THE OUTCOMES OF SINGLE EVENT MULTILEVEL SURGERY AND PHYSIOTHERAPY IN THE WALKING SPASTIC DIPLEGIC CHILD WITH CP OR HIV IN A RESOURCE POOR SETTING.

Linda Wood

A research dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of a Master of Science in Physiotherapy

January 2016

ABSTRACT

Cerebral palsy (CP) is the most commonly seen neurological disorder in children. The incidence of CP is two to four children per 1000 live births. With there being continuous advances in the medical field, the management of these children is continuously changing and evolving. The current preferred orthopaedic management of children with CP is single event multilevel surgery (SEMLS). Although SEMLS is well supported in the literature there is little evidence to show the outcomes of SEMLS in developing countries where resources are limited. Physiotherapy post SEMLS is less available in developing countries. There is little research showing whether the outcomes of SEMLS are still favourable with less physiotherapy intervention post surgery.

There is a high prevalence of children who are infected with the Human Immunodefiency Virus (HIV) in South Africa. Many of these children have HIV Encephalopathy (HIVE) and as a result present with spastic diplegia. There is very little research investigating the appropriate management of these children. There is no research available comparing the management of these children to the management of children with spastic diplegic CP.

The aim of this study was to determine the outcomes of SEMLS in children with spastic diplegia, either with CP or HIVE, Gross Motor Function Classification System (GMFCS) level two or three, who receive combined orthopaedic and physiotherapy management at Chris Hani Baragwanath Academic Hospital (CHBAH).

Ten children with spastic diplegia were enrolled (six with CP, four with HIVE). All children underwent SEMLS at CHBAH and received therapy at a local clinic or hospital or a special needs school. Therapy consisted of predominantly a home-based exercise program. All children were followed up for a period of twelve months. The primary outcome measures were the Gross Motor Function Measure (GMFM), the Functional Mobility Scale (FMS) and the Edinburgh Visual Gait Score (EVGS).

A total of sixty-seven procedures were performed with a mean of 6.7 procedures per child. From the baseline assessment there was an improvement in the EVGS of 6.8 at the six month follow-up and 6.4 at the one year follow-up assessment. There was a deterioration of 2.77% in the GMFM-66 scores at the six month assessment, with an improvement of 3.23% at the one year follow-up. The FMS also revealed an initial deterioration in function, with return to pre-operative function at the twelve month assessment. Changes in the EVGS for this study were not clinically significant. Changes in the GMFM-66 were found to be clinically significant. There was greater functional change post SEMLS in this study in comparison to

previous studies. When comparing children with CP to those with HIVE the changes in the gait parameters, as measured by the EVGS, and those in function, as measured by the GMFM-66, were similar. Children who received therapy at the schools had better results when looking at the EVGS, whereas children receiving therapy at health care facilities had better results according to the GMFM-66.

This study shows that SEMLS has similar outcomes in developing countries to those seen in developed countries. Children receiving therapy in different settings showed some differences with regards to improvement in function and gait parameters. This study also highlights the effectiveness of managing children with spastic diplegia due to HIVE similarly to children with spastic diplegic CP.

ACKNOWLEDGMENTS

I would like to thank the following people for their contribution to this dissertation:

Prof Joanne Potterton for her guidance and support.

Dr Greg Firth for his enthusiasm, guidance and support.

Chris Hani Baragwanath Academic Hospital for allowing me to conduct this study at the hospital.

The Chris Hani Baragwanath Academic Hospital Physiotherapy Department for their support and patience during data collection.

To all the children and their parents who participated in the study.

Dr Yammesh Ranguthy for his assistance with the gait analysis.

Tracey Bulmer and Sam Rosie for their support.

My family for their encouragement, support and understanding.

DECLARATION

I declare that this research report is my work unaided, with the exception of those works indicated in the reference citation and acknowledgements. It is being submitted in complete fulfilment of the requirements of the degree of Master of Science (Physiotherapy) at the University of the Witwatersrand. It has not been submitted before for any other degree or examination in any university.

Linda Wood

_____ day of _____ 2016

TABLE OF CONTENTS

ABSTRACT i

ACKNOWLEDGMENTS iii

DECLARATION iv

LIST OF TABLES: x

LIST OF FIGURES: x

LIST OF ABBREVIATIONS xi

Chapter One - Introduction 1

1.1 Background 1

1.2 Significance of the study 3

1.3 Problem statement 3

1.4 Research question 3

1.5 Aim of the study 4

1.6 Objectives of the study 4

Chapter Two - Review of the literature 5

2.1 Cerebral Palsy 5

2.1.1 Definition 5

2.1.2 Classification of Cerebral Palsy 6

2.1.3 Prognosis/ natural history 8

2.2 Human Immunodeficiency Virus (HIV) 10

2.2.1 HIV Encephalopathy (HIVE) 10
2.3 International Classification of Functioning, Disability and Health (ICF) 11
2.4 The management of CP 12
2.4.1 Physiotherapy 13
2.4.2 Orthopaedic management 17
2.5 The management of HIV encephalopathy 22
2.5.1 HAART 22
2.5.2 Physiotherapy 22
2.6 Outcome measures 23
2.6.1 Gait analysis 23
2.6.2 The Gross Motor Function Measure (GMFM) 25
2.6.3 The Functional Mobility Scale (FMS) 27
2.7 Conclusion 28
Chapter Three - Methodology 30
3.1 Study design 30
3.2 Location 30
3.3 Description of subjects 30
3.3.1 Inclusion criteria 31
3.3.2 Exclusion criteria 31
3.4 Assessment Tools 31
3.4.1 EVGS 31
3.4.2 GMFM 32
3.4.3 FMS 32

3.5 Procedure 32
3.5.1 Recruitment 32
3.5.2 Pre-operative management 33
3.5.3 Surgical management 33
3.5.4 Post-operative management 33
3.5.5 Measurement 34
3.6 Ethical considerations 35
3.6.1 Permission to conduct research 35
3.6.2 Ethical clearance 35
3.7 Statistical Considerations 35
3.7.1 Data Analysis 36
Chapter Four - Results 37
4.1 Demographics 37
4.2 Surgical procedures 39
4.3 Gait analysis 40
4.4 Functional outcome measures 42
4.4.1 GMFM-66 42
4.4.2 FMS 43
4.5 HIVE and CP 44
4.6 Place of therapeutic intervention 46
4.7 Conclusion 47
Chapter Five - Discussion 48
5.1 Gait 48

5.2 Functional outcomes 50
5.2.1 GMFM-66 50
5.2.2 FMS 51
5.3 HIVE and CP 52
5.4 Place of Therapy 54
5.5 Limitations of the study 56
5.5.1 Small sample size 56
5.5.2 Short follow-up period 57
5.5.3 Study design 57
5.5.4 Omission of assessment of quality of life indicator in the outcome measures 58
5.6 Strengths of the study 58
5.7 Suggestions for further research 59
Chapter Six – Conclusion 60
Chapter Seven - References 61
Appendix I: Gross Motor Function Curves 68
Appendix II: Summary of the systematic reviews on the physiotherapy management of children with CP. 69
Appendix III- The Edinburgh Visual Gait Score 71
Appendix IV- The Gross Motor Function Measure 71
Appendix V- The Functional Mobility Scale 76
Appendix IV- Parent information sheet and consent form 77
Appendix VII- Patient information sheet and assent form 79
Appendix VIII- Patient information sheet 81

Appendix IX- Home exercise programme sheet 83

Appendix X- Chris Hani Baragwanath Academic Hospital Physiotherapy treatment protocol for SEMLS. 85

Appendix XI- Ethical clearance certificate 88

Appendix XII- FMS scores for the pilot randomised control trial by Thompson et al (2011) . 89

LIST OF TABLES:

Table 4.1 Age, gender, GMFCS level, HIV status and place of therapy for all particpants... 38

Table 4.2 A summary of the surgical procedures performed per patient..... 39

Table 4.3.1 A comparison of pre-operative and post operative EVGS scores 40

Table 4.3.2 A summary of the average change in the EVGS scores 41

Table 4.4 A comparison of pre-operative and post-operative GMFM-66 scores 42

Table 4.5.1 A comparison of age, gender and GMFCS level for the CP group and the HIV encephalopathy group..... 44

