

Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy

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It all starts here [™]



PREFACE

This mini-dissertation will be presented in article format. Lucinda Lourens, the *Magister Scientiae* (MSc) student, wrote the article: “Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy” in accordance with the authors guidelines of the journal *Child: Care, Health and Development* to which the article (Chapter 3) will be submitted.

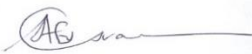
The co-authors of this article in Chapter 3, Dr R.C Dolman and Dr A.E van Graan, provided permission that the article be submitted for examination purposes. The article is still to be submitted to the journal, therefore no permission was obtained from the editor of the journal.

The following signatures and statement confirm that the student and co-authors provide permission to include the article (Chapter 3) in this mini-dissertation.

“By submitting this research assignment, I declare that all content of the work contained therein is my own, original work, that I am the sole author thereof and that I have not previously in its entirety or in part submitted it for obtaining any qualifications. I hereby provide consent for the article to be published as part of the *Magister Scientiae in Dietetics* mini-dissertation of Mrs L.C Lourens.”

R.Dolman

Dr R.C Dolman



Dr A.E van Graan

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ABSTRACT

Background

Cerebral palsy (CP) is found to be the most common cause of physical disability in childhood affecting multiple facets pertaining to health of which nutrition plays a major part in their quality of life (QOL) and ability to grow, develop and thrive. Parents with children suffering from spastic CP face various challenges. The nutrition-related problems that these children encounter are not well described in the South African setting. Therefore, the aim of this study was to identify nutrition-related concerns that parents encountered with their children affected by spastic CP, between the ages of one and ten years old, and explore the management of these difficulties together with the current feeding practices and parental perspectives on challenges pertaining to nutrition and health.

Methods

This cross-sectional quantitative research study made use of a self-administered, validated nutritional questionnaire to obtain information from participants at three facilities: the Pretoria Centre for Cerebral Palsy (PCCP), the Baby Therapy Centre (BTC) and New Hope School (NHS), situated in the Gauteng Province. Primary caregivers (parents or legal guardians) of children suffering from spastic CP were approached for inclusion in this study. Recruitment was done by healthcare professionals (HCPs) at each facility with the use of a screening tool. The recruitment process, data collection and capturing took place over a period of three months simultaneously at these facilities. The information was statistically analysed and extracted for interpretation.

Results and discussion

Thirty-four questionnaires were completed in total by parents and returned to the facilities. The most common nutrition-related concerns reported were constipation (47.1%), underweight (32.4%) and poor appetite (20.6%). The prevalence of food allergies or intolerances was reported to be low and only a small percentage of children reported to have iron-deficiency anaemia (11.7%). Nutrition-related problems were managed mostly by consulting any HCP (44.1%), obtaining advice from a book or magazine (41.2%), from a friend or relative (35.3%) and the Internet or social media (32.4%). Most children were seen by a multidisciplinary team (MDT) of therapists, but only 44% consulted a registered dietitian (RD). Information pertaining to past and current feeding practices showed that most children were breastfed from birth (52.9%) to the age of less than six months old (55.6%). Some nutritionally poor food choices such as consuming

deep fried food was reported, although most children consumed fresh foods from all food groups: starches (76.5%) including fresh fruit (44.1%) and vegetables (41.2%), protein (55.9%) including dairy products (61.8%) and fats (41.2%). Sugar-free drinks were always consumed by only 65% of children. Most children required assistance at mealtimes (61.8%) and most parents spent less than two hours daily on feeding their child (55.9%). Solids (64.7%) and pureed food (23.5%) were best tolerated. Most parents felt content with or very confident in their abilities in all the categories pertaining to feeding practices. Only some parents were anxious about the growth and development (20.6%) of their child. A mere 38.2% of parents were satisfied with how they dealt with nutrition-related problems and only a few parents were very confident in dealing with these problems (14.7%). Parents were satisfied, content or very confident regarding their child's overall health status.

Conclusion and recommendations

Nutrition-related concerns that these parents encountered with their children suffering from spastic CP, were common. The information parents use from various sources in managing these concerns also raises concern as to whether it is accurate, factual and science-based. The pivotal role of the RD in addressing and managing nutrition-related problems, advising on healthy feeding practices and parental support pertaining to nutrition, needs to be emphasised and remains a crucial part of treatment in this group of disabled children. The information gathered from this study can be used to evaluate where the need for nutrition education lies and where nutrition-related resources or guidelines for families taking care of a child with CP, can improve or be developed.

KEYWORDS

Cerebral palsy, children, nutrition-related problems, nutritional management, feeding practices, parental concerns, dietetic role

OPSOMMING

Agtergrond

Serebraal parese (SP) is die mees algemene oorsaak van fisiese gestremdheid in kinders. Dit beïnvloed verskeie fasette onder andere algemene gesondheid, ten aansien waarvan voeding 'n kardinale rol vervul in die lewenskwaliteit, groeivermoë en ontwikkeling van hierdie kinders. Verskeie uitdagings betstaan vir ouers met kinders geaffekteer deur spastiese SP. Die voedingsverwante uitdagings wat hierdie groep kinders in die gesig staar is steeds nie optimaal omskryf in Suid Afrika nie. Hierdie studie is dienoreenkomstig daarop gemik om voedingsverwante uitdagings vir ouers met kinders wat spastiese SP het, tussen die ouderdomme van een en tien jaar oud, te identifiseer en om die hantering of behandeling daarvan in konteks met die mees onlangse voedingspraktyke asook ouerlike perspektief, vas te stel.

Metode

Hierdie dwarsdeursnit, kwantitatiewe navorsingstudie was saamgestel vanuit en gebaseer op 'n self-geadministreerde, gevalideerde voedingsvraelys by wyse waarvan die nodige inligting vanaf vrywillige deelnemers bekom was te drie fasiliteite: Pretoria Sentrum vir Serebraal Parese (PSSP), die Baba Terapie Sentrum (BTS) en Nuwe Hoop Skool (NHS), geleë in die Gauteng Provinsie. Die deelnemers aan hierdie studie behels die primêre versorgers (ouers en voogde) van kinders met spastiese SP. Werwing was onderneem deur gesondheidspraktisyns te elke fasiliteit by wyse van 'n keuringsinstrument. Die werwingsproses, data insameling en verwerkings het oor 'n tydperk van drie maande gestrek en het gelyktydig by elkeen van die onderskeie fasiliteite plaasgevind. Die inligting sodanig bekom was daarna statisties geanaliseer en geïnterpreteer.

Resultate en bespreking

Vier en dertig vraelyste was voltooi deur ouers van kinders met spastiese SP en terug besorg aan elke fasiliteit. Die mees algemene voedingsverwante uitdagings gerapporteer was hardlywigheid (47.1%), ondergewig (32.4%) en swak eetlus (20.6%). Die teenwoordigheid van voedsel allergieë of intoleransies was laag en slegs 'n klein persentasie van kinders was gerapporteer om aan 'n yster-tekort anemie (11.7%) te ly. Voedingsverwante uitdagings was meestal aangespreek en behandel deur advies geraadpleeg vanaf enige gesondheidspraktisyn (44.1%), vanuit tydskrifte of boeke (41.2%), vanaf familielede of vriende (35.3%) of deur inligting vanaf die Internet of sosiale media (32.4%). Die meeste kinders was ondersoek deur 'n multi-dissiplinêre span van

terapeute, maar slegs 44% van hulle is deur 'n geregistreerde dieëtkundige ondersoek. Inligting ten aansien van gelede en bestaande voedingspraktyke was aanduidend dat meeste kinders geborsvoed was vanaf geboorte (52.9%) tot en met die ouderdom van ses maande oud (55.6%). Daar was vasgestel dat sekere swak voedsel keuses uitgeoefen was deur ouers, maar dat in meeste gevalle vars voedsel van alle voedselgroepe ingeneem was: stysel (76.5%) insluitend vars vrugte (44.1%) en groente (41.2%), proteïen (55.9%) insluitend suiwel produkte (61.8%) en vet (41.2%). Suiker-vrye drankies was in meeste gevalle verkies bo ander drankies, maar dit was slegs deur 65% van kinders ingeneem. Meeste kinders het 'n behoefte gehad aan bystand en hulp tydens maaltye (61.8%) en meeste ouers het minder as twee ure daaglik spandeer om hul kinders te voed (55.9%). Vaste kosse (64.7%) en puree kosse (23.5%) was die beste getollereer. Meeste ouers was tevrede of vertrouwd met hul vermoëns in alle kategorieë van voedingspraktyke. Slegs sekere ouers was angstig ten aansien van die groei en ontwikkeling van hul kinders (20.6%). Verdermeer, was slegs 38.2% van ouers tevrede met hoe hulle voedingsverwante uitdagings hanteer het en slegs 'n klein aantal ouers was baie vertrouwd met die hantering van hierdie uitdagings (14.7%). Ouers was tevrede of baie vertrouwd ten aansien van hul kinders se algemene gezondheidstoestand.

Gevolgtrekking en aanbevelings

Voedingsverwante uitdagings wat ouers met hul kinders geaffekteer deur spastiese SP teëkom, was algemeen. Die inligting wat ouers gebruik, wat hulle van verskeie bronne bekom, om hierdie uitdagings te hanteer of behandel wek ook sekere bekommernisse ten aansien van akkuraatheid sowel as die feitelike en wetenskaplike korrektheid van hierdie inligting. Die kardinale rol van 'n geregistreerde dieëtkundige in die proses om die voedingsuitdagings van hierdie kinders aan te spreek en te bestuur, om te adviseer op gesonder voedingspraktyke en verbandhoudende ouerlike ondersteuning, moet beklemtoon word en bly 'n belangrike deel van behandeling van hierdie groep gestremde kinders. Die inligting wat in hierdie studie ingewin was kan gebruik word om vas te stel waar die behoefte vir voedingsverwante onderrig lê en waar voedingsverwante hulpbronne of riglyne vir families met kinders geaffekteer deur SP, verbeter of ontwikkel kan word.

SLEUTELWOORDE

Serebraal parese, kinders, voedingsverwante uitdagings, voedingsbestuur, voedingspraktyke, ouerlike bekommernisse

TABLE OF CONTENTS

PREFACE.....	i
ACKNOWLEDGEMENTS.....	ii
ABSTRACT.....	iii
OPSOMMING.....	v
LIST OF TABLES.....	xi
LIST OF FIGURES.....	xii
LIST OF ABBREVIATIONS.....	xiii
CHAPTER ONE – INTRODUCTION.....	1
1.1 General introduction.....	2
1.2 Rationale for this study.....	3
1.3 Research aim.....	4
1.4 Research objectives.....	4
1.5 Structure of this mini-dissertation.....	4
1.6 Research outputs emanating from this study.....	5
1.7 Contributions of members of the research team.....	6
1.8 References.....	7
CHAPTER TWO – LITERATURE REVIEW.....	10
2.1 Introduction.....	11
2.2 Background on cerebral palsy.....	12
2.2.1 Brief history, causes and etiology.....	12
2.2.2 Diagnosis and classifications on the types of cerebral palsy.....	14
2.2.3 Prevalence of cerebral palsy.....	20
2.3 Nutrition-related concerns and difficulties regarding cerebral palsy.....	21
2.3.1 Growth abnormalities.....	23
2.3.2 Feeding difficulties and problems.....	25

TABLE OF CONTENTS (continued)

2.3.2.1	Dysphagia.....	27
2.3.2.1.1	Recommendations on managing dysphagia.....	29
2.3.2.2	Gastro-esophageal reflux disease (GERD).....	32
2.3.2.2.1	Recommendations on managing GERD.....	32
2.3.2.3	Constipation.....	34
2.3.2.3.1	Recommendations on managing constipation.....	34
2.3.3	Prolonged feeding times.....	35
2.3.3.1	Interventions to improve feeding time.....	36
2.3.4	Nutritional deficiencies and deficits.....	37
2.3.4.1	Macronutrients.....	37
2.3.4.2	Micronutrients.....	38
2.3.4.3	Addressing nutritional deficiencies.....	40
2.3.5	Malnutrition.....	42
2.3.5.1	The detrimental effects of malnutrition.....	43
2.3.5.2	Recommendations on managing malnutrition.....	44
2.3.5.2.1	Screening for malnutrition	44
2.3.5.2.2	Addressing malnutrition by means of nutrition.....	45
2.3.5.2.3	Other options in managing malnutrition.....	46
2.4	General management of nutrition-related problems in children with cerebral palsy	47
2.4.1	Managing nutrition-related problems.....	48
2.4.2	Nutrition support and interventions.....	52
2.5	Parental concerns and stress-related issues.....	54
2.5.1	How to address and manage stress-related concerns of parents.....	55
2.6	Multidisciplinary involvement and professional support.....	57
2.7	Summary of the literature and future research.....	60
2.7.1	Challenges and concerns in the field of cerebral palsy.....	60
2.7.2	Recommendations and future research.....	61
2.8	References.....	63

TABLE OF CONTENTS (continued)

CHAPTER THREE – ARTICLE	78
3.1 Title page	79
3.2 Author guidelines for the journal <i>Child: Care, Health and Development</i>	80
3.3 Article to be submitted to the journal <i>Child: Care, Health and Development</i>	89
Abstract.....	89
Introduction.....	90
Methods.....	91
Results.....	94
Discussion.....	104
Key messages.....	110
Acknowledgements.....	110
References.....	111
 CHAPTER FOUR – DISCUSSION, RECOMMENDATIONS AND SUMMARY	115
4.1 Introduction	116
4.2 Nutrition-related concerns that parents encountered	116
4.3 Management of nutrition-related concerns	117
4.4 Current feeding practices	118
4.5 Other nutrition-related concerns emanating from this study	119
4.5.1 Multidisciplinary support in taking care of a child affected by CP.....	119
4.5.2 The important role of a registered dietitian.....	120
4.6 Conclusions and practical recommendations	120
4.7 Limitations of the research project	121
4.8 Future research	121
4.9 References	123

TABLE OF CONTENTS (continued)

ANNEXURES	126
ANNEXURE A: The healthcare professionals that assisted with recruitment.....	127
ANNEXURE B: The screening tool used for recruitment.....	128
ANNEXURE C: Consent form for participants.....	129
ANNEXURE D: The Validated Nutritional Questionnaire – Afrikaans version.....	138
ANNEXURE E: The Validated Nutritional Questionnaire – English version	151
ANNEXURE F: Letters of approval to the various authorities / facilities.....	164
ANNEXURE G: Ethical approval from the North-West University Ethics Committee.....	173
ANNEXURE H: Approval letter from the Baby Therapy Centre.....	175
ANNEXURE I: Approval letter from the Gauteng Department of Education.....	176
ANNEXURE J: Approval letter from New Hope School.....	177
ANNEXURE K: Approval letter from the Pretoria Centre for Cerebral Palsy.....	178

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LIST OF TABLES

CHAPTER ONE

Table 1.1: List of members and their contributions to this research project.....	6
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CHAPTER TWO

Table 2.1: Risk factors for cerebral palsy.....	14
Table 2.2: Abnormal signs associated with cerebral palsy.....	15
Table 2.3: Four major components of cerebral palsy classification.....	18
Table 2.4: The five groups of the GMFCS developed for cerebral palsy children.....	19
Table 2.5: The processes and problems of the different phases of oro-pharyngeal dysphagia.....	28
Table 2.6: Focus areas in determining the need for nutritional intervention in a cerebral palsy child.....	48

CHAPTER THREE

Table 3.1: Inclusion and exclusion criteria.....	92
Table 3.2: Demographic information of the primary caregivers (parents) and their children with spastic cerebral palsy.....	95
Table 3.3: Nutrition-related problems of the child with spastic cerebral palsy.....	97
Table 3.4: Management of nutrition-related problems.....	98
Table 3.5: Diet history of the child with spastic cerebral palsy since birth.....	99
Table 3.6: Current feeding practices of the child with spastic cerebral palsy.....	101
Table 3.7: Factors contributing to mealtime preparation, feeding the child and food selection.....	103
Table 3.8: Parental perspectives and feelings of the primary caregivers on feeding practices regarding their child with spastic cerebral palsy.....	104

LIST OF FIGURES

CHAPTER TWO

Figure 2.1: Neurological classification of cerebral palsy.....	17
Figure 2.2: Proposed relationships between feeding problems, communication, positioning, motor impairment, neurological concerns, activity level and use of medication on the health status outcomes in children with moderate to severe cerebral palsy....	22
Figure 2.3: The World Health Organisation's model to illustrate interactions between components of the International Classification of Functioning, Disability and Health.....	49
Figure 2.4: The influence of correct postural alignment on oral control for feeding.....	52

LIST OF ABBREVIATIONS

BMI: body mass index

BTC: Baby Therapy Centre

CMP: cow's milk protein

CP: cerebral palsy

CT: computed tomography

DEXA: dual-energy X-ray absorptiometry

DoE: Department of Education

DRI: dietary reference intake

DSD: Department of Social Development

DWCPD: Department of Women, Children and People with Disabilities

EAR: estimated average requirements

FEES: flexible endoscopic evaluation of swallowing

FSC: family-centred service

GDE: Gauteng Department of Education

GERD: gastro-esophageal reflux disease

GI: gastrointestinal

GMFCS: gross motor function classification system

HCP: healthcare professional

HIE: hypoxic ischemic encephalopathy

ICFDH: International Classification of Functioning, Disability and Health

ID: intellectual disability

IQ: intelligent quotient

LIST OF ABBREVIATIONS (continued)

LBW: low birth weight

MACS: manual ability classification system

MDT: multidisciplinary team

MRI: magnetic resonance imaging

MUAC: mid-upper arm circumference

MUAFA: mid-upper arm fat area

NDT: neurodevelopmentally trained

NHANES: National Health and Nutrition Examination Questionnaire

NHIS: National Health Interview Questionnaire

NHS: New Hope School

NICU: neonatal intensive care unit

PCCP: Pretoria Centre for Cerebral Palsy

QOL: quality of life

RD: registered dietitian

RDA: recommended daily allowance

REE: resting energy expenditure

TSF: triceps skinfold

UNICEF: United Nations Children's Fund

VFSS: videofluoroscopic swallow study

VLBW: very low birth weight

WHO: World Health Organisation

CHAPTER ONE – INTRODUCTION

CHAPTER ONE – INTRODUCTION

1.1 General introduction

Cerebral palsy (CP) is the most common cause of physical disability in childhood. It is described in the literature as a group of permanent disorders which affects the development of movement and posture, resulting in restricted activity that occurs due to non-progressive disturbances in the infant brain or during foetal development (Bax, 1964; Rosenbaum *et al.*, 2007:9; Van Toorn *et al.*, 2007:74). Cerebral palsied children are faced with motor deficits and a range of disabilities and problems affecting quality of life (QOL), such as altered growth patterns, gastrointestinal (GI) functional abnormalities, intellectual disability, problems with nutrition, feeding and swallowing, hearing and visual deficits, respiratory infections and epilepsy (Ashwal *et al.*, 2004:851; Laughton, 2004:435, 436; Liptak & Accardo, 2004:s36; Reilly *et al.*, 1996:879, 880; Sullivan *et al.*, 2000:677). Children with severe motor impairment are most at risk of developing growth and nutritional complications and do not grow and develop as well as their neurologically normal peers (Andrew & Sullivan, 2010:357; Day *et al.*, 2007:169; Stevenson *et al.*, 2006:1011; Sullivan *et al.*, 2000:677).

Causes of poor growth are attributable to many factors, including nutritional, endocrine and/or neurological complications (Andrew & Sullivan, 2010:357; Stallings *et al.*, 1993). There is a complex interaction between these factors and the overall growth of children with CP which requires further clarification to understand it better. Poor growth and inadequate nutrition in these children adversely affect physical and brain growth and development, cognition and behaviour, muscle strength, cardiac function, immunity, healing and repair (Andrew & Sullivan, 2010:359).

Early involvement of a skilled multidisciplinary team (MDT) is essential to identify and reduce feeding difficulties, including nutritional intake and growth, by supporting and educating parents or caretakers in the daily care of the child (Andrew *et al.*, 2012:225; Gagliardi *et al.*, 2008:335; Jones *et al.*, 2007:226; Liptak & Accardo, 2004:s40; Marchand *et al.*, 2006:128; Murphy & Such-Neibar, 2003:152). Medical management includes individualised care plans from a MDT which considers the nutritional status, the medical, feeding and growth history, gross motor skills, oro-motor skills, the feeding environment, feeding ability, swallowing, seating and positioning and the energy requirements of the child with CP (Andrew & Sullivan, 2010:359; Andrew *et al.*, 2012:225; Mascarenhas *et al.*, 2008:600).

1.2 Rationale for this study

In the literature, it is clearly demonstrated that the nutritional intake and status of a child with CP is of utmost importance for its health, wellbeing and survival. Feeding difficulties and problems related to nutrition are extremely common and affect QOL, growth and development. Such difficulties further contribute to prolonged feeding times and inadequate food and fluid intake, which could result in dehydration, malnutrition and growth retardation, with insufficient intake to meet metabolic demand (Andrew & Sullivan, 2010:357; Arvedson, 2013:S9; Campanozzi *et al.*, 2007:28; Fung *et al.*, 2002:366; Gangil *et al.*, 2001:843; Spiroglou *et al.*, 2004:180; Sullivan *et al.*, 2000:679).

Severely affected children are fully dependent on a parent or caretaker for feeding (Grammatikopoulou *et al.*, 2009:625; Majnemer *et al.*, 2007:475; Soylu *et al.*, 2008:332; Sullivan *et al.*, 2000:678; Sullivan *et al.*, 2002:464). Parental stress and depression are of major concern in this population owing to the tremendous psychosocial impact of the condition, the financial implications, limited communication, prolonged feeding and lack of self confidence in nurturing and taking care of the CP child. By addressing the above challenges, one may provide families with helpful information to relieve stress and improve parent satisfaction (Law *et al.*, 2003:363, 364; Lindstrand *et al.*, 2002).

Early nutritional management with regular follow-ups is vital for optimal growth and development, especially for young children with CP (Day *et al.*, 2007:171; Mascarenhas *et al.*, 2008:605; Soylu *et al.*, 2008:333; Stevenson *et al.*, 2006:1014). Nutritional intervention enables appropriate growth and nutrition for neurologically impaired children and a well-planned diet will prevent overfeeding or underfeeding and improve quality of life (Andrew & Sullivan, 2010:360; Bell & Samson-Fang, 2013:S13; Karagiozoglou-Lampoudi *et al.*, 2012:652; Marchand *et al.*, 2006:128). Families need practical help with daily challenges when caring for a child suffering from cerebral palsy (Wood, 2006:291). In South Africa, there are very limited nutritional resources and few established nutritional guidelines for families taking care of a child with CP. We should focus on addressing the nutrition-related concerns that these families may face and provide ongoing support. Currently, there are limited support systems in place and most parents never get to consult a registered dietitian (RD) to assist with nutrition-related matters. Generating proper nutrition-related guidelines and providing practical advice to families will make a *significant* difference in the lives of families and children suffering from CP.

This study is therefore focused on determining the most common feeding difficulties and diet-related problems that parents or caretakers may encounter, as well as how these difficulties or problems are addressed when taking care of children with spastic CP from the age of one to ten years old.

With this in mind, one can use the information gathered from this study to assess and discover where the need for nutrition education lies and where nutrition resources and guidelines for families with a CP child can improve or develop.

1.3 Research aim

The aim of this study is to quantitatively explore the concerns and difficulties in the management of dietary problems that the primary caregiver (a parent or legal guardian) encounters with children affected by spastic CP (with a chronological age of one to ten years), by means of a self-administered, validated nutritional questionnaire.

1.4 Research objectives

To achieve the aim, the following specific objectives need to be attained by means of the validated nutritional questionnaire:

- 1.4.1 To identify from primary caregivers the common nutritional concerns and problem areas of children suffering from spastic CP who can eat orally.
- 1.4.2 To gather information from primary caregivers about the management of and current feeding practices used for specific dietary problems that spastic CP children may encounter.

1.5 Structure of this mini-dissertation

This mini-dissertation will be presented in article format according to the postgraduate guidelines of the North-West University (NWU). It consists of four chapters and decimal numbers are used to ensure a logical sequence. The directives found in the Manual for Master's and Doctoral Studies of 2013 of the NWU were strictly followed for the language format and the referencing style used in this mini-dissertation. All relevant references will be provided at the end of each chapter. The references used in chapters one, two, and four are presented as stipulated by the NWU mandatory referencing style. The references for the article in chapter three will be cited

according to the author guidelines instructions of the specific journal to which the article will be submitted for publication.

Chapter one provides a brief introduction to and rationale for the research project, as well as the aim and objectives of the project and the research outputs that will emanate from this study. Details regarding members of the research team and their contributions to this research project are also provided.

Chapter two consists of a review of the available literature that focuses on the nutrition-related concerns and problems that children with CP encounter, how these problems are managed and addressed, the impact that the care of these children has on parents or caretakers, and the important role of the MDT and their professional support of families and children suffering from CP. This information will assist in understanding the background to the research topic and will help in the comparison of the data derived from this study with what is found in the literature, which will be presented in the article in chapter three.

Chapter three includes the article containing all information regarding this research project, especially the background, the framework of what the project entails, and results found in the validated nutritional questionnaire. This article will be submitted for publication to the *Child: Care, Health and Development* journal. It is the official journal of the British Association of Community Child Health, the Swiss Paediatric Society, and the European Society for Social Paediatrics. The style, format and referencing for this article followed the author guidelines and instructions of the journal and therefore the numbering of headings, tables and figures differs from those in the other chapters.

Chapter four completes this mini-dissertation, providing a summary of the work and findings of this research project together with recommendations on future research and concluding remarks. This chapter is based on the aim and key objectives that have been identified for this study.

1.6 Research outputs emanating from this study

Once the results are available, feedback will be given to the various authorities: the Pretoria Centre for Cerebral Palsy (PCCP) at Groenkloof Life hospital, the Baby Therapy Centre (BTC) and New Hope School (NHS), where the Department of Education (DoE) will also be informed. This will be done by submitting a detailed report containing all the findings from the study. Feedback will be given to participants upon request. An article will be submitted to the journal

Child: Care, Health and Development. Results may also be shared at various congresses (national or international) with the consent of the participants.

1.7 Contributions of members of the research team

The following table lists the members of the research team and their contributions to this research project. They are also the authors, as listed in the article, who played a major role in this study.

Table 1.1: List of members and their contributions to this research project

Name and signature	Affiliation	Role in the study
Mrs L.C Lourens (Part-time MSc student)	Registered Dietitian Private Practice in Pretoria, Gauteng	Responsible for the planning, execution and management of this research project. Compiled the literature review after thorough research regarding CP. Data capturing obtained from the validated nutritional questionnaires. Interpretation of all data. Writing up of this mini-dissertation for publication.
Dr R.C Dolman (Supervisor)	CEN in the School for Physiology, Nutrition and Consumer Science of the NWU	Supervisor for Mrs LC Lourens in the completion of this mini-dissertation. Played a supervisory role in the planning and execution of the research project. Advice and recommendations given regarding the structure, layout, and technical aspects of this mini-dissertation. Assisted in compiling the nutritional questionnaire and the validation process.
Dr A.E van Graan (Co-supervisor)	Member of the MRC (SAFOODS) as Specialist Scientist	Co-supervisor for Mrs LC Lourens in the completion of this mini-dissertation. Played a supervisory role in the planning and execution of this research project. Advice and recommendations given regarding the structure, layout, and technical aspects of this mini-dissertation. Assisted in compiling the nutritional questionnaire and the validation process.

CEN: Centre of Excellence for Nutrition; **CP:** Cerebral Palsy; **MRC:** Medical Research Council; **NWU:** North-West University; **SAFOODS:** South African Food Data System

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CHAPTER TWO – LITERATURE REVIEW

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2.1 Introduction

Cerebral palsy (CP) is the most common cause of physical disability in childhood (Aisen *et al.*, 2011:844; Campbell *et al.*, 2008:260). It is described in the literature as a group of permanent, lifelong neurological disorders that affects the development of movement and posture, resulting in restricted activity due to non-progressive disturbances in the infant brain or during foetal development (Bax, 1964:295; Little Club, 1959:27; Mutch *et al.*, 1992:548).

Injury or abnormal formation of locations in the brain that include a white or grey substance are related to CP (Aisen *et al.*, 2011:844; Campbell *et al.*, 2008:261). Children affected by CP should acquire rehabilitative services and professional support to assist with problems and concerns (Campbell *et al.*, 2008:260, 261). Although muscles and nerves are affected, clinicians are still establishing the underlying medical diagnosis that results in CP to determine appropriate treatment options, prognosis, reappearing risks, and how to alleviate feelings of guilt and responsibility that parents may face (Campbell *et al.*, 2008:261).

Several factors can contribute to inadequate intake and feeding dysfunction that could hinder safe and effective feeding, including oral motor dysfunction, poor positioning at mealtimes, swallowing difficulties, pain, foregut dysmotility, gastrointestinal problems, gastro-esophageal reflux disease (GERD) and challenging feeding behaviours (Aggarwal *et al.*, 2015:298; Andrew & Sullivan, 2010:357; Andrew *et al.*, 2012:223; Bell *et al.*, 2010:2; Laughton, 2004:437; Stallings *et al.*, 1993; Umay *et al.*, 2014:785). These are also risk factors for impaired growth which cause sub-optimal fat deposition, lean body mass depletion, parental stress and poor general health (Andrew *et al.*, 2012:223; Finbråten *et al.*, 2015:861).

Survival and quality of life (QOL) are associated with the severity of CP and the number of functional extremities affected (Hutton & Pharoeh, 2002:85). The severity of the condition is assessed by looking at the presence of the following factors: mental retardation, poor communication, tube feedings, physical disability and the incidence of seizures (Aggarwal *et al.*, 2015:298; Katz, 2003:269; Umay *et al.*, 2014:781). Most children with CP today survive to adulthood because of improved medical treatment in neonatal intensive care units (NICUs), but those with severe impairment of mobility and feeding abilities continue having a high risk of mortality during infancy (Adams *et al.*, 2004:878; Blair & Stanley, 1997:188; Hutton *et al.*, 1994:434; McCormick, 1993:275; Sullivan, 2013:S3). Hutton *et al.* (1994:436) have found that

very severely affected children have a 50% probability of survival up to 27 years of age. Strauss *et al.* (1998:146) have reported that self-feeding skills and simple measures of mobility are highly associated with life expectancy. They found that 90% of children with CP with good to fair motor and feeding skills reached adulthood (Strauss *et al.*, 1998:147). They stressed the importance of nutrition and proper feeding skills in this population to enhance QOL and health.

Cerebral palsy is a lifelong condition with many challenges and demands that await the child, parents and families. Each child affected by CP should be managed and treated individually based on its history, the severity of the disease, and other underlying comorbidities (Jones *et al.*, 2007:151; Mascarenhas *et al.*, 2008:602; Wittenbrook, 2011:16). Most children with CP require the assistance of multiple healthcare professionals (HCPs), as well as of educational and social services, to treat, manage, support, and educate their parents and families; these services include medical care, rehabilitation, and, in severe cases, surgery (Aggarwal *et al.*, 2015:300; Jones *et al.*, 2007:152; Surveillance of Cerebral Palsy in Europe, 2000:816).

In this literature review, we explore the background and history of CP with emphasis on the nutrition-related concerns and difficulties of children with CP, recommendations for managing nutrition-related problems, parental concerns and stress-related issues, the role of the multidisciplinary team (MDT), professional support and challenges in the field of CP, as well as recommendations for future research.

2.2 Background on cerebral palsy

2.2.1 Brief history, causes and etiology

In ancient eras, CP was attributed to supernatural causes which included witchcraft, a Godly anger, or an incident of evil origin (Aisen *et al.*, 2011:844). In 1862, Sir William Little ascribed CP, which was initially referred to as 'Little's disease', to problems with childbirth and suggested that prolonged labour was the leading cause (Little, 1862:293). He also proposed that CP could be associated with birth asphyxia causing damage to the infant brain (Little, 1862:291). In 1897, Sigmund Freud had an alternative perspective and suggested that the cause was of prenatal origin during the development of the foetus and emphasised that extended labour was not the exclusive cause (Freud, 1897:327). Sir William Osler then further added a broader overview which included brain anatomy, etiology, and extremity involvement when diagnosing and classifying cerebral palsy (Osler, 1899:215). Around the 1980s, Dr Karin Nelson and colleagues from the National Institutes of Health, USA, found that most cases of CP were caused by prenatal

factors that were still unknown (Mutch *et al.*, 1992:547). In the 21st century, numerous advances in brain imaging, testing treatments in clinical trials, and improved understanding and knowledge of CP has redefined this disorder. Various comorbidities causing damage to the infant brain as well as restricted functional activity were included as important features (Aisen *et al.*, 2011:845). Research has since built on these findings and today there is evidence that CP is caused by a cascade of contributory factors acting along causal pathways (Aisen *et al.*, 2011:844; Campbell *et al.*, 2008:261). The challenge of identifying these pathways, however, remains (Campbell *et al.*, 2008:261).

The causes of CP have been robustly debated for over 150 years (Campbell *et al.*, 2008:261). The etiology and causes of CP seem to differ between developed and developing countries and because of changes in prenatal and paediatric care over the years (Aisen *et al.*, 2011:845; Van Toorn *et al.*, 2007:74). In developed countries, most cases of CP are attributable to events prior to labour, with prenatal genetic and environmental risk factors linked to 70% of CP cases, and intrapartum asphyxia being responsible for less than 10% to 20% (Campbell *et al.*, 2008:263; Speer & Hankins, 2003:179). Spastic hemiplegia and diplegia are the main types of CP in these countries (Speer & Hankins, 2003:179). In developing countries, on the other hand, there is a higher prevalence of post-neonatal acquired CP cases due to central nervous system infections, birth asphyxia, hypoxic ischaemic encephalopathy (HIE), and bilirubin toxicity (Hall *et al.*, 1996; Singhi *et al.*, 2002; Speer & Hankins, 2003:179; Sundrum *et al.*, 2005:15). Spastic quadriplegia and dystonic CP are the predominant types of CP found in these countries (Campbell *et al.*, 2008:262; Singhi *et al.*, 2002). Spastic CP develops when injury to the cortical spinal tract, responsible for movement, occurs during brain development (Campbell *et al.*, 2008:262). Babies born prematurely or with a very low birth weight (VLBW) have a higher risk of CP than full-term babies (Stanley & Alberman, 1984:58). Poor socioeconomic status has been strongly associated with an increased risk of CP, especially in babies born prematurely and/or with a low birth weight (LBW) (Sundrum *et al.*, 2005:15; Xavier *et al.*, 2014:27). This is clearly seen in developing countries where poverty is prominent (Sundrum *et al.*, 2005:18). Some CP cases have also been attributed to negligent care in illiterate and impoverished communities (Surveillance of Cerebral Palsy in Europe, 2000:817). There are also multiple genetic and acquired risk factors resulting in CP that disrupt areas of the developing brain responsible for controlling movement, as set out in Table 2.1 (Blair & Stanley, 1997:186, 190; Campbell *et al.*, 2008:261).

