

**UNIVERSITY OF THE WESTERN CAPE**  
**FACULTY OF COMMUNITY AND HEALTH SCIENCES**

**MINI-THESIS**

**RISK FACTORS FOR SEVERE MALNUTRITION IN CHILDREN WITH  
CEREBRAL PALSY IN LUSAKA, ZAMBIA**

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University of the Western Cape.**

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**Date: November, 2017**

**DECLARATION**

I declare that “**Risk factors for severe malnutrition in children with cerebral palsy in Lusaka, Zambia**” is my own work that it has not been submitted before to any institution, either by myself or any other person for any degree or examination. I further declare that all sources that I have used or quoted have been acknowledged by complete references.

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### Abstract

Over 80% of children with Cerebral Palsy (CP) present with feeding difficulties which consequently result in about 40-50% of them being malnourished. Many children with CP in low resource countries like Zambia, present with severe malnutrition and the extent of this problem remains unknown. The aim of this study was to identify the main risk factors associated with severe malnutrition in children with CP.

**Methodology:** A quantitative case control design was used. The study was carried out at the University Teaching Hospital (UTH) in Lusaka, Zambia, between June 2016 to May 2017. All children with CP accessing health care services at UTH in Lusaka were eligible for inclusion in the study. Controls were children with CP presenting with weight-for-age (WAZ) z-scores of  $\geq -2SD$ . Cases were children with CP presenting with clinical signs of severe malnutrition or with WAZ z scores of  $\leq -3 SD$  of the WHO growth standards. Two data capturing tools were used namely a Child data collection tool and Caregiver data collection tool. Data was collected through structured face to

face interviews with caregivers, physical examination of the child, anthropometric measurements and medical records. Data was analysed using epi Info version 7.2. Variables were described using frequency tables and graphs while chi-square tests and simple logistic regression were used for bivariate analysis. Multiple logistic regression was used to calculate adjusted odds ratios for associations between the dependent variable and various independent variables. A p-value of  $< 0.05$  was considered significant at 95% confidence interval.

**Results:** After placing significant variables in multiple logistic regression models according to different categories, the following were factors that were significantly associated with severe malnutrition (p-value  $< 0.05$ ): use a unflushed pit latrine toilet (p=0.0119); spastic quadriplegia or bilateral CP (p=0.0054); GMFCS level 4 or 5 (p=0.0001); history of illness in the past six months (p=0.0241); swallowing difficulties (p=0.0006); tonic bite (p= 0.0011); child not gained weight in the past 2 to 3 months (p=0.0001); dependent on feeding (p=0.0061); child only able to feed on semi-solids or liquids (p=0.0231); child feeding for more than 30 minutes (p=0.0381); child opening bowels after 3 or more days (0.0057); caregiver concerned about child's feeding difficulties (p=0.0076); not likely to be fed Irish potatoes (p=0.0008) and Fish (p=0.0001).

**Conclusion:** The risk factors identified in the current study are related to the child's severity and feeding difficulties as well as caregiver caring practices. The risk factors are also consistent with the UNICEF conceptual framework for malnutrition. Among the recommended measures to address these risk factors include introduction of low cost caregiver training programs, provision of High Energy Protein Supplements and introduction of gastrostomy tube feeding for children with severe feeding difficulties.

**Key words:** Cerebral palsy, severe childhood Malnutrition, Anthropometry, Oral Motor Dysfunction, Feeding Difficulties, socioeconomic factors, Zambia.



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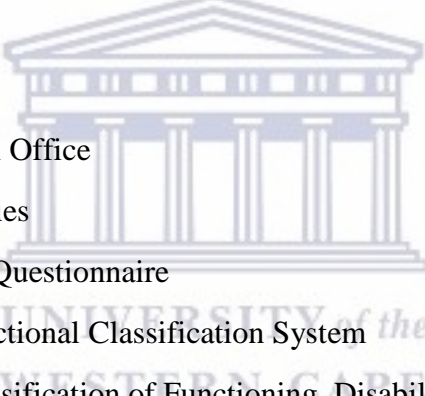
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## **ABBREVIATIONS**



BMI	Body Mass Index
CP	Cerebral Palsy
CSO	Central Statistical Office
FDs	Feeding Difficulties
FFQ	Food Frequency Questionnaire
GMFCS	Gross Motor Functional Classification System
ICF	International Classification of Functioning, Disability and Health
MOH	Ministry of Health
OMD	Oral Motor Dysfunction
SAM	Severe Acute Malnutrition
SCM	Severe Chronic Malnutrition
SCPE	Surveillance of Cerebral Palsy in Europe
SD	Standard Deviation
UTH	University Teaching Hospital
WAZ	Weight-for-Age Z-score
WHZ	Weight-for-Height Z-score

## DEFINITION OF TERMS

**Anthropometry:** Anthropometry is the branch of human sciences that deals with body measurements such as body size, shape, strength and working capacity (Pheasant & Haslegrave, 2005). It is a tool that is used for assessing nutritional status in individuals and communities (Duggan, 2010).

**Caregiver:** Caregivers are people who take care of the affected (sick or disabled) individuals in terms of help with basic daily skills (Narekuli, Raja & Kumaran, 2011). For children, a caregiver is usually the mother of the child, elderly member or any unemployed member of the family (Mbugua et al., 2011).

**Cerebral palsy:** Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain (Rosenbaum et al., 2007).

**Dyskinetic:** Type of cerebral palsy with extra pyramidal involvement characterised by rigidity, choreo athetosis and dystonic movements (Sankar & Mundkur, 2005).

**Dysphagia:** Impairment in one of the phases of swallowing process at the oral, pharyngeal or oesophageal phases (Penagini et al., 2015). It can be caused by oral-motor dysfunction, anatomical anomalies such as cleft palate, oral sensory impairments and oesophageal motility disorders (Calis et al., 2008).

**Feeding difficulties:** These are common in CP children and include difficulties with self-feeding, chewing, swallowing, food refusal, lack of initiation to take food, problems with biting and sucking, drooling, food/fluid loss during feeding and sequencing and rhythmicity difficulties (Aggarwal et al., 2015).

**Feeding practices:** For children, feeding practices are dependent on parents and includes parents practices on foods and portion sizes that children are offered, frequency of eating occasions and social context in which eating occurs (Birch, 2006).

**Gastroesophageal reflux:** Common in about 75% of children with neurological impairments and characterised by frequent regurgitation and vomiting. This may be due to oesophageal dysmotility,

hiatus hernia, prolonged supine lying, increased spasticity, scoliosis and seizures (Penagini et al., 2015).

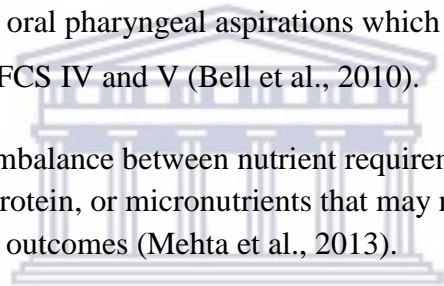
**Gastrostomy:** This is one of the methods used to feed patients with swallowing disabilities and it involves surgical insertion of the tube or the use of a feeding tube into the stomach via an endoscope (Percutaneous endoscopic gastrostomy) (Park, Rhie & Jeong, 2011)).

**Kernicterus:** A pathological term that describes the neuropathology of bilirubin induced brain injury, characterised by yellow staining of the deep nuclei of the infant's brain (Shapiro, 2005).

**Malnutrition:** Refers to deficiency or excess in macronutrient and micronutrient leading to adverse effects on the tissue and body form, function and clinical outcome (Joosten & Hulst, 2008).

**Oral motor dysfunction:** These are problems related to swallowing, poor saliva control, drooling, difficulty sucking, chewing and oral pharyngeal aspirations which are common in children with cerebral palsy classified as GMFCS IV and V (Bell et al., 2010).

**Undernutrition:** Refers to an imbalance between nutrient requirements and intake, resulting in cumulative deficits of energy, protein, or micronutrients that may negatively affect growth, development and other relevant outcomes (Mehta et al., 2013).



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# CHAPTER 1

## 1.1 Introduction

Cerebral palsy (CP) is one of the most common causes of childhood disability globally with an estimated prevalence of approximately 2 per 1000 live births globally and between 2 to 10 per 1000 live births in Southern Africa (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014). The prevalence of CP in Africa could be higher due to high levels of perinatal complications such as birth asphyxia and neonatal infections as well as the late presentation of symptoms and lack of early intervention services in poor resource countries (Donald et al., 2014).

## 1.2 Background

Children with CP present with disorders of the development of movement and posture and these are usually accompanied by disturbances of sensation, perception, cognition, communication and behaviour, as well as epilepsy, and secondary musculoskeletal problems (Rosenbaum et al., 2007). The life expectancy of children with disabilities such as CP has increased due to improved and advanced health care services. This increased survival of children with disabilities means that there is increased demand on the health care services to deal with the consequences and therefore there is need to understand the problems faced by these children in order to plan for effective interventions. Furthermore, children with disabilities have the same rights as non-disabled children to basic needs such as adequate food, clothing and housing (United Nations, 2007).

Among the many problems faced by children with CP are oral motor dysfunctions which result in feeding difficulties (FD), speech delay, drooling, risk of aspiration, prolonged feeding times, gastroesophageal reflux and vomiting after feeds (FDs) (Aggarwal et al., 2015; Santoro, et al., 2012). Feeding difficulties have been identified as one of the main factors contributing to under nutrition among children with CP (Dahleseng et al., 2012). According to Benfer and colleagues (2013), the prevalence of children with CP having FDs is 85%. Overall consequences of feeding problems in children with CP include growth retardation, under nutrition (Dahleseng et al., 2012) and stressful mealtimes for parents or caregivers (Diwan & Diwan, 2013). The high prevalence of malnutrition in children with CP is reported to be associated with the severity (Agarwal et al., 2015).

### **1.2.1 Childhood under-nutrition and disability**

Under-nutrition, which is a form of malnutrition, is said to be a major public health concern as it contributes to more than a third of under-five deaths globally (UNICEF, 2012). Childhood malnutrition, a consequence of poverty, is more prevalent in low-income countries where estimates showed that about 32% of children under the age of five years were stunted according to the WHO Child Growth Standards (Black et al., 2013). Despite the high prevalence of childhood malnutrition in the general population of these countries, children with disabilities have higher risks of developing malnutrition depending on the type of disability (UNICEF, 2012).

Literature shows that malnutrition and disability are often interlinked and countries that report high levels of malnutrition often report high levels of disability (Groce et al., 2014). It is estimated that about 80% of the disabled population live in poor resource settings, with the majority being in Africa (Kerac et al., 2014).

Severe acute malnutrition continues to be a problem in Sub Saharan Africa and countries like Zambia are not an exception. The prevalence of severe childhood malnutrition in the general population in Zambia is reported to be about 5% while underweight and stunting are at about 16% and 45% respectively (Zambia Central Statistics Office, 2007). These estimates place Zambia among the countries with the highest levels of childhood stunting in the United Nations (UN) sub-regions (Black et al., 2013). The factors associated with malnutrition can be explained using the UNICEF conceptual framework for childhood malnutrition (UNICEF, 1998). Using this framework, the causes of childhood malnutrition are at three levels, namely the immediate, underlying and basic determinants (UNICEF, 1998).

### **1.2.2 Malnutrition in children with cerebral palsy**

The prevalence of malnutrition among children with CP is estimated to be between 46 to 90% (Soylu et al., 2008). Findings from a systematic review of growth patterns and nutritional status of children with CP reported that under nutrition was more prevalent in developing countries while in developed countries it was reported that there was a high prevalence of overweight and obesity among children with CP (Aggarwal et al., 2015). This finding shows that besides oral motor dysfunction, there are other environmental factors that increase the risk of malnutrition in children with CP.

In developed countries, caring for children with feeding difficulties involves a range of expertise as well as use of high technology medical procedures such as gastrostomy with subsequent

improvements in general health for the child and caregiver (Snider et al., 2011; Sullivan, 2013). Contrary to this, the burden of caring for children with disabilities in developing countries falls on the family (Aggarwal et al., 2015). This is done under difficult socioeconomic conditions such as poverty and lack of access to health care and assistive equipment (Geere et al., 2013). Wilmshurst and colleagues (2011) also noted that child neurology services in African countries are characterised by lack of access to neurological services and lack of resources such as specialised facilities and skilled personnel to give specialist care to children with neurological disabilities.

Zambia, like many other developing countries has limited or no information on children with disabilities and this makes it difficult to plan for intervention for these children (Gladstone, 2010). However, the high poverty levels and prevalence of childhood malnutrition in Zambia coupled with limited neurological services, as stated by Wilmshurst and colleagues (2011), are an indication that the prevalence of CP and malnutrition among disabled children are expected to be high.

Identifying risk factors for malnutrition in children with CP in a low income country will help highlight the magnitude of malnutrition in children with CP so that country planning for children in the general population can also consider children with CP. Addressing the feeding problems in children with CP can be beneficial to both the children and their caregivers.

### **1.2.3 Definition, assessment and classification of malnutrition**

Malnutrition refers to deficiency or excess in macronutrients and/or micronutrients leading to adverse effects on the tissue and body form, function and clinical outcome (Joosten & Hulst, 2008). In this study, malnutrition refers to deficiency in macronutrients such as energy and proteins with subsequent loss of weight or underweight. Malnutrition can be acute, chronic or both and it can be classified as moderate or severe (Joosten & Hulst, 2008).

Assessment of nutritional status and monitoring of growth in individuals and populations can be done using anthropometry. The World Health Organization (WHO, 2006) developed growth standards using anthropometric indicators namely weight-for-age, length-for-age, height-for-age, weight-for-height and Body Mass Index (BMI)-for-age. These standards were recommended to be used for monitoring growth as well as assessing nutritional status in children between 0-60 months and from 5-19 years old. These measurements are interpreted using standard indices that are expressed in terms of z-score, percentile or percentage of median (WHO, 2006). The most commonly used indices

are the z scores because they allow for clinical tracking of patients whose anthropometric measures lie beyond the measurable limits of the percentile range such as in severe under nutrition or obesity (de Onis, et al., 2012). The three most commonly used anthropometric indices in children are weight for height, height for age and weight for age (WHO, 2006).

Using the anthropometric indicators, malnutrition is classified as underweight when the child presents with low weight- for-age, stunting when presenting with low height-for-age and wasting when child presents with low weight-for-height (Bose & Mandal, 2010). Acute malnutrition is determined using weight-for-height indices while chronic malnutrition can be determined using height-for-age indices (Joosten & Hulst, 2008). Weight-for-age indices do not differentiate between acute or chronic malnutrition, and since children with CP have malnutrition of chronic duration, the best indices to use for anthropometric measurements are the weight-for-age indices (Gladstone, et al., 2014; Karagiozoglou-Lampoudi, et al., 2012). Although triceps skin fold has been reported to be the best tool for assessing the nutritional status of children with CP, Karagiozoglou-Lampoudi, et al. (2012), found that WAZ correlated positively with triceps skin ford and therefore concluded that WAZ are also useful indicators for undernutrition in children with CP. Furthermore, the use of weight has been reported to be a simple and reliable measure compared to using more detailed and possibly unreliable combinations of measurements which may be difficult for children with CP (Brooks et al. 2011). For these reasons, this study chose to use WAZ indices to measure the nutritional status of children with CP.

When using the indices weight-for-age, height-for-age and weight-for-height as classification and using z-scores, the cut-off point of -2SD is used, with the standard score of weight-for-age, height-for-age and weight-for-height between -3SD and -2SD being moderate malnutrition and below -3SD as severe malnutrition. Using WHO standards, severe acute malnutrition can be defined as weight-for-height z scores below -3 SD, or mid-upper arm circumference < 11.5 cm, or by visible severe wasting or by presence of bilateral pedal oedema (WHO/UNICEF, 2009). Severe acute malnutrition in children can also be diagnosed by visible severe wasting which is characterized by muscle wasting in the gluteal region, loss of subcutaneous fat or prominence of bony structures (Mogeni et al., 2011). According to the WHO growth standards, severe chronic malnutrition in children is defined as height-for-age below or equal to -3 SD score of the median and it is characterized by stunted growth (WHO, 2011).



This study used the z-score system to measure malnutrition in children with CP and classified severe malnutrition (undernutrition) as weight-for-age, z-scores below or equal to -3SD.

### **1.3 Statement of the problem**

Literature shows that the main reasons for hospital admissions among children with CP are disorders of the respiratory system and the nervous system (e.g. epilepsy) (Murphy, Hoff, Jorgensen, Norlin, Young, 2006). In children attending physiotherapy at UTH in Lusaka, it has been observed that severe malnutrition is one of the leading causes of hospital admissions besides respiratory infections. This observation is consistent with findings from a study that was done in Pakistan to identify common problems associated with CP where it was reported that about 85% of the children with CP were malnourished (Malik et al., 2007). Malnutrition in children with CP has many consequences which include growth failure, reduced cerebral function leading to reduced potential for growth, inactivity and irritability (Sullivan, 2013). Other consequences are increased risk of infection due to impaired immunity, impaired circulation and diminished respiratory muscle strength leading to chest infections. These consequences have a negative impact on the health related quality of life for the affected children leading to increased burden of care on their families and health care services (Kupermic & Stevenson, 2008).

There has been no published study done in Zambia to determine the prevalence of children with CP or to identify the risk factors for severe malnutrition in children with CP. However, information obtained from the annual reports for a Lusaka based non-governmental organisation which provides services to children with disabilities shows that about 1,590 children with disabilities or mobility impairments were attending physiotherapy services in the 6 (six) Lusaka district urban health centres and UTH in 2015. This information further revealed that about 80 % of children who attend physiotherapy services in these institutions present with CP. In relation to caring for children with CP in Zambia, Singogo, Mweshi and Rhoda (2015), explored challenges faced by mothers caring for CP children in one of the Zambian districts. They reported that mothers faced challenges such as social isolation, lack of support from family members, community and health care providers (Singogo et al., 2015). These challenges could increase the risk of malnutrition among children with CP who depends on their mothers for their daily needs including nutrition.

It is important to identify the risk factors that are associated with severe malnutrition in children with CP so that measures to address this problem could be put in place. This is in line with Gladstone

(2010) who noted that without information on the prevalence and problems facing children with disabilities in developing countries, it will be difficult to plan for interventions for these children.

#### **1.4 Purpose of the study**

The purpose of this study was to identify the risk factors that are associated with severe malnutrition in children with CP in an urban setting of a developing country like Zambia. It is hoped that this information would help health care providers with planning interventions that could help reduce malnutrition in children with CP in a poor resource setting. Furthermore, results from this study could be used to influence policy related to nutrition for children with disabilities in poor resource settings where there is a high prevalence of malnutrition in the general population.



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## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Introduction

The literature review will start by describing in detail the UNICEF Conceptual Framework for malnutrition (UNICEF, 1990) and how it relates to malnutrition in children with CP. This will be followed by an overview of the prevalence of malnutrition in the general population in developing countries. The other topics to be reviewed are the prevalence of CP in both developing and developed countries, prevalence of malnutrition in children with CP, the risk factors for malnutrition in CP children, complications of feeding difficulties and assessment of feeding difficulties in CP children. Literature on the management of feeding difficulties in CP children will be reviewed and lastly the challenges faced by developing countries in managing feeding difficulties in CP children.

#### 2.2 Conceptual framework for childhood malnutrition

Many authors have constructed conceptual frameworks for guiding them in assessing and managing malnutrition. Almost all of these frameworks are adapted from the 1990 UNICEF framework for malnutrition (UNICEF, 1990). For example, Black et al. (2013) adapted a framework from the UNICEF framework and proposed one that emphasises optimal fetal and child growth and development other than just the determinants of undernutrition (Black et al. 2013).

Figure 1 shows the UNICEF conceptual framework which categorises causes of malnutrition at three levels that are interrelated in a hierarchical manner, namely the immediate, underlying and basic causes (UNICEF, 1998). According to this framework, the immediate causes are themselves caused by underlying factors and these underlying factors are as a result of basic factors (Schroeder, 2008). For example poor diet and illness may be caused by inability by families to access adequate food supplies, poor maternal practices and unhealthy environments which are further influenced by basic socioeconomic and political conditions within which families find themselves (Schroeder, 2008).

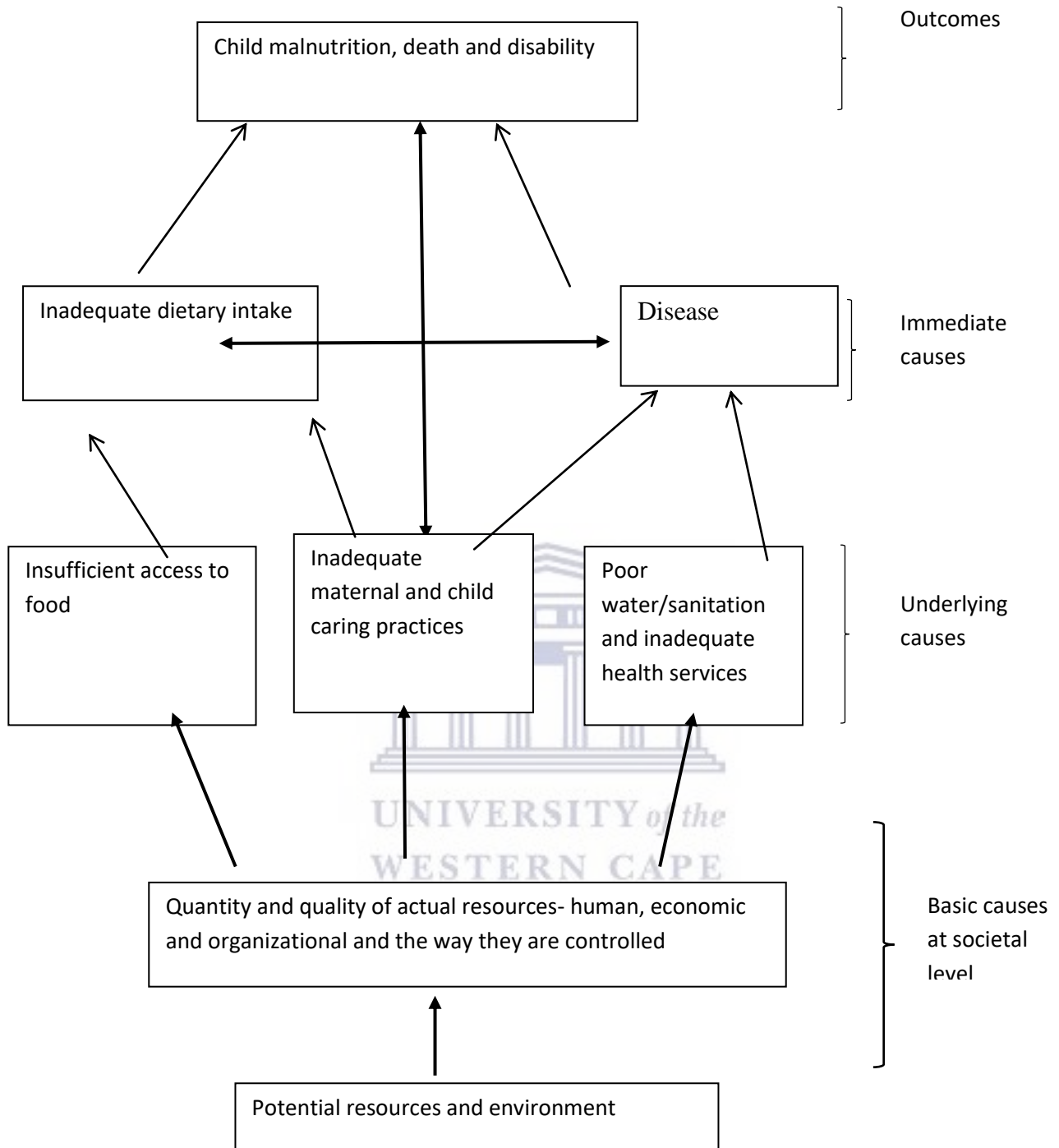
##### 2.2.1 Immediate causes of malnutrition

The immediate causes of malnutrition are biological, operating at the individual level and these are due to poor dietary intake and ill health (UNICEF, 1998).

Ill health or infection leads to loss of appetite and increases the body's nutrient requirements while poor or inadequate dietary intake makes the body more susceptible to infection or ill health (Pridmore & Carr-Hill, 2009), thus leading to a vicious malnutrition cycle (Katona & Katona, 2008). In the case of children with CP, inadequate dietary intake at the individual level are mainly due to feeding difficulties resulting from poor oral motor dysfunction, aspiration, prolonged feeding times, gastroesophageal reflux and vomiting after feeds (Santoro, et al., 2012). Other immediate causes in CP children include difficulties with self-feeding, chewing and swallowing, problems with biting and sucking, loss of food and fluid during feeding and refusal or lack of initiation to take food offered (Aggarwal et al., 2015). Furthermore, children with CP are said to have altered nutritional needs (Karagiozoglou-Lampoudi et al., 2012) and inadequate nutrient intake which can lead to malnutrition with consequences such as impaired linear growth, reduced peripheral circulation and wound healing, increased spasticity and irritability (Penagini et al., 2015).