Table 4.5 2 A comparison of pre-operative and post operative scores between the CP and HIV encephalopathy group..... 45

Table 4.6.1 A comparison of age, gender and GMFCS level for the children attending therapy at a school and those attending therapy at a health care facility……...46

Table 4.6.2 A comparison of pre-operative and post operative scores between the children attending therapy at the schools and those attending therapy at the health care facilities ... 46

LIST OF FIGURES:

Figure 4.4.1 Changes in FMS scores for the 5m, 50m, and 500m distances at the six month and one year follow-up. 43

LIST OF ABBREVIATIONS

AFO's - Ankle Foot Orthosis

CHBAH - Chris Hani Baragwanath Academic Hospital

CHQ - Child Health Questionnaire

CNS - Central Nervous System

CP - Cerebral Palsy

EVGS - Edinburgh Visual gait Score

FMS - Functional Mobility Scale

GGI - Gillette Gait Index

GMFCS - Gross Motor Function Classification System

GMFM - Gross Motor Function Measure

GPS - Gait Profile Score

HAART - Highly Active Antiretroviral Therapy

HEP - Home exercise programme

HIV - Human Immunodeficiency Virus

HIVE - HIV Encephalopathy

ICF - International Classification of Functioning Disability and Health

MCID - Minimum Clinically Important Difference

MINORS - Methodological Index for Non Randomised Studies

NDT - Neurodevelopmental Therapy

PODCI - Paediatric Outcomes Data Collection Instrument

OGS - Observational Gait Scale

ROM - Range of Motion

RCT - Randomised Controlled Trial

SEMLS - Single-Event Multilevel Surgery

VDRO - Varus Derotation Osteotomy

VGAS - Visual Gait Assessment Scale

WHO - World Health Organisation

Chapter One - Introduction

1.1 Background

Cerebral Palsy (CP) affects two to four children per 1000 live births and is the most commonly treated neurological disorder in children (Yeargin-Allsopp, 2011). Despite CP being defined as a single insult to the developing brain it is a lifelong diagnosis, resulting in a child with CP accessing health care indefinitely (Narayanan, 2012). Over the years, the progressive development in the understanding of the brain has seen the concurrent expansion in the treatment strategies for children with CP.

Currently, the treatment options available are vast and include the involvement of a variety of different health care professionals, namely neurologists, neurosurgeons, orthopaedic surgeons, speech therapists, occupational therapists and physiotherapists. When determining the appropriate treatment option, the treating clinicians need to bear in mind that each child with CP presents uniquely, and the management plan for each child should be determined according to their individual needs. A multidisciplinary approach with the whole team present at the time of decision making is extremely useful (Lukban, et al., 2009). The treatment offered by the health care professionals is diverse, with the more commonly accepted treatment options including prescription of medication, such as baclofen, anti-epileptics and Botulinum Toxin, surgical procedures such as selective dorsal rhizotomy, muscle lengthening and corrective bony surgery for lever arm disease (Novak, et al., 2013).

In recent times, the orthopaedic management of children with CP has seen a shift towards Single Event Multilevel Surgery (SEMLS) in preference to numerous single procedures being done over time. SEMLS is the term given to the surgical management of children with CP when two or more orthopaedic procedures are being performed to the musculoskeletal system, at more than one level, at one time (Harvey, et al., 2012; Narayanan, 2012; Bischof, 2010). The benefits of SEMLS include one hospital admission, one rehabilitation period and the prevention of further secondary deformities from occurring as a result from only addressing one deformity at a time (Bischof, 2010).

Bearing in mind that the natural progression for the walking child with CP is a regression in gross motor function (Hannah, et al., 2008; Beckung, et al., 2007), the aim of SEMLS in children with CP is to improve gait efficiency and appearance, gross motor function, independence and quality of life (Thomason, et al., 2011) and to maintain their ability to walk into adulthood. Current literature reveals that the gait and functional ability in children with CP does improve at a one and five year follow-up after SEMLS (Thomason, et al., 2011;

Rodda, et al., 2006) even though there is an initial regression in GMFCS level at three months post-surgery (Harvey, et al., 2007)

Despite these findings there has been some debate with regard to an adequate follow-up period to accurately determine the true outcomes of SEMLS, with some clinicians reporting that follow-up should be at least five years post-surgery (Bischof, 2010).Thompson et al (2013) found that results are maintained at the five year follow-up period. Further debate pertains to whether the current literature regarding the outcome of SEMLS is sufficient due to the lack of well-designed randomised control trials, providing a high level of evidence (Narayanan, 2012). In spite of these concerns, SEMLS has been shown to have favourable outcomes when looking at gait, function and quality of life and it is widely accepted as a suitable treatment strategy for children with CP.

With the majority of the research being conducted in developed countries there is little evidence to support the value of SEMLS in children with CP in developing countries. The discrepancy in the resources available in developing countries in comparison to developed countries leads to the need to investigate the effect that these resources have on the outcomes of the surgery. The lack of resources occurs in both the health care facilities as well as in the home setting. The former comprises of a lack of financial resources, clinician skills and capacity. The latter also includes financial resources as well as limited access to daily essentials, health care facilities and transport. The lack of resources can lead to the late diagnosis and treatment of children with CP resulting in an altered clinical picture with increased contractures and secondary complications (Khan, 2007). In light of this, one must question whether SEMLS will have the same outcomes in a developing country as in developed countries.

The high prevalence of HIV in sub-Saharan Africa (Donald, et al., 2015; Lowenthal, et al., 2014; Baillieu & Potterton, 2008) and the subsequent development and use of Highly Active Antiretroviral Therapy (HAART) has resulted in a population of children with associated sequelae who have previously not been treated and managed. HIVE is the most commonly seen neurological complication in HIV (Govender, et al., 2001), and these children present with bilateral hyperreflexia (Hilburn, et al., 2010). Thus with the children with HIVE presenting very similarily to children with CP, it is possible that, if the children who are HIV positive are compliant on HAART, that they can be managed successfully in the same manner as children with CP?

With no research on the treatment of these children, it needs to be questioned whether they can be treated with the same principles as children with CP who present similarly. Do

children who are HIV positive presenting with spastic diplegia as a result of HIVE, have the same outcomes after SEMLS and physiotherapy as those presenting with spastic diplegic CP?

Children in a developing country who had received little previous therapy showed an improvement in functional gait with SEMLS and intensive rehabilitation in the study conducted by Khan (2007). However when looking at many developing countries, the availability of a rehabilitation centre for intensive, long-term post operative rehabilitation after SEMLS is very limited. Further research needs to be done to determine the outcomes of SEMLS in a developing country where there is limited access to rehabilitation and therapy.

1.2 Significance of the study

Previously, very few surgical procedures were conducted on children with CP within the public health care setting in South Africa. With a consistent need for these services within our setting, it is essential to determine whether the gold standard of treatment in developed countries, stands strong in developing countries where resources available and therapy offered is limited. With the therapy offered in this setting differing slightly between that offered at schools compared to that offered in a health care facility, determining whether the place of therapy affects the outcomes of SEMLS is also essential. Lastly, many of the children receiving orthopaedic management in the public health care setting in South Africa have spastic diplegia as a result of HIVE. It is imperative to determine whether children with spastic diplegia due to HIVE who are receiving HAART can benefit from the same management as children with spastic diplegic CP.

1.3 Problem statement

The problem presented is two-fold, it is not known whether the outcomes of SEMLS in a public health care facility with limited resources and rehabilitation are the same as those seen in developed countries nor whether the outcome of SEMLS for children with static HIVE on HAART is similar to that of children with spastic diplegic CP.

1.4 Research question

What are the outcomes of SEMLS in children with spastic diplegia with Gross Motor Function Classification System (GMFCS) level two or three, who access health care at Chis Hani Baragwanath Academic Hospital (CHBAH), six months and one year post surgery?

1.5 Aim of the study

To determine the outcomes of SEMLS in children with spastic diplegia, either with CP or HIV encephalopathy, with GMFCS level two or three, who receive combined orthopaedic and physiotherapy management at CHBAH, six months and one year post surgery using the Edinburgh Visual Gait Score (EVGS), Gross Motor Function Measure (GMFM) and Functional Mobility Scale (FMS) to detect change over time.