Table 2.1: Risk factors for cerebral palsy (Adapted from: Campbell *et al.*, 2008:261)

Risk factors				
Maternal factors	Pregnancy Complications	Infant attributes	Neonatal Morbidities & Interventions	In childhood
- Maternal age (20 or > 35 years old) - History of infertility - Miscarriage - Elder sibling with CP - Thyroid disease - Diabetes Mellitus	- Maternal infection - Pre-eclampsia - Placental abruption - Placental insufficiency - Prolonged rupture of membranes	- Prematurity - Low birth weight - Multiple gestation - Growth retardation - Male gender <i>In vitro</i> fertilisation	- Genetic disorders - Congenital brain malformations - Hyperbilirubinemia - Placental infection - Post-natal steroids - Perinatal stroke - Birth asphyxia - Pneumothorax - Prolonged hypocarbia - Prolonged exposure to mechanical ventilation	- Brain infections - Vascular episodes - Brain injury (accidental / non-accidental)

CP: cerebral palsy

2.2.3 Diagnosis and classifications on the types of cerebral palsy

Diagnosis is made by taking a careful history and conducting a neurological examination of the child, as well as by investigating for signs that may appear soon after birth or during early childhood (Aisen *et al.*, 2011:844; Aneja, 2004:629; Campbell *et al.*, 2008:264). Early signs include difficulty in swallowing and poor oral motor skills (Aisen *et al.*, 2011:845). Other signs include significantly increased or decreased muscle tone, difficulty with head control and delayed developmental milestones such as rolling, sitting, crawling, standing or hand use, and can usually be seen before the age of three years (Aisen *et al.*, 2011:845; Campbell *et al.*, 2008:264; Rosenbaum, 2003:970). Abnormal signs and symptoms associated with CP are summarised in Table 2.2.

Table 2.2: Abnormal signs associated with cerebral palsy

(Adapted from: Jones *et al.*, 2007:149)

Abnormalities	Signs or symptoms
Delayed developmental milestones	- Fisting after five months - Not rolling at six months - Not walking by 15-18 months - Not sitting with support by eight months - Inconsistent motor and intellectual development
Increased or decreased muscle tone	- Dystonia - Head lag after six months - Poor trunk control and balance - Toe walking or scissoring - Abnormal motor patterns
Movement, posture & tone	- Clonus persisting after twelve months - Difference in functional ability of left or right extremities
Persistence of primitive reflexes	- Presence of primitive reflexes, which consist of: - o Asymmetric tonic neck reflex - o Parachute response - o Tonic labyrinthine reflex - o Plantar grasp - o Palmer grasp - o Stepping
Behavioural	- Jittery - Irritable - Excessive crying - Sleeping difficulties
Physical	- Delayed feeding milestones - Failure to thrive - Poor head growth - Poor sucking

A physical examination should include head circumference measurements, where microcephaly or hydrocephaly may be diagnosed, and a neurological examination of eye movements, muscle tone and reflexes is essential (Aneja, 2004:629; Jones *et al.*, 2007:149). Motor impairment is present in all CP cases, but other comorbidities may include epilepsy or seizure disorders, psychosocial abnormalities, cognitive deficits, learning difficulties, and intellectual delays (Aisen *et al.*, 2011:845, 846; Aneja, 2004:627; Rosenbaum, 2003:970). Brain scans, such as a

computed tomography (CT) scan or magnetic resonance imaging (MRI), provide useful images of the brain structure that may assist in understanding underlying causes of CP and serve as a tool for additional diagnostic testing (Ashwal *et al.*, 2004:853; Jones *et al.*, 2007:150). Some children may appear normal, especially those with genetic disorders, but motor delays start showing later in infancy or early childhood as a result of neurological injury (Blair & Stanley, 1997:186; Campbell *et al.*, 2008:264). In some often rare cases, it may require several examinations to determine whether findings suggest that the child has CP or another type of neurological condition (Campbell *et al.*, 2008:264).

There are different types of CP, including spastic, hypotonic, dyskinetic, ataxic or mixed, that are classified according to their clinical presentation, neurological examination and area of presumed cerebral dysfunction (pyramidal or extrapyramidal lesions) (Blair & Stanley, 1997:185; Morgan & Aldag, 1996:643). Pyramidal lesions are greatly associated with spasticity, increased deep-tendon reflexes, and hypertonia and are found in nearly 70-80% of all CP cases (Aisen *et al.*, 2011:845; Aneja, 2004:629; Jones *et al.*, 2007:148). Extrapyramidal lesions are mostly associated with chorea, ataxic and dyskinetic CP, where abnormal posture control, abnormal regulations of muscle tone, and coordination deficits are present (Aisen *et al.*, 2011:845). It accounts for approximately 15-20% of all CP cases (Jones *et al.*, 2007:148). The type of CP is further classified according to the distribution across the limbs and extent of involvement or according to the type of movement difficulty for example quadriplegia, hemiplegia or diplegia (Evans *et al.*, 1989:120; Nelson & Ellenberg, 1978). Additional information such as age, geographic region, setting, maternal, and clinical history may assist in classifying a child with CP accurately (Aneja, 2004:628; Marchand *et al.*, 2006:127; Rosenbaum *et al.*, 2007:12).

The following figure clearly illustrates the neurological classification of cerebral palsy.

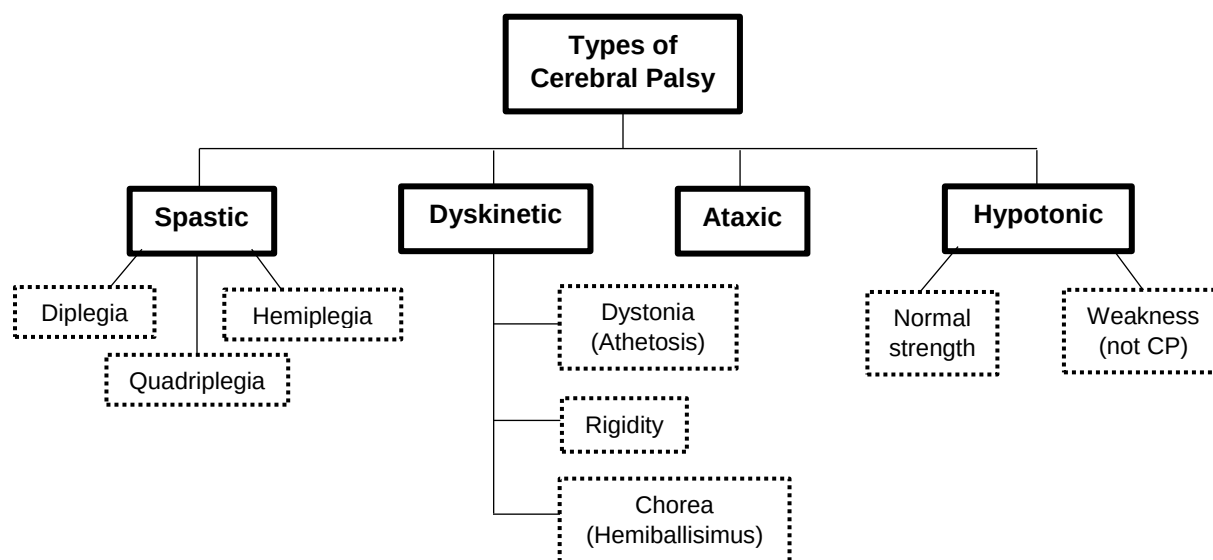


Figure 2.1: Neurological classification of cerebral palsy

(Adapted from: Campbell *et al.*, 2008:263)

Classification is an essential part of the treatment plan and its purposes include:

- 1) Prediction – where information provided can assist a HCP in planning or predicting current and future service needs that the CP individual may require;
- 2) Description – where detailed background information regarding the CP individual contributes in indicating the nature and severity of the problem;
- 3) Comparison – where sufficient information that has been provided can be compared with a series of CP cases found in various scenarios which can provide vital solutions for specific problems or concerns;
- 4) Evaluation of change – where the same CP individual can be monitored throughout different points in time, and these evaluations can be compared with one another to evaluate whether there is improvement or not (Rosenbaum *et al.*, 2007:11).

The following table (Table 2.3) depicts the four major components of CP classification and is recommended for use by HCPs (Rosenbaum *et al.*, 2007:12).

Table 2.3: Four major components of cerebral palsy classification

(Adapted from: Rosenbaum *et al.*, 2007:12)

Component	Features
1 Motor abnormalities	• The nature and typology of motor disorder, where: • Nature refers to hypotonia / hypertonia • Typology refers to spastic, ataxic, or dyskinetic • The functional motor abilities which include: • Oral motor function • Speech function
2 Additional impairments	• Presence or absence of later-developing musculoskeletal problems and/or additional non-motor neurodevelopmental or sensory problems, which may include: • Seizures • Hearing or vision impairments • Attentional, behavioural, cognitive, and/or communicative deficits • The extent of these impairments
3 Anatomical and neuro-imaging findings	• Anatomic distribution refers to body parts affected by motor impairment such as: • Limbs, trunk, bulbar region, et cetera • Neuro-imaging findings showing: • Ventricular enlargement • White matter loss, or • Brain anomaly
4 Causation and timing	• Whether the cause is clearly identified such as: • Brain malformation, head injury, meningitis, et cetera • The presumed time frame of the insult causing brain injury (if known)

According to the publication *International Classification of Functioning, Disability and Health* by the World Health Organisation (WHO), it is important to clearly highlight characterising functional consequences of disorders such as CP (WHO, 2001:12). No classification system is useful unless it has been validated and is reliable (Rosenbaum *et al.*, 2007:12). The gross motor function classification system (GMFCS) is a useful predictive tool mostly used to categorise the gross motor function in children with cerebral palsy (Rosenbaum *et al.*, 2008:24). It consists of five levels (I – V) where level “I” indicates the least motor impairment with minimum limitations and level “V” indicates severe motor impairment for which a wheelchair and/or assistance is required (Palisano *et al.*, 1997:215). These five levels were determined through a process where discriminating elements of motor function were examined (Rosenbaum *et al.*, 2008:250).

Table 2.4 summarises the inclusion criteria of the five categories (groups I to V) of the GMFCS in children with CP according to their gross motor skill and feeding ability. These groups are also further stratified according to gender (Palisano *et al.*, 1997:216).

Table 2.4: The five groups of the GMFCS developed for cerebral palsy children
(Palisano *et al.*, 1997:215)

Group	Description of the inclusion criteria of each group
I	▪ Balances well ▪ Walks well alone for at least six metres
II	▪ Does not balance well ▪ Does not walk well alone for at least six metres ▪ Walks with support or unsteadily alone for at least three metres
III	▪ Crawls, creeps, or scoots ▪ Unable to walk (wheelchair may be required)
IV	▪ Does not feed self ▪ Is not fed by feeding tube (i.e. gastrostomy) ▪ Unable to walk (wheelchair required) ▪ Unable to crawl, creep, or scoot
V	▪ Does not feed self ▪ Is fed by feeding tube (i.e. gastrostomy) ▪ Unable to walk (wheelchair required) ▪ Unable to crawl, creep, or scoot

The original version of the GMFCS was developed by Russell *et al.* (1989:341), but multiple errors were identified and therefore this system was reviewed in 1994 and has since been constantly improved on. Rosenbaum *et al.* (2008:251) drafted the final GMFCS with good content validity, reliability, and meaningful distinctions about function. Another classification tool with good reliability to classify upper extremity function is known as the manual ability classification system (MACS) and is the classification system mostly preferred by physiotherapists and occupational therapists (Eliasson *et al.*, 2006:549). Both GMFCS and MACS serve as basis to describe clinical characteristics among HCPs, and for treatment interventions in research studies (Campbell *et al.*, 2008:263). The modified Swedish classification system developed by Mutch *et al.* (1992) is a simple and easy tool used commonly in practice (Aneja, 2004:628). This classification system is based on tone and the number and distribution of affected limbs and is sometimes used as a quick reference when HCPs evaluate a child at risk of CP (Mutch *et al.*, 1992:553).

2.2.3 Prevalence of cerebral palsy

The rate of CP per live births is highest in babies born prematurely between 29 and 33 weeks gestation (Blair & Stanley, 1997:186; 187). The prevalence of CP is 1.5 to 2.5 per 1000 live births in European countries such as the United Kingdom and 3.6 per 1000 live births in the United States of America (Rosen & Dickinson, 1992:417; Surveillance of Cerebral Palsy in Europe, 2000:817). This figure can increase to 40 – 50 per 1000 live births in situations of poverty where inadequate obstetric care and low birth weight is found, which is common in developing countries (Sullivan *et al.*, 2000:678).

The prevalence of children with CP in South Africa is not as well documented and recorded, but has been reported in several articles (DSD *et al.*, 2012:22). The broad term “intellectual disability” (ID) has been used in articles to describe the prevalence of CP among children, which makes it challenging to provide an accurate prediction. *Intellectual disability* has been defined by the American Psychiatric Association (1994:52) as a significantly below average level of general intellectual functioning, which is defined by the intelligence quotient (IQ), accompanied by significant limitations in adaptive capabilities. Mung’ala-Odera and Newton (2007:254) have also reported that different techniques used to detect disabilities, such as questionnaires, census, key informants, and administrative data, all have shortcomings and limitations. These include underreporting of specific conditions, poorly developed health monitoring infrastructure, no reporting on diagnostic categories or risk factors pertaining to the disease, low sensitivity compared with other approaches, high costs, incorrect reporting of cases outside the population of interest, and high false positive rates (Mung’ala-Odera & Newton, 2007:251).

Christianson *et al.* (2002:182) determined the prevalence of ID in rural South African children between the ages of two and nine years in villages in the Northern Province. They found an 8.4% prevalence of children with CP in these areas. Couper (2002:550) conducted a similar study in twelve rural areas in the North-Eastern part of KwaZulu-Natal. The study reported a prevalence rate of 10 per 1000 live births of children with CP younger than the age of ten. Not many studies have been done in black South Africans, but an old study done by Arens *et al.* (1978:321) found that the condition among the black population was 2.6 times greater than among the Caucasian population in South Africa.

According to Statistics South Africa Census 2001, the number of disabled children between the ages of 0–9 years of age was 2.1% of the total population. The types of disabilities reported included disabilities of sight, hearing, communication, and included those that were physical,

intellectual, and emotional. The Census 2001 has been revised in 2012 by the Department of Social Development (DSD), the Department of Women, Children and People with Disabilities (DWCPD), and the United Nations Children's Fund (UNICEF) has revealed the most recent number of cases of ID among children in South Africa. Cerebral palsy was defined as a disability of a physical and intellectual nature (DSD *et al.*, 2012:34). It found more cases of ID in rural areas than in urban areas owing to increased poverty in the area, poor access to nutritious food, increased exposure to environmental and infectious diseases, uneducated and illiterate parents, and/or reduced access to medical assistance (DSD *et al.*, 2012:30, 31). Interestingly, the report stated that male children (2.6%) were more likely to have a disability than their female peers (2.4%) and the prevalence increased steadily with age: from 1.6% of infants between the ages of 0 and 4 years, to 3.2% among children between the ages of 5 and 17 years (DSD *et al.*, 2012:30). They also found that the prevalence of ID was much higher among black African infants and children (2.6%) with the lowest prevalence found among Indian and Asian children (1.6%) (DSD *et al.*, 2012:31). A very high prevalence of ID was found in infants and children living in orphanages (3.9%), in institutions (19.9%) or on the streets (24.2%), in comparison with non-orphaned (2.4%) infants and children living at home with their families (2.4%) (DSD *et al.*, 2012:33). Risk factors mostly associated with CP were found to be infections (neonatal and perinatal), prematurity and birth complications (DSD *et al.*, 2012:37, 38).

2.3 Nutrition-related concerns and difficulties regarding cerebral palsy

Feeding and nutrition plays an integral part in growth and development, but also presents some very specific challenges in this population of neurological diseases (Kuperminc *et al.*, 2013:S21). Cerebral palsied children are faced with motor deficits and a range of disabilities and problems affecting QOL, such as altered growth patterns, gastro-intestinal (GI) functional abnormalities, intellectual disability, nutrition, feeding and swallowing problems, hearing and visual deficits, respiratory infections and epilepsy (Ashwal *et al.*, 2004:851; Liptak & Accardo, 2004:s36; Reilly *et al.*, 1996:879, 880; Sullivan *et al.*, 2000:677). Nutritional and feeding problems that these children encounter also include underweight-for-age, failure to thrive, increased energy needs (in some cases and types of CP), inability to self-feed, poor swallowing coordination, and inability to communicate when hungry or thirsty (Fung *et al.*, 2002:363; Marchand *et al.*, 2006:124; Nadeem *et al.*, 2014:240; Ptomey & Wittenbrook, 2015:598). The following figure (Figure 2.2) illustrates the relationship between feeding dysfunction or problems and various other challenging aspects of CP on the health status outcomes in children suffering from moderate to severe CP.

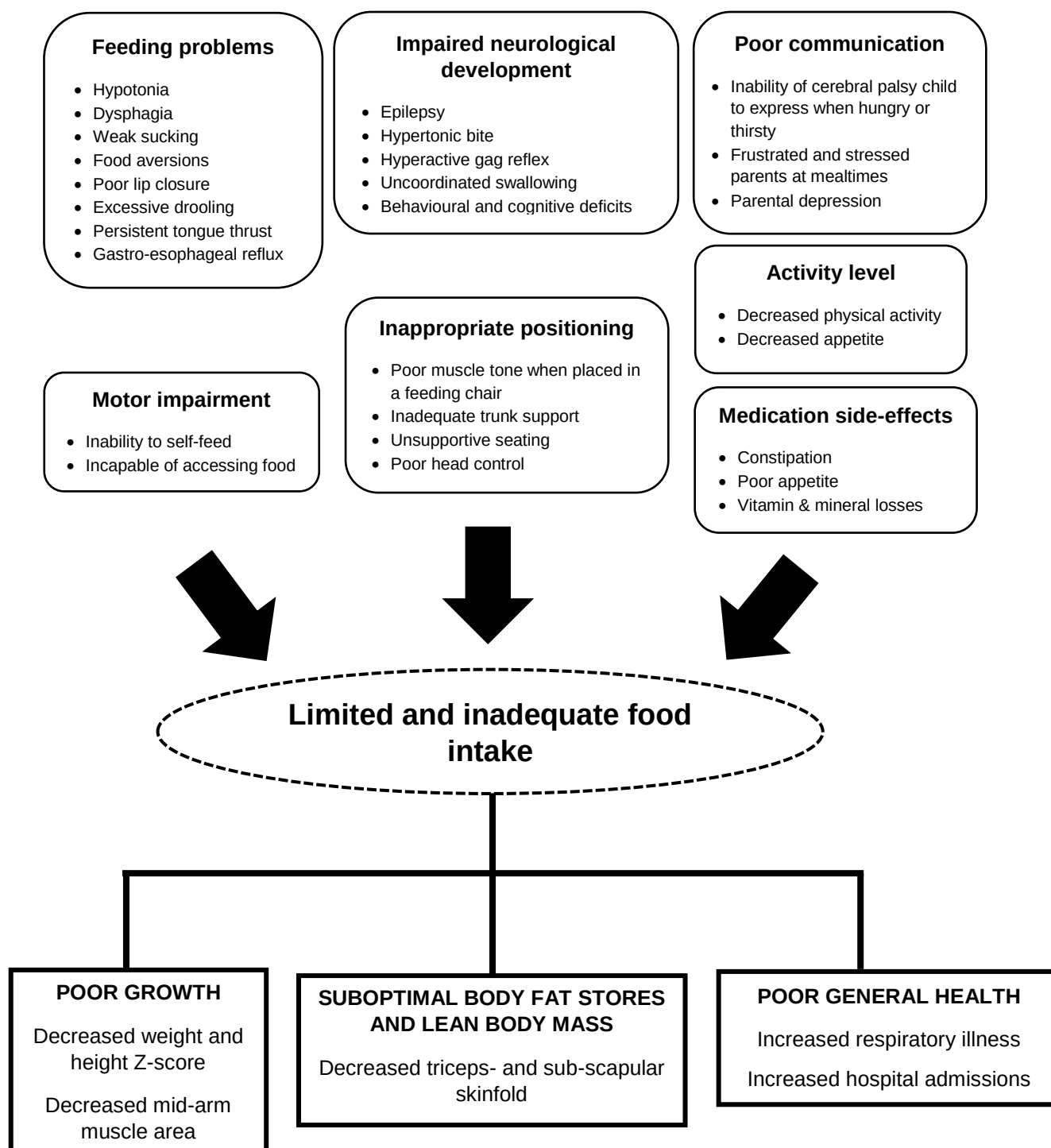


Figure 2.2: Proposed relationships between feeding problems, communication, positioning, motor impairment, neurological concerns, activity level, and use of medication in the health status outcomes of children with moderate to severe cerebral palsy (Adapted from: Fung *et al.*, 2002:366)

2.3.1 Growth abnormalities

Children with severe motor impairment are most at risk of developing growth and nutritional complications (Andrew & Sullivan, 2010:357; Day *et al.*, 2007:169; Stevenson *et al.*, 2006:1017). Owing to impaired mobility and inadequate nutrition, children with CP grow and develop differently from their neurologically normal peers (Kuperminc *et al.*, 2013:S21; Stevenson *et al.*, 2006:1011; Sullivan *et al.*, 2000:677). Anthropometric assessment is a fundamental aspect in evaluating the growth of children with CP as they are at risk of stunting (Kuperminc *et al.*, 2013:S21; Sullivan *et al.*, 2002:466). Walsh and Nel (2007:8) found that around 40% of disabled South African children in their study were stunted, mostly as a result of poor nutritional intake. Growth assessment, which includes anthropometric data, skinfold measurements and a feeding skills evaluation, is an important indicator of health and requires reliable and valid measures to be able to compare values with reference data adopted for this population (Karagiozoglou-Lampoudi *et al.*, 2012:653; Mascarenhas *et al.*, 2008:602; Stevenson *et al.*, 2006:1011). Finbråten *et al.* (2015:861) found that severely affected children with CP in Norway had a higher risk of stunted growth and lower lean body mass than those with a GMFCS level of I or II that are not as severely disabled.

Measuring growth in children with CP can be challenging and therefore anthropometric measurements should be completed using appropriate scales and equipment (Kuperminc *et al.*, 2013:S21; Trier, 2002:13). Skeletal deformities such as scoliosis, as well as physical abnormalities such as contractures and spasticity, also make it difficult to position the child in a suitable swallowing posture for better head control and trunk positioning (Gerek & Çiyiltepe, 2005:58; Mascarenhas *et al.*, 2008:598; Wittenbrook, 2011:21). Obtaining reliable measures of height or length may be challenging because these deformities make it difficult to assess and measure growth in childhood, especially in children with more severe motor dysfunction (Aneja, 2004:629; Brooks *et al.*, 2011:e299; Day *et al.*, 2007:171; Kuperminc & Stevenson, 2008:143). Alternative methods of obtaining accurate values of weight and height are essential when a child with CP is immobile or severely spastic (Aneja, 2004:629). These methods include the use of equations to estimate height or length, such as knee height, ulnar or tibial length, upper or lower arm length, as well as weight, where a wheelchair scale can be used (Kuperminc *et al.*, 2013:S21; Trier, 2002:13; Wittenbrook, 2011:21). Skinfold measurements are also valuable and cost-effective in assessing nutritional status and measure fat stores (Aneja, 2004:629; Finbråten *et al.*, 2015:861; Kuperminc & Stevenson, 2008:144). Stallings *et al.* (1995:838) found that anthropometric measures estimating fat mass and muscle stores are directly attributable to poor nutritional status, independent of other factors such as race, age, gender and disease severity.

Sullivan *et al.* (2002:466) found that upper arm circumference is an easy, effective, and appropriate way to determine the nutritional status. An improved nutritional status, particularly where a child with CP gains in fat-free mass, has a beneficial effect on growth and motor skills (Aisen *et al.*, 2011:848; Soylu *et al.*, 2008:332). Marchand *et al.* (2006:127) reported that an improved nutritional status decreases irritability and spasticity, enhances developmental progress, and improves wound healing and peripheral circulation in CP children. The nutritional status of CP children should, however, be used only as a guideline, as they do not grow and develop as their peers do (Aneja, 2004:629). Henderson *et al.* (2007:165) found that quadriplegic CP children who lived in a residential care facility had significantly higher weight, height, and skinfold measurements than those living at home. This study clearly demonstrated that environmental factors, whether in the form of adherence to a strict feeding schedule or intensive medical treatment, do affect the growth of children with CP (Henderson *et al.*, 2007:167).

It is important, however, to be aware that methods assessing body composition such as body mass index (BMI) or weight or height, are not valid and effective in children with CP as length and/or height measurements are difficult to obtain and do not take their altered body composition into account (Bandini *et al.*, 2015:313; Kuperminc *et al.*, 2010:828; Marchand *et al.*, 2006:124; Ptomey & Wittenbrook, 2015:602; Spender *et al.*, 1988:195; Wittenbrook, 2011:22). Methods such as underwater weighing and the dual-energy X-ray absorptiometry (DEXA) scan are very accurate measures of determining body composition in children with altered body composition, such as is found in cerebral palsy (Bandini *et al.*, 2015:313; Henderson *et al.*, 2001:330). This method is, however, not feasible in most facilities and therefore most centres invest in skinfold callipers or bioelectrical impedance equipment (Kuperminc *et al.*, 2013:S22).

The appropriate diagnosis-specific growth charts should be used to monitor growth, identify abnormal growth and assist in the early detection of major nutritional problems, health risks or complications (Brooks *et al.*, 2011:e304; Grummer-Strawn *et al.*, 2002:142; Kuperminc & Stevenson, 2008:145). When assessing growth and nutritional history, the patient's and the family's perspective should also be reviewed (Kuperminc & Stevenson, 2008:143; Samson-Fang & Bell, 2013:s5). Stevenson *et al.* (2006:1017) have developed growth curves for children with moderate to severe CP, where they correlated growth with markers of health and social participation. They found that children with CP that weighed more and that were taller had better indications of health, but more research is needed to verify these findings (Stevenson *et al.*, 2006:1017). Although children with CP are mostly smaller with reduced muscle and bone mass, fat stores and below average weight in comparison with their normal peers, there is insufficient

evidence to support the use of these growth curves developed by Stevenson *et al.* (2006:1017), specifically for children with CP (Fung *et al.*, 2002:371). Growth charts have been developed by Day *et al.* (2007:169, 170), using the GMFCS to stratify children with CP into the five groups to monitor anthropometric aspects of the child, which include weight, length/height and BMI for appropriate age. In their large study, they included the weight and height measurements of 24 920 children with CP between the ages of 2 and 20 years old to develop these growth charts (Day *et al.*, 2007:167). This is an improvement on the growth charts developed by Krick *et al.* (1996) using measurements based on 360 spastic quadriplegic children with CP up to the age of 10 years (Day *et al.*, 2007:167). Prior to charting information, it is essential to always calculate the adjusted age of the child with CP born prematurely (Jones *et al.*, 2007:149). Growth charts should be used not only to indicate how these children should grow, but also how they have grown up to now by observing their growth pattern (Brooks *et al.*, 2011:e308; Grummer-Strawn *et al.*, 2002:142). Therefore it is most important to follow the child's growth pattern over a period of time to assess and evaluate the child's own distinctive way of growth (Kuperminc *et al.*, 2013:S22).

Causes of poor growth are attributable to many factors, such as nutritional, endocrine and/or neurological complications, as well as environmental factors (Andrew & Sullivan, 2010:357; Kuperminc & Stevenson, 2008:142; Stallings *et al.*, 1993). There is a complex interaction between these factors and the overall growth of children with CP, which requires further clarification (Andrew & Sullivan, 2010:357). Growth abnormalities in a child with CP can also be attributed to the disease itself, such as asymmetrical growth in hemiplegia or growth restriction of legs in diplegia (Aneja, 2004:628). Feeding difficulties causing malnutrition may also be an important cause of growth failure in these children (Aneja, 2004:628; Karagiozoglou-Lampoudi *et al.*, 2012:652; Kuperminc & Stevenson, 2008:138; Trier, 2002:14). The consequences of poor growth and inadequate nutrition on children with CP adversely affect physical and brain growth, development, cognition and behaviour, muscle strength, cardiac function, immunity, healing and repair (Andrew & Sullivan, 2010:359; Arvedson, 2013:S9; Kuperminc & Stevenson, 2008:138). Poor growth is also associated with increased hospitalisation and school absences (Stevenson *et al.*, 2006:1017).

2.3.2 Feeding difficulties and problems

Feeding is a critical social component of a child's life and may affect a family greatly if problems arise (Samson-Fang & Bell, 2013:s5). Strauss *et al.* (1998:144) reported feeding to be one of the most important aspects for maintaining the health and wellbeing of children with CP. Feeding difficulties are multifactorial and usually occur in 40-50% of children with CP and are severe in

85% of spastic quadriplegic CP children (Gangil *et al.*, 2001:842; Stallings *et al.*, 1993:128; Sullivan, 2013:S3; Umay *et al.*, 2014:782). These difficulties contribute to growth failure, prolonged feeding times and inadequate food and fluid intake, which could result in dehydration and malnutrition with insufficient intake to meet the metabolic demand (Andrew & Sullivan, 2010:357; Arvedson, 2013:S9; Campanozzi *et al.*, 2007:28; Fung *et al.*, 2002:366; Spiroglou *et al.*, 2004:180; Sullivan *et al.*, 2000:679). Feeding problems also contribute to difficulty in breastfeeding, introduction of solids, biting and chewing, and consuming liquids (Reilly *et al.*, 1996:881).

Fung *et al.* (2002:365) found that the severity of a feeding disorder or dysfunction was strongly associated with indicators of poor health and nutritional status among children with CP that were mildly to severely affected. Poor nutritional status in these children is mostly attributed to oral motor dysfunction, inability to self-feed and inability to request food due to communication problems (Aggarwal *et al.*, 2015:298; Reilly *et al.*, 1996:880). These have been found to be common problems in this group of disabled children (Fung *et al.*, 2002:364; Sullivan *et al.*, 2000:679). Feeding risk factors such as inadequate intake, inappropriate food choices and self-feeding impairment, which have been identified by Karagiozoglou-Lampoudi *et al.* (2012:649), could compromise the nutrition status of children with CP. Liptak *et al.* (2001:368) found that children severely affected by CP, who were classified under group V of the GMFCS, had significantly more health-related problems compared to moderately affected CP children classified under groups III and IV. This group of children had the most respiratory complications, the lowest estimated mental age, required the most healthcare resources, needed the most medication and scored the lowest on the Global Health screening tool (Liptak *et al.*, 2001:367, 368). These results indicate how vulnerable this group of children is to developing nutrition-related complications and concerns compared with children that are only moderately affected (Liptak *et al.*, 2001:367).

Oral motor difficulties are affected by tongue thrust, hypertonic bite, drooling of saliva, hypersensitivity to touch and dental hygiene, which can all severely affect chewing abilities (Aneja, 2004:631). Skills such as sucking, chewing or swallowing are usually absent in a child affected by CP with oral motor complications (Field *et al.*, 2003:300). Reilly *et al.* (1996:879) found that sucking and swallowing problems in toddlers with CP were common in the first 12 months of life and the majority of these children had some form of oral motor dysfunction. A study by Gangil *et al.* (2001:840) reported that spastic quadriplegic as well as hypotonic children with CP had significantly poor feeding skills compared with other types of children with CP and that this had a

negative impact on their nutritional status. Gangil *et al.* (2001:844) also reported that 49% of parents in their study were not satisfied with their child's nutritional status and up to 90% of these children were unable to self-feed. Soylu *et al.* (2008:332) also found that 88% of parents in their study had to assist with the feeding of their spastic quadriplegic CP children as 73% of these children had feeding difficulties and poor feeding skills. These factors all contribute to mealtimes being time-consuming for parents or caretakers, which may be very unpleasant and stressful for both the parent and CP child (Soylu *et al.*, 2008:331; Sullivan *et al.*, 2002:466; Trier, 2002:14).

A feeding or swallowing problem is often identified in children with CP when mealtimes are stressful and proceed for longer than 30 minutes, when lack of weight gain is present over 2-3 months in young children, and when the child shows signs of respiratory problems such as coughing (Arvedson, 2013:S9; S10). Feeding intolerance is also common and may be associated with recurrent reflux, delayed gastric emptying, diarrhoea or constipation (Marchand *et al.*, 2006:130). Field *et al.* (2003:302) found that children with developmental disabilities have the highest risk of acquired feeding problems.

It has been reported that *dysphagia*, *GERD*, and *constipation* are the most common nutrition-related feeding problems found in CP children (Benfer *et al.*, 2015:5; Field *et al.*, 2003:303; Marchand *et al.*, 2006:130; Nadeem *et al.*, 2014:240; Ptomey & Wittenbrook, 2015:599; Sullivan, 2013:S3).

2.3.2.1 Dysphagia

Oral-motor dysfunction has been found in more than 90% of children with CP, dysphagia being reported in up to 40% of these children (Gerek & Çiyiltepe, 2005:69; Gustafsson & Tibbling, 1994:31; Umay *et al.*, 2014:785). Oro-pharyngeal dysphagia is characterised by problems that arise in any or all phases of swallowing. It includes problems such as reduced lip closure, poor tongue function and thrust, tactile hypersensitivity, delayed swallowing, reduced pharyngeal motility, excessive drooling and hypertonic bite reflex (Arvedson, 2013:S9; Kuperminc *et al.*, 2013:S22). Many children with CP have some degree of dysphagia and certain textures and feeding methods can affect the child's ability to ingest food and liquids (Kuperminc *et al.*, 2013:S22). Umay *et al.* (2014:785) found that 83% of children with CP had difficulty in eating solid foods, but if solid foods were replaced with semi-solids, only 12% of these children had difficulty consuming them. Benfer *et al.* (2015:6) found that most children affected by CP with dysphagia, struggle to consume thin liquids and this poses a risk of developing respiratory problems. In the Oxford Feeding Study, one of the largest epidemiological studies of feeding and

nutritional problems in disabled children conducted by Sullivan *et al.* (2000:677), it was found that there was a significant correlation between dysphagia and choking, prolonged feeding times and excessive drooling in children with CP. It is more prominent in children with severe motor impairment such as spastic quadriplegic CP (Arvedson, 2013:S9; Gerek & Çiyiltepe, 2005:58).

Table 2.5 summarises the processes and problems of the different phases of oro-pharyngeal dysphagia found in children with CP (Arvedson, 2013:S10)

Table 2.5: The processes and problems of the different phases of oro-pharyngeal dysphagia (Adapted from: Arvedson, 2013:S10)

Phase of swallowing	Process	Possible problem
Bolus formation	→ Getting food into the mouth → Manipulation via lip closure occurs → Jaw stability and tongue action present → Getting ready to propel the food or liquid posteriorly over the tongue	• Loss of food from the mouth • Food particles found in the anterior or lateral sulcus of the mouth • Limited chewing and tongue action
Oral transit	→ Moving food particles or liquid through the oral cavity (mouth) into to pharynx (throat)	• Forward motion of the tongue results in spillage from the mouth • Delayed initiation of the posterior tongue thrust
Pharyngeal phase & pharyngeal phase initiation	→ Involves critical timing of tongue thrust and closure of the airway → Involves active coordinated strong muscle function of the tongue → Pharyngeal constrictors present → Moving food particles or liquids through the pharynx into the UES	• Food particles or liquids in the valleculae or pyriform sinuses are present for more than one second before swallowing is initiated • Food particles or liquids are present on tonsil tissue or the PWW • Reduced airway closure results in aspiration – especially with thin liquids • Food residue in the pharynx causes reduced muscle strength – usually with thick food • Pharyngonasal backflow present • Reduced UES opening present
Upper esophageal phase	→ Opening of the UES where peristaltic action takes place to move the food bolus downwards through the esophagus	• Reduced UES opening present • Reduced duration of UES opening • Cricopharyngeal bar inhibit bolus transit time

UES: Upper Esophageal Sphincter; **PWW:** Posterior Pharyngeal Wall

Swallowing problems such as dysphagia increase the risk of aspiration with oral feeding, which is of great concern as it can result in severe pulmonary complications (Arvedson, 2013:S9). The risk of aspiration, however, does seem to lessen as the child matures developmentally (Arvedson, 2013:S9; Kuperminc *et al.*, 2013:S22). Other concerns of swallowing problems include the reduced volume of food and liquids ingested, inadequate hydration, possible nutrition deficits, limited ability to consume a range of textures, and slow development of oral skills (Arvedson,

2013:S9). A videofluoroscopic swallow study (VFSS) or flexible endoscopic evaluation of swallowing (FEES) is usually performed to evaluate the severity of dysphagia and the swallowing process, and to identify aspiration (Aneja, 2004:631; Arvedson, 2013:S10; Ptomey & Wittenbrook, 2015:597). The VFSS provides a very dynamic visualisation of the oral, pharyngeal, and upper esophageal phases of swallowing, whereas the FEES allows a more direct visualisation of certain aspects of the pharyngeal phase (Arvedson, 2013:S10).

