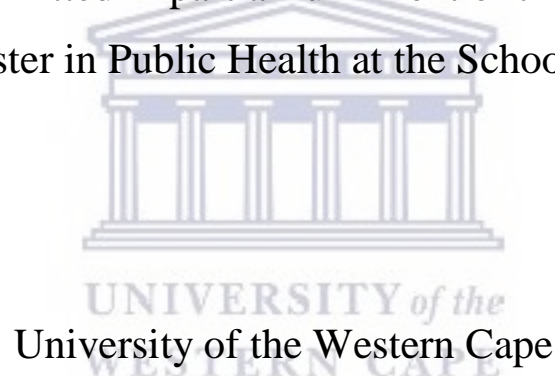


**THE CLINICAL PRESENTATION OF  
CEREBRAL PALSY IN CHILDREN IN  
RURAL KWAZULU-NATAL, SOUTH AFRICA**

HEATHER JOY COOMBE

A mini-thesis submitted in partial fulfilment of the requirements for  
the degree of Master in Public Health at the School of Public Health



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Co-supervisor: Mr Thuli Mthembu

October 2017

## Declaration

I declare that the work presented herein, The clinical presentation of cerebral palsy in children in rural Kwazulu-Natal, South Africa, is original and that it has not been submitted for any degree or examination in any other university or institution for the award of a degree or certificate and that all sources of information and data used or quoted have been duly indicated and acknowledged.

**Full Name:** Heather Joy Coombe

**Signature:**



**Date:** 6 October 2017

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WESTERN CAPE

## Key Words

Cerebral palsy

Subtype

Limb distribution

Classification

Gross motor function

Comorbidities

Children

Low resource setting

Rural

Rehabilitation



## Abbreviations

CDG	Care dependency grant
CP	Cerebral palsy
CSG	Care support grant
GMFCS	Gross motor function classification system
GMFCS-E&R	Gross motor function classification system extended and revised
HIE	Hypoxic ischaemic encephalopathy
HIV	Human immunodeficiency virus
ICF	International Classification and Functioning, Disability and Health
MACS	Manual abilities classification system
MDG	Millennium development goals
SASSA	South Africa Social Security Agency
SCPE	Surveillance of Cerebral Palsy in Europe group
SDG	Sustainable development goals



## Definition of Key Terms

Cerebral palsy: A common permanent but non-progressive disorder of movement and muscle tone that causes impairment of the ability to engage in activities and participate fully in life (Bax et al., 2005).

Clinical presentation: There are three subtype classifications of tone: spastic, ataxic and dyskinetic CP and this can affect all limbs (quadriplegia), one side of the body (hemiplegia) or the lower limbs (diplegia) (SCPE, 2000).

Spastic cerebral palsy: Abnormal movement patterns and posture with the presence of increased tone and pathological reflexes (SCPE, 2000).

Ataxia cerebral palsy: Abnormal movement patterns and posture with the loss of coordination that affects force, accuracy and rhythm (SCPE, 2000).

Dyskinetic cerebral palsy: Abnormal movement patterns and posture with reduced activity and increased tone or increased activity and decreased tone (SCPE, 2000).

Gross motor function: Classifies children's gross motor functional abilities based on actions used in daily life (Palisano, Rosenbaum, Bartlett, & Livingston, 2008).

Disability: A term that includes impairments, limitations to activities and restrictions to participation. There is interaction between these, the health condition, personal factors and the environment (WHO, 2002).

Low resource setting: A setting characterized by a lack of resources to cover health care costs which results in limited access to supplies and medication, poorly developed infrastructure and fewer health care workers (University of Washington, 2014).

Rural setting: In South Africa, a rural area is described as that which is not an urban area, that is determined by settlement type and land use (Statistics South Africa, 2004).

Rehabilitation: A process which enables people with disabilities to reach their optimal level of function (WHO, 2016).



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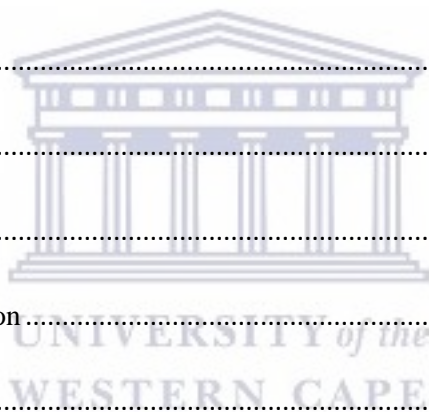
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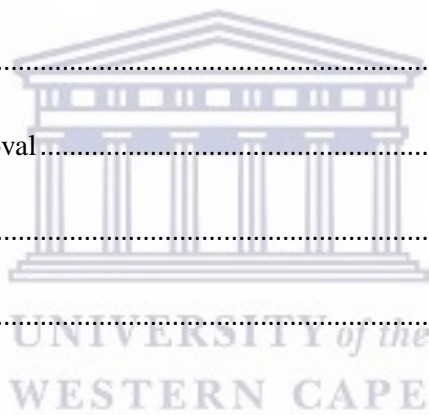
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## Abstract

Introduction: Cerebral palsy is a common neurological disorder with a prevalence of between 2 and 3 per 1000 live births globally and up to 10 per 1000 in rural South Africa. Children with cerebral palsy present with different tonal subtypes, limb distributions, co-morbidities and gross motor functioning. In South Africa, a large proportion of children with cerebral palsy present with spastic quadriplegia and limited gross motor function, however, studies have been conducted at tertiary hospitals and not in rural areas, thus little is known about the presentation of children with CP in these areas.

Aim: This research aimed to assess the clinical presentation of cerebral palsy and the relationship between gross motor function, limb distribution and tone classification in children aged 18 years and younger receiving rehabilitation at Bethesda hospital in Umkhanyakude district, KwaZulu-Natal.

Methodology: A retrospective chart review study design was used, collecting data from patients' clinical records, accessed through the database for children with disabilities. Participants were all children with cerebral palsy up to the age of 18 who attend therapy at Bethesda Hospital and its clinics.

Results: In total, 94 participants were included in the study. Spastic CP was the most common tonal subtype (56,4%) and the most common limb distribution was quadriplegia (71,2%). Spastic quadriplegia (27,6%) and dystonia (26,6%) were the two most common classifications. Severe limitations in gross motor function were common with most participants classified as GMFCS level 4 (22,3%) and 5 (31,9%). There was a statistically significant association between limb distribution and GMFCS level. Provision of appropriate assistive devices and equipment was low, as was access to appropriate schooling.

Conclusion: Common presentations of CP in this study include spastic quadriplegia and dystonia, with limited gross motor function. This necessitates appropriate provision of rehabilitation, medical care, assistive devices and appropriate schooling or care. It is recommended that larger, multi-site research is conducted in both rural and urban settings within South Africa.



# CHAPTER 1

## 1.1. Introduction

Cerebral Palsy (CP) is a common permanent disorder of movement and muscle tone that causes impairment of the ability to engage in activities and participate fully in life (Bax et al., 2005). This is due to damage to the brain during foetal development (congenital), or as an infant before the age of two (acquired). The aetiology of cerebral palsy can be described as prenatal, perinatal or postnatal and this can often be determined by physical examination and neuroimaging (Russman & Ashwal, 2004). The prenatal period refers to time before birth and risk factors for CP include infections, stroke, pre-eclampsia and placental abruption. The WHO defines the perinatal period as 22 weeks of gestation to seven days of life (WHO, 2013) and risk factors for CP include hypoxic ischaemic encephalopathy (HIE) and jaundice (Russman & Ashwal, 2004). Postnatal period refers to the after birth and risk factors include infections and trauma.

CP is not a progressive diagnosis but secondary complications such as contractures are common (Bax et al., 2005). The prognosis of the child depends on the classification, secondary complications and associated impairments (Rogers, 2010). Associated impairments include disturbances of sensations, intellectual impairment, learning difficulties, impaired perception, difficulties with communication, behavioural problems and epilepsy (Bax et al., 2005). Early identification is imperative to the family and child accessing services which will assist the child to reach their potential and prevent secondary complications (Rogers, 2010). Activity limitations and participation in mobility, self-care, schooling, play and recreation need to be addressed through medical services, therapeutic services and assistive devices (Rogers, 2010).

## 1.2. Classification of Cerebral Palsy

There are three classifications of CP: spastic, ataxic and dyskinetic, all which have abnormal movement patterns, tone and postures (SCPE, 2000). The Surveillance of Cerebral Palsy in Europe (SCPE) group define spastic CP as the presence of increased tone and pathological reflexes. Ataxic CP is defined as loss of coordination that affects the force, accuracy and rhythm of movement. Children with ataxic CP may present with low tone, but must have signs of ataxia. Dyskinetic CP is defined as the presence of uncontrollable and involuntary movements. Dyskinetic CP can be further classified as dystonic CP which presents as reduced activity and increased tone, or choreoathetoid which presents as increased activity and decreased tone. Children with CP can also be classified as mixed if they present with symptoms of two subtypes.

Limb distribution is also used to describe and classify children with CP (SCPE, 2000). The SCPE describe the limb distribution as quadriplegia, when all limbs are affected, and hemiplegia, when limbs on one side of the body are affected. Quadriplegia includes diplegia, when the lower limbs are more affected than the upper limbs, but is commonly described separately in literature.

There are several outcome measures that can be used to assess functional levels and severity of CP. The most commonly used outcome measure for gross motor function is the expanded and revised Gross Motor Function Classification System (GMFCS E&R) which classifies children's gross motor functional walking abilities into five levels according to age. In upper income countries, there is a higher prevalence of children with spastic hemiplegia and good gross motor functions (Carnahan, Arner, & Hägglund, 2007) in comparison to lower income countries where more children present with spastic quadriplegia and severe gross motor function (Kakooza-Mwesige, Forssberg, Eliasson, & Tumwine, 2016).



### **1.3. Prevalence of Cerebral Palsy**

The prevalence of CP globally is reported to be between 2 and 2.5 per 1000 live births (Odding, Roebrock, Stam, Roebroek, & Stam, 2006) with a recent systematic review reporting a pooled prevalence of about 2 per 1000 live births (Oskoui, Coutinho, Dykeman, Jette, & Pringsheim, 2013). There is very little literature about CP in Africa (Donald, 2016). However, a review of African studies reports a prevalence of between 2 and 10 per 1000 which could be due to heterogeneous research methods between studies. (Donald, Samia, Kakooza-Mwesige, Bearden, & Donald, 2014).

It has been reported that there is a high prevalence of children with CP in Umkhanyakude District, KwaZulu-Natal as 10 per 1000 children under the age of ten were found to have cerebral palsy (Couper, 2002). The aetiology of CP in Africa is likely more due to perinatal and postnatal problems than low birth weight and prematurity (Kakooza-Mwesige et al., 2016). This highlights the need for further research into the aetiology of CP in Africa to advance prevention measures. There is also a need for multidisciplinary management of children who have CP. In the African context, there is a lack of early identification and management of children with CP due to a shortage of medical staff and rehabilitation workers, and specifically those trained in the management of CP in rural areas (Donald et al., 2014).

In South Africa, previous studies investigating the clinical presentation of children with CP have been based at urban tertiary hospitals (Govender, Hepworth, Bagwandeem, & Chetty, 2015; van Toorn, Laughton, Zyl, Doets, & Elsinger, 2007). These hospitals have the advantage of trained specialists and radiological imaging which can be used to formally diagnose the children. Tertiary hospitals will only provide care for a percentage of the population, as most rehabilitation services are provided by clinics and district hospitals. Although all children should have access to tertiary services, children in more rural areas do not always get referred

for medical check-ups and a diagnosis is often made by a medical officer with rehabilitation workers. It is not known whether children in rural areas present differently to those in urban areas. In Umkhanyakude district, there is a high HIV prevalence of 35.2% among pregnant women (Mahlawe & Massyn, 2014) and this places many infants at a higher risk of low birth weight and premature birth (Xiao et al., 2015). Further, only 60% of pregnant women have their first antenatal visit before 20 weeks (Wandai, 2015). These factors may result in differing clinical pictures of children with CP.