1.6 Objectives of the study

- To determine the gait pattern and functional level of children with spastic diplegia GMFCS level II or III referred to CHBAH pre SEMLS using the EVGS, the FMS, and the GMFM-66.
- To determine the gait pattern and functional level of children with spastic diplegia GMFCS level II or III referred to CHBAH six months and one year post-SEMLS using the above mentioned tools.
- To compare the gait pattern and functional level of children with spastic diplegia GMFCS level II or III pre and post SEMLS.
- To describe the outcomes of SEMLS in both children with HIV encephalopathy and those with spastic diplegic CP.
- To discuss the outcomes of SEMLS in children receiving therapy at schools and at health care facilities.

Chapter Two - Review of the literature

CP has been described in the literature for over a century. The ever-evolving medical understanding and continuing research has brought with it a constant change in the management of children with CP. This literature review aims to describe the current recognised best practice with regards to the management of these children. It will also discuss the management of children with spastic diplegia as a result of HIVE in order to determine whether it is beneficial to manage the two conditions similarly.

The literature was obtained through a comprehensive search using the Pubmed search engine via the Wits website, as well as google scholar. Key words used in the searches were: cerebral palsy, orthopaedic surgery, single-event multilevel surgery, physiotherapy, therapy, HIV, HAART and spastic diplegia. Literature that was published over the last ten years was reviewed, and only English literature was searched. Reference lists from sourced articles were used to find other relevant literature.

2.1 Cerebral Palsy

2.1.1 Definition

Cerebral palsy (CP) is defined as a “group of disorders of the 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, and/or behaviour, and/or by a seizure disorder” (Rosenbaum, et al., 2005) .

CP was originally described by Little in 1861 and was seen as a purely motor disorder for many years (Dzienkowski, et al., 1996). In association with the advances in the understanding of the development of the brain as well as the in the physiology and pathology of CP, came the realization that CP was not only a motor disorder, but the effects of the associated impairments, for example in cognition and behaviour, are an integral part of the condition (Rosenbaum, et al., 2005)

As per the current definition, cerebral palsy results from a non-progressive insult to the developing brain. Although there is often not a clear understanding of the exact mechanism and pathway that resulted in the injury (Rosenbaum, et al., 2005), due to the continuing advancements made in the field of neurobiology our understanding is increasing. Looking specifically at the timing of the insult, this can occur whilst the foetus is still in the womb, during the birth process or after the baby is born, while the brain is still developing. Maternal

substance abuse, trauma during pregnancy, haemorrhages in the premature brain, birth asphyxia and infections just to name a few are examples of insults which can result in CP (Hayes, 2012; Dzienkowski, et al., 1996).

2.1.2 Classification of Cerebral Palsy

Children who present with CP differ immensely from one another, and they all have unique needs. The size of the lesion, the area of the lesion and the timing of the insult dictate the severity and type of movement disorder (Mayston, 2001; Dzienkowski, et al., 1996). This has resulted in the vast variety in presentation of children with CP, which has made it essential to classify CP into different categories. Professor Graham, in his commentary "Classifying Cerebral Palsy" looks at the classification of CP in three dimensions, the type of movement disorder, the topography or distribution, as well as the severity (Graham, 2005) which has been discussed similarly by others in the literature (Narayanan, 2012; Badr & Purdy, 2006).

Type of movement disorder

The purpose of classifying the type of movement disorder is to ensure that other significant aspects of the child's condition, which can include sensory aspects amongst others, are not overlooked when planning the management of the child (Hayes, 2012). There are five main categories that are mentioned in the literature which are spastic, dyskinetic, athetosis, hypotonia and mixed. Although these are the most commonly mentioned categories, there is some variety with regards to the categories within the literature.

Children with spastic CP present with muscle over-activity, spasticity, increased tendon reflexes, spasms, weakness and loss of dexterity (Narayanan, 2012; Hayes, 2012; Sheean, 2002; Dzienkowski, et al., 1996). Dyskinetic CP will result in fluctuation in tone, involuntary movements, poor muscle control and as a result poor movement patterns (Hayes, 2012; Dzienkowski, et al., 1996) Hypotonic CP occurs when there is a consistent underlying low tone with decreased muscle activity. This type of CP is rarely seen and the link to the damage to the specific area of the brain is not widely reported on (Hayes, 2012). Another type of CP that is not commonly seen is ataxic CP and the features include poor balance, motor planning and co-ordination (Hayes, 2012; Dzienkowski, et al., 1996). Often children with CP do not fit perfectly into one category or another, but when classifying these children they must be classified according to their predominant feature (Rosenbaum, et al., 2005).

Anatomical distribution

When referring to the distribution of CP, one refers to the anatomical distribution (Hayes, 2012). The anatomical distribution should correlate with the MRI findings. Generally children with dyskinetic, hypotonic and ataxic CP present with whole body involvement, therefore anatomical distribution is commonly referred to with children with spastic CP. However this is not always the case, and when specific distribution occurs it should be stipulated. When referring to the distribution of tone, there are again variances within the literature (Graham, 2005). Most commonly cited distributions are hemiplegia, diplegia or quadriplegia. With hemiplegia occurring when only one side of the body is affected, diplegia refers to the occurrence of the legs being more affected than the arms, and quadriplegia referring to the whole body involvement, with the arms often more affected than the legs (Hayes, 2012).

Gross Motor Function Classification System (GMFCS)

There is no gold standard or common outcome measure used when classifying children with CP according to the type of movement disorder and topography. This can be problematic, as it can result in poor communication and understanding amongst health care professionals and can therefore compromise patient care (Hayes, 2012; Palisano, et al., 2008; Graham, 2005; Morris & Bartlett, 2004). However, the development of the GMFCS in 1997 facilitated an alternative way to classify children with CP. It is a simple, universal, easy to use tool, which has provided health care professionals with a validated outcome measure to assess function as well as a tool which provides insight into prognosis and therapy goals (Morris, 2008; McDowell, 2008; Graham, 2005; Rosenbaum, et al., 2005). The GMFCS is a classification system designed specifically for use with children with CP. It is a five point ordinal scale and children are classified within a certain level according to the acquisition of specific gross motor skills. The GMFCS also has age specific criteria which have been decided upon according to age appropriate motor skills (Palisano, et al., 2008).

The GMFCS has been widely reported on in the literature and it has been found to have good interrater reliability (kappa of 0.75) when tested amongst 51 physiotherapists and occupational therapists with no formal training (Palisano, et al., 2008). The validity has been investigated extensively, through the nominal group method and the Delphi consensus method, as well as through correlation between the GMFCS and the GMFM (Narayanan, 2012; Palisano, et al., 2008; Beckung, et al., 2007; Graham, 2005; Morris & Bartlett, 2004).

Morris & Bartlett (2004) conducted a systematic review of the literature to determine the extent of the use of the GMFCS, as well as to determine what the tool had been utilized for

when conducting research. Review of the literature found that the GMFCS has been used throughout the world, with translations into many languages including German, Swedish and Japanese. The validity of the tool was maintained after the translation was done. They also found that the GMFCS has been used extensively in observational and experimental research internationally.

In 2007, McDowell conducted a study looking at the interrater reliability of the GMFCS between the treating physiotherapist, an experienced research physiotherapist, the care-giver and a computer generated GMFCS. One hundred and forty three patients were included in the study. The results of the study revealed that the treating physiotherapist often scored the patient higher than the care-giver and the research physiotherapist. It was suggested that the treating physiotherapist assessed the capacity, rather than the day to day function whereas the research physiotherapist and the care-giver assessed the child's consistent function. McDowell concluded a moderate to good agreement (kappa=0.63-0.75) using the GMFCS between health care professionals and families of children with CP (McDowell, et al., 2007).

Over the years, as the use of the tool increased, and the tool was used in different populations across the world, there came a need to expand and revise the GMFCS. When developing the Gross Motor Function Classification System, Expanded and Revised (GMFCS-E&R) the developers of the tool included the ICF framework, in order to take into account environmental and social factors that may affect performance. They also added an extra age band for children between the ages of 12-18 years (Morris, 2008). Pallisano et al (2008) used the nominal group technique and the Delphi survey consensus method to determine the content validity of the GMFCS-E&R. Eighteen physiotherapists participated in the nominal group technique, and 30 health care professionals participated in the Delphi survey. All participants were experienced in the field. Through this process the GMFCS-E&R was found to have content validity with an agreement of 80% (Palisano, et al., 2008).With the GMFCS having been researched extensively over the years, and having been found valid, reliable and stable, it has been cited it as the principle classification system for children with CP (Graham, 2005; Morris & Bartlett, 2004).