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**Figure 2.1 Malnutrition conceptual framework (Source: UNICEF, 1998)**

### **2.2.2 Underlying causes of malnutrition**

The underlying causes of malnutrition arise when there is inadequate food security in the household, poor child care practices, inadequate access to health care and unhealthy environment (Benson & Shekar, 2008). These factors are dependent on the family's socioeconomic status and ability to access sufficient and quality food, better child feeding and hygiene practices, adequate supplies of clean water and good quality health care services (Jayawardena, 2014). In a study that was done in Tanzania, underlying factors that were associated with childhood malnutrition included poor feeding practices, poor complementary foods and inadequate sanitation (Minja et al., 2015). Children from poor families are more likely to be exposed to disease causing agents because of their poor living conditions and when they get sick, access to quality health care is not guaranteed (Blas & Kurup, 2010).

In developing countries where caring for children with disabilities is a responsibility of the family (Adams et al., 2012), children with CP are more likely to be exposed to underlying causes of malnutrition. This is because issues related to household food security, environmental factors and health care are more common in these regions. For example, studies done in developing countries have reported factors such as limited time and facilities to make special meals for the child and lack of access to rehabilitation services as contributing factors to malnutrition among children with CP (Adams et al., 2012; Wilmshurst et al., 2011).

### **2.2.3 Basic causes of malnutrition**

The basic causes of malnutrition constitute the social determinants of health (WHO, 2008). The social determinants relates to the way society is organised regarding distribution of resources and this is in turn determined by the economic structure, political and cultural factors (Benson & Shekar, 2008). Children below the age of five years are more susceptible to socioeconomic inequities because they depend on others for their health (Blas & Kurup, 2010). Literature shows that childhood malnutrition, which is a consequent of poverty, is more prevalent in developing countries (Black et al., 2013). Even within developing countries, the Poverty and disability, which are also more prevalent in developing countries, are said to have a causal relationship in the sense that poverty on one hand reduces an individual's access to resources such as health care, water and sanitation, good nutrition and living conditions and this places an individual at risk of poor health or disability (Banks

& Polack, 2014;). On the other hand, persons with disabilities are more likely to be excluded from education and work which further increases their poverty levels (Banks & Polack, 2014). This explains the reasons for the findings in a systematic review by Agarwal et al. (2015), where more CP children in developing countries were undernourished while the majority in developed countries was obese.

### **2.3.1 Prevalence of malnutrition in the general population**

Although malnutrition affects people of different age groups in the population, infants and young children have a higher risk because of their high nutritional requirements for their growth and development (Blossner & de Onis, 2005).

Literature shows that malnutrition is responsible for about 53% of deaths in children under the age of five years and the majority of these deaths occur in developing countries (Muller & Krawinkel, 2005). In 2011, global estimates of under-nutrition for children under the age of five years showed that about 165 million children were stunted, more than 100 million (16%) were underweight while prevalence for wasting was 52 million (8%) according to the WHO Child Growth Standard (Black et al., 2013). The highest prevalence of stunting was in East Africa which had a prevalence of 42% while West Africa and South-Central Asia had 36%. Zambia is among the 23 African countries with a prevalence of childhood stunting that is above 40% (Black et al., 2008). According to a study that was done in Zambia, it was reported that risk factors for childhood under-nutrition included household per capita expenditure, parental education, area of residence, quality of domestic water source and sanitation, sex and age (Masiye et al., 2010).

The global estimates for severe wasting in children show that about 19 million children had severe wasting, with the highest percentages being in South-central Asia and central Africa (Black et al., 2013). The UNICEF/WHO/World Bank Group joint child malnutrition estimates for 2014 shows that the global prevalence of childhood wasting was about 7.5% and of these, 2.4% were severely wasted (UNICEF/WHO/World Bank, 2015). Severe acute malnutrition in children under the age of five years is a life threatening condition which is reported to have a mortality rate of about 5 to 20 times higher among the affected children compared to well-nourished children (WHO, WFP, & UNICEF UNSCN, 2007). It is estimated that 35% of deaths that occurs annually among children under the age of five years globally are attributed to malnutrition and of these, 4.4% are due to severe wasting (WHO, 2013). In developing countries such as those in Sub-Saharan Africa, the mortality rate for

children admitted in hospital for SAM is reported to be between 20% to 30% (Briend & Collins, 2010). A study that was done in Zambia to investigate the effect of diarrhoea and HIV in children with SAM reported a mortality of 40% among children who were admitted to hospital (Irena, Mwambazi & Mulenga, 2011) Another study that was done in Kenya to determine the outcome of children admitted with SAM and diarrhoea at a Kenyan district hospital reported the mortality rate of 19% for those with diarrhoea and 9% for those without diarrhoea (Talbert et al., 2012).

All types of malnutrition namely stunting, underweight and wasting increase the risk of death from diseases such as diarrhoea, pneumonia, measles, and other infectious diseases (Black et al., 2013). A systematic review that explored the interaction between malnutrition and pneumonia reported that both moderate and severe malnutrition increases the risk of mortality in children presenting with pneumonia (Chisti et al., 2009). The risk of dying increases with severity for all the three types of malnutrition, with severe wasting being responsible for about 449 000 child deaths each year (Black et al., 2008).

The high mortality rate associated with severe childhood malnutrition has led WHO to release guidelines on management of SAM in order to reduce the global burden of childhood malnutrition (WHO, 2013). However, these guidelines have not been easy to implement in developing countries such as Sub-Saharan Africa due to severe co-morbidity as well as overloaded, demotivated, eroded and under resourced child health services (Heikens, 2007).

### **2.3.2 Causes of severe childhood malnutrition in the general population**

Severe malnutrition consists of both severe acute malnutrition (SAM) and severe chronic malnutrition (SCM). Severe acute malnutrition is defined by weight-for-height measurements while severe chronic malnutrition is defined by a height-for-age indicator (Manary & Sandige, 2008) and when using anthropometry, both are below -3SD z scores. SAM can be a direct consequence of immediate causes of malnutrition such as ill health and inadequate dietary intake. SAM is an unstable condition which results from a short duration of nutritional deficit often complicated with recurrent infectious illnesses and has a high mortality risk (Collins, 2007). According to the UNICEF conceptual framework for malnutrition, a malnourished child may have lowered immunity resulting in frequent episodes of infections which further leads to reduced dietary intake. The affected child will enter into a potentially fatal malnutrition-infection cycle which is characterized by episodes of infections with worsening of the nutritional status (UNICEF, 1998). Severe acute malnutrition is



associated with many complications including suppression of the immune response and disturbances of the normal physiology resulting in electrolyte imbalances and altered fluid distribution (WHO, 2013). The underlying causes of ill health and malnutrition can sometimes be the result of inadequate household food security which in turn could be caused by political factors at both national and international levels (katona & Katona, 2008). In developing countries were continuous inadequate food intake occurs with repeated infections, SAM and SCM have been reported to co-exist in the same child. In a study that was done in Bangladesh, it was reported that of the 322 children who were diagnosed with SAM, 162 also had SCM (Shams et al., 2012).

Low height-for-age (Stunting) which depicts chronic malnutrition reflects inadequate dietary intake over a long period of time or recurrent and prolonged illness (Das, Hossain, & Islam, 2008). Severe chronic malnutrition (SCM) may also result from prolonged episodes of undernutrition for both the pregnant mother and the child during the first two years of life (Collins, 2007). Maternal and child nutrition can be influenced by both underlying and basic causes of malnutrition which includes caring practices at household and community levels, food insecurity, social justice and welfare systems and the effectiveness of broader and social policies (UNICEF, 2009). Although SCM is regarded as less serious, there is evidence showing that even children with severe chronic malnutrition may have their health status drop quickly during acute episodes of illnesses such as diarrhea, respiratory tract infections or measles. (Shams et al., 2012). This may be possible in poor resource settings characterized by low family socioeconomic status, poor environment and housing, inadequate access to food and safe water and improper guidance and health care services (UNICEF, 2012).

#### **2.4 Prevalence of cerebral palsy**

The reported global incidence and prevalence of CP varies by region, population, age and severity (McAdams & Juul, 2011). A recent systematic review of studies done on the prevalence of CP reported that the global prevalence is estimated to be 2.11 per 1000 births (Oskoui, et al., 2013). However, this estimate cannot be generalised to most African countries because there was only one study from one African country (Kenya) that met the inclusion criteria for this review. There are many variations regarding the prevalence of CP reported between developed and developing countries. Firstly, the risk factors for CP in developed countries are associated with prematurity and low birth weight, whereas in developing countries, risk factors include birth asphyxia, central

nervous system infections and kernicterus in full term babies (Burton, 2015; Dolnald, et al., 2014). Furthermore, most of the studies done in developed countries are mainly population based whereas most of the studies done in developing countries are institutional based (Gladstone, 2010).

The prevalence of CP may be higher in developing countries than in developed countries because of the higher levels of perinatal complications such as birth asphyxia and neonatal infections (Donald, et al., 2014). Furthermore, the estimation by WHO that about 80% of the world's disabled population live in low income countries such as Africa is a clear indication that even the prevalence of CP could be higher in these countries (Gladstone, 2010). A systematic review that was done in African countries found the prevalence of CP to be between 2 to 10 per 1000 children in the community (Donald, et al., 2014). This may still not be the actual prevalence of CP in Africa because as observed by Mung'ala-Odera, et al. (2006), there is no data in most African countries and where it is available; it is usually of poor quality making it difficult to estimate the actual burden.

## **2.5 Prevalence of malnutrition in children with Cerebral palsy**

Children with neurological impairments such as CP present with lower linear growth and weight for age compared to those in the healthy population of children (Sangermano et al., 2014). It is estimated that about one third of children with CP are undernourished (Karagiozoglou-Lampoudi, et al. 2012). The risk of malnutrition in children with CP is higher in those with severe motor impairment compared to those with mild impairments (Kuperminc & Stevenson, 2008). A study that was done on the impact of feeding difficulties among children with CP attending a specialised clinic in a tertiary hospital in sub-Saharan Africa found that malnutrition was common among the children under review (Kakooza-Mwesige et al., 2015b).

Additionally, underweight and stunting were the most prevalent conditions, while muscle wasting was three times more common than in the general population (Kakooza-Mwesige et al., 2015b). In another study done in Tanzania, the prevalence of the three types of undernutrition in relation to severity of neurological impairment was found to be higher among those with moderate neurological impairments than those with severe or mild (Minja et al., 2015). This study reported that the prevalence of wasting ( $WHZ \leq -2$  SD) was 29.3% for moderate, 4.9% for severe and 2.4% for mild cases of CP. The prevalence for underweight was 43.9% for moderate CP, 6.5% for severe CP and 4.1% for mild CP, while the prevalence of stunting was 48% for moderate, 8.9% for severe and 7.3% for mild cases of CP (Minja et al., 2015).

## **2.6 Risk factors for malnutrition in children with cerebral palsy**

Children with CP often present with poor growth in terms of linear growth, weight gain and body composition (Kuperminc & Stevenson, 2008). This may be due nutritional factors such as inadequate dietary intake and feeding difficulties as well as non-nutritional factors such as reduced weight bearing, endocrine dysfunction, socioeconomic status, severity of impairment and age (Aggarwal et al., 2015). In a study that was done in Tanzania to assess the impact of neurological disability on the nutritional status of children, it was reported that the main contributing factors to undernutrition among these children were inadequate food intake, food losses during feeding, oral motor dysfunction, nutritional ignorance and poverty (Minja et al., 2015). Other factors associated with poor nutrition among children with neurological disorders that were reported by Minja and colleagues (2015) included sociocultural practices, severity of the neurological disability and the socioeconomic status of the families. These risk factors are discussed separately including how they relate to the UNICEF conceptual framework for malnutrition.

### **2.6.1 Inadequate dietary intake**

In children with CP, inadequate dietary intake may be the consequence of feeding difficulties, excessive nutrient loss due to Gastroesophageal reflux or altered energy metabolism as well as other non-nutritional factors (Penagini et al. 2015). Literature shows that children with motor disabilities have low energy intake compared to the normal population (Kilpinen-Loisa et al., 2009). Furthermore, children with spastic CP are also reported to have increased metabolic rates due to hypertonia and movement disorders. Poor oral motor dysfunction is said to impair the child's ability to consume calories and nutrients (Kuperminc & Stevenson, 2008). A study that was done in Indonesia to determine the feeding difficulties and malnutrition in children with CP reported that 78 % of the children had inadequate energy intake and that this was related to malnutrition (Sjakti, Syarif, Wahyuni, & Chair, 2008). Both malnutrition and low energy intake were significantly associated to severity of CP (Sjakti et al., 2008). In a study that was done in Brazil to assess the food pattern and nutritional status of children with CP, it was reported that 52% of children had diet low in carbohydrates, 53% had adequate protein diets and 43% reported high lipid diets (Lopes et al., 2013). In another study that was done in South Africa to determine the nutritional status of children with disabilities, it was reported that levels of micronutrients were lower than the lowest Daily Recommended Allowance (RDA) among most of the children in the three learning institutions

(Dannhauser, Walsh & Nel, 2007). These micronutrients included calcium, selenium, vitamins A, B, C and folate.

### **2.6.2 Feeding difficulties**

About 30% to 40 % of children with CP are reported to have feeding difficulties which contribute to inadequate dietary intake and growth failure (Andrew & Sullivan, 2010). A study that was done in Queensland, Australia reported a much higher prevalence (85%) of Oropharyngeal dysphasia, which is a type of feeding difficulties, among children with CP (Benfer et al., 2013). The most common factors associated with feeding problems in children with CP include severity of CP, Oral motor dysfunction (OMD), type of CP, comorbidities, challenging feeding behavioural problems, postural problems and age (Aggarwal, et al., 2015; Andrew & Sullivan, 2010). Other problems associated with feeding difficulties include inability to self-feed, choking, longer feeding time, constipation and frequent vomiting (Andrew & Sullivan, 2010).

Oral motor dysfunction (OMD) is the main cause of feeding difficulties among children with CP and Literatures show that over 70% of children with CP present with oral motor dysfunction (Wilson & Hustad, 2009; Sjakti et al., 2008). The main types of OMD include sucking and swallowing difficulties, drooling, poor lip closure, perioral and hypo/hyper sensitivity (Aggarwal et al., 2015). Other less common types of OMD are tongue thrusting, limited tongue movements, choking, bite reflex, jaw instability, poor respiratory coordination, poor gag reflex, lip retraction and primitive chewing reflex (Sjakti et al., 2008). These factors are consistent with the findings by Diwan and Diwan (2013) in a study done in India to assess the magnitude and extent of feeding dysfunction among CP children who reported that the common feeding problems were sucking and swallowing difficulties, inability to self-feed (48.5%), prolonged feeding time (Mean = 22.42 minutes), improper feeding positions, coughing and choking during feeding, vomiting, recurrent chest infections, oral motor dysfunction, drooling, cry/strong extensor thrust during feeding.

Another study that was done at Faisalabad hospital in Pakistan to identify common problems associated with CP, reported that 75% of the children had OMD with the most common being drooling (79%), swallowing difficulties (73%), gastroesophageal reflux 66% and speech problems with 44% (Malik et al., 2007).

In a study that was done in Uganda to describe functional deficits among children who survive cerebral malaria, it was reported that feeding difficulties were the main cause of malnutrition among children who presented with spasticity (Idro et al., 2010). In another study that was done in the mid-west portion of the United States to describe the feeding skills in children with CP, it was reported that about 78% of the children had clinical evidence of oral motor dysfunction (Wilson & Hustad, 2009). Another study that was done in Indonesia on feeding problems in children with CP reported that 76% of children had feeding difficulties and of these, 56% were due to OMD (Sjakti et al., 2008). The common feeding problems reported by parents in a study by Sjakti et al. (2008) included swallowing difficulties (57%), longer feeding time (38%), frequent choking/coughing (34%), difficult in drinking (31%) and frequent vomiting (24%). The prevalence of OMD in children with CP often correlates with the severity of motor involvement (Wilson & Hustad, 2009).

### **2.6.3 Severity and type of impairment**

The severity and type of CP have been reported to be associated with the nutrition and growth status of children with CP (Agarwal et al., 2015). A systematic review on studies of feeding problems and nutritional status of children with CP found a positive association between severity of CP and feeding difficulties (Agarwal et al., 2015). Feeding ability which is a determinant of the nutritional status is reported to be poor among those children with severe impairment (Diwan & Diwan, 2013). In a study that was done in Greece to assess the nutritional status of children with CP using WHO growth standards, it was reported that the prevalence of undernutrition was higher among children with severe impairment and those who were unable to self-feed (Karagiozoglou-Lampoudi et al., 2012). Severity of impairment has been reported to affect OMD even in children presenting with hemiplegia or diplegia. Findings from part of a longitudinal study that was done in Queensland, Australia to determine prevalence of OMD and its association with gross motor functional skills showed that 70% of children with hemiplegia and diplegia whose GMFCS were low had OMD (Benfer et al., 2013).

In relation to type of CP, a review by Agarwal et al. (2015) found spastic quadriplegia to be highly associated with feeding difficulties. This review of studies also found that feeding difficulties were common among children with tetraplegia, Hypotonia and dyskinetic types and less common among diplegia and hemiplegia types of CP (Agarwal et al. 2015).

In a study that was done in Brazil to determine growth and anthropometric differences between the affected and non-affected limbs among children with hemiplegic CP found that the mean anthropometric values for weight, length and head circumference were within the normal range (Zonta et al., 2009). In another study that was done in Brazil to assess the food intake pattern and nutritional status of children with CP at a rehabilitation centre, it was reported that difficulties with chewing and swallowing were more prevalent among children with quadriplegia while none of the children with diplegia reported any of these problems (Lopes et al., 2013). Karagiozoglou-Lampoudi and colleagues (2012) also found that undernutrition was more prevalent among children with quadriplegia compared to other types. Another study done in India reported that maximum inadequate feeding skills were prevalent in 75% of children with spastic quadriplegia while about 40.9% of children with spastic diplegia scored maximum normal feeding skills (Diwan & Diwan, 2013). These findings are similar to the studies done in Africa, such as the one that was done in South Africa which reported that children presenting with severe neurological impairments were more likely to be malnourished due to feeding difficulties (Dannhauser et al., 2007).

#### **2.6.4 Sociocultural and feeding practices**

Children with disabilities depend on caregivers or parents for most or all of their activities of daily living. According to Minja et al. (2015), the quality of food consumed by children with disabilities is determined by the economic status of the family as well as family and community beliefs on nutrition and disabilities. It is therefore important that when assessing growth and nutrition for children with feeding difficulties, we should first review the patient's and family's perspectives concerning growth and nutrition. Caregivers of children with disabilities in developing countries experience many challenges including those related to the burden of caring for the disabled child which leaves the caregivers stressed (Hartley et al., 2005). This stress may promote unresponsive and often abusive feeding practices which may lead to distressing mealtimes for both the child and caregiver (Adams et al., 2012).

Findings from a study that was done in Pakistan to identify OMD as perceived by parents in relation to actual feeding difficulties in CP children reported that most of the parents were unaware of their child's problems and their perceptions about the feeding problems were mostly in contrast with the actual problems (Ghayas et al. 2014).

Caregivers' beliefs can also influence their caring practices as evidenced from findings of a study that was done in Kenya where some caregivers reported that they had never sought medical attention for their disabled child because they thought the disability was caused by environmental factors (Kuper et al., 2015). In the same study, it was also reported that some caregivers looked at their disabled children as a burden because they could not help with household chores and would not bring in a dowry (Kuper et al., 2015). Such negative attitudes towards disabled children among caregivers are likely to affect caring practices including feeding patterns.

### **2.6.5 Socioeconomic status of the family**

In the general population, low household or family socioeconomic status has been associated with high prevalence of childhood undernutrition (Pongou, Ezzati, & Salomon, 2006; Blakely et al., 2005). Blakely and colleagues (2005) found the relative risks to be two to three times greater for those living on  $\leq$  US \$ 1.00 per day compared to those living on  $\geq$  US \$ 2.00 per day.

According to Minja and colleagues (2015), poverty is likely to affect the quantity and quality of food given to the child with neurological disorders. Findings from a study that was done in Uganda to understand how families of disabled children cope within their communities showed that poverty was one of the challenges experienced (Hartley et al., 2005). This study identified two subthemes from poverty namely lack of funds for basic necessities such as food and clothing and lack of funds for hospital charges, transport and assistive devices (Hartley et al., 2005). The situation is even more challenging for parents of children with CP because of their increased energy requirements and the need for special preparation such as longer cooking time (Adams et al., 2012).

It may be difficult for parents of children with CP in poor resource settings to meet the energy requirements of their children because families may not be able to afford the cost and time needed to prepare this type of food (Adams et al., 2012). Furthermore, in poor resource settings, caring for the disabled child is done by the caregiver who does all activities for the child such as assisting with mobility, positioning and transfers, as well as activities of daily living such as dressing, bathing, eating and drinking (Geere et al., 2013).

### **2.6.6 Age and gender**

In developing countries, malnutrition for children under five years of age is said to be more prevalent in boys than girls and this correlates with the under-five mortality rate which is higher in boys (Black et al., 2013). Early age has been associated with a high prevalence of feeding problems such as weak

suck, delayed or absent tongue lateralization, persistent tongue thrust, poor lip closure and trunk instability (Aggarwal et al., 2015). In relation to growth, findings by Stevenson et al, (2006) in a study done to describe the growth pattern in children with moderate to severe CP showed that these children tend to be thinner, smaller and lighter than their peers of the same age and gender in the healthy population. These differences become more pronounced as children grow older.

In a study that was done by Lopes et al. (2013) in Brazil, it was reported that children with CP below the age of three (3) years had adequate energy intake but above this age, consumption was reported to be below the recommended values. This was probably due to difficulties with chewing and swallowing associated with the introduction of more solid foods. Contrary to this, a study that was done in Uganda among children with CP found that children under the age of five years were six times more likely to be underweight than those above this age (Kakooza-Mwesige et al., 2015b). This finding could be associated with the high prevalence of malnutrition in the general population of children under the age of five years as well as challenges faced by parents of CP children in poor resource settings regarding preparing special meals for children who present with feeding difficulties (Adams et al., 2012).

#### **2.6.7 Other factors**

Literature shows that some children with CP grew more slowly compared to the normal population and this decline in linear growth was not related to the nutritional status of the children (Aggarwal et al., 2015). Some of the factors that are associated with poor nutritional status in children with CP include constipation, gastro-oesophageal reflux, poor health status and respiratory complications (Sjakti et al., 2008). Mental or intellectual disability has also been associated with poor nutrition due to the patient's inability to communicate hunger and inability to request for food or drink (Penagini et al., 2015). Endocrinopathy is another factor that has been reported to be associated with abnormal growth in children with CP (Kuperminc & Stevenson, 2008). Children with CP are said to have deficiency in Growth Hormone (GH) because they tend to have lower levels of insulin-like Growth Factor 1 (IGF-1) and IGF binding protein-3 compared to their counterparts in the healthy population (Andrew & Sullivan, 2010). A systematic review by Aggarwal et al. (2015) found that several studies reported abnormalities in the secretion of GH in about 60-100 % of children with CP.



### **2.6.8 Risk factors for malnutrition in children with CP and the UNICEF conceptual framework**

The discussed risk factors for malnutrition in children with CP are related to all the three causes outlined in the UNICEF conceptual framework. The inadequate dietary intake can be due to immediate causes such as feeding difficulties, Gastroesophageal reflux, constipation, poor health status, respiratory complications, endocrinopathy and severity and type of motor impairment. Other immediate causes are intellectual disability, inability to self-feed or communicate hunger as well as age and gender. Immediate causes at an individual level can be managed by either conservative methods (caregiver training in positioning, thickening of food and liquids and extending feeding time) or gastrostomy tube feeding. These management methods are further influenced by underlying factors as well as basic factors as they relate to access to health care professional who should be able to train the caregivers and well as availability of expertise and tools to be used for managing long term gastrostomy tube feeding for the affected children.

The underlying causes of malnutrition in CP include feeding practices and family socioeconomic status. Caregiver's lack of knowledge on the child's problems, poor positioning during feeding and poor diet due to fear of aspiration can influence caring practices which can in turn lead to inadequate dietary intake (Minja et al. 2015; Groce et al. 2014). The socioeconomic status of the family is an underlying cause of malnutrition as it determines the family's access to basic needs such as food, safe drinking water, sanitation and health care services (UNICEF, 1998). These underlying causes may be due to basic causes such as political, legal and cultural factors which include lack of policies for children with disabilities (UNICEF, 1998). According to the WHO global disability action plan 2014-2021 (WHO, 2015), people with disabilities in developing countries face widespread barriers in accessing services such as health care, education, employment and social services due to inadequate legislation, policies and strategies. (WHO, 2015).

