

A Descriptive Study of Children with Cerebral Palsy at

Chris Hani Baragwanath Academic Hospital

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A research report

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Degree

Of

Master of Medicine in the branch of Paediatrics.

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DECLARATION

I, Ntombizodwa Mahlaba declare that the research report is my own work. It is being submitted for the degree of Master of Medicine in the branch of Paediatrics in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

N Mahlaba

31 Day of July 2015.

I, certify that the study contained in this thesis has the approval of the Committee for Research in Human Subjects of the University of the Witwatersrand, Johannesburg. The ethics clearance number is M130377.

N Mahlaba

31 Day of July 2015

DEDICATION

I give thanks to Him I can do nothing without, my Lord Jesus Christ. I thank my wonderful husband and friend, Dr S'fisosikayise Madi, for his love and support in completing this, and every other project.

ABSTRACT:

TITLE: A DESCRIPTIVE STUDY OF CHILDREN WITH CEBRAL PALSY AT CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL.

Cerebral Palsy is a motor disability that is due to a non-progressive insult to the motor brain that is still developing. The term thus describes a group of disorders that are due to the insult. The motor disturbances present are often accompanied by seizures together with impairment in sensation, communication, cognition, and perception. There is limited knowledge about the demographics of children with CP seen at Chris Hani Baragwanath Academic Hospital CP clinic, this study was aimed at describing these demographics, to expand on what is currently known about these patients. The study was a retrospective descriptive study of clinic files of new CP patients seen at CP clinic from 1st January to 31st December 2012. The objectives of the study were: to determine the age at presentation; to establish the commonest types of CP seen at the clinic; to determine imaging abnormalities; and to assess the level of functional capabilities of patients using the Gross Motor Functional Classification Scale. The data was collected from 145 patient's clinic files, and managed using REDCap and a statistical programme: STATA 12.0. 145 patients files were reviewed, 92 were males, 53 were females. The average age at presentation was 34.17 months (2.8 years); most patients had moderate type of CP (46.2%), predominately mixed spastic diplegia (20.7%). The most common imaging modality used was a CT scan (60.7%); it revealed hypoxic ischemic brain injury in 42% of cases. The level of severity as described by the GMFCS was level III in most cases (37.50%). Cerebral palsy is a common, debilitating disorder; this study has highlighted some of the demographics of these patients at Chris Hani Baragwanath Academic Hospital, CP clinic.

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LIST OF ABBREVIATIONS

Botox	Botulinum toxin
CP	Cerebral Palsy
CDC	Center for Disease Control
CNS	Central nervous system
CFCS	Communication Function Classification System
CT scan	Computed Tomography Scan
FMS	Functional Mobility Scale
GMFCS	Gross Motor Function Classification System
GMFCS-ER	Gross Motor Function Classification System Expanded and Revised
IVH	Intraventricular Haemorrhage
MACS	Manual Ability Classification Scale
MRI Scan	Magnetic Resonance Imaging Scan
OT	Occupational Therapy
PVL	Periventricular Leukomalacia
REDCap	Research Electronic Data Capture
ELBW	Extreme Low Birth Weight
VLBW	Very Low Birth Weight
LBW	Low Birth Weight

PREFACE

Cerebral palsy is a common, debilitating disorder that presents frequently in patients seen at Chris Hani Baragwanath Academic Hospital. A study that evaluates the demographics of these patients has not been undertaken before. This study describes the characteristics of patients with CP at Chris Hani Baragwanath Academic Hospital, seen at the CP clinic, to further expand our knowledge of these patients.

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CHAPTER 1

1. INTRODUCTION and LITERATURE REVIEW

1.1 Definition

Cerebral Palsy (CP) is a motor disability that is caused by a non-progressive insult to the developing motor brain. The term thus describes a combination of disorders that are due to the insult. The motor disturbances present are often accompanied by seizures together with impairment in sensation, communication, cognition, and perception.¹The clinical manifestations though typically evolve with the patient's advancing age.

1.2 Epidemiology

Cerebral Palsy is the most common motor disability during childhood. In current population-based studies from around the world, the prevalence estimates of CP have been reported to be ranging from 1.5 to more than 4 per 1000 live births, in both developing and developed countries.² This is also true in children of a defined age range, that is, from birth to five years of age. There is also a male predominance, with a male to female ratio of 4:1.² South Africa lacks resources to establish a proper registry of children living with CP. Government reports, study trends and collections of statistics indicate the incidence is high. The Center for Disease Control (CDC) and prevention reports the incidence in South Africa to be 3 per 1000 children, which is similar to the world trend.²

1.3 Aetiology

The brain develops continuously during the first five years of life, hence CP may result from a brain insult that has occurred during the prenatal, perinatal or postnatal periods. In developing countries, approximately 60%, 20%, 10% of causes are due to perinatal, prenatal, and postnatal events, respectively. In 10% of cases the cause is unknown.³ There are a number of causes of CP under each category. (Table 1.1)

Birth complications, together with asphyxia, are currently estimated to account for 6% of patients presenting with CP⁴. In normal birth weight infants, the exposure to maternal intrauterine infections is associated with increased risk of CP. In preterm infants there appears to be a 2-fold increase risk of CP from chorioamnionitis, and in term infants the risk is about 4-fold. Major lesions that contribute to CP in premature or very low birth weight (VLBW) infants are intracerebral haemorrhage and periventricular leukomalacia.⁴ Bacterial meningitis, viral encephalitis, hyperbilirubinemia, and trauma, account for 10-20% of postnatal acquired CP.⁴

Table 1.1: Causes of Cerebral palsy³

Prenatal	Perinatal	Postnatal
Toxaemia of pregnancy	Prematurity	Head injury
Genetic factors	SGA	Infections
Antenatal bleeding	Birth asphyxia	(meningitis, encephalitis)
Hydrocephalus	Hypoxic/ischemic	Metabolic
Cerebral malformations	Encephalopathy	<ul style="list-style-type: none"> • Hypoglycaemia
Ante-natal infections	Kernicterus	<ul style="list-style-type: none"> • Hypocalcaemia
	Metabolic (hypoglycaemia)	<ul style="list-style-type: none"> • Hyponatraemia
	Infections	<ul style="list-style-type: none"> • Hypernatremia
	Cerebral haemorrhages	Vascular
	Perinatal strokes	<ul style="list-style-type: none"> • Arterio-venous malformations
	Hydrocephalus	<ul style="list-style-type: none"> • Strokes • Thrombosis/embolism
		Toxins/drugs
		Hydrocephalus