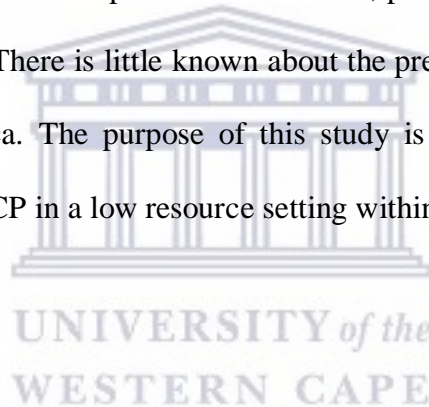
At Bethesda Hospital, children with risk factors for the CP and developmental delays, are given follow up dates to see the occupational therapist at 14 weeks of age. Through this programme, and referrals from nurses and doctors, children with CP are mostly identified by the therapist who then refers the child to the doctor to a formal diagnosis. This involves the doctor discussing the patient with the paediatrician or neurologist at the regional paediatric hospital. If the CT scan is functional, the child will be sent for a scan and review at this hospital, if not, the child is diagnosed by the doctor in verbal consultation with the paediatrician or neurologist. Classification is made by the occupational therapist and physiotherapist who have received inservice training, or attended a course on classification of CP. All doctors and therapists have limited experience, and many are completing their community service year. It is therefore possible that children are incorrectly diagnosed and classified.

#### **1.4. Problem Statement**

Classification of a child with CP is essential to describe the nature and severity of the child's presentation, which assists to predict the child's potential and prognosis and measure change that occurs (Bax et al., 2005). Previous studies highlight that early identification and treatment of children with CP results in improved functional outcomes and increases parents'

engagement in the rehabilitation process and quality of life for the child and family (Dimitrijević & Jakubi, 2005; Scherzer, Chhagan, Kauchali, & Susser, 2012) and prevents secondary complications (Rogers, 2010). Knowing a child's classification is useful to engage parents, plan therapy to optimise the potential, plan services that provide appropriate and timely issuing of assistive devices. It also ensures that staff can be adequately trained to provide rehabilitation and services for comorbidities such as epilepsy. It has been noted that at district hospital and its clinics, early identification, diagnosis and classification is a challenge to inexperienced medical officers and rehabilitation therapists.

It is suspected that there is a large percentage of children classified as spastic CP and a large percentage with severe gross motor impairments. However, previous studies have focused on urban tertiary hospitals only. There is little known about the presentation of children with CP in rural areas of South Africa. The purpose of this study is thus to describe the clinical presentation of children with CP in a low resource setting within South Africa



### **1.5. Research question**

What is the clinical presentation of children living with cerebral palsy in the receiving rehabilitation at Bethesda hospital in Umkhanyakude district, KwaZulu-Natal? Is there a relationship between gross motor function, limb distribution and tone?

### **1.6. Aims and objectives**

#### Aim

To assess the clinical presentation of children living with cerebral palsy and the relationship between gross motor function, limb distribution and tone in children receiving rehabilitation at Bethesda hospital in Umkhanyakude district, KwaZulu-Natal.

## Objectives

- To determine the prevalence of tone subtypes, limb distribution and limited gross motor functioning in children with cerebral palsy
- To determine the relationship between limb distribution and gross motor function in children with cerebral palsy
- To determine the relationship between tone group and gross motor function in children with cerebral palsy

### **1.7. Significance of this Research**

The results of this study will add to the knowledge on the presentation of children with CP in rural areas of South Africa. This is useful in planning of hospital and clinic services for medical practitioners, and rehabilitation professionals such as physiotherapists, occupational therapists and speech-language therapists. Having knowledge and a better understanding of the presentation and gross motor severity may assist in improving planning of services, education and involvement of the family in goal setting. This allows children with CP to reach their potential level of function and participation within their home and community through rehabilitation and medical services.

The results of this study may be used to plan for continued professional development of rehabilitation therapists and medical personnel to gain insight into the prevention, early identification, primary and secondary management of children with CP. The results will also assist in budgeting, ensuring that appropriate assistive devices are available. The results can assist in determining type of educational services, or social services required in rural areas and in turn inform service provision by the Department of Education and Social Services.

Many countries and regions maintain surveillance databases and programmes which should be considered in South Africa. As this research is based on a database from a small hospital, it could assist in providing recommendations for improving databases and surveillance of children with CP, as well as those who are at a high risk for disability. This could assist in epidemiological research about CP in South Africa, especially considering the litigation occurring currently.

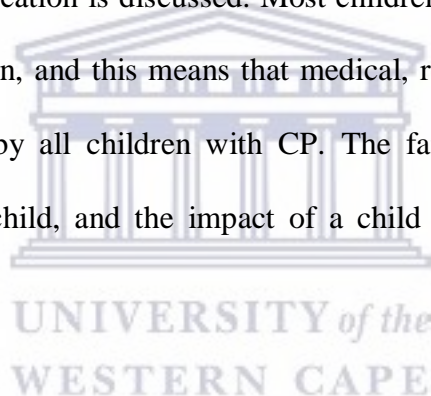


## CHAPTER 2

### 2.1. Literature Review

This chapter reviews literature relevant to this study and its main objectives. The literature review begins with a definition and description of cerebral palsy and how this definition has changed over time. The prevalence of CP globally, in African and South Africa varies, and is compared in relation to differing etiologies across high and low-income countries.

The process of screening, diagnosis and classification by tonal subtype and limb distribution is described. The GMFCS E&R is presented as a measure of gross motor function and its clinical use and relation to CP classification is discussed. Most children with CP have comorbidities which impact on their function, and this means that medical, rehabilitative, educational and social services are required by all children with CP. The family are the most important environmental factor to the child, and the impact of a child with CP on the caregiver is discussed briefly.



### 2.2 Cerebral Palsy

Cerebral palsy was first described by Little in 1843, and has since been defined in slightly differing terms by a variety of people (Bax et al., 2005). CP refers to a group of heterogeneous disorders, which means that defining the aetiology, impairments and functional status is difficult. Most recently, CP was defined by the Executive Committee for the Definition of Cerebral Palsy with the aim to reach an international consensus about the definition of CP (Bax et al., 2005). Their definition was informed by new research about developmental neurobiology, aetiology, and the impairments and functional status of people with CP. The committee defined CP as

“a group of permanent disorders of development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, behaviour, and/or by a seizure disorder” (Bax et al., 2005, pg 572)

Commentaries on the definition are mixed. One author proposes that there is a need to clarify the difference between definition and classification, as classification can change based on new research (Armstrong, 2007). The author therefore proposes that the second sentence is reworded to be broader and links to the International Classification of Functioning, Health and Disability (ICF). Other authors commended that it included classification and non-motor features of CP which reinforces the need for management by a multidisciplinary team (Carr, 2005; Reddy, 2005). Reddy (2005), calls for even more clarity on level of severity, activity limitations, classification and other syndromes which are similar to CP. There is concern that the definition does not clarify aetiology and the age of injury (Armstrong, 2007; Blair & Love, 2005; Carr, 2005; Reddy, 2005) as well as what is meant by non-progressive (Blair & Love, 2005). This is important as there are functional and medical changes as a person ages (Stevens, 2005). In Africa, the term CP is often used to describe all motor impairments in children, resulting in difficulty in comparison in research (Donald et al., 2015).

### **2.3. Prevalence of Cerebral Palsy**

CP is one of the most common physical disabilities of childhood and therefore, despite the differences in definition, classification and management of CP, it is a relevant public health topic, affecting the health of children and families. Children with CP make up a large proportion of patients at paediatric and neurology clinics with the prevalence of CP ranging

between 15% and 65% (Burton & Allen, 2003; Nasir, Tahir, Ahmed, & Shinwari, 2004; Ogunlesi, Ogundeyi, Ogunfowora, & Olowu, 2008). It therefore has a major impact on the provision of health services, among others. As medical services improve, children with CP become adults with CP, and there is a need to consider their differing health needs and access to health services (Aisen et al., 2011). The prevalence of CP in Europe is between 1.5 and 3 per 1000 live births (SCPE, 2000) and in Sweden, the prevalence between 2003 – 2006 was 2.18 per 1000 live births (Himmelmann & Uvebrant, 2014). The global prevalence of CP is reported to be between 2 and 2.5 per 1000 live births (Odding et al., 2006) and recently the pooled prevalence was reported as 2.11 per 1000 live births (Oskoui et al., 2013). Research shows that this prevalence has remained constant in studies over the past ten years.

In Africa, there are a few studies which investigate the prevalence of CP, and of the studies conducted, there is a heterogeneity between study methodologies (Donald et al., 2014). This has resulted in a reported wide prevalence of between 2 and 10 per 1000 live births. A study conducted in a region in Umkhanyakude, KwaZulu-Natal reports a prevalence of CP of 10 per 1000 in children under the age of ten (Couper, 2002). In another study in a rural area in Mpumalanga, the prevalence of motor disabilities was 0.5% in children aged two to nine (Kromberg et al., 2008). This is congruent with studies which have reported a higher prevalence of CP in rural areas compared with urban areas (Finkenflugel et al., 1996, as cited by Dambi & Jelsma, 2014) and in low socio-economic groups (Odding et al., 2006; Ogunlesi et al., 2008). This indicates that, despite the lack of reliable statistics and rigorous methods of studies, the prevalence of CP in South Africa, particularly rural areas, is likely higher than the global prevalence.



## 2.4. Aetiology of Cerebral Palsy

The aetiology of CP can be described as prenatal, perinatal or postnatal and this can often be determined by neuroimaging (Russman & Ashwal, 2004). Some children with CP have normal neuroimaging and one study reports that in Sweden this was seen in 10% of a cohort which was lower than the previous cohort (Himmelman & Uvebrant, 2014). In a recent study in Uganda, 31% of children with CP had normal CT scans (Kakooza-Mwesige et al., 2016).

In a review of studies conducted in low resource settings, Gladstone (2010) reports that low birth weight contributes, birth asphyxia, neonatal jaundice, convulsions and infections are common causes. Much research has been conducted to understand role of prematurity and low birth weight. The highest pooled prevalence is in children born prematurely before 28 gestational weeks, and the risk significantly decreases as gestational age increases (Oskoui et al., 2013). The highest pooled prevalence is in children born 1 to 1.5kg and the risk decreases significantly as birthweight increases (Oskoui et al., 2013). Interestingly, in a cohort of children with CP in Sweden, 71% had been admitted to the neonatal unit (Himmelman & Uvebrant, 2014). Of a cohort of children with CP in Uganda, those with hospital admissions after birth were about three times more likely to have a grey matter injury. In Sweden, there is an increase in the classification of spastic hemiplegia, accounting for 44% of the cases of CP, mostly in those born at term (Himmelman & Uvebrant, 2014).

It is likely that the aetiology, as well as presentation of CP differs between upper-income countries and lower-income countries (Kakooza-Mwesige et al., 2016). In Uganda, very few participants presented with primary white matter injuries, which is associated with premature births. Most (44%) participants had primary grey matter injuries, with bilateral spastic CP and severe impairments (Kakooza-Mwesige et al., 2016). Of those participants, 62% had a history of delayed crying after birth, indicating perinatal causes of CP. Those with cerebral infarct,

presented with hemiplegia which is in line with other literature. In Botswana, the most common causes of CP were reported as intrapartum hypoxic events, postnatal meningitis, infarcts and prenatal infections (Bearden et al., 2016). The research suggests that the aetiology of CP in Africa is in the perinatal period and that this results in more severe motor impairment and bilateral spastic CP. This literature impacts prevention measures. In Africa, post-natal causes have been attributed to TB meningitis, neuro-infections such as malaria, and epilepsy (Kakooza-Mwesige et al., 2016; Levin, 2006; Wilmshurst, 2014). Further, malnutrition, HIV, poverty and general maternal and child health conditions play a role (Donald et al., 2015, 2014).

As countries have aimed to reduce maternal and child mortality to reach the Millennium Development Goals (MDG) and now Sustainable Development Goals (SDG), there has been an increase in survival of children who are at a high risk of disability, and the incidence of disability and developmental delays has increased (Scherzer et al., 2012). With the increase in babies born preterm and classified as low birth weight, there was an expectation that the incidence and prevalence of CP would increase, however, improved medical management has resulted in a constant prevalence. (Oskoui et al., 2013). Medical management includes cooling for birth asphyxia, antenatal corticosteroids and magnesium sulphate. In South Africa, there has been an increase in litigation for adverse events that occur in pregnancy and birth (Cooper, 2015), necessitating prevention of the risk factors which cause amongst others CP.

## **2.5. Screening and Diagnosis**

The Ten Questions Questionnaire is commonly used to screen children for disability, however there is inconsistent data regarding its sensitivity and specificity in different populations (Couper, 2002; Donald et al., 2014; Durkin et al., 1994; Gladstone et al., 2010; Maulik & Darmstadt, 2007; Mung'ala-odera & Newton, 2007). One common conclusion is that it

identifies children with more severe functional limitations only. However, as a low cost, rapid screening tool, it is still useful. Mild cases of CP may also be missed due to a the lack of appropriate screening tools and inexperienced health care workers (Gladstone, 2010; Kakooza-Mwesige et al., 2015). In South Africa, the Road to Health Booklet now includes a developmental screening page which health professionals and community health workers can complete to screen children (Scherzer et al., 2012). The authors advocate for screening children's development at each contact with the health system, much like malnutrition is screened for regularly. This should result in early identification of children with developmental delays. Assessment for abnormal movements and motor delays should be incorporated into surveillance programmes (Palmer, 2004), especially of those with risk factors for cerebral palsy such as those who have been admitted to the neonatal unit. CP can be accurately predicted by a lack of fidgety movements between two and four months (Adde et al., 2010), abnormal kicking patterns or cramped movements (Bruggink et al., 2009).