### **2.7 Complications of feeding difficulties in children with cerebral palsy**

Malnutrition in children has been reported to have devastating consequences on physiological, motor, neurological and psychological function of children with CP especially during their early development (Kuperminc & Stevenson, 2008).

The most common complications of feeding problems in children with CP are malnutrition, dehydration and respiratory complications (Petersen, Kedia, Davis, & Newman, 2006). Arvedson (2013) also noted that the consequences of feeding difficulties would include inadequate growth, prolonged feeding times, delayed progression of oral feeding skills and recurrent respiratory infections. Arvedson further noted that children with CP who present with feeding and swallowing problems (dysphagia) are often at risk of aspiration with consequent pulmonary complications and mealtimes are often long and stressful for both the child and caregiver. A study done in a South African tertiary hospital to describe the infants and children requiring gastrostomy reported that aspiration was the second most common indication for gastrostomy because it occurred more frequently in children with neurological conditions, who were the majority of the participants (Norman et al., 2011).

Studies done on the consequences of feeding problems in children with CP have revealed that between 45 to 50 % of children with CP are undernourished (Petersen et al., 2006). Literature has also shown that children with neurological impairments have low energy intake as well as low micronutrient intake compared to normal children (Kalra et al., 2015; Sjakti et al., 2008). A study that was done at a tertiary hospital in North India to compare the micronutrient levels in children with CP and non-neurologically impaired children found that CP children had significantly lower levels of micronutrients and their overall energy intake was also lower (Kalra et al., 2015).

## **2.8 Assessment of growth and nutritional status in children with cerebral palsy**

The high prevalence of malnutrition and its consequences in children with CP underscores the importance of identifying and correction of malnutrition in this population. Nutritional assessment of children with CP is an important aspect of management of such children because it can provide the basis for individual treatment as well as planning of public health interventions (Lopes et al., 2013). The proposed areas for assessment of growth and nutritional status in children with neurological impairments include taking the nutrition and feeding history, medical history, anthropometric measurements and laboratory tests (Samsung-Fung & Bell, 2013).

Information to be gathered under nutrition and feeding history include type (consistency) and amount of food taken, amount of food spilled, duration of meal, degree of dependency on caregiver and stress or fatigue during meal times (Marchand, 2012; Thompson & Subar, 2008).

Medical history should include the neonatal history, underlying condition, level of functioning (GMFCS), tone, abnormal movements, respiratory problems, gastrointestinal problems, antiepileptic drugs, etc. (Penagini et al. 2015; Samsung-Fung & Bell, 2013; Marchand, 2012). The social history should include the child's living condition, family situation and socioeconomic status and main caregiver (Marchand, 2012).

The recommended method of assessing malnutrition at population level is the use of anthropometric measurements which involves construction of indices from body measurements such as weight, length/height, head and arm circumference and triceps and subscapular skin fold thickness (De Onis & Blossner, 2003). The constructed indices, which are expressed in terms of z-scores, percentiles or percentages of median, enables comparison of a child or children with the reference population (De Onis & Blossner, 2003).

In children with CP, nutritional assessment using anthropometric measurements is challenging because of factors such as scoliosis, spasticity, contractures or limb length differences (Wittenbrook, 2011). Because of these and other problems associated with using WHO growth standards, some authors have suggested the use of specific growth charts for children with CP (Araujo & Silva, 2013). However, other authors have noted that specific growth charts do not necessarily describe what is ideal and therefore they advise clinicians to use the standard population growth charts because they give a clear perspective of the broad range of growth in children with CP (Kuperminc & Stevenson, 2008). Furthermore, the use of CP specific charts is questionable because of the unreliable measurement methods used and their validity is unknown (Kuperminc & Stevenson, 2008).

## **2.9 Management of feeding difficulties in children with cerebral palsy**

Identifying and addressing the feeding problems in children with CP has been found to be beneficial to both the children and their caregivers. As noted by Arvedson (2013), the highest priority in management of feeding problems is to ensure an adequate health status in relation to nutrition, hydration and pulmonary function. Furthermore, Aggawal and colleagues (2015) noted that the primary of nutritional management for children with CP is to improve the quality of life for both the child and the family.

Depending on the severity of the feeding problems, management of feeding difficulties can be done by conservative methods such as positioning, techniques to facilitate lip closure and swallowing, sensorimotor techniques, caloric supplements, thickening food and liquid and extending feeding time (Agarwal et al. 2015; Adams et al., 2012). Conservative methods have been reported in most studies to result in improvements in nutritional status of the affected children. In a study that evaluated the effects of nutritional support on clinical findings among children with CP in Turkey, it was reported that there were improvements in anthropometric parameters and a decrease in the number of infections after the intervention (Soylu et al., 2008). The nutritional interventions included supplements to cater for energy and nutrient deficiencies as well as giving advice to caregivers on positioning and modifying food textures according to the child's feeding abilities (Soylu et al., 2008).

In severe cases where conservative methods have failed, gastrostomy is the method of choice in which a feeding tube is surgically inserted into the stomach through the abdominal wall (Sullivan et al., 2005). Enteral feeding is the recommended choice of management in cases where oral intake is insufficient to promote weight gain or linear growth, where feeding takes excessive length of time or when there is a risk of aspiration (Penagini et al., 2015). Gastrostomy tube feeding has been reported to have both significant positive effects as well as negative effects. In a study that was done in the United Kingdom to measure the outcomes of gastrostomy tube feeding in children with CP, it was reported that there were marked improvements in weight gain for age and sex among children (from -3 SD at baseline to -1.6 SD at 12 months) and all parents reported significant improvements in their children's health as well as reduction in time spent on feeding (Sullivan, et al., 2005). In another study that was done in Australia to compare the protein intake and various protein markers between CP children fed orally and enterally as well as non-CP controls, it was reported that orally fed children had significantly reduced z scores for weight, height and BMI compared to controls while the enterally fed group had slightly improved z scores for weight and BMI compared to the orally fed group (Schoendorfer et al., 2012).

Despite the successes reported with procedures such as percutaneous endoscopic gastrostomy, such procedures are rarely available in African countries (Kerac et al., 2014). However, South Africa has reported placement of gastrostomy among children and infants. For example, in a study by Norman et al. (2011), gastro-intestinal tract and neurological conditions such as CP were reported as the major indications for gastrostomy.

## **2.10 Challenges faced by developing countries in managing feeding difficulties in children with cerebral palsy**

In developed countries, caring for children with feeding difficulties involves a range of expertise as well as use of high technology medical procedures such as gastrostomy with subsequent improvements in general health for the child and caregiver (Sullivan et al., 2005).

In developing countries, where most of the burden of caring for a disabled child is on the family, the child's feeding problems are worsened by poverty, limited time and facilities to make special meals as well as lack of access to rehabilitation services (Adams, et al., 2012). Furthermore, many children with dysphagia are not referred for feeding assessment (Barratt & Ogle, 2010). Based on their findings from an outpatient paediatric neurodevelopmental clinic, Barratt and Ogle (2010) recommended mandatory dysphagia screening assessments to help identify children at risk so that early intervention could be implemented.

Despite these challenges, the prevalence of comorbidities such as poor feeding, orthopaedic complications and cognitive impairments which are reported in developed countries are likely to be higher among children with CP in African settings due to high prevalence of severe forms of CP (Donald et al., 2014). Identifying and addressing the feeding problems in children with CP have been found to be beneficial to both the children and their caregivers. However, as noted by Gladstone (2010), there is lack of data on prevalence of children with disabilities in developing countries and hence it is difficult to plan for intervention for these children.

Child neurology services in African countries are characterised by lack of access to neurological services and lack of resources such as specialised facilities and skilled personnel to give specialist care to children with neurological disabilities (Wilmschurst, et al., 2011). Furthermore, a systematic review of studies done on paediatric CP revealed that despite challenges such as limited access to health care and specialists and lack of adaptive equipment, children with CP in Africa face high levels of social stigma which contributes to parents' unwillingness to seek treatment even when it is available (Donald et al., 2014).

## CHAPTER 3

### METHODOLOGY

#### 3.0 INTRODUCTION

This chapter explains the design that was used in this study under the following headings: Aim, objectives, study setting, study population, inclusion and exclusion criteria, sample size, sampling procedure, data collection, data analysis and ethical consideration.

#### 3.1 Aim

The aim of this study was to identify the risk factors associated with severe malnutrition among children with CP who are accessing health care services at UTH.

#### 3.2 Objectives

The objectives of this study were as follows:

1. To compare the clinical profile and nutritional status between children with CP presenting with severe malnutrition and children with CP without severe malnutrition.
2. To compare demographic characteristics of primary caregivers for children with CP presenting with severe malnutrition and those for children with CP without severe malnutrition.
3. To compare family socioeconomic characteristics between children with CP presenting with severe malnutrition and children with CP without severe malnutrition.
4. To compare the feeding patterns and practices between children with CP presenting with severe malnutrition and children with CP without severe malnutrition.
5. To determine the risk factors which are significantly associated with severe malnutrition in children with CP.

#### 3.3 Study design

A case control design was used to identify the risk factors that are associated with severe malnutrition in children with CP. This was done by comparing the clinical profile, demographic characteristics of the children, caregiver demographic characteristics and feeding practices, family

socioeconomic characteristics and feeding patterns/difficulties between children with CP presenting with severe malnutrition and those without severe malnutrition. The purpose of case control designs is to investigate causes of disease (Bonita, Beaglehole & Kjellstrom, 2006). Case control studies are observational studies which start with identification of individuals with a disease of interest (cases) who are then compared with a suitable control group of individuals without the disease of interest (Bonita, et al., 2006). Case control studies are quantitative in nature and therefore data collection for this study used quantitative methods. The purpose of quantitative research is to count occurrences, establish statistical links between variables and generalise findings to the population from which the sample was drawn (Bradley, Curry, & Devers, 2007). In this study, a group of children with CP who had severe malnutrition were compared with another group of children with CP who did not have severe malnutrition. The purpose was to determine if certain variables or characteristics are more prevalent among those with severe malnutrition compared to those without malnutrition.

### **3.4 study setting**

This study was conducted in Lusaka, the capital city of Zambia, at the University Teaching Hospital (UTH). University Teaching Hospital serves as the national referral center as well as the principal training institution for health disciplines. This hospital provides a range of primary, secondary and tertiary health care services to both in-patients and out-patients. Besides being a public institution, UTH also offers fee paying services to those who wish to access the services without a referral from another institution. Children with CP come to UTH for a variety of services which include Physiotherapy, medical care, fitting of orthotics, multidisciplinary assessment for school enrolment and special equipment. Children accessing medical care include both in-patients and out-patients. In-patients are those patients admitted in the paediatric wards in A-block as well as D-block. Paediatric wards in A-block include the admission ward and wards A01 up to wards A08.

The initial sites for data collection included only Ward A07, which is the paediatric malnutrition ward at UTH and the UTH physiotherapy out-patient clinic. However, during data collection, the number of controls was difficult to reach and this resulted in the researcher including all facilities within UTH which provides services to children with CP. The children who access services at UTH come from areas within Lusaka as well as outside Lusaka. This study only included those children with CP who live in Lusaka. Lusaka district has 170 Urban Health Centres and of these, only six (6) health centres have Physiotherapy services.

### **3.5 Study population**

The study population included all children with CP who accessed health care services (both in-patients and out-patients) at UTH during the study period. These services included Physiotherapy, medical care, fitting of orthotics, multidisciplinary assessment for school enrolment and those who came for special equipment such as special chairs, standing frames and walkers.

In the normal population, prevalence of malnutrition is high in children aged 6-24 months due to weaning practices, low protein diet and frequent infections (Muller & Krawinkel, 2005). However, in children with CP, the prevalence of malnutrition has been found to be higher in older children such as those above 18 months (May, et al., 2014; Lopes, et al., 2013; Stevenson et al., 2006). Therefore this study included male and female children with CP aged between two (2) to ten (10) years.

#### **3.5.1 Case description**

The use of the WHO growth standards to interpret the nutrition status and growth for children with CP may not be easy or appropriate (Gladstone, et al., 2014). Literature shows that using the normal standard growth charts tends to over-estimate malnutrition in individuals with CP (Araujo & Silva, 2013). This is because the growth patterns for children with CP are different from the normal population in the sense that children with CP have below average weight, linear growth, muscle mass, fat stores and bone mass density compared to the normal population (Gladstone, et al., 2014; Day et al., 2007).

Regardless of these challenges, Samson-Fang and Bell (2013) noted that any lack of growth or deviation from the normal curve should be considered abnormal. For this reason, this study defined as cases children with CP with WHO z-scores of weight-for-age (WAZ) of  $\leq -3$  SD.

In order to take account of the fact that children with CP have growth patterns below those of the normal population, the controls for this study were those children with CP presenting with WAZ z-score of  $\geq -2$  SD of the WHO growth standards.

### **3.6 Inclusion and exclusion criteria**

#### **3.6.1 Inclusion and exclusion criteria for cases**

**Inclusion:** All children with CP aged between 2-10 years, who accessed health care services at UTH and presenting with WHO WAZ z-scores of  $\leq -3$ SD.



**Exclusion:** a) Children with CP who accessed services at UTH but presenting with other chronic illnesses such as TB, sickle cell disease or other chromosomal abnormalities.

b) Children with CP who accessed services at UTH but were not residents of Lusaka.

### **3.6.2 Inclusion and exclusion criteria for controls**

**Inclusion:** All children with CP aged between 2-10 years and presenting with WHO WAZ z-scores of  $\geq -2SD$ , who accessed health care services at UTH.

**Exclusion:** a) All children with CP in this setting who are presenting with other medical conditions such as TB, sickle cell disease or other chromosomal abnormalities.

b) All children with CP who accessed health care services at UTH but are not residents of Lusaka.

c) Children with CP who accessed health care services at UTH but have history of severe malnutrition or being admitted to hospital in the past three (3) months.

### **3.7 Sample size**

Sample size was calculated using Epi Info version 7.2. The assumptions for sample size calculation were as follows:

- The odds ratio to be detected was (4). Cases assumed to be 4 times more likely to have oral motor dysfunctions than controls.
- Ratio of cases to controls (1:2),
- Confidence interval (95%)
- Statistical power (80%)
- Expected frequency of oral motor dysfunction in cases to be at 50% for cases and 20% for controls.

In relation to expected frequency of exposure, the most important exposure for malnutrition in CP to be considered here will be oral motor dysfunction. Literature shows that over 50% of children with CP will have feeding problems due to oral motor dysfunction and consequently malnourished

(Wilson & Hustad, 2009; Sjakti et al., 2008). Considering the above specifications and using Epi Info statCalc tool for sample size and power calculation in unmatched case control study (Epi Info 7.2), the expected sample size was 33 for cases and 66 for controls.

### **3.8 Sampling procedure**

Sampling for both cases and controls was done time delimited as this depended on the number of children who were admitted in UTH or those who accessed out-patient services according to the days on which that particular service is offered or assigned date of follow up visit. Selection for cases who were admitted to ward A07 depended on the new admissions.

For those who accessed out-patient services, selection for either cases or controls, was done during the respective clinic. Out-patient Physiotherapy clinics for children are held on Mondays, Wednesdays and Fridays from 08:00 hours to 12:00 hours. About 80% of children who come to Physiotherapy clinics have CP and an average of 20 children attend the clinic on each of the three days. Each child is expected to attend one clinic per week except for a few who have been asked to be coming twice in a week. During the Physiotherapy out-patient clinics, the researcher would identify eligible cases or controls by checking from the clinic register the age and then getting consent from the caregivers to take anthropometric measurements. Upon ascertaining the children's nutritional status, those with severe malnutrition were labeled as cases while those with moderate to no malnutrition were controls. Caregivers were informed about the study and those who accepted to participate were interviewed on the same day or a later date which could be another day when the child was brought for Physiotherapy.

Other areas which provide services to children with CP also have their out-patients clinics on different days of the week. The pediatrics Neurology out-patient clinic is held on Fridays from 08:00 hours, the Orthotics and Prosthetics out-patient clinic on Wednesdays from 14:00 hours and the Appropriate Paper Technology assessment day for special equipment is held on Wednesdays from 09:00 hours to 12:00 hours. The researcher would alternate in visiting these areas because some of the days would coincide with the Physiotherapy out-patient clinics. Selection of cases or controls in these areas depended on the number of patients with CP who came for these services on the clinic days as well as those who met the inclusion criteria.

In all these clinics, the researcher would seek for permission from the caregivers to take measurements for their children and those who met inclusion criteria were included in the study upon obtaining consent from the caregivers. There were two (2) controls taken for each case. Cases and controls were just assigned randomly without matching for any variables.

### **3.9 Data collection**

#### **3.9.2 Procedure for data collection**

The researcher requested for written permission to conduct the study from the UTH management. Upon receiving the approval letter from UTH management, the researcher got permission from the Head of Paediatric Department, the Senior Medical Consultant at Paediatric Neurology Clinic, the nursing officer in charge of ward A07, the chief physiotherapist, the Head of Orthotics and Prosthetics department and the Manager for Appropriate Paper Technology Center.

Identification of cases or controls was done by taking anthropometric measurements using WHO guidelines for anthropometry (WHO, 2006). When a case or control is identified, the researcher would introduce herself to the child's mother or caregiver and explain the purpose of the study and the procedure to each one of them.

The researcher used the child's medical records to ascertain the nutrition status for those who were admitted to Ward A07. After ascertaining the nutritional status, the researcher would then seek for permission from the caregiver. If the caregiver accepted to be interviewed, the interview and assessment of the child was done there and then or later in the day at a time appropriate to the caregiver.

As for out-patients, ascertaining of nutritional status was done after the researcher took anthropometric measurements which were then compared with the WHO growth standards. Upon ascertaining the nutritional status, the purpose of the study was then explained to the caregivers and those who gave consent were recruited and interviewed done or scheduled to a later date.

Before conducting the interview and assessment of the child, the researcher would introduce herself and explain the purpose of the study to the caregiver using an information sheet. Informed consent was obtained to those caregivers who accept to participate by reading the informed consent for them or by themselves which they later signed. All data for the Child data collection tool was done by the

researcher assessing the child as well as face to face interviews with the caregivers. For the Caregiver data collection tool, data was either collected through face to face interviews or self-administered for those caregivers who were able to read and write.

### **3.9.3 Methods of data collection**

Data collection was carried out by the researcher and using two structured data collection instruments. One instrument, known as the Child data collection tool was used to collect data on the child through physical examination, anthropometric measurements, records from the clinical file and interviews with caregivers. The other instrument which was known as the Caregiver data collection tool was used to record information on caregiver and family socioeconomic characteristics. These instruments were developed by the researcher using the UNICEF Conceptual Framework for Malnutrition, study objectives and as well as adapted for literature on this topic (Kakooza-Mwesige et al., 2015b; Penagini et al., 2015; Minja et al., 2014; Arvedson, 2013; Kuperminc et al, 2013; Samson-Fang & Bell, 2013; Secker, & Jeejeebhoy, 2012; Kuperminc & Stevenson, 2008; UNICEF, 1998). The purpose of this study was to identify the main exposures (independent variables) for severe malnutrition (dependent or outcome variable) among children with CP.

The information collected using the Child data collection tool included the child's demographic data, obstetric history of this child's pregnancy, the child's clinical profile, anthropometric measurement as well as the child's feeding patterns and problems.

- i) Child's demographic characteristics: This included the child's gender, age, position in the family, number of younger siblings, guardian and primary caregiver.
- ii) Obstetric history included history of illness for the mother during pregnancy, problems during birth and mode of delivery.
- iii) Clinical profile included the following variables:
  - Type of CP: Classification of CP was done according to the criteria of Surveillance of CP in Europe (SCPE) (Cans et al., 2007). The main types will include spastic, ataxic and dyskinetic. Sub-types for spastic CP were classified as hemiplegia (unilateral CP), diplegia and quadriplegia (Bilateral CP) while those for dyskinetic CP were classified as dystonic or choreoathetosis (Cans et al., 2007). Classification was done by the researcher who is a Senior

Physiotherapist at UTH as well as trained in Bobath Neuro-Developmental Therapy by the South African Neuro-Developmental Therapy Association.

- Severity of CP: This was done by the researcher using the Gross Motor Functional Classification System (GMFCS) which consists of 5 levels, from level 1 as the mildest form to level 5, which is the most severe form of CP in terms of mobility (Dahlseng, 2012; Rosenbaum et al. 2008).
  - Birth history
  - History of breast feeding
  - Presence of associated impairments such as speech, epilepsy, vision, hearing and learning difficulties (Cans et al. 2007).
  - History of illness in past six months and whether child is on any medication
  - HIV status
- iv) Anthropometry: The measure of nutrition status in children was done using anthropometric measurements because the measurements obtained from these are sensitive to a broad spectrum of malnutrition (Blossner & Onis, 2005). These include obtaining measurements of weight, length (all in recumbent position), and anthropometric z-scores (Karagiozoglou-Lampoudi et al., 2012; Caram, Morcillo, & da Costa Pinto, 2010). This study mainly utilized the weight for age measurements as these were more reliable compared to the length for age as some children had contractures and hence difficult to measure length. Weight-for-age indices were converted into z scores using EPI-info version 7.2. The procedure for collecting age, weight and length were based on the WHO recommended measurement protocols (Onis, 2006). For example, chronological age was determined by asking the mother or caregiver the birth date of the child and compared with the one recorded on the hospital record or growth monitoring card. Body weight was obtained to the nearest 0.1 kg (A&D Personal Precision Scale, Tokyo, Japan). Individuals who could not stand unsupported were weighed with a care giver holding the child and subtracting the weight of the caregiver from the total combined weight. Length for all children was done in recumbent position and was determined using a stadiometer to the nearest 1mm.
- v) Information on feeding patterns and feeding difficulties included presence of feeding difficulties due to oral motor dysfunction as well as complications arising from these feeding difficulties such as history weight gain in the past 2 to 3 months or if child is dependent or

totally independent on feeding. Other complications of feeding difficulties breathing difficulties when feeding, history of chest infections, consistency of food eaten by child and opening bowels (constipation). History of constipation was measured by how often child opens bowels which is defined as “scybalous, pebble-like, hard stools in more than 25% of defaecations and defaecation frequency less than three times a week, or large stools palpable on abdominal examination (scybala), or laxative use or manual disimpaction of faeces (Veugelers et al. 2010). Due to limitations in expertise to confirm constipation according to this definition, the current study defined as opening bowels after 2 to more than 3 days. Lastly information on presence of any behavioral problems associated with feeding was collected.

The information that was collected on the Caregiver data collection tool included caregiver demographic characteristics, family socioeconomic characteristics and feeding practices which involved types of foods given to the child.

- i) Primary caregiver demographic characteristics: In this study, a primary caregiver is the person who is responsible for taking care of the child’s activities of daily living. Included information on the primary caregiver such as gender, relationship with the child, marital status, age, highest educational level and whether caregiver takes alcohol or smokes.
- ii) Family socioeconomic status: Information on socioeconomic status was based on the Central Statistical Office (CSO) [Zambia], Ministry of Health (MOH) [Zambia], and ICF International (2014), variables which are used for measuring family socioeconomic characteristics. The information collected included in whose house the child stays, income earner for the family, highest education for income earner, employment status of income earner, family residential area, ownership of house, number of people living in the house, electricity in the house, source of water, type of toilet used by family, type of fuel used for cooking and number of rooms in the house.
- iii) Feeding practices and concerns: This involved questions on who feeds the child on a regular basis, whether caregiver acknowledges that child has feeding difficulties, how long it takes to feed the child, whether meals are stressful for both the child and caregiver, how many times child is fed per day, whether caregiver prepares food in a special way and whether caregiver is concerned about the child’s feeding patterns (Samsung-Fung & Bell, 2013).

iv) According to Thompson and Subar (2008), dietary assessment methods such as the 24 hour recall are not useful in case-control studies because they require information about diet before on-set of disease. The recommended methods are the Food Frequency Questionnaire (FFQ) or the diet history interview. In the current study, the information about food eaten by the child was adapted from literature including that of Secker and Jeejeebhoy, (2012)'s questionnaire. Caregivers were asked to select the types of food which they usually fed the child most of the time. This list included food groups such as cereals, vegetables, legumes, fruits, meat/poultry, dairy and drinks (fluids). Each group of food consisted of all the common foods including traditional Zambia foods.

### **3.10 Data analysis**

Before analysis, all the data in the questionnaires were checked for missing values and cleaned for any inconsistencies. Data from the questionnaires was entered in Epi info version 7.2 and coded for analysis. All anthropometric raw data was entered into Epi nutrition survey for calculation of z scores.

#### **Descriptive analysis**

Descriptive summaries of individual variables were displayed in frequency tables and histograms for categorical variables as well as means and standard deviations for numerical variables. Comparisons between the dependent variable and continuous independent variables was done by comparing the means between cases and controls and Mann-Whitney U test was used to test the significance of the association because of non-normal distribution of variables. Comparisons between categorical variables were done using cross tabulations in 2 x 2 tables and chi-square was used to test the significance of these associations.