1.4 Clinical manifestations

Cerebral palsy is categorized into distinct major motor syndromes. The motor syndromes are distinguished from each other according to the pattern of neurological involvement, neuropathology, and aetiology (Table 1.2). The physiological taxonomy identifies the chief motor abnormality, whereas the topographic distribution indicates the affected extremities.⁵

Table 1.2: Types of Cerebral Palsy¹

Spastic
<ul style="list-style-type: none">• Hemiplegia (unilateral involvement)• Diplegia (disproportionate lower extremity involvement)• Quadriplegia (whole body involvement)• Monoplegia (single limb involvement)
Dyskinetic
<ul style="list-style-type: none">• Choreoathetoid• Dystonic
Mixed
Hypotonic (with or without ataxia)

Spasticity is the most prevalent tone aberration in children with CP. Spasticity is defined as a stretch dependent hypertonus which can be abolished by posterior root section and may be of two types: 1) phasic spasticity which is velocity dependent and 2) tonic spasticity. Spasticity occurs as a result of an injury to the central nervous system (CNS) that produces upper motor neuron signs. ⁴

1. Spastic hemiplegia: infants show reduced voluntary movements of the side that is affected, they demonstrate hand preference at an early age. The upper limb is commonly more affected than the lower limb, but this depends on the distribution of the arterial insult. The hindrance in hand manipulation is often distinguishable by the age of 1 year. The gait is distinctive, due to the increased tone in the gastrocnemius muscles, there is tiptoe-walking, and the upper extremity is held in a flexed position⁵.
2. Spastic diplegia: there is bilateral spasticity of the legs that is greater than in the arms. It is determinedly linked to damaged immature oligodendroglia that occurs between 20-30th week of gestation⁵. It is more common in premature infants and can be the result of increased grades of intraventricular haemorrhage.
3. Spastic quadriplegia: is the extreme form of CP. It is characterized by marked motor impairment of all extremities, and an increased risk of seizures, mental retardation, and swallowing difficulties (due to bulbar palsy) leading to aspiration pneumonia.⁵

Choreoathetoid CP is also known as athetoid, extrapyramidal, or dyskinetic cerebral palsy. Choreoathetoid CP is less common than spastic CP and comprises of up to 15-20% of patients with cerebral palsy. Infants have decreased tone and show poor head control with head lag. These children habitually acquire increased tone with rigidity and dystonia some years later⁵.

Dystonia is a movement disorder which is characterized by involuntary continuous or intermittent muscle contractions cause twisting and repetitive movements, abnormal posture or both⁵. In choreoathetoid CP the upper limbs are more involved than the lower limbs. Feeding may be a problem due to tongue thrust, and drooling is a prominent feature. Speech is impaired owing to the involvement of muscles of the oropharynx.⁵

Hypotonic CP: hypotonia is a low muscle tone. Hypotonic CP occurs as a result of damage to the cerebellum, which is involved in control of coordination and balance. Injury to the cerebellum may occur due to intrauterine infections and hypoxic insults, which cause damage to the developing brain. Another very important factor that results in hypotonic CP is genetic factors that result in cerebellar hypoplasia and syndromes associated with cerebellar malformation (for example: Dandy-Walker syndrome, Walker-Warburg syndrome)

The child with hypotonic CP presents, as a neonate and in infancy, with headlag, and may be floppy like a rag-doll. As the child matures, there is truncal hypotonia preventing the child from sitting unsupported. There may be an ataxic gait which limits the ability of the child to walk. The truncal hypotonia often evolves into a mixed form of CP, with limbs displaying spasticity at a later stage.³

1.5 Classification

Patients with cerebral palsy are classified according to their functionality. There are a number of classification systems that are employed as aids to assess ambulation and communication. These include the Gross Motor Function Classification System (GMFCS), Functional Mobility Scale (FMS), Manual Ability Classification Scale (MACS), and Communication Function Classification System (CFCS).

1. The Gross Motor Function Classification System (GMFCS) is the system used at CP clinic at Chris Hani Baragwanath Academic Hospital. This system rates the patient's locomotive function, taking in to consideration, the use of mobility aids and the execution of sitting, standing and walking activities. The updated version of the scale is called the Gross Motor function classification system Expanded and Revised (GMFCS-ER). The GMFCS is a functional assessment and not a clinical classification into the different clinical types such as Spastic, Dyskinetic, Ataxic, and Mixed. The GMFCS-ER is divided in to five age categories, and five levels of severity. Severity level one representing mild functional impairment, and level five representing severe debilitation.⁶ (Appendix II)
2. The FMS is a tool used to assess the ambulatory performance in children with CP. It is superior discriminator of differences in ambulatory function among children with CP. The FMS is a functional scale that accounts for the fact that children may express different ambulatory abilities and use different assistance devices to walk various distances.

The FMS is also useful as a means of classifying ambulatory ability.

Like the GMFCS the FMS assesses a child's average performance in daily life in opposition to their maximal capability. The FMS uses a rating system where the child's ambulatory ability is rated from 1-6, one representing a wheelchair bound child and six denoting a child not requiring any assistive devices.⁶ (Appendix III)

3. The MACS is applied to children of all ages, and was designed to describe upper extremity's ability to execute activities of daily living for children with CP. It takes into account the fact that upper limb function is influenced by personal, environmental and contextual factors. It reports on performance of upper limb tasks in daily living, regardless of how they are accomplished and the collaboration of both hands together. The MACS has five levels that rate the child's ability to handle objects and perform tasks.⁶ (Appendix IV)
4. The CFCS also has a five level classification system that is modelled after the GMFCS and MACS. This system helps parents and clinicians understand how different communication tasks affect the CFCS level and assist in individual goal setting for communication. All methods of communication performance are considered in determining the CFCS level. These include use of speech, gestures, behaviours, eye gaze, facial expression and argumentative and alternative communication (manual signs, pictures, books, talking devices.) The distinction between levels is based on the performance of the sender and receiver roles, pace of communication and type of conversational partner.⁷ (Appendix V)

Cerebral palsy can also be classified according to the degree or level of severity. The severity graded from mild to severe, based on the magnitude of impairment. In mild CP, the patient is able to perform self-help skills that are required to manage personal needs. There are insignificant speech difficulties and the patient is able to move about without appliances. In moderate CP, speech is impaired and special equipment may be needed for ambulation. Patients need assistance in activities of daily living and rehabilitation therapy. In severe CP patients have poor self-help skills, ambulation and speech development even with rehabilitation.⁹

1.6 Diagnosis

Cerebral palsy is diagnosed clinically. By taking a proper history and doing a thorough physical examination, one is able to exclude an advancing central nervous system disease. Establishing the aetiology of the child's disability and weeding out other diagnoses is important, as well as elimination of diseases that require different types of treatment. A MRI scan of the brain is used to ascertain the site and dimensions of the lesion or accompanying congenital aberrations.⁵

1.7 Treatment

Physical treatment methods such as passive stretching are commonly used to treat increased tone. There is evidence that passive stretching can increase the range of motion and decrease spasticity especially if sustained stretching is used. Sustained stretching is easily achieved through bracing or serial casting.