The diagnosis of CP is made by clinical examination of the child and neuroimaging, exclusion of genetic conditions and exclusion of degenerative conditions (American Academy of Neurology, n.d.). The first step in a diagnosis of CP is a physical examination (Russman & Ashwal, 2004). This is to ensure that the symptoms are from an upper motor neuron lesion, and that it is not progressive. As the child ages, further examinations may be useful to confirm the diagnosis. Clinical examination includes ensuring that there is an impairment in motor function (SCPE, 2000). Impairment to motor functions is the main feature of CP and present as abnormal muscle tone, poor coordination of movements, abnormal postures and patterns of movement (Bax et al., 2005).

After a physical examination, neuroimaging should be obtained to determine the aetiology of the CP (Palmer, 2004; Russman & Ashwal, 2004). Magnetic resonance imaging (MRI) can

assist in determining whether the cause is prenatal, perinatal or postnatal and whether this is congruent with etiological history and clinical examination (American Academy of Neurology, n.d.). Neuroimaging can show primary white matter injuries, primary grey matter injuries, a combination of the two, congenital malformations and focal infarcts (Kakooza-Mwesige et al., 2016). If there is a brain malformation, there is a need to rule out genetic conditions. Those with hemiplegia, often show evidence of a cerebral infarct which could be caused by a coagulation disorder and should therefore be investigated (Russman & Ashwal, 2004). It is also necessary to assess for epilepsy and assess IQ, vision, hearing, speech and language difficulties. Routinely, there is no need for metabolic and genetic studies. The SCPE group included participants who had a brain syndrome or chromosomal abnormalities, as long as they met the above-mentioned criteria (SCPE, 2000). They excluded children who presented with pure hypotonia and an absence of ataxia. The SCPE (2000), presents a decision tree for the inclusion of cases on their register which covers the above aspects (appendix A).

In a review of 27 cerebral palsy surveillance programmes in first world countries, there were four different definitions, classifications and eligibility criteria used (Goldsmith et al., 2016). This means that comparison is difficult. More than 50% of the programmes included patients with hypotonia which does not correlate with many definitions and classifications. In two reviews, authors found that there is inconsistency in the definition of who is classified and diagnosed with CP (Donald et al., 2015; Gladstone, 2010). Inconsistencies included varying cut of ages for postnatal causes, a lack of diagnostic tools low resource settings and many studies referred to all motor disabilities as CP. Further, there is inconsistency in referral of children to higher centers for correct diagnosis and medical care (Donald et al., 2014).

## **2.6. Classification of Cerebral Palsy**

After diagnosis, the classification of CP needs to be determined. The most commonly used terminology is the classification system used by the Surveillance of Cerebral Palsy in Europe (SPCE) group. This is in terms of dominant tonal subtype and limb distribution which is presented as a classification tree by the SCPE (2000). There are three subtype classifications of tone: spastic, ataxic and dyskinetic CP, all characterised by abnormal movement patterns and postures. Spastic CP is defined as the presence of increased tone and pathological reflexes. Ataxic CP is defined as loss of coordination that affects the force, accuracy and rhythm of movement. Children with ataxic CP may present with low tone, but must have signs of ataxia. Dyskinetic CP is defined as the presence of uncontrollable and involuntary movements. Dyskinetic CP can be further classified as dystonic CP which presents as reduced activity and increased tone or choreoathetoid which has an opposite presentation of increased activity and decreased tone. Children with CP can also be classified as mixed if they present with symptoms of two subtypes.

Secondly, the limb distribution is described. The SCPE (2000) describe the limb distribution as quadriplegia when all limbs are affected and hemiplegia when limbs on one side of the body are affected. Quadriplegia includes diplegia, when the lower limbs are more affected than the upper limbs, but is commonly described separately in literature.

## **2.7. Gross Motor Function**

The functional abilities of a child are of greatest interest to the rehabilitation professional, and relate to the ICF (Rosenbaum & Stewart, 2004). CP impacts body structures, functions, activities and participation (Novak et al., 2013). The ICF acknowledges the importance of the environment, of which the family is often the most important to the child's health and wellbeing

(Rosenbaum & Stewart, 2004). This provides support for family centred practice for CP. The ICF also describes the difference between capacity and performance, which may be different and related to the classification of gross motor function. The ICF highlights that capacity needs to be acknowledged in rehabilitation, to improve performance. Importantly, the ICF recognises personal factors which need to be recognised in rehabilitation and management of the person with CP. Thus, rehabilitation and management, should no longer focus on the impairment, but rather also on the personal and environmental factors to achieve the desired outcome of function and participation.

The expanded and revised Gross Motor Function Classification System (GMFCS E&R) has been widely adopted for the use in clinical practice, research and administration (Rosenbaum, Palisano, Bartlett, Galuppi, & Russell, 2008). There are five levels and differing age bands which account for age related differences and is a simple tool which classifies children's gross motor functional abilities based on actions used in daily life. Table 1 provides a summary of the levels. More details can be found in appendix B.

**TABLE 1: GMFCS E&R LEVELS**

<b>Level</b>	<b>Description</b>
1	Walks without limitations
2	Walks with limitations
3	Walks with a handheld mobility device
4	Limitations in self-mobility, may use powered mobility
5	Transported in a manual wheelchair

(Palisano, Rosenbaum, Bartlett, & Livingston, 2007)

The authors hoped that the tool could validly predict gross motor function (Palisano et al., 2008). However, the authors do acknowledge that as children age, their preferred methods of mobility may change due to personal factors, personal choices and environmental factors. Thus, when classifying, one looks at capacity and performance under normal circumstances. Rosenbaum (2003) reports that parents often want to know whether their child will be able to walk, this therefore allows appropriate education to be given to caregivers, and promotes realistic goal setting.

In a study investigating whether the GMFCS level at age 12 was predictive of gross motor function as an adult, there was an 88% probability of remaining in the classification of GMFCS 1 or 2, and 96% probability of remaining in the classification of GMFCS 4 or 5 (McCormick et al., 2007). Another study reports that test-retest reliability improved as the participants became older. From age one to two, to 6 to 12, the reliability was 0.79 (Wood & Rosenbaum, 2000). Further, the predictive value of a child's ability to walk indoors between the ages of 6 to 12 when they are classified as GMFCS level 1 to 3, was 0.74. They conclude that the GMFCS can be used to predict the gross motor function of children and is useful to parents and rehabilitation staff. It is useful to incorporate into clinical settings as it relies on routine clinical and does not require special skills or training (Wood & Rosenbaum, 2000). The GMFCS can be used to guide the answer of 'will my child ever walk'.

Research conducted in Canada found that there was a general decline in gross motor functioning in adolescents classified as GMFCS 3, 4 and 5, over a four year period (Bartlett, Hanna, Avery, Stevenson, & Galuppi, 2010). The researchers report that this is significantly correlated to the mean limitations in range of motion, spinal alignment and pain experienced. Another study reports that over a seven year period, no significant decline in gross motor

function was found (Smits et al., 2013). Children classified at lower GMFCS levels reached their gross motor limits at a later age than those with higher GMFCS levels.

In a study of the association between GMFCS and Manual Abilities Classification System (MACS) there is a correlation between the two measures (Carnahan et al., 2007). However, the strength varied by subtype classification of the child, and other comorbidities such as cognitive ability. In children with spastic hemiplegia, the MACS score is lower than the GMFCS score. All children with spastic quadriplegia were classified as GMFCS 5 and most were classified as MACS 5. In those with dyskinetic CP, all had lower GMFCS and MACS scores indicating severe functional limitations and there was a strong association between two measures. Participants with ataxia had good motor functional abilities and half of them were classified as GMFCS and MACS 1.

Other gross motor outcome measures include the Gross Motor Functional Measure (GMFM) 66 and 88 and Paediatric Evaluation of Disability Inventory which are reported as the most appropriate outcome measures for children with CP and can be used to appropriately differentiate between the levels of the GMFCS (Debus & Brace, 2011).

## **2.8. Relationship Between Classification and Gross Motor Function**

In studies of the relationship between limb distribution, tonal classification and gross motor function, limb distribution and gross motor function are correlated, but with differing significance (Carnahan, Arner, & Hägglund, 2007; Gorter et al., 2004; Hidecker et al., 2012). Limb distribution and function had a low but significant correlation, and the authors conclude that limb distribution and classification of tone is not a useful prognostic factor for gross motor function (Gorter et al., 2004). The authors report that 88% of children with hemiplegia were classified as GMFCS level 1 and most with quadriplegia were classified as level 3, 4 or 5 (Gorter et al., 2004). Another study reported differing levels of weak correlations with limb

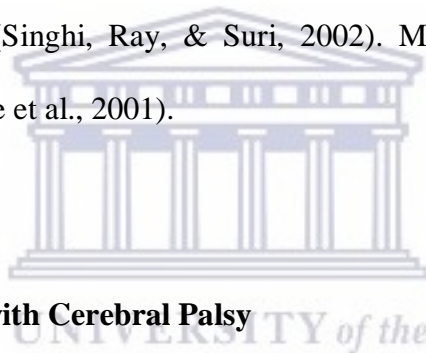


distribution and the GMFCS (Hidecker et al., 2012). In a large study in Sweden, of those with spastic hemiplegia, 88% were classified as GMFCS 1, with only 2% of participants being classified as GMFCS 3 (Carnahan et al., 2007). All participants with spastic quadriplegia were classified as GMFCS 5. Those with diplegia, 34% were GMFCS 1 and there was an equal presentation of GMFCS 2, 3 and 4, with only 2% of participants classified as GMFCS 5. Of those with dyskinetic CP, 74% were classified as GMFCS 4 or 5, with participants falling on all levels of the GMFCS scale. Of those with ataxia, 42% were GMFCS 2, and there were no participants classified as GMFCS 5. Knowing a child's functional presentation is most useful to direct rehabilitation, the families' expectations and schooling prospect (Gorter et al., 2004).

Studies in low- and middle- income countries have shown that there is a high proportion of children with more severe gross motor functions, comorbidities, dyskinetic CP and spastic quadriplegia (Gladstone, 2010). A recent study in Africa reports more severe gross motor function in children with spastic quadriplegia and dyskinetic CP (Kakooza-Mwesige et al., 2015). Further, comorbidity scores between the tone classifications and gross motor were statistically significant. In South Africa, studies have been conducted in Gauteng, Limpopo, Durban and Cape Town reporting generally high prevalence of between 56% and 81% of children with CP classified as spastic (Govender et al., 2015; Saloojee, Rosenbaum, Westaway, & Stewart, 2009; van Toorn et al., 2007). The classification of Dyskinetic CP ranged from 7.5% to nearly 30%. There was a high prevalence of limited motor functions and severity as approximately 60% of all children presented on level 4 and 5 of the GMFCS scale in two studies (Govender et al., 2015; Saloojee et al., 2009).

## **2.9. Comorbidities**

Becher (2002) describes common impairments as uncontrollable mirror movements, involuntary synergies, the presence of postural reflexes, co-contraction of muscles, stiffness and therefore shortening of muscles and poor gait patterns. A review of CP in Africa reports that common comorbidities are epilepsy, hearing impairments, low visual acuity, speech impairments, cognitive impairments, malnutrition and feeding difficulties (Donald et al., 2014). Authors suggest that there is a higher proportion of children with more severe CP and that children have more comorbidities and secondary complications due to poor access to health care services. In a Nigerian study, 90% of the children had comorbidities and most presented with a spastic tonal pattern (Ogunlesi et al., 2008). In a larger study of children in India, 75% had associated impairments (Singhi, Ray, & Suri, 2002). Malnutrition is also cited as a presenting factor (McConachie et al., 2001).



## **2.10. Services for Children with Cerebral Palsy**

Health care services for children with CP require a multidisciplinary team that focuses on motor weakness, tonal abnormalities, cognitive impairments, seizure disorders, psychosocial problems and oromotor impairments, using a family based approach (Aisen et al., 2011). Most commonly, the occupational therapist, speech-language pathologist and physiotherapist are involved in rehabilitation.