#### **Inferential analysis**

Bivariate analysis and multivariate analysis using simple and multiple logistic regression were used to investigate the association between severe malnutrition and other independent variables. The significance of the associations were determined by unadjusted odds ratios for bivariate analysis using simple logistic regression and adjusted odds ratios using multiple logistic regression. Variables that had more than two categories were dichotomised in order to enable analysis in logistic regression. Variables that had p-values less than 0.05 during simple logistic regression were entered

into multiple logistic regression for adjusted analysis. After entering variables in a multiple logistic regression model, all those that were not significant with p-values greater than 0.05 were eliminated, starting with those with the highest p-value until only those with p-values of less than 0.05 were left in the model. Odds ratios and 95% confidence intervals and p-values were reported for statistically significant associations between the dependent and independent variables. For all analysis, a p-value of  $< 0.05$  was considered significant at 95% confidence interval.

### **3.11 Pilot test**

A pilot test for both data collection tools was carried out at one of the urban health centers which provide physiotherapy services in Lusaka. For each of the two data collection tools, 10 questionnaires were filled in and this enabled the researcher to identify any difficulties or irregularities that may arise with the data collection techniques. The researcher was also able to determine how long it would take to collect data for both questionnaires, remove any unnecessary information as well as including all relevant information that was left out in the initial tools.

### **3.12 Validity**

Errors such as chance and bias in this study were minimized because there was no chance of non-response as data collection was done by the researcher only on those participants who accepted to participate. Malnutrition was clearly defined using standardized tools and measurement for both cases and controls was done in the similar manner by the researcher. Both cases and controls were clearly defined using the WHO classification for malnutrition and all cases and controls were obtained from the same institution (UTH). Confounding variables such as history of illness within the past three (3) months, presence of other illnesses such as TB, sickle cell disease and other chromosomal disorders were excluded from the study. During analysis, possible confounders such as age and gender were addressed by stratifying them and all were found to have no effect on the presence of severe malnutrition.

### **3.13 Reliability**

Reliability was addressed by clearly defining variables using standard measures and all anthropometric z-scores were calculated using Epi nutrition survey with the help of a statistician. Collection of data on variables such classification and severity of CP was done by the principle researcher who is qualified physiotherapist and Bobath trained therapist, using standardized



classification systems such as the Surveillance of CP in Europe (SCPE) (Cans et al. 2007) and the GMFCS (Rosenbaum et al. 2008).

Other methods of ensuring reliability of anthropometric measurements included the researcher taking measurements twice (intra rater), regular calibration of the scale and prevention of tiredness on the person taking the measurements (Ulijaszek & Kerr, 1999). Since this study only considered weight for age, there were minimal errors because weight measurements are said to be the easiest and most reliable measures of anthropometry (Yin et al., 2013).

### **3.14 ETHICAL CONSIDERATION**

Ethics approval was obtained from the Senate Research Committee of the University of the Western Cape (**Reference no.15/7/253**). Ethics clearance was also sought from the Excellence in Research Ethics Science (ERES) Converge in Zambia (**Reference no. 2016-Apr-008**). Written permission to conduct the study at UTH was obtained from the UTH management. The study objectives and procedures were explained to the caregivers of eligible children, using the information sheet that was translated into four (4) common local languages. Caregivers were informed that there would be no direct benefits from participating, but results from this study may help with improving health care services for children with CP. Caregivers were also informed that they have the right to withdraw at any time without any consequences to the child's health care services and that there would be minimal harm arising from this study. If any harm arises in the form of emotional or psychological stress, they were informed that measures have been put in place to be attended to by professionals in this area. They were also assured of confidentiality and that they would only be identified using codes and any information they give was only known by the researcher and used for purposes of this research. Consent was then obtained by asking them to read and sign the consent form.

## CHAPTER 4

### RESULTS

#### 4.1 Introduction

This chapter outlines the results of the current study presented under descriptive and inferential statistics. Descriptive statistics are presented using frequency tables and graphs for categorical data and means and standard deviations for numerical data. Cross tabulations are used to test for associations between the dependent and independent variables. Inferential statistics for associations between the dependent and independent variables are presented as crude odds ratios for bivariate analysis and adjusted odds ratios for multiple logistic regression analysis. A p-value of  $< 0.05$  and 95% confidence intervals was considered significant.

The results of descriptive statistical analysis are presented first followed by inferential statistics showing results of the associations between malnutrition and the various descriptive characteristics:

#### 4.2 Descriptive analysis

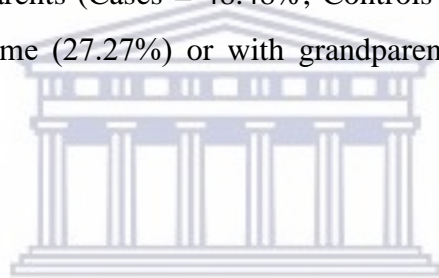
The results of descriptive analysis will be presented under demographic characteristics, obstetric and birth history, child clinical profile, feeding problems and complications, feeding practices and concerns and lastly type of children given to the child:

- Demographic characteristics: Child demographic characteristics, demographic characteristics of primary caregiver, income earner characteristics and family socioeconomic characteristics.
- Obstetric and birth history: History of mother ill during pregnancy, problem during birth, mode of delivery, history of child crying at birth, history of illness after birth, history of child breast feeding.
- Child clinical profile: Type of CP, classification, GMFCS, history of illness in the past six months, currently taking medication, condition for which medication is taken, HIV status of child and associated impairments.
- Feeding problems and complications
- Feeding practices and concerns
- Types of food given to child

#### 4.2.1 Child demographic characteristics

The study consisted of a sample of 99 children with CP that included 33 cases and 66 controls. There was no matching for any variables and therefore the gender and age distribution of cases and controls are not the same. The sample included 45 males and 54 females, with age ranging from 24 months to 120 months. The mean age for cases was 60.52 months (SD = 33.0) while 59.97 months (SD = 27.67) was for controls. Mean weight for age z-scores (WAZ) for cases was -4.7170 and -1.3280 for controls and Mann-Whitney U test shows that this was statistically significant (0.0001).

Cases and controls did not differ significantly in most demographic characteristics such as gender ( $p= 0.0868$ ), age in months ( $p= 0.78920.0$ ), position in family ( $p= 0.0654$ ) and number of younger siblings ( $p= 0.9502$ ). Table 4.1 also shows that majority of both cases and controls had biological parents alive (cases = 84.84%; controls = 90.91%). However, despite the majority of cases living in the house of both biological parents (Cases = 48.48%; Controls = 66.67%), there were more cases living in a single mother's home (27.27%) or with grandparents (24.24%) compared to controls (10.61%; 12.12% respectively).



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**Table 4.1 Demographic characteristics of cases and controls**

Variable	Cases n =33 (%)	Controls n=66 (%)	All n=99 (%)	p-value
<b>GENDER</b>				<b>0.0868</b>
Male	19 (57.58)	26 (39.39)	45 (45.45)	
Female	14 (42.42)	40 (60.61)	54 (54.55)	
Total	33 (100.00)	66 (100.00)	99 (100.00)	
<b>Age (Months)</b>				<b>0.8186</b>
Mean	60.5152	59.9697	59.9490	
Median	50.00	61.00	56.00	
Mode	28.00	24.00	24.00	
Standard deviation	33.0985	25.7635	28.2757	
<b>Weight for age Z-score (WAZ)</b>				<b>0.0001</b>
Mean	-4.7170	-1.3280	-2.4577	
Median	-5.0000	-1.4800	-1.9800	
Mode	-5.0000	-2.0900	-5.0000	
Standard deviation	0.4731	0.9327	1.7968	
<b>Is this child the first born?</b>				<b>0.0654</b>
Yes	23 (69.70)	33 (50.00)	56 (57.57)	
No	10 (30.30)	33 (50.00)	43 (43.43)	
Total	33 (100.00)	66 (100.00)		
<b>Number of younger siblings</b>				<b>0.9502</b>
0	22 (66.67)	43 (65.15)	65 (65.66)	
1	8 (24.24)	21 (31.82)	29 (29.29)	
2	3 (9.09)	2 (3.03)	5 (5.05)	
Total	33 (100.00)	66 (100.00)	99 (100.00)	
<b>Both biological parents alive</b>				<b>0.6011</b>
Yes	28 (84.85)	60 (90.91)	88 (88.89)	
No	5 (15.15)	6 (9.09)	11 (11.11)	
Total	33 (100.00)	100 (100.00)		
<b>Child stays in whose house</b>				<b>0.0149</b>
Both biological parents	16 (48.48)	44 (66.67)	60 (60.61)	
Grandparents	8 (24.24)	8 (12.12)	16 (16.16)	
Single mother	9 (27.27)	7 (10.61)	16 (16.16)	
Other	0 (0.00)	7 (10.61)	7 (7.07)	
Total	33 (100.00)	66 (100.00)	99 (100)	

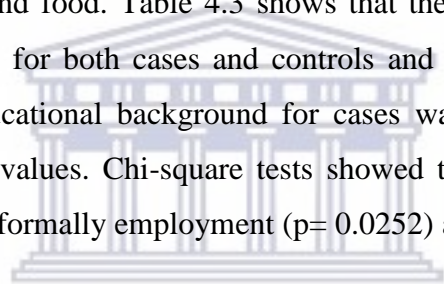
#### **4.2.2 Demographic characteristics of primary caregivers**

Majority of the primary caregivers for both cases and controls were biological mothers and their education background was mainly primary or secondary education as shown in Table 4.2. Majority of caregivers were aged between 25 to 34 years for both cases and controls, while the minority were aged 45 years and above for both cases and controls.

Results on most of the demographic characteristics of primary caregivers show that the two groups were not very different from each other (Table 4.2). Chi-square tests showed no significant association between severe malnutrition and caregiver demographic characteristics as all p-values were above 0.05 as shown in Table 4.2.

#### **4.2.3 Demographic characteristics of income earner**

The income earner in this study is any person who is responsible for providing the basic needs of the family which include shelter and food. Table 4.3 shows that the father or mother was the income earner for majority of families for both cases and controls and therefore this was not statistically significant. Income earner educational background for cases was not very different from that of controls as shown from the p-values. Chi-square tests showed that statistically significantly more income earners of controls had formally employment ( $p= 0.0252$ ) as shown in Table 4.3.



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**Table 4.2 Demographic characteristics of primary caregiver**

Characteristic	Case n=33 (%)	Controls n=66 (%)	P-value
<b>Primary care giver</b>			0.1425
Biological mother	27 (81.82)	47 (71.21)	
Grandmother	3 (9.09)	6 (9.09)	
Aunt	2 (6.06)	3 (4.55)	
Other	1 (3.03)	10 (15.15)	
Total	33 (100.00)	66 (100.00)	
<b>Gender of caregiver</b>			0.2136
Male	0 (0.00)	63 (95.45)	
Female	33 (100.00)	3 (4.55)	
Total	33 (100.00)	66 (100.00)	
<b>Age range for caregivers</b>			0.6608
15-24	9 (27.27)	13 (19.70)	
25-34	15 (45.45)	27 (40.91)	
35-44	6 (18.18)	17 (25.76)	
45 years and above	3 (9.09)	9 (13.64)	
Total	33 (100.00)	66 (100.00)	
<b>Highest Level of education</b>			0.6802
No education	0 (0.00)	2 (3.03)	
Primary education	9 (27.27)	24 (36.36)	
Junior secondary level	12 (36.36)	17 (25.76)	
Senior secondary level	10 (30.30)	17 (25.76)	
Tertiary (Certificate or diploma)	2 (6.06)	5 (7.58)	
University degree (BSc, Master, PHD)	0 (0.00)	1 (1.52)	
Total	33 (100.00)	66 (100.00)	
<b>Does caregiver smoke?</b>			0.1583
Yes	1 (3.03)	0 (0.00)	
No	32 (96.97)	66 (100.00)	
Total	33 (100.00)	66 (100.00)	
<b>Does caregiver take alcohol?</b>			0.0773
Yes	3 (0.09)	1 (1.56)	
No	30 (90.91)	63 (98.44)	
Total	33 (100.00)	64* (2 missing responses)	
<b>Marital status if caregiver is mother</b>	(n=27) (%)	(n=47)	0.4173
Married	18 (66.67)	36 (75.00)	
Separated/Divorced	1 (3.70)	2 (4.17)	
Single	6 (22.22)	9 (18.75)	
Widowed	2 (7.41)	1 (2.08)	
Total	27 (100.00)	47 (100.00)	

**Table 4.3 Demographic characteristics of income earner**

Variable	Case n= 33 (%)	Control n =66 (%)	P-value
<b>Income earner</b>			<b>0.2969</b>
<b>Father or mother</b>	24 (72.73)	54 (81.82)	
<b>Other</b>	9 (27.27)	12 (18.18)	
<b>Total</b>	33 (100.00)	66 (100.00)	
<b>Highest Level of education of income earner</b>			<b>0.7653</b>
No education	1 (3.03)	1 (1.54)	
Primary education	5 (15.15)	14 (21.54)	
Junior secondary level	5 (15.15)	7 (10.77)	
Senior secondary level	12 (36.36)	19 (29.23)	
Tertiary (Certificate or diploma)	9 (27.27)	18 (27.69)	
University degree (BSc, Master, PHD)	1 (3.03)	6 (9.23)	
Total	33 (100.00)	65* (100.00)	
<b>Employment status of income earner</b>			<b>0.0252</b>
Formal employment	11 (33.33)	32 (49.23)	
Self-employed	19 (57.58)	33 (50.77)	
Not employed	3 (9.09)	0 (0.00)	
Total	33 (100.00)	65* (1 missing response)	

#### 4.2.4 Family socioeconomic characteristics

Table 4.4 shows that the family socioeconomic characteristics were similar in most variables between cases and controls except for type of toilet which had a p-value less than 0.05 during cross tabulation ( $p=0.0365$ ). Results on type of toilet used by family shows that 72.73% of cases' families used unflushed pit latrine compared to controls (45.45%) who reported using flushed toilet with sewerage system (40.91% vs 15.15%).

**Table 4.4 Family socioeconomic characteristics**

Variable	Case n= 33 (%)	Controls n = 66 (%)	P-Value
<b>Residential area</b>			<b>0.14</b>
Low density area	2 (6.06)	12 (18.18)	
Medium density area	10 (30.30)	24 (36.36)	
High density area	21 (63.64)	30 (45.45)	
Total	33 (100.00)	66 (100.00)	
<b>House ownership</b>			<b>0.4715</b>
Own	11 (33.33)	22 (33.33)	
Rented	19 (57.57)	27 (40.91)	
Other	3 (9.09)	17 (25.75)	
Total	33 (100.00)	66 (100.00)	
<b>Number of people living in house</b>			<b>0.1354</b>
Less than 4	14 (42.42)	18 (27.27)	
5-6 people	8 (24.24)	25 (37.88)	
7-10 people	9 (27.27)	19 (28.79)	
More than 10 people	2 (6.06)	4 (6.06)	
Total	33 (100.00)	66 (100.00)	
<b>Electricity in the house</b>			<b>0.2969</b>
Yes	24 (72.73)	54 (81.82)	
No	9 (27.27)	12 (18.18)	
Total	33 (100.00)	66 (100.00)	
<b>Source of water (Own tap)</b>			<b>0.8443</b>
Yes	15 (45.45)	42 (63.64)	
No	18 (54.55)	24 (36.36)	
Total	33 (100.00)	66 (100.00)	
<b>Type of toilet used by household</b>			<b>0.0365</b>
Flush toilet to piped sewer system	5 (15.15)	27 (40.91)	
Flush toilet piped to piped septic tank	2 (6.06)	7 (10.61)	
Flush pit latrine	2 (6.06)	2 (3.03)	
Unflushed pit latrine	24 (72.73)	30 (45.45)	
Total	33 (100.00)	66 (100.00)	
<b>Do you share toilet with other household</b>			<b>0.0667</b>
Yes	22 (66.67)	31 (46.97)	
No	11 (33.33)	35 (53.03)	
Total	33 (100.00)	66 (100.00)	
<b>Number of sleeping rooms in house</b>			<b>0.0763</b>
1 or 2	25 (75.76)	38 (57.58)	
3 or more	8 (24.24)	28 (42.42)	
Total	33 (100.00)	66 (100.00)	



#### 4.2.5 Obstetric history

Majority of mothers of cases and controls reported uneventful pregnancy histories except for 19.70% of controls whose mothers had hypertension (Table 4.5). During birth, over half (54.55%) of the mothers of cases were reported to have prolonged labour compared to controls (34.85%). The majority of cases and controls were born through normal spontaneous vaginal delivery. None of the variables under obstetric history were statistically significant as can be seen from the p-values in Table 4.5.

**Table 4.5 Pregnancy history for cases and controls**

Variable	Cases n (%)	Controls n (%)	P-value
Did mother suffer from any of the following during pregnancy?	Yes =n (%)	Yes =n (%)	<b>0.421</b>
Measles	0 (0.00)	0 (0.00)	
Diabetes	0 (0.00)	0 (0.00)	
Hypertension	1 (3.03)	13 (19.70)	
Malaria	1 (0.00)	3 (4.55)	
Other problems	3 (9.09) **	4 (6.06) **	
Did any of the following happen during birth?	Yes =n (%)	Yes =n (%)	<b>0.4232</b>
Prolonged labour	18 (54.55)	23 (34.85)	
Premature birth	0 (0.00)	5 (7.58)	
Pre-eclampsia	0 (0.00)	2 (3.03)	
Breech delivery	4 (12.12)	6 (9.09)	
Other problems	4 (12.12) **	8 (12.12) **	
What was the mode of delivery	n= 33 (%)	n= 66 (%)	<b>0.6512</b>
Spontaneous vaginal delivery	30 (90.91)	58 (87.88)	
Caesarian section	3 (9.09)	8 (12.12)	
Total	33 (100.00)	66 (100.00)	

NB: \*\*Results for complications during pregnancy and during birth will not add up to 100% because some mothers did not experience any of the complications.

#### 4.2.6 Birth history

Results on birth history show that over 50% of children for both cases and controls did not cry at birth. Problems suffered by the child at birth were all not statistically significant as shown in Table 4.6. Seizures were reported to be the most common problem experienced among cases and controls, with the frequency being higher in cases (63.64%) compared to controls (49.18%). When cross tabulation was done for seizures alone, chi-square tests showed that this was still not statistically

significant ( $p= 0.0879$ ). Over 90% of both cases and controls were breast fed and the average breastfeeding period in both cases and controls was between 13 to 18 months.

**Table 4.6 Birth history for cases and controls**

Variables	Cases n= 33 (%)	Controls n= 66 (%)	P-value
<b>Did baby cry at birth</b>			<b>0.1719</b>
Yes	11 (34.38)	30 (49.18)	
No	21 (65.63)	31 (50.82)	
Total	32* (1 missing response)	61* (5 missing responses)	
<b>Did child suffer from any of the following after birth</b>	<b>Yes= n (%)</b>	<b>Yes= n (%)</b>	
Seizures/epilepsy	21 (63.64)	30 (45.45)	0.0879
Meningitis	5 (15.15)	12 (18.18)	0.7063
Difficulty breathing	9 (27.27)	15 (22.73)	0.6188
Cerebral malaria	0 (0.00)	1 (1.52)	0.4773
Head trauma (other)	0 (0.00)	0 (0.00)	0.8469
Hydrocephalus	2 (6.06)	3 (4.55)	0.7455
Jaundice	8 (24.24)	13 (19.70)	0.6020
Total	**	**	
<b>Was child breast fed</b>	<b>n= 33 (%)</b>	<b>n= 66 (%)</b>	<b>0.5792</b>
Yes	30 (90.91)	62 (93.94)	
No	3 (9.09)	4 (6.06)	
Total	33 (100.00)	66 (100.00)	
<b>How long was child breast fed?</b>			<b>0.9520</b>
0-6 months	3 (9.09)	5 (8.06)	
7-12 months	5 (15.15)	9 (14.52)	
13-18 months	13 (43.33)	24 (38.71)	
17-24 months	8 (26.67)	21 (33.87)	
Over 24 months	1 (3.33)	3 (4.84)	
Total	30* (3 missing responses)	62* (4 missing responses)	

NB:\*\* Total will not add up to 100% because some children did not experience any problems while other experienced more than one problem

## 4.2.7 Clinical profile of cases and controls

### 4.2.7.1 Type of cerebral palsy

The type of CP consisted of spastic, ataxic and dyskinetic CP. In both groups combined as well as separately, the most common type of CP was spastic CP followed by Dyskinetic CP as shown in Table 4.7. Despite spastic CP being the most common type of CP for both groups, there were more cases with spastic CP compared to controls. However, chi-square tests showed no significant association between severe malnutrition and type of CP ( $p= 0.0879$ ).

**Table 4.7 Types of cerebral palsy**

Variables	Cases n= 33 (%)	Controls n= 66 (%)	All n= 99 (%)	P-value
				0.4687
<b>Spastic</b>	21 (63.64)	36 (54.55)	57 (57.58)	
<b>Dyskinetic</b>	12 (36.36)	28 (42.42)	40 (40.40)	
<b>Ataxic</b>	0 (0.00)	2 (3.03)	2 (2.02)	
<b>Total</b>	33 (100.00)	66 (100.00)	99 (100.00)	

**4.2.7.2 Classification of cerebral palsy**

The classification of CP consisted of quadriplegia (Bilateral CP), hemiplegia (Unilateral CP), diplegia, choreoathetosis, dystonia and ataxia. Figure 4.1 shows that the most common classification of CP for cases was quadriplegia (48.48%) while choreoathetosis (39.39%) and diplegia (31.82%) were the most common among controls. Cross tabulation for classification of CP using chi-square tests showed a significant association between severe malnutrition and type of CP (Chi-square= 23.5712; df= 4; p= 0.0001).

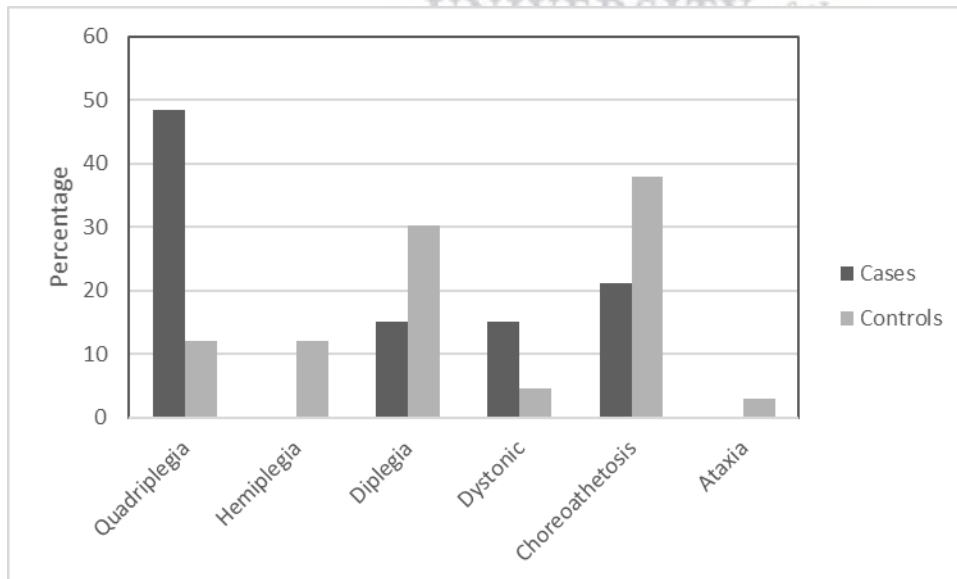


Figure 4.1. Classification of cerebral palsy

#### 4.2.7.3. Gross motor functional classification system (GMFCS)

Figure 4.2 shows the GMFCS levels for cases and controls. Results showed that majority of controls (52%) were level III GMFCS while majority of cases (58%) were level V GMFCS. The proportion of children with level IV GMFCS was equal for cases and controls. Chi-square tests for GMFCS yielded statistically significant results with p-value of 0.0001 (df= 3).