2.1.3 Prognosis/ natural history

Researchers at the CanChild Centre for Childhood Disability Research have been the forerunners with regards to the understanding of gross motor function and predicted outcomes in children with CP. The centre has been responsible for the development of the GMFM as well as the GMFCS. These tools are both valid and reliable and are seen as the

gold standard within their category (Narayanan, 2012; Debuse & Brace, 2011; Palisano, et al., 2008; Beckung, et al., 2007; Graham, 2005; Morris & Bartlett, 2004). Following the validation and extensive use of these tools, the researchers at the CanChild Centre then sought to determine whether it was possible to predict the expected gross motor outcomes using the GMFCS level of a child, based on GMFM scores for a population of children with CP over time. From this they developed the Gross Motor Function Curves (Appendix I), which graphically indicate the average GMFM scores at a specific age for each GMFCS level. These curves have been further elaborated on to illustrate the percentile in which a child will fall, on scoring a specific GMFM-66 score, according to GMFCS level and age (Hannah, et al., 2008).

Beckung et al (2007) used the GMFM and the GMFCS in order to predict gross motor outcome in children with CP according to the GMFCs level. Their study revealed similar results to that conducted by Hannah et al (2008).The gross motor function of children with a GMFCS level of five was shown to plateau at around three years of age, while children who fell within the GMFCS level one group reached a plateau in gross motor function at around eight years of age. A decline in function can be seen as early as at seven years of age in children falling within GMFCS level five, but only after 12 years of age in children with a GMFCS level of three and up (Hannah, et al., 2008; Beckung, et al., 2007).

When looking at the GMFM scores per GMFCS level, the children within the GMFCS level five group reached a maximum GMFM score of twenty, with the level one group reaching close to ninety (Hannah, et al., 2008; Beckung, et al., 2007). Within each curve for each GMFCS level there is an expected variation of up to a score of 20 points. These variations have been calculated in percentiles for each GMFCS level (Hannah, et al., 2008). From the research it was determined that the Gross Motor Function Curves have been found to be valid and reliable in the prediction of gross motor function according to GMFCS level in children with CP. (Hannah, et al., 2008)

When looking at the plateau and decline in the gross motor function of children with CP over time, one must consider the factors contributing to this. Bell et al (2002) looked at the gait parameters as well as joint range of motion in children with CP who did not undergo surgical intervention, over an average period of 4.4 years. They cited cadence, stride length, popliteal angle as well as specific joint range of motion during gait as aspects that significantly changed over time in children with CP who did not undergo surgical intervention. (Bell, et al., 2002). This deterioration in the gait parameters and joint range of motion could most likely be one of the compounding factors leading to the deterioration in gross motor function in these children (Bell, et al., 2002).

With the above in mind it is important to remember that the natural progression in children with CP is a plateau in function, with an ultimate decline in function. Therefore an intervention that produces either an increase in function or maintains the plateau in function would be considered beneficial for a child with CP.

2.2 Human Immunodeficiency Virus (HIV)

The current estimated number of children infected with Human Immunodeficiency Virus (HIV) is 3.4 million, with more than 90% of them residing in sub-Saharan Africa (Donald, et al., 2015; Lowenthal, et al., 2014; Baillieu & Potterton, 2008). Vertical transmission occurs in 95% of children with HIV in sub-Saharan Africa (Hilburn, et al., 2010). The early infection results in an increased susceptibility of the brain to the HIV virus, as the brain tissue is still developing and maturing (Hilburn, et al., 2010). Children with HIV have been found to have significant motor, cognitive, and language delay (Donald, et al., 2015; Hilburn, et al., 2010) with at least 50% of children with HIV presenting with associated neurological impairments such as visual impairment, auditory impairment, seizures, peripheral neuropathy and behavioural disturbances amongst others (Donald, et al., 2015; Govender, et al., 2001; Mitchell, 2001).

2.2.1 HIV Encephalopathy (HIVE)

HIVE is the most common CNS related complication in children infected with HIV (Govender, et al., 2001). High viral loads and infection at a young age increases the risk of HIVE (Mitchell, 2001) which is defined as disease, damage or malfunction of the brain as a direct result of the HIV virus and it can be static or progressive (Donald, et al., 2015; Mitchell, 2006; Mitchell, 2001). HIVE can be clinically diagnosed if any two of the following are present; child must be HIV positive, the child may have a lack of growth in his or her head circumference, the child may show a regression or cessation in the acquisition of developmental milestones, and the child may present with diffuse symmetrical hyperreflexia (Hilburn, et al., 2010).

HIVE has been divided into three sub categories, acute progressive, plateau and static. Acute progressive encephalopathy is associated with acquired microcephaly, a regression in milestones and deterioration in motor and cognitive functioning. The plateau category presents similarly to the progressive type, however deterioration is far more subtle. The static sub-category consists of non-progressive neurodevelopmental deficits. The ability to learn and achieve developmental milestones is present, although slower than normal (Mitchell, 2006).

One of the most commonly seen clinical manifestations of HIVE is spastic diplegia. There is very little evidence reporting gait in children with spastic diplegia as a result of HIVE. Many people have suggested that these children present similarly to children with spastic diplegic CP (Langerak, et al., 2014). The study by Langerak et al (2014) gives the first indication of gait parameters in children who have HIVE and present with spastic diplegia. They found that children with spastic diplegia due to HIVE can be divided into two categories as per finding on gait analysis. The first group were minimally involved, with their gait parameters close to those of a normal gait pattern. They had a mild increase in tone, mainly in the plantar flexors. This group had no limitations in joint Range Of Motion (ROM) and had no rotational abnormalities. The second group showed a more abnormal gait pattern, with a stiff knee and equinus at the ankle. They had increased tone in the lower limbs, which increased from proximal to distal. Some of these children in the second group had decreased ROM in the knees and ankles. The findings as per gait analysis differ from the gait abnormalities commonly seen in children with CP. The authors suggest that intervention be decided upon according to clinical findings and that further research in this area is needed to fully understand the therapeutic needs of children with spastic diplegia associated with HIVE.

2.3 International Classification of Functioning, Disability and Health (ICF)

For just over a decade, there has been a shift in focus amongst health care providers. Historically the health care provider focussed more on the systemic effects of the health condition, which was the focus of treatment. More recently the focus has shifted to the effect that the health condition has on the patients' ability to function, with the main aim being to improve quality of life, the ability to complete everyday activities and to participate within the community (Novak, et al., 2013). This shift in focus has been accompanied by the development of the ICF, which was developed by the World Health Organization (WHO). It is a conceptual framework designed to be used in the management of all persons with illness and disability (Shula & Rihtman, 2008).

The adoption of the framework was aimed at providing an internationally recognised framework, giving health care providers an internationally accepted "language" with which they could communicate patients' needs, treatment modalities used as well as treatment goals (Franki, et al., 2012). The framework breaks down the patients' condition into the different components that all affect the outcome of the patients' condition.

Franki et al (2012) gives the breakdown and definition for these components, which are body structures and functions, activity, participation, environmental factors and personal factors. All anatomical structures and physiological functions are incorporated into the body

structures and functions category. Activity is defined as the performance of a task, with participation being defined as the involvement in life situations and can be looked at as one's highest level of function (Franki, et al., 2012; Shula & Rihtman, 2008). The effect of the environmental factors, such as access to health care and resources at home, as well as family structure and support, has a crucial effect on participation. Personal factors include age, gender and underlying health conditions to name a few (Franki, et al., 2012). The inclusion of the final two components of the ICF is essential for a complete understanding of the effects that a disease or disability has on the patients' outcome and ultimately their involvement in life situations. The patients' understanding of the condition as well as motivation could alone be the difference between one patient being able to participate in a specific life situation in comparison to another patient with the same disease or disability and impairment components (Shula & Rihtman, 2008).

With a greater understanding of the ICF the ultimate aim of an intervention has been altered. Although most intervention strategies are aimed at making a change or correction at the body structure level, the outcome must show an improvement in participation or quality of life for the intervention to be deemed beneficial to the patient.