Oral medication including benzodiazepines (e.g. diazepam) are able to act supraspinally and at the spinal cord level, and have been shown to decrease generalized spasticity, hyperreflexia and muscle spasm. Baclofen (a gamma-aminobutyric acid derivative) reduces the release of excitatory neurotransmitters and substance P when it binds to GABA_b receptors. It primarily acts at spinal cord level, and it has been shown to decrease spasms, clonus and resistance to stretch, and it has anxiolytic effects.¹⁰ Dantrolene sodium (a skeletal muscle relaxant) acts at the site of skeletal muscle as opposed to the other oral agents, which act on neurotransmitter systems. It reduces clonus and muscle spasms resulting from innocuous stimuli. Alpha 2-adrenergic agonist (Tizanidine) acts on receptors in the brain and spinal cord. This drug causes a decrease in muscle tone through hyperpolarisation of motor neurons¹⁰.

Neuromuscular blockade/ chemodenervation are other ways to treat hypertonia. Phenol and ethyl alcohol are injected perineurally, they incite denervation via axonal degeneration. The effect is not durable, with re-innervation occurring over months to years. They are seldom used these days, due to the damage caused to muscle fibres. An exotoxin called Botulinum toxin, is produced by *Clostridium botulinum*, this toxin acts at the neuromuscular junction, where it prevents the release of acetylcholine and thus causing muscle weakness.¹⁰

Neurosurgical treatment of spasticity, selective dorsal rhizotomy, is a procedure that is done by performing a laminoplasty, whereby the dura is opened; dorsal rootlets from T12-S1 are separated. Each rootlet that shows an abnormal continuous response, on electromyography, is severed. Spasticity is reduced by severing the dorsal root thus decreasing the excessive bombardment from the muscle spindles on the anterior horn cells.

Intrathecal baclofen is injected directly into the intrathecal space using a catheter that is connected to an implanted pump. As direct delivery of the drug into the nervous system is achieved, the dose required is less than 1% of orally delivered dose, therefore there are reduced side effects.¹⁰

All patients with childhood dystonia receive a trial of carbidopa or levodopa. These are very effective in treatment of dopa- responsive dystonias and other disorders affecting dopamine synthesis. If dopaminergic agents are not effective, anticholinergics should be tried. In children who have a secondary dystonia caused by cerebral palsy, benefits have been seen with the use of trihexyphenidyl.¹¹ Intramuscular injection of botulinum toxins are used to manage dystonia. Botulinum toxin is preferentially taken up by the most active muscle fibres, thus it may block involuntary movement but preserve muscle strength. Neurosurgical pallidal stimulation/ deep brain stimulation (DBS) has an acceptable morbidity rate. It is preferred as it provides the opportunity for reversal or modification. The results are highly variable, resulting in no benefit to major betterment of function. This procedure is for patients with dystonia.¹¹

1.8 Comorbidities

The spastic CP patient can develop contractures which further limit fine and gross motor function. They are prone to osteopenia, osteoporosis, and fractures due to lack of ambulation. Gastrointestinal problems (vomiting, constipation, and bowel obstruction) are related to decrease in gastric emptying and defective autonomic control of gastrointestinal activity, and prolonged inactivity.

The impaired oral-motor functions lead to dysphagia with aspiration pneumonia, reflux, drooling, poor nutrition, and failure to thrive. Patients are inclined to epileptic seizure disorders, mental retardation, cognitive impairment, and auditory and visual abnormalities. Urinary incontinence is also a common problem.

1.9 Prognosis

Life expectancy of persons with CP varies in relation to the type of CP and the severity of motor deficits as well as certain associated non-motor deficits. Premature death, which may occur within the first five years of life, tends to be more confined to individuals with spastic quadriplegia. Gastrointestinal reflux and epilepsy may also reduce the life expectancy. Modern approaches to the care of individuals with CP have decreased the risk of premature deaths. Individuals with CP, including the severe forms, may survive into adulthood.⁸

Cerebral palsy (CP) has devastating effects on the quality of life of affected individuals.

There is little known about the demographics of children with CP at Chris Hani Baragwanath Academic Hospital, which serves the community of Soweto and surrounding areas.

CHAPTER 2

2.1 AIMS OF THE STUDY

The study obtained information about children with Cerebral Palsy at Chris Hani Baragwanath Academic Hospital. This was done by evaluating the demographics of children seen at the CP clinic from 1st January 2012 to the 31st of December 2012. The information that was intended to be ascertained by this study is listed in the objectives below:

The objectives of the study were

1. To determine the age at presentation.
2. To establish the commonest types of CP seen at the clinic.
3. To determine imaging (CT scan or MRI and cranial sonar) abnormalities, if such investigations were requested.
4. To assess the level of functional capabilities of patients using the Gross Motor Functional Classification Scale (GMFCS). The physiotherapist use this score to assess functional capabilities of every new patient seen at CP clinic.

2.2 MATERIALS AND METHODS

The study was a retrospective descriptive study of children seen at CP clinic at Chris Hani Baragwanath Academic Hospital from 1st January 2012 to the 31st of December 2012. The data was collected from patient's clinic files, entered into a data collection sheet(Appendix I), and managed using REDCap (Research Electronic Data Capture), which uses a MySQL database via a secure web interface, with data checks used during data entry to ensure data quality.¹⁹

The clinic files used were those of the new patients seen from the 1st of January 2012 to the 31st of December 2012(over a period of one year). Patient's name, hospital number and date of birth (corresponding with the patient identifier) were kept on a separate file to maintain confidentiality.

The CP clinic at Chris Hani Baragwanath Academic Hospital is held every week on a Tuesday. Children with CP from Soweto and surrounding areas are seen. It is run by two specialist neurologists, and two paediatric registrars rotating through neurology; nurses, physiotherapists, speech therapists and occupational therapists. At the clinic approximately four to five new patients are seen by the neurologists. The most common types of CP seen are predominately mixed CP, spastic, dystonic and hypotonic CP. The services provided at the clinic are consultancy, referral for physiotherapy, occupational therapy (OT), speech therapy, orthopaedics and dietetics. Selected patients are treated with botulinum toxin (Botox).