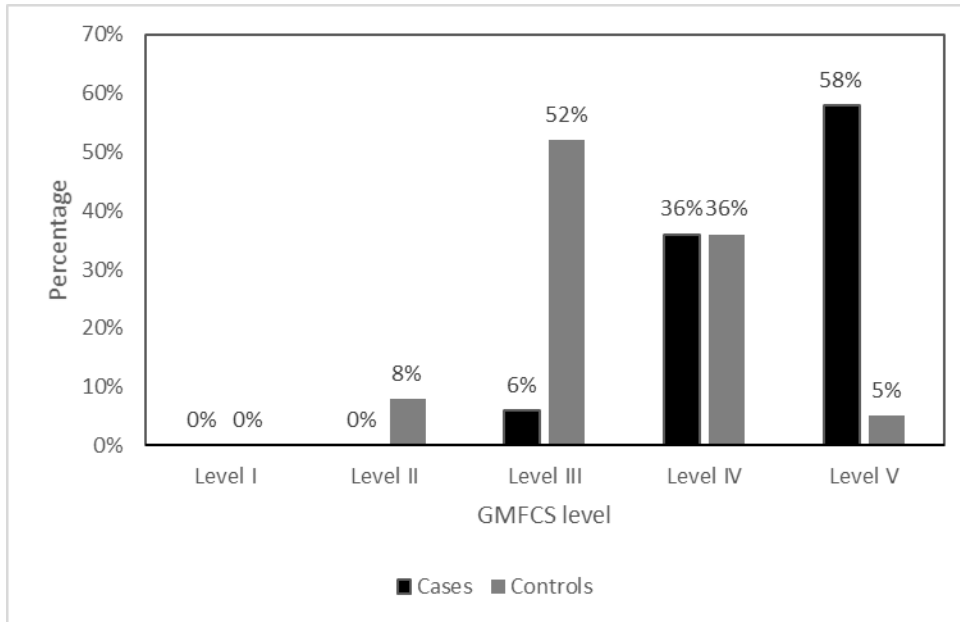


Figure 4.2. Gross Motor Functional Classification Scale for cases and controls

#### 4.2.7.4 Child history of illness and associated impairments

Table 4.8 shows the distribution of the history of illness and associated impairments for both cases and controls. The table shows that more cases were reported to be ill in the past six months and were taking medication compared to controls, with both of these two variables being statistically significant with chi-square p-values of 0.0271 and 0.0079 respectively. Table 4.8 also shows that associated impairments were statistically significant with p-values less than 0.05 were vision and epilepsy.

**Table 4.8 Child history of illness and associated impairments**

Variables	Cases n= 33 (%)	Controls n= 66 (%)	P-value
History of illness past six months			<b>0.0271</b>
Yes	15 (46.88)	16 (24.62)	
No	17 (53.13)	49 (75.38)	
Total	32* (1 missing)	65* (1 missing)	
Currently taking any medication			<b>0.0079</b>
Yes	21 (63.64)	23 (35.38)	
No	12 (36.36)	42 (64.62)	
Total	33 (100.00)	65* (1 missing)	
If taking medical, for what condition	n = 21 (currently taking medication)	n = 23 (currently taking medication)	NA
Epilepsy	15 (71.43)	16 (69.56)	
Infection in severe acute malnutrition	3 (14.29)	0 (0.00)	
Spasticity	2 (9.52)	1 (4.35)	
Cough	0 (0.00)	1 (4.35)	
HIV	0 (0.00)	3 (13.04)	
Epilepsy and spasticity	1 (4.76)	2 (8.70)	
Total	21 (100.00)	23 (100.00)	
HIV status of child	n=33 (%)	n=66 (%)	<b>0.8528</b>
Positive	2 (6.06)	6 (9.09)	
Negative	28 (84.85)	55 (83.33)	
Unknown	3 (9.09)	5 (15.15)	
Total	33 (100.00)	66 (100.00)	
Associated impairments	Yes=n (%)	Yes=n (%)	
- Vision	7 (21.21)	4 (6.06)	<b>0.0237</b>
- Epilepsy	20 (60.61)	21 (31.82)	<b>0.0061</b>
- Speech	32 (92.97)	55 (83.33)	<b>0.0500</b>
- Hearing	1 (3.03)	2 (3.03)	<b>1.0000</b>
- Cognitive impairments	5 (15.15)	15 (22.73)	<b>0.3761</b>
- Total	**	**	

NB: \*\* Not adding up to 100% as some children had more than one associated impairment while others did not have any problem.

#### 4.2.8 Feeding difficulties experienced by the child

Feeding difficulties experienced by the child included the common feeding difficulties resulting from oral motor dysfunction and the complications that are associated with these feeding problems. Feeding difficulties due to oral motor dysfunction included chewing, swallowing, vomiting, choking/coughing, food regurgitation, problems opening the mouth, tonic bite and tongue thrust. Table 4.9 shows that most of the feeding difficulties were statistically significantly more prevalent in cases than controls thus associated with severe malnutrition.

**Table 4.9 Feeding difficulties experienced by the child**

Variable	Cases n=33 (%)	Controls n = 66 (%)	P-value
<b>Chewing difficulties</b>			<b>0.0001</b>
Yes	27 (81.82)	27 (40.91)	
No	6 (18.18)	39 (59.09)	
	33 (100.00)	66 (100.00)	
<b>Swallowing difficulties</b>			<b>0.0001</b>
Yes	18 (54.55)	6 (9.09)	
No	15 (45.45)	60 (90.91)	
	33 (100.00)	66 (100.00)	
<b>Vomiting</b>			<b>0.0010</b>
Yes	11 (33.33)	5 (7.58)	
No	22 (66.67)	61 (92.42)	
	33 (100.00)	66 (100.00)	
<b>Chocking/coughing</b>			<b>0.0015</b>
Yes	18 (54.55)	15 (22.73)	
No	15 (45.45)	51 (77.27)	
	33 (100.00)	66 (100.00)	
<b>Problems opening mouth</b>			<b>0.0265</b>
Yes	5 (15.15)	2 (3.03)	
No	28 (84.85)	64 (96.97)	
	33 (100.00)	66 (100.00)	
<b>Food regurgitation</b>			<b>0.0206</b>
Yes	8 (24.24)	5 (7.58)	
No	25 (75.76)	61 (92.42)	
	33 (100.00)	66 (100.00)	
<b>Tonic bite</b>			<b>0.0001</b>
Yes	15 (45.45)	3 (4.55)	
No	18 (54.55)	63 (95.45)	
	33 (100.00)	66 (100.00)	
<b>Tongue thrust</b>			<b>0.0007</b>
Yes	13 (39.39)	7 (10.61)	
No	20 (60.61)	59 (89.39)	
<b>Total</b>	33 (100.00)	66 (100.00)	

Complications that were associated with feeding problems were obtained through questions that were asked to the caregivers. These questions were: ‘has the child gained weight in the past 2 to 3 months’, ‘are there any signs of difficulty breathing during feeding’, ‘does child frequently suffer from chest infections’, ‘is child totally dependent on feeding’, ‘how long it takes to feed the child’, ‘what is the consistency of food given to the child’ and ‘whether the child open bowels after 3 days’.

Table 4.10 shows that a higher percentage of the cases were reported to have

**Table 4.10 Complications of feeding difficulties**

Variable	Cases n =33 (%)	Controls n= 66 (%)	P-value
Does child have any feeding problems?			0.0005
Yes	30 (90.91)	37 (56.06)	
No	3 (9.09)	29 (43.94)	
Total	33 (100.00)	66 (100.00)	
Has child gained weight in past 2 to 3 months?			0.0001
Yes	8 (24.24)	62 (93.94)	
No	25 (75.76)	4 (6.06)	
Total	33 (100.00)	66 (100.00)	
Any signs of difficult breathing during feeding?			0.0143
Yes	10 (30.30)	7 (10.61)	
No	23 (69.70)	59 (89.39)	
Total	33 (100.00)	66 (100.00)	
child totally dependent on feeding			0.0005
Yes	32 (96.97)	30 (45.45)	
No	1 (3.03)	36 (54.55)	
Does child frequently suffer from chest infections?			0.0007
Yes	13 (39.39)	7 (10.61)	
No	20 (60.60)	59 (89.39)	
Total	33 (100.00)	66 (100.00)	
What is the consistency of food given to child?			0.0006
Semi-solids	26 (78.79)	26 (39.39)	
Liquids	1 (3.03)	1 (1.52)	
Both solids and liquids	6 (18.18)	39 (59.09)	
Total	33 (100.00)	66 (100.00)	
How long does it take to feed child?			0.0012
Less than 10 minutes	1 (3.03)	5 (7.58)	
Less than 30 minutes	10 (30.30)	43 (65.15)	
30 to 60 minutes	18 (54.55)	17 (25.76)	
More than 60 minutes	4 (12.12)	1 (1.52)	
Total	33 (100.00)	66 (100.00)	
Does child open bowels after more 3 or more days?			0.0001
Yes	20 (60.61)	6 (9.09)	
No	13 (39.39)	60 (90.91)	
Total	33 (100.00)	66 (100.00)	

feeding problems (90.91%) compared to controls (56.06%). Majority of cases did not gain weight in the past 2 to 3 months (75.76%) compared to controls who reported gaining weight during the same period (93.94%). Table 4.10 also shows that most of the cases were totally dependent on feeding, only fed on semi-solids and would only open bowels once after 3 or more days compared to controls.

Length of feeding showed that majority of cases were reported to take 30 to 60 minutes feeding (54.55%) compared to majority of controls who took less than 30 minutes (65.15%). Chi-square tests showed that all complications of feeding difficulties reported by caregivers were significantly associated with severe malnutrition as shown from the p-values in Table 4.10.

#### **4.2.9 Caregiver feeding practices and concerns**

Table 4.11 shows the caregiver feeding practices and concerns for both cases and controls. Although the mother was reported to be the person who feeds the child on a regular basis for both cases and controls, cases (78.13%) were more likely to be fed by mothers compared to controls (42.42%). The variable “who feeds child on a regular basis” was statistically significant with chi-square tests showing a p-value of 0.0082. Most of the cases were reported to feed 3 times a day compared to most of controls who were fed 4 times a day and this was statistically significant ( $p= 0.0008$ ). Results from Table 4.11 also shows that majority of caregivers for both cases and controls were not able to prepare special meals for the child and therefore this was not statistically significant ( $p= 0.3384$ ). Although over half of caregivers for cases reported that meals were not stressful (54.55), there were more caregivers who reported stressful meals for either the child, caregiver or both compared to controls and this was statistically significant ( $p=0.0230$ ). Table 4.11 also shows that majority of caregivers for cases were concerned about the child’s feeding patterns (84.85%) compared to caregivers for controls who were concerned (45.31%) and this was statistically significant ( $p= 0.0002$ ).

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**Table 4.11 Feeding practices**

Feeding practices	Cases n= 33 (%)	Controls n= 66 (%)	P-value
<b>Who feeds child on a regular basis?</b>			<b>0.0016</b>
Mother	25 (78.13)	28 (42.42)	
Self	1 (3.13)	19 (28.79)	
Other	6 (18.75)	19 (28.79)	
Total	32* (1 missing response)	66 (100.00)	
<b>Are meals stressful?</b>			<b>0.0230</b>
No	18 (54.55)	54 (81.82)	
Yes to child only	4 (12.12)	4 (6.06)	
Yes to both	8 (24.24)	4 (6.06)	
Yes to caregiver only	3 (9.09)	4 (6.06)	
Total	33 (100.00)	66 (100.00)	
<b>How often do you feed child?</b>			<b>0.0008</b>
Less or equal to 3 times	16 (48.48)	11 (16.67)	
More than 3 times	17 (51.52)	55 (83.33)	
Total	33 (100.00)	66 (100.00)	
<b>Do you prepare food for this child in a special way?</b>			<b>0.3384</b>
Yes	11 (33.33)	16 (24.24)	
No	22 (66.67)	50 (75.76)	
Total	33 (100.00)	66 (100.00)	
<b>In what special ways do you prepare food?</b>	n = 11 (%)	n = 15 * (%) *1 missing response	<b>0.5559</b>
Over cooking only	4 (36.36)	3 (20.00)	
Over cooking and pureeing	2 (18.18)	5 (33.33)	
Pureeing only	5 (45.45)	7 (46.47)	
<b>Have you been concerned about child's feeding patterns?</b>			<b>0.0002</b>
Yes	28 (84.85)	29 (45.31)	
No	5 (15.15)	35 (54.69)	
Total	33 (100.00)	64* (* 2 missing responses)	

#### 4.2.10 Types of food given to the child (Diet)

The types of foods given to the child were categorized into cereals; vegetables; legumes; fruits, meat/poultry/ fish; dairy products; and drinks. With regards to cereals, Table 4.12 shows that both cases and controls were reported to be feeding mainly on maize meal porridge and Nshima. However, controls were also more likely to eat bread (71.21%) and rice (72.73%) than cases and therefore not eating these two cereals were significantly associated with severe malnutrition (Bread  $p = 0.0001$ ; Rice  $p = 0.005$ ). As for vegetables, Table 4.12 shows that cases were less likely to eat most of the vegetables compared to controls and chi-square tests yielded significant p-values except

for green beans ( $P= 0.5163$ ) and carrots ( $p= 1.0000$ ). With regards to legumes, there were very little differences between cases and controls except for beans which was eaten significantly more by controls ( $p=0.0297$ ). There were also similarities between cases and controls with regards to fruits eaten except for mangoes ( $0.0062$ ) and apples/grapes ( $p= 0.0014$ ) which were less likely to be eaten by cases compared to controls. In the meat/poultry/fish category, Table 4.12 shows that cases were less likely to be fed on these foods when compared with the controls. Instead, cases were reported to be more likely to be fed on soups of these products as shown in Table 4.12 and this was statistically significant ( $0.0001$ ).

Except for yoghurt of which significantly fewer cases were likely to consume (Cases = 42.42%; Controls = 65.15%;  $p= 0.0310$ ) there was no statistical significant difference in the proportion of cases and controls who consumed dairy-, fruit- or carbonated drinks as shown in table 4.12. The most common dairy products eaten by both cases and controls were sour milk and yogurt.



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**Table 4.12 Type of food given to the child**

Food types	Cases	Yes= n (%)	Controls	Yes= n (%)	p-value
<b>Cereals</b>					
Bread	9	(27.27)	47	(71.21)	0.0001
Rice	12	(36.36)	48	(72.73)	0.005
Noodles	1	(3.03)	9	(13.64)	0.9877
Maize meal porridge	32	(96.97)	56	(84.85)	0.0704
Nshima (Pulp)*	27	(81.82)	62	(93.94)	0.0592
<b>*A Local thick porridge made with maize meal that is eaten as the main staple food in Zambia.</b>					
<b>Vegetables</b>					
Cassava leaves*	4	(12.12)	27	(40.91)	0.0035
Rape	11	(33.33)	49	(74.24)	0.0001
Cabbage	9	(27.27)	44	(66.67)	0.0002
Sweet potato leaves	1	(3.03)	18	(27.27)	0.0039
Bean leaves*	0	(0.00)	13	(19.70)	0.0062
Carrots	0	(0.00)	6	(9.09)	1.0000
Green beans	1	(3.03)	4	(6.06)	0.5163
Sweet potatoes	2	(6.06)	21	(31.82)	0.0042
Irish potatoes	17	(51.52)	60	(90.91)	0.0001
Bondwe*	11	(33.33)	44	(66.67)	0.0017
Pumpkin leaves*	11	(33.33)	51	(77.27)	0.0001
Mupilu*	2	(6.06)	15	(22.73)	0.0382
Other (Soup for vegetables)	12	(36.36)	3	(4.54)	0.0003
<b>*These are local vegetables commonly eaten in Zambia</b>					
<b>Legumes</b>					
Beans	29	(87.88)	62	(93.94)	0.0297
Peas	1	(3.03)	4	(6.06)	0.5163
Peanuts	18	(54.55)	41	(62.12)	0.4690
Soya beans	11	(33.33)	14	(21.21)	0.1907
Soya chunks*	1	(3.03)	11	(16.67)	0.0500
<b>*Legumes made from soya</b>					
<b>Fruits</b>					
Mangoes	1	(6.06)	20	(30.30)	0.0062
Oranges	19	(57.58)	47	(71.21)	0.1748
Bananas	24	(72.73)	54	(81.82)	0.2969
Pawpaw	2	(6.06)	2	(3.03)	0.4704
Watermelon	1	(3.03)	5	(7.58)	0.3716
Avocado	4	(12.12)	7	(10.61)	0.8211
Pineapples	0	(0.00)	2	(3.03)	0.3124
Other (Grapes or apples)	0	(0.00)	17	(25.76)	0.0014
<b>Meat, Poultry and fish</b>					
Beef	14	(42.42)	54	(81.82)	0.0001
Pork	0	(0.00)	4	(6.06)	0.1488
Lamb	0	(0.00)	0	(0.00)	-
Goat	1	(3.03)	8	(12.12)	0.1380
Chicken	15	(45.45)	54	(81.82)	0.0002
Duck	0	(0.00)	0	(0.00)	-
Liver	2	(6.06)	8	(12.12)	0.3455
Kidney	0	(0.00)	1	(1.52)	0.4773
Fresh/Dry fish	8	(24.24)	51	(77.27)	0.0001
Eggs	16	(48.48)	43	(65.15)	0.1111
Caterpillars	0	(0.00)	2	(3.03)	0.3124
Other (Soups only)	18	(54.54)	8	(12.12)	0.0001
<b>Dairy products</b>					
Fresh milk	7	(21.21)	24	(36.36)	0.1254
Sour milk	21	(63.64)	45	(68.18)	0.6511
Yogurt	14	(42.42)	43	(65.15)	0.0310
Cheese	0	(0.00)	1	(1.52)	0.4773
<b>Type of drinks</b>					
Pure fruit juices	6	(18.18)	20	(30.30)	0.1964
Carbonated drinks	5	(15.15)	14	(21.21)	0.4704
<b>Other types of drinks</b>					
Kabanna*	6	(18.18)	11	(16.67)	
Concentrated juices	3	(9.09)	15	(22.72)	
Supershake*	7	(12.21)	6	(9.09)	
Yess drink*	2	(6.06)	5	(7.58)	
<b>*These are locally produced milk based drinks.</b>					

**NB: The totals for cases and controls under this subheading of food will not be adding up to 100% because some children were fed more than one food item in each category while others did not eat any of the foods in a category.**

### 4.3 Association between severe malnutrition and other independent variables

Tests of association were first done by calculating odds ratios for individual predictor variables using simple logistic regression. Logistic regression analysis was done only on variables that were statistically significant in cross tabulations. Before carrying out simple logistic regression, variables that had more than 2 categories were dichotomised for easy analysis. Variables that were statistically significant with p-values less than 0.05 in simple logistic regression were entered in a multiple logistic regression model for adjusted odds ratios. Using stepwise backward elimination, variables with p-values above 0.05 were eliminated until only those with p-values less than 0.05 remained.

#### 4.3.1 Association between severe malnutrition and family socioeconomic characteristics

Demographic characteristics that were significantly associated with severe malnutrition during cross tabulation were as follows: In whose house the child stays, employment status of income earner and type of toilet used by family. After using simple logistic regression with dichotomous variables, only type of toilet was statistically significant under socioeconomic characteristics as shown in Table 4.13.

**Table 4.13. Family socioeconomic characteristics**

Variable	Crude odds ratio	CI (95%)	p-value**
In whose house does child stay?	0.9186	0.3439-2.4533	0.8654
Is the income earner in formal employment? Yes/No	0.5313	0.5313-0.2226	0.1542
Does toilet flush? Yes/No	0.3125	0.1262-0.7736	0.0119*

\*\*Statistical significance at p-value <0.05.

#### 4.3.2 Association between severe malnutrition and child's clinical profile

The variables under child's clinical profile that were statistically significant during cross tabulation and chi-square tests were classification of CP, GMFCS, history of illness in the past six months, if child is currently taking medication, visual impairment and epilepsy. Table 4.14 presents results of bivariate analysis of the same variables but this time dichotomised and using simple logistic regression. Before adjusting for other variables, the crude odds ratios for all the variables, were statistically significant with p-values less than 0.05 as shown in Table 4.14.

**Table 4.14 bivariate analysis for child's clinical profile**

Variable	Crude odds ratio	CI (95%)	p-value*
Bilateral spastic CP	8.7499	3.3494-22.8562	0.0001
GMFCS level 4 or 5	22.3734	4.9359-101.4144	0.0001
History of illness in the past 6 months	2.7022	1.1044 - 6.6116	0.0271
Currently taking any medication	3.1924	1.3341- 7.6393	0.0091
Epilepsy (Yes/No)	3.2939	1.3809-7.8566	0.0072
Vision (Yes/No)	4.1651	1.1230 – 15.4482	0.0329

\*Statistical significance at p-value <0.05.

In multiple logistic regression using backward elimination, the only variables that remained statistically significant under child clinical profile were CP spastic quadriplegia, GMFCS level 4 and 5 and history of illness in the past 6 months as shown in Table 4.15. Epilepsy and vision were not statistically significant as they had p-values greater than 0.05 after being adjusted for other variables.

**Table 4.15 Multiple logistic regression analysis for child's clinical profile**

Variable	Adjusted odds ratio	CI (95%)	*p-value
CP spastic quadriplegia	5.3858	1.6442-17.6415	0.0054*
GMFCS level 4 or 5	98.4113	10.8196-895.1128	0.0001*
History of illness in the past 6 months	4.0750	1.2023-13.8109	0.0241*
Epilepsy (Yes/No)	0.20752	0.6707-6.4207	0.2052
Vision (Yes/No)	0.9179	0.1849-4.5563	0.9165

\*Statistical significance at p-value <0.05.

### 4.3.3 Association between severe malnutrition and feeding difficulties

Descriptive analysis for the feeding difficulties resulting from oral motor dysfunction showed that most of the cases were more likely to experience these feeding difficulties compared to controls, with chi-square tests showing significant associations between severe malnutrition and all variables under feeding difficulties. In Bivariate analysis using simple logistic regression,

Table 4.16 shows that all the variables under feeding difficulties were statistically significant with p-values less than 0.05.

**Table 4.16 Bivariate analysis for feeding difficulties experienced by children**

Variable	Crude odds ratio	CI (95%)	p-value*
Chewing difficulties	6.5000	2.3636 - 17.8750	0.0003
Swallowing difficulties	12.0000	4.0612 - 35.4576	0.0001
Vomiting	6.1000	1.9045 - 19.5383	0.0023
Chocking and coughing	4.0754	1.6655 - 9.9726	0.0021
Problems opening mouth	5.6997	1.0433 - 31.1386	0.0445
Food regurgitation	3.8981	1.1621 - 13.0754	0.0276
Tonic bite	17.4677	4.5495 - 67.0662	0.0001
Tongue thrust	5.4786	1.9181 - 15.6481	0.0015

\*Statistical significance at p-value <0.05.

When variables under feeding difficulties were put in a multiple logistic regression model (Table 4.17), the only variables that remained statistically significant were swallowing difficulties (OR= 7.9747; CI= 2.4499-25.9583; p= 0.0006) and tonic bite (OR= 11.0462; CI= 2.6036-46.8652; p= 0.0011).

**Table 4.17 Multiple logistic regression analysis for feeding difficulties**

Variable	adjusted odds ratio	CI (95%)	P-value (<0.05)
Chewing difficulties	3.0419	0.9199-10.0593	0.0683
Swallowing difficulties	7.9747	2.4499-25.9583	0.0006*
Vomiting	0.5841	0.1097-3.1097	0.5285
Chocking and coughing	1.1652	0.3397-3.9966	0.8080
Problems opening mouth	1.9793	0.2302-17.0173	0.5340
Food regurgitation	0.7031	0.1149-4.3035	0.7032
Tonic bite	11.0462	2.6036-46.8652	0.0011*
Tongue thrust	1.6396	0.4392-6.1203	0.4619

\*Statistical significance at p-value <0.05.

All variables under complications associated with feeding difficulties were statistically significant during cross tabulation using chi-square tests. In simple logistic regression, all

variables under this category were significant with p-values less than 0.05 as shown in Table 4.18.

**Table 4.18 Bivariate analysis for complications associated with feeding difficulties**

Variable	unadjusted odds ratio	CI (95%)	p-value*
Does child have any feeding problems?	7.8172	2.1706- 28.1532	0.0017
Has child gained weight in past 2 to 3 months?	0.0207	0.0057-0.0748	0.0001
Breathing difficulties when feeding?	3.6609	1.2441-10.7726	0.0184
Does child frequently suffer chest infections?	5.4786	1.9181-15.6481	0.0015
Totally dependent on feeding	38.3974	4.9509-297.7952	0.0005
Food consistency semi-solids or liquids?	6.4985	2.3633-17.8695	0.0003
Feeding more than 30 minutes?	5.3333	2.1596-13.1708	0.0003
Open bowel after 2 to 3 days (Constipation)	15.3845	5.1637-45.8360	0.0001

\*Statistical significance at p-value <0.05.

When placed in a multiple logistic regression model using backward elimination (Table 4.19), the only variables under complications associated with feeding difficulties that remained statistically significant (p-value <0.05) were child not gained weight in the past 2 to 3 months (p= 0.0001), totally dependent for feeding (p= 0.00061), taking only semi-solids or liquids (0.0231) and opening bowels after 3 or more days (0.0057).