Treatment methods are either aimed at treating the cause of the CP that is the injured parts of the brain, or managing impairments and functional outcomes (Goldstein, 2004). These are either medical or therapeutic methods. The author advocates for the evaluation of treatment modalities with better research methods to answer important questions regarding when, for how long, how much and for whom.

Of 166 systematic reviews, only 16% provided conclusive evidence and were labelled as green 'go ahead' interventions (Novak et al., 2013). Evidence based interventions included the use of anticonvulsant therapy for seizures, botulinum toxin, selective dorsal rhizotomy and diazepam for management of spasticity and range of motion, hip surveillance and pressure care, bisphosphonates for bone density. Therapy should use bimanual training, casting, constraint-induced movement therapy, context-focused therapy, fitness training, goal-directed training, home programmes and occupational therapy after botulinum toxin. These interventions are all aimed at the body structures and functions, and activity levels of the ICF, but the goal of therapy is to ensure that children with CP live an inclusive life and experience good quality of life. All interventions need to be individualised due to the heterogeneous nature of CP and need to balance management of the primary deficit as well as preventing future secondary deficits (Papavasiliou, 2009). There should be a focus on increasing function, capabilities and independence (Rosenbaum, 2003).

Quality of life is also an important concept and one study found that in order to improve quality of life of the adolescent, there is a need to address pain, child psychological problems and parents coping mechanisms (Rapp et al., 2017). Research reports that quality of life decreases slightly between childhood and adolescence and quality of life in childhood predicts that of adolescence (Rapp et al., 2017). Severity of CP, and demographic factors did not influence quality of life, apart from severity of CP affecting autonomy. To prevent loss of motor function, range of motion, spinal alignment and pain needs to be managed (Bartlett et al., 2010).

A family based approach focuses on the context of the child, which is mostly the family. Rehabilitation is a long process, and short term goals need to be set with the caregiver and the child (Becher, 2002). Setting realistic goals requires correct classification and understanding of the potential prognosis for that classification and gross motor function level. In South

Africa, a study reported only 28% of the participants had the appropriate assistive device and a lack of knowledge about the rehabilitation services that are available resulted in only a quarter of children attending rehabilitation (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007).

In a systematic review, Donald et al. (2014) summarise the barriers to medical and rehabilitation services as difficulty with access and transportation, a lack of assistive devices, stigma about disabilities and poverty. This is particularly true for older children as they are more difficult to carry (Kakooza-Mwesige et al., 2015). Medical complications such as epilepsy also reduce attendance at therapy (McConachie et al., 2001). Therefore, research shows that community based rehabilitation is more acceptable to parents (Donald et al., 2014) as it negates some of the transport cost and increases social support with those living nearby (Dambi & Jelsma, 2014). Community based rehabilitation has also been shown to have positive effects such as improved motor function and reaching older children (Dambi & Jelsma, 2014). However, a shortage of rehabilitation staff, particularly in rural areas and poor administration and supply chain management impacts rehabilitation and medical services (Donald et al., 2015).

In addition to medical care, children with CP require services from teachers, social workers, psychologists and social services (Aisen et al., 2011). In particular, stigma and access to schooling needs to be addressed (Maulik & Darmstadt, 2007). In South Africa, many children with disabilities are not attending school because mainstream schools sometimes refuse to accept learners with special educational needs and special schooling services are often far away from children's homes (Saloojee et al., 2007). Financial difficulties and parents' perception of the child's ability to cope and learn in the school also played a role. A report focusing on inclusive education in the Umkhanyakude district found that parents and children had similar difficulties in accessing education services (Hodgson & Khumalo, 2016).

### **2.11. Caregivers of Children with Cerebral Palsy**

Mothers of children with cerebral palsy spend a considerable amount of time caring for their children, on average six hours on a weekday, and 8.3 hours on a weekend (Sawyer et al., 2011). Perceived time pressure was significantly related to depressive symptoms and this was not impacted by the severity of the disability as measured by the GMFCS and MACS. Unemployment was also significantly related to depressive symptoms (Sawyer et al., 2011). Maternal mental health care is therefore a necessary service that needs to be included in the child's care. In a South African study, the caregiver was often not the mother of the child (Potterton, 1996). The caregivers felt that their biggest challenge is that there was not a day care, school or institution for the children to attend, and therefore they were unable to work. This impacts their socio-economic status and wellbeing of the family.

### **2.12. Conclusion**

There is a high prevalence in CP in lower income countries, and rural areas. There are more children with severe limitations in gross motor function, and more children classified with dyskinetic and spastic CP. The aetiology in lower and middle income countries is also more likely due to perinatal factors than in higher income countries. In Africa, the definition of CP, and the methods of diagnosis, particularly neuroimaging, vary greatly. Most commonly, the SCPE classification and the GMFCS E&R is used clinically. Limb distribution and gross motor function have a weak but significantly correlation.

## CHAPTER 3

### 3.1. Methodology

This chapter provides an outline of the study methods used to access, collect and analyse the data. The chapter starts by describing the aims and objectives of the study and then the study design which is most appropriate for the aim and objectives. The study population used in this study and the sampling process is described, followed by the data collection and analysis methods. Issues related to validity and reliability are discussed.

### 3.2. Study Design

This study aimed to determine the clinical presentation of children with CP, and therefore a quantitative approach was best suited to quantify the sub-type, classification and gross motor function. Prevalence, in this case the frequency of sub groups within the population, and the relationship between subtype, classification and gross motor function was be measured. A retrospective chart review was used. The advantage of this study design was that it is economical in terms of time and money and that it could be used to determine the health needs of population of children with CP. The disadvantage of this study design was that it did not allow conclusions about causation (Morrone & Myer, 2007). Poor record keeping could negatively impact on the reliability of the results.

### 3.3. Study Setting

The study setting was Bethesda Hospital within the Umkhanyakude Health District of KwaZulu-Natal, South Africa. It is a deep rural area with very poor roads and the terrain is either mountainous or soft sand. The district is classified as one of the poorest districts in South Africa, with an unemployment rate of 42.8% (Mahlawe & Massyn, 2014). Service delivery of

water, electricity and refuse removal is low, and there is a low level of education within the community. Problems with access to health care facilities, the high cost of transport and the lack of appropriate transport for people with disabilities and CP has been documented across Africa (Donald et al., 2014). To try to overcome this at Bethesda Hospital, the rehabilitation team consisting of an occupational therapist, physiotherapist and speech-language therapist provide rehabilitative services to people at their local clinic since 2014 which has increased attendance by nearly 40% according to a 2016 internal audit (unpublished). Other health services are provided by a full allied health team including doctors to all residential clinics.

#### **3.4. Study population and sampling**

The research setting was the Bethesda Hospital catchment area, a population of approximately 100 000 people. The study sample is all children with CP attending rehabilitation services at Bethesda Hospital between 2014 and 2017. There were 145 cases of cerebral palsy on the Bethesda Hospital Occupational Therapy database for children with disabilities and this is the means of accessing the study population. All children on the database who met the inclusion and exclusion criteria below were included in the study sample. This is a sample of convenience, which is not likely to be representative of the true population (Bruce, Pope, & Stanistreet, 2008).

Inclusion criteria for records: All children, both male and female, up to the age of 18, as this is the definition of a child in South Africa (Republic of South Africa, 2006). All children with a diagnosis of CP who have received rehabilitation between 2014 and 2017, and have had a full rehabilitation assessment were included in the study. These children have received rehabilitation at their nearest clinic or at the hospital.

Exclusion criteria: Children who have yet to receive a formal diagnosis who have been added to the database with a queried diagnosis of cerebral palsy.

The sample was accessed from the database for children with disabilities for those who attend Bethesda Hospital and its clinics. The database was held at Bethesda Hospital even though most of the children access services at the clinic. Additionally, the case sheets and monthly statistics were checked against the database as it is possible that rehabilitation therapists have not added the details to the database. In reviewing all of this, it was noted that there were many children who appeared on the database more than once. The sample size was calculated using EpiInfo, using a 95% confidence interval, a prevalence of limited gross motor function level of 65%, an acceptable margin of error of 5% and a population size of 170 (equivalent to a 1% prevalence of the population of children). The sample size required was 114.

Due to participants repeated on the database, some files not having enough information and the inability to use other hospital databases because they did not contain enough relevant data, the final sample size was 94 (see Figure 1). For this sample size of 94, maintaining the same prevalence of limited gross motor function level of 65%, the margin of error increases from 5% to 10%.

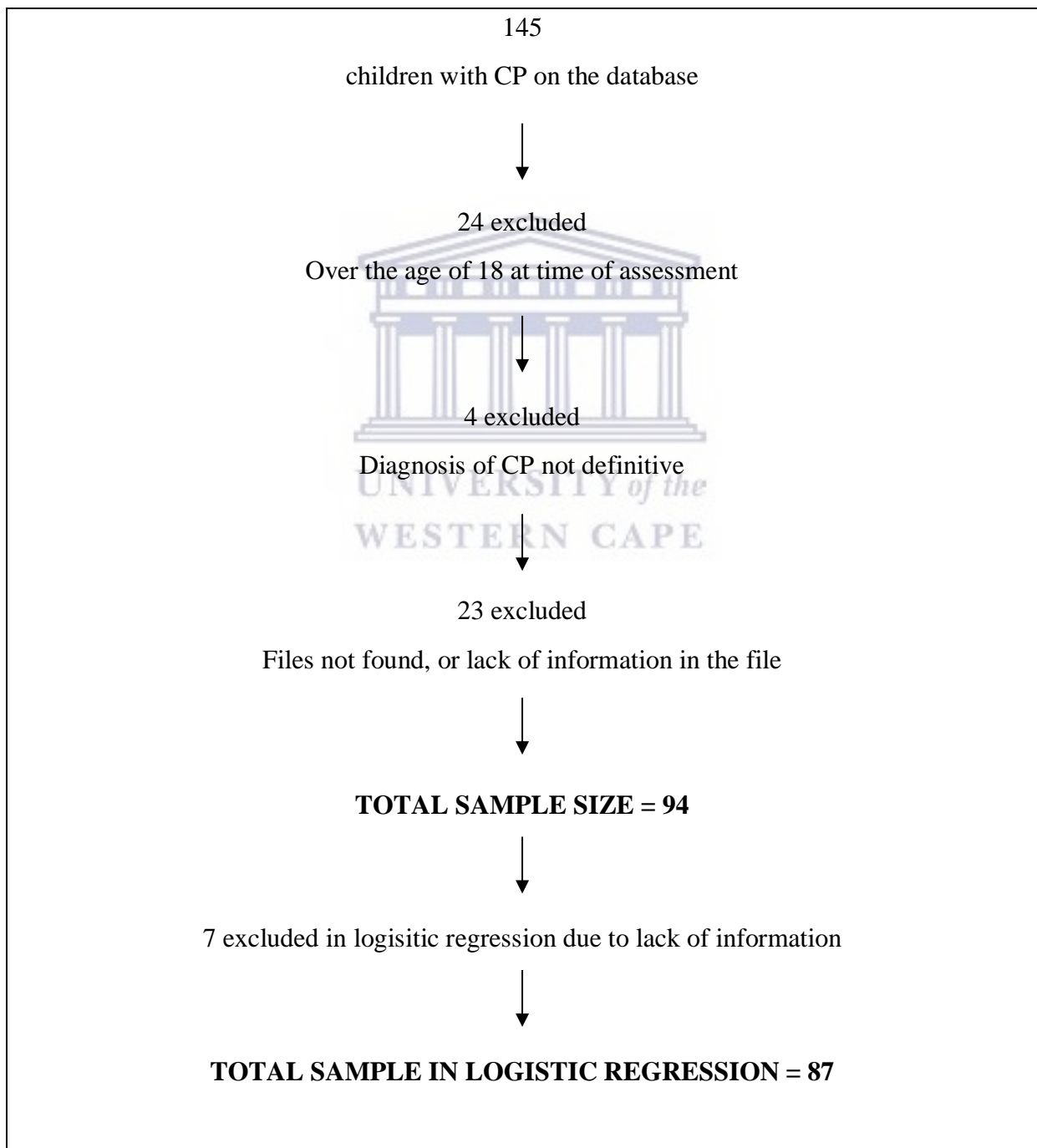
### **3.5. Data Collection**

Data collection was a review of medical records in the Occupational Therapy Department and outpatient records card. Quality of records was poor, and 23 participants were excluded a lack of information in the file, or the file not being found. Demographic data included age, gender, access to a social grant, and the relationship of the child to the primary caregiver. Clinical information about the participant's tonal subtype, limb distribution and GMFCS level was



collected, and information about the type of equipment the child uses, the level of schooling and whether the child has epilepsy. The information was recorded on a data extraction sheet and then transferred to a Microsoft Excel spread sheet, using codes and checked for errors. The data extraction form is attached in Appendix C.