Cerebral palsied children have a high risk of dysphagia because of a central nervous system disorder in which passive tone is inconstant, active tone is normal or sometimes mildly decreased, and primitive reflexes may be persistent (Arvedson, 2013:S9; Umay *et al.*, 2014:785). They have a high hard palate arch, which prevents them from forming a bolus when eating, and therefore making food ingestion difficult (Arvedson, 2013:S9; Gerek & Çiyiltepe, 2005:58; Umay *et al.*, 2014:785). These children also have an abnormal movement pattern of the lips, tongue, cheeks and soft palate during bolus formation. The lack of tongue propulsion also makes it difficult to chew and form a bolus for swallowing. This all contributes to delayed activation of the swallowing reflex and premature bolus spillage, which are the main reasons for dysphagia (Arvedson, 2013:S9; Gerek & Çiyiltepe, 2005:58).

The consequences of dysphagia can be characterised by:

- 1) Extended and prolonged feeding time due to slow oral transit time;
- 2) Poor bolus formation and bolus control, which can contribute to aspiration;
- 3) Choking or coughing due to the presence of food residue in the velo-pharyngeal region during and after food intake as a result of poor primary peristalsis.

(Arvedson, 2013:S9; Gerek & Çiyiltepe, 2005:58)

2.3.2.1.1 Recommendations on managing dysphagia

Traditional methods of treating dysphagia, especially bolus or saliva control and enhancing bolus consistencies, have shown effectiveness, especially in improving deglutition skills (Gerek & Çiyiltepe, 2005:58; Marchand *et al.*, 2006:128). It can be challenging to implement due to the complex nature of problems accompanying children with cerebral palsy (Gerek & Çiyiltepe, 2005:58). The *Castillo-Morales* hard plate device, used as part of prosthodontic management, has been shown to have satisfactory results by significantly improving bolus formation, triggering the involuntary phase of swallowing, and improving saliva control, as well as showing positive effects on oral-motor performance and mid-facial expression development. These all contribute

to an improvement in food intake of a higher consistency and therefore successfully managing dysphagia in CP children (Gerek & Çiyiltepe, 2005:69, 70).

Methods of thickening or modifying food and liquids have shown promising and effective results and should always be adapted according to individual needs (Arvedson, 2013:S10; Bell & Samson-Fang, 2013:S14; Benfer *et al.*, 2015:5; Ptomey & Wittenbrook, 2015:597). Food should always be modified and implemented under the guidance of a specialised feeding therapist, such as a qualified neurodevelopmental therapy (NDT) speech therapist, to assess its safety and efficacy (Bell & Samson-Fang, 2013:S14; Benfer *et al.*, 2015:7). Most children with CP are not able to chew during bolus formation of the oral phase, and therefore most are usually fed pureed-type food products to assist in swallowing and reduce fatigue during mealtimes (Bell & Samson-Fang, 2013:S14; Gangil *et al.*, 2001:843; Gerek & Çiyiltepe, 2005:58). Thickened foods with a smooth, lumpy or mashed consistency may appear to be tolerated better by a child with CP, but not in all instances as food residue can spill into the open airway after swallowing (Arvedson, 2013:S10; Bell & Samson-Fang, 2013:S14; Benfer *et al.*, 2015:5; Kuperminc *et al.*, 2013:S22). Benfer *et al.* (2015:4) reported that food and fluid textures were modified in up to 78% of toddlers affected by CP with dysphagia that were classified as level IV to V of the GMFCS, where purees and semi-solids were mainly consumed. In some cases, the boluses can be manipulated to a smaller or bigger size for safe ingestion (Arvedson, 2013:S10). Oral feeding is always preferred and encouraged as it has several benefits for both the child and the parent (Craig, 2013:S18; Day *et al.*, 2007:170). Cerebral palsied children may find pleasure in tasting different textures and flavours and oral feeding can contribute to language development and also allow parents to enjoy these special times with them (Craig, 2013:S18). Severely affected children may, however, require alternative feeding methods, such as gastrostomy tube feeding (Aisen *et al.*, 2011:848; Day *et al.*, 2007:170; Mascarenhas *et al.*, 2008:603). Indications for tube feeding include prolonged dysphagia, inefficient and/or insufficient intake or excessive stress during oral feeding (Gottrand & Sullivan, 2010:S20; Jones *et al.*, 2007:227; Liptak *et al.*, 2001:368).

A *clinical feeding evaluation* is often completed to assess the presence of an oral sensorimotor deficit, where a child with CP is observed in a mealtime setting (Arvedson, 2013:S10; Marchand *et al.*, 2006:127; Mascarenhas *et al.*, 2008:601).

It is important to differentiate between a *sensory* and a *motor* disorder:

- Cerebral palsied children with primarily oral *sensory* disorders often hold food under their tongues to avoid swallowing. When they vomit, it may only be due to a certain texture. They

usually do not accept oral stimulation and reject certain practices such as tooth brushing. (Arvedson, 2013:S10)

- Cerebral palsied children with primarily oral *motor* disorders are mostly unable to hold and manipulate food on their tongues, causing food to fall out of their mouths when trying to eat. Vomiting is not related to food texture and tooth brushing is usually tolerated in this group. (Arvedson, 2013:S10)

Evidence-based feeding or swallowing interventions are limited and the evidence regarding the use of these interventions is poor (Arvedson, 2013:S11). The reason for this is that randomised controlled trials are extremely difficult to carry out, and therefore empirical data are limited (Arvedson, 2013:S11). Some of the interventions have shown ineffective results regarding feeding efficiency or weight gain in children with CP.

The following interventions have shown positive and beneficial effects in children affected by CP with dysphagia, although they lack validation with systematic data collection:

- Taste stimulation should be part of the daily routine during family meals for children to improve oral skill development and pleasure. Tube-fed children should be given 2-5 minutes per day for a taste stimulation session (Gisel, 2008:171; Kuperminc *et al.*, 2013:S22);
- A spoonful of water may be tolerated without compromising pulmonary status to improve hydration status. A few drops of lemon juice or ice water may also assist in stimulating swallowing without increasing the risk of aspiration or its detrimental consequences (Rogers, 2004:S30);
- Pureed foods rather than solids may improve safety and eating efficiency in children who are prone to aspirate. This technique of feeding has shown to be more effective in enhancing feeding safety and efficiency, but well-designed studies are limited (Benfer *et al.*, 2015:7; Gangil *et al.*, 2001:843; Gisel, 1995:539);
- Small but frequent amounts of mashed foods are safer to ingest, swallowed more quickly, and decrease the risk of aspiration compared to solid foods – evidence is limited (Croft, 1992:268);
- An electric feeder may assist with weight maintenance, but it is not as effective in long-term interventions (Pinnington & Hegarty, 1999:23).

Children with moderate-to-severe dysphagia are managed most effectively by means of a MDT where all factors contributing to dysphagia are addressed in a coordinated manner (Arvedson, 2013:S9).

2.3.2.2 Gastro-esophageal reflux disease (GERD)

Gastro-esophageal reflux disease (GERD) is often caused by esophageal dysmotility, resulting in intra-esophageal reflux, foregut dysmotility, poor lower esophageal sphincter function and delayed gastric emptying (Trier, 2002:14; Wittenbrook, 2011:29). It has been found that around 75% of children with CP show signs of GERD, which is a common nutrition-related problem (Gerek & Çiyiltepe, 2005:58; Gustafsson & Tibbling, 1994; Ravelli & Milla, 1998:61). Soylu *et al.* (2008:332) reported that 40% of spastic quadriplegic children with CP struggled with GERD, especially those that were severely affected. They also reported that the prevalence of GERD was based on subjective results, as it is defined mainly by the symptoms of reflux and can therefore be unreliable in severely affected children as they cannot communicate or indicate signs of discomfort such as heartburn or abdominal pain (Soylu *et al.*, 2008:332). Diagnostic studies, such as pH monitoring or an upper GI endoscopy, are needed to reveal the true prevalence and rate of GERD in these children (Del Guidice *et al.*, 1999:309). Del Guidice *et al.* (1999:310) found that diagnostic studies were able to detect reflux in 70-90% of severely affected children with CP. Umay *et al.* (2014:785) reported that 41% of children with CP in their study had symptoms of GERD, associated mostly with a poor feeding position and the severity of CP. Gastro-esophageal reflux may further contribute to the development of esophagitis and in severe cases it can result in iron deficiency as a result of blood losses (Trier, 2002:14). Swallowing difficulties, choking, coughing and/or GERD may cause food aversions which may affect the child's QOL and increase the risk of aspiration (Aneja, 2004:631; Barrett & Ogle, 2010:39; Field *et al.*, 2003:303; Gerek & Çiyiltepe, 2005:58; Ptomey & Wittenbrook, 2015:599). Food aversions occur when a child avoids a particular food related to the appearance, smell, texture, taste and/or temperature of the food, which may be due to sensory, physical or psychological difficulties (Kreipe & Palomaki, 2012:426). Food refusal is quite common in children with CP (about 30%) and is aggravated by food sensitivities for type or texture, GERD, dysphagia or pain (Gerek & Çiyiltepe, 2005:58).

2.3.2.2.1 *Recommendations on managing GERD*

The use of thickeners is mostly standard therapy advised by HCPs to manage regurgitation or vomiting in infants or children (Wittenbrook, 2011:28). However, whether it is effective for GERD in neurologically impaired children still needs to be investigated (Trier, 2002:14). Miyazawa *et al.* (2008:4) found that pectin-containing products partially decreased reflux by up to 81.5%, decreased the number of episodes of vomiting and might even improve respiratory symptoms such as wheezing in children with CP. They further recommend that a semi-solid meal with an added thickener of pectin has a beneficial effect on reflux in these children without causing

delayed gastric emptying (Miyazawa *et al.*, 2008:5). The effect of pectin on fat and ferrous iron absorption should, however, still be investigated (Miyazawa *et al.*, 2008:5). The quantity and quality of the feed, the infusion rate and concentration of the feed should also be assessed and evaluated in cases of severe vomiting (Marchand *et al.*, 2006:130).

Gastro-esophageal reflux can be the result of a cow's milk protein (CMP) allergy and in these instances, products containing CMP should be eliminated from the diet (Vandenplas, 2005:S42). Post-pyloric feeding is ideally indicated in children affected by CP with severe GERD and vomiting that have contributed to growth faltering and aspiration in the child (Gottrand & Sullivan, 2010:S19). Post-pyloric feeding routes include a nasojejunal tube, gastrojejunostomy or a jejunostomy (Bell & Samson-Fang, 2013:S14). The use of this feeding method is limited, however, because of the increased incidence of complications and tube replacements. Therefore, gastric feeding remains the preferred route when possible as tube insertion is less complicated, is more physiological and bolus feeds can easily be administered (Gottrand & Sullivan, 2010:S19).

Medical and surgical treatment may be required in severe GERD in children with CP (Bell & Samson-Fang, 2013:S15). Proton-pump inhibitors and histamine antagonists are often prescribed to treat severe gastro-esophageal reflux (Vandenplas, 2005:S42; Wittenbrook, 2011:29). Surgery such as Nissan-fundoplication may be needed if medical treatment is unsuccessful, but it does increase the risk of dumping syndrome (Wittenbrook, 2011:29). Enteral tube feeding, such as gastrostomies or jejunostomies, should be considered when oral intake remains unsafe for the child (Andrew *et al.*, 2012:223; Marchand *et al.*, 2006:128; Wittenbrook, 2011:30). Pentiuk *et al.* (2011:376) have reported that homemade pureed food given via gastrostomy may reduce the incidence of gagging and retching in children with CP that have undergone Nissan-fundoplication surgery. There is, however, limited evidence to support this claim (Bell & Samson-Fang, 2013:S15). On the other hand, Pentiuk *et al.* (2011:377) found that the nutritional adequacy and safety of home-prepared gastrostomy tube feeds are a matter of concern, even with the involvement of a dietitian, and poor weight gain has been reported. Roberts & Lyman (2008:86) also reported that homemade tube feeds are of major concern to immune-compromised children regarding safety and hygiene. They further explain that home-prepared formulas are appealing to some parents as they are cheaper to purchase and prepare, may have more health benefits if fresh food products are used, and allow the child to participate in meal preparation at home (Roberts & Lyman, 2008:87). If tube feeds are prepared at home, parents should strongly consider involving a dietitian to closely monitor the composition and

adequacy of these homemade feeds and give recommendations on how to safely store and administer them (Mascarenhas *et al.*, 2008:604).

2.3.2.3 Constipation

Delayed gastric motility, hypotonia, use of medications and inadequate fluid and fibre intake may contribute to constipation in children with CP (Jones *et al.*, 2007:231; Ptomey & Wittenbrook, 2015:599; Reily *et al.*, 1996:879; Wittenbrook, 2011:28). Constipation can further reduce appetite and therefore contribute to insufficient food and fluid intake (Jones *et al.*, 2007:231; Reily *et al.*, 1996:880). Most children with CP are poorly hydrated as a result of their inability to swallow fluids, which may further exacerbate the prevalence of constipation (Arvedson, 2013:S9). Veugelers *et al.* (2010:e218) found that constipation is commonly found in children with CP, especially in those that are more severely affected and on medications such as narcotics or diazepam. A study by Del Guidice *et al.* (1999:308) found that 52% of children with CP had chronic constipation, where the delay in colonic transit was found mainly in the proximal section of the colon (52%) and rectum (36%). Soylu *et al.* (2008:331, 332) reported that 71% of spastic quadriplegic children with CP in their study struggled with constipation mainly because of inadequate feeding, poor intake of dietary fibre, poor muscle tone and prolonged immobility. These findings were similar to those of Walsh & Nel (2007:12) where the fibre intake of disabled South African children was below the recommended amount. In the Oxford Feeding Study, Sullivan *et al.* (2000:679) found that constipation was a common gastrointestinal problem, where 59% of parents reported that their child struggled with constipation at some point in time. Kilpinen *et al.* (2009:1331) reported that severely disabled children with CP only met half of their daily fibre needs (52%), according to a three-day food diary that parents had to complete.

2.3.2.3.1 *Recommendations on managing constipation*

Optimal intake of dietary fibre and adequate fluid is essential in treating constipation (Bell & Samson-Fang, 2013:S15). American guidelines suggest that an intake of 0.5 g/kg body weight of fibre would assist in preventing constipation in disabled children (Trier, 2002:14). Wittenbrook (2011:28) suggests that the dietary reference intake (DRI) for fibre can be recommended and used as a guideline to determine the optimal fibre needs for a child with CP. The use of fibre-containing feeds or supplements may be helpful; however, medication may be required in severe cases of constipation (Elia *et al.*, 2008:130; Mascarenhas *et al.*, 2008:604; Wittenbrook, 2011:28). Medical management includes the use of single or multiple laxatives and stool softeners (Marchand *et al.*, 2006:131). These are required when fibre supplements or increased intake of

fluid do not successfully treat constipation (Wittenbrook, 2011:28). Veugelers *et al.* (2010:e220) reported that the use of laxatives may be helpful in relieving constipation; however, in their study they found that one third of children with CP remained constipated despite the use of laxative treatment. They also found that increased fluid intake of up to 90% of the child's needs together with sufficient amount of fibre may manage constipation (Veugelers *et al.*, 2010:e220). Prokinetic agents, such as metoclopramide or erythromycin, are often used to improve gastric motility and the feeding regimen may be adjusted to promote gastric emptying (Elia *et al.*, 2008:130; Marchand *et al.*, 2006:131).

2.3.3 Prolonged feeding times

Severely affected children with CP are fully dependent on a parent or caretaker for feeding and need more time to complete feeding tasks than their peers (Arvedson, 2013:S9; Marchand *et al.*, 2006:124; Sullivan *et al.*, 2000:678). Problems such as prolonged feeding, limited communication abilities and feeding difficulties make mealtimes difficult and challenging (Aggarwal *et al.*, 2015:299; Majnemer *et al.*, 2007:475; Reily *et al.*, 1996:878; Soylu *et al.*, 2008:332). Prolonged feeding times have been associated with parental depression that is due to frustration and tense interactions at mealtimes (Hurley *et al.*, 2008:803; Reilly & Skuse, 1992:382). They can therefore increase parental stress which may negatively impact the QOL of both the child and parent (Soylu *et al.*, 2008:331; Sullivan *et al.*, 2000:678; Sullivan *et al.*, 2002:464). This can lead to an abusive feeding manner and unresponsive feeding practices, which can aggravate existing feeding difficulties (Hurley *et al.*, 2008:803). Prolonged feeding also contributes to reduced total intake of nutrients, resulting in growth failure or malnutrition (Marchand *et al.*, 2006:124; Mascarenhas *et al.*, 2008:598; Reilly & Skuse, 1992:384).

Parents with disabled children may spend up to three to five hours daily feeding their child, compared to 0.8 hours for parents with non-disabled children, which can be exhausting for both parent and child (Soylu *et al.*, 2008:331; Sullivan *et al.*, 2000). In a study by Gangil *et al.* (2001:844), 38% of parents spent 30-45 minutes on feeding a meal to their CP child. Umay *et al.* (2014:784) found that 62% of parents were spending more than 45 minutes feeding their CP child at each mealtime. It has been reported that some mothers take up to seven hours per day feeding their disabled child (Reily *et al.*, 1996:878). Sullivan *et al.* (2000:679) suggested that if a mother is spending more than three hours per day feeding her CP child, a gastrostomy feeding tube should be considered. They also found that this method of feeding improves the QOL for both the child and parent and does not impose additional burdens on caregivers (Sullivan *et al.*, 2000:679). When mealtimes last longer than 30 minutes, there may be a feeding problem

(Kuperminc *et al.*, 2013:S23). Sullivan *et al.* (2000:679) reported that feeding time can be used as a reliable measure to assess the severity of a feeding impairment. Parents and caretakers should be cautious at mealtimes as increased feeding duration can result in unsafe swallowing, fatigue and reduced attention, increasing the risk of aspiration (Arvedson, 2013:S9; Kuperminc *et al.*, 2013:S22).

2.3.3.1 Interventions to improve feeding time

Simple interventions such as changing the child's seating position and posture, adjusting the food consistency and use of appropriate feeding utensils can be employed to improve feeding abilities and make it more efficient and safer for a child with CP to consume food and liquids (Bashar *et al.*, 2015:13; Gangil *et al.*, 2001:845; Kuperminc *et al.*, 2013:S22; Trier, 2002:15). A study by Trier (2002:14), however, found that modifying the consistency of food for a child with CP may not always assist in better swallowing. It reported that, compared with their healthy peers, children with CP took two to twelve times longer to swallow pureed food and up to fifteen times longer to chew and swallow solid foods (Trier, 2002:14). These findings were similar to those of Reilly *et al.* (1996:879), which indicated that severely poor oral motor skills can cause a child with CP to take up to 18 times longer than normal to manage one mouthful of food.

A study conducted by Bashar *et al.* (2015:12) reported that feeding and seating interventions have a profound impact on improving the child's food intake and consistency acceptance. They found that when implementing this intervention programme, children with CP who could only consume liquids were able to start eating semi-solid food (42% of children) or a combination of semi-solid and solid food (48% of children), which also decreased their risk of respiratory infections due to aspiration, improved the child's behaviour during meals, reduced feeding time from 60 minutes to 15-30 minutes and improved self-feeding skills in up to 56% of CP children (Bashar *et al.*, 2015:13). Ideally, the child and family should find mealtimes pleasurable and stress-free (Gangil *et al.*, 2001:845). Positioning a child in a suitable feeding chair allows eye contact, facilitates communication and can make mealtimes more enjoyable, easier and quicker (Redstone & West, 2004:98). It is advised that the child should take part in family mealtimes, even if the child is not being fed orally, for social interactions with other family members and to improve sensory responses (Arvedson, 2013:S11). A feeding tube may be recommended if feeding times become exhausting or mealtimes too stressful (Day *et al.*, 2007:171).

2.3.4 Nutritional deficiencies and deficits

Cerebral palsied children that are not willing to try a new food are at risk of developing nutritional deficiencies (Gerek & Çiyiltepe, 2005:70). Gerek and Çiyiltepe (2005:70) have found that food selectiveness was partially due to the limited knowledge of parents on how to prepare a soft diet, parents being unfamiliar with the use of food thickeners, or children becoming bored with the same type of food for a long period.

Children with CP have a high risk of low bone mineral density as a result of feeding difficulties, use of specific medications, poor nutritional status, prolonged immobilisation, growth retardation, poor weight gain and low intake of calcium and vitamin D (Cohen *et al.*, 2009:963; Kuperminc & Stevenson, 2008:144; Umay *et al.*, 2014:784). Kakooza-Mwesige *et al.* (2015:8) reported that circumstances in the neonatal period and severity of CP were significantly associated with the nutritional status of the child. Nutrition deficits are multifactorial in neurologically impaired children and are related to inappropriate dietary intake of both macronutrients and micronutrients, nutrient losses that include food spillage and GERD and abnormal energy expenditure relative to their nutritional requirements (Marchand *et al.*, 2006:124, 125; Mascarenhas *et al.*, 2008:598, 599; Sullivan, 2013:S3).

2.3.4.1 Macronutrients

A subgroup of the Oxford Feeding Study conducted by Sullivan *et al.* (2000:676) was used to determine the impact of feeding problems on the nutritional intake of children with CP by means of a detailed dietetic and comprehensive anthropometric assessment. In this sub-study, Sullivan *et al.* (2002:461) found that feeding problems in this group of disabled children had a significant impact on nutrient intake. Protein intake was found to be 96% of estimated average requirements (EAR) for specific age groups, as milk and milk-based products form the basis of most diets (Sullivan *et al.*, 2002:464). Schoendorfer *et al.* (2011:e260) also found that the protein intake of the severely affected children with CP that were fed orally or enterally was well over the current recommendations for protein intake for age and gender. They did report, however, that it was significantly lower than that of their normally developing peers (Schoendorfer *et al.*, 2011:e260). These findings were also demonstrated by Kalra *et al.* (2015:143) and Walsh and Nel (2007:8) who found no significant difference in the mean protein intake between children with CP and their healthy peers.

The major nutritional deficit of macronutrients was found to be in energy intake, where only 20% of children with CP met the EAR for their specific age groups (Sullivan *et al.*, 2002:464). This supports the findings of Patrick and Gisel (1990:118) who stated that reduced energy intake was due to the fact that most CP children cannot complete meals and liquids, therefore contributing to the energy deficit. Poor energy intake has been linked to dysphagia, mobility and the activity level of a child with CP (Patrick & Gisel, 1990:119; Schoendorfer *et al.*, 2010:740). Kalra *et al.* (2015:143), Reilly *et al.* (1996:880) and Walsh and Nel (2007:8) found that children with CP consume significantly less energy than their peers due to the inability to communicate when they are hungry, what their food preferences are and when they have reached satiety. Kilpinen-Loisa *et al.* (2009:1331) also found that insufficient energy and nutrient intake is common in children with motor disabilities. They reported an energy intake of 76% of the age-specific recommended amounts in children with CP that were severely disabled and able to eat orally (Kilpinen-Loisa *et al.*, 2009:1331, 1332). It has also been suggested that disabled children may require less energy than their peers (Sullivan *et al.*, 2002:466). However, low energy intake may contribute to adverse health effects such as poor growth and decreased weight for age (Kilpinen-Loisa *et al.*, 2009:1332; Schoendorfer *et al.*, 2010:740; Sullivan *et al.*, 2002:466).

Not much research has focused on the differences in energy expenditure between the various types of CP, such as hypertonic or spastic and hypotonic CP. Interestingly, Azcue *et al.* (1996:873) found that the resting energy expenditure (REE) in children with spastic, quadriplegic CP was significantly lower than in higher functioning children with CP as well as the WHO prediction equations. They concluded that the central nervous system plays an essential role in energy regulation in children with CP and therefore individual energy expenditure should be measured to achieve an optimal nutritional status (Azcue *et al.*, 1996:874). A study by Stallings *et al.* (1996:631) found very similar results, but also found that the dietary intake of spastic, quadriplegic children with CP is markedly overreported in this population. They also reported that children with lower fat stores had a lower REE in comparison with children with adequate fat stores (Stallings *et al.*, 1996:629).

2.3.4.2 Micronutrients

Micronutrients play an important role in health, social participation, cognitive development and behavioural outcomes in children with CP (Kalra *et al.*, 2015:143). Micronutrient deficiencies have been found in children with neurodevelopmental disabilities and may be underreported or are unrecognised (Kalra *et al.*, 2015:140; Sullivan *et al.*, 2002:466; Walsh & Nel, 2007:8). Parents have reported that meat, fruit and vegetables are often excluded from the child's diet because of

feeding difficulties, which contributes to micronutrient deficiencies (Sullivan *et al.*, 2000:674). Stathopolou and Thomas (1997:672) have found that 15-50% of neurologically impaired children have micronutrient deficiencies. These deficiencies include calcium, iron, zinc, vitamin A, vitamin B12, vitamin C, vitamin E, selenium, folate and essential fatty acids (Bell *et al.*, 2010:5; Hillesund *et al.*, 2007:1196; Kalra *et al.*, 2015:142; Patrick & Gisel, 1990:119). Some of these deficiencies have been confirmed by Sullivan *et al.* (2002:464). Approximately 50% of the EAR for micronutrient intake of vitamin A in the form of retinol (26%), selenium (43%), zinc (44%), iron (46%) and magnesium (52%) for specific age groups was found in this study, and was consumed mainly in the form of fortified products such as breakfast cereals (Sullivan *et al.*, 2002:464). Dietary intakes of phosphorus were found to be the highest of micronutrients, at around 96% of EAR for the specific age groups, followed by riboflavin (89%), thiamine (86%), calcium (77%) and vitamin C (71%) (Sullivan *et al.*, 2002:464). Schoendorfer *et al.* (2011:e260) compared the micronutrient intake of severely disabled children with CP that were fed orally or enterally, specifically via gastrostomies, to developing and healthy children that matched their age groups. They found that there was a significant difference in zinc iron, and copper intake between children with CP that were orally fed or fed via gastrostomies, and their healthy peers (Schoendorfer *et al.*, 2011:e262). Kalra *et al.* (2015:142) also demonstrated similar results where they compared the micronutrient intake of children affected by CP with that of neurologically normal peers. They found that the intake of iron, copper and magnesium was significantly lower in these children compared with their healthy peers (Kalra *et al.*, 2015:142). Schoendorfer *et al.* (2011:e260) further found that the calcium, magnesium, iodine and potassium intake of orally fed children with CP was inadequate, according to the recommended dietary allowance (RDA) for age. The micronutrient intake was best in the normally developing and healthy children group and the lowest in children with CP that consumed food orally (Schoendorfer *et al.*, 2011:e261). They therefore suggested that children who eat orally be evaluated and monitored more frequently for micronutrient deficiencies and that their meals be supplemented with an appropriate feed or vitamin and mineral supplement (Schoendorfer *et al.*, 2011:e261). This suggestion is further supported by a study conducted by Schoendorfer *et al.* (2013:99), which demonstrated how orally fed children with CP have a higher incidence of micronutrient deficiencies compared with enterally fed children. Deficiencies in vitamin C, which can also contribute to low iron levels, magnesium and zinc, were found in orally fed children with CP (Kalra *et al.*, 2015:142; Schoendorfer *et al.*, 2013:100).

The effect of micronutrient deficiencies on the nutritional status of children with CP has not yet been fully researched and explored, but several studies have shown that such deficiencies may have detrimental consequences on bone health, immunity and cognitive function. An inadequate micronutrient status can contribute to an increased risk of infection, poor appetite and poor wound healing, but this has not been fully demonstrated in the CP population (Schoendorfer *et al.*, 2010:741). The risk of infection is higher when a child is malnourished and even greater when nutrient intake is inadequate (Kuperminc & Stevenson, 2008:143).

Kilpinen-Loisa *et al.* (2009:1331) found that the vitamin D intake of severely disabled children met only 76% of the age-specific recommendation. Inadequate intake of calcium and vitamin D may increase the risk of developing osteopenia, leading to bone fractures (Kuperminc *et al.*, 2013:S21; Mascarenhas *et al.*, 2008:598; Piccoli *et al.*, 2002:583). It has been found that non-ambulatory children have lower bone mineral density than mobile and active children, which increases their chances of developing osteopenia and fractures (Henderson *et al.*, 2004:418). The incidence of fractures in children with CP has been estimated at around 5-30% and most fractures occur in the lower extremities (Munns & Cowell, 2005:269; Piccoli *et al.*, 2002:583). Recurrent fractures worsen QOL and may shorten life expectancy (Munns & Cowell, 2005:269; Kuperminc & Stevenson, 2008:143). Lack of exposure to sunlight and the use of anti-seizure medications may also trigger the development of rickets (Aneja, 2004:628; Kuperminc *et al.*, 2013:S23).

2.3.4.3 Addressing nutritional deficiencies

Estimating the nutritional needs for a neurological impaired child is challenging owing to variations in energy requirements related to the heterogeneity of the group, reduced physical activity (especially if the child is wheelchair bound), use of medications and altered body composition (Bell & Samson-Fang, 2013:S13; Kuperminc *et al.*, 2013:S23; Mascarenhas *et al.*, 2008:599; Wittenbrook, 2011:23). There is currently no accepted method to accurately estimate and calculate the true macronutrient needs of children with CP, especially if they are underweight or overweight (Bandini *et al.*, 2015:312; Bell & Samson-Fang, 2013:S13; Kilpinen-Loisa *et al.*, 2009:1331; Ptomey & Wittenbrook, 2015:602). When the nutritional needs are calculated for a child with CP, the DRIs for macronutrients may be used as a starting point (Marchand *et al.*, 2006:128; Mascarenhas *et al.*, 2008:599; Wittenbrook, 2011:23). Taylor and Shelton (1995:282) indicated that severely impaired children may require less total energy per day for nutritional support when energy equations are used to estimate their needs. It has been found that children with severe CP that are wheelchair bound have estimated energy needs that are 60-70% of those of their peers (Walker *et al.*, 2012:1312). The typical use of prediction equations has been found

to overestimate the energy needs of disabled tube-fed children by as much as 20% (Dickerson *et al.*, 1999:67). Lee *et al.* (2011:533) found that there is a significant difference between the mean energy expenditure (determined by means of indirect calorimetry from actual intake) and predicting energy expenditure (by means of prediction equations) of children with spastic CP. They reported that prediction equations overestimated the energy needs of these children by almost 50% of their mean energy expenditure and overfeeding can easily occur when energy requirements are estimated (Lee *et al.*, 2011:534). The use of indirect calorimetry should be considered where possible and feasible in a facility to predict reliable energy needs of these children (Lee *et al.*, 2011:534). There are also currently no specific recommendations for children with CP regarding dietary intakes of vitamins, minerals and trace elements and therefore the standard recommendations for micronutrient intake are advised (Bell & Samson-Fang, 2013:S13).

When registered dietitians (RDs) assess the needs of a child with CP, they still have to consider including qualitative and quantitative information to set realistic goals for requirements and intake (Aisen *et al.*, 2011:848; Bell & Samson-Fang, 2013:S13; Rosenbaum, 2003:972). Dietary needs or nutritional requirements should be calculated as accurately as possible and adapted for each individual, but this process, which requires skill and experience, may be very challenging (Aneja, 2004:629; Mascarenhas *et al.*, 2008:597). It is not only the types of food and drink that must be considered, but also the actual intake, wastage and drooling of liquids during mealtimes (Trier, 2002:15). It is essential that a child with CP should be thoroughly assessed when feeding difficulties are present in order to ensure that the child receives adequate intakes of food and fluid to meet the RDA of vitamins and minerals, adequate energy, fibre and fluid intake (Jones *et al.*, 2007:227,231). Vitamins and minerals that are deficient should be checked at least every three months until levels are within the normal range (Cohen *et al.*, 2009:964). Micronutrient-rich foods should be recommended for inclusion in the diet if a CP child has micronutrient deficiencies or is at risk of such a deficiency (Bell & Samson-Fang, 2013:S13). It is suggested that the meals of children that have feeding problems contributing to a compromised food intake be supplemented with a vitamin, mineral and trace element mixture to meet their requirements (Trier, 2002:15). Nutritional supplements, given orally or via gastrostomy tubes, may significantly improve energy intake and the micronutrient status of children with CP and should strongly be considered in these children with depleted micronutrient stores (Hillesund *et al.*, 2007:1197; Kilpinen-Loisa *et al.*, 2009:1332).

Calcium supplementation has been shown to increase bone mineral density by 5% over a period of four years in healthy children, but this has not yet been investigated in neurologically impaired

children (Matkovic *et al.*, 2005:180). Henderson *et al.* (2002:648) found that the use of bisphosphonates increased bone mineral density in children with CP by up to 89% over a period of 18 months. They do, however, advise that bisphosphonates should not be used as part of a treatment plan yet, as the long-term effects are unknown (Henderson *et al.*, 2002:649).

Ongoing assessment is needed to monitor appropriate growth and weight gain and prevent underfeeding or overfeeding, especially after a child has started on a specific dietary plan and regimen (Aneja, 2004:627; Marchand *et al.*, 2006:124; Mascarenhas *et al.*, 2008:597; Wittenbrook, 2011:23).

2.3.5 Malnutrition

Malnutrition refers to both underweight and overweight or obesity (Mascarenhas *et al.*, 2008:597). The true prevalence of malnutrition in disorders such as CP in children is unknown (Marchand *et al.*, 2006:124).

Most children with CP struggle with malnutrition, which may occur in up to 52% of children (90% in severely disabled children), especially undernutrition and wasting, at around 45% of children (Karagiozoglou-Lampoudi *et al.*, 2012:652; Reilly *et al.*, 1996:880; Sterling, 1960:132; Sullivan *et al.*, 2000:679; Walsh & Nel, 2007:8). Khan *et al.* (1998:752) found that severe malnutrition, especially undernutrition, was the leading cause of death of children with CP in both urban and rural populations. Kakooza-Mwesige *et al.* (2015:2) investigated the prevalence of malnutrition in a developing country such as Uganda and found that 42% of children with CP were underweight, especially children older than five years of age, as well as those that had feeding difficulties in the perinatal period. Karagiozoglou-Lampoudi *et al.* (2012:651) and Stallings *et al.* (1995:833) found that undernutrition is most commonly found in spastic quadriplegic children with CP. This is caused mainly by nutrition deficits as a result of inappropriate dietary intake, contributing to fat loss and/or muscle atrophy (Karagiozoglou-Lampoudi *et al.*, 2012:651; Marchand *et al.*, 2006:123; Walsh & Nel, 2007:8). Other factors contributing to undernutrition include oral motor dysfunction, poor dental care, early satiety, inability to communicate, behavioural problems and increased dietary needs (Aggarwal *et al.*, 2015:298; Mascarenhas *et al.*, 2008:597; Soylu *et al.*, 2008:332; Sullivan, 2013:S3; Umay *et al.*, 2014:781).