**Table 4.19 Multiple logistic regression analysis for complications associated with feeding difficulties**

Variable	Adjusted odds ratio	CI (95%)	p-value*
Does child have any feeding problems?	0.4172	0.0274-6.3626	0.5294
Has child gained weight in past 2 to 3 months?	0.0247	0.0040-0.1516	0.0001*
Breathing difficulties when feeding?	0.3644	0.0443-2.9947	0.3475
Does child frequently suffer chest infections?	1.9715	0.2904-13.3845	0.4873
Totally dependent on feeding	51.8398	3.0910-869.4038	0.0061*
Food consistency only semi-solids or liquids?	0.0615	0.0055-0.6820	0.0231*
Feeding more than 30 minutes?	7.5529	1.1176-5.0412	0.0381*
Open bowel after 3 days	10.9714	2.0050-60.0360	0.0057*

\*Statistical significance at p-value <0.05.

#### 4.3.6 Association between severe malnutrition and feeding practices/concerns

Caregiver feeding practices and concerns that were statistically significant during cross tabulation with chi-square tests were as follows: who feeds the child on a regular basis, if meals are stressful, how often the child is fed and if caregiver is concerned about the child's feeding difficulties. Apart from caregiver concerned about child's feeding difficulties, the other three variables were dichotomised for analysis in logistic regression as shown in Table 4.20. During bivariate analysis in simple logistic regression, variables that were statistically significant were child being fed by mother regularly (p=0.0024), child fed for 3 times or less per day (p=0.0013) and caregiver concerned about the child's feeding difficulties (p=0.0005) as shown in Table 4.20.

**Table 4.20 Bivariate analysis of feeding practices**

Variable	Crude odds ratio	Confidence interval	p-value
Child regularly fed by mother?	4.2410	1.6668-10.7906	0.0024
Are meals stressful (Yes/No)	1.5501	0.3260-7.3699	0.5817
Child fed ≤ 3 times? Yes/No	4.6986	1.8341-12.0368	0.0013
Caregiver concerned about child's feeding?	6.7557	2.3145-19.7187	0.0005

\*Statistical significance at p-value <0.05

When the variables that were significant at bivariate analysis were entered in multiple logistic regression model, variables that remained statistically significant were child fed 3 times or less per day and caregiver concerned about the child's feeding difficulties as shown in Table 4.21.

**Table 4.21 Multiple logistic regression analysis of feeding practices**

Variable	Odds ratio	Confidence interval	p- value*
Child regularly fed by mother?	3.0354	1.0133-9.0922	0.0473 (=0.05)
Child fed ≤ 3 times? Yes/No	5.4434	1.8137-16.3373	0.0025*
Caregiver concerned about child's feeding	5.0040	1.5350-16.3127	0.0076*

\*Statistical significance at p-value <0.05

#### 4.3.7 Association between severe malnutrition and types of food given to child

All foods that were significant during cross tabulation were analysed in simple and multiple logistics regression according to categories. Later, all those foods that were statistically



significant during adjusted analysis within individual categories were entered in a multiple logistic regression model with other foods from other categories.

The cereals that were significant during cross tabulation were bread and rice. These remained statistically significant even in simple logistic regression as shown in Table 4.22. When the two cereals were entered in a multiple logistic regression model, both cereals remained statistically significant as shown in Table 4.23.

**Table 4.22 Bivariate analysis for cereals given to child**

Variable	Crude odds ratio	CI (95%)	p-value*
Bread	0.1516	0.0596 - 0.3855	0.0001
Rice	0.2143	0.0878 - 0.5231	0.0007

\*Statistical significance at p-value <0.05

**Table 4.23 Multiple logistics regression analysis for cereals given to the child**

Variable	Crude odds ratio	CI (95%)	p-value*
Bread	0.2086	0.9782-0.5564	0.0017
Rice	0.3378	0.011281-0.8905	0.0282

\*Statistical significance at p-value <0.05

#### **4.3.8 Association between severe malnutrition and vegetables given to child**

During cross tabulation, all vegetables (except carrots and green beans) were statistically significant with chi-square tests showing p-values of less than 0.05. When these vegetables which were statistically significant during cross tabulation were analysed in simple logistic regression, the results shows that most of them still remained statistically significant as shown in Table 4.24.

**Table 4.24 Bivariate analysis for Vegetables**

Variable	Crude odds ratio	CI (95%)	p-value*
Cassava leaves	0.1993	0.0628 - 0.6324	0.0062
Rape	0.1735	0.0698 - 0.4310	0.0002
Cabbage	0.1875	0.0746 - 0.4711	0.0004
Sweet potato leaves	0.0	0.0106 - 0.6557	0.0038
Bean leaves	0.0001	Undefined	0.0062
Sweet potatoes	0.1382	0.0302 - 0.6326	0.0108
Irish potatoes	0.1063	0.0360 - 0.3134	0.0001
Bondwe	0.2500	0.1030 - 0.6066	0.0022
Pumpkin leaves	0.1471	0.0583 - 0.3708	0.0001
Other (Soup for vegetables)	6.9714	2.1961 - 22.1302	0.0010

\*Statistical significance at p-value <0.05

During adjusted analysis of vegetables using multiple logistic regression, vegetables that remained statistically significant were pumpkin leaves and Irish potatoes as shown in Table 4.25.

**Table 4.25 Multiple logistic regression analysis for Vegetables**

Variable	Adjusted odds ratio	CI (95%)	p-value
Cassava leaves	0.9284	0.1918-4.4936	0.9265
Rape	0.7297	0.1879-2.8335	0.6489
Cabbage	1.0781	0.2293-5.0686	0.9241
Sweet potato leaves	0.1262	0.0130-1.2229	0.0741
Sweet potatoes	0.3445	0.0654-1.8162	0.2090
Irish potatoes	0.1388	0.0436-0.4423	0.0008*
Bondwe	1.4925	0.3269-6.8135	0.6052
Pumpkin leaves	0.1868	0.0689-0.5063	0.0010*
Other (Soup for vegetables)	1.1468	0.2373-5.5428	0.8647

\*Statistical significance at p-value <0.05

When legumes were analysed using cross tabulation, chi-square tests showed that only beans was statistically significant with a p-value of 0.0297 as shown in Table 4.12 under descriptive analysis. When beans was analysed in simple logistic regression, it was not statistically significant as the p-value yielded from this was 0.3059.

#### **4.3.9 Association between severe malnutrition and Meat/Poultry/Fish given to child**

When Meat/Poultry/Fish products were analysed in cross tabulation, the foods that were statistically significant were beef, chicken, fish and soups for these products. In simple logistic regression, results shows that these variables remained statistically significant with cases less likely to be fed beef, chicken and fish but more likely to be fed soups for these foods (Table 4.26).

**Table 4.26 Bivariate analysis for Meat/Poultry/Fish**

Variable	Crude Odds ratio	CI (95%)	p-value*
Beef	0.1637	0.0645-0.4157	0.0001
Chicken	0.1852	0.0732-0.4683	0.0004
Fish (Dry/Fresh)	0.0941	0.0352-0.2514	0.0001
Meat/poultry soups	9.4117	3.1904-27.7650	0.0001

\*Statistical significance at p-value <0.05

When the Meat/Poultry/Fish products that were statistically significant at bivariate analysis were put in multiple logistic regression and using backward elimination, only Fish remained significant as the food that was less likely to be fed to cases (p=0.0022) as shown in Table 4.27.

**Table 4.27 Multiple logistic regression analysis for meat/poultry/fish products**

Variable	Adjusted Odds ratio	CI (95%)	p-value
Beef	1.4435	0.2810-7.4165	0.6602
Chicken	1.0020	0.0974-10.3129	0.9987
Fish (Dry/Fresh)	0.1569	0.0479-0.5142	0.0022*
Meat/poultry soups	2.6667	0.7146-9.9507	0.1443

\*Statistical significance at p-value <0.05

#### **4.3.10 Association between severe malnutrition and Fruits given to child**

Cross tabulation for fruits using chi-square tests showed that only mangoes remained statistically significant with a p-value of 0.0062 as shown in Table 4.12. In simple logistic regression, mangoes remained statistically significant with an odds ratio of 0.1489, CI= 0.0325-0.6816 and a p-value of 0.0141.

#### **4.3.11 Association between severe malnutrition and dairy products**

Cross tabulation for dairy products showed that only yogurt was statistically significant with a p-value of 0.0310 (Table 4.12). In simple logistic regression for yogurt, this remained statistically significant with odds ratio of 0.3942, CI of 0.1675-0.9280 and a p-value of 0.0331.

#### 4.3.12 Multiple logistic regression for all foods that were statistically significant during adjusted analysis within their categories

All foods that remained statistically significant during adjusted analysis within their categories included bread, rice, Irish potatoes, pumpkin leaves and fish. Mangoes and yogurt did not undergo multivariate analysis in their food categories because they were the only significant foods in simple logistic regression as well as chi-square tests using cross tabulation. These foods were adjusted for foods that were significant in other categories and results of the multivariate analysis for these foods are shown in Table 4.28. This analysis showed that only Irish potatoes and Fish remained statistically significant as foods that were less likely to be given to cases with p-values of 0.0008 and 0.0001 respectively.

**Table 4.28 Multivariate analysis of foods from all significant food categories**

Variable	Adjusted Odds ratio	CI (95%)	p-value
Bread	0.5733	0.1572-2.0901	0.3992
Rice	0.4580	0.1497-1.4632	0.1917
Irish potatoes	0.1181	0.0340-0.4106	0.0008*
Fish (Dry/Fresh)	0.1017	0.0346-0.2986	0.0001*
Pumpkin leaves	0.3325	0.1100-1.0051	0.0511
Mangoes	0.2234	0.0321-1.5549	0.1300
Yogurt	0.9600	0.2987-3.0850	0.9453

#### 4.4 Summary of chapter 4

This case control study compared characteristics of children with cerebral palsy who had severe malnutrition and those without severe malnutrition. Both chi-square tests and logistic regression were used to determine the strength of associations between severe malnutrition and other independent variables. Variables that were significant during cross tabulation using chi-square tests were entered into simple logistic regression and crude odds ratios were calculated. Those that were statistically significant were then entered into multiple logistic regression according to different categories and the following variables remained statistically significant.

Under family socioeconomic characteristics, only type of toilet used by the family remained statistically significant. Cases were more likely to use a non-flushed pit latrine toilet compared to controls ( $p=0.0119$ ). Variables under child's clinical profile that remained statistically significant after multiple logistic regression were spastic quadriplegia or bilateral CP ( $p=0.0054$ ), GMFCS level 4 or 5 ( $p=0.0001$ ) and history of illness in the past six months ( $p=0.0241$ ). The clinical profile of children showed that cases were more likely to be spastic quadriplegia, more likely to be level 4 or 5 GMFCS and more likely to be reported to be ill in the past six months.

With regards to feeding difficulties, cases were reported to be likely to have swallowing difficulties ( $p=0.0006$ ) and tonic bite ( $p=0.0011$ ) as these variables remained statistically significant in multiple logistic regression. As for complications of feeding difficulties, variables that remained significant after multiple logistic regression were child not gained weight in the past 2 to 3 months ( $p=0.0001$ ), child dependent on feeding ( $p=0.0061$ ), child only able to feed on semi-solids or liquids ( $p=0.0231$ ), child feeding for more than 30 minutes ( $p=0.0381$ ) and child opening bowels after 3 or more days ( $p=0.0057$ ). With regards to feeding practices, variables that remained statistically significant were child being fed for 3 times or less per day ( $p=0.0025$ ) and caregiver concerned about the child's feeding difficulties ( $p=0.0076$ ). Foods that remained statistically significant after multiple logistic regression of all food categories were Irish potatoes and Fish. Results showed that cases were less likely to be fed on Irish potatoes ( $p=0.0008$ ) and Fish ( $p=0.0001$ ).

## CHAPTER 5

### DISCUSSION

#### 5.1 Introduction

This chapter discusses the findings of the current study in relation to relevant literature. The main objective of this study was to determine the risk factors that are associated with severe malnutrition in children with cerebral palsy. The discussion will be presented broadly under demographic characteristics, obstetric and birth history, child clinical profile, feeding problems and their complications, caregiver feeding practices and concerns and type of food given to the child.

#### 5.2 Demographic characteristics

This study was an unmatched case control design which involved selection of cases and controls from a hospital based population. The ratio of case to control was one case to two controls. From a total of 99 participants (33 cases and 66 controls), there were 45 males and 54 females with a male to female ratio of 1:1.2. Despite this not being a matched case control design, cases and controls were similar in many demographic characteristics. The mean age for cases was 60.5152 while that of controls was 59.9697. Other similar characteristics were position of child in family and the primary care giver for majority of cases and controls was the mother. Chi-square tests showed that most of the child characteristics such as age, position in family and number of younger siblings were not statistically significant.

There was no association between severe malnutrition and age of the child in the current study. Similar findings where age was not associated with undernutrition in CP children were reported in Taiwan (Hung et al. 2003), Nigeria (Adekoje et al. 2016) and Australia (Weir et al. 2013). Contrary to this finding, a study that was done in Uganda found that CP children over the age of 5 years were more likely to be malnourished compared to those below this age (Kakooza-Mwesige et al. 2015b). In another study that was done in India by Kamal et al. (2014), it was reported that children aged between five to eight years had more feeding difficulties.

There were more male (57.58%) cases than females compared to controls who had 39.39% males. However, this gender difference was not statistically significant ( $p= 0.00868$ ). Similar

findings where gender was not associated with malnutrition in CP children have been reported in other studies including those done in Botswana and Uganda (Johnson et al. 2017; Kakooza-Mwesige et al. 2015b). Contrary to this finding, other studies found that girls were more likely to have malnutrition than boys. A study that was done in Turkey to assess the nutritional status of children with CP found that the prevalence of underweight was significantly higher in girls ( $\chi^2 = 4.481$ ) compared to boys (Tuzun et al. 2013). Another study that was done in Taiwan to investigate the risk factors for undernutrition in children with spastic CP found that at multiple logistic regression analysis, being a girl was significantly associated with undernutrition (Hung et al. 2003).

None of the caregiver demographic characteristics were significantly associated with severe malnutrition in the current study as chi-square tests yielded p-values above 0.05. Caregiver demographic characteristics for cases and controls were similar for most variables. For instance, the majority of caregivers for the both cases and controls were aged between 25 to 34 years and majority of caregivers were biological mothers. The educational background for majority of caregivers for both cases and controls were between primary education and secondary education. Only 6.06% of cases and 7.58% of controls had a tertiary education with only one control caregiver having a degree level education. Similar findings were maternal age and education background were not significantly associated with malnutrition in children with CP were reported in Botswana (Johnson et al. 2017).

The finding in this study where majority of caregivers or mothers of CP children for both cases and controls have low education background is consistent with findings from other studies done on CP children. For example, a retrospective cohort study that was done in California to determine the impact of race, ethnicity and socioeconomic status on prevalence of CP found that women with education background lower than a diploma were more likely to have CP children (Wu et al. 2011). Contrary to this finding, a study that was done in Nigeria to assess the quality of life for caregivers of CP children found that majority of CP caregivers had a tertiary level of education (Fatudimu et al. 2013). Caregiver or parental education is an important indicator of socioeconomic status of the family, and this can subsequently have an impact on the child's nutritional status.



The finding in this study where the mother was the main caregiver for both cases and controls is similar to findings by other studies done on children with CP and other disabilities including those done in Nigeria (Fatudimu, Hamzat & Akinyinka, 2013), India (Diwan & Diwan 2013), Kenya (Geere et al. 2013) and Turkey (Tuzum et al. 2013). For instance, Tuzum et al (2013) reported that the mother was the main caregiver in 98% of CP children in their study. The role of caregiving in most African (and African/American) and Asian cultures is usually given to the female gender and in case of children with disabilities, the mother usually takes up this role (Dezoti et al. 2015; Pharr et al. 2014). Reasons why the mother is usually the primary caregiver for children with CP, as reported by other authors, include mothers not willing to leave the child under the care of someone else (Dezoti et al. 2015), mothers being the preferred feeders by most CP children (Diwan & Diwan, 2013) or other family members not willing to be involved in caring for the CP child (Huang, Kellett & St John, 2012).

Family socioeconomic characteristics consisted of characteristics of income earner and family economic status. Like child and caregiver demographic characteristics, family socioeconomic characteristics for cases and controls were similar in many areas except for employment status of income earner and type of toilet used by family which were significant during cross tabulation. Using simple and multiple logistic regression analysis, only use of unflushed pit latrine remained statistically significant with a p-value of 0.0119. Although this study did not find many variables under socioeconomic status to be significantly associated with severe malnutrition, other studies have reported significant associations between family socioeconomic status malnutrition (Aggarwal et al. 2017). In a study that compared the anthropometric indices between children with CP and normal children in Nigeria, it was reported that there was a significant association between malnutrition and socioeconomic status (Okeke & Ojinnaka, 2010). One reason for the lack of significant association between severe malnutrition in CP children and family socioeconomic characteristics in the current study could be explained by the fact that both cases and controls were CP children and literature shows that CP is more prevalent among families from low socioeconomic status compared to the higher status (Sundrum et al. 2005). This is consistent with findings from another study that was done in Nigeria where 70% of children with CP belonged to a lower social economic class (Ogunlesi et al. 2008).

### 5.3 Obstetric history and birth history

Pregnancy history for both cases and controls was reported to be fine except for a few controls who reported hypertension among mothers of control and prolonged labour which was high among mothers of cases (54.55%) compared to controls (34.85%). The high incidence of prolonged labour among cases correlates with the high incidence of seizures (63.64%) after birth, which is a symptom of birth asphyxia (Ellenberg & Nelson, 2013). The mode of delivery for the majority of cases and controls was via spontaneous vaginal delivery (SVD). This finding is similar to findings from another study that was done in Uganda in which 73.6% of CP children were reported to have been born through SVD (Kakooza-Mwesige et al. 2015a). All cases in the current study were reported to be delivered at full term while only a few controls were born prematurely or preterm (7.58%). Full term delivery for CP children has been reported to be more common in developing countries compared to developed countries where preterm delivery is common among CP children (Benfer et al. 2014). No variable under obstetric history was statistically significant at analysis and therefore did not qualify for Multivariate analysis.

Despite the proportion of cases who did not cry at birth being higher (65.63%) than that of controls (50.82%), chi-square tests showed that this was not statistically significant (0.1719). Inability of a baby to cry at birth in a full term baby is also a sign of birth asphyxia and according to a systematic review done by McIntyre et al (2013), birth asphyxia was reported to be the strongest and most consistent risk factor for CP in full term babies. Furthermore, the high incidence of birth asphyxia among cases correlates with the high incidence of spastic quadriplegia among this group, hence confirming an observation by Gladstone (2010) who noted that higher rates of spastic quadriplegia in low income countries reflect the increased perinatal causes of CP such as birth asphyxia. Birth asphyxia secondary to prolonged labour was reported as the most frequent cause of CP in a study that was done in Nigeria to investigate the psychosocial impact of caring for a CP child on the family (Ogwumike, Adeniyi & Obidiegwu, 2012). A high frequency of seizures (54.0%) among children who suffered from birth asphyxia was also reported by Ogwumike and colleagues (2012). The few differences noted in birth history between cases and controls in the current study were not statistically significant. Similarly, in another study that was done in Botswana, it was reported that among the most common comorbidities among children with CP was malnutrition, and these comorbidities did not vary by aetiology (Bearden et al. 2016).

#### 5.4 Child clinical profile

Spastic CP was the most common type of CP for both cases and controls. However, the frequency of spastic CP was higher among cases (63.64%) than controls (54.55%). This finding where spastic CP is the most common type of CP is similar to findings from other studies including those done in Nigeria (Adekoje, Ibeabuchi & Lesi, 2016), Botswana (Bearden et al. 2016), Uganda (Kakooza-Mwesige et al. 2015a) and Romania (MINCIU, 2012). The high rates of spastic CP in low income countries have also been reported in a systematic review that was done by Gladstone (2010). These high rates of severe spastic CP cases in low income countries are associated with high perinatal and post natal causes such as birth asphyxia and bacterial meningitis respectively (Gladstone, 2010). Although the prevalence of spastic CP in the current study was high for both cases (63.64%) and controls (57.58%), cases had a higher frequency compared to controls. This difference was however very small and therefore not statistically significant. Contrary to these findings, a study that was done in Brazil to evaluate the association between the nutritional status and the oral motor performance of children and adolescents with CP found that children with spastic CP presented with greater oral motor impairments compared to those with other types of CP (Pinto et al. 2016).

Variables that were statistically significant under child clinical profile in bivariate analysis using simple logistic regression were of spastic quadriplegia (bilateral spastic CP) ( $p=0.0001$ ), GMFCS ( $p=0.0001$ ), history of illness in the past six months ( $p=0.0271$ ), child is currently taking medication ( $p=0.0091$ ), visual impairment ( $p=0.0329$ ) and epilepsy ( $p=0.0072$ ).

Bilateral spastic CP has been reported in other studies as a major risk factor for poor growth and malnutrition in children with CP (Karagiozoglou-Lampoudi et al. 2012). Bilateral spastic CP is associated with severe CP and these children have been reported to have more feeding problems compared to other types of CP (Kamal et al. 2014; Dahlseng et al. 2012). Contrary to this finding, a study that was done in India to identify nutritional and feeding problems among children with CP found that the nutritional status of children with bilateral CP spastic (quadriplegia) was better compared to those with diplegia and choreoathetosis and they alluded this to the greater energy expenditure among choreoathetosis and immobility among those with spastic quadriplegia (Kamal et al. 2014). Another study that was done in Uganda by Kakooza-Mwesige and colleagues (2015a) found bilateral spastic CP to be significantly associated with

malnutrition during unadjusted analysis but no association was found when adjusted for other variables in multiple logistic regression analysis.

Results from this study also showed that the majority of cases were level 5 GMFCS while majority of controls were level 3, and both unadjusted and adjusted odds ratios shows that GMFCS level 4 and 5 were significantly associated with severe malnutrition (Unadjusted:  $p=0.0001$ ;adjusted:  $p=0.0001$ ). Similar findings have been reported in many studies (Johnson et al. 2017; Herrera-Anaya et al. 2016; Diwan & Diwan, 2013; Kim et al. 2013; Dahlseng et al. 2012). In a study that was done in Botswana to identify risk factors for malnutrition in CP children, Johnson and colleagues (2017) reported that children with CP with GMFCS level 4 and 5 were more likely to have malnutrition and this finding was statistically significant at both unadjusted (OR= 13.8, 95% CI= 3.8-50.1,  $p= 0.001$ ) and adjusted analysis (OR= 3.8, 95% CI= 1.5-9.6,  $p= 0.006$ ). Poor growth and malnutrition in children with CP are associated with feeding problems which in turn are associated with severity of CP. In a study that was done in Norway to estimate the prevalence of feeding and nutrition problems in CP children, it was reported that children with CP with GMFCS level 4 and 5 who had feeding problem had lower weight and BMI z- scores compared to those without feeding problems (Dahlseng et al. 2012). Similarly another study that was done in Korea to report on the characteristics of dysphagia in CP children in relation to gross motor function reported that problems associated with dysphagia were more common in children with CP with GMFCS level 4 and 5 (Kim et al. 2013). GMFCS which is a standardised system to measure severity of movement in children with CP has also been reported to be a predictor of survival among these children, with those in level 5 having a significantly poorer survival at both bivariate and multiple logistic regression analysis (Touyama et al. 2013).

At bivariate analysis, cases were more likely to have a history of illness in the past 6 months ( $p= 0.0271$ ), and more likely to be taking medication ( $p= 0.0091$ ). When adjusted for other variables, history of illness in the past 6 months remained significant ( $p= 0.0241$ ) while currently taking medication was not significant. History of illness in the past 6 months could be associated with frequency of chest infections in children with CP, which in this study had a frequency of 39.39% for cases compared to 10.61% for controls. Literature shows that children with CP who have been reported to have feeding difficulties have also reported high incidence of recurrent chest infections (Usman & Asghar, 2017). With regards to taking medication, the current study

reported 63.64% of cases to be currently taking medication compared to 35.38% % of controls. The reason for taking medication in the majority of children for both cases and controls was due to epilepsy which was present in 60.61% of cases and 31.82% of controls. The findings from this study therefore show that taking medication was associated with prevalence of epilepsy and we can therefore discuss taking medication in relation to studies that reported association of epilepsy with malnutrition in CP children. Furthermore, the current study also found that both taking medication and epilepsy were significantly associated with severe malnutrition during unadjusted analysis while not significantly associated when adjusted for other variables. Similar findings where epilepsy and pneumonia (representing ‘frequent chest infections’) were not significantly associated with malnutrition in children with CP were reported by Hung and colleagues (2003) in a study that was done in Taiwan to investigate the nutrition status of children with CP and identify risk factors for undernutrition.

