (Snider et al., 2011). CP is a heterogeneous condition and each child presenting with the disability displays varying degrees of severity and motor function. It is, therefore, imperative that each child receive intervention that is specifically targeted at improving their functional abilities, environment and their participation in their environment.

As CP is a permanent neurological disorder that results in spasticity and contractures, feeding complications, drooling, intellectual and communication impairments, osteoporosis, pain and functional gastrointestinal defects which may result in intestinal blockage, vomiting and constipation, a transdisciplinary team approach to intervention that is family-centered, is necessary. A physiotherapist, occupational therapist and speech-language therapist should be included in the treating team.

6.4.2 Recommendations for future research

Novak et al. (2013) indicated in their systematic review that NDT was not effective in terms of maintaining the skills acquired in intervention. However, in terms of improving function, recent research has shown that the provision of NDT more frequently and for longer periods of time is beneficial, but that the approach should still be used with caution (Novak et al., 2013). It is recommended, therefore, that future researchers use the NDT approach in the same manner as that of the current study, but in more frequent blocks over a longer period of time. It is a challenge to conduct longitudinal research in a population of children with CP in a rural area, given financial implications,

setting (far from healthcare facilities and services) and transportation difficulties as a result of the remote location of the rural areas. It is, therefore, recommended that only one intensive intervention block be conducted in the rural area, but that intervention is provided more regularly and for a longer period of time.

It is also recommended that future researchers use a control group of children with CP that do not receive intervention in order to make a comparison between the group that receives intervention and the group that does not receive intervention. A stronger research design, such as one that involves a control group, may allow the researcher to make more accurate deductions on the effect of the intervention in children with CP.

Finally, it is recommended that future researchers conduct statistical analyses to determine if there is an association between caregivers aware of and concerned about their children's feeding difficulties and weight and the feeding performance of the children with CP.

6.5 Final conclusion

The main aim of the current study was to determine if there was a change in the anthropometric measurements and feeding performance of children with CP over an 18-month period, following NDT feeding intervention and caregiver training, and if there was a change in caregiver awareness of and concerns about their children's feeding difficulties and weight over the same period in a rural South African community.

Statistically significant differences were observed in the mean weight, length/height and MUAC measurements of the child participants over the 18-month period, while no significant difference occurred in the mean triceps skinfold thickness measurement. Despite significant differences in the anthropometric measurements of the child participants, this difference appeared minimal from a clinical perspective. It is also difficult to say whether the changes in anthropometric measurements in the child participants were as a result of intervention and caregiver training or if they were purely

due to natural growth and development over time. There was a statistically significant increase in the number of child participants able to tolerate ground/lumpy foods over the 18-month period. Although no statistically significant differences in the remaining reported feeding performance skills of the group of child participants were observed, individual participants demonstrated improvement in and maintenance of certain feeding skills, including the ability to eat cut-up chunky foods, finger feed, use a spoon and a knife to cut food, lift a cup to drink and lift a cup securely with one hand, over time. No statistically significant differences were observed in the number of caregiver participants aware of and concerned about their children's feeding difficulties and weight over the 18-month period. However, a trend was observed in that, as the number of aware and concerned caregiver participants increased, so did the number of children able to perform a particular feeding skill. Likewise, as the number of aware and concerned caregiver participants decreased, so did the number of child participants able to perform certain feeding skills.

Families of children with CP naturally want their children to receive the most appropriate and beneficial treatment possible. In rural areas, where unemployment rates and the number of single caregiver homes are high, caregivers rely upon intervention that is economical and easily accessed as they live in remote areas that are far from healthcare facilities and services. Therefore, it is important to provide treatment and services that are easily accessible, effective and cost-efficient (Novak et al., 2013). Interventions that were classified as effective in the systematic review conducted by Novak et al. (2013), included medication such as botulinum toxin to reduce muscle spasticity, the use of gastrostomies for improving nutrition, the use of casting for improving ankle range of motion, and hip surveillance for maintaining hip joint integrity, all of which require either funding or access to regular therapeutic services. This is not always possible in a rural setting such as in South Africa due to poverty and the remote locations of rural areas.

NDT was the intervention approach used in the current study as it appeared to be cost-effective and easily accessible for the participants living in the rural area, in that caregiver training was provided throughout the intervention blocks. This training of the

caregivers allowed them to employ appropriate feeding techniques at home, as their location was too far from healthcare facilities that provided regular therapeutic services. In the systematic review conducted by Novak et al. (2013), home programs were found to be an effective intervention for improving motor activity performance and self-care in children with CP. NDT itself was not classified as an effective intervention approach as it did not result in improvements above those of other available interventions (Novak et al., 2013). However, in terms of improving function, recent research has shown that the provision of NDT more frequently and for longer periods of time is beneficial, but that the approach should still be used with caution (Tsorlakis et al., 2004). As no control group was used in the current study, it is difficult to say whether the improvements in anthropometric measurements and feeding performance demonstrated in individual participants were as a result of the intervention and caregiver training provided.

Despite children with CP being a heterogeneous population, making it a challenge to find cost-efficient and effective intervention solutions to the wide range of difficulties they present with, continuing efforts should be made to find ways of improving independent functioning in children with CP.

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Appendices

Appendix A: Ethical clearance provided by the Research Ethics Committee (Faculty of Humanities, University of Pretoria)

Appendix B: Letter of permission to use data (Dr Saloojee)

Appendix C: Ethical clearance given to Dr Saloojee by the University of the Witwatersrand

Appendix D: Caregiver information sheet (English)

Appendix E: Caregiver information sheet (isiXhosa)

Appendix F: Written caregiver informed consent form

Appendix G: Verbal caregiver informed consent form

Appendix H: Written informed assent form for children who were able to read and understand

Appendix I: Verbal informed assent form for children

Appendix J: Demographic questionnaire

Appendix K: PEDI (Pediatric Evaluation of Disability Inventory)

Appendix L: Feeding Profile (English)

Appendix M: Feeding Profile (isiXhosa)

Appendix N: Short-term treatment goals for children with CP

Appendix O: Statistics Sheets