2.4 The management of CP

With the diversity of features in children with CP, comes the need for a wide-range of interventions used for the treatment and management of these children. This diversity necessitates the careful consideration of the entire management team in order to determine the intervention strategies appropriate to the individual's needs and impairments (Friedman & Goldman, 2011). This leads to the importance of a holistic, thorough initial assessment, as well as on-going assessments to determine current, future and changing needs.

According to the literature, the management of children with CP addresses two aspects, either the brain, where the motor disorder stems from, or the musculoskeletal components that occur secondary to the brain lesion (Lukban, et al., 2009). Therapy, which includes physiotherapy, occupational therapy and speech therapy, ultimately addresses the root cause of CP trying to lay down new motor paths by experience. Surgical management aims to change the musculoskeletal components of CP (Thomason, et al., 2011).

With the ever increasing understanding of CP, has come a continuing, evolving practice with regards to the therapeutic practices and management of these children. Although vast research has been done, there is still a great need for further research to determine best clinical practice with regards to the treatment and management of children with CP in

different contexts. There is still a larger gap between the treatments that have an evidence base to support their use in the treatment and management of children with CP and the treatment approaches used in clinical practice (Novak, et al., 2013).

2.4.1 Physiotherapy

Physiotherapy, occupational therapy and speech therapy have been well established as appropriate and necessary interventions for the management of children with CP. The aim of physiotherapy intervention is to treat the musculoskeletal pathology in order to obtain improved movement patterns and muscle activation. The ultimate aim is to assist the children to achieve their highest level of function with the primary focus being gait and lower limb function. In conjunction with this the physiotherapists aim to minimise contractures and secondary complications and maintain function into adulthood (Martin, et al., 2010). Despite physiotherapy being seen as an essential element of the management of children with CP there is very little evidence of high quality to support this.

The lack of clinical evidence may be due to a number of factors such as; a difficulty in measuring the outcomes of the therapy, the diverse features in CP resulting in the diverse therapeutic intervention strategies used, the intervention used is not always appropriate according to the clinical picture of the child and the studies conducted are generally of low level of evidence (Martin, et al., 2010; Anttila, 2008). This calls for caution and understanding when reviewing the literature with regard to the outcomes of the therapeutic management of children with CP as well as careful discernment when choosing a specific therapeutic intervention.

The large number of physiotherapy interventions used in the treatment and management of children with CP brings with it difficulty when determining which techniques are appropriate. Four recent systematic reviews on the effectiveness of physiotherapy treatment for children with CP were reviewed in order to determine the most common practice with regards to physiotherapy intervention. The reviews covered a large range of treatment modalities from Neurodevelopmental Therapy (NDT), strengthening, stretching, aerobic exercises to constraint induced therapy and therapy with animals. For the purpose of this review the most common therapeutic modalities have been discussed below. A full summary of the reviews can be found in appendix II.

Neurodevelopmental Therapy (NDT)

The Bobath concept was pioneered by Dr and Mrs Bobath over sixty years ago and was originally established for the treatment of stroke patients. Over time the concept evolved,

and the principles were revised for the use in the treatment and management of children with CP. This subsection of the Bobath Concept was named Neurodevelopmental Therapy (NDT). As defined by Mrs Bobath, one of the founders of the Bobath and NDT concept, in 1981, the Bobath concept is "…. A whole new way of thinking, observing, interpreting what the patient is doing, then adjusting what we do in the way of our techniques- to see and feel necessary, possible for them to achieve. We do not teach movements, we make them possible," NDT uses the therapists' understanding of the factors associated with the child's functional limitations, in order to choose the correct treatment techniques to achieve that function. NDT was not designed to be used in isolation, but to be used in conjunction with other therapy and medical adjuncts such as Botulinum toxin (Mayston, 2008). Research performed since the NDT concept was established has led to the greater understanding of the neurology and pathophysiology of CP, which in turn has resulted in the development of the concept over the years (Mayston, 2008).

Although NDT is widely recognised, the use of NDT has become increasingly controversial. This controversy has been due to articles such as the systematic review by Novak et al (2013) stating that NDT is not effective in the treatment of children with CP and that it should be no longer used in the treatment and management of these children. The outcomes looked at within the review was improvement of movement patterns, contracture prevention and improved gross motor function, with only some evidence showing improvement in gross motor function (Novak, et al., 2013).

Anttila et al (2008) found that NDT in conjunction with other therapeutic techniques such as infant stimulation had better outcomes than just the use of NDT alone. More intensive NDT therapy also showed better results than a less intensive programme. Correspondingly Martin et al (2010) found that more intensive NDT therapy had greater effects than less intensive therapy. Furthermore the studies that they reviewed found a significant change in the GMFM post intervention with intensive NDT. Unfortunately, of the three studies reviewed only one was of a high level of evidence.

A common trend in the research in all three reviews showed very poorly conducted clinical trials on the outcomes of NDT on the treatment on children with CP, with the majority having small sample sizes and low level of evidence (Novak, et al., 2013; Martin, et al., 2010; Anttila, 2008). The current literature does not provide enough evidence to support the use of NDT with regards to the CP population. This highlights the need for well conducted clinical trials, looking specifically at the outcomes of NDT in the management and treatment of children with CP. Future studies would also need to take into account the natural history of

CP, which is, as stated earlier, the plateau and ultimate decline in the functional ability of these children (Beckung, et al., 2007; Hannah, et al., 2008).

Strength training

Strength training in CP is a very broad concept. Included within strength training in CP is functional strength training, home-based strength training, as well as specific types of strength training such as isotonic, isometric, isokinetic and mixed strength training (Franki, et al., 2012). Three out of the four systematic reviews mentioned previously found a high level of evidence for the efficacy of strength training in children with CP (Franki, et al., 2012; Martin, et al., 2010; Anttila, 2008). Novak et al (2013) found that strength training had a relatively low level of evidence to support the use of it in the therapy of children with CP, and it should probably not be used.

The benefits of specific strength training as well as functional strength training were similar. The benefits were seen mainly at the body structure and function level of the ICF and included localised improvement in muscle strength and increased endurance. Further benefits occurred at the activity level with improvements seen in gait parameters and gross motor function. Although differing results were found with regards to the improvement of gross motor function, the majority of the studies showed a significant improvement on the GMFM. There was however no investigation into the effects of strength training at the participation level of the ICF (Franki, et al., 2012; Martin, et al., 2010; Anttila, 2008).

Studies that included a follow-up period after the conclusion of the strengthening program showed deterioration in strength after the completion of the strengthening program (Franki, et al., 2012). Some of the results at the follow-up period varied with the possible suggestion for the variation being the inclusion of the strengthening program into the daily routine at home (Martin, et al., 2010). Home exercise programs were shown to improve the performance of functional activities (Novak, et al., 2013). It can be concluded that strengthening programs do have their place in the treatment and management of children with CP, however the strengthening program needs to be included in the children's' daily routine in order to sustain the effects of the exercise.

Treadmill training

The concept of treadmill training in children with CP is underpinned by the motor learning theory (Chrysagis, et al., 2012; Mutlu, et al., 2009; Willoughby, et al., 2009). The motor learning theory suggests that the acquisition of new motor skills is determined by the laying down of new neuronal pathways during the repetition of that task (Chrysagis, et al., 2012)

(Willoughby, et al., 2009). Treadmill training therefore aims to give the children with CP the opportunity to lay down the neuronal pathways for normal movement patterns during gait.

Studies for treadmill training in CP have been done with and without body weight support. The systematic reviews by Novak et al (2013), Martin et al (2010), Mutlu et al (2009) and Willoughby et al (2009) all show varying results within the literature with regards to the outcomes of treadmill training in children with CP. Very few well designed randomised control trails have been conducted and the sample sizes of the studies were very small. Little reference in the articles was given to the amount of body weight support used, the length of each treadmill training session, the frequency and length of intervention period as well as the varying treatment protocols per each GMFCS level. Few studies included a follow-up period. Outcome measures used assessed gross motor function, using the GMFM, gait parameters namely energy expenditure and speed as well as the effect on spasticity. The outcome measures of the studies focussed mainly on body structure and function as well as activity level, with none of the studies reviewed looking at participation within the community (Mutlu, et al., 2009; Willoughby, et al., 2009).