Findings on associated impairments such as epilepsy, hearing, speech visual cognitive impairments showed that the prevalence of epilepsy was high among cases (60.61%) compared to controls (31.82%). Prevalence of speech impairment was high for both cases (96.97%) and controls (87.88%) and therefore chi-square tests showed no significant association ( $P=0.0500$ ). Other associated impairments that were not significantly associated with severe malnutrition at bivariate analysis were hearing and cognitive impairment. Similar findings in which hearing and cognitive impairments were not associated with malnutrition in children with CP were reported by Johnson and colleagues (2017) in a study that was done in Botswana to identify risk factors for malnutrition in CP children. Contrary to these findings, a study that was done in Brazil to determine the association between nutritional state and oral motor dysfunction for CP children and adolescents, reported that cognitive impairment was significantly associated with underweight at bivariate analysis but after adjusting for other variables, the association was not significant (Pinto et al. 2016). In another study that was done in Uganda to investigate the nutritional status of children with CP, it was reported that cognitive impairment was one of the variables that were significantly associated with malnutrition at adjusted analysis (Kakooza-Mwesige et al. 2015b).

In the current study, epilepsy and visual impairment were significantly associated with severe malnutrition at bivariate analysis with p-values of  $p= 0.0072$  and  $p= 0.0329$  respectively. Similar

findings in which epilepsy was associated with undernutrition were reported in a study that was done in Brazil where children who were on medications such as anticonvulsants were more likely to be underweight (Pinto et al. 2016). Epilepsy was also reported to be associated with feeding difficulties such as swallowing problem, cough/choking, vomiting, recurrent chest infection, drooling and regurgitation, in a study that was done in Pakistan on children with CP (Ghayas et al. 2014). In another study that was done in Australia to examine the relationship between parent reported eating ability and gross motor functional abilities, it was reported that children with epilepsy were less likely to eat food of all types of textures compared to those without epilepsy ( $p= 0.001$ ) (Weir et al. 2013). Failure to eat all food types including chewables is associated with severe forms of CP such as those in level 4 and 5 GMFCS (Benfer).

Both epilepsy and visual impairments were not statistically significant when adjusted for other variables under clinical profile such as classification of CP, GMFCS and history of illness in the past six (6) months. Similarly, a study that was done in Botswana to identify risk factors for malnutrition in children with CP found that most of the CP comorbidities, including epilepsy and visual impairments, were not associated with malnutrition as there were no significant differences between cases and controls (Johnson et al. 2017). Reason for these findings could be because these comorbidities such as epilepsy, visual impairments, speech impairments, cognitive impairments are among the most common impairments found in CP children in general (Donald et al. 2014).

## **5.5 Feeding difficulties and their complications**

Feeding difficulties experienced by children included those that were directly due to oral motor dysfunction and those that were complications of problems related to oral motor dysfunction. Feeding difficulties that were directly due to oral motor dysfunction are chewing, swallowing, vomiting, choking /coughing, food regurgitation, and problems opening the mouth, tonic bite and tongue thrust.

The most common feeding difficulty reported among both cases and controls was chewing difficulty, although the frequency was much higher among cases (81.82%) compared to controls (40.91). At bivariate analysis, all variables under feeding difficulties were significantly associated with severe malnutrition with  $p$ -values  $< 0.05$ . These feeding difficulties resulting from poor oral motor control have been reported in many other studies to be significantly associated with

malnutrition and severe types of CP (Aggawal et al. 2015; Rempel, 2015; Kamal et al. 2014; Diwan & Diwan, 2013; Sjakti et al. 2008). In a study that was done in India to identify nutritional and feeding problems among children with CP, it was reported that most of the feeding problems identified were significantly associated with stunting (Kamal et al. 2014). Another study that was done in Jakarta to determine the prevalence of feeding difficulties and malnutrition in CP children found that 96% of children with spastic quadriplegia and 70% of those with spastic diplegia had feeding difficulties and majority of them also presented with malnutrition (Sjakti et al. 2008). In a systematic review that was done by Aggarwal and colleagues (2015) to assess the growth pattern and nutritional status of children with CP, it was reported that children with severe feeding difficulties tend to have lower weight, height, mid-arm muscle area, and skinfold thickness while those with mild feeding difficulties are at high risk. Decreasing z-scores in anthropometric parameters have been reported to be associated with increasing levels of GMFCS because feeding difficulties are more prevalent in children with CP who present with severe gross motor function and gastrointestinal dysfunctions (Herrera-Anaya et al. 2016).

After entering all the variables under feeding difficulties in a multiple logistic regression model, and using backward elimination, only swallowing difficulties ( $p=0.0006$ ) and tonic bite ( $p=0.0011$ ) remained statistically significant. The low prevalence of swallowing difficulties among controls in the current study could be attributed to the fact that most of the controls were in level 3 GMFCS. However, the possibility of underreporting among caregivers as observed in another study by Calis et al. (2008) could not be ruled out. This is so because there is a bigger variation in the proportion of controls who experienced swallowing difficulties (9.9%) and those who experienced choking/coughing (22.73%) difficulties compared to the cases who reported the same proportion (54.55%) for swallowing and choking/coughing difficulties. Swallowing problems have been reported in other studies to be associated with severe forms of CP which are associated with lower z-scores for anthropometric parameters (Herrera-Anaya et al. 2016). In a study that was done in the Netherlands, Calis and colleagues (2008) found that about 99% of children with CP had dysphagia (Swallowing difficulties), with the prevalence being higher among those with severe forms of CP. In another study that was done by (Lopes et al. 2013), it was reported that children with quadriplegia had a higher prevalence of chewing and swallowing difficulties as well as low z-score ( $< -2$ ) in most of the anthropometric parameters.

In the current study, tonic bite or abnormal bite reflex was found to be significantly associated with severe malnutrition at both unadjusted ( $p= 0.0001$ ) and adjusted ( $p= 0.0011$ ) analysis. Abnormal tonic bite or bite reflex is one of the abnormal oral motor reflexes that are observed in most children with CP and contributes to oral motor dysfunction (Dadgar, Hadian, & Lira, 2016). Involuntary tonic bite in children with neurological disabilities may be a sign of oral hypersensitivity which is usually accompanied by generalised increase in whole body extension (Diwan & Diwan, 2013). While the author did not find any study that investigated the association between tonic bite reflex and malnutrition in children with CP, there were studies that showed that abnormal oral reflexes such as tonic bite reflex were associated with severe GMFCS levels and spastic CP (Dadgar & Soleymani, 2010; Ghayas et al. 2014; Sjakti et al. 2008). In a study that was done in Iran to examine the relationship between oral reflexes and number of affected limbs in children with CP, abnormal bite reflex was found to be significantly associated with spastic quadriplegia than diplegia (Dadgar & Soleymani, 2010). Contrary to findings from the current study, a study that was done in Taiwan to investigate the nutritional status of children with CP and identify risk factors for undernutrition found that bite reflex was not associated with malnutrition even at bivariate analysis ( $p= 0.096$ ) (Hung et al. 2003).

Arvedson (2013) suggested that assessment of feeding problems for children with CP should involve key questions such as any weight gain in the past 2 to 3 months, if meals are stressful, how long it takes to feed child and any signs of respiratory problems. In order to find out the complications associated with feeding difficulties, the researcher asked the caregivers some questions related to the following: Does the child have feeding difficulties, has the child gained weight in the past 2 to 3 months, any breathing difficulties when feeding, frequency of chest infections, totally dependent on feeding, food consistency, length of feeding and how often child opens bowels. All these variables were significantly associated with malnutrition at bivariate analysis but in multiple logistic regression model, variables that remained statistically significant were child not gained weight in the past 2 to 3 months ( $p= 0.0001$ ), totally dependent for feeding ( $p= 0.0061$ ), taking only semi-solids or liquids (0.0231) and opening bowels after 3 or more days (0.0057).

The current study showed that most of the caregivers for cases acknowledged that the child had feeding difficulties but this finding was only significant at bivariate analysis ( $p=0.0017$ ) and not



significant at multivariate analysis ( $p=0.05294$ ). A study that was done by Weir and colleagues (2013) found that parent reported eating ability was significantly associated with gross motor functional ability of children with CP. On the contrary, a study that was done in Pakistan to identify the association between parent reported oral motor impairments and feeding difficulties in children with CP found that despite the majority of parents being conscious of the children's feeding problems, there was a significant difference between the parental perceived problems and actual feeding problems (Ghayas et al. 2014). According to Ghayas and colleagues (2014), majority of parents in their study were only aware of the more visible feeding difficulties but not aware of symptoms such as coughing before, during and after swallowing. This might be the case even in the current study because caregivers were just asked to state whether the child has feeding difficulties or not. Although parental reports can be a source of bias, Wilson and Hustad (2009) noted that this method is also important because it can provide valuable insight into typical everyday feeding practices that cannot be replicated in a controlled laboratory environment.

One of the complications of feeding difficulties is lack of weight gain. Findings from the current study shows that the majority of caregivers for cases (75.76%) said that the child did not gain weight in the last 2 to 3 months compared to controls in which only 6.06% were reported not to have gained weight. According to Arvedson (2013), lack of weight gain for over 2 to 3 months could be a sign that the child has feeding difficulties and this would consequently result in undernutrition. Rempel (2015) also noted that children with CP who are at greater risk of developing malnutrition are those who present with, among other things, poor weight gain at a younger age.

With regards frequency of breathing difficulties during feeding and frequency of chest infections, cases were more likely to be reported as having these problems compared to controls and this was statistically significant at bivariate analysis. However, looking at the frequencies of swallowing difficulties reported among cases, it would be expected that frequencies of breathing difficulties when feeding and frequent chest infections would be higher than the reported frequencies. Literature shows that most parents of children with CP are unaware of the symptoms of cough before, during and after swallow and even the presence of pneumonia because the children fail to cough when food enters the airways (Ghayas et al. 2014). In a

systematic review of literature on dysphagia and drooling in neurologically affected children, it was reported that many children with CP may repeatedly aspirate due to dysphagia, severe drooling or gastro-oesophageal reflux, without coughing or choking leading to frequent chest infections (Erasmus et al. 2012). The chances of having difficulties with breathing or frequent chest infections among children with CP are higher because of the high prevalence of swallowing dysfunction which is characterised by impaired coordination between swallowing and ventilation resulting in aspiration and frequent chest infection (Erasmus et al. 2012). Many studies have reported the prevalence of feeding problems such as coughing, choking, regurgitation and aspiration with subsequent recurrent chest infections to be common among children with CP (Kamal et al. 2014; Diwan & Diwan 2013; Ghayas et al. 2014; Wilson & Hustad, 2009; Sjakti, et al. 2008). In a study that was done in Pakistan to determine the frequency of feeding difficulties in children with CP, it was reported that drooling was the most common feeding problem identified (66%) while the most common complication identified was recurrent chest infections (53.3%) (Usman & Asghar, 2017).

Majority of cases in the current study were totally dependent on caregivers for feeding (96.97%). Totally dependent on caregiver for feeding was significantly associated with severe malnutrition at both unadjusted ( $p= 0.0005$ ) and adjusted ( $p= 0.0061$ ) analysis. Dependence on caregivers for feeding among CP children is a common feeding problem which has been reported to be associated with severity of motor impairments in many studies (Aggarwal et al. 2015; Kakooza-Mwesige et al. 2015b; Karagiozoglou-Lampoudi et al. 2012; Diwan & Diwan, 2013; Melunovic et al. 2017). In a study that was done in Uganda to investigate the nutritional status of children with CP, it was reported that at bivariate analysis, inability to feed independently was associated with malnutrition but when adjusted for other variables, the variable was not significant (Kakooza-Mwesige et al. 2015b). Similarly, in another study that was done in Greece to assess the nutritional status of children with CP, it was reported that the prevalence of undernutrition was higher among children with severe impairment and those who were unable to feed without help from caregivers (Karagiozoglou-Lampoudi et al. 2012).

With regards to length of feeding, majority of cases were reported to take between 30 to 60 minutes feeding compared to most controls who took less than 30 minutes. Cases were reported to be more likely to feed for more than 30 minutes during a meal and this was significant at both

bivariate ( $p=0.0003$ ) and multivariate analysis ( $p=0.0381$ ). Prolonged feeding time of more than 30 minutes has been cited as a common factor that hinder adequate food intake with subsequent undernutrition among children with CP (Arvedson, 2013; Rempel, 2015). Longer feeding times have been reported in many other studies and is said to be associated with severe types of CP (Ghayas et al. 2014; Diwan & Diwan, 2013; Wilson & Hustad, 2009; Melunovic et al. 2017). In a study that was done in Sarajevo (Bosnia and Herzegovina), it was reported that the probability of occurrence of malnutrition increases with increasing length of meal and length of daily feeding (Melunovic et al. 2017). Contrary to these findings where prolonged feeding time was associated with severity of CP and undernutrition, Hung and colleagues (2003) in a study that was done in Taiwan to investigate the nutritional status of children with spastic CP found that shorter feeding duration of less than 20 minutes was associated with undernutrition. This finding could be explained by the fact that majority of severely affected children in Hung's study were being fed on proprietary baby foods which would not require chewing and may be easier to swallow.

With regards to consistency of food, cases were more likely to be fed on semi-solids and liquids while controls were more likely to feed on both solids and liquids. Food consistence was significantly associated with severe malnutrition at both bivariate ( $p= 0.0003$ ) and multivariate ( $p=0.0231$ ) level. Literature has shown that inability of CP children to eat a variety of food textures during meal times is associated with severity in GMFCS which results in oral motor dysfunction with subsequent poor nutrition and poor growth among the affected children (Benfer et al. 2015; Ghayas et al. 2014; Parkes et al. 2010). In a study that was done in Brazil to assess the food intake pattern and nutritional status of CP children, it was reported that the group of children with tetraplegia had a higher prevalence of chewing and swallowing difficulties and had difficulties with chewing solid foods (Benfer et al. 2015). Another study that was done in Australia to examine the association between parent reported ability of CP children to manage food textures and gross motor functional abilities reported that children with GMFCS level 4 or 5 were significantly less likely to be able to manage a range of food textures than those in level 1 regardless of age (Weir et al. 2013).

Cases were more likely to have constipation or opening bowels after 3 or more days (Constipation). Constipation was significantly associated with severe malnutrition at both

unadjusted ( $p= 0.0001$ ) and adjusted analysis ( $= 0.0057$ ). This finding is similar to findings from other studies which reported constipation to be associated with severe GMFCS (Usman & Asghar, 2017; Herrera-Anaya et al. 2016; Kamal et al. 2014). For example in a study that was done in Colombia to determine the association between gross motor function and nutritional status in children with CP, it was reported that constipation and chewing difficulties were common in children with advanced levels of motor dysfunction, and these children were also reported to have lower z-scores (Herrera-Anaya et al. 2016). In another study that was done in the Netherlands to identify the prevalence and characteristics of constipation in children with multiple disabilities, it was reported that the prevalence of constipation was high among children with CP with GMFCS level 5 at both unadjusted ( $p= 0.003$ ) and adjusted ( $p= 0.035$ ) analysis (Veugelers et al. 2010). Constipation in children with CP presenting with severe GMFCS levels is reported to be due to low body mobility and difficult in fluid intake resulting from dysphagia and rigidity of abdominal muscles (Lopes, et al. 2013).

## **5.6 Caregiver feeding practices and concerns**

Variables that were under feeding practices included the following questions which were asked to caregivers: Who feeds the child on a regular basis, are meals stressful, how often is the child fed per day, does caregiver prepare meals for this child in a special way and whether caregiver is concerned about child's feeding patterns. During analysis, logistic regression analysis, variables that were not binary were dichotomised for easy analysis.

At bivariate analysis, the variables that were statistically significant were child being fed by the mother on a regular basis ( $p=0.0024$ ), the child being fed for 3 times or less per day ( $p=0.0013$ ) and the caregiver being concerned about the child's feeding (0.0005). During adjusted analysis, the variables that remained statistically significant were the child being fed 3 times or less in a day ( $p=0.0025$ ) and caregiver acknowledging that the child had feeding difficulties ( $p= 0.0076$ ).

The finding in the current study about the mother being the main caregiver has been discussed in the first subheading under child demographic characteristics. With regards to feeding the child, the main caregiver is expected to be the main person who actually feeds the child. This variable "child fed by mother on a regular basis" is significant because despite the mother being the main caregiver for most controls, most of them were able to feed themselves (28.79%) compared to cases (3.3%). As already alluded to earlier, cases who are usually severe forms of CP, would be

more likely to be fed by their mothers because mothers would not be comfortable to give another person to feed the child (Dezoti et al. 2015) or other relatives may not be willing to assist due to feeding difficulties experienced by the child (Huang et al. 2012).

The caregivers were asked to state whether meals were stressful for the child, caregiver or both. This variable was dichotomised to “yes” if meals were stressful for either the child, caregiver or both and “no” if none of them was stressed. Although cases were more likely to be reported as ‘yes’ (OR= 1.5501), this finding was not statistically significant even at bivariate analysis ( $p=0.5817$ ). In a study that was done in India, Diwan and Diwan (2013) reported that mothers of children with CP who had poor feeding skills revealed that rather than being enjoyable, meals were stressful for both the child and caregiver. Stress during mealtimes is mainly associated with lengthy mealtimes, coupled with spillage of food, bouts of coughing, choking, regurgitation, crying, inability to communicate and negative feeding behaviours (Ghayas et al. 2014; Rempel, 2015; Marques & Sa, 2016; Adams et al. 2012 ). Prolonged feeding time can cause fatigue and stress for both the caregiver and the child (Rempel, 2015). Caregivers caring for children with CP have been reported to experience physical, psychological, emotional, social and financial stressors due to their caregiving experience (Wijesinghe, Fonseka & Hewage, 2013).

With regards to number of meals per day, four to five meals should be adequate to provide the necessary nutrient intake for the child (Lopes et al. 2013). The question about how many times the child was fed per day in this study could be prone to response bias because some caregivers could have only reported about the main meals while others reported even about in-between snacks. This was because the questionnaire did not clearly distinguish between main meals and snacks. In the current study, majority of cases were reported to be fed for 3 times a day compared to majority of controls who were fed 4 times a day. Feeding for less or equal to 3 times per day was significantly associated with severe malnutrition at both unadjusted ( $p=0.0013$ ) and adjusted analysis ( $p=0.0025$ ). Contrary to this finding, a study that was done in Taiwan to investigate the nutritional status of children with spastic CP found that the frequency of meals was not associated with the nutritional status of children, though they noted that undernourished children took shorter duration of time during taking a meal (Hung et al. 2003). In another study that was done in Saudi Arabia to determine dietary practices of children with CP, it was reported that majority of children had three main meals/day (71.3%) and yet the authors observed that dietary

practices for these children were satisfactory (Al-Hammad, 2015). This was because dietary practices included well balanced diets for main meals as well as in-between meals consisting of assorted snacks (Al-Hammad, 2015).

Findings from the current study show that the prevalence of caregivers who prepared food for the child in a special way was low for both cases (33.36%) and controls (24.24%) and chi-square tests showed that this was not significantly different for the two groups ( $p= 0.3384$ ). This is despite the fact that both caregivers for cases and controls reported higher frequencies of children who had feeding difficulties (90.91% and 56.06% respectively). Similarly, another study that was done in Kenya to assess whether children with disabilities were included in humanitarian and food security responses reported that 90% of caregivers of children with disabilities said that they do not prepare meals for the disabled child differently from the rest of the family (Kuper et al. 2015). In poor resource countries, the reasons for caregivers not preparing separate meals for these children could be due the assertions made by Aggarwal et al. (2015) who noted that feeding and nutritional problems among children with CP are increased due to lack of resources to buy nutritious food, limited time and facilities to prepare separate meals and lack of awareness among caregivers. Contrary to findings from the current study, parents in a study that was done in Portugal to identify parents difficulties regarding feeding children with CP found that one of the difficulties parents experienced was that they had to prepare separate meals for the child (Marques & Sa, 2016). Food textures for children with CP who have feeding difficulties need to be modified in order to ensure airway safety, maximise eating efficiency and reduce fatigue during mealtimes (Kuperminc et al. 2013).

Caregivers were asked if they were concerned about the child's feeding pattern and results showed that caregivers for cases were more likely to be concerned compared to controls. This variable was statistically significant at both bivariate analysis ( $p= 0.0005$ ) and multiple logistic regression ( $p= 0.0076$ ). Because most caregivers for cases acknowledged the presence of feeding difficulties in their children, it was obvious that they would be concerned about their children's feeding problems. According to Marques and Sa (2016), feeding difficulties in children with CP such as chewing and swallowing can cause major anxieties among parents because not only do they lead to inadequate diet, but they also put the children at risk of choking and aspiration of vomit. Another reason why caregivers would be concerned could be attributed to stress as

reported in a study by Diwan and Diwan (2013) where parents reported that mealtimes were stressful and time consuming for both the children and those feeding them. In a study that was done in Nigeria to compare the quality of life of mothers caring for children with CP and those caring for non-CP children, it was reported that caregivers of children with CP had lower scores for WHO quality of life Brief scores and they noted a positive correlation between GMFCS and WHO quality of life Brief scores (Fatudimu et al. 2013). Managing a child with CP in a developing country with limited or no access to basic facilities can be very challenging for parents as they require more time to take care of the child at home as well as manage his/her health problems Marques & Sa (2016).

### **5.7 Types of food given to child**

The types of food that were usually given to children were categorised into cereals, vegetables, legumes, meat/poultry/fish, fruits, drinks and dairy products. There were significant differences reported between cases and controls with regards to certain types of foods. For instance, cases were reported to be less likely to be fed on most cereals, vegetables and meat/poultry/fish foods. However, there were no differences on other foods such as legumes, fruits, drinks and dairy products given to cases or controls. Analysis of foods for associations was done by simple logistic regression for bivariate analysis and multiple logistic regression for significant variables within each food category. The foods that remained statistically significant after multiple logistic regression for each category were entered into a multiple logistic regression model with other foods that were significant from other categories. Foods that were statistically significant after multiple regression of different food categories were Irish potatoes ( $p= 0.0008$ ) and Fish ( $p= 0.0001$ )

In the cereals category, results from cross tabulation showed that cases were less likely to be fed on bread, rice, pasta and nshima but more likely to be fed only on Maize meal porridge. However, during bivariate analysis with simple logistic regression and multivariate analysis with multiple logistic regression only bread and rice were significant with  $p$ -values less than 0.05.

As for vegetables, cases were less likely to be fed on most of the vegetables and only likely to be given soups for vegetables with some of the vegetables being significant at unadjusted analysis. In a multiple regression model of vegetables that were significant at bivariate analysis, only Irish potatoes remained statistically significant as the only vegetable less likely to be eaten by cases ( $p= 0.0001$ ).

The other foods that were given to children were legumes and none of these were significant at bivariate analysis. Among the meat/poultry/fish foods, bivariate analysis for these foods show that cases were less likely to be given beef ( $p= 0.0001$ ), chicken ( $p= 0.0004$ ) and fish ( $p= 0.0001$ ) but more likely to be given only soups for these foods ( $p= 0.0001$ ). In multiple logistic regression analysis, only fish remained statistically significant as the only product under this category that was less likely to be eaten by cases ( $p= 0.0001$ ). Bivariate analysis of fruits shows that cases were also less likely to be given fruits such as oranges, mangoes and bananas but more likely to eat avocados though this was not statistically significant. At both unadjusted and adjusted analysis for fruits, results from this study showed that only mangoes were statistically significant as fruits not likely to be eaten by cases with  $p$ -values less than 0.05. Cases were also less likely to be fed on most of the dairy products although only yogurt was statistically significant at bivariate analysis ( $p= 0.0331$ ). None of the drinks given to children were statistically significant as both cases and controls were less likely to be given fruit juices or carbonated drinks.

Eating a balanced and varied diet is an essential need and right of every child (Marques & Sa, 2016). Findings from the current study regarding food types given to children show that cases had poor dietary intake because they were not given a variety of essential foods such as proteins. In another study that was done in Portugal to identify parents' difficulties in feeding a child with CP, inability to provide a balanced diet was among the main difficulties that were reported by parents of children with CP (Marques & Sa, 2016). From the types of food that were not likely to be eaten by cases in the current study, it was evident that most of those foods require chewing and majority of the cases had severe forms of CP with oral motor dysfunction and therefore could not manage most of these foods. Inability of children with CP to eat a variety of food textures is associated with severe GMFCS levels and bilateral spastic CP as has been reported in many other studies (Marques & Sa, 2016; Lopes et al. 2013; Weir et al. 2013). This is consistent with an observation by Benfer and colleagues (2015) who noted that oropharyngeal dysphagia can limit the range of food/fluid textures that children can safely and efficiently consume, leading to reduced dietary intake and consequently affecting the nutritional status. The inability of caregivers of cases to give their children a variety of foods was further compounded by the fact that majority of caregivers in the current study did not prepare food for children with CP separately to make it easier for the child to eat. This is consistent with an observation by



Marques and Sa (2016), who observed that there is usually monotony in the way parents of children with CP cook and feed their children because they have to choose food that is easier to cook and with the same consistency which the child would be able to eat.