Obesity in developmentally and physically disabled children is on the rise and has serious health-related consequences (Bandini *et al.*, 2015:310; Oftedal *et al.*, 2015:1808). The overall prevalence of obesity has been reported to be between 16% and 29% of children with CP (Oftedal *et al.*, 2015:1809). This has been seen particularly among children classified as level I or II on

the GMFCS relating to functional mobility (Ofstedal *et al.*, 2015:1808). As the National Health and Nutrition Examination Questionnaire (NHANES) of 2005-2012 and the National Health Interview Questionnaire (NHIS) of 2008-2013 clearly showed, children with disabilities needing special healthcare demonstrated higher rates of obesity compared with their peers (Centres for Disease Control and Prevention, 2012). Disabled children were 35% to 59% more likely to become obese, according to the NHANES and NHIS respectively, compared with their peers (Centres for Disease Control and Prevention, 2012). It has also been found that children with mobility limitations and intellectual or developmental disabilities have a higher risk of developing obesity than any other disabilities, which include visual and hearing impairment (Akinbami & Ogden, 2009:1578; Walsh & Nel, 2007:8). Non-ambulatory spastic children with CP are most at risk of becoming overweight or obese (Finbråten *et al.*, 2015:863; Taylor & Shelton, 1995:282). Because of physical inactivity, diets high in sugar and energy-dense fats that are easier to consume, use of medication, parents' lack of knowledge regarding nutrition and lack of proper education and support from HCPs, the risk of obesity increases (Bandini *et al.*, 2015:311, 312).

2.3.5.1 The detrimental effects of malnutrition

Malnutrition has detrimental effects on social participation, health and QOL as it causes growth failure, impaired development, reduced muscle strength, impaired immunity, poor wound healing, bone demineralisation and increased risk of fractures, impaired GI function, increased irritability and apathy, and reduced strength for rehabilitation (Kuperminc & Stevenson, 2008:138; Stevenson *et al.*, 2006:1011; Sullivan, 2013:S3). Undernutrition has also been linked to various adverse consequences, including growth failure, decreased cerebral function, impaired immunity, diminished respiratory muscle strength and poor circulation (Kuperminc *et al.*, 2013:S21; Marchand *et al.*, 2006:125). Overweight and obesity affect linear growth, decrease the QOL and increase difficulty of care for the child with CP (Mascarenhas *et al.*, 2008:597; Stevenson *et al.*, 2006:1016; Taylor & Shelton, 1995:281).

2.3.5.2 Recommendations on managing malnutrition

Malnutrition is to a large extent reversible if detected in the early stages of development (Sullivan *et al.*, 2000:679). However, long-term undernutrition can have irreversible effects on growth (Stevenson *et al.*, 2006:1017). Nutritional intervention enables appropriate growth for neurologically impaired children and a well-planned diet will prevent overfeeding or underfeeding and improve QOL (Andrew & Sullivan, 2010:360; Bell & Samson-Fang, 2013:S13; Marchand *et al.*, 2006:128). Once the nutritional status of the child with CP has been evaluated, it is important to establish a target weight and ideal growth pattern (Kuperminc & Stevenson, 2008:145).

2.3.5.2.1 *Screening for malnutrition*

The best screening tool for malnutrition in children with CP is the tricep skinfold (TSF) measurement (Frisancho, 1981:2544). Samson-Fang and Stevenson (2000:165) demonstrated that TSF measurements less than the 10th percentile on growth charts can be used as a validated and reliable tool to detect depleted fat stores and malnutrition in children with CP. They further suggest that the actual body weight may be used in calculating nutritional needs in children with a TSF between the 25th and 90th percentile and the adjusted body weight may be used for obese children (Samon-Fang & Stevenson, 2000:167). In recent years, the mid-upper arm circumference (MUAC) has become very popular in screening normal, developing children for malnutrition. As children with CP have altered body compositions, they have a significantly lower MUAC compared with their healthy and normal peers and therefore one cannot extrapolate the cut-off values of the MUAC to this population group (Aggarwal *et al.*, 2015:737; Contreras *et al.*, 2014:840). However, Aggarwal *et al.* (2015:739) and Karagiozoglou-Lampoudi *et al.* (2012:652) mentioned that children with CP without feeding problems have better mean Z-score values for MUAC than those with multiple feeding difficulties. The mid-upper arm fat area (MUAFA) has been found to be more realistic and accurate in predicting malnutrition than MUAC values and weight-for-height centiles should be used only to depict acute malnutrition (Samson-Fang & Steveson, 2000:165). If the MUAC value is used in the CP population, it is recommended that one should convert it to a Z-score value and interpret it according to the Frisancho reference tables (Contreras *et al.*, 2014:834, 841; Wittenbrook, 2011:22).

Another study done by Brooks *et al.* (2011:e304) found that children with CP who are malnourished (with weights below the 20th percentile on the GMFCS growth charts) have more extreme medical conditions and have an increased risk of mortality. A physical and clinical

examination of the skin, hair and limbs may be needed to identify signs of malnutrition (Marchand *et al.*, 2006:127; Mascarenhas *et al.*, 2008:601).

2.3.5.2.2 Addressing malnutrition by means of nutrition

Undernutrition is addressed by increasing the nutritional intake of fats and protein by fortifying and enriching the current diet (Bell & Samson-Fang, 2013:S14). High fat spreads or oils, milk powders, mashed avocado, eggs, pureed meats, dairy products, lentils and legumes added to meals are common examples of foods that increase the energy, protein and fat intake of a CP child (Bell & Samson-Fang, 2013:S14). Nutritionally complete or modular supplements or sip feeds (milk- or juice-based) can also be considered if there is no improvement on the nutritional status on dietary intake alone (Bell & Samson-Fang, 2013:S14; Kuperminc & Stevenson, 2008:145, 146; Mascarenhas *et al.*, 2008:603). When these supplements or sip feeds are advised, it is important to consider the child's total nutrient consumption to ensure that the macronutrient and micronutrient intake are within the safe recommendations for the specific nutrient and not exceeding the upper limit (WHO/FAO/UNU, 2004:19). The response to nutritional supplements should be accurately monitored, especially for weight gain, linear growth and skinfold measurements (Kuperminc & Stevenson, 2008:145; Marchand *et al.*, 2006:123; Sullivan, 2013:S3). Soylu *et al.* (2008:333) investigated the effect of nutritional support in spastic quadriplegic children with CP who were malnourished and wasted. They found a significant improvement in some anthropometric measurements, such as weight, height, head circumference and mid-upper arm circumference, suggesting the need for adequate nutritional support in this group of children (Soylu *et al.*, 2008:332). Energy intake as well as the feeding volume should be reduced and the necessary dietary changes should be implemented to ensure a safe and healthy weight status (Pencharz, 2010:S6).

It is essential to understand the etiology of the development of obesity in disabled children in order to provide an appropriate treatment intervention (Bandini *et al.*, 2015:312). Overweight or obese children with CP are usually put on a hypocaloric diet restricted in sugar, refined carbohydrates and high-fat content food products and liquids (Bell & Samson-Fang, 2013:S14). It is also important to consider the current dietary intake, energy expenditure, family-based lifestyle, behaviour and environmental factors of the disabled child when providing recommendations for an overweight or obese CP child (Bandini *et al.*, 2015:313).

2.3.5.2.3 Other options in managing malnutrition

Some clinicians recommend video recording mealtimes to assess actual intakes of the child. It can also be used to assess and identify problems at mealtimes such as positioning when feeding and skills in communicating hunger or satisfaction that could be managed more appropriately (Reily *et al.*, 1996:881; Trier, 2002:15). It is essential to monitor closely the eating behaviour and energy intake of CP children, (Aisen *et al.*, 2011:848; Wittenbrook, 2011:30). A three-day food diary has been recommended by various clinicians to assess the intake of children with CP, but it is important to interpret this information with caution as it may be overreporting the true intake of the child (Gangil *et al.*, 2001:845; Mascarenhas *et al.*, 2008:600). These diaries should be used primarily for qualitative purposes, to assess food types, food preferences and variety of foods in the diet and not to focus on the quantity eaten at mealtimes (Mascarenhas *et al.*, 2008:600; Samson-Fang & Bell, 2013:s5). Meal observations are also popular methods for evaluating feeding and often indicate that children consume less, spill more and/or are offered fewer food products than reported by a parent (Marchand *et al.*, 2006:127; Mascarenhas *et al.*, 2008:601).

Tube feeding is also recommended to improve nutritional status if severe swallowing problems are present, resulting in undernutrition, poor weight gain and insufficient fluid intake (Arvedson, 2013:S11; Bell & Samson-Fang, 2013:S14; Jones *et al.*, 2007:227; Kuperminc & Stevenson, 2008:145; Liptak *et al.*, 2001:368). This type of nutritional support is especially beneficial to underweight children with CP where feeds can be administered continuously overnight and the formulas can be tailored to meet specific needs (Wood, 2006:290). Schoendorfer *et al.* (2011:e261) demonstrated that weight improved in children with CP fed via a gastrostomy tube compared with those fed orally. Short-term tube feeding methods include nasogastric tubes, as they are relatively less invasive (Bell & Samson-Fang, 2013:S14; Kuperminc & Stevenson, 2008:145). If needed, they are then replaced with a gastrostomy for long-term use, which is a more comfortable option that does not require frequent tube changes (Bell & Samson-Fang, 2013:S14; Gottrand & Sullivan, 2010:S19; Kuperminc & Stevenson, 2008:145). Gastrostomy feeding can be used as a sole source of nutrition or to supplement oral intake, depending on how safely the child can consume food and liquids orally (Bell & Samson-Fang, 2013:S14). Parents may need to be reassured that the child may consume food and liquids by mouth, in most cases, without having the pressure to consume it all orally (Kuperminc & Stevenson, 2008:145). Children fed via gastrostomy tubes have the greatest risk of becoming overweight or obese (Lee *et al.*, 2011:533; Mascarenhas *et al.*, 2008:598). Weight gain needs to be closely monitored as an

increase in fat stores rather than lean body mass may have long-term detrimental implications (Finbråten *et al.*, 2015:861; Trier, 2002:15). Excess and rapid weight gain is therefore not recommended and should be prevented (Schoendorfer *et al.*, 2011:e261).

2.4 General management of nutrition-related problems in children with cerebral palsy

Early identification of CP is vital in establishing effective treatment to manage this disorder and its complications successfully (Aisen *et al.*, 2011:844; Campbell *et al.*, 2008:264; Fung *et al.*, 2002:367). This is usually done when a baby is older than four months or, in less affected babies, after eight months of age (Aneja, 2004:627). Fung *et al.* (2002:366) have demonstrated that a structured questionnaire, completed by parents, is a useful method for screening children with CP for nutritional risks and identifying a feeding disorder.

Nutrition intervention for children with CP is required if the following indicators are present:

- Deviation from an established growth pattern - either rapid weight gain or weight loss;
- Evidence of low lean body mass and/or low subcutaneous fat stores in combination with low weight;
- Prolonged or stressful oral feeding;
- Signs of pulmonary aspiration or dehydration;
- Clinical signs and evidence of micronutrient deficiencies.

(Bell & Samson-Fang, 2013:S13; Mascarenhas *et al.*, 2008:602)

When determining the need for intervention, the clinician should always consider the nutrition history, medical history, anthropometric measurements and biochemical parameter of the child with CP (Gangil *et al.*, 2001:845; Kuperminc & Stevenson, 2008:143; Marchand *et al.*, 2006:126; Samson-Fang & Bell, 2013:S6). This is illustrated and explained in Table 2.6 below.

Table 2.6: Focus areas in determining the need for nutritional intervention in a CP child

(Adapted from: Samson-Fang & Bell, 2013:s5-s7; Wittenbrook, 2011:17)

Nutrition History	Medical History	Anthropometric measurements and interpretations	Blood values
Weight & growth - Underweight / Overweight / Stunted Feeding method - Oral / Enteral / Parenteral / Mixed Mealtimes, including: - Preparation of meals - Duration of mealtimes - Positioning when feeding - Frequency of meals & snacks - Feeding experience at mealtimes - How illness affects mealtimes - Mealtimes at school Current diet, including: - Eating patterns - Preferred foods - Variety of the diet - Supplement intake - Caloric density of foods - Micronutrient, fibre & fluid intake Previous feeding interventions Recurrent nutritional concerns	Underlying conditions - Osteopenia / Scoliosis Level of mobility - Ambulatory / Non-ambulatory / Wheelchair-bound / Assistive devices Degree of tone - Hypertonia / Hypotonia Respiratory concerns GI difficulties - Dysphagia / Constipation / Dysmotility / GOR Medications - Drug-nutrient interactions/ Side-effects on muscle tone, bowel movements and appetite	Weight & length/height Alternative measurements for length/height: - Upper arm length - Knee height - Tibial length Body fat percentage measured using: - Bioelectrical impedance - Skinfolds - DEXA Ideal body weight Body mass index Growth velocity Interpretations done on: - Growth charts: (weight and length / height) - WHO (< 2 years old) - GMFCS (2 – 20 years old)	Assess for deficiencies: - Zinc - Iron - Folate - Carnitine - Vitamin D - Vitamin B12 - Serum electrolytes - CRP or inflammatory markers - Albumin / Pre-albumin Screen for hormonal abnormalities: - TSH - IGF-1

CRP: C-Reactive Protein; **DEXA:** Dual X-ray absorptiometry; **GI:** Gastrointestinal; **GMFCS:** Gross Motor Function Classification System; **GER:** Gastro-esophageal reflux; **IGF-1:** Insulin-like Growth Factor 1; **TSH:** Thyroid Stimulating Hormone; **WHO:** World Health Organisation

2.4.1 Managing nutrition-related problems

Early nutritional management with regular follow-ups is vital for optimal growth and development, preventing failure to thrive and swallowing difficulties especially for young children with CP (Aisen *et al.*, 2011:848; Day *et al.*, 2007:171; Mascarenhas *et al.*, 2008:605; Soylu *et al.*, 2008:333; Stevenson *et al.*, 2006:1014). Soylu *et al.* (2008:332) reported that a third of parents in their study did not attend follow-up sessions with their spastic child with CP, which was not ideal and could hold detrimental consequences for both the parent and child. Sullivan *et al.* (2000:674) found that 64% of disabled children never underwent a feeding and nutrition assessment, which is of major

concern. Nutritional assessment and management is a very challenging process in children with CP and a RD has to rely on accurate information and measurements to develop a successful, strategic plan (Mascarenhas *et al.*, 2008:597; Samson-Fang & Bell, 2013:s7). There is currently no “gold standard” for managing and treating children with cerebral palsy. However, a substantial amount of evidence has emerged in the past 20 years to support best practices in methods used to understand, measure and intervene in order to optimise the nutritional status and growth abilities of these children (Hurwitz *et al.*, 2015:290; Kilpinen-Loisa *et al.*, 2009:1331; Kuperminc *et al.*, 2013:S21).

The WHO has designed a framework that has been published in the *International Classification of Functioning, Disability and Health* (2001) to provide a multi-perspective approach for HCPs as part of an interactive and evolutionary process. This model can be used to guide a HCP when treating children with CP (WHO, 2001:18). The following framework (Figure 2.3) illustrates the interactions between the components of the International Classification of Functioning, Disability and Health (ICFDH) in CP children.

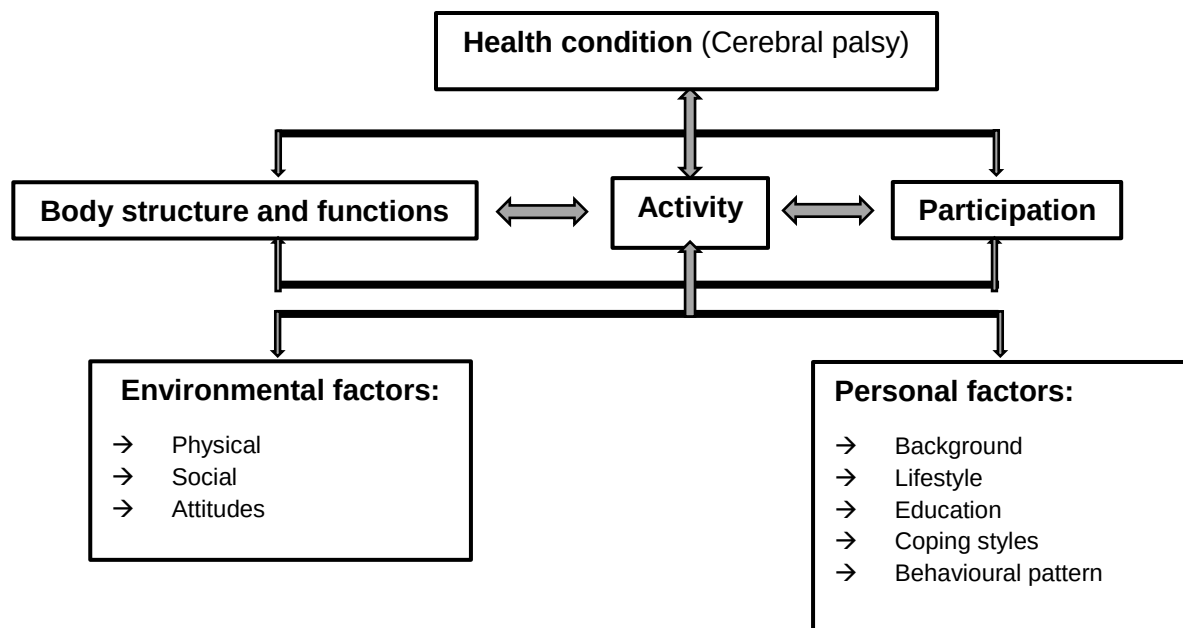


Figure 2.3: The World Health Organisation’s model to illustrate interactions between components of the International Classification of Functioning, Disability and Health (ICFDH) (Adapted from: Redstone & West, 2004:97)

The treatment approach of the MDT should, however, be *individualised* for each child (Kuperminc *et al.*, 2013:S21; Mascarenhas *et al.*, 2008:602; Xavier *et al.*, 2014:30). The following questions regarding nutrition, feeding and growth may assist in guiding decision making and management and in setting goals (Craig, 2013:S17; Kuperminc *et al.*, 2013:S21, S22; Sullivan, 2013:S3):

- 1) Have the psychosocial support needs of the child and caregivers been assessed?
- 2) Is the child growing properly and appropriately?
- 3) Is the method of feeding safe for the child?
- 4) What feeding route is used to feed the child?
- 5) Is feeding efficient for the child and the family?
- 6) What are the ideal nutritional requirements of the child?
- 7) Does the child require additional nutritional support?

Information regarding the feeding method, food consistencies or textures, duration of mealtimes and presence of choking and/or coughing while feeding, is also essential in a management plan (Aneja, 2004:631). Strauss *et al.* (1998:145) suggested that feeding function and skills may be an essential indicator of a child's health outcome. A skilled therapist can assist in elucidating the oral motor skills of a baby by observing them during mealtimes (Aneja, 2004:631; Mascarenhas *et al.*, 2008:601; Reily *et al.*, 1996:881). Food consistencies may be adjusted according to recommendations made by a speech or feeding therapist when poor feeding, unsafe swallowing, food spillage and food aversion is present (Aisen *et al.*, 2011:848; Barratt & Ogle, 2010:40; Ptomey & Wittenbrook, 2015:597). This will ensure airway safety, but also maximise eating efficiency and decrease fatigue during mealtimes (Kuperminc *et al.*, 2013:S22).

Adams *et al.* (2011:881) found that low-cost and low-technology caregiver training, as part of an intervention programme, has a substantial beneficial effect on improving feeding practices of caregivers of children with CP in poor and rural areas. They reported that, even with a minimum of four training sessions, they found a significant improvement in the children's respiratory health, including reduced frequency of aspiration and pneumonia, improvement in their overall mood reduced assistance needed during mealtimes and reduced stress on the caregiver (Adams *et al.*, 2011:884). They suggested that ongoing training of caregivers has a profound and positive impact on the care of the child and is especially important in situations of poverty and in rural communities where there is a lack of education, resources, finances and time (Adams *et al.*, 2011:886). Similar results were found by Nadeem *et al.* (2014:241) and Xavier *et al.* (2014:30), where caregiver training resulted in positive consequences and improvement of oro-motor impairments in children with CP.

One of the most basic, low-cost and effective treatments for managing feeding or swallowing problems in children with CP is adequate *positioning* by facilitating trunk and head alignment (Redstone & West, 2004:100). Postural control is an essential component in the normal swallowing process and contributes to the progression of developmentally mature stages of oral control in children suffering from CP (Aggarwal *et al.*, 2015:300; Redstone & West, 2004:97). A customised feeding chair or brace can also be used at mealtimes for additional body and head support to ensure safety during swallowing (Barratt & Ogle, 2010:40). Proper positioning of the child at mealtimes should include the following:

- 1) The child must be seated in an upright position where the chair seat and back should be at a 90-degree angle for the child to remain upright;
- 2) The child must be in a symmetrical position;
- 3) The hips, knees and feet must be in 90-degree flexion;
- 4) The feet and pelvis must be stable – foot support should be provided if feet do not touch the floor;
- 5) A well-positioned, tight seat belt may be used;
- 6) A solid and stable table surface is essential;
- 7) The head must be in a chin tuck position.

(Redstone & West, 2004:99)

Redstone and West (2004:97) demonstrate in the following figure how correct postural alignment can contribute to and assist in improved oral intake and swallowing in children with CP.

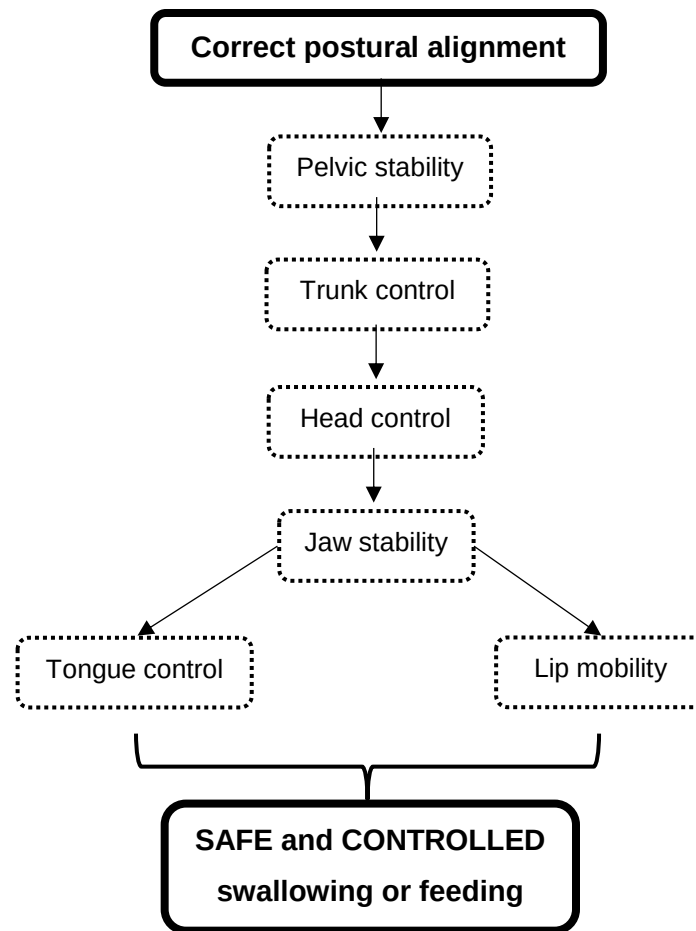


Figure 2.4: The influence of correct postural alignment on oral control for feeding
(Adapted from: Redstone & West, 2004:97)

2.4.2 Nutrition support and interventions

The type of nutritional support a child with CP should receive depends on the nutritional status of the child, his or her ability to consume adequate amounts of food and liquids orally and the risk of pulmonary aspiration (Walker *et al.*, 2012:1311). Ideally, oral intake is recommended where possible and the aim is to gradually supply sufficient amounts of energy, protein and micronutrients meeting the child's needs (Kuperminc *et al.*, 2013:S23). Complete oral nutritional supplements can be given in cases where a child is underweight, immune-compromised, or vitamin- or mineral-deficient (Trier, 2002:14). These supplements contribute to the additional intake of macronutrients and micronutrients (Andrew *et al.*, 2012:223). Complete oral feeding is

not a realistic goal for all children with CP and in some cases may even be harmful (Kuperminc *et al.*, 2013:S22). If it is physiologically possible and safe for the child to consume some food and liquid orally and fits in with the social situation of the child and family, oral feeding should be encouraged (Gangil *et al.*, 2001:843). Alternative feeding routes should be discussed and carefully explored in a sensitive way as this may cause most parents to feel anxious and concerned (Gottrand & Sullivan, 2010:S20). Parents often resist the insertion of tube feeds for various reasons such as lack of control over food intake, feeling of failure to nurture the child, and cultural aspects (Mascarenhas *et al.*, 2008:603). The entire MDT is required to give input if and when alternative feeding routes such as a nasogastric tube, gastrostomy, or post-pyloric feeding tube should be considered (Kuperminc *et al.*, 2013:S22; Mascarenhas *et al.*, 2008:603). Numerous enteral feeds are available and include polymeric, semi-elemental and elemental formulas which vary in energy density, macronutrient and micronutrient composition, digestibility, osmolality, packaging and fibre content. Each formula has unique characteristics and beneficial effects and should therefore be chosen according to the child's needs or to improve feeding tolerance (Walker *et al.*, 2012:1312).

When implementing these nutritional interventions, it is essential to give enough time to assess whether the interventions implemented are helping and improving the nutritional status of the child (Mascarenhas *et al.*, 2008:605). Depending on the age of the child, the severity of the child's clinical condition, nutritional status and existing nutritional deficiencies, a period of one to three months is appropriate to schedule a follow-up session for monitoring and evaluation of older children with CP and to adapt their diet if needed (Bell & Samson-Fang, 2013:S14; Kuperminc *et al.*, 2013:S22; Mascarenhas *et al.*, 2008:605). Babies and infants should be reviewed more frequently (Bell & Samson-Fang, 2013:S14). The effectiveness of any nutrition intervention is determined through regular monitoring of the actual nutrient intake, weight status, management of difficulties regarding feeding tolerance, safety of feeds and nutrient intake, balance between oral and tube feeding (where appropriate) and overall wellbeing of the CP child as well as the parents or caretakers (Bell & Samson-Fang, 2013:S15; Benfer *et al.*, 2015:7; Marchand *et al.*, 2006:123; Stevenson *et al.*, 2006:1011; Wittenbrook, 2011:30). Once a child has regained a healthy nutritional status and nutrition intervention has been implemented and followed successfully at home, follow-up sessions every 6-12 months have been suggested (Kuperminc *et al.*, 2013:S23; Marchand *et al.*, 2006:128; Mascarenhas *et al.*, 2008:601). Regular reassessments, especially for infants and younger children, are essential to determine the response to nutrition interventions and treatment and whether modifications need to be implemented (Aisen *et al.*, 2011:848; Andrew & Sullivan, 2010:360; Wood, 2006:291).

Feeding disorders that are not managed appropriately can result in complications, including esophagitis, airway diseases, bedsores and aspiration pneumonia (Bohmer *et al.*, 1999:808; Sullivan *et al.*, 2000:678). Respiratory complications such as pneumonia are commonly found in children with dysphagia who require assistance with feeding, resulting in prolonged feeding times (Sullivan *et al.*, 2000:678). Proper diagnosis-specific treatment and nutritional management for feeding disorders is therefore essential and has also been shown to significantly improve energy consumption and the nutritional status of children with developmental disabilities (Schwarz *et al.*, 2001:671). Schwarz *et al.* (2001:675) have demonstrated the efficacy of nutritional interventions on the clinical outcome of these children with beneficial results such as reduced hospital admissions and a significant decrease in morbidity. They also emphasised the importance of a structured approach when treating neuro-disabled children and propose a diagnostic and treatment algorithm for these children who have a suspected feeding disorder (Schwarz *et al.*, 2001:675).

One should always strive to achieve weight gain and growth, a safe eating experience for both the child and family and a balanced diet, which includes a variety of foods to provide fibre and micronutrients for these children (Redstone & West, 2004:100; Samson-Fang & Bell, 2013:s7).

2.5 Parental concerns and stress-related issues

Cerebral palsy carries a tremendous psychosocial impact, not only for the child affected with the disorder, but for the parent or caretaker too, as mealtimes are part of an important social interaction between child and parent or caretaker (Andrew *et al.*, 2012:224; Craig *et al.*, 2003:185; Reilly & Skuse, 1992:382; Sullivan *et al.*, 2000:677, 678; Umay *et al.*, 2014:768). It is important to ensure the wellbeing not only of children, but also their families tackling issues that their child with CP are faced with (Rosenbaum, 2003:970). Emotional and behavioural difficulties are commonly found and may cause substantial distress to the family members (Aneja, 2004:631; Arvedson, 2013:S9). Mothers of children with CP may be at risk of depression and burnout from social isolation (Manuel *et al.*, 2003:199; Umay *et al.*, 2014:787). Gangil *et al.* (2001:845) reported that the psychological impact of having a severely disabled child can at times be so overwhelming that parents do not fully grasp the need to review, treat and manage a feeding problem.

In the study conducted by Sullivan *et al.* (2000:678), 20% of parents described feeding times as severely stressful and unenjoyable, and aspects such as severe motor deficit, drooling and choking significantly contributed to stressful mealtimes. They also found that the child's disability significantly limited the family's social participation in their community (Sullivan *et al.*, 2000:678).

A study by Umay *et al.* (2014:770) evaluated the psychological impact and QOL of caregivers taking care of children affected by CP with dysphagia with the use of the Beck Anxiety and Depression scale. They reported that anxiety and depression levels were high among caregivers and their QOL deteriorated regarding their energy levels, emotional reactions, sleep and general distress levels. Fung *et al.* (2002:366) found that feeding dysfunction in children with CP has a direct impact on the family regarding participation in daily activities. They also reported an association with feeding problems and the substantial emotional impact it has on parents (Fung *et al.*, 2002:366). A study by Quinn and Gordon (2011:194) explored the perceptions of rural South African mothers on early attachment of their children with CP. They found that factors such as inability to communicate, caring for the child being physically and emotionally demanding, lagging developmental milestones and a non-supportive community hindered bonding and maternal response to needs of the child (Quinn & Gordon, 2011:195). The emotional bond between a mother and her child with CP was shown to be affected by the severity of the condition and disability (Quinn & Gordon, 2011:195). They further reported that these mothers needed both psychological and maternal support to be able to strengthen early attachment behaviours and nursing practices with their child (Quinn & Gordon, 2011:196). In developing countries, poverty and limited resources also contribute to multiple difficulties when seeking medical care (Aneja, 2004:633).

Feeding is seen by parents or caregivers mostly as a reflection of their ability to nurture and care for their child (Kuperminc *et al.*, 2013:S21; Kuperminc & Stevenson, 2008:138). Constant support throughout therapy is therefore essential to ensure a good relationship within the family and to address concerns regarding feeding (Samson-Fang & Bell, 2013:s5).

2.5.1 How to address and manage stress-related concerns of parents

By addressing the above-mentioned challenges and explaining the condition as well as the progress of the child to parents or caretakers, one may provide families with helpful information to relieve stress and improve parent satisfaction (Aneja, 2004:633; Lindstrand *et al.*, 2002). A family-centred approach, where a family's individuality, cultural boundaries and circumstances are respected throughout therapy, should be considered a "best practice approach" in paediatric rehabilitation and is strongly recommended (Aisen *et al.*, 2011:847; King *et al.*, 2004:84; Law *et al.*, 2003:365; Rosenbaum, 2003:972). Law *et al.* (2003:357) found that parent satisfaction regarding services for their disabled child, was strongly influenced and improved when sufficient family-centred services (FCS) were provided and when these services were available at a number of places.

Parental satisfaction is essential as it has been shown to increase adherence to treatment, decrease stress, anxiety or depression, and improve wellbeing (Liptak *et al.*, 2011:e1327; Rosenbaum *et al.*, 1998:14). Palisano *et al.* (2009:89) found that over 50% of parents expressed family needs for information regarding current and future services with the help of a FCS, as well as their assistance in locating community activities and the need for more personal time. The family needs differed significantly according to the gross motor function of the child with CP, with families of severely affected children having higher financial, health and social needs (Palisano *et al.*, 2009:90).

The guiding principles of a FCS are that:

- 1) Each family should decide on how it wants to be involved in the decision-making process of their child;
- 2) Each family member should be treated with respect, at all times;
- 3) Parents should have the ultimate responsibility for taking care of their child;
- 4) The needs of the parents and family should be considered throughout the treatment process;
- 5) All family members should be encouraged to be actively involved in the decision-making process and treatment options;
- 6) The MDT should have the needed knowledge and skills to understand the priorities and needs of CP children in order to assist families appropriately.

(Liptak *et al.*, 2011:e1322; Palisano *et al.*, 2009:85; Rosenbaum *et al.*, 1998:12)

Law *et al.* (2003:365) further suggests that organisations can improve parent satisfaction by adapting a family-centred approach, appointing a specific person to lead the development of a FCS, providing information regarding FCS at the family's initial appointment, ensuring continuous training of staff in a FCS, decreasing waiting lists, producing user-friendly reports and providing a welcoming environment. Palisano *et al.*, (2009:90) stated that HCPs play an essential role, with a responsibility to assist families by giving sufficient information and addressing their concerns and needs within a family-centred service. Emotional, practical and financial concerns should be addressed by a HCP and support should be provided throughout interventions (Craig, 2013:S17; Kuperminc *et al.*, 2013:S21; Liptak *et al.*, 2011:e1327). It is essential to communicate with families throughout the management and treatment process and be honest, open and sensitive to their concerns and queries (Rosenbaum, 2003:971). Therapy during rehabilitation includes improving psychosocial disorders that the child, parents and caregivers face (Aisen *et al.*, 2011:847; Craig, 2013:S17). A neuropsychologist, social worker and occupational therapist are mainly involved in this stage of therapy (Aisen *et al.*, 2011:847).

2.6 Multidisciplinary involvement and professional support

Caring for a disabled child can be very demanding for a parent and family members as these children require frequent visits to HCPs, may have prolonged feeding times, are often ill, or need to be hospitalised (Craig, 2013:S17). Early involvement of a skilled MDT is essential to identify and reduce feeding difficulties, including nutritional intake and growth, by supporting and educating parents or caretakers in the daily care of the child (Andrew *et al.*, 2012:225; Gagliardi *et al.*, 2008:335; Jones *et al.*, 2007:226; Liptak & Accardo, 2004:s40; Marchand *et al.*, 2006:128; Murphy & Such-Neibar, 2003:152; Xavier *et al.*, 2014:30). They are also responsible for continually educating, counselling and empowering the families and caretakers of an affected child (Aisen *et al.*, 2011:847; Liptak *et al.*, 2011:e1322; Rosenbaum, 2003:972). Projects that include early intervention programmes should be executed worldwide. In South Africa, the Pietermaritzburg Cerebral Palsy Association and Malalumelele Onward project have successfully been implemented, offering support services for children affected by CP and their families and improving information dissemination (DSD *et al.*, 2012:95, 96).