All reviews stated that there was some evidence to support body weight supported treadmill training, with benefits seen in gross motor function and speed over short distances. However the evidence was too low to make assumptions about the population. Further randomised controlled trials with a large sample size are needed in order to prove whether partial body-weight support treadmill training has positive outcomes on gait, quality of life and function in children with CP (Novak, et al., 2013; Martin, et al., 2010; Mutlu, et al., 2009; Willoughby, et al., 2009).

Aerobic exercise

Aerobic exercise or endurance training has been found to have positive outcomes in children with CP (Novak, et al., 2013; Franki, et al., 2012; Anttila, 2008). These outcomes fall into all categories of the ICF. In terms of body structure and function, improvement has been seen in aerobic and anaerobic activity, muscle strength and agility, oxygen uptake, bone mineral density as well as weight control (Novak, et al., 2013; Franki, et al., 2012; Anttila, 2008). Franki et al (2012) was the only systematic review to comment on the outcomes at the level of activity, participation and quality of life. Their findings were that the GMFM scores improved, indicating an improvement in the activity level on the ICF. They also stated that patients reported improved participation and quality of life. Although outcomes of aerobic exercise have been shown to be favourable, the question remains as to the amount of exercise required and whether the effects will be sustained over a period of time.

Franki et al (2012) found the effects of the endurance training to be sustained at a nine week follow up period. On the other hand Novak et al (2013) in their review, suggest that the aerobic exercise needs to be sustained and a part of everyday life for the effects to be maintained over a prolonged period. It is questionable whether the follow-up period of nine weeks was long enough to determine the long term outcomes. It is likely, as with the normal population, that in order to maintain the outcomes, exercise will need to become a part of the child's daily life. Further research will need to be done in this area to clarify this hypothesis.

2.4.2 Orthopaedic management

The orthopaedic management of children with CP GMFCS level one to three is primarily aimed at improving the abnormal gait pattern with the ultimate aim to maintain the ability to walk into adulthood. As already discussed, the gross motor function of children with CP, GMFCS level one to three, reaches a plateau around the age of seven years, and then shows a gradual deterioration over time (Hannah, et al., 2008; Beckung, et al., 2007). It has also been found that gait parameters deteriorate over time which is often related to pain, weakness, fatigue and balance issues (Harvey, et al., 2012). The abnormal gait parameters stem from the chronic muscle imbalance seen in these children. This chronic muscle imbalance also results in secondary skeletal changes, which further compound the abnormal gait pattern (Luca, 1991). With this in mind the early orthopaedic management is more conservative. Due to the structural changes that occur in these children over time, surgical management is indicated in the older child with CP (Bell, et al., 2002). These structural changes that occur can be both muscular and bony changes. Muscular changes that occur are known as fixed contractures, which occur due to the hypertonicity and decreased active use of the muscles. Bony changes occur as a result of the abnormal pull of the muscles as well as the delay in the attainment of motor milestones, which contributes to the moulding the bones. This abnormal bony development results in lever arm disease (Narayanan, 2012).

Previously, one surgical procedure was done at a time, which often resulted in unpredictable outcomes, recurrence of the deformity, as well as a need for annual surgeries, casting and physiotherapy. It was also found that the correction of one deformity needed to be accompanied by the correction of an associated deformity; otherwise the corrected deformity would re-occur (Luca, 1991). As a result SEMLS is the current preferred orthopaedic management of ambulant children with CP (Thomason, et al., 2013; Harvey, et al., 2012; Rutz, et al., 2012; Godwin, et al., 2009).

According to Thomason et al (2013) the principle behind the SEMLS is to achieve sagittal and axial plane balance, which will result in improved gait pattern and functioning. SEMLS refers to the surgical management of a child with CP when more than one orthopaedic procedure, either a muscular or bony procedure, is performed at more than one joint at one time (Godwin, et al., 2009). The advantage of this is one hospital admission, one rehabilitation period and the prevention of secondary deformities that can occur if only one abnormality is addressed at a time (Narayanan, 2012; Bischof, 2010).

SEMLS has been widely reported on over the last 25 years, with the advantages including increased joint range, improved gait pattern, decreased knee pain and discomfort, decreased energy expenditure during gait and the prevention of structural deformities from occurring (Thomason, et al., 2013; Godwin, et al., 2009; Gorton III, et al., 2009). Most recent studies have also shown improvement in function and independence post SEMLS which results in an improvement in quality of life (Thomason, et al., 2013; Harvey, et al., 2012; Thomason, et al., 2011; Godwin, et al., 2009). However on review of the literature, three systematic reviews were compiled stating concerns with regards to the current body of literature having insufficient high level evidence to support its use.

McGinley et al (2012) conducted a systematic review of the literature that has been published on the outcomes of SEMLS from 1985 till 2010. The aim of the review was to determine the quality of the studies conducted on the outcomes of SEMLS. The literature search was conducted using four electronic databases, and after overview of 408 abstracts, 58 articles met with the inclusion criteria which were then assessed for the review. The quality of the studies was assessed using the Methodological Index for Non-Randomised Studies (MINORS). Although there was an overall improvement in the quality of the studies that were conducted over the years, there were still some recently published studies that scored very poorly and were of very low quality.

Some of the main concerns that the authors had with regards to the current literature was the small sample size, the lack of any details regarding rehabilitation, inadequate recording of the type of procedures as well as any complications. The authors also determined that in order to assess the outcomes of SEMLS, one should consider more than one aspect with regard to the ICF. Therefore the outcomes measures used should look at gait, function as well as quality of life. The advantages of this article were that the authors reviewed a large number of articles, and strict inclusion criteria were used. Furthermore, there were two authors, and reviews were done separately and then discussed. The review was then compiled with consultation of a more experienced professional in the field, which helped to decrease bias. The final conclusion was that further research in the field should be

conducted as a Randomised Control Trial (RCT), as this is a higher level of evidence and it will add value to the current body of knowledge. They also determined that prospective studies were more beneficial than retrospective studies as it decreased the amount of bias (McGinnley, et al., 2012).

Bischoff (2010) compiled a systematic review that focussed on the outcomes of the research as well as the quality of the research conducted. She concluded that the follow-up of current studies was too short and that the type of surgical procedures differed. Furthermore she noted that there was no comparison between single level and multilevel surgeries and that no randomised control trials had been conducted. Taking these factors into consideration she concluded that the current level of evidence for SEMLS in children with CP was low. Bischoff also concluded that long term follow-up was essential and that there was not sufficient literature to validate SEMLS over single level surgeries (Bischof, 2010).

Narayanan (2012) stated, after his review of the literature, that the comparative studies that have been conducted have had a small sample size and short term follow up. Furthermore, there is no evidence to prove whether the improved function was due to the SEMLS or due to the intensive physiotherapy that the child received post surgery. The outcome measures used, that showed significant change looked at perceived outcome, and little change was noted in functional outcome measures such as the GMFM (Narayanan, 2012).

It is apparent from the above reviews that further research in this area is required. There is enough evidence to validate the specific procedures used in the correction of specific deformities, however some clinicians' main concern is that there is not enough literature which comprises of studies of a good quality, high level of evidence and long term follow up to support that SEMLS is effective in improving gait and function in children with ambulant CP (McGinnley, et al., 2012; Narayanan, 2012; Thomason, et al., 2012). This is not only due to the fact that very few randomised control studies have been conducted, but there have also been very few comparative studies conducted (Narayanan, 2012; Bischof, 2010). There was also a call for more prospective, well-designed studies to be conducted in favour of retrospective studies. Other questions that remain include what are the outcomes of SEMLS after a long follow up period, as well as what an adequate follow up period would be. The outcome measures used need to look at the actual function, not perceived function, at all levels of the ICF (McGinnley, et al., 2012; Narayanan, 2012; Bischof, 2010).

Subsequent to the publication of the above mentioned reviews a pilot randomised control trial was conducted. Thomason et al carried out a pilot randomised control trail in 2011. The control trial was a single-centre pilot study to determine the sample size needed for a multi-

centre study. Nineteen children were enrolled into the pilot study, 11 children were in the experimental group and eight in the control group. The follow up period was only 12 months, with the control group receiving surgery after the 12 month period. The Gait Profile Score (GPS) and the Gillette Gait Index (GGI) were used as objective outcome measures to analyse the effects of SEMLS on gait. The Functional Mobility Scale (FMS), GMFM-66 and time spent in upright were used to assess the functional outcome. The Child Health Questionnaire (CHQ) was used to assess the quality of life of the patient.