**FIGURE 1: SAMPLE SIZE**



### **3.6. Data Analysis**

The data was cleaned and checked for errors and outliers, in Excel and then imported into EpiInfo 7 and STATA, statistical programmes, for analysis. Data was initially explored using frequencies for categorical data (tone subtype, limb distribution and GMFCS level) and measures of central tendency and dispersion such as means and standard deviation for numerical data such as age. Bivariate analysis was done by computing chi-square tests and associated p-values to assess for any significant associations between variables and outcomes. Lastly, multivariate logistic regression was used to determine the relationship between the dependent variable gross motor functioning and independent variables tone subtype and limb distribution and other variables. Odds ratios and associated 95% confidence intervals are reported.

In analysing the relationship between limb distribution and tone type, and GMFCS, those classified as GMFCS 4 and 5, were grouped together as they have severe limitations in mobility and use a wheelchair mostly. GMFCS levels one, two and three were grouped together as less severe gross motor ability. Participants with missing limb distribution, tone type or GMFCS classification were excluded and the total number analysed was 87.

### **3.7. Validity and Reliability**

The study used the extended and revised Gross Motor Function Classification System (GMFCS-E&R) measure which has been validated and it is reliable (Löwing, Arredondo, Tedroff, & Tedroff, 2015; Palisano et al., 2008). To ensure reliability, all rehabilitation staff were trained in assessment of CP particularly, assisting in clarifying that a child has CP, and the sub-type, classification, gross motor functions and comorbidities. This was been done using the SCPE diagrams in in-service trainings with all rehabilitation therapists who complete the

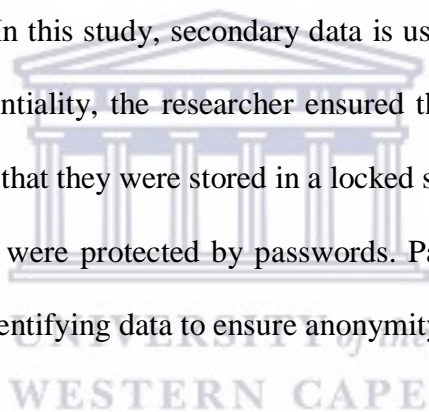
case sheets and with new community service therapists. Generally, the case sheet was completed by an occupational therapist, physiotherapist and speech-language pathologist who all came to a consensus about the child's classification. In most cases, one of these therapists would have attended a short course on CP and will have more clinical experience. To ensure reliability, the researcher reassessed 5% of the cases to determine the reproducibility of the assessment findings of the therapist who assessed the child initially and found 100% reliability. This was done by reassessing the first 5% of children who presented to the occupational therapy department in the month after data collection was completed.



## CHAPTER 4

### 4.1. Ethical Considerations

Ethical approval for this research was obtained from the University of the Western Cape Biomedical Research Ethics Committee (reference number BM/17/1/12, Appendix D) and the KwaZulu-Natal Department of Health (reference number KZ\_2017RP36\_112, Appendix E). Further, permission to conduct the study at Bethesda Hospital and use clinical records was obtained from the Umkhanyakude Health District (Appendix F) and Bethesda Hospital (Appendix G). As the research involves children, individuals who have impaired decision-making capacity, and within the context are vulnerable to stigma, it is highly important that ethical principles are upheld. In this study, secondary data is used and therefore the risks are minimised. To ensure confidentiality, the researcher ensured that while the case sheets and patient cards were being used, that they were stored in a locked space to ensure confidentiality and that computer documents were protected by passwords. Participant numbers were used rather than names and other identifying data to ensure anonymity.



## CHAPTER 5

### 5.1. Results

This chapter presents the findings of the study from the data collected. The demographic data of the participants is presented, including schooling and assistive devices and equipment. Results of the clinical presentation of the participants, gross motor function and relationship between these variables is summarised.

### 5.2. Demographics characteristics

Of all participants, 62,7 % were male while 38,3% were female. The age range of participants was six months to 15 years, nine months and the mean age of participants was six years, seven months (SD +/- 4 years). Participants whose records clearly indicated that they have epilepsy and take medication for it, represented 34% (n = 32) of the sample.

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**TABLE 2: AGE CROUPS FOR PARTICIPANTS**

Age group	Number	Percentage
0 – 5	34	35,4
6 - 10	40	41,7
11 - 15	20	22,9
TOTAL	94	100%

Mothers were the primary caregivers for 69,1% (n = 65) of the participants, with a grandmother as the primary caregiver for 19,2% (n = 18) of the participants (table 3). Other primary caregivers were either both parents, the father, great grandmother, sister or aunt, and accounted

for 9,6% (n = 9) of the participants. The relationship of the primary caregiver was not stated for two participants.

**TABLE 3: RELATIONSHIP TO CAREGIVER**

Caregiver	Number	Percentage
Mother	65	69,1
Grandmother	18	19,2
Other	11	11,7
TOTAL	94	100%

For ten participants, it was not clear what type of social grant they received, or whether they received a grant and two participants did not receive a social grant as their mothers did not have identity documents (Table 4). Most children received a child dependency grant (CDG), accounting for 73,4% (n = 69) and 15,9% (n = 13) received a child support grant (CSG).

**TABLE 4: SOCIAL GRANTS RECEIVED**

Grant received	Number	Percentage
CDG	69	73,4
CSG	13	13,8
Other	12	12,8
TOTAL	94	100%

Birth history was recorded, or partially recorded in 43 participants files and results are presented in table 5. Three participants had Dandy Walker syndrome. One had tuberculosis meningitis when three months old, and another hypoxic brain injury at two years of age. Three participants had hydrocephalus. Seven participants had low birth weight, 12 were born prematurely, three were twins, 16 had hypoxic ischaemic encephalopathy or birth asphyxia, eight had neonatal seizures and 12 had low Apgar scores.

**TABLE 5: BIRTH HISTORY**

<b>Risk factor</b>	<b>Number of observations</b>	<b>Number with positive risk factor</b>	<b>% with positive risk factor</b>
Apgar scores	34	12	35,30%
Birth weight	28	7	25%
Prematurity	27	12	44,40%
Multiple birth	4	3	75%
HIE	17	16	94,10%
Neonatal seizures	8	8	71,40%

The demographic characteristics of age, gender, social grant status and epilepsy status were included in bivariate analysis in relationship to GMFCS level, but not were statistically significant (table 7).

### **5.3. Schooling**

Most children did not attend school. A total of 78,7% (n = 74) of the sample were not in school. Seven participants (7,5%) attend schooling at a local special school while one attended the local full-service school (Table 6). Six participants (6,38%) attended a main stream school and

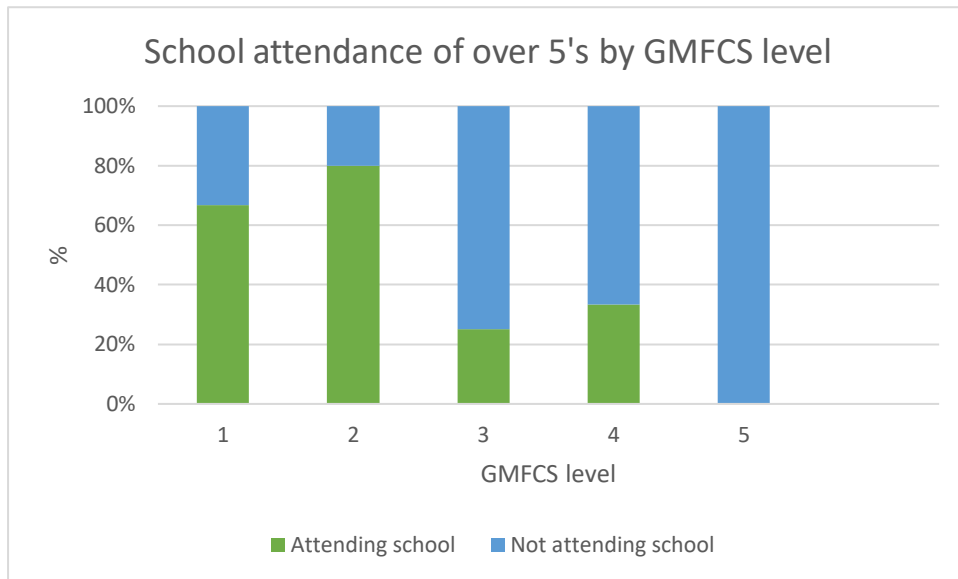
six attended creche. In the bivariate analysis, there was a significant relationship between school attendance and GMFCS level ( $p=0,002$ ) (table 7). Children with better gross motor function, classified as GMFCS 1, 2, or 3 were nearly three times more likely to be attending school [odds ratio (OR) 2,4; 95% CI 1,2–4,8;  $p = 0.012$ ] (table 8).

A special school application was completed for 23,4% ( $n = 22$ ) of the participants. This equates to 40% of the participants who are not at a special school, and who are of school going age. Children are only assisted to apply for special schooling once they are five years old, and 34% ( $n = 32$ ) of the participants were under the age of five. Of those who are under the age of five, two of the 34 participants (5,9%) attended creche. Of the 60 participants older than five, 6,7% ( $n = 4$ ) attended creche and 70% ( $n = 42$ ) did not attend any school.

Of those older than five years of age, none of the 22 participants classified as GMFCS 5 attended school. Of those classified as GMFCS 4, five (33.3%) attended school and ten (66.7%) did not (figure 2). Only two (40%) of the five classified as GMFCS 3 attended school while eight (80%) of the ten classified as GMFCS 2 attended school. Four (66,7%) of those classified as GMFCS 1 attended school, while two did not. Two of the 34 participants under the age of five attended school.



**FIGURE 2: SCHOOL ATTENDANCE OF OVER 5'S BY GMFCS LEVEL**



**TABLE 6: GMFCS, CLASSIFICATION, SCHOOLING AND EQUIPMENT**

		GMFCS levels					Unkn	Total	%
		1	2	3	4	5			
<b>Number</b>		8	11	17	21	30	7	<b>94</b>	
<b>Percentage</b>		8,5	11,7	18,1	22,3	31,9	7,4		
<b>Classification</b>	<b>Spastic</b>								
	<b>Quadriplegia</b>	-	-	-	8	15	3	<b>26</b>	<b>27,6%</b>
	<b>Hemiplegia</b>	5	5	3	-	-	2	<b>15</b>	<b>16,0%</b>
	<b>Diplegia</b>	-	4	5	3	-	-	<b>12</b>	<b>12,8%</b>
	<b>Dyskinetic</b>								
	<b>Dystonic</b>	-	-	3	9	13	-	<b>25</b>	<b>26,6%</b>
	<b>Choreoathetoid</b>	-	-	1	-	2	-	<b>3</b>	<b>3,2%</b>
<b>Ataxic</b>									
<b>Hypotonic</b>	2	2	5	-	-	-	<b>9</b>	<b>9,6%</b>	
<b>Unknown</b>									
		-	-	-	-	-	2	<b>2</b>	<b>2,1%</b>
		1	-	-	1	-	-	<b>2</b>	<b>2,1%</b>
									<b>100,0%</b>
<b>Schooling</b>	<b>Over 5's</b>								
	<b>Attending</b>	4	8	1	5	-	-	<b>18</b>	<b>19,2%</b>
	<b>Not attending</b>	2	2	3	10	22	3	<b>42</b>	<b>44,7%</b>
	<b>Under 5's</b>								
<b>Attending</b>	1	-	1	-	-	-	<b>2</b>	<b>2,0%</b>	
<b>Not attending</b>	1	1	12	6	8	4	<b>32</b>	<b>34,1%</b>	
									<b>100,0%</b>
<b>Equipment</b>	<b>Wheelchair</b>	-	1	1	10	15	2	<b>29</b>	<b>30,9%</b>
	<b>Walking aid</b>	-	-	3	-	-	-	<b>3</b>	<b>3,2%</b>
	<b>Walking aid and wheelchair</b>	-	-	3	1	-	-	<b>4</b>	<b>4,2%</b>
	<b>None</b>	8	10	10	10	15	5	<b>58</b>	<b>61,7%</b>
									<b>100,0%</b>

**TABLE 7: BIVARIATE ANALYSIS BETWEEN VARIABLES AND GMFCS**

<b>Variables</b>	<b>Pearson Chi</b>	<b>P-value</b>
Age	2,734	0,255
Gender	0,227	0,633
Grant	5,244	0,073
Epilepsy	0,853	0,356
Schooling	17,059	0,002
Equipment	16,336	0,001
Limb distribution	35,553	< 0,001
SCPE classification	62,031	< 0,001
Subtype	22,18	< 0,001