A structured treatment approach is important and all critical decisions regarding the management of feeding and/or swallowing problems should be made regarding the primary needs of the child with CP. The interventions should be non-stressful for the child, but also for the caregiver (Arvedson, 2013:S9; Bashir *et al.*, 2015:13). Families need practical help with daily challenges when caring for a child suffering from CP (Wood, 2006:291). Education programmes which can alleviate stress and enrich parents' knowledge can be developed to teach them how to care for their child with CP (Quinn & Gordon, 2011:197). Patient and family participation is also vital when making therapeutic decisions and taking into account their experiences (Aisen *et al.*, 2011:847; Craig, 2013:S17). Ethical considerations are particularly important in the decision-making process and the parental wishes should be considered and respected (Liptak *et al.*, 2011:e1322; Marchand *et al.*, 2006:131). Parents of these children may require increased educational and emotional support when deciding on therapeutic care that requires surgery, such as administering a gastrostomy or inserting an intrathecal baclofen pump (in a case where a child is spastic) (Fung *et al.*, 2002:369). Including information on these decisions and management options for their CP child will alleviate pressure and anxiety (Campbell *et al.*, 2008:261).

It is essential that a HCP establish a relationship with the parents and family that is trustworthy and in which consistent and continuous care and service is valued by parents (Craig, 2013:S17; Rosenbaum, 2003:973; Xavier *et al.*, 2014:26). Ideally, a child should be treated and managed in a multidisciplinary setting with a variety of subspecialists (Eileen, 2004:127; Kuperminc *et al.*,

2013:S21). An ideal MDT should include a paediatrician with experience in neurological rehabilitation, orthopaedists, a psychologist, a physiotherapist, an occupational therapist, a speech therapist, a social worker, a nutritionist or dietitian and a school teacher specialising in teaching special needs children (Aneja, 2004:627; Gerek & Çiyiltepe, 2005:57; Jones *et al.*, 2007:152; Marchand *et al.*, 2006:123; Mascarenhas *et al.*, 2008:597; Palisano *et al.*, 2009:90). A well-established relationship between the medical and rehabilitative team as well as other HCPs is essential throughout treatment and thorough communication is of utmost importance (Campbell *et al.*, 2008:261). Each HCP in this team should have an intensive, goal-directed individual treatment plan where treatment goals are established and discussed with family members or caretakers (Aisen *et al.*, 2011:844; Campbell *et al.*, 2008:264; Liptak *et al.*, 2011:e1322; Mascarenhas *et al.*, 2008:602). Ideally the team members should provide continuous care throughout the child's lifetime and offer support at times of transition such as starting school or socialising (Aisen *et al.*, 2011:847; Rosenbaum, 2003:973).

The entire family should be included in the management plan and treatment should be given in the context of their needs, values and requests (Craig, 2013:S18; King *et al.*, 2004:84; Rosenbaum, 2003:970). Other important aspects that need to be evaluated are the family's home situation, which includes the family size, financial resources and family support structure (Aneja, 2004:633). If the living conditions of the CP child are clearly understood, therapy can be tailored to meet the needs of the child in his familiar environment and surroundings (Aneja, 2004:633; King *et al.*, 2004:82; Rosenbaum, 2003:972). This ultimate management strategy is essential for an optimal outcome where a CP child can develop to his or her full potential (Campbell *et al.*, 2008:264). Effective management requires a comprehensive understanding of the causes, manifestations and treatment options for children suffering with cerebral palsy (Campbell *et al.*, 2008:261). Management is usually divided into rehabilitative, medical and surgical components (Campbell *et al.*, 2008:265). Overall management of children with CP should focus on optimising QOL and function by improving muscle strength and endurance, improving academic achievement, assisting with personal hygiene, treating associated disabilities or concerns and preventing medical complications, which include poor growth, joint abnormalities and reduced bone mass or fractures (Campbell *et al.*, 2008:264). Therapy during rehabilitation includes strengthening of muscle mass and improving tone abnormalities, cognitive function, as well as oral motor impairment (Aisen *et al.*, 2011:847). Gangil *et al.* (2001:841) have found that after nutritional rehabilitation there is a reduction in feeding problems, especially in choking during meals, reflux and swallowing.

Medical and nutritional assessment and management includes individualised care plans from a MDT which considers the nutritional status, the medical, feeding and growth history, gross motor and oro-motor skills, clinical signs, feeding environment, feeding ability, swallowing, seating and positioning and energy requirements of the child on assessment (Andrew & Sullivan, 2010:359; Andrew *et al.*, 2012:225; Kuperminc & Stevenson, 2008:143; Mascarenhas *et al.*, 2008:600). Pharmacological treatment, oral medicines, botulinum toxin injections, various nerve block agents and botox may be considered (Aisen *et al.*, 2011:847). Medical therapy also includes assessing and treating motor weakness and cognitive function, diagnosing and treating comorbidities, counselling in psychosocial disorders, and the use of nutritional and enteral supplements (Aisen *et al.*, 2011:847; Wittenbrook, 2011:30). The long-term consequences of surgery need to be considered, but unfortunately these have not been well documented. Decisions on whether to undergo surgery should consider the physical or health-related QOL of daily activities in all life stages (Aisen *et al.*, 2011:846).

It is always critical to involve and rely on the expertise of a RD, not only in the formulation of nutritional interventions and diet plans, but also to encourage the prevention of nutrition-related problems and to give recommendations regarding hydration status, growth patterns, food sensitivities or allergies (Arvedson, 2013:S11; Eileen, 2004:128; Lee *et al.*, 2011:534; Ptomey & Wittenbrook, 2015:597). Nutritional goals should support growth, maximise oral intake of food and fluids (where possible), prevent malnutrition, avoid overfeeding and support and strengthen bone health (Kuperminc & Stevenson, 2008:145; Mascarenhas *et al.*, 2008:597). Reily *et al.* (1996:881) found that very few parents had been informed of the importance of adequate nutrition for their child with CP and reported that most of these parents were unfamiliar with methods of increasing the energy density of meals. Sullivan *et al.* (2000:678) reported that 83% of children affected by CP from the Oxford Feeding Study had never been seen or assessed by a RD and 53% had never been seen by any HCP within a period of twelve months. Adequate nutritional support has been shown to improve both linear growth and weight gain, enhance QOL and health and decrease the frequency of hospitalisation and is therefore essential (Marchand *et al.*, 2006:130).

2.7 Summary of the literature and future research

Since CP is an incurable disease, its epidemiology needs to clarify etiological mechanisms and origins in order to find ways of preventing this condition (Blair & Stanley, 1997:186; Surveillance of Cerebral Palsy in Europe, 2000:816). Recognising the causal events that contribute to CP enables us to explore ways of preventing these events or incidents (Blair & Stanley, 1997:186). This can be done by developing and implementing cost-effective, reliable and more sensitive and accurate techniques of measuring and depicting the prevalence of CP in a specific region, so that more details can be provided on diagnostic categories and factors pertaining to the condition (Mung'ala-Odera & Newton, 2007:254). This information will be essential to formulate and implement prevention and rehabilitation programmes (Mung'ala-Odera & Newton, 2007:255). Ongoing therapy, education, and technology can assist in developing each child's potential by improving QOL and functional abilities (Benfer *et al.*, 2015:7; Craig, 2013:S17; Jones *et al.*, 2007:146; Sullivan *et al.*, 2000:679).

2.7.1 Challenges and concerns in the field of cerebral palsy

It is unfortunate that the advances of evidence-based approaches to the clinical care of CP have been slow, leading to gaps in services as well as in opportunities for improving QOL, providing cost-effective care and reducing morbidity (Aisen *et al.*, 2011:844; Hurwitz *et al.*, 2015:295; Rosenbaum, 2003:970). Delays have been due to conflicting evidence and differences in medical treatment approaches (Aisen *et al.*, 2011:844). It has clearly been found and highlighted that feeding difficulties are common in children with neurological impairment, such as CP, and these are both stressful and worrying to the parents or caretakers (Kilpinen-Loisa *et al.*, 2009:1331; Sullivan *et al.*, 2000:678). The nutrition and growth deficits in children with CP are often under-recognised and sometimes even considered to be a low priority (Kuperminc *et al.*, 2013:S21; Sullivan *et al.*, 2000:679; Xavier *et al.*, 2014:23). The development of feeding skills is often not addressed at an early stage and the window of opportunity to correct a nutrition-related problem, when improvements are more likely, is then usually overlooked (Fung *et al.*, 2002:368). It has also been found that HCPs at times seem to manage CP children in isolation or that the MDT treating the child lacks experience (Kuperminc *et al.*, 2013:S21; Nadeem *et al.*, 2014:242). In some settings there are limited professional resources and lack of a RD on most MDTs (Fung *et al.*, 2002:368). Many therapies in medical care, education, orthopaedic care and nutritional support lack rigorous scientific evaluation (Bax, 1993:1035; Sullivan *et al.*, 2000:679). There are no official nutritional guidelines set out for each type and form of CP in children (Finbråten *et al.*,

2015:861; Kilpinen-Loisa *et al.*, 2009:1331). There is currently also no simple, quick, validated screening tool for a MDT to assess the presence and severity of feeding problems in children with CP (Fung *et al.*, 2002:368; Sullivan, 2013:S4). Reliable and validated instruments that are available for assessing oral-motor function in this population are labour intensive and not easily utilised in a busy clinic setting (Reilly & Skuse, 1992:386; Skuse *et al.*, 1995:198). Fung *et al.* (2002:368) reported that caregivers also receive limited or even no assistance with their child's feeding, which may add a significant amount of stress to both parents and family. They further explained that both feeding and nutritional therapy sessions are time-consuming and in some cases, are not available to these children (Fung *et al.*, 2002:369). Day *et al.* (2007:171) mentioned how moderately affected children with CP do not always return for follow-up sessions as parents do not think it is necessary. These aspects are particularly disturbing as structured support and care for parents and children affected by CP should be embedded from an early age and is usually required throughout the child's life (Kuperminc *et al.*, 2013:S22).

2.7.2 Recommendations and future research

In the last couple of decades, the nutritional needs of children with CP have become a field of interest and more research on nutrition and health in this population group is emerging (Sullivan, 2013:S3). Future research should include well-designed clinical trials focusing on pharmacological and non-pharmacological approaches in treating individuals with CP (Aisen *et al.*, 2011:850). Research efforts are underway towards the primary prevention of brain injury in infants that are at risk or exposed to hypoxic brain injuries (Rosenbaum, 2003:973; Xavier *et al.*, 2014:32). Studies should focus on how to improve the nutritional status of children with CP as an essential part of their overall clinical and therapeutic management (Kuperminc *et al.*, 2013:S21). They should also focus on how optimal health, QOL and wellbeing can be determined by employing nutritional measurements and the ranges of optimal growth, as there are currently no clear guidelines or indications (Hurwitz *et al.*, 2015:294; Kuperminc & Stevenson, 2008:146; Xavier *et al.*, 2014:32). As obesity is on the rise among disabled and developmentally delayed children, studies targeting obesity prevention and treatment are becoming essential and should be encouraged by expertise in the field (Bandini *et al.*, 2015:314). Treatment interventions should, however, be based on credible research and not testimonials or anecdotal evidence (Rosenbaum, 2003:973). Parental perception regarding feeding problems should be investigated as it has been found by Gangil *et al.* (2001:845) that some parents are unaware of the problems associated with cerebral palsy. Research expertise regarding feeding and nutrition in children with CP needs to

improve and develop appropriately for the benefit of disabled individuals and their families (Bax, 1993:1036; Nadeem *et al.*, 2014:242).

Healthcare professionals, especially RDs in the field of nutrition are required to keep up to date with the latest evidence-based interventions and information on CP, (Hurwitz *et al.*, 2015:295; Nadeem *et al.*, 2014:244). Dietitians should be more involved and recognised in the process of nutritional assessments for individuals with CP as part of their overall care (Ptomey & Wittenbrook, 2015:597; Sullivan *et al.*, 2000:679; Sullivan *et al.*, 2002:467). As energy intake is mostly poor in these children, it will be beneficial to this population to determine the appropriate energy needs for maintaining energy balance to ensure sufficient growth and development according to the degree of impairment (Sullivan *et al.*, 2002:467). It does, however, remain a challenge to estimate their energy needs and it is suggested that population-specific prediction equations should be developed for children with CP (Lee *et al.*, 2011:534). There is also a need for routine micronutrient monitoring and supplementation policies in CP children, especially those that are orally fed and who have swallowing disorders and are malnourished, as deficiencies have been reported and these are not always promptly assessed and addressed (Adams *et al.*, 2011:886; Kalra *et al.*, 2015:143; Schoendorfer *et al.*, 2010:742; Schoendorfer *et al.*, 2013:99).

Educational interventions may assist mothers to accept CP as a condition of disability and to develop positive attitudes towards their affected child (Bashar *et al.*, 2015:13; Quinn & Gordon, 2011:197). A consistent goal of the WHO and a big challenge faced in modern times is how to integrate children and adolescents with CP to become part of their communities and participate in all areas of society (Palisano *et al.*, 2009:90; Rosenbaum, 2003:973). Parenting programmes that train parents on all aspects of raising their child with CP may promote and contribute to public awareness, especially in rural and urban settings, and assist these children to become independent and live life to the fullest (Quinn & Gordon, 2011:197).

2.8 References

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CHAPTER THREE – ARTICLE

**Nutrition-related concerns of the primary caregiver regarding children
with spastic cerebral palsy**

CHAPTER THREE – ARTICLE

3.1 Title page

Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy: a cross-sectional, quantitative research study

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This article will be submitted to the journal *Child: Care, Health and Development*

On behalf of all the authors, I declare this research study has not been published and is not being considered for publication elsewhere.

Word count: 4450

Keywords: Cerebral palsy, children, nutrition-related problems, nutritional management, feeding practices, parental concerns, dietetic role

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3.3 Article to be submitted to the journal *Child: Care, Health and Development*

Abstract

Background: Parents with children suffering from spastic cerebral palsy (CP) face various challenges regarding their child's health; these challenges affect their nutritional status, growth, development and quality of life (QOL). The nutrition-related challenges that these children encounter are not well described in the South African setting. These concerns and their management, current feeding practices and parental perspectives were also investigated.

Methods: This cross-sectional, quantitative research study made use of a self-administered, validated nutritional questionnaire to obtain information from participants at three facilities: the Pretoria Centre for Cerebral Palsy (PCCP), the Baby Therapy Centre (BTC) and New Hope School (NHS), situated in the Gauteng Province. Recruitment and data collection took place over a period of three months. Data were captured and the information was statistically analysed and extracted for interpretation.

Results: Thirty-four questionnaires were completed by parents and returned. The most common nutrition-related concerns reported were constipation (47.1%), underweight (32.4%) and poor appetite (20.6%). Nutrition-related problems were managed mostly by consulting a healthcare professional (HCP). Most children were seen by a multidisciplinary team (MDT) of therapists, but only 44% consulted a registered dietitian (RD). Information pertaining to the current feeding practices showed that most children required assistance at mealtimes (61.8%). Some nutritionally poor food choices such as deep fried food and sugary drinks were reported, although most consumed fresh foods from all food groups. Solids (64.7%) and pureed food (23.5%) were mostly tolerated. Most parents (55.9%) spent less than two hours daily on feeding their child. Parents were either satisfied or content when dealing with nutrition-related problems.

Conclusion: Nutrition-related concerns that these parents encountered with their spastic CP children were common. The role of the RD in addressing and managing nutrition-related problems, advising on healthy feeding practices and parental support pertaining to nutrition, needs to be emphasised and remains a crucial part of treatment in this group of disabled children.

Introduction

Cerebral palsy (CP) is the most common cause of physical disability in childhood. It is described as a group of permanent disorders which affects the development of movement and posture, resulting in restricted activity that occurs due to non-progressive disturbances in the infant brain or during foetal development (Bax, 1964; Rosenbaum *et al.*, 2007:9; Van Toorn *et al.*, 2007:74).

Cerebral palsied children have a range of disabilities and problems such as altered growth patterns, gastrointestinal (GI) functional abnormalities, intellectual disability, difficulties with nutrition, feeding and swallowing, hearing and visual deficits, respiratory infections and epilepsy (Ashwal *et al.*, 2004:851; Laughton, 2004:435; Sullivan *et al.*, 2000:677). Children with severe spasticity and motor impairments are most at risk of developing growth and nutritional problems and do not grow as well as their neurologically normal peers (Andrew & Sullivan, 2010:357; Day *et al.*, 2007:169). The consequences of poor growth and nutrition for children with CP are adverse effects on the quality of life (QOL) of these children, influencing physical and brain growth and development, cognition and behaviour, muscle strength, cardiac function, immunity, healing and repair (Andrew & Sullivan, 2010:359).

Feeding difficulties are present in 30-40% of this population group and contribute to growth failure, prolonged feeding times and inadequate intake, resulting in dehydration and malnutrition when intake is insufficient to meet metabolic demand (Andrew & Sullivan, 2010:357; Campanozzi *et al.*, 2007:28; Spiroglou *et al.*, 2004:180; Sullivan *et al.*, 2000:679). Dysphagia has been reported in up to 40% of children with CP and is more prominent in children with severe motor impairment, while 75% show signs of gastro-esophageal reflux disorder (GERD) which is common in children with CP (Gerek & Ciyiltepe, 2005:58). Swallowing difficulties may affect the child's QOL and increase the risk of aspiration (Aneja, 2004:631; Barrett & Ogle, 2010:39). It is essential that a child with CP be assessed when feeding difficulties are present in order to ensure adequate food and fluid intake which meet the recommended daily allowance (RDA) for vitamins and minerals, adequate energy, fibre and fluid (Jones *et al.*, 2007:227,231).

This disorder has a tremendous psychosocial impact, not only on the child, but also on the carer, as mealtimes are part of an important social interaction between child and primary caregiver (Andrew *et al.*, 2012:224; Craig *et al.*, 2013:S18). These children are dependent on a primary caregiver for feeding and problems such as prolonged feeding, behavioural difficulties, messy feeding and limited communication abilities make it difficult and challenging, thus increasing parental stress and negatively impacting the QOL of both the child and caregiver

(Grammatikopoulou *et al.*, 2009:625; Majnemer *et al.*, 2007:475; Soylu *et al.*, 2008:332). Early involvement of a skilled MDT is important to assist with feeding difficulties, optimal nutritional intake and growth, through supporting and educating parents in the daily care involving nutrition and feeding of the child (Andrew *et al.*, 2012:225; Gagliardi *et al.*, 2008:335; Jones *et al.*, 2007:226; Marchand *et al.*, 2006:128). Regular reassessments, especially for infants and younger children, are essential to determine the response to nutrition interventions and whether modifications are needed (Andrew & Sullivan, 2010:360; Wood, 2006:291). By addressing the challenges mentioned above, one may provide families with helpful information to alleviate problems causing stress pertaining to nutrition and also improve parent satisfaction (Law *et al.*, 2003:363, 364; Lindstrand *et al.*, 2002). Families need practical help with these daily challenges that involves nutrition when caring for a child suffering from CP (Wood, 2006:291).

The overall aim of this study was to explore the concerns of nutrition related problems that the primary caregivers encountered with their children affected by spastic CP, between the ages of one and ten years, by means of a self-administered, validated nutritional questionnaire. This study also gathered information regarding the management of these specific diet-related problems, the current feeding practices and parental perspectives on dealing with aspects pertaining to meals, the feeding routine and nutrition-related concerns, faced.

Methods

Study design and setting

A cross-sectional quantitative research study design was chosen to conduct this study. The three largest facilities providing services for children with CP in the broader Pretoria area were chosen to partake in this study and included: the Pretoria Centre for Cerebral Palsy (PCCP) situated in Life Groenkloof Hospital, the Baby Therapy Centre (BTC) and New Hope School (NHS) for special needs children, all situated in Gauteng Province.

Participants

Primary caregivers (parents or legal guardians) of children suffering from spastic CP were approached for inclusion in the study. They were specifically chosen to participate as they would be best informed and understand their child's needs, feeding routine and nutrition-related concerns. A total of 34 participants, all of whom were parents, enrolled in the study. A MDT of healthcare professionals (HCPs) including physiotherapists, speech therapists and a registered

dietitian (RD) (see Annexure A) assisted in the recruitment process at each facility. A screening tool (see Annexure B) with the inclusion- and exclusion criteria (Table 3.1) was used to identify and select participants suitable for this study.

Table 3.1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Primary caregivers had to be: • Able to write, read and understand Afrikaans or English • The parent or legal guardian of a child with spastic CP (preferably the mother) • Willing to give consent to share thoughts and experiences on specific topics concerning nutrition and nutrition-related problems • Involved in the child's daily feeding routine, purchasing of food products, meal preparation and feeding	Primary caregivers with children that: • Made use of a feeding device (such as a PEG or PEJ) • Were not able to eat orally • Were younger than one or older than ten years old

CP – cerebral palsy; PEG – percutaneous endoscopic gastrostomy; PEJ – percutaneous endoscopic jejunostomy

As only a small number of children with spastic CP between the ages of one and ten years old can eat orally at these facilities, all primary caregivers were approached and considered for inclusion. Informed, voluntary consent to participate was obtained by means of a consent form (see Annexure C). A power calculation was not required because of the small target group. The researcher therefore had to recruit a minimum of 30 participants.

Methods

Information was gathered from a self-administered, validated nutritional questionnaire (see Annexure D and E) and all information was kept strictly confidential. These questionnaires were available in both Afrikaans and English for participants to complete fully after giving informed consent.

The self-administered, validated nutritional questionnaire

The questionnaire for this study was compiled following an analysis of the literature by the researcher and supervisors who are experienced researchers in the field of dietetics and nutrition. It consisted mainly of focused nutrition-related questions asked in multiple-choice format and by means of a Likert scale (options from one to five) for ease of data capturing for analysis and improve data management. The topics of the nutritional questionnaire were kept strictly nutrition-related and participants were not compelled to complete answers to questions that they did not feel comfortable with.

Validation of the nutritional questionnaire

To assess content validity, the nutritional questionnaire was sent to three experts, all RDs, working with special needs children. They focused on the scientific aspects of the questionnaire, how the questions were formulated to prevent confusion, and provided technical and practical input. Three mothers, not related to the study, completed the nutritional questionnaire and focused on comprehension of questions and time taken to complete the questions. This was done to ensure that the questionnaire was clear, unambiguous and user-friendly. A statistician assessed face validity and suggestions were made regarding wording of questions and the questionnaire layout. Lastly, it was reviewed by at least two academics in the field of dietetics to finalise the concluding questionnaire used as the nutritional questionnaire for this study.

Procedure

Recruitment and data collection took place over a period of three months simultaneously at the various facilities to give sufficient time for data collection and processing. This was done when parents brought their child for a scheduled medical appointment at the PCCP or the BTC or when their child was brought to or collected from NHS. Participants were asked to return the completed questionnaire to the HCP within one week after signing the screening tool and consent form. The researcher collected all the completed questionnaires from the facilities. As this is a vulnerable group of participants, there was a psychologist on standby for counselling on request and if required.

Data and statistical analysis

Data analysis for this study commenced when all nutritional questionnaires were collected from the various facilities. The questions were numbered and coded into categories, which facilitated the process of analysis and data capture. Anonymity and confidentiality was ensured during data analysis as subject numbers were allocated to all participants, and no identifying data were captured. The researcher captured all quantitative data from questionnaires using Microsoft Excel 2013.

The computer software package IBM SPSS[®] Statistics version 22 (Statistical Package for Social Sciences, IBM, NY, USA) was used for statistical analysis. Descriptive statistics, where variables were measured on a nominal or ordinal scale and reported in the form of frequencies and percentages, were determined from the data captured. Conclusions and recommendations were drawn from these findings and explained in detail in the results section.

Ethics

This study was carried out in accordance with the declaration of Helsinki and ethical approval was obtained from the North-West University's Health Research Ethics Committee (reference number NWU-00040-15-S1). Letters for approval were obtained from the facilities (PCCP, BTC and NHS) and permission was granted by the Gauteng Department of Education (GDE) to conduct this study at NHS (see Annexures F to J).

Results

During the three-month recruitment period, 40 questionnaires were given to prospective participants, of which 34 completed questionnaires were returned to the facilities: BTC (n=3), NHS (n=28) and PCCP (n=3). Participants completing the nutritional questionnaire were all mothers, except for one father. Some reasons given by parents for not completing and returning the questionnaire included: lost interest in participation (n=2), lost the questionnaire (n=4), child had undergone surgery (n=2).

Demographic information of both the parents and their children with spastic CP are summarised in Table 3.2. Interestingly, only 44% of children with CP were seen by a dietitian, whereas all children had been seen by a physiotherapist and speech therapist (100%) and most had seen an occupational therapist (97%) and/or specialist (97%).

Table 3.2: Demographic information of the primary caregivers (parents) and their children with spastic cerebral palsy

Primary caregivers (parents)			Children with spastic CP			
		n (%)			n (%)	
Age group (years)	< 20	1 (2.9)	Gender	Male	18 (52.9)	
	20 – 30	2 (5.9)		Female	16 (47.1)	
	31 – 40	20 (58.8)				
	41 – 50	10 (29.4)				
	> 50	1 (2.9)				
Number of children	1	7 (20.6)	Age (years)	1	1 (2.9)	
	2	15 (44.1)		2	2 (5.9)	
	3	7 (20.6)		3	4 (11.8)	
	> 3	5 (14.7)		4	4 (11.8)	
				5	4 (11.8)	
Use of a caretaker	Yes	17 (50)		6	5 (14.7)	
	No	17 (50)		7	1 (2.9)	
				8	11 (32.4)	
				9	2 (5.9)	
				10	n/a	
Type of caretaker	Nanny or au-pair	9 (52.9)	Gestational weeks born	< 30	10 (29.4)	
	Relative	8 (47.1)		31 – 37	9 (26.5)	
				38 – 40	9 (26.5)	
				> 40	6 (17.6)	
Educational level	None	2 (5.9)	Complications during:	Pregnancy Labour or delivery Post delivery	Yes [n]	No [n]
	Gr.1 – Gr.7	1 (2.9)			15	19
	Gr.8 – Gr.11	1 (2.9)			12	22
	Gr.12	6 (17.6)			25	9
	Tertiary education	24 (70.6)	Attending a playgroup / crèche / school	Yes No	33 (97.1)	
Marital status	Married	30 (88.2)			1 (2.9)	
	Divorced	2 (5.9)	Seen by a HCP:	Dietitian Dentist Occupational therapist Physiotherapist Psychologist Social worker Speech therapist Specialist Other: Music therapist Swallowing kinesiologist Neurosurgeon Ophthalmologist Orthotist		
	Widowed	1 (2.9)				
	In a relationship	n/a				
	Single	1 (2.9)				
Employment status	Full-time job	22 (64.7)				
	Part-time job	6 (17.6)				
	Piece job	n/a				
	Unemployed	6 (17.6)				
Only income for household	Yes	5 (17.9)				
	No	23 (82.1)				
Other contributors to household income	Husband / wife	27 (96.4)				
	Boyfriend / girlfriend	n/a				
	Sibling	n/a				
	Ex-husband	1 (3.6)				
Monthly income	< R5 000	2 (5.9)				
	R5000 – R10000	3 (8.8)				
	R10001 – R20000	7 (20.6)				
	R20 001 – R30 000	8 (23.5)				
	> R30 000	12 (35.3)				
	Grants	2 (5.9)				
Medical aid for their child	Yes	29 (96.7)				
	No	1 (3.3)				

CP – cerebral palsy; **Gr** – Grade; **HCP** – healthcare professional; **n** – number; **n/a** – not applicable; **R** – Rand
Please refer to the nutritional questionnaire in Annexure D and E for more information and detail

Nutrition-related concerns and management practices reported by parents are summarised in Tables 3.3 and 3.4. Various nutrition-related problems were quite common among children with CP. The most common problems reported were constipation (47.1%), underweight or loss of weight (32.4%), poor appetite (20.6%), flatulence (17.6%) and vomiting or reflux (17.6%). The prevalence of food allergies or intolerances was reported to be low and only two children had multiple food allergies. Milk and peanut allergies were the most commonly found (8.8% and 5.9%, respectively). Only a small percentage of children reported to have iron deficiency anaemia (11.7%). There was only one case of vitamin C deficiency reported.

Nutrition-related problems were managed mostly by consulting with any of the HCPs (44.1%), following advice from a book or magazine (41.2%), advice from a friend or relative (35.3%) and the Internet or social media (32.4%). Only one parent joined a support group for advice. Most parents reported that they would want to receive recommendations from a RD regarding the management of nutrition-related concerns (64.7%).

Table 3.3: Nutrition-related problems of the child with spastic cerebral palsy

		n (%)	
Type of nutrition-related problem*:		Yes	No
	Allergies / intolerance	5 (14.7)	29 (85.3)
	Aspiration	5 (14.7)	29 (85.3)
	Anaemia	4 (11.8)	30 (88.2)
	Constipation	16 (47.1)	18 (52.9)
	Diarrhoea	n/a	34 (100)
	Dysphagia	1 (2.9)	33 (97.1)
	Flatulence	6 (17.6)	28 (82.4)
	Growth retardation	4 (11.8)	30 (88.2)
	Insufficient food intake	3 (8.8)	31 (91.2)
	Irritable bowel syndrome	3 (8.8)	31 (91.2)
	Overweight / obesity	1 (2.9)	33 (97.1)
	Peptic / oral ulcers	1 (2.9)	33 (97.1)
	Poor appetite	7 (20.6)	27 (79.4)
	Underweight / loss of weight	11 (32.4)	23 (67.6)
	Vitamin / mineral deficiency	3 (8.8)	31 (91.2)
	Vomiting / reflux	6 (17.6)	28 (82.4)
Type of allergy or intolerance*:		Yes	No
	Egg	1	33
	Milk	3	31
	Gluten	1	33
	Peanut	2	32
	Soya	n/a	34
	Wheat	1	33
	I do not know	8	26
Type of anaemia*:		Yes	No
	Vitamin B12	n/a	34
	Folate	n/a	34
	Iron	4	30
	I do not know	7	27
Type of mineral deficiency*:		Yes	No
	Calcium	n/a	34
	Iron	3	31
	Magnesium	n/a	34
	Zinc	n/a	34
	I do not know	7	27
Type of vitamin deficiency*:		Yes	No
	Vitamin A	n/a	34
	Vitamin C	1	33
	Vitamin D	n/a	34
	Vitamin E	n/a	34
	I do not know	7	27

CP – cerebral palsy; n – number; n/a – not applicable

* Self-reported information provided by the participants (parents)

Please refer to the nutritional questionnaire in Annexure D and E for more information and detail

Table 3.4: Management of nutrition-related problems

		n (%)	
Currently treating nutrition-related problems:		Yes	No
	Consulted a HCP	15 (44.1)	19 (55.9)
	Joined a support group for advice	1 (2.9)	33 (97.1)
	Followed advice from a friend or relative	12 (35.3)	22 (64.7)
	Followed advice from a book or magazine	14 (41.2)	20 (58.8)
	Sought advice on the internet or social media	11 (32.4)	23 (67.6)
	<i>Other:</i>		
	Followed gut feeling	1	n/a
	Food preferences	1	n/a
	Kinesiologist	1	n/a
Parents that want to receive nutrition-related recommendations from a RD	Yes	22 (64.7)	
	No	12 (35.3)	

CP – cerebral palsy; **HCP** – healthcare professional; **n** – number; **n/a** – not applicable; **RD** – Registered Dietitian
Please refer to the nutritional questionnaire in Annexure D and E for more information and detail

The data pertaining to the dietary intake of the children since birth is summarised in Table 3.5 which forms part of past feeding practices. Most children were mainly breastfed from birth (52.9%) to the age of less than six months old (55.6%). The most common reasons why mothers did not breastfeed were physical or medical problems, insufficient breastmilk and poor latching. Most participants were advised by a HCP regarding breast- and formula feeding (73.5%). Complementary solid foods were commenced mainly beyond six months of age (in 41.2% of children). Most children had three meals (76.5%), with two snacks (61.8%) daily and a drink more than three times daily (58.8%). Children mostly consumed starches (76.5%) and dairy products (61.8%). Surprisingly, proteins were always consumed by merely 55.9% of children; fats were also consumed (41.2%), as well as fresh fruit (44.1%) and vegetables (41.2%). Sugar-free drinks were always consumed, yet by only 65% of children. Savoury and sugary treats and drinks were restricted, but still consumed often or sometimes.

Table 3.5: Diet history of the child with spastic cerebral palsy since birth

		n (%)				
Breastfed since birth	Yes	18 (52.9)				
	No	16 (47.1)				
Breastfed up to (age in months)	< 6	10 (55.6)				
	7 – 12	5 (27.8)				
	13 – 24	3 (16.7)				
	> 24	n/a				
Reasons for not breastfeeding		Yes [n]		No [n]		
	Work-related issues	n/a		16		
	Insufficient breastmilk	5		11		
	Poor latching	4		12		
	Uncomfortable or unfamiliar	n/a		16		
	Physical or medical problems	6		10		
	Problems with breast health	n/a		16		
	Stressed or pressurized	1		15		
	Feeling of embarrassment	n/a		16		
	Unsupportive partner or family	n/a		16		
	Concerns about pain	n/a		16		
	Other:					
	Adopted	2		n/a		
	Time-consuming	1		n/a		
Had triplets	1		n/a			
Advised by a HCP regarding breast- or formula feeding	Yes	25 (73.5)				
	No	9 (26.5)				
Started complementary solid foods (age in months)	< 4	3 (8.8)				
	4 – 5	9 (26.5)				
	6	8 (23.5)				
	> 6	14 (41.2)				
Amount of meals, snacks and drinks per day		Twice		3 x / day		> 3 x /day
	Meals	3 (8.8)		26 (76.5)		5 (14.7)
	Snacks	21 (61.8)		10 (29.4)		3 (8.8)
	Drinks	1 (2.9)		13 (38.2)		20 (58.8)
Food groups given to the CP child		Always	Often	Sometimes	Seldom	Never
	Protein	19 (55.9)	12 (35.3)	2 (5.9)	n/a	1 (2.9)
	Starch	26 (76.5)	8 (23.5)	n/a	n/a	n/a
	Fats	14 (41.2)	14 (41.2)	4 (11.8)	1 (2.9)	1 (2.9)
	Dairy	21 (61.8)	8 (23.5)	4 (11.8)	n/a	1 (2.9)
	Fresh fruit	15 (44.1)	15 (44.1)	1 (2.9)	3 (8.8)	n/a
	Fresh vegetables	14 (41.2)	14 (41.2)	6 (17.6)	n/a	n/a
	Sugary treats	6 (17.6)	8 (23.5)	10 (29.4)	8 (23.5)	2 (5.9)
	Savoury treats	2 (5.9)	10 (29.4)	11 (32.4)	6 (17.6)	5 (14.7)
	Sugary dinks	4 (11.8)	10 (29.4)	7 (20.6)	7 (20.6)	6 (17.6)
	Sugar-free drinks (including water)	22 (64.7)	6 (17.6)	4 (11.8)	2 (5.9)	n/a

CP – cerebral palsy; **HCP** – healthcare professional; **n** – number; **n/a** – not applicable

Please refer to the nutritional questionnaire in Annexure D and E for more information and detail

The current feeding practices of the child with CP and factors contributing to mealtime preparation, feeding the child and food selection are summarised in Tables 3.6 and 3.7. Most children needed assistance at mealtimes (61.8%), yet 73.4% did not make use of specific feeding utensils. Those that did use them reported that they made a difference at mealtimes. Food consistencies best tolerated were solids (64.7%) and pureed foods (23.5%), while liquids (2.9%) were found to not be tolerated well. These consistencies (solids and pureed food) were not specifically recommended by a ST and most parents followed their gut instinct and what the child was comfortable with. Thickeners were not used by most participants (82.4%), but those that used them tried mashed potato or sweet potato (83.3%), oats (66.7%) and cake flour (33.3%) to improve feeding tolerance.