The allied team screens the new patients at the Tuesday clinic and refer them for appropriate therapy -Physiotherapy, OT and Speech therapy. They also evaluate which patients need assistive devices and refer them appropriately. The allied team has a separate clinic, the Neurology Rehabilitation Clinic, where these patients are seen and treated.

2.3 SAMPLE SIZE

Approximately four to five new patients are booked for CP clinic every Tuesday, thus it was expected that the study sample size would equal to two hundred and fifty (250) to two hundred and sixty (260) patients, but many patients did not attend the CP clinic. During the study period 201 new patients were seen. 56 patients were excluded because their clinic records did not state what age they were at first presentation. Patients were also excluded if their clinic record did not state what type of CP was diagnosed, and when the grade of their level of functionality was not stated or the description of the functionality was too poor to judge the level of functionality of the patient and what type of CP the patient is presenting with. The sample size of the study was 145 patients over the stipulated time period (n=145).

2.4 DATA ANALYSIS

All data was captured from clinic files and entered on a data collection sheet. Categorical data was analysed using frequencies and proportions and further reproduced using histograms and tables. Continuous data was analysed using standard deviation and means and further reproduced using summaries and pie charts. The data was reproduced using a statistical programme: STATA (version 12.0).

2.5 LIMITATIONS

The study was a retrospective study done using files from CP clinic; the accuracy of the information was largely dependent upon the adequacy of the information entered onto the clinic files. Patients were lost to follow up, and some did not attend the clinic at the appointment date.

2.6 ETHICS

Approval was obtained from the ethics committee of the University of the Witwatersrand.

The protocol is Protocol number M130377. (Appendix II)

CHAPTER 3

3. RESULTS

3.1 Characteristics

Patient records were reviewed for the period of 1st January 2012-31st December 2012 from the CP clinic. A total of 145 patient records were retrieved and reviewed. The age of first presentation (the age when the patient first presented to CP clinic) was stated in 144 of the 145 patients seen (this patient was included in the study as the date of first presentation corresponded with the stipulated study timeline). The patients that were born at Chris Hani Baragwanath are inborn, and those referred from clinics and hospitals outside Chris Hani Baragwanath are outborn. (Table 3.1)

Table 3.1: Characteristics of the patients seen at CP clinic

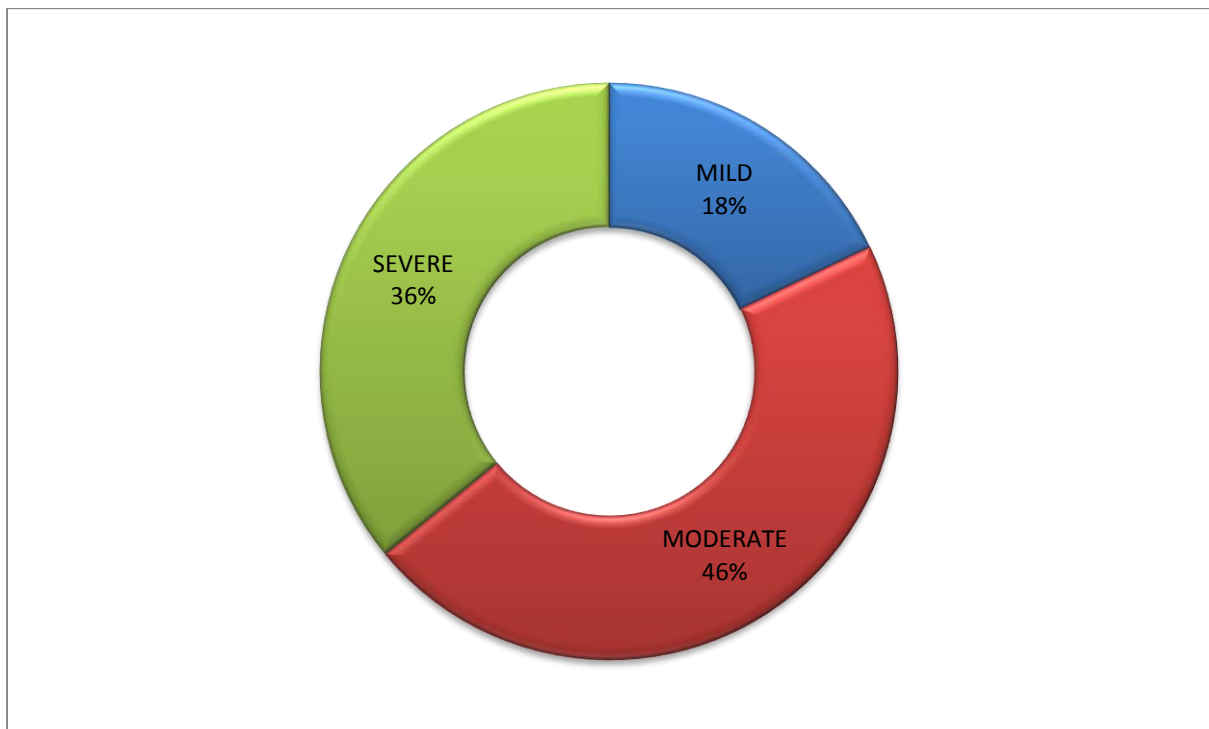
Characteristic	Mean (Range)
Age at first presentation (months) n=144	34.17 (1.5– 189.2)
Gestational Age	
Term(≥ 37 weeks)	37.9
Preterm(<34 weeks)	28.8
Late Preterm(34-36 weeks)	35.2
Birth Weight (g)	
ELBW(<1000)	761
VLBW(1000-1499)	1327
LBW(1500-2499)	1969
Normal birth weight(≥ 2500)	3089
Mode of delivery:	
• Vaginal	95 (66.9%)*
• Caesarean section	47 (33.1%)*
Place of delivery:	
• Inborn	73 (50.7%)*
• Outborn	71 (49.3%)*
Gender	
• Male	92(63.4%)*
• Female	53 (36.6%)*

*Number (%)

3.2 Level of severity

The level of severity, or degree of severity of CP, is classified into mild, moderate or severe depending on the level of functional impairment. Forty six percent (46.2%) of patients were diagnosed with moderate CP. In this group of patients, speech was impaired and special equipment was needed for ambulation (GMFCS III). The severe degree of CP was seen in thirty five percent (35%) of CP patients; these patients had poor self-help skills, speech and ambulation, despite rehabilitation therapy (GMFCS IV and V). In mild CP, self-help skills were adequate to care for personal needs (GMFCS I and II). In the study eighteen percent (18%) of patients were found to have mild CP. These patients had adequate speech and could ambulate independently, without assistive devices. (Figure 3.1)