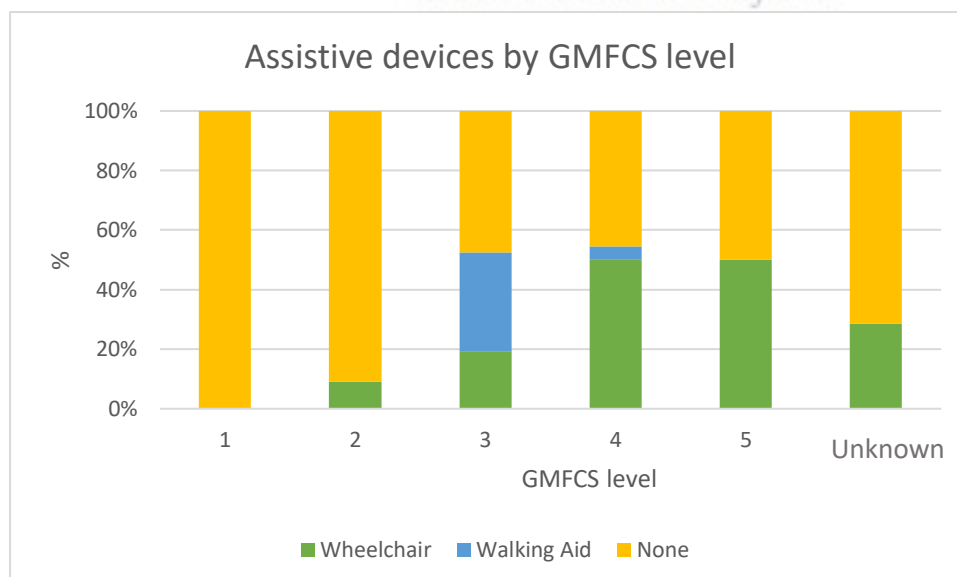
**TABLE 8: MULTI VARIATE ANALYSIS BETWEEN VARIABLES AND GMFCS**

<b>Variables</b>	<b>Odds ratio</b>	<b>p-value</b>	<b>95% CI</b>	
Schooling	2,439	0,011	1,227	4,846
Equipment	0,729	0,168	0,465	1,143
Subtype	0,188	0,106	0,025	1,429
Limb distribution	0,071	< 0,001	0,020	0,252
SCPE classification	1,402	0,590	0,410	4,789

## 5.4. Equipment

The total number of participants who had not been issued with any assistive devices was 58 (61,7%). Four participants had more than one type of assistive device. Participants using wheeled mobility totalled 33, with 15 using a buggy, and 18 using a wheelchair (Table 6). Six participants had a walking aid, and two had boots and irons. None of the participants classified as GMFCS 1 had been issued with any equipment (figure 3). Of those classified as GMFCS 2, only one had a wheelchair. The participants classified as GMFCS 3, one had a wheelchair only, three had a walking aid only, four had a wheelchair and walking aid, and ten had no assistive devices. Of those classified as GMFCS 4 and 5, 26 had a wheelchair or buggy, and 25 had no equipment. In the bivariate analysis, there was a significant relationship between equipment issued and GMFCS level ( $p=0,001$ ) (table 7). This reflects the definition of the GMFCS E&R, that those with higher GMFCS levels require wheeled mobility, and with lower levels of GMFCS walk independently, or use a walking aid or wheeled mobility for long distances.

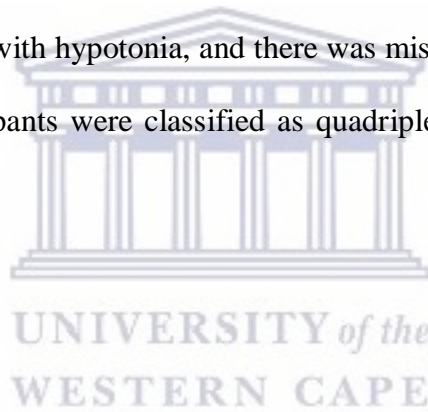
**FIGURE 3: ASSISTIVE DEVICES BY GMFCS LEVEL**



## 5.5. Cerebral Palsy Classification

The most common subtype of CP in the participants was spastic CP. A total of 56,4% (n = 53) were classified as spastic with 27,7% (n = 26) of the participants classified with spastic quadriplegia, 16% (n = 15) with spastic hemiplegia, and 12,8% (n = 12) with spastic diplegia (Table 6).

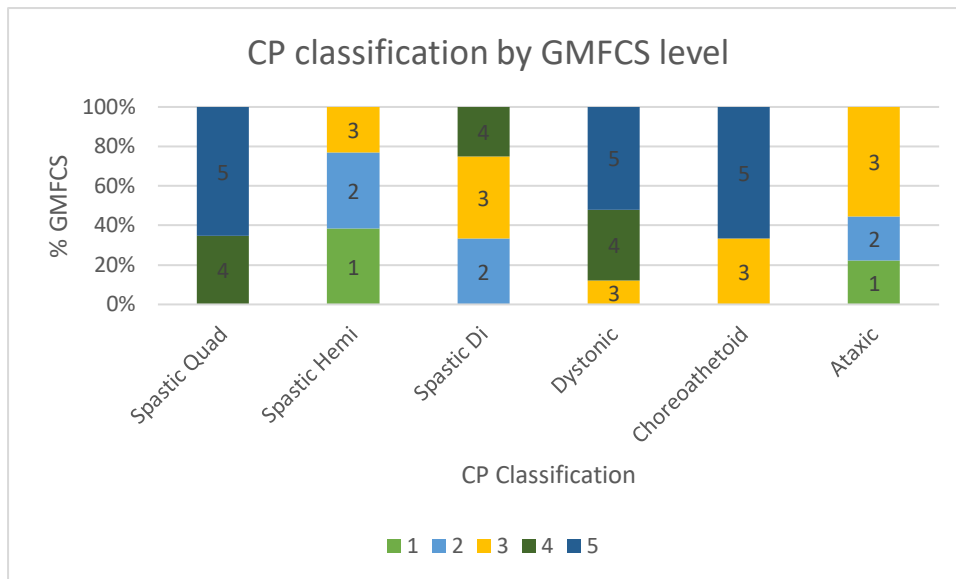
The second most common classification was dyskinetic CP with 26,6% (n = 25) of the participants classified with dystonic CP and 3,2% (n = 3) classified with choreoathetoid CP. Ataxia accounted for the smallest classification, representing 9,6% (n = 9) of the participants. Two children were classified with hypotonia, and there was missing data for two participants. In total, 70,2% of the participants were classified as quadriplegic, 16% as hemiplegic, and 12,8% as diplegic.



## 5.6. Gross motor function

Gross motor function was measured using the GMFCS E&R. The most frequent level of functioning was GMFCS 5, with 31,9% (n = 30). Secondly, 22,3% (n = 21) of participants were classified as GMFCS 4. This means that a total of 54,2% of participants were classified with severe limitations in gross motor function. Of the participants classified as being able to walk, 18,1% (n = 17) were classified as GMFCS 3, 11,7% (n = 11) as GMFCS 2, and 8,5% (n = 8) as GMFCS 1. It was not possible to classify 7,5% (n = 7) participants due to a lack of information in clinical records.

**FIGURE 4: CP CLASSIFICATION BY GMFCS LEVEL**



All participants classified with spastic quadriplegia ( $n = 23$ ) were classified with severe limitations in gross motor functions as GMFCS 4 or 5 (figure 4). All with spastic hemiplegia ( $n = 13$ ) were classified with better gross motor functions as GMFCS 1, 2, or 3. Of those with spastic diplegia, 75% ( $n = 12$ ) could walk and classified as GMFCS 2 or 3. While 25% ( $n=3$ ) were classified as GMFCS 4. Participants with dystonia and choreoathetosis were analysed together as dyskinetic CP, and 85,7% ( $n = 24$  of 28) were classified as having severe limitations in gross motor function as GMFCS 4 and 5. Only four were classified as GMFCS 3, still indicating that they require assistive devices to mobilise.

In the bivariate analysis, there was a significant relationship between each of the variables limb distribution, subtype, and the classification according to SCPE; and GMFCS level ( $p < 0,001$ ). Quadriplegia and spastic CP had a statistically significant causal association with more limitations in gross motor function classified as GMFCS 1, 2 and 3. Hemiplegia and diplegia had a statistically significant protective association with GMFCS 1, 2, and 3. Dyskinetic and

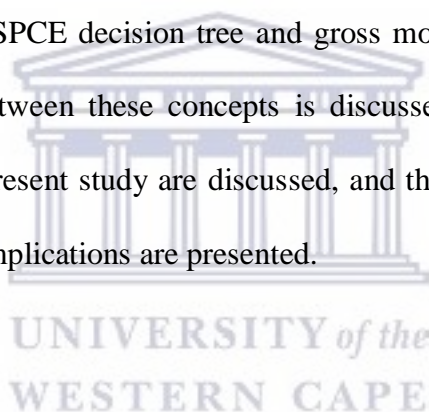
ataxia CP also had statistically significant protective association with GMFCS 1, 2, and 3. Only limb distribution was significant in the multivariate analysis. Quadriplegia had a statistically significant association (protective) with GMFCS levels 1, 2 and 3 [odds ratio (OR) 0,071; 95% CI 0,021–0,252;  $p < 0.001$ ] (table 8).



## CHAPTER 6

### 6.1. Discussion

This chapter discusses the key findings of the study as presented in chapter 5, in comparison to other relevant literature. The aim of this study was to describe the clinical presentation of children with cerebral palsy and the relationship between gross motor function and clinical presentation, at a rural hospital and its clinics in KwaZulu-Natal. This chapter discusses the demographics of the participants in terms of their gender, age, the relationship to the primary caregiver, the comorbidity of epilepsy, access to schooling and social grants. The clinical presentation of participants is discussed in relation to their clinical subtype and limb distribution according to the SPCE decision tree and gross motor function according to the GMFCS. The relationship between these concepts is discussed in comparison to relevant research. Limitations of the present study are discussed, and the significance of the research findings and future research implications are presented.



### 6.2. Demographics

The demographics of the 94 participants included in the study indicate that the majority (62,7%) are male. This is supported by several international and local studies which report that the majority of participants are male, with a range from 53 to 60% (Dambi & Jelsma, 2014; Gorter et al., 2004; Govender, Hepworth, Bagwandeen, & Chetty, 2015; Hidecker et al., 2012; Kakooza-Mwesige, Forssberg, Eliasson, & Tumwine, 2015; van Toorn, Laughton, Zyl, Doets, & Elsinger, 2007). In this study, the frequency of the male gender is higher than these studies. A study reports that the gender differences in CP could be due to neurobiological differences



which impact the response to brain injury, between male and females (Johnston & Hagberg, 2006).

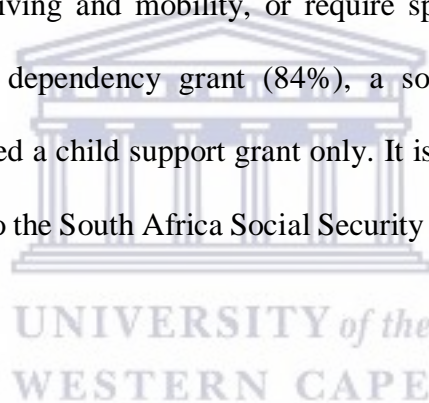
The age range of the participants in this study was six months to 15 years. The minimum age in this study is lower than in other studies reviewed, where participants are only included after the age of two, so that the diagnosis of CP is confirmed (Gorter et al., 2004; Govender et al., 2015; Hidecker et al., 2012; Kakooza-Mwesige et al., 2015). All children who were recorded in the database were included as this is a sample of convenience and the main purpose of the study was to describe the clinical presentation of the known patients. The mean age was six years, seven months. The mean age is higher than a similar South African study, which reported a mean age of 3,3 years and a standard deviation of +/- 2,6 years (Saloojee et al., 2009). The mean age in this study could be due to a low percentage of the sample attending school.

One inclusion criterion for this study was children up to the age of 18, however, the oldest participant was 15 years old. Reasons for this could include that older children are at school and not attending regular rehabilitation at the hospital or clinic. Life expectancy is lower in cerebral palsy than the general population, despite an increasing life expectancy, which could also influence the age range of the study (Aisen et al., 2011).

Most of the study participants were cared for by their mother (69%), with 19% of the participants cared for by their grandmother. In two African studies, the proportion of participants primarily cared for by their mother was higher, and in both studies, only 11% of participants were cared for by their grandmothers (Dambi & Jelsma, 2014; Ngubane & Chetty, 2017). In this study, this could be due to the rural setting, where many mothers will move to urban settings to study or work, leaving the children to be cared for by their grandmothers.