Total time spent feeding the child with spastic CP daily was within two hours for most participants (55.9%) and food preparation time of meals, snacks and drinks were mostly completed within 30 minutes (70.6%, 94.1% and 97.1%, respectively). Healthy cooking methods were mostly preferred, such as boiling (94.1%), steaming (79.4%) and baking (70.6%). Pan frying and deep frying cooking methods (67.8% and 64.7%, respectively) were also popular. Increased feeding duration was mostly due to food refusal (55.9%), feeding difficulties (55.9%), positioning difficulties (35.3%), environmental difficulties (35.3%) and disruptive mealtime behaviour (20.6%). Most children always or often completed their meals, snacks and drinks and at least $\frac{3}{4}$ of the meal. Results suggest that children had a unique way of indicating when they were hungry or thirsty and when they had reached satiety after a meal or snack. Most children communicated verbally when hungry or thirsty (64.7%) and when satiety had been reached (58.8%). Others made a specific noise (35.3%), pointed at the food or drink (32.4%) or cried or signalled (29.4%) when hungry or thirsty. When satiety was reached, children also turned their heads away (55.9%), locked their lips together (41.2%), pulled the parent's hand away (32.4%) or made a specific noise (17.6%).

Table 3.6: Current feeding practices of the child with spastic cerebral palsy

	n (%)		
Assistance needed at mealtimes	Yes No	21 (61.8) 13 (38.2)	
Use of specific utensils for feeding	Yes No	9 (26.5) 24 (73.5)	
Utensils or equipment recommended by a HCP	Yes No	4 (44.5) 5 (55.5)	
Utensils or equipment make a difference at mealtimes	Yes No	8 (88.8) 1 (11.2)	
Food consistencies tolerated best:		Yes	No
	Liquid	1 (2.9)	33 (97.1)
	Pureed	8 (23.5)	26 (76.5)
	Lumpy	3 (8.8)	31 (91.2)
	Solids	22 (64.7)	12 (35.3)
	<i>Other:</i> All consistencies	7 (20.6)	27 (79.4)
Consistencies recommended by a speech therapist	Yes No	7 (20.6) 27 (79.4)	
Use of <i>thickeners</i> to improve feeding tolerance	Yes No	6 (17.6) 28 (82.4)	
Thickeners used:		Yes	No
	Oats	4 (66.7)	2 (33.3)
	Maizena	1 (16.7)	5 (83.3)
	Cake flour	2 (33.3)	4 (66.7)
	Thick & Easy	1 (16.7)	5 (83.3)
	Mashed potato / sweet potato	5 (83.3)	1 (16.7)
	<i>Other:</i> Baby rice cereal	1	n/a
Thickeners recommended by a HCP	Yes No	1 (16.7) 5 (83.3)	
Estimated duration (in minutes) to prepare a:	< 30 minutes	30 – 60 minutes	
1) Meal	24 (70.6)	10 (29.4)	
2) Snack	32 (94.1)	2 (5.9)	
3) Drink	33 (97.1)	1 (2.9)	
Cooking methods used:		Yes	No
	Boil	32 (94.1)	2 (5.9)
	Bake	24 (70.6)	10 (29.4)
	Steam	27 (79.4)	7 (20.6)
	Poach	10 (29.4)	24 (70.6)
	Roast	23 (67.6)	11 (32.4)
	Pan fry	22 (64.7)	12 (35.3)
	Deep fry	5 (14.7)	29 (85.3)
Total time spent on feeding daily	< 2 hours 19 (55.9)	2 – 3 hours 11 (32.4)	> 3 hours 4 (11.8)

Reasons for increased feeding duration:	Food refusal		Yes		No	
	Feeding difficulties		19 (55.9)		15 (44.1)	
	Positioning difficulties		19 (55.9)		15 (44.1)	
	Environmental difficulties		12 (35.3)		22 (64.7)	
	Disruptive behaviour		12 (35.3)		22 (64.7)	
			7 (20.6)		27 (79.4)	
The child with CP finishes:	Always	Often	Sometimes	Seldom	Never	
	1) Meals	14 (41.2)	16 (47.1)	3 (8.8)	n/a	1 (2.9)
	2) Snacks	18 (52.9)	11 (32.4)	4 (11.8)	1 (2.9)	n/a
	3) Drinks	25 (73.5)	8 (23.5)	1 (2.9)	n/a	n/a
Completion of meals	$\frac{3}{4}$ plate		$\frac{1}{2}$ plate		$\frac{1}{4}$ plate	
	22 (64.7)		10 (29.4)		2 (5.9)	
Ways of indicating hunger or thirst:			Yes		No	
	Cries / signals		10 (29.4)		24 (70.6)	
	He / she tells you		22 (64.7)		12 (35.3)	
	Points at food or drink		11 (32.4)		23 (67.6)	
	Makes a specific noise		12 (35.3)		22 (64.7)	
Ways of indicating satiety after a meal or snack:			Yes		No	
	Turns head sway		19 (55.9)		15 (44.1)	
	He / she tells you		20 (58.8)		14 (41.2)	
	Locks lips together		14 (41.2)		20 (58.8)	
	Pulls your hand away		11 (32.4)		23 (67.6)	
	Makes a specific noise		6 (17.6)		28 (82.4)	

CP – cerebral palsy; **HCP** – healthcare professional; **n** – number; **n/a** – not applicable

Please refer to the nutritional questionnaire in Annexure D and E for more information and detail

Parents of children with CP were more involved in purchasing of groceries (94.1%), cooking and preparing meals (85.3%) and feeding their child with CP (85.3%) than the caretakers (Table 3.7). Factors contributing to food choices and product selection were mainly availability (79.4%), nutritional content (79.4%), familiarity with the product (76.5%), practical reasons (67.6%) and preference (67.6%). Interestingly, the price and convenience of goods did not influence the purchasing of specific food products.

Table 3.7: Factors contributing to mealtime preparation, feeding the child and food selection

		n (%)	
Caretaker or parent mostly involved in:		Caretaker	Parent
	Buying groceries	2 (5.9)	32 (94.1)
	Cooking / preparing meals	5 (14.7)	29 (85.3)
	Feeding of the child with CP	5 (14.7)	29 (85.3)
Factors contributing to food selection:		Yes	No
	Availability	27 (79.4)	7 (20.6)
	Nutritional content	27 (79.4)	7 (20.6)
	Price	14 (41.2)	20 (58.8)
	Familiar	26 (76.5)	8 (23.5)
	Practical	23 (67.6)	11 (32.4)
	Preference	23 (67.6)	11 (32.4)
	Convenience	17 (50)	17 (50)
	Advice from a HCP	11 (32.4)	23 (67.6)

CP – cerebral palsy; **HCP** – healthcare professional; **n** – number

Please refer to the nutritional questionnaire in Annexure D and E for more information and detail

Parental perspectives and feelings regarding feeding practices of their child with spastic CP is summarised in Table 3.8. Most parents felt content with or very confident in their abilities in all the categories related to feeding practices. Only some parents were anxious about the growth and development (20.6%) of their child. A mere 38.2% of parents were satisfied with how they dealt with nutrition-related problems and few parents were very confident in dealing with these problems (14.7%). Parents were satisfied, content or very confident regarding their child's overall health status.

Table 3.8: Parental perspectives and feelings of the primary caregivers on feeding practices regarding their child with spastic cerebral palsy

	n (%)				
	Lacking confidence	Anxious	Satisfied	Content	Very confident
Choosing food products	1 (2.9)	1 (2.9)	3 (8.8)	14 (41.2)	15 (44.1)
Buying groceries	1 (2.9)	1 (2.9)	4 (11.8)	10 (29.4)	18 (52.9)
Decision-making on what meals or snacks to prepare	2 (5.9)	n/a	8 (23.5)	13 (38.2)	11 (32.4)
Preparing or cooking meals and snacks	1 (2.9)	1 (2.9)	6 (17.6)	12 (35.3)	14 (41.2)
Prior to feeding	1 (2.9)	2 (5.9)	4 (11.8)	18 (52.9)	9 (26.5)
During feeding	1 (2.9)	2 (5.9)	7 (20.6)	15 (44.1)	9 (26.5)
After feeding	1 (2.9)	1 (2.9)	6 (17.6)	16 (47.1)	10 (29.4)
Dealing with nutrition-related problems	1 (2.9)	3 (8.8)	13 (38.2)	12 (35.3)	5 (14.7)
Growth and development	n/a	7 (20.6)	9 (26.5)	13 (38.2)	5 (14.7)
Overall health	n/a	4 (11.8)	10 (29.4)	10 (29.4)	10 (29.4)

n – number; n/a – not applicable

Please refer to the nutritional questionnaire in Annexure D and E for more information and detail

Lastly, parents reported that they would like to be given feedback on where to improve (76.5%), practical nutrition advice (44.1%), guidance and support (32.4%), recommendations (17.6%) and the opportunity for others to understand their life experiences and concerns (5.9%) when the study has been completed.

Discussion

This study aimed to explore the concerns and management of difficulties of diet-related problems encountered by the primary caregivers with a child affected by spastic CP, between the ages of one and ten years, and that can eat orally. Demographic information of the participant and child, the diet history, current feeding practices and routine and information on parental perspectives were also obtained by means of a validated nutritional questionnaire.

There were various nutrition-related concerns that parents in this study encountered with their children suffering from spastic CP. Common nutritional challenges described in literature vary across different regions worldwide and depend on several aspects such as socio-economic status, parental literacy and education level, access to adequate healthcare facilities, premature birth, type and severity of CP and available support systems (Guellec *et al.*, 2016:93, 95; Strand *et al.*, 2016:924; Wittenbrook, 2011:17, 18). Malnutrition – either underweight and obesity – constipation, reflux, poor bone density, growth retardation and dysphagia are very common

concerns in this population group, especially in those with severe motor impairments (Andrew & Sullivan, 2010:357; Edwards & Bacon, 2014:125; Geullec *et al.*, 2016:97; Pinto *et al.*, 2016:1; Stanek *et al.*, 2016:931; Strand *et al.*, 2016:925; Wittenbrook, 2011:22). Most of these problems are due to feeding difficulties, delayed gastric emptying, medication use, poor nutritional status and a diet deprived of vitamins and minerals (Stanek *et al.*, 2016:931; Strand *et al.*, 2016:925; Wittenbrook, 2011:25). The most common problems reported in this study population were constipation, underweight or weight loss, poor appetite, flatulence, and vomiting or reflux, which is consistent with literature findings.

The diet histories of children with spastic CP were reported from birth in this study. The World Health Organisation (WHO) recommends that infants be breastfed exclusively up to six months of age and that breastfeeding be continued up to the age of two years or beyond. There is unfortunately limited information on breastfeeding practices in South Africa (Du Plessis *et al.*, 2016:110). Information in the literature on breastfeeding in the population of children with CP is limited; however, Guellec *et al.* (2016:95) found that a mere 20% of mothers of premature children with CP were breastfeeding. The breastfeeding rate of 52% from our study was higher than expected, especially when considering the results from the study by Guellec *et al.* (2016:95) and the national breastfeeding rate of around 39% (although most do initiate breastfeeding at birth (88%); only a mere 8% of mothers exclusively breastfeed up to six months of age) (Du Plessis *et al.*, 2016:110). Breastfeeding a child affected by CP can be difficult due to poorly co-ordinated tongue and jaw movements, poor lip closure, difficulty in latching and a weak sucking reflex (Remijn *et al.*, 2013:2). Mothers from our study were unable to breastfeed due to physical or medical problems, insufficient breast milk and poor latching. Very few mothers continued breastfeeding their babies after six months of age. Safe complementary (solid) foods should be introduced from six months of age (World Health Organisation, 2016). Most children in this study started solids after the age of six months. However, most children were born prematurely, with compromised feeding abilities and difficulties and developmental delays contributing to the delay in commencing complementary foods.

Children with CP have specific nutritional requirements that need to be adapted according to the type and severity of CP (Andrew & Sullivan, 2010: 358; Kalra *et al.*, 2015:140; Wittenbrook, 2011:23). Very limited information is available on the dietary intake of children with CP and some studies have even found inconsistent reporting of food intake in this population (Edwards & Bacon, 2014:127). A study by Kalra *et al.* (2015:141) reported that the energy and protein intake of children severely affected with spastic CP are generally poor. Reasons for decreased intake

were feeding difficulties, fatigue during feeding, or incorrect food consistency (Kalra *et al.*, 2015:142). These children also have an increased risk of mineral deficiencies such as iron, copper and magnesium, if their food intake from a varied diet is not optimal (Kalra *et al.*, 2015:140; Penagini *et al.*, 2015:9408). Two other studies by Grammatikopoulou *et al.* (2009:624) and Sullivan *et al.*, (2002:464) found that children with CP had a poor energy intake and only a fifth of their study population achieved 100% of their nutritional requirements.

The trends towards the food intake of children in this study, according to individual food groups, were rather worrying. This highlights the pivotal role that a RD plays in educating parents on healthy food choices and practices, especially considering that only a small percentage of parents reported to be very confident with their child's overall health, growth and development and dealing with nutrition-related problems. Parents did make use of healthy cooking methods such as baking, steaming and boiling. However, deep fried foods were often consumed together with sugary and savoury treats and sugary drinks which is consistent with the findings of Al-Hammad (2015:863). Protein food products, heart healthy fats, fresh fruit and vegetables were not always consumed by most of the children in this study, whereas starches and dairy products were consumed daily. This contradicts the findings of Penagini *et al.* (2015:9410) and Al-Hammad (2015:860) where Penagini *et al.* (2015:9410) found reduced energy and carbohydrate intake and increased intake of protein and fats in neurologically impaired children, including those with CP. Al-Hammad (2015:860) found that the main meals of children with CP included meat, vegetables, fruits and puddings and that drinks consisted of fruit juices and water. Hydration is essential, especially to replace liquids lost by drooling and sweating, although fluid requirements are often difficult to meet because of the inability to consume sufficient amounts of liquids (Andrew & Sullivan, 2010:324; Arvedson, 2013:S9; Benfer *et al.*, 2015:1060; Wittenbrook, 2011:23). Most children in our study had a sufficient fluid intake and always consumed sugar-free drinks that included water.

Andrew & Sullivan (2010:357), Bashar *et al.* (2015:12); Edwards & Bacon (2014:124), Kalra *et al.* (2015:141) and Pinto *et al.* (2016:4) reported that most spastic children with CP do suffer from a range of nutrition-related problems where most are not able to self-feed, which is consistent with the findings in our study. This is commonly found and varies according to the degree of severity and type of CP (Andrew & Sullivan, 2010:358; Bashar *et al.*, 2015:12; Weir *et al.*, 2013:495; Wittenbrook, 2011:17). Proper positioning and specific feeding utensils are useful in improving feeding abilities but should be used appropriately (Andrew & Sullivan, 2010:324; Ferluga *et al.*,

2013:12). Very few children in this study made use of special feeding utensils at mealtimes which most parents initiated themselves. Those using special and specific feeding utensils reported that it has made mealtimes easier.

Gisel (2015:989) stressed the importance of educating parents on safe oral intake of food and fluids. Arvedson (2013:S9), Benfer *et al.* (2015:1060) and Weir *et al.* (2013:500) reported that children severely affected with CP are less capable of consuming complex textured foods and liquids than pureed or thick fluid options. Very few children in this study, however, could tolerate liquids which is consistent with literature studies. Most children in our study tolerated mainly solids or pureed food and some even consumed all forms of textures, despite oral motor impairments or nutrition-related problems. Food thickeners were not generally used or needed by the children in this study, which is consistent with the findings of Weir *et al.* (2013:500) that reported only a small number of children with CP needing additional thickeners to assist with swallowing if pureed food is not available. However, modifications to fluid textures by using thickeners is mostly needed to ensure safety and tolerance as the risk of aspiration is higher when thin fluids or liquids are consumed (Arvedson, 2013:S9; Benfer *et al.*, 2015:1056). Food modifications are required especially in younger children with CP and in the presence of dysphagia in severely affected children (Benfer *et al.*, 2015:1058, 1060).

In our study, most children completed their meals, snacks and drinks within thirty minutes and most parents did not spend more than two hours daily on feeding the child with CP, which was a shorter duration than what had been reported in the literature. The feeding duration mentioned in the literature varied from three to seven hours daily (Andrew & Sullivan, 2010:357; Arvedson, 2013:S9; Bashar *et al.*, 2015:12; Edwards & Bacon, 2014:127). It was not clear whether the children in the literature studies had any form of therapy or intervention, whereas nearly all the children in our study were seen by an occupational therapist and speech therapist, which could explain why parents in our study fed their children much more easily and quickly. Very few parents in our study reported insufficient food intake and most children completed at least three quarters of food on their plate. Lack of communication from the child with spastic CP can make it very difficult for parents to identify hunger, thirst and satiety cues (Andrew & Sullivan, 2010:322; Kalra *et al.*, 2015:143; Wittenbrook, 2011:16). However, most parents in this study reported that their child had a unique way of indicating when hungry, thirsty or when they reached satiety by communicating it verbally, crying, signalling or by means of specific facial expressions.

Safe feeding and management practices should be established prior to feeding a child with CP (Bashar *et al.*, 2015:13; Ferluga *et al.*, 2013:16; Wittenbrook, 2011:29). Information on how to manage specific nutritional problems is based on numerous aspects such as religion, access to healthcare facilities, parental literacy, socio-economic situation and cultural beliefs (Wittenbrook, 2011:29). Multiple studies stress the imperative role that the MDT plays in alleviating nutrition-related concerns by managing them safely and appropriately with a co-ordinated plan (Andrew & Sullivan, 2010:325; Bashar *et al.*, 2015:11; Edwards & Bacon, 2014:124; Ferluga *et al.*, 2013:14; Penagini *et al.*, 2015:9407). Interestingly, a study by Al-Hammad (2015:862) found that parents in Saudi Arabia collected dietary information mainly from newspapers, radio or television, their local dentist, the child's healthcare centre and the child's school. The specific practices used for each unique problem were not investigated extensively in this study. Nutrition-related problems were mostly managed by consulting a HCP, which is consistent with findings in the literature, following advice from a book or magazine, a friend or relative or by means of modern technology such as using the Internet or social media. The question arises whether the content shared with parents from these resources constitutes accurate, valid and science-based evidence.

Our study also found that a low percentage of parents were very confident when dealing with nutrition-related problems. They expressed concern about the growth, development and overall health of their children with spastic CP. This is also seen in the literature as parents have reported oral feeding to be enjoyable and socially acceptable, but extremely stressful and frustrating (Andrew & Sullivan, 2010:321; Arvedson, 2013:S9; Edwards & Bacon, 2014:128; Stanek *et al.*, 2016:931). Feeding difficulties have psychosocial implications for the caregiver as they reduce quality time and social participation in families (Andrew & Sullivan, 2010:322). Edwards & Bacon (2014:127) reported a significant need for families dealing with concerns affecting their child with CP to receive emotional support, education on dealing with nutrition-related issues and psychosocial matters and acceptance in a communal, home and school setting. Ideally, one would like parents to be confident in all aspects of their child's health, development and especially, their nutritional status. Ongoing parental support is essential to improve their confidence when dealing with nutrition-related problems. Each member of the MDT should have a structured treatment plan for individual needs. Support groups are very useful and effective as part of a parental support system as they share thoughts and ideas with others possibly facing the same concerns with their children (Edwards & Bacon, 2014:127). Only one parent in our study joined a support group for advice on managing her child's nutrition-related concerns. This emphasises

the need to develop support groups within facilities or centres to involve parents and promote ongoing support from the entire MDT.

Although most parents in this study did not make use of a RD, most would like to receive recommendations, practical nutrition advice, support and guidance in managing nutrition-related concerns. In the Oxford Feeding study, a mere 17% of parents had contact with a dietitian within the period of a year that, suggested shortfalls in the professional input of a RD on feeding and nutrition (Sullivan *et al.*, 2002:676). The role of a dietitian needs to be emphasised at facilities dealing with children with spastic CP. One should focus not only on the children, but also on the parents, who need encouragement, empowerment, guidance and support.

The strengths of this study were that we could identify nutrition-related concerns that parents face over a board spectrum of nutrition-related areas. The research team could also identify a range of other concerns that need to be addressed. There were very few participants that did not complete the nutritional questionnaire and most questionnaires were fully completed. Furthermore, the current feeding practices and parental perspectives were established from this study. The information gathered can be useful to RDs in their nutritional education of parents with special needs children such as CP, as well as in giving guidance on where and how to support parents in alleviating and managing nutrition-related problems.

Limitations of this study include the fact that this was an observational study that included only three facilities. The results are merely a reflection of this population group and can therefore not be extrapolated to all settings where there are children living with spastic CP. The population group of parents involved in this study was small and one could have involved more special needs facilities in Pretoria. The assessment was self-administered; thus, information was self-reported. The nutritional questionnaire was validated only by a group of mothers, RDs, and senior lecturers in the field of dietetics. The strength of the validity is therefore unknown. Furthermore, more information on portion sizes of meals, snacks and drinks, detailed management practices of each nutrition-related concern and anthropometrical indicators could have added value to this study.

In light of the findings outlined in this article, further research should investigate the nutrition-related concerns of parents in a bigger population group from various regions that includes children with all other types and levels of severity of CP. More information on the dietary and management practices for these problems will also be beneficial to HCPs dealing with special needs children.

Key messages

- Children with spastic CP encounter various nutrition-related problems that needs proper and safe management, individualised care and support.
- The input from a RD plays a pivotal role in the health and wellbeing of children with CP and this needs to be emphasised at facilities and centres dealing with these conditions.
- Nutrition education and recommendations should be science-based and patient-specific and should focus on improving current feeding practices to make better and healthier food choices.
- Working in a MDT is essential in the care of spastic CP children and early involvement of a skilled MDT is important to identify and reduce feeding difficulties.
- Parents with children suffering from spastic CP need ongoing support, guidance and empowerment from the entire MDT of professionals. One should establish a good relationship with families and provide them with simple, practical and effective ways to fulfil their own needs in taking care of their child with special needs.

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CHAPTER FOUR – GENERAL DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

CHAPTER 4 – GENERAL DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

This final chapter will provide a summary of the main findings of this research project as well as general conclusions and recommendations. The aim and objectives of this study are repeated below to provide an easy reference as to what was to be addressed in this mini-dissertation.

Research aim

The aim of this study was to quantitatively explore the concerns and difficulties in the management of dietary problems that the primary caregiver (a parent or legal guardian) encounters with children affected by spastic cerebral palsy (CP) (with a chronological age of one to ten years old), by means of a self-administered, validated nutritional questionnaire.

Research objectives

The objectives of this research study were to:

- i. Identify from primary caregivers the common nutrition-related concerns and problem areas of children suffering from spastic CP who can eat orally.
- ii. Gather information from primary caregivers about the management of and current feeding practices used for specific dietary problems that children with spastic CP may encounter.

4.2 Nutrition-related concerns that parents encountered

The presence of nutrition-related concerns in the population of severely neurologically impaired children, such as those affected by CP, has been reported in various literature reviews (Aggarwal *et al.*, 2015:298; Andrew & Sullivan, 2010:358; Benfer *et al.*, 2015:5; Kuperminc *et al.*, 2013:S21; Liptak & Accardo, 2004:S36; Soylu *et al.*, 2008:332; Umay *et al.*, 2014:782). These concerns are sometimes difficult to detect owing to miscommunication, poor parental involvement and underlying conditions affecting feeding behaviour (Andrew & Sullivan, 2010:358). Dysphagia, gastro-esophageal reflux disease (GERD) and constipation are reported to be the most common nutrition-related feeding problems affecting most severely spastic children with CP (Nadeem *et al.*, 2015:240; Ptomey & Wittenbrook, 2015:599; Pinto *et al.*, 2016:5; Strand *et al.*, 2016:924). The current study found several nutrition-related concerns identified by the parents of children

with CP, especially constipation, underweight, poor appetite, flatulence and reflux; these particular concerns are also supported by findings in the literature.

It is clear from the literature that the nature and types of nutrition-related problems that these children face vary between developed and developing countries (Al-Hammad, 2015:863; Pinto *et al.*, 2016:6). Some studies were conducted in rural areas with the limited support of a multidisciplinary team (MDT) to provide guidelines on appropriate food consistency, food utensils and seating positioning to alleviate nutrition-related problems (Al-Hammad, 2015:861; Westwood, 2015:2). Parents that participated in this study were mainly wealthy and had full access to a MDT of experts for advice and support. Even so, they still encountered some nutrition-related concerns affecting their children with CP. This raises the importance of cross-referral between the members of the MDT to ensure that all aspects that could alleviate symptoms have been dealt with.

Studies have found that if feeding problems are not addressed, children with CP have reduced growth, poor neurodevelopmental outcomes, poor nutritional status, poor cognitive development and inadequate catch-up growth (Guellec *et al.*, 2016:97; Pinto *et al.*, 2016:1; Strand *et al.*, 2016:929). An experienced MDT is therefore critical in identifying and addressing nutrition-related problems. The quality of information that parents share also plays an important role in recognising these problems at an early stage.

4.3 Management of nutrition-related concerns

Management of complex feeding difficulties of neurologically challenged children may be a daunting task and therefore requires a co-ordinated, practical and careful plan involving the entire MDT of healthcare professionals (Andrew & Sullivan, 2010:325; Arvedson, 2013:S11; Kuperminc *et al.*, 2013:S21; Westwood, 2015:3). There is currently no gold standard for managing all nutritional problems in the CP population and therefore each concern should be managed uniquely and individually and may be treated medically, nutritionally and/or physically (Al-Hammad, 2015:863; Bell & Samson-Fang, 2013:S13; Edwards & Bacon, 2014:125; Kuperminc *et al.*, 2013:S21). Feeding should aim to achieve optimal growth and development according to each child's potential (Andrew & Sullivan, 2010:325; Pinto *et al.*, 2016:6; Strand *et al.*, 2016:924). Although this study did not clarify how each problem was treated individually, it did provide an indication of how parents managed these problems and how most made use of a MDT for intervention.

Recommendations given to parents for managing nutrition-related problems should always be safe and comfortable in order to create a pleasant feeding experience for both parent and child (Andrew & Sullivan, 2010:325; Arvedson, 2013:S9; Benfer *et al.*, 2015:1062; Kuperminc *et al.*, 2013:S22). As some parents in this study made use of internet sources or took advice from friends and relatives, one should always recommend that parents access sources that are evidence-based and that they should be cautious of pseudo-scientific recommendations or unreliable resources. These may cause confusion or frustration and even pose a health and safety risk for the child if not recommended or implemented by a registered healthcare professional. Successful management lies in a family-centred approach sometimes involving communities and other relatives or family friends (Edwards & Bacon, 2014:127; Kuperminc *et al.*, 2013:S24; Weir *et al.*, 2013:501).

4.4 Current feeding practices

It is essential for a child affected by CP to establish healthy eating habits and patterns. Early involvement of a skilled and experienced MDT is crucial to avoid poor and unsafe nutritional practices, including unhealthy food choices, incorrect positioning at mealtimes, inappropriate feeding methods or utensils and poor oral health that affects their feeding ability (Al-Hammad, 2015:862; Andrew & Sullivan, 2010:322; Edwards & Bacon, 2014:126; Kuperminc *et al.*, 2013:S22). Feeding interventions, including proper positioning, adaptive feeding equipment and altered food consistencies, have been shown to decrease feeding fatigue, increase safety, improve self-feeding abilities and texture tolerability, improve child behaviour and to have a positive effect on mealtime length and eating efficiency (Bashar *et al.*, 2015:12; Bell & Samson-Fang, 2013:S14; Edwards & Bacon, 2014:127; Ferluga *et al.*, 2013:15).

The diet of neurologically impaired children such as those with CP is generally poor in micronutrients, essential fatty acids and amino acids (Kalra *et al.*, 2015:140; Penagini *et al.*, 2015:9406). A three-day food diary has been shown to be effective in identifying these deficiencies and poor feeding patterns or food choices, but cautious interpretations are needed and one should not overlook spillage or vomiting that affects the child's intake (Andrew & Sullivan, 2010:322; Kalra *et al.*, 2015:143). Books, illustrations and photos of portion sizes and food sources may be useful to assess the quantity and, most importantly, the quality of the diet, which is an essential factor for growth in this population (Kalra *et al.*, 2015:143). Children with CP usually grow normally when their fibre and micronutrient intake is increased and their energy intake is moderate (Vernon-Roberts *et al.*, 2010:1101; Weir *et al.*, 2013:500). A registered

dietitian (RD) should be responsible for assessing the quantity and quality of the diet and the need for specific supplements. Modifications to food and fluid should always be recommended and implemented by a speech therapist when warranted. This is useful to ensure the intake of a balanced diet with the appropriate consistency, as Benfer *et al.* (2015:1060) found that children with CP tend to develop aversions to specific foods and liquids that are not well tolerated. This demonstrates and emphasises how important it is for a RD to work closely with a neurodevelopmentally trained (NDT) speech therapist and/or occupational therapist when modifying food or fluid consistencies and adjusting current feeding practices.

4.5 Other nutrition-related concerns emanating from this study

4.5.1 Multidisciplinary support in taking care of a child affected by CP

The need for sufficient MDT support for parents and pertaining to nutrition and health is an important aspect identified by the research team in this study. It is clear from this study that parents seek advice from HCPs regarding nutrition-related concerns and how these should be managed. Such support should therefore be encouraged as literature finds that the emotional status of the parent can have a tremendous effect on the development of a child with CP, in all aspects of health and wellbeing (Pinto *et al.*, 2016:6).

Parents taking care of a child with long-term health concerns, such as CP, are greatly affected by depression, fatigue, anxiety, frustration, fear and failure to nurture, causing major distress and discomfort on both an individual and a communal level (Andrew & Sullivan, 2010:322; Arvedson, 2013:S9; Edwards & Bacon, 2014:127; Garip *et al.*, 2016:4; Westwood, 2015:1). Caregiver training and home-based care and support groups have proved to be extremely effective in guiding parents and equipping them with the necessary coping mechanisms (Bashar *et al.*, 2015:14; Ferluga *et al.*, 2013:15; Kuperminc *et al.*, 2013:S22; Pinto *et al.*, 2016:6). Parental input on their own needs and perspectives is essential (Kuperminc *et al.*, 2013:S22). All healthcare professionals need to strive to achieve a healthy, loving and happy relationship between the parent and the child. Successful interventions are those that improve the quality of life (QOL) of both the parent and child, maximise independence in daily activities, improve the mobility of the child and establish a good nutritional foundation (Ferluga *et al.*, 2013:13; Kuperminc *et al.*, 2013:S22; Penagini *et al.*, 2015:9406; Weir *et al.*, 2013:498). Bashar *et al.* (2015:13) indicated how these improvements boost parental confidence and enhance mother-child interactions at mealtimes. One can therefore see that if parental needs, which include the nutritional practices

and health of their child, are met, the relationship with their child will improve. We therefore encourage the involvement of HCPs from the entire MDT at an early stage to assist with and manage nutrition-related problems and, in turn, empower the parents with the knowledge which can enhance their confidence and alleviate frustrations due to nutrition and feeding malpractice.

Facilities, centres and schools for children with special needs should therefore endorse these interventions and develop ways to engage with parents and involve them in interventions, such as support groups, to assist in and advise on taking care of their children with nutrition-related problems or other concerns affecting their health. Home visits from the MDT may be very helpful to parents in stressful situations. This needs to be strongly considered in situations where parents are not coping or struggling to adjust to their daily routine.

4.5.1 The important role of a registered dietitian

Good nutrition should form the cornerstone of healthy growth and development in neurologically impaired children and be routinely monitored by a skilled RD. A RD is indispensable during the nutritional rehabilitation process as she needs to assess the nutritional requirements of the child, advise on appropriate and healthy food and/or supplements, counsel on eating habits and review the progress of the child (Andrew *et al.*, 2012:226; Bell & Samson-Fang, 2013:S14; Kalra *et al.*, 2015:140; Kuperminc *et al.*, 2013:S23; Westwood, 2015:3).

The pivotal role of a RD was seen to be underestimated in this study population and needs to be emphasised in a multidisciplinary environment. As RDs are the experts on nutrition, they can make appropriate adjustments to the child's current diet to provide optimal nutrition to meet its nutritional needs.

4.6 Conclusions and practical recommendations

- i. Firstly, nutrition-related problems are common in children affected with CP and parents require support and practical advice from a MDT of experts on how to manage these concerns. Each concern should be treated individually and progress should be monitored continuously.
- ii. Evidence-based nutrition should guide parents in making informed and healthy decisions regarding nutrition and improving their current feeding practices. Involvement of the speech

therapist and/or occupational therapist is needed to enhance the quality and safety of these practices for parents and children to make mealtimes easier and less frustrating.

- iii. Lastly, the role that a RD plays in the growth, development and nutritional health status of a child with CP should be emphasised in facilities, centres or schools dealing with neurologically impaired children, such as those affected by CP. It is imperative that RDs be part of a MDT in working with this population group of children.

4.7 Limitations of the research project

A few limitations in this study have been identified:

- i. Only a small group of participants enrolled in this research study. More facilities, centres or schools for children with CP could have been identified and involved to increase the participation of parents.
- ii. A focus group discussion with the participants could have added value and depth to the current findings.
- iii. The nutritional questionnaire was quite extensive and included a great deal of detailed background information. Questions could have been condensed for ease of completion.
- iv. Lastly, the study lacked detailed information on the management of nutrition-related problems. One could therefore not identify the exact procedures used in the management of each unique problem and whether these practices were successful.

4.8 Future research

In conducting the current research projects, gaps were identified in the available literature that could be addressed by future research studies. These may include the following:

- i. In the *early* stages, validated, ready-to-use screening tools should be compiled and used in identifying nutrition-related problems. Studies should focus more on the awareness and detection of these concerns by parents and healthcare professionals.
- ii. Educational material on how to manage nutrition-related problems can be useful and studies can look into how they can assist in improving the knowledge of proper nutrition in the CP population.

- iii. The information obtained from this study should be used to identify where the *need* for nutritional education lies and where nutritional resources and guidelines for families with a child affected by CP can be improved or expanded in the South African setting. Therefore, studies focusing on specific nutritional concerns are needed.

In conclusion, the aim and objectives of this study were reached and the findings of this research project, irrespective of its limitations, add value to the literature regarding the nutrition-related concerns, management of problems and current feeding practices that parents encounter with their children affected by CP.