#### **5.10 How the results relates to the UNICEF Conceptual Framework**

The UNICEF conceptual framework for malnutrition categorises the causes of malnutrition into immediate, underlying and basic causes (UNICEF, 1998). Findings from the current study are consistent with the UNICEF conceptual frame work regarding causes of malnutrition in children with CP. According to the UNICEF malnutrition frame work, the immediate causes of malnutrition operate at the individual level and these include poor dietary intake and ill health. In the current study, factors that were significantly associated with severe malnutrition in children with CP which are at individual level included CP spastic quadriplegia, GMFCS level 4 and 5, history of illness in the past 6 months, swallowing difficulties, tonic bite, lack of weight gain in the past 2-3 months, totally dependent on feeding and opening bowels after 3 or more days (Constipation). These factors have been reported by other authors as factors that contribute to inadequate dietary intake with subsequent undernutrition among children with CP (Aggarwal et al., 2015).

The underlying factors for malnutrition in the current study included those that were related to caregiver caring practices. Factors related to underlying factors that were statistically significant included caregiver feeding the child for only 3 times or less per day, caregiver not able to prepare special meals specifically for the child with CP and not feeding the child on a balanced diet (all food categories). Reasons for such caring practices could be due to individual feeding problems experienced by the child which makes it difficult for the caregiver to feed the child, thereby resorting to feeding the child only foods which they feel would be easy to eat without difficulties. These feeding difficulties experienced by children with CP can be ameliorated by a variety of approaches such as adjusting food textures, better positioning, optimising calorie intake by adding oral calorie supplements, increasing frequency of feeding, treating medical conditions such as constipation and ensuring adequate protein and micronutrient diet (Kuperminc & Stevenson, 2008). Despite all these approaches being possible, majority of caregivers in the current study actually reported that they do not make special meals specifically for this child. This could be due to lack of resources to buy special food for the child or limited time and

facilities to make special meals for the child (Adams et al., 2012). It could also be possible that majority of caregivers had no nutritional knowledge regarding feeding a child with severe oral motor dysfunction. Nutritional ignorance was reported as one of the contributing factors to undernutrition among children with neurological disabilities in a study that was done in Tanzania (Minja et al., 2015). Studies that have undertaken interventions such as training caregivers in low cost techniques of feeding and positioning the child have revealed positive results, an indication that caregiver knowledge was lacking before the intervention (Bashar, et al., 2015; Adams et al., 2012).

The supposed reasons for caregiver feeding practices in the current study may be related to basic causes of malnutrition. Basic causes of malnutrition constitute the social determinants of health which in turn are related to the way society is organised in relation to distribution of resources (WHO, 2008). The caregivers' lack of knowledge in the current study could be attributed to lack of access to appropriate services such as Speech and Language Pathologists who are experts in managing children with feeding difficulties. Furthermore, low socioeconomic status among caregivers for cases in the current study, which was indicated by use of unflushed pit latrine, is evidence of basic determinants of malnutrition. This could be one of the reasons why caregivers would not have resources to buy special foods with adequate proteins, calories and other micronutrients. Findings from the current study are consistent with literature which shows that caregivers of children with disabilities in developing countries take care of their children under difficult socioeconomic conditions such as poverty and lack of access to health care and assistive equipment (Geere et al., 2013).

### **5.11 Summary of discussion**

This chapter discussed the findings of this study and how they relate to relevant literature. Factors that were significantly associated with severe malnutrition after adjusting for other variables were as follows:

- Child clinical profile: CP spastic quadriplegia, GMFCS level 4 and 5, history of illness in the past 6 months.
- Family socioeconomic characteristics: Use of unflushed pit latrine

- Feeding difficulties and complications: Swallowing difficulties, tonic bite, child not gained weight in the past 2-3 months, totally dependent on feeding, opening bowels after 2 to 3 days,
- Feeding practices and concerns: Caregiver acknowledging that the child had feeding difficulties, child being fed for less or equal to 3 times per day,
- Types of food given to child (Diet): Child not being fed on Irish potatoes and fish.



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## CHAPTER 6

### CONCLUSION AND RECOMMENDATIONS

#### 6.1. Conclusion

The main objective of this study was to identify risk factors for severe malnutrition in children with CP at the University Teaching Hospital in Lusaka, Zambia. This was done through a case control design which compared the characteristics of children with CP presenting with severe malnutrition and those without severe malnutrition. The objectives of the study were achieved because the risk factors that were associated with severe malnutrition were identified. Variables that remained significant after adjusted analysis were identified as risk factors for severe malnutrition in this study. These factors included using a non-flushed pit latrine toilet ( $p=0.0119$ ); spastic quadriplegia or bilateral CP ( $p=0.0054$ ); GMFCS level 4 or 5 ( $p=0.0001$ ); history of illness in the past six months ( $p=0.0241$ ); swallowing difficulties ( $p=0.0006$ ); tonic bite ( $p=0.0011$ ); child not gained weight in the past 2 to 3 months ( $p=0.0001$ ); dependent on feeding ( $p=0.0061$ ); child only able to feed on semi-solids or liquids ( $p=0.0231$ ); child feeding for more than 30 minutes ( $p=0.0381$ ); child opening bowels after 3 or more days ( $p=0.0057$ ); caregiver concerned about child's feeding difficulties ( $p=0.0076$ ); not likely to be fed Irish potatoes ( $p=0.0008$ ) and Fish ( $p=0.0001$ ).

The identified risk factors are related to several aspects on different levels of proximity to the child and his/her nutritional status (as an outcome). When these findings are compared to the UNICEF conceptual framework it confirms that several factors contribute to nutritional status (as an outcome) of children with cerebral palsy. These include on an immediate level aspects of the quality and quantity of the diet consumed such as being able to consume only or being fed only fluid or semi-solid foods, as well as consuming a less diverse diet. Also on the immediate level of causation is the type and severity of the condition of the child as well as reports of recent illness (in the past month) and lack of regular bowel movements. The latter is again linked with the diet consumed by the child as fluid or semi-solid diets is unlikely to provide sufficient fiber for regular bowel movements. Underlying factors that were significant in this study are mainly categorized as care practices. Again these care practices are influenced by the severity and condition of the child resulting and if a mother is the sole care provider may contribute to the

lower frequency of feeding observed, especially given the long duration of feeding and feeding difficulties experienced by these children. Although access (or note) to hygienic toilet facilities was statistically significantly associated with severe malnutrition in this study, it appears as if the underlying socio-economic conditions and access to resources were not the driving forces of the severe malnutrition observed in cases, but rather the care related practices (leading to limited quality and quantity of dietary intake) as well as the severity of the disease of the child. As the presence of weight loss over the last 2-3 months was significantly associated with severe malnutrition (the cases), any observed weight loss should be used as an early indicator for implementing more regular monitoring as well as possible interventions. Such interventions or recommendations to the caregivers should include exploration of the type of diet fed to the child in terms of consistency, frequency of feeding and diversity of food items given to the child. Furthermore child care practices should be explored and where possible support for caregivers to relieve the burden of care could be considered.

Findings from the current study have shown that the risk factors for severe malnutrition among children with CP are similar to what has been reported in literature for both developing and developed countries. Furthermore, this study has also shown that caregiver caring practices have a major impact on the health and nutritional status of children with CP.

### **6.1 Limitations of the study**

This being a case control design, the most probable limitation was recall bias among caregivers. The study did not take into considerations the measurement of actual dietary intake and therefore the researcher only relied on the information given by caregivers concerning the types of food they give to the children. Furthermore, information obtained from caregivers concerning the number of times the child is fed per day may not be a true reflection of the practice as some caregivers may not have included snacking while others would have included it.

### **6.2 Significance of the study**

Findings from the current study have a potential to highlight the important aspects concerning risk factors that are associated with severe malnutrition in children with CP.

It is therefore the researcher's hope that policy makers could use this information to come up with strategies of preventing malnutrition among children with CP. Furthermore, this study is

expected to contribute to the body of knowledge on the factors that contribute to severe malnutrition in children with CP in a developing country.

## **6.2 Recommendations**

1. During data collection, the researcher found it easy to find cases and very difficult to find controls because majority of the children with CP were underweight. It is therefore important to undertake a large scale study to determine the prevalence of malnutrition in children with CP and identify risk factors.

2. Following the findings from this study that revealed the poor feeding practices among caregivers, there is a need to put in place a deliberate policy of empowering caregivers of children with disabilities who present with feeding difficulties with knowledge on feeding practices as well as any other problems associated with CP.

3. Currently, the only rehabilitation services available for children with CP in Zambia are Physiotherapy services. There is need for Government to consider training personnel in Speech and Language Therapy as well as Nutrition professionals, who would be addressing feeding and language/speech impairments associated with CP.

4. Like in many other African countries where procedures such as gastrostomy are rarely done (Kerac et al., 2014), there was no child in the current study who was fed via gastrostomy. It is advised that children with severe feeding difficulties should be recommended for gastrostomy, a procedure that is common in developed countries and has been reported to result in marked improvements in weight gain for the children (Sullivan, et al., 2005).

5. As for all children at risk of developing malnutrition, all children with CP in the country should be put on a deliberate programme for food supplements such as High Energy Protein Supplements which are readily available in most health centers in the country. People in charge of these supplements should not be waiting until children with CP develop malnutrition as is the case at the moment.

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## Appendices

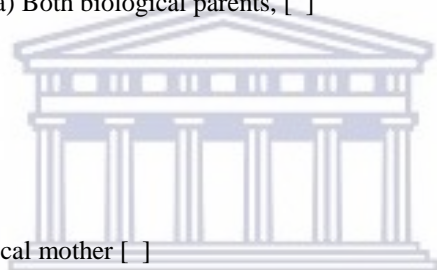
### Appendix 1

#### CHILD DATA COLLECTION TOOL

#### RISK FACTORS FOR SEVERE MALNUTRITION IN CHILDREN WITH CEREBRAL PALSY IN LUSAKA, ZAMBIA

##### SECTION A: Child demographic data

1. Date of data collection: .....
2. Participant no: [ ]
3. Case or control: [ ]
4. Gender: Male [ ], Female [ ]
5. Date of birth: .....
6. Age in months: .....
7. Position of child in family: [ ]
8. Number of younger siblings: [ ]
9. Child stays at whose house? a) Both biological parents, [ ]  
b) Single mother, [ ]  
c) Grandparents, [ ]  
c) Other [ ], specify
10. Primary caregiver: a) Biological mother [ ]  
b) Grandmother [ ]  
c) Aunt/uncle [ ]  
d) Sibling [ ]  
e) Maid: [ ]  
f) Other: [ ]



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##### SECTION B: Obstetric history

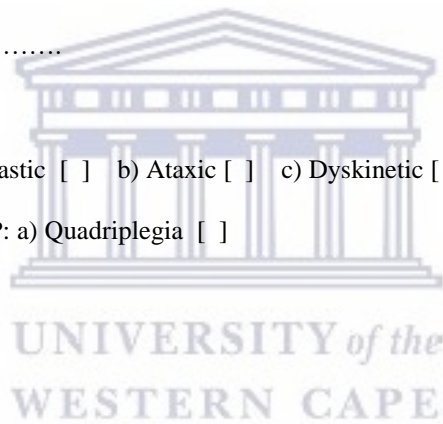
1. Did mother suffer from any of the following during pregnancy?
  - i) Measles [ ]
  - ii) Malaria [ ]
  - iii) Diabetes [ ]
  - iv) Hypertension [ ]

- v) Other [ ]
  - vi) Specify if other: .....
2. What was the mode of delivery?
- i) Spontaneous vaginal delivery [ ]
  - ii) Caesarian section [ ]
3. Did any of the following happen during the birth of this child?
- i) Prolonged labour [ ]
  - ii) Premature birth [ ]
  - iii) Pre-eclampsia [ ]
  - iv) Breech delivery [ ]
  - v) Other [ ]
  - vi) Specify if other: .....

**SECTION C: Child clinical profile**

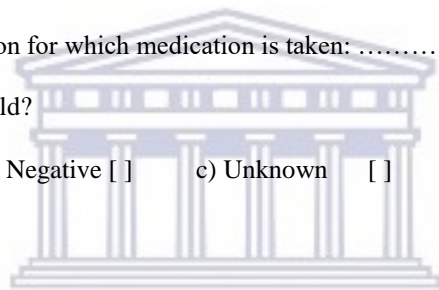
1. Type of cerebral palsy: a) Spastic [ ] b) Ataxic [ ] c) Dyskinetic [ ]
2. Classification/sub-type of CP: a) Quadriplegia [ ]
  - b) Diplegia [ ]
  - c) Hemiplegia [ ]
  - d) Dystonic [ ]
  - e) Choreoathetosis [ ]
3. GMFCS level: a) Level I [ ]
  - b) Level II [ ]
  - c) Level III [ ]
  - d) Level IV [ ]
  - e) Level V [ ]
4. Did child suffer from any of the following condition from the time of birth up to the age of 2 years?
 

a) Seizures/ epilepsy [ ]	b) Meningitis [ ]	e)
c) Difficulty breathing [ ]	d) Trauma to head [ ]	
e) Hydrocephalus [ ]	f) Cerebral malaria [ ]	
g) Jaundice [ ]	h) Other [ ]	
i) Other [ ]	j) Specify if other: .....	





5. Was this child breastfed? A) Yes [ ] b) No [ ]
6. If answer to question 5 is yes, for how long did child breastfeed?
- a) 0-6 months [ ] b) 7-12 months [ ]
- c) 13-18 months [ ] d) 17-24 months [ ]
- e) Over 24 months [ ]
7. Associated impairments: a) Vision [ ] b) Hearing [ ] c) Epilepsy [ ]
- d) Speech [ ] e) Cognitive [ ]
8. History of illness in the past six months: a) Yes [ ] b) No [ ]
9. If answer to question 8 is yes, did you seek any medical attention?
- a) Yes [ ] b) No [ ]
10. Currently taking any medication: a) Yes [ ] b) No [ ]
11. If yes to question 10, condition for which medication is taken: .....
12. What is the HIV status of child?
- a) Positive [ ] b) Negative [ ] c) Unknown [ ] d) Cannot disclose [ ]



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**ANTHROPOMETRY**

Weight 1 Taken to the nearest 0.1kg

Weight 2

			.		kg
			.		kg

Head circumference: .....

**SECTION D: Feeding patterns and problems**

1. Has child gained weight in the last 2 to 3 months? A) No [ ], b) Yes [ ]
2. Does child feed him/herself?
- a) Totally dependent [ ] b) Partially dependent [ ] c) Totally independent [ ]
3. Are there signs of difficult breathing when child is feeding? a) No [ ] b) Yes [ ]
4. Does the child frequently suffer from chest infections? a) Yes [ ] b) No [ ]



1. Participant no: .....
2. Gender: a) Female [ ]                      b) Male [ ]
3. Date of interview: .....
4. Case or control caregiver: a) Case [ ]                      b) Control [ ]
5. Relationship with child: a) Biological mother, [ ]
- b) Grandmother, [ ]
- c) Aunt/uncle, [ ]
- d) Sibling, [ ]
- e) Maid, [ ]
- f) Other [ ]
- g) Specify if other: .....
6. If mother to child, marital status:
- a) Married [ ]
- b) Single [ ]
- c) Widowed [ ]
- d) Separated/divorced [ ]
7. Age of last birth day?
- a) 15-24 years [ ]
- b) 25-34 years [ ]
- c) 35-44 years [ ]
- d) 45 years and above [ ]
5. Highest level of education attained:
- a) No education [ ]
- b) Grade 7 and below [ ]
- c) Junior secondary level [ ]
- d) Senior secondary level [ ]
- e) Tertiary (Certificate or diploma) [ ]
- f) University degree (BSc, Masters, Doctor) [ ]



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6. Do you drink alcohol? a) Yes [ ] b) No [ ]

7. Are both biological parents to child alive? A) Yes [ ] b) No [ ]

**SECTION B: FAMILY SOCIAL ECONOMIC CHARACTERISTICS**

1. In whose house does child and caregiver live?

- a) Both biological parents [ ]
- b) Single mother [ ]
- c) Grandparents [ ]
- d) Other [ ]
- e) Specify other: .....

2. Income earner: a) Father [ ] b) Mother [ ]

c) Both mother and father [ ] d) Other [ ]

e) Specify other: .....

3. Highest level of education attained by income earner:

- a) No education [ ]
- b) Primary education [ ]
- c) Junior secondary level [ ]
- d) Senior secondary level [ ]
- e) Tertiary (Certificate or diploma) [ ]
- f) University degree (BSc, Masters, Doctor) [ ]



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4. What is the employment status of the household income earner:

- a) Formal employment [ ]
- b) Self-employed [ ]
- c) Not employed [ ]

4. Residential area: a) Low density [ ]

b) Medium density [ ]

c) High density [ ]

5. Ownership of house in which child's family lives?

- a) Rented [ ]
- b) Own [ ]

6. If rented house, who pays for house rentals?

- a) Occupant [ ]
- b) Employer of occupant [ ]
- c) Other [ ]
- d) Specify if other: .....

7. How many people live in the house?



Mupilu [ ], Other [ ], Specify if other: .....

c) **Legumes:** Beans [ ], peas [ ], peanuts [ ], soybeans [ ], Soya chunks [ ], Other [ ],

Specify if other: .....

d) **Fruits:** Mangoes [ ], bananas [ ], pawpaw [ ], watermelon [ ], avocado [ ], Oranges [ ], Pineapples [ ], other fruits [ ], Specify if other: .....

e) **Meat, poultry and fish:** Beef [ ], pork [ ], lamb [ ], goat [ ], chicken [ ], duck [ ], liver [ ], kidney [ ], Caterpillars [ ], Kapenta [ ], Fresh/dry fish [ ], eggs [ ],

Other [ ], Specify if other: .....

f) **Dairy products:** Milk [ ], yogurt [ ], cheese [ ], Sour milk [ ], Other [ ], Specify if other: .....

g) **Drinks:** Water [ ], Carbonated drinks [ ], Fruit drinks [ ], Other [ ], Specify if other: .....

13. How often do you feed the child in a day?

a) 3 times [ ],

b) 4 times [ ]

c) 5 times [ ]

d) Less than 3 times [ ]

e) More than 5 times [ ]

f) Cannot count [ ]

14. Do you prepare this child's food in a special way?

a) Yes [ ]

b) No [ ]

15. If answer to question 14 is yes, how long does it take you to prepare food for this child?

a) Less than 10 minutes [ ]

b) Less than 30 minutes [ ]

c) 30 to 60 minutes [ ]

d) More than 60 minutes [ ]

16. Have you been concerned about the child's feeding patterns? a) Yes [ ] b) No [ ]

17. If you have been concerned, what are your concerns? .....

Thank you for your time.

### Appendix 3



## UNIVERSITY OF THE WESTERN CAPE

School of Public Health

Private Bag X 17, Bellville 7535, South Africa

*Tel: +26 0955881730*

E-mail: micamutuna@yahoo.co.uk

## **INFORMATION SHEET**

### **Project Title: RISK FACTORS FOR SEVERE MALNUTRITION IN CHILDREN WITH CEREBRAL PALSY IN LUSAKA**

#### **What is this study about?**

This is a research project being conducted by Mrs Mica M Simpamba at the University of the Western Cape. We are inviting you to participate in this research project because you are a caregiver/mother of a child with cerebral palsy. The purpose of this research project is to identify factors associated with malnutrition in children with cerebral palsy. It is hoped that this information would help health care providers with planning interventions that would help with reducing malnutrition in children with cerebral palsy in a poor resource setting.

#### **What will I be asked to do if I agree to participate?**

You will be asked to provide information on the socioeconomic status of the family, demographic characteristics of primary caregiver, relationship of primary caregiver to child and feeding practices for the child. You will also be asked to provide information about the feeding patterns of the child such as how long it takes to feed the child, if meals are stressful, whether the child has gained weight in the past 2-3 months and history of recurrent chest infections. These interviews will take about 30 minutes. Besides this information which you will provide, the researcher will also examine your child and take some measurements such as weight and head circumference to determine the child's clinical and nutritional status. The examination of the child will take about 20 to 30 minutes.

#### **Would my participation in this study be kept confidential?**

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, you will not be identified by names but codes will be used and any information you will give will only be known by the researcher and used for purposes of this research. To ensure your confidentiality, the information you will provide will be kept under lock which will only be accessed by the researcher and all the survey forms will use identification codes. When the information is transferred on the computer, the researcher will put an access password to this information so that only she will be able to access the information.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

**What are the risks of this research?**

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about the risk factors associated with malnutrition in children with cerebral palsy. We hope that, in the future, other people might benefit from this study through improved understanding of these risk factors among health care providers. It is hoped that this will assist with planning interventions that would help with reducing malnutrition in children with cerebral palsy.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**What if I have questions?**

This research is being conducted by Mica Mutuna Simpamba at the University of the Western Cape. If you have any questions about the research study itself, please contact Micah Mutuna Simpamba at: University Teaching Hospital, phone no. +260 955881730 or e-mail: micamutuna@yahoo.co.uk.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

The Chairperson:  
ERES CONVERGE IRB  
33 Joseph Mwilwa Road  
Rhodes Park  
Lusaka  
Zambia  
Tel: 0955 155633/4

OR



Dean of the Faculty of Community and Health Sciences:

Prof José Frantz

University of the Western Cape

Private Bag X17

Bellville 7535

[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)

This research has been approved by the University of the Western Cape's Senate Research Committee and the ERES Converge Research Ethics Committee in Zambia.



UNIVERSITY *of the*  
WESTERN CAPE

**Appendix 4**



**UNIVERSITY OF THE WESTERN CAPE**

School of Public Health

Private Bag X 17, Bellville 7535, South Africa

*Tel: +26 0955881730*

E-mail: micamutuna@yahoo.co.uk

**CONSENT FORM**

**Title of Research Project: RISK FACTORS FOR SEVERE MALNUTRITION IN CHILDREN WITH CEREBRAL PALSY IN LUSAKA**

The study has been described to me in the language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

**Participant's name**.....

**Participant's signature**.....

**Date**.....

**Witness's name**.....

**Witness's signature**.....

**Date**.....

## Appendix 5



### DEPARTMENT OF RESEARCH DEVELOPMENT

14 December 2015

#### To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:  
Mrs MM Simpamba (School of Public Health)

Research Project:	Risk factors for severe malnutrition in children with cerebral palsy in Lusaka.
Registration no:	15/7/253

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.



*Ms Patricia Josias*

## Appendix 6



33 Joseph Mwiliso Road  
Rhodes Park, Lusaka  
Tel: +260 955 155 633  
+260 955 155 634  
Cell: +260 966 765 503  
Email: eresconverge@yahoo.co.uk

I.R.B. No. 00005948  
EWA. No. 00011697

15<sup>th</sup> April, 2016

**Ref. No. 2016-Apr-008**

The Principal Investigator  
Ms. Micah Mutuna Simpamba  
University Teaching Hospital  
P/B RW1X,  
LUSAKA.

Dear Ms. Simpamba,

**RE: RISK FACTORS FOR SEVERE MALNUTRITION IN CHILDREN WITH CEREBRAL PALSY IN LUSAKA, ZAMBIA.**

Reference is made to your submission of the corrected version of your protocol dated 12<sup>th</sup> April, 2016. The IRB resolved to approve this study and your participation as Principal Investigator for a period of one year.

Review Type	<b>Ordinary</b>	Approval No. <b>2016-Apr-008</b>
Approval and Expiry Date	Approval Date: 17 <sup>th</sup> May, 2016	Expiry Date: 16 <sup>th</sup> May, 2017
Protocol Version and Date	Version – Nil	16 <sup>th</sup> May, 2017
Information Sheet, Consent Forms and Dates	<ul style="list-style-type: none"> <li>English, Bemba, Nyanja.</li> </ul>	16 <sup>th</sup> May, 2017
Consent form ID and Date	Version-Nil	16 <sup>th</sup> May, 2017
Recruitment Materials	Nil	16 <sup>th</sup> May, 2017
Other Study Documents	Data Collection Tool.	16 <sup>th</sup> May, 2017
Number of participants approved for study	-	

Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.

#### **Conditions of Approval**

- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address.
- All protocol deviations must be reported to the IRB within 5 working days.
- All recruitment materials must be approved by the IRB prior to being used.
- Principal investigators are responsible for initiating Continuing Review proceedings. Documents must be received by the IRB at least 30 days before the expiry date. This is for the purpose of facilitating the review process. Any documents received less than 30 days before expiry will be labelled "late submissions" and will incur a penalty.
- Every 6 (six) months a progress report form supplied by ERES IRB must be filled in and submitted to us.

Should you have any questions regarding anything indicated in this letter, please do not hesitate to get in touch with us at the above indicated address.

On behalf of ERES Converge IRB, we would like to wish you all the success as you carry out your study.

Yours faithfully,  
**ERES CONVERGE IRB**

  
Dr. Esther Munalula-Nkandu  
BSc (Hons), MSc, MA Bioethics, PgD R/Ethics, PhD  
**CHAIRPERSON**