Of the participants, 34% had epilepsy. This is lower than the reported proportion of 66% in participants in a small urban based study in KwaZulu-Natal (Govender, Hepworth, Bagwandeem, & Chetty, 2015) and another study in Botswana which reported a proportion of 76% (Bearden et al., 2016). It does however, fall within the global average of 20 to 40% (Odding, Roebroek, Stam, Roebroek, & Stam, 2006). It is also possible that participants had epilepsy, but it was not recorded in their clinical file due to poor record quality.

All South African citizens under the age of 18, with a permanent and severe disability and not being cared for in a state institution qualify for a care dependency grant of R1600 per month (SASSA, 2017). All children in this study qualify for a grant as they need some assistance with self-care, activities of daily living and mobility, or require special schooling. Most of the participants received a care dependency grant (84%), a social grant for children with disabilities, while 16% received a child support grant only. It is presumed that the caregivers of the children were referred to the South Africa Social Security Agency (SASSA) to apply for a care dependency grant.



Information about birth history was not available for all participants, however, of the risk factors, 16 participants had hypoxic ischaemic encephalopathy (HIE), 12 were premature, seven had a birth weight of less than two kilograms, and eight had neonatal seizures. This information cannot be used to make any conclusions, but does give some indication to the risk factors for CP which are relevant to the rural setting in South Africa. According to research conducted in low resource settings in Africa, in this study context, one would expect low birth weight contributes, birth asphyxia, neonatal jaundice, convulsions and infections to be common risk factors for CP (Gladstone, 2010). Results of a recent study conducted in Uganda suggest that the aetiology of CP in lower income countries is perinatal in full term infants, and not complications of preterm births (Kakooza-Mwesige et al., 2016).

There has been an increase in litigation for adverse events that occur in pregnancy and birth (Cooper, 2015), necessitating prevention of the risk factors which cause amongst others CP. Medical staff should monitor those with risk factors for CP, especially those admitted to the neonatal unit, through surveillance programmes for abnormal movements and motor delays (Palmer, 2004). This is done at Bethesda Hospital through the high risk baby programme which aims to identify children with developmental delays and disabilities as early.

### **6.3. Schooling**

Only one other study reported that 20% of the participants attended school (Kakooza-Mwesige et al., 2016). In this study, 21% of the participants attended school, while 70% of those over the age of five years and older did not attend school and a special school application had only been completed for 40% of those five years and older. Gross motor function was statistically significantly associated with school attendance, with children presenting with better gross motor function more likely to attend school. School attendance at a special school, mainstream school and creche was almost equal.

Every child in South Africa has the constitutional right to access basic education and for children with disabilities, this is further supported by the policy of inclusive education (Hodgson & Khumalo, 2016). In a South Africa study, 53% of parents did not send their child with a disability to school because they deemed schooling to be unsuitable for their child's abilities (Saloojee et al., 2007). Finding a school where the child is accepted is also problematic. A report by Equal Education on inclusive education in the Umkhanyakude District highlights the long waiting lists and failure of the Department of Education to ensure that children who are not at school are accommodated in school as soon as possible (Hodgson & Khumalo, 2016). The report also highlights other problems which disadvantaged children with disabilities, in

particular living in rural areas include large classes, a lack of staff, poor infrastructure and lack of adequate transport.

#### **6.4. Equipment**

This study reports most of the participants have not been issued with any assistive devices related to mobility. Gross motor function was statistically significantly associated with participants using assistive. None of the participants classified as GMFCS 1 had any equipment and according to the definition of this classification, they do not need any assistive devices. All participants classified as GMFCS 4 and 5, should use wheeled mobility daily, and those classified as GMFCS 3 will use wheeled mobility to mobilise within the community environment. Only 50% of the participants classified as GMFCS 4 and 5 had a wheelchair or buggy. The reason for this should be investigated. However, it is likely due to poor supply chain and financial management and needs to be addressed to provide the assistive devices children with CP require to reach their functional capacity within their environments. Assistive devices also prevent secondary complications such as contractures and deformities which are more likely to develop when lying down. Rehabilitation staff also need to be trained in supply chain management, financial management and wheelchair seating to be able to provide children with the correct devices with appropriate timing. Very few participants had walking aids, and this could be due to an error in recording in files and poor record keeping. This should also be investigated further.

#### **6.5. Cerebral palsy classification**

The American Academy of Neurology (n.d.) recommend that the diagnosis of CP is made by clinical examination, neuroimaging, exclusion of genetic conditions and degenerative

conditions. In this study, information about neuroimaging and exclusion of other conditions was not available in the clinical files. The diagnosis was made by inexperienced medical officers with the assistance of inexperienced rehabilitation staff and their clinical examination. Some had been referred to the nearest paediatric hospital for further assessment and diagnosis. This means that children who do not have CP, could have been included in the sample. Although the Surveillance of Cerebral Palsy in Europe (SCPE) group excluded children who presented with pure hypotonia and an absence of ataxia (SCPE, 2000), children classified as hypotonic were included in this study as other studies within South Africa included this classification (Saloojee et al., 2009; van Toorn et al., 2007). This confirms the inconsistencies in research about children with CP (Goldsmith et al., 2016). This research also highlights the inconsistency of referral of children to higher referral centres for neuroimaging and diagnosis (Donald et al., 2014). This also means that this research will be comparable with South African research, but not international research.

The most common classification system used by rehabilitation therapists is the classification tree published by the SCPE (2000). Again, therapists are inexperienced, and there could be misclassification. The most common classification seen at Bethesda Hospital and its clinics, is spastic CP, with 56,4% of the participants classified as spastic CP. This result is similar to other research conducted in South Africa which reported a 55,5% frequency of spastic CP ( Saloojee, Rosenbaum, Westaway, & Stewart, 2009). The frequency of participants with a classification of dystonia, is also similar to this study's result of 29,8%. However, it is different to other studies which report higher frequencies of spastic CP and lower frequencies of dyskinetic CP (Rosenbaum & Stewart, 2004).

## 6.6. Gross motor function

The use of the GMFCS as a tool to classify children with CP speaks to the ICF and the importance of focusing on the child, and their capacity and performance within their environment, rather than the impairment (Bartlett et al., 2010; McCormick et al., 2007; Palisano et al., 2008). Participants in the study were classified according to the GMFCS, however, for eight children, there was poor record keeping, and no classification was available in the clinical files. The GMFCS can validly predict gross motor function, however, preferred methods of mobility may change due to personal factors and choices and environmental factors (Rosenbaum, 2003). This is important in giving caregivers appropriate education and facilitates realistic goal setting (Govender et al., 2015; Saloojee et al., 2009). It is also important to prevent limitations in range of motion, spinal alignment and pain experienced to maintain gross motor functions (Bartlett, Hanna, Avery, Stevenson, & Galuppi, 2010).

This study reports that the proportion of participants with better gross motor functions, classified as GMFCS 1, 2 and 3, was 41,3%. This was higher than other South African studies (Saloojee et al., 2009), however, it was lower than a Zimbabwean study (Dambi & Jelsma, 2014), and the same as the results of a study conducted in Botswana (Bearden et al., 2016). Studies in upper income countries report a higher proportion of participants with GMFCS 1, 2 and 3 (Carnahan, Arner, & Hägglund, 2007; Gorter et al., 2004; Hidecker et al., 2012).

In analysing the relationship between classification and gross motor function, this study reports that there is a statistically significant relationship between subtype, limb distribution and classification according to SPCE, and the GMFCS classification. However, in multivariate analysis, only limb distribution and schooling had a statistically significant association with gross motor functioning (GMFCS classification). The result on limb distribution differs from that of a large study which found that limb distribution and subtype were both correlated to

GMFCS classification, and that limb distribution was only weakly correlated (Gorter et al., 2004). All participants with spastic quadriplegia had limited gross motor function and were classified as GMFCS 4 and 5. This is similar to results reported in Sweden (Gorter et al., 2004; Hidecker et al., 2012), whereas other studies report that participants with spastic quadriplegia present with gross motor functions through the full spectrum of the GMFCS (Carnahan et al., 2007; Gorter et al., 2004; Hidecker et al., 2012).

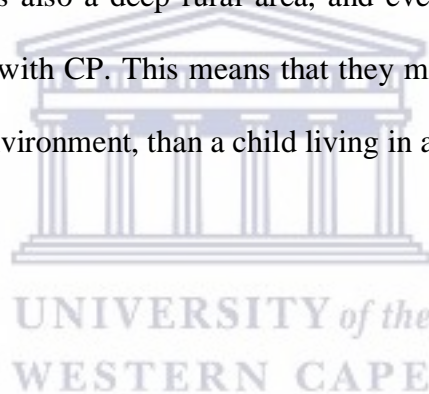
Participants with spastic hemiplegia presented only as GMFCS 1, 2 or 3, which is similar to other studies, which report a small proportion of the sample presenting as GMFCS 4 and 5 (Carnahan et al., 2007; Gorter et al., 2004; Hidecker et al., 2012). In this study, the proportion of participants classified as GMFCS 1 and 2, were equal, whereas the other studies report a higher proportion of participants classified as GMFCS 1.

Participants with diplegia, presented as either GMFCS 2, 3 and 4, with 41,7% classified as GMFCS 3. This is different to other studies which report a higher proportion of diplegia participants classified as GMFCS 1 (Carnahan et al., 2007; Gorter et al., 2004; Hidecker et al., 2012).

Most of the participants with dyskinetic CP, were classified as GMFCS 4 (53,6%), with no participants classified as GMFCS 1 or 5. Other studies report that participants with dyskinetic CP present with gross motor functions through the full spectrum of the GMFCS, with a larger majority classified as GMFCS 4 or 5 (Carnahan et al., 2007; Gorter et al., 2004). This study also reports a higher prevalence of those classified as GMFCS 3.

Most of the participants with ataxic CP were classified as GMFCS 3. Although the other studies report that almost all participants with ataxic CP are classified as GMFCS 1, 2, or 3, the proportion in each GMFCS level varies greatly (Carnahan et al., 2007; Gorter et al., 2004).

It is possible that a lack of rehabilitation services results in differing results. At Bethesda Hospital and its clinics, patients are only booked to be seen by an inexperienced rehabilitation therapist once a month. Due to the relatively high cost of transport and low socio-economic status, patients do not necessarily even attend therapy once a month. This could result in children with CP not reaching their gross motor function potential, and they could present with more secondary complications. They will therefore rely more on assistive devices for mobility. The Umkhanyakude district is also a deep rural area, and even home environments can be difficult to access for a child with CP. This means that they may use assistive devices more regularly within their home environment, than a child living in an urban area.



### **6.7. Limitations**

There are limitations to this study. The study design used evaluated the relationship between exposures but does not allow conclusions about causation (Morrone & Myer, 2007). This was a chart review, and poor clinical record keeping means that some of the participants were excluded because there was not enough information in their file, or because their file was not found in the admissions office. It is possible that not all cases of CP are known, or were not captured in the database. This could especially be possible with milder cases of CP, and with those who are older and attending school.

As this was a chart review, it is also possible that there was misclassification of participants made by the rehabilitation staff who assessed the child. This is possible especially as most



rehabilitation therapists working at Bethesda Hospital are completing their first year of work. The sample size of this study was small, which affected the significance of results and the generalisability of the findings to other similar settings.



## CHAPTER 7

### 7.1. Conclusion

This chapter discusses the main findings and discussions from this study. The aim of this study was to describe the clinical presentation of children with cerebral palsy and the relationship between gross motor function and clinical presentation, at a rural hospital and its clinics in KwaZulu-Natal. This retrospective chart review included clinical information of 94 participants from the database for children with disabilities at Bethesda Hospital. Information about demographics, clinical presentation in terms of tonal subtype and limb distribution, gross motor function, schooling and equipment were collected. Recommendations for future research and practice are presented.

### 7.2. Main findings

The most common tonal subtype of participants in this study was spastic CP, and the most common limb distribution was quadriplegia. Spastic quadriplegia and dystonia were the two most common classifications according to the SCPE. Gross motor function, as classified according to the GMFCS, showed that most participants in this study presented with severe limitations in gross motor function and were classified as GMFCS level 4 and 5. The clinical presentation of participants in this study was most similar to those presented in a South African study which studied children in poorly resourced urban, peri-urban and rural areas. Gross motor function was associated with school attendance, equipment used, subtype and limb distribution although only limb distribution and schooling were statistically significantly associated (protective) in the multivariate analysis.

Provision of appropriate assistive devices and equipment was poor, as was access to appropriate schooling. This needs to be improved to support the family and child in achieving function and participation within the child's environment. While most participants were cared for by their mother, a large proportion were cared for by their grandmothers. Most participants received the appropriate child dependency grant.