Figure 3.1: Level of Severity

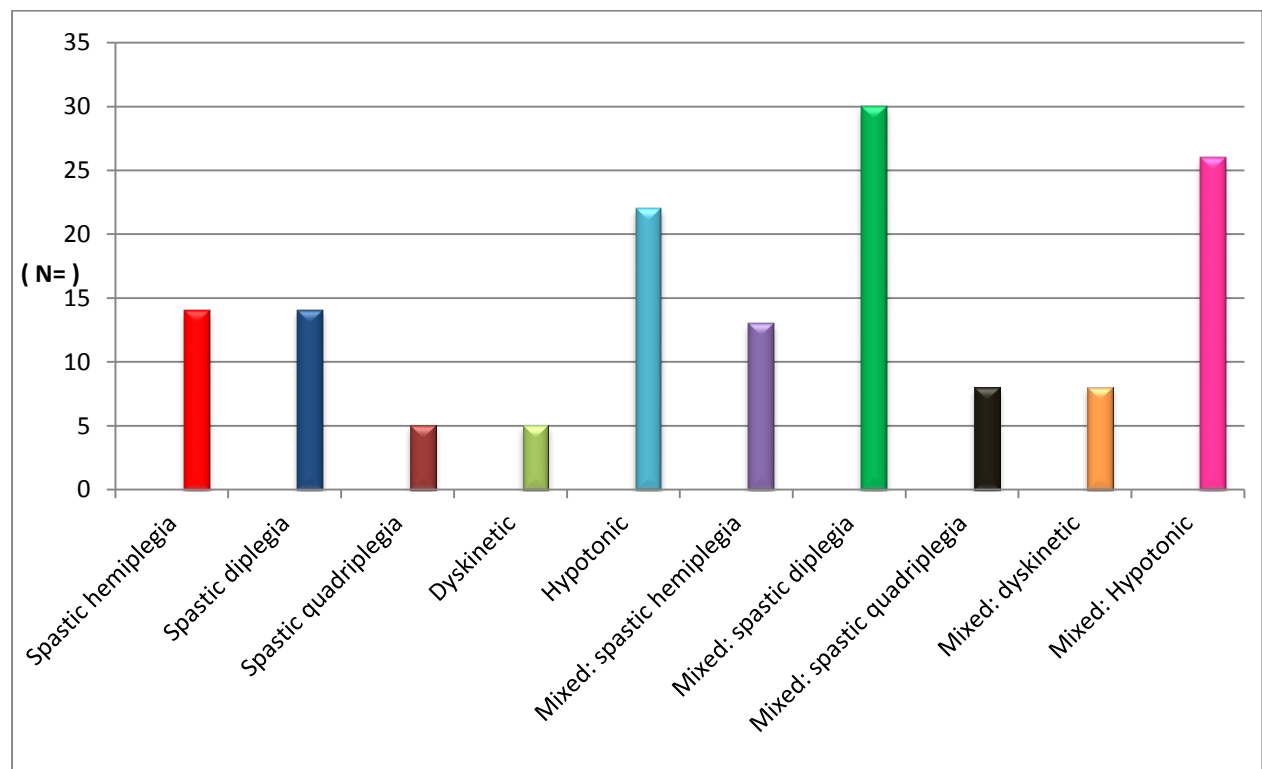


Number of observations: 145

3.3 Commonest type of CP

The most common type of CP seen in the patients reviewed in the study was mixed CP, predominately spastic diplegia, which occurred in 20.7% (n=30) of patients at the CP clinic. The patients who had mixed CP predominately spastic diplegia were mostly term infants (n=24). The second commonest presenting subtype of CP was mixed predominately hypotonic, seen in 17.9% (n=26) of patients, this type of CP was the most frequent among preterm infants. Hypotonic CP was documented in 15% (n=22) of patients. The other motor syndromes of CP were less frequent, spastic hemiplegia and spastic diplegia both being diagnosed in 9.7% (n=14) of CP patients; and mixed CP predominately spastic hemiplegia in 9% (n=13). The different dyskinetic subtypes and spastic quadriplegic subtypes were seen in a smaller proportion of patients. (Figure 3.2)

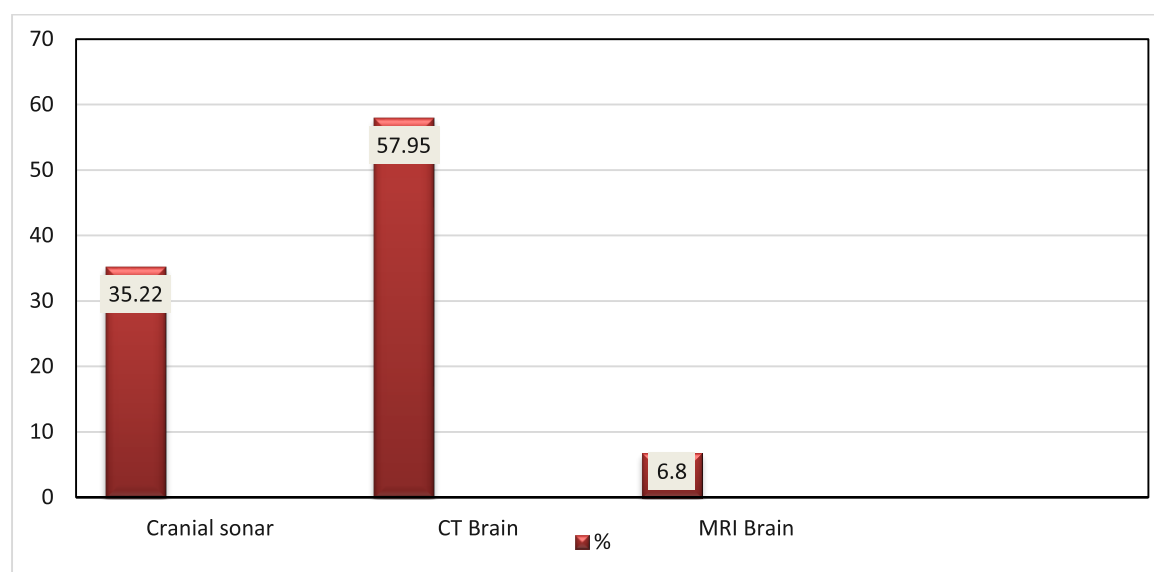
Figure 3.2: Type of CP



3.4 Imaging modality

Imaging in the form of cranial ultrasound, computed tomography (CT) scan, and magnetic resonance imaging (MRI) of the brain, was performed in 89 of the 145 patients reviewed (Figure 3.3). At the CP clinic, new patients who were found to have focal or intractable seizures, and patients with quadriplegia, had imaging done. Neuroimaging was done to find out what was the cause of CP, if this was not clear on history and examination, and to rule out structural brain malformations (important for genetic counselling regarding future pregnancies). Imaging is not necessary to exclude CP. The cranial sonar, which was performed in 35.2% of patients, was usually done in the neonatal period for various indications, but especially in patients diagnosed with perinatal asphyxia (37 patients were diagnosed with perinatal asphyxia). The CT Brain and MRI Brain scan was done in 57.9% and 6.8% of patients respectively. These were performed for patients with seizures, and to diagnose those with structural brain lesions. The type of modality used was dependent upon the level of severity of CP, and the availability of the requested imaging modality.