The findings were that there was significant improvement in gait after the 12 month follow-up period in the surgery group, as compared to the control group. There were no significant changes in the control group after the 12 month period, despite physiotherapy consisting of a resistance strength programme of 12 weeks. There was also no significant improvement in functional ability or quality of life in the surgery and the control group at the 12 month follow-up period (Thomason, et al., 2011).

Although the sample size was small, this study was able to answer some of the above mentioned questions. This randomised control trial revealed that there is a significant improvement in gait in children with CP at a one year follow-up post SEMLS and physiotherapy. A further revelation was that there was no significant difference in gait in children who only received physiotherapy. This led the researchers to question whether it is ethical to retain a child in a randomised control trial for the period of more than a year, when the known progression of CP is deterioration in gait and functioning. Due to the outcomes of the study, all patients who were in the control group were then operated on, as the researchers felt that failing to operate on these children would lead to poor practice as the benefits of surgery were very evident (Thomason, et al., 2013).

Despite the majority of the research that has been conducted having small sample sizes, there are some studies with large sample sizes which could help to understand the outcomes with regards to the population. Gorton et al (2009) conducted a well-designed cohort study to compare the outcomes of children with CP who received SEMLS to those who continued with regular standard physiotherapy. They had a total of 75 patients who underwent surgery and were matched by age, gender and GMFCS level to participants who did not undergo surgery. Significant improvement was seen in the children who received SEMLS at the one year follow up with regards to gait, as measured by the GGI, and quality of life as measured by the PedsQL in the gait domain. There was no significant change noted in the group of children who received only regular physiotherapy. Although improvements were noted in body structure and functioning, there was no evidence to prove that these would result in improvement at the activity and participation level of the ICF

(Gorton III, et al., 2009). The conclusions reached corroborates with the current literature (Thomason, et al., 2013; Harvey, et al., 2012; Gorton III, et al., 2009). As per the literature, there is improvement in gait and quality of life one year post SEMLS in comparison to children with CP who receive only physiotherapy. However, a one year follow up period is not enough to determine whether SEMLS results in a significant change at the activity and participation level of the ICF.

Thompson et al (2013) conducted a five-year prospective follow-up study on 18 of the patients that participated in their randomised control trial pilot study. The patients were reassessed at one, two and five years post surgery. Improvements were noted at the one year follow-up period with regards to gait parameters, and at the two year follow-up period with regards to motor function and participation. They recorded an improvement of 3,3% on the patients' GMFM-66 scores at the five year follow-up period, in comparison to pre-operatively, as well as an improvement in the FMS over all three distances (Thomason, et al., 2013). When looking at a follow-up period of this length, it is essential to acknowledge the natural history of gait and function of children with CP, which is a plateau and then a decline, as mentioned above (Bell, et al., 2002). It can therefore be concluded that there is improvement in gait, motor function and participation post SEMLS at the two year follow-up period, and that this improvement is maintained at the five year follow-up period.

Despite the lack of current literature that directly compares SEMLS with single level surgeries, there have been numerous well designed prospective studies which have concluded that there is an improvement in gait as well as function after a one to two year follow-up period following SEMLS (Thomason, et al., 2013; Harvey, et al., 2012; McGinnley, et al., 2012; Rutz, et al., 2012; Thomason, et al., 2011; Badr & Purdy, 2006; Godwin, et al., 2009). With this in mind, many experts in the field regard well designed, prospective studies, with a long term follow up sufficient evidence to support that SEMLS has good outcomes in children with ambulant CP (Thomason, et al., 2012).

Although there have been many studies conducted looking at SEMLS in developed countries, very few studies have been done in developing countries. Khan (2007) looked at the outcomes of SEMLS in children with previously untreated CP. Eighty five children were included in the study. All children had spastic diplegic CP and were not mobilising functionally prior to surgery. The children received intensive physiotherapy post-operatively which included a comprehensive home exercise programme. Appropriate orthotics were issued to the children. Mean follow-up assessment was done at 3.5 years post surgery. All children were able to walk post-surgery, with only 21% being therapeutic walkers and the rest being functional walkers, either with or without assistive devices. This study showed that

the outcomes of SEMLS can differ in developing countries in untreated CP in comparison to those seen in developed countries.

2.5 The management of HIV encephalopathy

2.5.1 HAART

Highly active antiretroviral therapy (HAART) has changed the outcomes and lengthened the life expectancy of children living with HIV. According to Lowenthal et al (2014) prior to the advent of HAART, 50% of children with living with HIV died before their second birthday. HAART has dramatically increased the life expectancy of these children, with many of these children now living into adolescence and adulthood (Lowenthal, et al., 2014).

Patel et al (2009) looked at 2398 perinatally HIV-infected children over a period of ten years, and found the occurrence of HIVE decreased with the increased administration of HAART to children with HIV. Furthermore they suggested that HAART decreases the HIV dissemination in the CNS and it slows or stops replication of the active infection in the brain (Patel, et al., 2009). HAART has also been associated with a more static encephalopathy (Langerak, et al., 2014). Early administration of CNS penetrating HAART is now seen as the gold standard of treatment for children with HIV (Hilburn, et al., 2010). In spite of this, HAART is not readily available to children in developing countries, and it is often given only after the initial insult to the brain has occurred (Hilburn, et al., 2010). Although HAART will assist in diminishing the risk for further damage, the initial insult has already occurred, and the children will need to receive appropriate treatment aimed at the management of the consequences of the damage (Hilburn, et al., 2010; Patel, et al., 2009).

2.5.2 Physiotherapy

HAART has changed the clinical picture of children with HIV, with many of them requiring continued rehabilitation and medical support (Lowenthal, et al., 2014; Potterton, et al., 2010). Little research has been done on the recommended therapy required for children with HIVE and other associated neurological complications related to HIV in children (Langerak, et al., 2014). Baillieu & Potterton (2008) found that with 77.5% of children with HIV showed significant motor delay, and suggested that physiotherapist will play a large role in assisting these children to reach their appropriate milestones. This hypothesis has been well supported in the literature, although there is little evidence to support it (Nixon, et al., 2011; Hilburn, et al., 2010; Baillieu & Potterton, 2008; Potterton & Van Aswegen, 2006).

Potterton et al (2010) in their randomised control trial found a significant improvement in the motor and cognitive development in children infected with HIV who received a basic home-based exercise programme in comparison to those who did not receive a home-based exercise programme. This study illustrates the effectiveness of therapeutic intervention in children with HIV, provided that the intervention is appropriate. Nixon et al (2011) proposed that the treatment of children with HIV, and by association HIVE, be aimed at activity and participation of the individual. Consequently it can be suggested that intervention of these children should be aimed at the treatment of the associated symptoms and complications as for children who are not HIV positive in order to improve activity and participation. Additional research in this area is required to determine whether children who are HIV positive can be treated according to their symptoms and whether they will have similar outcomes as their HIV negative counterparts.

2.6 Outcome measures

Using the ICF framework, assessment tools were selected with the aim of assessing the outcomes at the body structure and functioning, as well as at the activity level.

2.6.1 Gait analysis

With the advent of SEMLS for the surgical management of children with CP, came the need to accurately and objectively assess patients prior to surgery in order to ensure the correct management of patients. It has been found that clinical assessment alone does not give an accurate picture of the child's needs. Patients with the same findings on clinical assessment may present differently when assessing their gait, and therefore have different surgical needs (Luca, 1991; Bjørn Lofterød, et al., 2007). Three-dimensional gait analysis is the current gold standard for the pre-operative assessment of children with CP (Bella, et al., 2012; Maathuis, et al., 2005). It is seen as an objective outcome measure used to enhance subjective gait analysis (Bell, et al., 2002). The use of gait analysis assists with determining the appropriate surgical intervention as well as with the amount of correction required with regards to the derotation of the femurs (Wren, et al., 2013).

Bjorn Lofterod et al (2007) compared the surgical plan for a patient as determined by clinical assessment, to the surgical plan as determined by gait analysis. They determined that the surgical plan differed when including three-dimensional gait analysis. They suggested that there is a need for three-dimensional gait analysis in order to accurately determine the appropriate surgical management for children with cerebral palsy.