### **7.3. Recommendations**

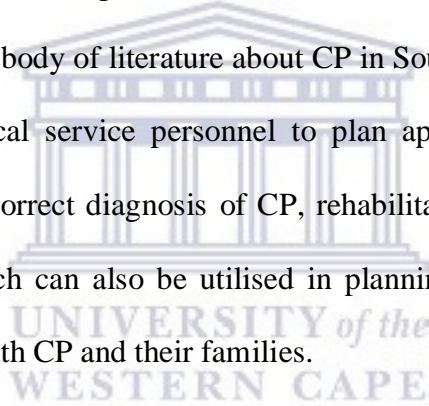
Further research into CP is required in South Africa, and particularly rural South Africa, as litigation against hospitals increases. Causal factors need to be identified to improve prevention methods, and so that there can be better follow up and early identification of children who are at high risk to develop CP, and other disabilities. Considering this, follow up programmes should be prioritised and all staff involved in the follow up of infants, should be trained to identify CP. Improved access to paediatricians and neuroimaging will also ensure that children are correctly diagnosed and that causal pathways can be established. Maintenance of databases for children with CP should be started by all hospitals, to assist in the monitoring of clinical presentation and potential causal factors in South Africa. It is recommended that larger, multi-site research is conducted in both rural and urban settings within South Africa.

The Departments of Education and Social Development need to be involved in planning education and placement services for children with disabilities. Very few children over the age of five attended school, and this needs to be addressed as a priority. As most of the children in the study presented with severe limitations in gross motor functions, it is imperative that there is budget available for children to access assistive devices and equipment. Rehabilitation staff need to be trained in supply chain management, financial management and wheelchair seating to be able to provide children with the correct devices with appropriate timing.

#### **7.4. Conclusions**

Cerebral palsy is a common permanent disorder of movement and muscle tone that causes impairment of the ability to engage in activities and participate fully in life (Bax et al., 2005). It is important to diagnose CP early so that the family and child can access services which will assist the child to reach their potential and prevent secondary complications. Correct diagnosis and classification assist in answering parents questions about whether their child will be able to walk, which ensures that appropriate education is given to caregivers, and realistic goals are set (Rosenbaum, 2003).

This study has described the clinical presentation of children with CP in a rural hospital in KwaZulu-Natal. It adds to the body of literature about CP in South Africa and can be used by rehabilitation staff and medical service personnel to plan appropriate services, including prevention of CP, early and correct diagnosis of CP, rehabilitation of CP, and provision of assistive devices. This research can also be utilised in planning appropriate education and support services to children with CP and their families.



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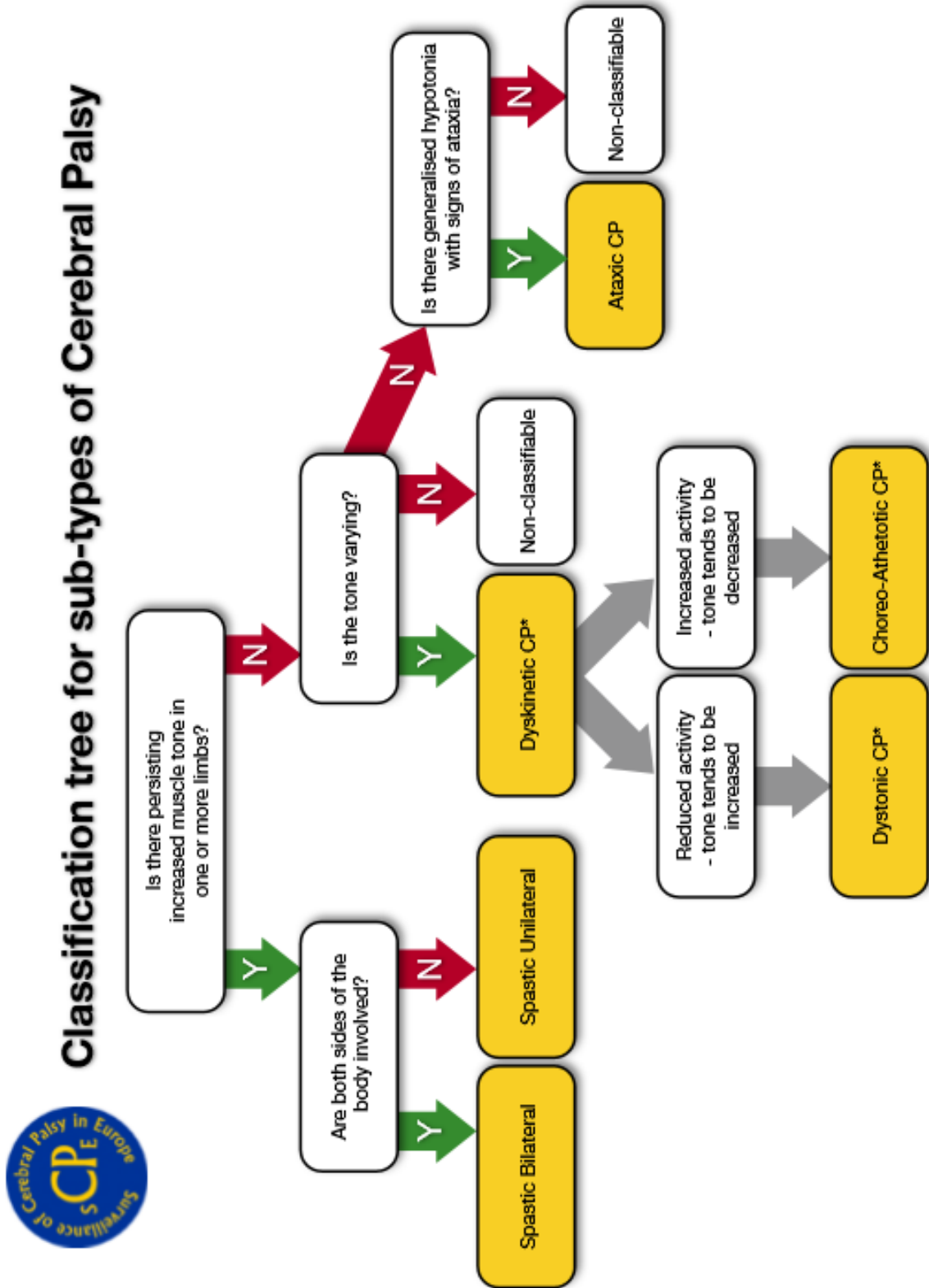


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## Appendix A

### Cerebral Palsy Classification Tree (SCPE, n.d.)



## Appendix B

### GMFCS descriptions

(Rosenbaum et al., 2008)

GMFCS level	General description	Before 2 years old	2 to 4 years old	4 to 6 years old	6 to 12 years old	12 to 18 years old
1	Walks without limitations	Learn to walk between 18 months and 2 years. Before they move into sitting and use both hands to play, crawl, pull to stand and cruise on furniture.	Children mostly walk, and can stand up and sit down independently.	Walk indoors and outdoors and are starting to run and jump.	Can participate in sports and physical activities however coordination and balance may be limited. Independent in community mobility.	
2	Walks with limitations in balance, stairs, running and jumping.	Need their hands to maintain sitting balance. Creep on stomach or crawl and may pull to stand and cruise on furniture.	Crawl with reciprocal pattern, cruise on furniture or walk with an assistive device.	Walk indoors on level surfaces without an assistive device. Hold a railing to climb stairs. Unable to run and jump.	Participate in sports with adaptations due to limitations in running and jumping skills. Mostly walk but experience some difficulties and may use assistive device or wheelchair.	Environmental factors affect mobility choices. Mostly walk but may use wheelchair for long distances.

3	Walks using hand held mobility device indoors, and may use a wheelchair outdoors.	Sit when given back support, can roll and creep on stomach.	Walk short distances with an assistive device and physical assistance. Pull to stand and cruise short distances. Mostly creep on stomachs or crawl.	Walk with an assistive device on level surfaces. Need assistance to climb stair and use a wheelchair outdoors or for long distances. Pelvic or trunk support maximizes hand function.	Use assistive device to walk indoors and a wheelchair outdoors. Need railing and assistance with stairs. Need pelvic support when seated.	Use assistive devices to walk, a manual wheelchair or a powered wheelchair. May need pelvic support when seated and assistance to transfer.
4	Limitations in ability to sit independently and in self-mobility, may use powdered mobility	Sit when given trunk support and can roll.	Move by rolling, creeping or crawling. Sit when placed and use their hands for balance. Need adaptive equipment for sitting and standing.	Walk short distances with an assistive device and physical assistance. Use a wheelchair outdoors. Trunk support maximizes hand function. May need assistance to stand up.	Walk short distances but mostly use powered wheelchair or are pushed in a wheelchair. Need pelvic and trunk support in sitting. Need assistance with transfers.	Mostly use a wheelchair and require physical assistance with transfers. May walk short distances. Can use a powered wheelchair.
5	Transported in a manual wheelchair due to poor head and trunk control.	Unable to hold head against gravity in sitting or prone and require assistance to roll.	All areas of motor function are limited and not compensated for by assistive technology.	No means of moving independently and use a wheelchair. Some can use a powered wheelchair.	Transported in a wheelchair and need complete assistance with all transfers.	Use a powered wheelchair if extensive adaptations are provided.

## Appendix C

### Data Extraction Sheet

Variables	Responses
<b>Demographic Data</b>	
1	What was the child's date of birth? ____/____/____
2	What is the age of the child? __ months
3	What is the sex of the child? ____ Male    ____ Female
4	Does the child receive a grant? ____ No    ____ CSG    ____ CDG
5	Does the child attend school? ____ No    ____ Creche    ____ Mainstream school    ____ SS
6	What is the primary caregivers' relationship to the child ____ Mother    ____ Father    ____ Grandmother    ____ Aunt ____ Sibling    ____ Other: _____
<b>Clinical Information</b>	
7	What is the tone subtype? ____ Spastic    ____ Ataxic    ____ Dystonic
8	What is the limb distribution? ____ Quadriplegia    ____ Hemiplegia    ____ Diplegia
9	What is the GMFCS level? ____ 1    ____ 2    ____ 3    ____ 4    ____ 5
10	What equipment does the child have at home? ____ Chair    ____ Wheelchair    ____ Buggy ____ Walking aid    ____ Orthotic appliance
11	What comorbidities does the child have? ____ Epilepsy    ____ Contractures

## Appendix D

### UWC Ethical Approval



OFFICE OF THE DIRECTOR: RESEARCH  
RESEARCH AND INNOVATION DIVISION

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19 January 2017

Ms H Coombe  
School of Public Health  
Faculty of Community and Health Sciences

**Ethics Reference Number:** BM/17/1/12

**Project Title:** The clinical presentation of cerebral palsy in children in rural Kwazulu-Natal, South Africa.

**Approval Period:** 15 December 2016 – 15 December 2017

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

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

A handwritten signature in black ink, appearing to read 'Josias'.

*Ms Patricia Josias  
Research Ethics Committee Officer  
University of the Western Cape*

**PROVISIONAL REC NUMBER -130416-050**

# Appendix E

## KwaZulu-Natal Department of Health Ethical Approval



HRKM Ref: 057/17  
NHRD Ref: KZ\_2016RP36\_112

Date: 13 February 2017  
Dear Ms H. Coombe  
University of the Western Cape

### Approval of research

1. The research proposal titled '**The clinical presentation of Cerebral Palsy in children in rural KwaZulu-Natal, South Africa**' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at Bethesda Hospital; Bethesda Gateway, Gedleza, Jozini, Madonela, Makhathini, Mhlekezi, Mkuze and Ophansi clinic.

2. You are requested to take note of the following:
  - a. Make the necessary arrangement with the identified facility before commencing with your research project.
  - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge

Chairperson, Health Research Committee

Date: 13/02/17

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## Appendix F

### Umkhanyakude District Approval



**health**

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

304 Ntsinde Road, Jozini 3969  
PB X026, Jozini 3969  
Tel: 035 572 1327 Fax: 035 572 1245 Email: hervey.williams@kznhealth.gov.za  
www.kznhealth.gov.za

**DIRECTORATE:**

District Clinical Specialist Team  
Umkhanyakude Health District Office

**Enquiries : Dr CH Vaughan Williams  
Telephone : 035-5721327 Ext 114**

27 January 2017

Dear Heather Coombe,

I have pleasure in informing you that permission has been granted to you by the District Office to conduct research on in this district, entitled:

**'The clinical presentation of Cerebral Palsy in children in rural KwaZulu-Natal, South Africa'**

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. The District Office will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the District Office.

Sincerely,

C H Vaughan Williams  
Family Physician, Umkhanyakude Health District Office

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# Appendix G

## Bethesda Hospital Approval