Figure 3.3: Imaging modality



Number of observations: 89

3.5 Imaging results

Imaging was performed on sixty one percent (n=89) of patients, only 88 patients had the report of the imaging stated in their clinic files, one patient was said to have had the investigation but there was no record of the results in the records. The finding of hypoxic ischemic injury was the most commonly reported imaging abnormality. It was found in 42% (n=37) of patients seen at CP clinic. Other abnormalities such as cerebral oedema, ventriculomegaly or slit-like ventricles, cerebral atrophy and normal imaging were found in 36.4% (n=32). Periventricular leukomalacia was reported in 12.5% (n=11) and hydrocephalus in 6.8% (n=6) of CP patients reviewed in the study. The least diagnosed lesions were intraventricular haemorrhage and basal ganglia lesions, seen in 4.5% (n=4) and 3.4% (n=3) of patients, respectively. The patients who had cranial sonar findings that were confusing or complicated, and those with poor sonar windows, would get a CT/MRI brain to clarify or confirm findings. (Table 3.2).

Three patients were found to have normal appearing MRI brain scans. The first patient was born prematurely at 28 weeks with a birth weight of 1830g and had normal apgars of 8 (5 minutes) and 10 (10 minutes). The patient had delayed milestones, and had been diagnosed clinically as having mixed spastic and dystonic CP and the MRI was normal. The second patient was 9 months old when they were first seen at CP clinic. The gestational age and birth weight of the patient were not stated, but had apgars of 3 (5 minutes) and 7 (10 minutes). The patient had delayed milestones, and was diagnosed clinically with mixed predominately hypotonic CP, the MRI was normal. The third patient was 2 years old when they first attended CP clinic. The birth history was not stated in the clinic record, but the patient had delayed milestones and had dyskinetic CP, the MRI was normal.

Table 3.2: Imaging Results

Imaging Results	
Acute findings	Chronic/delayed
Hypoxic Ischemic Injury	Periventricular leukomalacia
Intraventricular haemorrhage	Hydrocephalus
Cerebral oedema	Cerebral Atrophy
Slit-like ventricles	Structural abnormalities
Basal ganglia lesions(hemorrhagic infarct)	Ventriculomegaly
Normal	Basal ganglia lesions (atrophy)

3.6 Level of Functionality (GMFCS)

The level of functionality was graded using the GMFCS (Gross Motor Function Classification System) that rates patient's ambulatory function (Appendix II). In Table 3.3, 144 patient's level of functionality was graded, one patient's level of functionality was not stated in the records, and the patient's ambulatory function could not be assessed. The most frequent level of functioning was grade III, 37% (n=54). These children could sit, stand, and needed devices for ambulation during long distances.

Twenty seven percent had Grade IV GMFCS. They required mobility devices, and could not sit without support. Grade II GMFCS was seen in 16% of the study population. These patients could walk in most settings and had limitations when running or jumping. The patients with Grade I GMFCS were the least affected and needed very minor assistance in activities of daily living; these were 6% of the reviewed patients. Grade V GMFCS were seen in 18% of patients, which had severe limitations and used assistive devices in all settings; they could not stand, sit, and had none or poor head control.

Table 3.3: Level of functionality N=144

Level of functioning	Number	Percent (%)
I	9	6.25
II	24	16.67
III	54	37.50
IV	39	27.08
V	18	12.50
Total	144	100.00

CHAPTER 4

4. DISCUSSION

Cerebral palsy is the most common cause of childhood disability worldwide and especially in our country with an estimated incidence of 3 per 1000 live births.²The true incidence of children with cerebral palsy in South Africa is poorly defined and a proper registry of children with CP is yet to be developed. These children's life expectancy is improving and it is becoming more important to integrate persons with cerebral palsy into our society as independent, able individuals.

The average age at first visit was found to be 34.1 months (2.8 years). In other studies the average age at first presentation has been reported to be 8.2-23.4 months.¹³The late age at presentation of our study population with cerebral palsy is due to the fact that CP is diagnosed clinically, and the diagnosis is also based on parental reports about a child failing to attain the expected developmental milestones. It must be stated that, CP patients at Chris Hani Baragwanath Academic Hospital are seen at the Neonatal Follow-Up Clinic by Neurology Rehabilitation Team (the physiotherapists, OT, speech therapists, and paediatricians) from birth to one year of age, thereafter, they are referred to CP clinic. Some of these children, however, do present late to health care facilities. This explains why most children are diagnosed late, after the second year of life. The youngest patient was 1.5 months and the oldest was 189.2 months (15 years). The early diagnosis of CP may be possible by the follow-up of high risk patients, especially those with a poor birth history from the perinatal period.

Several studies, including this study, have revealed that CP is more frequent amongst the male gender.¹¹In our study the males were 63.4% (92/145) versus females which were 36.6% (53/145). The incidence of CP in males was 30% higher versus females (p value = < 0.01, calculated using the Kolmogorov-Smirnov Test on Statistica 12.5). The research into the causes of CP has revealed that gender differences in the immature brain are strongly influenced by intrinsic differences between male and female cells.¹⁴This is due to their distinct chromosomal complements. Evidence suggests that cellular pathways involved in neuronal death after the infant's brain injury, are different in males versus females. The reason was found to be the sex chromosomes rather than sex hormones. Males have a higher incidence of brain-based developmental disabilities as they are prone to extreme prematurity and its complications.¹⁴

The type (clinical subtype) of cerebral palsy most commonly seen at Chris Hani Baragwanath Academic Hospital CP clinic was mixed predominately spastic diplegia (20.7%).The high rate of mixed predominately spastic diplegic CP could be due to improved prenatal, natal, and neonatal intensive care of premature infants. The least diagnosed type of CP was spastic quadriplegia and dyskinetic CP both of which were seen in 3.4% of patients. The low rate of dyskinetic CP could be due to proper treatment and prevention of neonatal hyperbilirubinemia and kernicterus. The classification of children into different types of CP according to the topographical taxonomy is largely dependent on the examiner and inter-rater reliability of examiners which is not very high, this is a factor that is implicated in other studies as well.¹⁵Inter-rater reliability amongst examiners, has not been tested at Chris Hani Baragwanath Academic Hospital.