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ANNEXURES

ANNEXURE A: The healthcare professionals that assisted with recruitment

Facility or Centre	Healthcare professional	Job Title	Contact details
Baby Therapy Centre	Janine Van Niekerk Mehnaaz Karim	Registered Dietitian Speech Therapist	vanniekerkj@gmail.com mehnaaz_karim@yahoo.com
New Hope School	Christa Fourie Yvette Sunshine	Speech therapist Physiotherapist	christafourie57@gmail.com yvette.sunshine@absamail.co.za
PCCP at Life Groenkloof hospital	Hester Venter	Physiotherapist	hesterventer@lantic.net

PCCP: Pretoria Centre for Cerebral Palsy

ANNEXURE B: The screening tool used for recruitment

Research Topic	Inclusion Criteria	YES	NO
Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy	Can you read, write & speak Afrikaans or English?		
	Is the child diagnosed with spastic CP ?		
	Is the CP child able to eat orally ?		
	Is the CP child between the ages of 1-10 years old?		
	Are you the parent (preferably the mother) or legal guardian of the CP child?		
	Are you mostly involved in the CP child's daily feeding routine?		

*If the prospective participant answers **YES to ALL** of the questions = May **INCLUDE** in the study!*

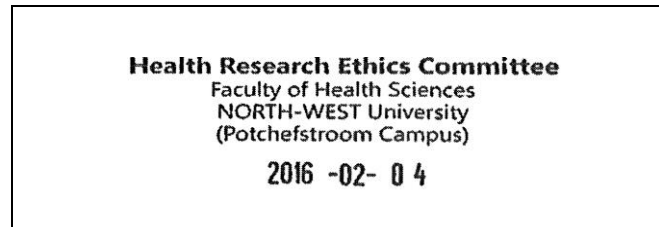
*Please provide a **consent form** to this participant and explain the information.*

Date: _____

I agree that ALL information shared regarding the study will remain strictly confidential:

(Signature of the healthcare professional that completed this screening form)

ANNEXURE C - Consent form for participants



PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR THE PRIMARY CAREGIVER OF SPASTIC CEREBRAL PALSY CHILDREN BETWEEN THE AGES OF ONE AND TEN YEARS OLD

TITLE OF THE RESEARCH PROJECT:

Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy

REFERENCE NUMBERS: NWU-00040-15-S1

PRINCIPAL INVESTIGATOR: Mrs. Lucinda Lourens (B.Sc Dietetics)

SUPERVISOR: Dr. Robin Claire Dolman (PhD Dietetics)

ADDRESS:

230 Julius Jeppe Street
Waterkloof
Pretoria
0181

CONTACT NUMBER: 084 078 1406

You are being invited to take part in a research project that forms part of identifying nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy. Please take some time to read the information presented here, which will explain the details of this project.

Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved.

Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University** (NWU–00040-15-S1) and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and Ethical Guidelines for Research of the National Health Research Ethics Council. It might be necessary for the research ethics committee members to inspect the research records.

What is this research study all about?

*This study will be conducted at **three** facilities including the Pretoria Centre for Cerebral Palsy (PCCP) at Groenkloof Life Hospital, the Baby Therapy Centre, and New Hope School, all allocated in Pretoria, and will involve a validated nutritional questionnaire in the form of a questionnaire to be completed. It has been compiled by experienced researchers in dietetics and nutrition such as the researcher and supervisor.*

The objectives of this research are:

- 1) *To identify the common nutritional information and problem areas of children suffering from spastic CP who are able to eat orally by means of a nutritional questionnaire.*
- 2) *To gather useful information from a nutritional questionnaire regarding the management and current feeding practises of specific dietary related problems that spastic CP children may encounter, from these primary caregivers.*

Why have you been invited to participate?

You have been invited to participate because you as primary caregiver of a spastic CP child best know and understand your child and can therefore share thoughts and experiences regarding nutrition-related concerns or problems that you have encountered, and how these problems have been managed or treated.

You have also complied with the following inclusion criteria:

- *Able to write, read and understand Afrikaans or English;*
- *The primary caregiver of the spastic CP child: a parent (preferably the mother) or legal guardian;*
- *Willing to give consent to share thoughts and experiences on specific topics concerning nutrition and nutrition-related problems regarding their spastic CP child;*
- *Involved in most of the CP child's daily feeding routine which includes purchasing of food products, preparing meals and snacks, and feeding the child at mealtimes.*

You will be excluded if you have:

- *A spastic CP child that makes use of a feeding device (such as a PEG or PEJ) and are not able to eat orally;*
- *A spastic CP child younger than one or older than ten years old.*

What will your responsibilities be?

You will be expected to fully complete a nutritional questionnaire, in Afrikaans or English, consisting of focussed nutrition-related questions in your own time. It has been compiled by the researcher and her supervisor. It consists of demographic information and information regarding nutrition and feeding practises that you make use of when purchasing, preparing, and feeding your spastic CP child. It also includes more personal information regarding perceptions when dealing with nutrition-related problems or concerns. If you do not want to answer specific questions, you are not compelled to do so.

*You will have a period of **one week** to complete this nutritional questionnaire and return it to the healthcare professional that has explained the study to you at the facility. If you are not able to do so, please contact the researcher to arrange getting these documents to her.*

Will you benefit from taking part in this research?

The indirect benefits will be that the information that you share in these nutritional questionnaires will be very helpful and valuable to the research team as we will use this information to better understand the need for nutritional guidelines to address your concerns and improve current management practices. Valuable input from these nutritional questionnaires will assist in developing a nutritional guideline booklet in future to support, advice and empower the primary caregiver of spastic CP children.

Are there risks involved in your taking part in this research?

*The risks in this study are negligible. The topics of the nutritional questionnaire will strictly be kept nutrition-related and it also includes some questions regarding personal information. If you wish to not answer specific questions, you are not compelled to do so. Your personal details will be kept confidential and only the team of researchers will work with the information that you have shared in these nutritional questionnaires. To put you at ease, there will be a psychologist, Liezel van der Westhuizen, on stand-by for counselling if needed. Please do not share or discuss these questions or comments with other prospective participants as I would like to obtain **your** personal input and would not like you to be influenced by someone else's opinion.*

The benefits in this study far outweighs the risks.

What will happen in the unlikely event of some harm / form of discomfort occurring as a result of your taking part in this research study?

Should you have the need for further discussions after feeling insecure, anxious, uncomfortable or distressed when sharing personal information, an opportunity will be arranged for you to meet the supervisory psychologist for counselling if needed.

She will refer participants to other relevant psychologists if needed.

Who will have access to the data?

*You will remain **anonymous** during data analysis and no names will be reported in the study after completion. The nutritional questionnaire will only contain a subject number for coding purposes and no other personal information. Data will be coded to ensure that no link can be made to a specific participant at any stage.*

The healthcare professional assisting in recruiting participants in this study will be required to sign the screening tool after completion to not share any information gathered from participants within the study. Reporting of findings will be anonymous. Therefore, confidentiality of participants will be ensured.

*Only the researchers capturing the information gathered from the nutritional questionnaires and a statistician, Marike Cockeran, will have access to the data. The statistician will sign the completed data sheet to ensure that information shared will be private and confidential at all times. She will not be familiarised with the participants as all questionnaires will be given a subject number and all answers will be coded. Nowhere will it be needed for participants to share their personal details, only a contact number **if** it is needed to discuss specific questions into more depth.*

All documentation of participants will be kept safe, secure, and confidential in the researcher's possession at her private residence in a password protected safe.

Information will be stored for seven years as it is recommended as a general rule that data should not be stored for less than seven years. It may be needed in future when a booklet regarding nutrition in toddlers with cerebral palsy, will be compiled.

What will happen with the data?

This is a once-off collection and data analysis for this study will commence when all validated nutritional questionnaires have been collected from the various facilities or centres.

Each participant will remain anonymous during data analysis as subject numbers will be allocated to all participants and all answers will be coded. The researcher will be responsible for capturing quantitative data using Microsoft Excel 2013. All information shared within these questionnaires will be transferred and captured on this data sheet to ease analysis.

This data sheet will then be sent to the statistician, Marike Cockeran, where she will import all the information captured on the Excel sheets into a database system using statistical software, known as IBM SPSS version 22, to conduct the data analysis.

All information shared in the Excel spreadsheet will however be expressed in the form of numbers (coding) to make information more confidential.

Conclusions and recommendations will be drawn from these findings and explained in-depth. The information gathered from these nutritional questionnaires will be used to identify valuable aspects which need to be addressed.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study. You will however receive a card from the research team with great gratitude thanking you for your participation in this study after completion. There are also no costs involved to partake in this study.

Is there anything else that you should know or do?

*The questionnaire for the Nutritional Questionnaire will be **validated** by at least three experts, mostly registered dietitians, who work with CP children in order to assess the content validity.*

Validity refers to whether a questionnaire is measuring what it is intended for with regards to a specific purpose (Rattray & Jones, 2007:238). An important aspect of the quality of questionnaire research is to pre-test the questionnaires used for a study to determine its validity and quality (Pinsonneault & Kraemer, 1993:94; Taylor-Powell, 1997:14). Pre-testing can be done by requesting respondents that are not part of the study population, colleagues or specialists in the field to complete the questionnaire and give thorough feedback (Pinsonneault & Kraemer, 1993:95; Roberts, 1999:67; Taylor-Powell, 1997:14). Pre-testing is also essential to determine whether the questions produce information needed to satisfy the study's purpose and how much it will contribute to the study (Taylor-Powell, 1997:14). Content validity is an essential aspect that every questionnaire has to be evaluated for. It is done by means of expert opinion with regards to whether what is represented in the questionnaire, truly measures the proposed concept (Rattray & Jones, 2007:238).

The registered dietitians will focus on the scientific aspect of the questionnaire, how the questions have been formulated to prevent confusion, as well as giving technical and practical suggestions.

At least three mothers, not related to the study, will also be asked to complete the nutritional questionnaire, focusing more on the understanding of questions and time taken to complete the answers. This will all help to ensure that the questionnaire is clear, not ambiguous, user-friendly, and of good quality. Face validity will be assessed by the statistician, Marike Cockeran, and suggestions will be made regarding question wording and the questionnaire layout.

After this, recommended changes will be made and adapt accordingly and the final draft will be compiled. It will then be reviewed for the last time by at least two academics in the field of nutrition or dietetics to finalise the concluding questionnaire used as the nutritional questionnaire for this study.

*The experts, mothers and academics that will be recruited for validation according to how **willing** they are to give their input and advice regarding the questionnaire content, practicality, and layout, and their **availability** to do so.*

Bibliography:

Pinsonneault, A. & Kraemer, K.L. 1993. Questionnaire research methodology in management information systems: An assessment. *Journal of Management Information System*, 10(2):75-105.

Rattray, J. & Jones, M.C. 2007. Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, 16:234-243.

Taylor-Powell, E. 1997. Questionnaire design: Asking questions with a purpose. *Program development and evaluation*, 1-17.

You can contact Mrs. Lucinda Lourens at 084 078 1406 if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee via Mrs. Carolien van Zyl at 018 299 2089; carolien.vanzyl@nwu.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

How will you know about the findings?

The findings of the research will be shared with you upon request. You are welcome to contact us as soon as it is available.

Declaration by participant

By signing below, I agree to take part in this research study: Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy.

I declare that:

- I have read this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2016

.....

Signature of participant

.....

Signature of witness

Declaration by the person obtaining consent (Healthcare professional)

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) on (*date*) 2016

.....
Signature of person obtaining consent *

.....
Signature of witness

* I.e. the healthcare professional recruiting participants for this study

DIE VOEDINGSOPNAME

TITEL: Voedingsverwante probleme wat 'n primêre versorger moet behartig rakende hul spastiese serebraal parese (SP) kind

DOEL: Die **doel** van hierdie studie is om te ondersoek watter voedingsverwante probleme en bekommernisse 'n primêre versorger ('n ouer of voog) het rakende hul spastiese SP kind, en op watter wyse word hierdie probleme of bekommernisse aangespreek en behandel. Dit gaan deur middel van 'n *voedingsverwante vraelys* bepaal word.

KONTAKBESONDERHEDE:

Vir enige *navrae* skakel gerus die:

- **Navorser** – Lucinda Lourens: lcdacamara@gmail.com / 084 078 1406

Vir enige *klagtes* skakel gerus die:

- **Gesondheidsnavoring Etiese Komitee van die Gesondheidswetenskappe Fakulteit van die Noordwes Universiteit** – Mrs. Carolien van Zyl: carolien.vanzyl@nwu.ac.za / 018 299 2089

INSTRUKSIES: U het 'n tydperk van **een week** om hierdie voedingsverwante vraelys te voltooi en dit dan terug te besorg aan die gesondheidsprofesionele personeel wat hierdie studie aan u verduidelik het. Indien dit nie moontlik is nie, skakel asseblief die navorser om reëlins te tref om die nodige dokumente aan haar te besorg. Vul asseblief hierdie vraelys so deeglik en eerlik as moontlik in.

M.Sc Skripsie

Voedingsverwante probleme wat 'n primêre versorger moet behartig rakende hul spastiese serebraal parese kind.

Geagte Deelnemer,

Baie dankie dat u tyd afgestaan het om hierdie voedingsopname te voltooi.

Hierdie vraelys bevat algemene-, persoonlike-, en voedingsverwante vrae rakende u spastiese serebraal parese (SP) kind. U deelname word hartlik waardeer. U mag enige tyd onttrek sonder dat daar enige nagevolge sal wees. Hierdie studie sal help om insig te gee oor hoe jy spesifieke voedingsverwante probleme ervaar, behandel, en aanspreek rakende u SP kind en ons ook 'n idee gee oor hoe u dit hanteer. Hierdie waardevolle inligting sal 'n groot bydrae lewer tot die ontwikkeling van 'n voedingsverwante inligting boekie waar riglyne en advies oor voeding in SP kinders verskaf sal word om u kennis te verryk.

Let wel dat alle inligting wat verskaf word vanaf hierdie voedingsopname *streng konfidensieel* sal wees aan die navorsingspan en geen inligting sal gedeel word met ander sonder u toestemming nie.

Vriendelike groete,

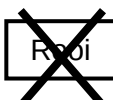
Lucinda Lourens (M.Sc student)

ALGMENE INLIGTING

Deelnemer Nr:

ALLE inligting moet duidelik met 'n "X" gemerk word

Byvoorbeeld:



LET WEL: SP = Serebraal Parese

Inligting oor die deelnemer (primêre versorger)

1	Geslag	Manlik ¹	Vroulik ²				
2	Ouderdom (jare)	< 20 ¹	20 – 30 ²	31 – 40 ³	41 – 50 ⁴	> 50 ⁵	
3	Hoeveel kinders het u?	1 ¹	2 ²	3 ³	>3 ⁴		
4	Is u die ouer of voog van die SP kind?				Ouer ¹	Voog ²	
5	Maak u gebruik van 'n versorger om na u SP kind om te sien?				Ja ¹	Nee ²	
6	Indien u antwoord ja is, spesifiseer asseblief:		Oppasser OF Au-pair ¹		Naasverwante ²	Ander: ³ (Spesifiseer asb) _____	
7	Etnisiteit (Slegs vir statistiese doeleindes)	Swart ¹	Blank ²	Kleurling ³	Indieër ⁴	Ander: ⁵ (Spesifiseer asb) _____	
8	Opvoeding / Onderrig	Geen ¹	Gr.1 - Gr.7 ²	Gr.8 - Gr.11 ³	Gr. 12 ⁴	Tersiêre onderrig ⁵	
9	Huwelikstatus	Getroud ¹	Geskei ²	Weduwee ³	In 'n verhouding ⁴	Enkellopend ⁵	
10	Werkstatus:	Voltyds ¹	Deeltyds ²	Gedeeltelik ³	Werkloos ⁴		
11	Indien u werk, genereer u werk die enigste inkomste in die huishouding?				Ja ¹	Nee ²	
12	Indien nie, wie anders dra by tot die huishoudelike inkomste?		Man / Vrou ¹	Kêrel / Meisie ²	Broer / Suster ³	Ander ⁴ (Spesifiseer asb) _____	
13	Wat is u maandelikse inkomste (ongeveer)? (Verwys na <i>netto</i> inkomste)			< R 5000 ¹	R 5000 – R 10 000 ²	R 10 001 – R 20 000 ³	
R 20 001 – R 30 000 ⁴				> R 30 000 ⁵	Hulptoelaag ⁶		
14	Het u mediese fonds?				Ja ¹	Nee ²	
15	Indien ja, is u SP kind as afhanklike geregistreerd op u mediese fonds?				Ja ¹	Nee ²	

Inligting oor u spastiese SP kind

16	Geslag	Manlik ¹	Vroulik ²	17 Ouderdom (jare)		_____ jaar ¹				
18	Gebore op hoeveel weke?	Ek weet nie	< 30 ¹	31 – 37 ²	38- 40 ³	> 40 ⁴				
19	Was daar enige komplikasies:			Tydens swangerskap?		Ja ¹	Nee ²			
				Tydens geboorte?		Ja ¹	Nee ²			
				Na geboorte?		Ja ¹	Nee ²			
20	Is hy/sy in 'n speelgroep / crèche / skool?					Ja ¹	Nee ²			
21	Was u kind al deur een van die volgende gesondheids-praktisyne gesien sedert hy/sy gediagnoseerd was met spastiese SP? (Merk asseblief die ja of nee opsie)	Dieetkundige ¹	JA	NEE	Tandarts ²	JA	NEE	Arbeidsterapeut ³	JA	NEE
		Fisioterapeut ⁴	JA	NEE	Sielkundige ⁵	JA	NEE	Maatskaplike werker ⁶	JA	NEE
		Spraakterapeut ⁷	JA	NEE	Spesialis * ⁸	JA	NEE	Ander: ⁹ _____		
LET WEL * Tipes "spesialiste" verwys na 'n Oor-, Neus- & Keel, Gastro-enteroloog, Ortoped, Pediater, of Neuroloog)										

VOEDINGSVERWANTE INLIGTING RAKENDE SPASTIESE SP KINDERS

Afdeling A

Verskaf asseblief inligting rakende u SP kind se **dieetgeskiedenis** vanaf geboorte.
(Kies asseblief die relevante opsie):

A1	Was u SP kind geborsvoed vanaf geboorte?	Ja ¹	Nee ²				
A2	Indien wel, tot watter ouderdom het u geborsvoed?	< 6 maande ¹	7 – 12 maande ²				
		13 – 24 maande ³	> 24 maande ⁴				
A3	Indien nie, wat was die rede(s) hoekom u nie geborsvoed het nie? (Merk asseblief ja of nee opsie)	Werksverwante probleme ¹	JA NEE	Onvoldoende borsmelk ²	JA NEE	Swak hegting ³	JA NEE
		Ongemak tydens borsvoeding ⁴	JA NEE	Fisiese of mediese probleme ⁵	JA NEE	Probleme met bors gesondheid ⁶	JA NEE
		Spanning / onder druk ⁷	JA NEE	Gevoel van vernedering ⁸	JA NEE	Geen ondersteuning van familie / vriende ⁹	JA NEE
		Bekommerd oor pyn ¹⁰	JA NEE	Ander (Spesifiseer asb): ¹¹ _____ _____			
A4	Het u al ooit advies van 'n gesondheidspraktisyn ontvang rakende borsvoeding of formule voeding?	Ja ¹	Nee ²				
A5	Wanneer het u met komplimentêre (soliede) voeding begin (ouderdom)?	< 4 maande ¹	4 - 5 maande ²				
		6 maande ³	> 6 maande ⁴				
Hoeveel maaltye, versnapperings en drankies berei u vir u SP kind per dag voor?							
A6	Maaltye	1 ¹	2 ²	3 ³	>3 ⁴		
A7	Versnapperings	1 ¹	2 ²	3 ³	>3 ⁴		
A8	Drankies ("Drankies" sluit water, tee, sap of melk in)	1 ¹	2 ²	3 ³	>3 ⁴		

Gee u van die volgende voedselgroepe vir u SP kind?						
(Merk asseblief die relevante opsie duidelik met 'n "x")						
		1	2	3	4	5
		Altyd	Gereeld	Partykeer	Soms	Nooit
A9	Proteïen (Voorbeelde: vleis, maer maalvleis, hoender, vis, lewer, eiers, maer spek)					
A10	Stysel (Voorbeelde: pap, pasta, rys, aartappel, soet patats, pampoen, botterskorsie, brood)					
A11	Vette (Voorbeelde: margarien, olie, avocado, grondboontjiebotter, neut & sade, olywe)					
A12	Suiwel (Voorbeelde: Kaas, joghurt, melk)					
A13	Vars vrugte					
A14	Vars groente					
A15	Soet happies (Voorbeelde: sjokolade, lekkers, koekies, koek, roomys)					
A16	Sout happies (Voorbeelde: springmielies, biltong, skyfies, rys koekies)					
A17	Suiker-bevattende drankies (Voorbeelde: Vrugtesap, koeldrank, versoete drankies of melkskommels)					
A18	Suiker-vry drankies (Voorbeelde: water, tee, suiker-vry ys-tee of koeldrank)					

LET WEL:

"**Altyd**" verwys na daaglik; "**Gereeld**" verwys na 2-3 keer per week; "**Partykeer**" verwys na 2-3 maande;

"**Soms**" verwys na < 2 keer per maand; "**Nooit**" verwys na om die voedselgroep *nooit* in die dieet in te sluit nie

Afdeling B

Wie in die huis in meestal betrokke by die:

B1	Koop van kruideniersware vir die SP kind?	Versorger ¹ (Au-pair / Oppasser)	Ouer ² (ma / pa / voog)	Naasverwante ³	Broer / Suster ⁴					
B2	Vorbereiding en gaarmaak van maaltye en versnapperinge?	Versorger ¹ (Au-pair / Oppasser)	Ouer ² (ma / pa / voog)	Naasverwante ³	Broer / Suster ⁴					
B3	Voer van maaltye vir die SP kind?	Versorger ¹ (Au-pair / Oppasser)	Ouer ² (ma / pa / voog)	Naasverwante ³	Broer / Suster ⁴					
B4	Hoe besluit u watter voedselprodukte om te koop en maaltye en versnapperinge voor te berei vir u SP kind? (Merk asseblief die ja of nee opsie)	Beskikbaarheid ¹	JA	NEE	Voedings-waarde ²	JA	NEE	Prys ³	JA	NEE
		Voorkeur ⁴	JA	NEE	Bekend ⁵	JA	NEE	Gerieflikheid ⁶	JA	NEE
		Advies van 'n gesondheids-praktisyn ⁷	JA	NEE	Prakties ⁸	JA	NEE	Ander: ⁹ _____		
B5	Waar koop u meestal u kruideniersware? (Merk asseblief die ja of nee opsie)	Shoprite / Checkers ¹	JA	NEE	Pick & Pay ²	JA	NEE	Woolworths Food Market ³	JA	NEE
		Spar ⁴	JA	NEE	Food Lovers Market ⁵	JA	NEE	Fruit & Veg City ⁶	JA	NEE
		OK Foods ⁷	JA	NEE	Game ⁸	JA	NEE	Ander: ⁹ _____		

Afdeling C

C1	Maak u gebruik van spesifieke eetgerei en voedingstoebehore om u SP kind te voed? (Eetgerei verwys na 'n spesiale lepel / beker / vurk / mes, ens.)	Ja ¹	Nee ²
C2	Was hierdie eetgerei aanbeveel deur 'n gesondheids-praktisyn?	Ja ¹	Nee ²
C3	Maak hierdie eetgerei en voedingstoebehore enige verskil tydens maaltye? (Byvoorbeeld: minder mors tydens maaltye, verbetering in voedingstyd, meer gemaklik om kind te voed, ens.)	Ja ¹	Nee ²
C4	Benodig u SP kind enige hulp om te kan eet tydens maaltye? (“Hulp” impliseer dat iemand hom/haar moet voer omdat hy/sy nie self kan eet nie)	Ja ¹	Nee ²

Hoe lank (in minute) neem dit om u SP kind te **voer** of **verskaf** tydens of met:

(LET WEL: “n Maaltyd” verwys na ontbyt, middagete en aandete; “n Versnappering” verwys na enigiets wat geëet of gedrink word tussen maaltye; “n Drankie” verwys na water, sap, tee of melk)

C5	‘n Maaltyd?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴					
C6	‘n Versnappering?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴					
C7	‘n Drankie?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴					
C8	Na aanleiding van die vorige vraag, hoeveel tyd (ongeveer) spandeer u per dag om u SP kind te voed en vloeistowwe te verskaf?			< 2 ure ¹	2-3 ure ²					
				> 3 ure ³						
C9	Wat is die rede(s) vir ‘n toename in voedingstyd wanneer u maaltye, versnapperinge of drankies verskaf? (Merk asseblief die ja of nee opsie)	Posisionerings-faktore ¹	JA	NEE	Voedings-faktore ²	JA	NEE	Omgewings-faktore ³	JA	NEE
		Moeilike gedrag tydens maaltye ⁴	JA	NEE	Eetstaking of weier om te eet ⁵	JA	NEE	Ander: ⁶ _____ _____		
LET WEL: “Voedingsfaktore” verwys na swak of problematiese kou, suig, of sluk van voedsel soos disfagie ens. wat vomering of reflux kan veroorsaak; Ongepaste voedingstoehore en eetgerei, ens. “Posisioneringsfaktore” verwys na onvoldoende kop- of postuur beheer tydens maaltye / swak spiertonus wanneer die kind in die eetstoel geplaas word, ens. “Omgewingsfaktore” verwys na ‘n ongepaste eetstoel / raserige omgewing / beperkte spasie, ens. “Moeilike gedrag tydens maaltye” verwys na onophoudelike huilbuie / onbeheerbare bewegings, ens. “Eetstaking of weier om te eet” as gevolg van ‘n selektiewe eter / voedsel aversies / swak aptyt, ens.										

Hoeveel tyd (in minute) spandeer u op voorbereiding en gaarmaak van die volgende:												
C10	'n Maaltyd?	< 30 min ¹	30-60 min ²		61-90 min ³		> 90 min ⁴					
C11	'n Versnappering?	< 30 min ¹	30-60 min ²		61-90 min ³		> 90 min ⁴					
C12	Van watter voedingstoebehore maak u gebruik om maaltye en versnapperinge voor te berei vir u SP kind? <i>(Merk asseblief die ja of nee opsie)</i>	Voedsel-verwerker ¹	JA	NEE	Rasper ²	JA	NEE	Sny-apparaat ³	JA	NEE	Ander: ⁵ _____	
		Perser ⁴	JA	NEE								
C13	Van watter kookmetodes maak u van gebruik? <i>(Merk asseblief die ja of nee opsie)</i>	Kook ¹	JA	NEE	Stoom ²	JA	NEE	Rooster ³	JA	NEE		
		Diep-vet braai ⁴	JA	NEE	Pan-braai ⁵	JA	NEE	Bak ⁶	JA	NEE		
		Posjeer ⁷	JA	NEE								
C14	Volg u enige resepte wanneer u maaltye en versnapperinge voorberei?					Ja ¹		Nee ²				
C15	Watter tipe voedsel konsistensie tolereer u SP kind die beste?		Vloeistof ¹		Puree ²		Klonterig ³					
			Solied ⁴		Ander: ⁵ _____							
C16	Was hierdie konsistensies deur 'n gesondheidspraktisyn aanbeveel, soos 'n spraakterapeut?					Ja ¹		Nee ²				
C17	Is dit nodig dat u maaltye of versnapperinge moet verdik om voedingstoleransie te verbeter? (‘Voedingstoleransie’ verwys na ‘n verbetering in kou en sluk; vermindering in opgooi, refluks of opgeblaasde abdomes, ens.)					Ja ¹		Nee ²				
C18	Indien ja, watter tipe verdikkingsmiddels maak u van gebruik? <i>(Merk asseblief die ja of nee opsie)</i>	Thick & Easy ¹	JA	NEE	Nestargel ²	JA	NEE	Hawermout ³	JA	NEE		
		Fyngemaakte aartappel or patat ⁴	JA	NEE	Maizena ⁵	JA	NEE	Koekmeel ⁶	JA	NEE		
		Heuning of stroop ⁷	JA	NEE	Ander: ⁸ _____							
C19	Was hierdie verdikkingsmiddels deur 'n gesondheidspraktisyn aanbeveel?					Ja ¹		Nee ²				

Maak u SP kind sy / haar maaltye, versnapperinge en drankies klaar?											
(Merk asseblief die relevante opsie duidelik met 'n 'x')											
		1	2	3	4	5					
		Altyd	Gereeld	Partykeer	Soms	Nooit					
C20	Maaltye?										
C21	Versnapperinge?										
C22	Drankies?										
LET WEL: "Altyd" verwys na daaglik; "Gereeld" verwys na 2-3 keer per week; "Partykeer" verwys na 2-3 maande; "Soms" verwys na < 2 keer per maand; "Nooit" verwys na hom/haar wat dit nooit klaar maak nie											
C23	Indien u SP kind nie 'n maaltyd of versnappering klaarmaak nie, hoeveel van die maaltyd of versnappering neem hy/sy meestal in?			$\frac{3}{4}$ ¹		$\frac{1}{2}$ ²		$\frac{1}{4}$ ³			
C24	Hoe bepaal u wanneer u SP kind honger of dors is? (Merk asseblief die ja of nee opsie)	Hy / sy vertel jou ¹	JA	NEE	Wys na 'n voedsel of drankie ²	JA	NEE	Maak 'n spesifieke geluid ³	JA	NEE	
		Huil ⁴	JA	NEE	Ek weet nie ⁵						
C25	Hoe bepaal u indien u SP kind versadig is na 'n maaltyd of versnappering? (Merk asseblief die ja of nee opsie)	Hy / sy vertel jou ¹	JA	NEE	Pers lippe teen mekaar ²	JA	NEE	Trek jou hand weg ³	JA	NEE	
		Draai kop weg ⁴	JA	NEE	Maak 'n spesifieke geluid ⁵	JA	NEE	Ek weet nie ⁶			

Afdeling D: Voedingsverwante probleme – IDENTIFISERING & BEHANDELING

Sukkel u SP kind met die volgende **voedingsverwante probleme**?

D1	Allergieë / Intoleransies	Ja ¹	Nee ²	D9	Anemie [#]	Ja ¹	Nee ²
D2	Aspirasie ^{\$}	Ja ¹	Nee ²	D10	Hardlywigheid	Ja ¹	Nee ²
D3	Diarree	Ja ¹	Nee ²	D11	Winderigheid	Ja ¹	Nee ²
D4	Disfagie [@]	Ja ¹	Nee ²	D12	Vertraagde groei	Ja ¹	Nee ²
D5	Onvoldoende voedsel inname [*]	Ja ¹	Nee ²	D13	Spastiese kolon	Ja ¹	Nee ²
D6	Oorgewig / Obesiteit	Ja ¹	Nee ²	D14	Gastriese of orale ulkuse [^]	Ja ¹	Nee ²
D7	Swak aptyt	Ja ¹	Nee ²	D15	Ondergewig / Gewigsverlies	Ja ¹	Nee ²
D8	Vitamiene of mineraal tekort	Ja ¹	Nee ²	D16	Vomerig / Refluks	Ja ¹	Nee ²

\$ Aspirasie: Wanneer voedsel stukkie of vloeistof perongeluk ingesam of ingesluk word en in die longe beland
@ Disfagie: Moeilike, pynlike of ongemaklike sluk
*** Onvoldoende voedsel inname:** Dit kan veroorsaak word deur suig, sluk, of kou probleme; Tand probleme soos erosie; Oortollige spoeg, ens.
Anemie: 'n Toestand wat voorkom indien daar 'n tekort aan rooibloedselle of hemoglobien in die bloed is
^ Gastriese of orale ulkuse: Sere of blasies wat in die mond, slukderm of maagwand voorkom

Spesifiseer asseblief die **tipe, indien en waar** van toepassing:

D17	<i>Allergieë / Intoleransie</i>	Eier ¹	Melk ²	Gluten ³			
		Neut ⁴	Soja ⁵	Graan ⁶	Ek weet nie ⁷		
D18	<i>Anemie</i>	Vitamiene B12 ¹	Foliesuur ²	Yster ³	Ek weet nie ⁴		
D19	<i>Mineraal tekort</i>	Kalsium ¹	Yster ²	Magnesium ³	Sink ⁴	Ek weet nie ⁵	
D20	<i>Vitamiene tekort</i>	Vitamiene A ¹	Vitamiene C ²	Vitamiene D ³	Vitamiene E ⁴	Ek weet nie ⁵	
D21	Het u al ooit advies of riglyne ontvang oor hoe om voedingsverwante probleme te behandel of hanteer?				Ja ¹	Nee ²	
D22	Was hierdie advies of riglyne effektief en het dit gehelp om hierdie probleme te behandel of hanteer?				Ja ¹	Nee ²	
D23	Sal u graag voedingsverwante advies of riglyne vanaf 'n geregistreerde dieetkundige wil ontvang?				Ja ¹	Nee ²	

D24	Hoe het u tot op hede voedingsverwante probleme behandel of hanteer ? <i>(Merk asseblief die ja of nee opsie)</i>	Advies van 'n vriend / naasverwante gevolg ¹	JA	NEE	'n Gesondheidspraktisyn gesien ²	JA	NEE
		Advies op internet of sosiale media gesoek ³	JA	NEE	Aangesluit by 'n ondersteuningsgroep ⁴	JA	NEE
		Advies van 'n boek of tydskrif gevolg ⁵	JA	NEE	Ander: ⁶ 		

Afdeling E

Hoe voel u oor die volgende **voedingspraktyke** rakende u SP kind in die volgende senarios?

Voltooi asseblief die volgende tabel (Merk die relevante opsie duidelik met 'n "x"):

		1	2	3	4	5
		Onvoldoende selfvertroue	Gespanne	Tevrede	Gemaklik	Baie selfvertroue
E1	Kies van voedselprodukte					
E2	Kruideniersware koop					
E3	Besluitneming oor watter maatyte of versnapperinge om voor te berei					
E4	Vorberei / kook van maaltyte en versnapperinge					
E5	Voor voedingstye					
E6	Tydens voedingstye					
E7	Na voedingstye					
E8	Behandel of hanteer van voedingsverwante probleme					
E9	Groei en ontwikkeling					
E10	Algehele gesondheid					

Afdeling F				
F1	In jou opinie, wat wil u graag vanuit hierdie studie hê of ontvang?	Praktiese voedingsadvies ¹	Terugvoer ontvang oor waar om te verbeter ²	Ondersteuning en leiding ³
		Vir ander om u ervaring en probleme te verstaan ⁴	Riglyne te verskaf ⁵	
		Ander: ⁶ _____		
F2	Mag die navorser u kontak indien addisionele inligting nodig is na aanleiding van hierdie vraelys?	Ja	Nee	
Indien ja, verskaf asseblief u kontaknommer : _____				

BAIE DANKIE DAT U HIERDIE VRAELYS VOLTOOI HET 😊

ANNEXURE E: The Validated Nutritional Questionnaire – English version

THE NUTRITIONAL QUESTIONNAIRE

TITLE: Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy.

AIM: The aim of this study is to quantitatively explore the concerns and management of dietary related problems that the primary caregiver (a parent or legal guardian) encounters with children affected by spastic cerebral palsy (CP).

CONTACT DETAILS:

For any *questions* please contact the:

- **Researcher** – Lucinda Lourens: lcdacamara@gmail.com / 084 078 1406

For any *complaints*, please contact the:

- **Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University** – Mrs. Carolien van Zyl: carolien.vanzyl@nwu.ac.za / 018 299 2089

INSTRUCTIONS: You will have a period of **one week** to complete this nutritional questionnaire and return it to the healthcare professional that has explained the study to you at the facility. If you are not able to do so, please contact the researcher to arrange getting these documents to her.

Please complete this questionnaire as thoroughly and honestly as possible.