Spastic CP is the most common type of CP, hypotonic CP accounts for less than half of cases. In the study population, a substantial amount of CP cases (not greater than spastic cases) were found to be due to hypotonic CP (15%), and mixed predominately hypotonic CP (17.9 %). During the first few months of life only hypotonia may be present in the child with CP, but as the child begins to move, ataxia is seen, the truncal hypotonia evolves into mixed form of CP with the limbs displaying spasticity at a later stage³. This could explain the reason for the high number of hypotonic CP cases in the study population, that they were seen at an early age before the spasticity developed. There were 22 patients diagnosed with hypotonic CP, of these 63% (n=14) were below 1 year of age when they first presented at CP clinic.

The majority of patients had moderate CP (46.2%). These patients had speech impairment and needed special equipment for ambulation. They needed assistance in activities of daily living and rehabilitation therapy. The mild degree of severity was only seen in 17.9% of patients and these patients were mostly of the hypotonic type of CP diagnosed early in infancy. The patients with mild CP could ambulate without assistance devices and had normal speech and self-help skills. The patients with severe CP (35.9%) were those with predominately quadriplegia and had complications of CP such as intractable seizures and poor feeding. They had poor quality of life despite rehabilitation.

Imaging was performed on 89 out of the 145 new patients seen during the study period. Imaging is expensive and only used 'on a need to' basis. Poor record keeping resulted in some patient's reports of cranial sonar or CT scans or MRIs being omitted from the clinic files. The CT scan of the brain was the most frequently used imaging modality being used in 57.9% of patients. Cranial sonar was used in the neonatal period especially in children admitted to neonatal ICU or neonatal high care at Chris Hani Baragwanath Academic Hospital.

The MRI of the brain was the least used, in 6.8% of patients; these patients presented with seizures and had epilepsy that was not controlled on more than two drugs. MRI brain was the least used imaging modality, because there is only one day dedicated to the paediatric patients. There is a long waiting list. MRI brain was requested if it was thought to have an impact on or changed management. Three patients were found to have normal MRI brain scans. It was not stated whether these patients had a metabolic or genetic work-up done to exclude inherited conditions and/or metabolic conditions that could mask CP, and no other alternative diagnoses was made.

In a study by Ruba Benini, et al²⁵, they investigated normal appearing MRI scans using patients from a population-based CP registry. They evaluated 126 records of CP patients who had MRI scans performed. 29% of these CP patients had normal MRI findings. The most common type of CP in these patients was dyskinetic CP. In our study cohort, 3 out of the 89 patients had normal appearing MRI findings. The types of CP in these patients were varied from hypotonic to dyskinetic and mixed predominately spastic CP.

The possible reason of the normal MRI findings could be the experience of the radiologist, but this is unlikely as our patients' MRI brain scans are reviewed by the pediatric neurologist team and a consultant radiologist. The other reason could be the sensitivity of the MRI scanner in defining brain injury. The sensitivity of MRI has improved over the years with addition of new technologies such as magnetic resonance force microscopy, diffusion tensor imaging, and spectroscopy, these modalities have improved the quality and sensitivity of MRI scans. Genetic causes of CP are rare and estimated to represent less than 4% of cases, their true incidence is not known.²⁶ Genetic conditions increase an individual's susceptibility to brain injury, prematurity and cerebral dysgenesis, which can lead to CP. Examples of these genetic conditions are Rett syndrome, Angelman syndrome, and hereditary spastic paraplegia. Metabolic disorders such as urea cycle defects and congenital lactic acidemias may present as CP, obscuring the true diagnoses. Metabolic disorders must be excluded in a CP patient with a normal appearing MRI.²⁵

Neuro-imaging in the form of cranial ultrasound, CT scan or MRI was undertaken in 61.3% of patients seen at the CP clinic from January to December 2012. The most common imaging abnormalities were hypoxic ischemic injuries, seen in 42% of patients with CP. The hypoxic ischemic injury lesions that were diagnosed were: focal or diffuse cerebral infarcts in watershed areas and grey matter infarcts, intraventricular haemorrhage and periventricular white matter lesion. In the literature only 5% of patients with CP have been reported to have hypoxic ischemic injury, while in our study the majority of patients had hypoxic ischemic injury reported especially on CT scans and MRIs¹⁶.

The most common structural brain abnormality seen in our study population was hydrocephalus seen in 6.8% of patients. Other imaging abnormalities included: schizencephaly, polymicrogyria, lissencephaly, agenesis of the corpus callosum, holoprosencephaly, septo-optic dysplasia, cerebellar anomalies, cerebral atrophy, abnormal ventricles (slit-like or ventriculomegaly), meningitis and cerebral oedema. These lesions occurred in 36.4% of patients, which is similar to the trend seen in literature.¹⁵

Periventricular leukomalacia (PVL) is a form of white matter injury. It is commonly seen in ischemic brain injuries of premature infants, who later develop CP. PVL was seen in 12.5% (11/89) of patients. In the literature, PVL is the commonest imaging abnormality seen in patients with the spastic types of CP.¹⁷ Intraventricular haemorrhage (IVH) reported in 4.5% of our study population is a complication of prematurity especially of very low birth weight infants. Patients with intraventricular haemorrhage have a 50% risk of developing CP.¹⁸ Basal ganglia lesions were the least seen imaging abnormalities, and they were seen in patients with acute asphyxia. These lesions are associated with congenital hyperbilirubinemia and kernicterus, and patients present with dyskinetic and ataxic type of CP.

Basal ganglia lesions were seen in 3.4% patients (these patients were those that presented with dyskinetic CP), this was consistent with the findings in the study by Tosun A and Gokben S, et al.¹²

Intrapartum asphyxia can be divided into two major patterns that correspond to two pathophysiological processes. The first is called acute near total asphyxia, the second is prolonged partial asphyxia, the two processes can also occur in combination. Acute near total asphyxia has an abrupt onset (usually lasts for 5-30minutes); there is sudden and complete interruption of oxygen supply to the fetus. The possible etiological processes are rupture of the uterus, severe cord compression, and placental abruption. Prolonged partial asphyxia is less severe, and occurs due to lack of oxygen supply over hours or days, from etiologies such as placental insufficiency.²³

The MRI pattern produced by acute near total asphyxia is a Basal ganglia–thalamus pattern (BGT); there is injury predominantly affecting bilaterally the central grey nuclei (ventrolateral thalami and posterior putamina) and perirolandic cortex. Associated involvement of the hippocampus and brain stem is not uncommon. A watershed predominant pattern of injury (WS) is the pattern of injury seen following prolonged partial asphyxia. The vascular watershed zones (anterior–middle cerebral artery and posterior–middle cerebral artery) are involved, affecting white matter, and in more severe cases the overlying cortex is affected. The lesions can be unilateral or bilateral, posterior and/or anterior.²⁴

The level of functioning was described using the GMFCS expended and revised version (Appendix II). The GMFCS has been used as a measure of severity. Level I denotes the least impairment in physical capabilities and level V denotes the worst impairment. In this study most patients were found to be functioning at level III (37.50%). These patients were able to perform certain activities, such as walking and sitting, when using assistive mobility devices. They had limitations in performing gross motor skills but could be taught adaptations to enable them to perform in physical activity.