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Web: <http://www.nwu.ac.za>

Nutrition Department

Tel: (018) 299 4059
Fax: (018) 299 2464
Email: Robin Dolman: robin.dolman@nwu.ac.za

Researcher's Contact Details

Lucinda Lourens
Cell: 084 078 1406
Email: lcdacamara@gmail.com

M.Sc Dissertation

Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy.

Dear participant,

Thank you for taking for taking the time to completing this nutritional questionnaire.

This questionnaire will contain personal content and questions regarding your spastic cerebral palsy (CP) child. Your participation will be appreciated tremendously, but feel free to withdraw at any point without any consequences. This study will give us insight into how you experience, address and manage specific nutrition-related problems or concerns of your CP child and assist us with understanding how you deal with them. This valuable information will contribute to the development of a nutritional guideline booklet in future where nutrition-related recommendations and advice will be given to enrich the knowledge of parents taking care of CP children.

Please note that information shared in this nutritional questionnaire will be *strictly confidential* to the research team and will not be shared with anyone else without your consent.

Regards,

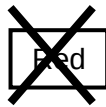
Lucinda Lourens (M.Sc student)

BACKGROUND INFORMATION

SUBJECT No:

ALL information should be clearly marked with an “X”

Example:



Information of the participant (primary caregiver)

1	Gender	Male ¹	Female ²			
2	Age (years)	< 20 ¹	20 – 30 ²	31 – 40 ³	41 – 50 ⁴	> 50 ⁵
3	How many children do you have?	1 ¹	2 ²	3 ³	>3 ⁴	
4	Are you the parent or legal guardian of the CP child?			Parent ¹	Legal guardian ²	
5	Do you make use of a caretaker to look after you CP child?			Yes ¹	No ²	
6	If you answered yes to question 5 , please specify:		Nanny OR Au-pair ¹	Relative ²	Other: ³ (Please specify)	
7	Ethnicity (For statistical purposes only)	Black ¹	White ²	Coloured ³	Indian ⁴	Other: ⁵ (Specify):
8	Educational level	None ¹	Gr.1 - Gr.7 ²	Gr.8 - Gr.11 ³	Gr. 12 ⁴	Tertiary education ⁵
9	Marital status	Married ¹	Divorced ²	Widowed ³	In a relationship ⁴	Single ⁵
10	Employment status	Full time job ¹	Part-time job ²	Piece job ³	Unemployed ⁴	
11	If employed, does your job generate the only income in the household?				Yes ¹	No ²
12	If not, who else contributes to the household income?		Husband / Wife ¹	Boyfriend / Girlfriend ²	Sibling ³	Other: ⁴ (Specify): _____
13	What is your monthly income (approximately)? (Refer to <i>netto</i> income)		< R 5000 ¹		R 5000 – R 10 000 ²	R 10 001 – R 20 000 ³
			R 20 001 – R 30 000 ⁴		> R 30 000 ⁵	Grants ⁶
14	Do you have medical aid?			Yes ¹	No ²	
15	If you answered yes to question 14 , is your CP child covered under your medical aid?			Yes ¹	No ²	

Information of the spastic CP child

16	Gender	Male ¹	Female ²	17	Age (years)		_____ years ¹			
18	Born at how many weeks?		I don't know	< 30 ¹	31 – 37 ²	38- 40 ³	> 40 ⁴			
19	Were there any complications during:			Pregnancy?			Yes ¹	No ²		
Labour or delivery?				Yes ¹	No ²					
After labour or delivery?				Yes ¹	No ²					
20	Is he/she in a playgroup / crèche / school?						Yes ¹	No ²		
21	Has the child been seen by any of the following healthcare professionals since diagnosed with spastic CP? (Please tick the yes or no option)	Dietitian ¹	YES	NO	Dentist ²	YES	NO	Occupational therapist ³	YES	NO
Physio-therapist ⁴		YES	NO	Psychologist ⁵	YES	NO	Social worker ⁶	YES	NO	
Speech-therapist ⁷		YES	NO	Specialist * ⁸	YES	NO	Other: ⁹ _____			
NOTE * Types of "specialists" refers to an Ear-, Nose- & Throat, Gastrointestinal, Orthopedic, Paediatrician, or Neurologist)										

THE NUTRITIONAL INFORMATION OF SPASTIC CP CHILDREN

Section A

Please provide information on your CP child's **diet history** since birth.
(Please tick the relevant box and complete):

A1	Did you breastfeed your child since birth?	Yes ¹			No ²					
A2	If so, until what age did you breastfeed him/her?	< 6 months ¹			7 – 12 months ²					
		13 – 24 months ³			> 24 months ⁴					
A3	If not, what was the reason(s) to not breastfeed and give formula milk? (Please tick the yes or no option)	Work-related issues ¹	YES	NO	Insufficient breastmilk ²	YES	NO	Poor latching ³	YES	NO
Uncomfortable or unfamiliar with breastfeeding ⁴		YES	NO	Physical or medical problems ⁵	YES	NO	Problems with breast health ⁶	YES	NO	
Stressed or pressurized ⁷		YES	NO	Feeling of embarrassment ⁸	YES	NO	Unsupportive partner / family ⁹	YES	NO	
Concerns about pain ¹⁰		YES	NO	Other (Please specify): ¹¹ _____ _____						
A4	Were you ever advised by a healthcare professional regarding breastfeeding or formula feeding?	Yes ¹			No ²					
A5	When did you start complementary (solid) foods (age)?	< 4 months ¹			4 - 5 months ²					
		6 months ³			> 6 months ⁴					
How many meals, snacks and drinks do you prepare for your CP child per day ?										
A6	Meals	1 ¹	2 ²	3 ³	>3 ⁴					
A7	Snacks	1 ¹	2 ²	3 ³	>3 ⁴					
A8	Drinks (Drinks include water, tea, juice or milk)	1 ¹	2 ²	3 ³	>3 ⁴					

Do you give of the following food groups to your CP child? (Please mark with a clear "x")						
		1	2	3	4	5
		Always	Often	Sometimes	Seldom	Never
A9	Protein (Example: meat, lean mince meat, chicken, fish, livers, eggs, bacon)					
A10	Starch (Example: porridge, pasta, rice, potato, sweet potato, pumpkin, butternut, bread)					
A11	Fats (Example: margarine, oil, peanut-butter, avocados, nuts & seeds, olives)					
A12	Dairy (Example: Cheese, yoghurt, milk)					
A13	Fresh fruit					
A14	Fresh vegetables					
A15	Sugary treats (Example: chocolates, sweets, biscuits, cake, ice-cream)					
A16	Savoury treats (Example: microwave popcorn, biltong, crisps, rice cakes)					
A17	Sugary drinks (Example: Juice, colddrink, flavoured drinks or milk shakes)					
A18	Sugar-free drinks (Example: water, tea, sugar-free ice-tea or coldrink)					

NOTE:

"**Always**" refers to daily; "**Often**" refers to 2-3 per week; "**Sometimes**" refers to 2-3 per month; "**Seldom**" refers to < 2 per month; "**Never**" refers to never including it in the diet

Section B

Who in the household is mostly involved in:

B1	Buying groceries for the CP child?	Caretaker ¹ (Au-pair / Nanny)	Parent ² (mother / father / legal guardian)			Relative ³			Sibling ⁴		
B2	Cooking / preparing meals and snacks for your CP child?	Caretaker ¹ (Au-pair / Nanny)	Parent ² (mother / father / legal guardian)			Relative ³			Sibling ⁴		
B3	Feeding your CP child?	Caretaker ¹ (Au-pair / Nanny)	Parent ² (mother / father / legal guardian)			Relative ³			Sibling ⁴		
B4	How do you decide on what food products to buy to prepare meals or snacks for your CP child? (Please tick the yes or no option)	Availability ¹	YES	NO	Nutritional content ²	YES	NO	Price ³	YES	NO	
		Preference ⁴	YES	NO	Familiar ⁵	YES	NO	Convenience ⁶	YES	NO	
		Advice from a healthcare professional ⁷	YES	NO	Practical ⁸	YES	NO	Other: ⁹ _____			
B5	Where do you mostly buy your groceries? (Please tick the yes or no option)	Shoprite / Checkers ¹	YES	NO	Pick & Pay ²	YES	NO	Woolworths Food Market ³	YES	NO	
		Spar ⁴	YES	NO	Food Lovers Market ⁵	YES	NO	Fruit & Veg City ⁶	YES	NO	
		OK Foods ⁷	YES	NO	Game ⁸	YES	NO	Other: ⁹ _____			

Section C

C1	Are there specific feeding utensils or equipment you use to feed your CP child? (Feeding utensils refer to a special spoon / cup / fork / knife, etc.)	Yes ¹	No ²
C2	Were these utensils or equipment recommended by a healthcare professional?	Yes ¹	No ²
C3	Do these utensils or equipment make a difference at mealtimes? (For example: less spillage or mess, improves feeding time, more comfortable to feed with, etc.)	Yes ¹	No ²
C4	Does your CP child need assistance with feeding at mealtimes? (“Assistance” implies that one has to feed him/her as he/she cannot feed self)	Yes ¹	No ²

How long (in minutes) does it take to **feed** or provide your CP child with:

(Note: "A meal" refers to breakfast, lunch and supper; "A snack" refers to anything eaten or drunk between meals; "A drink" refers to water, juice, tea or milk)

C5	A meal?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴					
C6	A snack?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴					
C7	A drink?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴					
C8	With regards to the previous question, how much time do you spend (approximately) per day in feeding or providing fluids to your CP child?			< 2 hours ¹	2-3 hours ²					
				> 3 hours ³						
C9	What are the reason(s) for an increased feeding duration when providing meals, snacks or drinks? (Please tick the yes or no option)	Positioning difficulties ¹	YES	NO	Feeding difficulties ²	YES	NO	Environmental difficulties ³	YES	NO
		Disruptive mealtime behaviour ⁴	YES	NO	Food refusal ⁵	YES	NO	Other: ⁶ _____ _____		
Please Note: "Feeding difficulties" refers to poor chewing, sucking, or swallowing such as dysphagia etc. that can lead vomiting or reflux; Inappropriate use of utensils, etc. "Positioning difficulties" refers to poor head control or posture when holding the toddler during mealtimes / poor muscle tone when placed in a feeding chair, etc. "Environmental difficulties" refers to an inappropriate feeding chair, noisy environment, limited space, etc. "Disruptive mealtime behaviour" refers to prolonged crying, uncontrollable jerking movements, etc. "Food refusal" refers to picky eating, food aversions, having poor appetite, etc.										

How much time (in minutes) do you spend on preparing & cooking the following:											
C10	A meal?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴						
C11	A snack?	< 30 min ¹	30-60 min ²	61-90 min ³	> 90 min ⁴						
C12	What equipment do you make use of when preparing meals & snacks for your CP child? <i>(Please tick the yes or no option)</i>	Food blender / liquidizer ¹	YES	NO	Grater ²	YES	NO	Slicer / Dicer ³	YES	NO	
		Masher ⁴	YES	NO	Other: ⁵ _____						
C13	What cooking methods do you mainly make use of? <i>(Please tick the yes or no option)</i>	Boil ¹	YES	NO	Steam ²	YES	NO	Roast ³	YES	NO	
		Deep fry ⁴	YES	NO	Pan fry ⁵	YES	NO	Bake ⁶	YES	NO	
		Poach ⁷	YES	NO							
C14	Do you follow any recipes when preparing meals or snacks?				Yes ¹		No ²				
C15	What type of food consistency does your CP child tolerate best?	Liquid ¹		Pureed ²		Lumpy ³					
		Solids ⁴		Other: ⁵ _____							
C16	Were these food consistencies recommended by a speech therapist?				Yes ¹		No ²				
C17	Do you need to thicken meals or snacks to improve feeding tolerance? (‘Feeding tolerance’ refers to improved chewing & swallowing; prevent vomiting, reflux or bloating, etc.)				Yes ¹		No ²				
C18	If yes, what type of thickeners do you use? <i>(Please tick the yes or no option)</i>	Thick & Easy ¹	YES	NO	Nestargel ²	YES	NO	Oats ³	YES	NO	
		Mashed potato or sweet potato ⁴	YES	NO	Maizena ⁵	YES	NO	Cake flour ⁶	YES	NO	
		Honey or syrup ⁷	YES	NO	Other: ⁸ _____						
C19	If yes, were these thickeners recommended by a healthcare professional ?				Yes ¹		No ²				

Does your CP child finish his / her: (Please mark with a clear 'x')											
		1 Always	2 Often	3 Sometimes	4 Seldom	5 Never					
C20	Meals?										
C21	Snacks?										
C22	Drinks?										
		NOTE: "Always" refers to daily; "Often" refers to 2-3 per week; "Sometimes" refers to 2-3 per month; "Seldom" refers to < 2 per month; "Never" refers to never including it in the diet									
C23	If your CP child does not finish a meal or snack, how much does he / she consume mostly?			$\frac{3}{4}$ ¹		$\frac{1}{2}$ ²		$\frac{1}{4}$ ³			
C24	How do you determine when your CP child is hungry or thirsty ? <i>(Please tick the yes or no option)</i>	He / she tells you ¹	YES	NO	Points at food or a drink ²	YES	NO	Makes a specific noise ³	YES	NO	
		Cries / signals ⁴	YES	NO	I don't know						
C25	How do you determine whether your CP child has reached satiety after a meal or snack? <i>(Please tick the yes or no option)</i>	He / she tells you ¹	YES	NO	Locks lips together ²	YES	NO	Pulls your hand away ³	YES	NO	
		Turns head away ⁴	YES	NO	Makes a specific noise ⁵	YES	NO	I don't know			

Section D NUTRITION-RELATED PROBLEMS – ADDRESS & MANAGEMENT

Does your CP child struggle with the following **nutrition-related problems**?

D1	Allergies / Intolerance	Yes ¹	No ²	D9	Anaemia [#]	Yes ¹	No ²
D2	Aspiration ^{\$}	Yes ¹	No ²	D10	Constipation	Yes ¹	No ²
D3	Diarrhoea	Yes ¹	No ²	D11	Flatulence	Yes ¹	No ²
D4	Dysphagia [@]	Yes ¹	No ²	D12	Growth retardation	Yes ¹	No ²
D5	Insufficient food intake [*]	Yes ¹	No ²	D13	Irritable bowel syndrome	Yes ¹	No ²
D6	Overweight / Obesity	Yes ¹	No ²	D14	Peptic or oral ulcers [^]	Yes ¹	No ²
D7	Poor appetite	Yes ¹	No ²	D15	Underweight / Loss of weight	Yes ¹	No ²
D8	Vitamin or mineral deficiency	Yes ¹	No ²	D16	Vomiting / Reflux	Yes ¹	No ²

^{\$} **Aspiration**: When one swallows or breathes in food particles or fluid by accident into the lungs
[@] **Dysphagia**: Difficult, painful or uncomfortable when swallowing
^{*} **Insufficient food intake**: * This may be due to sucking, chewing or swallowing problems; Dental carries; Excessive drooling, etc.
[#] **Anaemia**: A condition where there is a low amount of red blood cells or haemoglobin in the blood
[^] **Peptic or oral ulcers**: Sores or blisters found in the mouth, esophagus or stomach lining

Please specify the **type**, **if** and **where** applicable:

D17	<i>Allergies / intolerance</i>	Egg ¹		Milk ²		Gluten ³	
		Peanut ⁴		Soya ⁵		Wheat ⁶	I don't know ⁶
D18	<i>Anaemia</i>	Vitamin B12 ¹		Folate ²		Iron ³	I don't know ⁴
D19	<i>Mineral deficiency</i>	Calcium ¹	Iron ²	Magnesium ³	Zinc ⁴	I don't know ⁵	
D20	<i>Vitamin deficiency</i>	Vitamin A ¹	Vitamin C ²	Vitamin D ³	Vitamin E ⁴	I don't know ⁵	
D21	Have you been given advice or recommendations on how to treat any nutrition-related problems?					Yes ¹	No ²
D22	Did these recommendations or advice assist you in treating or managing these problems effectively ?					Yes ¹	No ²
D23	Would you like to receive nutrition-related recommendations or advice from a registered dietitian ?					Yes ¹	No ²

D24	How have you been managing or treating nutrition-related problems? (Please tick the yes or no option)	Followed advice from a friend / relative ¹	YES	NO	Consulted a healthcare professional ²	YES	NO
		Sought advice on the internet or social media ³	YES	NO	Joined a support group for advice ⁴	YES	NO
		Followed advice from a book or magazine ⁵	YES	NO	Other: ⁶ _____ _____		

Section E

How do you feel about the following **feeding practices** with regards to your CP child in the following scenarios? Please complete the following table (Mark the relevant option using 'x'):

		1 Lacking confidence	2 Anxious	3 Satisfied	4 Content	5 Very confident
E1	Choosing food products					
E2	Buying groceries					
E3	Decision-making on what meals or snacks to prepare					
E4	Preparing / cooking meals & snacks					
E5	Prior to feeding					
E6	During feeding					
E7	After feeding					
E8	Dealing with nutrition-related problems					
E9	Growth & development					
E10	Overall health					

Section F					
F1	In your opinion, what would YOU like to gain from THIS study?	Practical nutrition advice ¹	Feedback on where to improve ²	Guidance & support ³	
		For others to understand your life experiences and concerns ⁴	Give recommendations ⁵		
		Other: ⁶ _____			
F2	May the researcher contact you if additional information is needed from this questionnaire?	Yes	No		
If yes, please provide a contact number : _____					

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE! ☺

ANNEXURE F - Letters of approval to the various authorities / facilities



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Researcher's Contact Details

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To identify nutrition-related concerns and management practises of children suffering from spastic cerebral palsy

CONSENT TO ASSIST IN RESEARCH PROJECT BY IDENTIFYING PARTICIPANTS

We are a team of researchers from the Nutrition department of the North-West University undertaking a study to determine what the concerns and current management of dietary related problems are that the primary caregiver (parents or legal guardians) may encounter with spastic CP children and we would like to invite you to assist us by identifying possible and suitable participants for our study. To follow is information about the study to understand and give clarity about our study population.

1. PURPOSE OF THE STUDY

The aim of this study is to **explore and understand** the concerns and management of nutrition-related problems that the primary caregiver encounter with children affected by spastic CP between one to ten years of age, by means of a validated nutritional questionnaire.

1.1 Objectives

In order to achieve the aim, the following specific objectives need to be obtained by means of the validated nutritional questionnaire:

- 1) To identify the common nutritional concerns and problem areas of children suffering from spastic CP who are able to eat orally.
- 2) To gather useful information regarding the management and current feeding practises of specific dietary related problems that spastic CP children may encounter, from the primary caregivers.

2. STUDY SETTING, POPULATION, SAMPLE SIZE, RECRUITMENT & METHODS

2.1 Study setting:

The study will be conducted at the Pretoria Centre for Cerebral Palsy (PCCP) situated in Groenkloof Life hospital, the Baby Therapy Centre (BTC), and New Hope School (NHS), all situated in Pretoria, Gauteng Province.

All areas where prospective participants will be seen by the healthcare professional (HCP) are chosen specifically to be isolated from the waiting area (at PCCP and BTC) and classrooms (at NHS) to ensure confidentiality and privacy of information shared and discussed. These locations were also specifically chosen at these facilities for them to feel most comfortable and familiar with surroundings that are easily accessible. These locations are spacious, safe, and a quiet environment where the least distractions or factors can influence the quality of sessions between the HCP and prospective participants, such as noise, echo, and sounds within the room or outside. All of these locations are equipped with a table and chairs for both the HCP and primary caregiver to make use of.

2.2 Study population and sample size

The study population will consist of parents (preferable mothers) or legal guardians, which are the primary caregivers, of spastic CP children that best meet the inclusion- and exclusion criteria for the study. They have been specifically chosen to participate because they, as primary caregiver of a spastic CP child, best know and understand their child and can therefore share thoughts and experiences regarding nutrition-related concerns or problems that they have encountered, and how these problems have been managed or treated.

As there is only a small amount of spastic CP children between the ages of one and ten years old that are able to eat orally at these facilities, all parents or legal guardians (primary care givers) will be considered as prospective participants that comply with the criteria of the study after being assessed by the HCP by means of a screening tool. They will then be given the opportunity to decide whether to partake in the study or not. The sample size therefore varies according to the maximum number of participants that are willing to complete the nutritional questionnaire within the period of recruitment (one month). The researcher will aim to recruit a minimum of **30 participants**.

Inclusion criteria:

Participants must be:

- ✓ Able to write, read and understand Afrikaans or English;
- ✓ The primary caregiver of the spastic CP child: a parent (preferably the mother) or legal guardian;
- ✓ Willing to give consent to share thoughts and experiences on specific topics concerning nutrition and nutrition-related problems regarding their spastic CP child;
- ✓ Involved in most of the CP child's daily feeding routine which includes purchasing of food products, preparing meals and snacks, and feeding the child at mealtimes.

Exclusion criteria:

- ✗ Primary caregivers of spastic CP children that make use of a feeding device (such as a gastrostomy – or jejunostomy tube) and are **not** able to eat orally;
- ✗ Primary caregivers of spastic CP children younger than one or older than ten years old.

2.3 Recruitment of participants

We have identified **your** facility / centre to assist in obtaining potential participants (the primary caregiver) within the centre for this study. Recruitment will take place over a period of **three months** simultaneously at the various facilities to still give enough time for data collection and processing.

All participants will be identified by a HCP (dietitian, physiotherapist or speech therapist) working at the centre or facility according to the inclusion- and exclusion criteria for the primary caregiver and CP children, for the study.

Prospective participants will be identified and screened for this study by means of a **screening tool**. They will be seen by the allocated HCP doing the recruitment for the study in confidentiality and in a private area. In this session, the HCP will complete the screening tool in his/her presence. They are expected to **sign the screening tool** form after completion to acknowledge that the screening tool was completed in private and that all information shared or gathered from the primary caregiver will remain confidential at any point in time.

The HCP will make use of the following **screening tool** to assist in recruiting participants for this study.

Table 1: Screening tool to be used for recruitment by a healthcare professional

Research Topic	Inclusion Criteria	YES	NO
Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy	Can you read, write & speak Afrikaans or English ?		
	Is your child diagnosed with spastic CP ?		
	Is your CP child able to eat orally ?		
	Is your CP child between the ages of 1-10 years old?		
	Are you the parent (preferably the mother) or legal guardian of the CP child?		
	Are you mostly involved in the CP child's daily feeding routine ?		

*If the prospective participant answers **YES to ALL** of the questions = May **INCLUDE** in the study!*

If the primary caregiver qualifies to become part of the study according to the screening tool and are interested in participating in the study, the HCP will then supply the primary caregiver with an **informed consent form** that gives an extensive description and detail of the study and will also include all ethical aspects regarding the study. The HCP should please explain this consent form to the prospective participant. The primary caregiver will be given an opportunity to thoroughly read through the consent form prior to deciding as to whether the primary caregiver is amenable to partake in the study. They should complete and sign this form if all information is clear to them. The completed and signed consent form should be returned to the HCP **within one week**. In the event that there are any uncertainties, the researcher whose contact details are given on the consent form, can be contacted directly.

Should the primary caregiver be willing to partake in the study as aforesaid, and signed the consent form as requested, the primary caregiver will be provided with the nutritional questionnaire for completion. They will have **one week** to fully complete the nutritional questionnaire and return it to the HCP at the specific facility. The researcher will gather all the consent form documents and completed nutritional questionnaires from all the HCPs at the various facilities or centres as soon as they are handed in.

If they are unable to return the completed informed consent document or nutritional questionnaire within the specific period, they can arrange with the researcher, Lucinda Lourens, to collect it at a location suitable for them.

2.4 Methods: Nutritional questionnaire

The information will be gathered from validated nutritional questionnaire that will be completed by participants *after* giving informed consent, as previously mentioned.

2.4.1 Validated nutritional questionnaire

The nutritional questionnaire will mainly consist of focused nutrition-related questions and will be compiled in Afrikaans and English. It will be used to gather quantitative data for this study.

The following table provides the outline on what the questionnaire assessed.

Table 2: The outline of the nutritional questionnaire

Demographics	1. Participant *: Background, personal details, age, gender, ethnicity, education level, marital status, employment status, approximate income, medical aid 2. Spastic CP child: Gender, DOB, birth history, diagnosis and cause of CP, social information, healthcare professionals dealt with
Nutritional information **	Diet history from birth (BF or FF); complimentary foods; meals, snacks and drinks;
Household logistics *	Purchasing of food products; cooking meals and snacks
Mealtimes **	Feeding time; utensils and equipment; food consistency
Management of nutrition-related problems **	Nutrition-related problems such as: allergies, diarrhoea, constipation, loss of weight, vomiting / reflux, loss of appetite; Other nutrition-related concerns. Advice and recommendations on treating nutrition-related problems
Perceptions and experiences*	Feelings with regards to feeding practices in the following scenarios: - Choosing & buying food products - Preparing & cooking meals & snacks - Mealtimes (prior, during & after feeding) - Dealing with nutrition-related problems - Growth & development of spastic CP child - Overall health

* With regards to the *primary caregiver* such as the parent or legal guardian (the participant)

** With regards to the *spastic CP child*

BF: Breastfeeding; **CP:** Cerebral Palsy; **DOB:** Date of birth; **FF:** Formula feeding

The nutritional questionnaire will be given *after* the consent form has been signed and returned to the HCP at the facility and centre where the participant has been identified. It needs to be completed and returned **within a week** to the healthcare professional. Participants will need to contact the researcher if any section of the nutritional questionnaire is unclear.

3. EXPECTED OUTCOMES OF RESEARCH

After completing this study, we would like to obtain the following outcomes:

- To be able to identify nutrition-related concerns or problems that the primary caregiver encounter with their spastic CP child and how these are managed;
- To explore how meals, snacks and drinks are purchased and prepared;
- To assess mealtimes of the spastic CP child;
- To understand how the primary caregiver feels towards the feeding practices of spastic CP children.

4. POSSIBLE CONCERNS

From these nutritional questionnaires, it will be required of participants to share their experiences, concerns and current management practises regarding their spastic CP child. As this may be a sensitive subject participants might feel anxious, uncomfortable or distressed to openly express and share information about their CP child. The nutritional questionnaire also includes some questions regarding personal details and if participants wish to not answer specific questions, they are not compelled to do so. To put them at ease, there will be a psychologist on stand-by to assist if needed. Personal details will be kept confidential and only the team of researchers will work with the information that they have shared.

5. BENEFITS OF THIS STUDY

The information shared within these nutritional questionnaires will be very helpful and valuable to the research team as we will use this information to better understand the need for nutritional guidelines to address their concerns and improve current management practices.

Valuable input from the nutritional questionnaire will assist in developing a nutritional guideline booklet in future to support, advice and empower the primary caregiver of spastic CP children.

6. COSTS

There will be no costs required to participate in this study.

7. PAYMENT

Participants will receive no payment for their participation. They will however receive a card from the research team with great gratitude thanking them for their participation in this study after completion.

8. QUESTIONS

You and the participants are welcome to ask any questions to a member of the research team before deciding to give consent. You are also welcome to contact Mrs. Lucinda Lourens, the master student, if you have any further questions concerning the research study or the consent form at 084 078 1406.

9. FEEDBACK OF FINDINGS

You are welcome to contact us regarding the findings of the research. We will be sharing the findings with you as soon as it is available and upon request and whether the participants give us informed consent to do so.

Yours Sincerely,

Lucinda Lourens

RD (SA) B.Sc Dietetics (NWU-Potchefstroom)



NORTH-WEST UNIVERSITY
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South Africa 2520

Tel: (018) 299-1111/2222
Web: <http://www.nwu.ac.za>

Nutrition Department

Tel: (018) 299 4037
Fax: (018) 299 2464
Email: Robin: robin.dolman@nwu.ac.za

Researcher's Contact Details

Cell: 084 078 1406
Email: lcdacamara@gmail.com

CONSENT FORM

PARTICIPATION IN THIS RESEARCH STUDY

Should your facility or centre be willing to assist us in this study, you are requested to sign below:

_____ (facility / centre) hereby voluntarily give consent to assist in identifying and recruiting possible participants to participate in the above mentioned study. Personal details will not be disclosed to anybody who is not part of the study and that the information will be kept confidential.

Date

Signature of person obtaining consent
(Representing Facility or Centre)

ANNEXURE G – Ethical approval from the North-West University Ethics Committee



NORTH-WEST UNIVERSITY
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NOORDWES-UNIVERSITEIT
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Private Bag X6001, Potchefstroom
South Africa 2520

Tel: 018 299-1111/2222
Web: <http://www.nwu.ac.za>

Ethics Office
Tel: 018-299 2092
Fax: 018-299 2088
Email: Minrie.Greeff@nwu.ac.za

9 December 2015

Dr RC Dolman
Nutrition

Dear Dr Dolman

HREC APPROVAL OF YOUR APPLICATION

Ethics number: NWU-00040-15-S1

Kindly use the ethics reference number provided above in all correspondence or documents submitted to the Health Research Ethics Committee (HREC) secretariat.

Project title: Nutrition-related concerns of the primary caregiver regarding children with spastic cerebral palsy

Project leader/supervisor: Dr RC Dolman

Student: L Lourens

Application type: Full Single

Risk level descriptor: Medium

You are kindly informed that at the meeting held on 11/03/2015 of the HREC, Faculty of Health Sciences, the aforementioned was approved.

The period of approval for this project is from 09/12/2015 to 08/12/2016.

After ethical review:

Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HREC (if applicable).

The HREC requires immediate reporting of any aspects that warrants a change of ethical approval. Any amendments, extensions or other modifications to the protocol or other associated documentation must be submitted to the HREC prior to implementing these changes. Any adverse/unexpected/unforeseen events or incidents must be reported on either an adverse event report form or incident report form.

A progress report should be submitted within one year of approval of this study and before the year has expired, to ensure timely renewal of the study. A final report must be provided at completion of the study or the HREC must be notified if the study is temporarily suspended or terminated. The progress report template is obtainable from Carolien van Zyl at

Carolien.VanZyl@nwu.ac.za. Annually a number of projects may be randomly selected for an external audit.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.

Please note that for any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

The HREC complies with the South African National Health Act 61 (2003), the regulations on Research with Human Participants of 2014 of the Department of Health and Principles, the Declaration of Helsinki, 2013, the Belmont Report and the Ethics in Health Research: Principles, Structures and Processes (SANS document).

We wish you the best as you conduct your research. If you have any questions or need further assistance, please contact the Ethics Office at Carolien.VanZyl@nwu.ac.za or 018 299 1206.

Yours sincerely



Prof Minnie Greeff
HREC Chairperson

Current details: (13210572) C:\Users\13210572\Documents\HREC\HREC - Applications\2015 Applications\Applications 02 - 11 March 2019\NWU-00040-15-S1 (RC Dolmen-L. Lourens)\NWU-00040-15-S1 (RC Dolmen-L. Lourens) - AL\NWU-00040-15-S1 (RC Dolmen-L. Lourens) - AL.docx
25 January 2018

File reference: 9.1.5.3

ANNEXURE H – Approval letter from the Baby Therapy Centre



NORTH-WEST UNIVERSITY
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Private Bag X6001, Potchefstroom
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Tel: (018) 299-1111/2222

Web: <http://www.nwu.ac.za>

Nutrition Department

Tel: (018) 299 4037

Fax: (018) 299 2464

Email: Robin: robin.dolman@nwu.ac.za

Averalda: averalda.vangraan@nwu.ac.za

Researcher's Contact Details

Cell: 084 078 1406

Email: lodacamara@gmail.com

CONSENT FORM

PARTICIPATION IN THIS RESEARCH STUDY

Should your facility or centre be willing to assist us in recruiting participants for the focus group discussion sessions, you are requested to sign below:

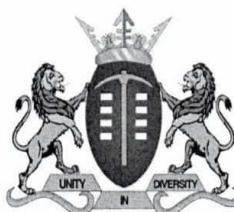
BABY THERAPY CENTRE (facility / centre) hereby voluntarily give consent to assist in identifying and recruiting possible participants to participate in the above mentioned study. Personal details will not be disclosed to anybody who is not part of the study and that the information will be kept confidential.

09. 07. 2014
Date

Signature of person obtaining consent

(Representing Facility or Centre)

ANNEXURE I – Approval letter from Gauteng Department of Education



GAUTENG PROVINCE

EDUCATION
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no. D2016 / 218 A
Enquiries: Diane Bunting 011 843 6503

GDE AMENDED RESEARCH APPROVAL LETTER

Date:	14 September 2015
Validity of Research Approval:	8 February 2016 to 30 September 2016
Previous GDE Research Approval letter reference number	D2015 / 398 dated 4 February 2015
Name of Researcher:	Lourens L.C.
Address of Researcher:	230 Julius Jeppe Street; Waterkloof; Pretoria; 0181
Telephone / Fax Number/s:	084 028 1406
Email address:	lcdacamora@gmail.com
Research Topic:	Nutrition- related concerns of the primary caregiver regarding children with spastic Cerebral Palsy
Number and type of schools:	ONE Primary School
District/s/HO	Tshwane South

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved. A separate copy of this letter must be presented to the Principal, SGB and the relevant District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted. However participation is VOLUNTARY.

The following conditions apply to GDE research. The researcher has agreed to and may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

CONDITIONS FOR CONDUCTING RESEARCH IN GDE

1. The District/Head Office Senior Manager/s concerned, the Principal/s and the chairperson/s of the School Governing Body (SGB.) must be presented with a copy of this letter.

1

Making education a societal priority

Office of the Director: Knowledge Management and Research

9th Floor, 111 Commissioner Street, Johannesburg, 2001

ANNEXURE J – Approval letter from New Hope School

77

 NORTH-WEST UNIVERSITY
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Private Bag X6001, Potchefstroom
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Tel: (018) 259-1111/2222
Web: www.nwu.ac.za

Nutrition Department
Tel: (018) 259-4037
Fax: (018) 259-2404
Email: Robin.Gorman@nwu.ac.za

Researcher's Contact Details
Lucinda Lourens
Cell: 084 079 1426
Email: lourensl@pruul.com

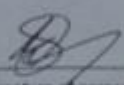
CONSENT FORM

PARTICIPATION IN THIS RESEARCH STUDY

Should your facility or centre be willing to assist us in recruiting participants for the focus group discussion sessions, you are requested to sign below:

New Hope School (facility / centre) hereby voluntarily give consent to assist in identifying and recruiting possible participants to participate in the above mentioned study. Personal details will not be disclosed to anybody who is not part of the study and that the information will be kept confidential.

2015-02-19
Date


Signature of person obtaining consent
(Representing Facility or Centre)

ANNEXURE K – Approval letter from the Pretoria Centre for Cerebral Palsy



NORTH-WEST UNIVERSITY
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Private Bag X6001, Potchefstroom
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Tel: (018) 299-1111/2222

Web: <http://www.nwu.ac.za>

Nutrition Department

Tel: (018) 299 4037

Fax: (018) 299 2464

Email: Robin: robin.dolman@nwu.ac.za

Researcher's Contact Details

Cell: 084 078 1406

Email: lcdacamara@gmail.com

INFORMED CONSENT FORM

PARTICIPATION IN THIS RESEARCH STUDY

Should your facility or centre be willing to assist us in this study, you are requested to sign below:

Pretoria Centre for Cerebral Palsy (facility / Centre) hereby voluntarily give informed consent to assist in identifying and recruiting possible participants to participate in the above mentioned study. Personal details will not be disclosed to anybody who is not part of the study and that the information will be kept confidential.

2014/02/04
Date

[Signature]
Signature of person obtaining consent
(Representing Facility or Centre)