Patients with level IV (27.08%) and level V (12.5%) functioning were the most severely affected. These patients had no means of independent movement and were diagnosed with quadriplegic (8.9%) or dyskinetic (3.4%) types of CP. Thirty nine percent of patients were severely affected with a GMFCS level of IV-V this correlated with severe types of CP. With improved care of new-borns with hyperbilirubinemia, the rate of dyskinetic CP is low. With regular therapy the GMFCS grade can improve. However at Chris Hani Baragwanath Academic Hospital, patients at 5 years of age are down referred to a community health centre close to their place of residents. At these clinics they continue to receive therapy in the form of physiotherapy, occupational therapy, and speech therapy. Parents are also thought how to perform exercises at home. The demand outstrips the availability of allied health care workers who cannot cope with the number of patients fed into the clinic at Chris Hani Baragwanath.

CHAPTER 5

5.1 CONCLUSION

Cerebral palsy is the most common cause of disability in children and is becoming more important to diagnose and treat in a comprehensive and multidisciplinary manner. This study has highlighted some important information with regards to the causes and types of CP. This information may aid in the prevention and management of patients with CP at Chris Hani Baragwanath Hospital. The most common cause of CP was found to be hypoxic ischemic brain injury. The prevention and management of hypoxic ischaemic brain injury is fundamental in decreasing the incidence and complications of CP. Treatment modalities such as induced hypothermia has been shown in literature to improve outcome of patients with hypoxic and traumatic brain injury. The life expectancy of individuals with CP is also improving and it is thus important to enable these patients to be integrated into society as functional individuals. The importance of early physical treatment also needs emphasis, as individuals with a poor GMFCS score (grade III and IV) may regain some functionality with intense treatment.

5.2 RECOMMENDATIONS

The early referral of patients with CP combined with early intervention has been shown to improve outcome, as seen in the study by Poposka A and Georgieva D et al.²²

Parent education about proper infant development may improve health-seeking behaviours and early diagnosis of the affected infant. The counselling of parents about the infant at risk will in addition lead to regular follow-up at neonatal follow-up clinic and at the CP clinic.

MRI scans are the imaging of choice as CT scans add too much radiation to the body. The majority of patients at the Chris Hani Baragwanath CP clinic had CT scans done as part of management. This was due to logistical matters such as long waiting lists, too few machines, and the need for general anaesthesia in children. Thus obtaining more machines and employing more personnel is required.

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APPENDICES

Appendix I: Data collection sheet

Patient identifier: _____

Gestational Age: _____

Date of 1st visit: _____ Age at 1st visit: _____

Gender:

Male: ☐

Female: ☐

Type of CP:

- | | |
|---|--------------------------|
| 1. Spastic Hemiplegia | <input type="checkbox"/> |
| 2. Spastic Diplegia | <input type="checkbox"/> |
| 3. Spastic Quadriplegia | <input type="checkbox"/> |
| 4. Dyskinetic | <input type="checkbox"/> |
| 5. Hypotonic | <input type="checkbox"/> |
| 6. Mixed with spastic predominance | <input type="checkbox"/> |
| 7. Mixed with hemiplegia predominance | <input type="checkbox"/> |
| 8. Mixed with diplegia predominance | <input type="checkbox"/> |
| 9. Mixed with quadriplegia predominance | <input type="checkbox"/> |
| 10. Mixed with dyskinetic predominance | <input type="checkbox"/> |
| 11. Mixed with hypotonic predominance | <input type="checkbox"/> |

Level of severity:

- | | |
|-------------|--------------------------|
| 1. Mild | <input type="checkbox"/> |
| 2. Moderate | <input type="checkbox"/> |
| 3. Severe | <input type="checkbox"/> |

Imaging:

- | | |
|------------------|--------------------------|
| 1. Cranial Sonar | <input type="checkbox"/> |
| 2. CT Brain | <input type="checkbox"/> |
| 3. MRI brain | <input type="checkbox"/> |

Features on imaging:

- | | |
|----------------------------------|--------------------------|
| 1. Peri-ventricular leukomalacia | <input type="checkbox"/> |
| 2. Intraventricular haemorrhage | <input type="checkbox"/> |
| 3. Hydrocephalus | <input type="checkbox"/> |
| 4. Hypoxic-ischemic injury | <input type="checkbox"/> |
| 5. Basal ganglia lesion | <input type="checkbox"/> |
| 6. Other | <input type="checkbox"/> |

Level of functionality (GMFCS):

- 1
- 2
- 3
- 4
- 5

Appendix II: Ethics Approval



R14/48 Dr Ntombizodwa Mahlaba

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130377

NAME: Dr Ntombizodwa Mahlaba
(Principal Investigator)

DEPARTMENT: Department of Paediatrics
Chris Hani Baragwanath Academic Hospital

PROJECT TITLE: A descriptive study of children with Cerebral Palsy at Chris Hani Baragwanath Academic Hospital

DATE CONSIDERED: 05/04/2013

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Dr F Nakwa

APPROVED BY: 
Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 05/04/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**

N Mahlaba
Principal Investigator Signature

Date 7/6/2013

Appendix III: Gross Motor Classification System Expanded and Revised⁶

Can Child Centre for Childhood Disability Research.

Before 2nd birthday

LEVEL I: Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

LEVEL III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

LEVEL IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

LEVEL V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll

Between 2nd and 4th birthday

LEVEL I: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III: Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

Between 4th and 6th birthday

LEVEL I: Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

LEVEL II: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a handheld mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

LEVEL III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when travelling for long distances or outdoors on uneven terrain.

LEVEL IV: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology.

At Level V, children have no means of independent movement and are transported.

Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

Between 6th and 12th birthday

Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when travelling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When travelling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Between 12th and 18th birthday

Level I: Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a handheld mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when travelling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility.

Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.