The downfall with three-dimensional gait analysis is that it is an expensive tool that is not always accessible in developing countries (Gupta & Raja, 2012). Another negative aspect to take into account is the fact that it is very time consuming, which is a concern in the context of developing countries where resources, including time, are limited (Bella, et al., 2012). Observational gait scales have been developed to be used in health care settings where three-dimensional gait analysis is not feasible. As stated by Bella et al (2012) there are some limitations to the use of observational gait tools, namely poor validity, reliability, sensitivity and specificity, however their role in the surgical assessment of children with CP is still important.

The Edinburg Visual Gait Score (EVGS)

There are a number of observational gait assessment tools that have been developed, with the tools having various positive and negative features and varying in validity and reliability. Bella et al (2012) compared three observational gait tools namely; the Edinburg Visual Gait Score (EVGS), the Visual Gait Assessment Scale (VGAS) and the Observational Gait Scale (OGS). Eight children with CP GMFCS level one and two were included in the study. Four videos were taken of each child walking a distance of four meters. The observational gait tools were assessed by three experienced physiotherapists who received appropriate training on the tools. The highest interrater agreement was found for the EGVS, followed by the VGAS. Poor correlation was found between the examiners scores for the OGS. When comparing the results between the three tools there was significant correlation between the EVGS and the VGAS, but non-significant correlation between EVGS and the OGS as well as between the VGAS and the OGS ($p=0.05$). The EVGS had the best results of the three observational tools, showing almost perfect agreement with the kinetic analysis. The examiners determined that the EVGS and the VGAS were able to more accurately describe the gait of children with CP. Furthermore they stated the advantage of the EVGS over the VGAS was that the EVGS looked at all components of gait, including the pelvis and trunk, whereas analysis of these components has not been included in the VGAS (Bella, et al., 2012). Therefore it can be deduced that the EVGS is the most accurate and appropriate observational gait tool when comparing it to the VGAS and the OGS. A copy of the EVGS can be seen in Appendix III.

The EVGS was developed at the Princess Margaret Rose Orthopaedic Hospital in Edinburgh by Read et al and was published in 2003. It consists of a 17 point assessment tool, with each point consisting of a description of an anatomical feature during gait. The tool is scored according to the deviation from normal of the specific anatomical feature during gait, with zero being within normal range, one being a slight deviation and two being a large deviation

from the normal gait pattern. Each point is accompanied by a description of the normal and the deviation so as to assist the scoring process and to standardise the tool (Read, et al., 2003).

In order to validate the EVGS, Read et al looked at intra-rater reliability and interrater reliability as well as to compare the results from the EVGS to the results from three dimensional gait analysis. Video recordings of five patients were assessed by five experienced examiners. There was good intra-rater reliability for all five examiners, with non-significant differences seen between all the scores. A significant difference was calculated as 3.2 points. Complete agreement was found for 70% of the observations when looking at interrater reliability, with all 17 points on the scale having positive Kappa values. When comparing the joint angles of the assessments made with the EVGS to the results from the Vicon analysis, it was found that there was a 64% complete agreement between the two assessments (Read, et al., 2003). Further studies have also found the EVGS to have good interrater and intra-rater reliability, however clinical experience in the management of children with CP as well as in gait analysis results in greater interrater reliability (Viehweger, et al., 2010; Ong, et al., 2008).

Gupta and Raja (2012) looked at the ability of the EVGS to detect change post-surgery. Fifty children who underwent surgery were assessed pre-operatively, at six months and one year post-operatively. There was found to be a significant difference between pre-operative scores and scores at six months and one year after the operation using post hoc analysis (Z = j5.31, P = 0.000; Z = j5.28, P =0.000, respectively). They determined that the meaningful clinically important difference (MCID) at the six month and one year post-operative assessment are 11 and 15 respectively. (Gupta & Raja, 2012).

From the above findings it can be concluded that the EVGS is a valid and reliable tool and it is able to detect change after intervention. It can be used as an observational gait analysis tool in developing countries where three dimensional gait analysis is not available (Gupta & Raja, 2012; Maathuis, et al., 2005; Read, et al., 2003).

2.6.2 The Gross Motor Function Measure (GMFM)

The Gross Motor Function Measure (Appendix IV) is a standardised assessment tool used to assess the gross motor function of children with CP. The development of the GMFM was started in the 1980's, with the first edition published in 1990. Over the years it has been worked on and developed and there are now two editions of the GMFM, the GMFM-88, which was developed first, and the GMFM-66 which was developed from it. The GMFM-88

consists of 88 items, which were originally selected from a review of the literature as well as input from clinicians, and evaluation of the Motor Control Assessment. The 88 items chosen fall within five dimensions, namely; lying and rolling, crawling and kneeling, sitting, standing, walking, running and jumping (Russel, et al., 2002). Each item is scored using a 4-point scale, with the scoring ranging from zero to three, with zero being unable to attempt and three being completed. As discussed by Debuse & Brace (2011) the GMFM looks at the capacity of a child, which is the child's once-off performance in a structured environment, instead of capability, which is the child's performance in a familiar environment which is usually assessed via a parent report questionnaire (Debuse & Brace, 2011). The GMFM has been used extensively in many settings and has been found valid (0.9 for younger than 48 months, 0.6 for children older than 48 months) and reliable (intraclass correlation coefficient 0.99) (Debuse & Brace, 2011). It has also been proven to be able to detect change over time after interventions such as botulinum toxin, dorsal rhizotomy, physiotherapy and orthopaedic surgery (Debuse & Brace, 2011; Beckung, et al., 2007).

With use of the tool therapists identified some limitations with the GMFM-88. The GMFM-88 can take up to one hour to complete, which can be impractical due to the time constraints faced in the clinical setting. The tool has a nominal scale, which means that the there is no set interval between different items on the scale making it difficult to interpret change in the scores. Lastly, if an item is not tested when using the GMFM-88 the child will receive a score of zero, rather than unachieved resulting in a score that does not accurately reflect the child's ability (Russel, et al., 2000).

Taking these limitations into account the developers of the tools set out to develop another tool based on the GMFM-88. Using Rasch anaylsis the developers of the tool managed to obtain interval scores. During this process the GMFM was shortened to a 66 item version, which was now scored using a computer program, and where uncompleted items can be taken into account and no longer scored as zero. With the tool having fewer items, it also meant that the time to complete the measure was less (Russel, et al., 2000).

The GMFM-66 has subsequently been found as a valid (intraclass correlation coefficient =0.99) and reliable tool which is able to detect change after an intervention ($P < .0001$) (Russel, et al., 2000). With the above mentioned properties the GMFM-66 is the ideal tool to be used during clinical research. The GMFM-88 does still have added benefits when used in the clinical setting in certain circumstances. Both the GMFM-88 and the GMFM-66 have been used extensively in research world-wide.

In their systematic review of all outcomes measures used to assess the activity of children with CP, Debuse and Brace (2011) highlight some important aspects that need to be taken into account when using the GMFM for research. The GMFM only looks at the gross motor function of children, which leads it to be less sensitive in older children, as the attainment of gross motor skills in children with CP usually plateaus around the age of seven. Despite this, as mentioned earlier, the GMFM has been proven to detect change in gross motor function in children with CP over the age of seven after interventions that are focussed on the improvement of gross motor function, such as botulinum toxin or orthopaedic surgery (Russel, et al., 2002). The review also highlighted that the GMFM assesses mainly the function of the child and some activities that the child can perform, but no participation limitations are evaluated using the tool (Debuse & Brace, 2011). With the current trend in the focus of health care being that of activity and participation limitation (Shula & Rihtman, 2008), with the utilization of the ICF framework as discussed earlier, it would be preferable to use the GMFM in conjunction with another valid and reliable tool which will assess the domains of activity and participation (Debuse & Brace, 2011).

2.6.3 The Functional Mobility Scale (FMS)

With no tools available to describe the functional mobility of children with CP, Graham et al (2004) sought to develop a tool that accurately described the mobility of children with CP, either with or without assistive devices, over different distances. The Functional Mobility Scale (FMS) (Appendix V) is a simple tool that can be completed either by the treating surgeon, physiotherapist or the parent. The scale rates the walking ability of the children at three different distances, 5m, 50m and 500m. These distances essentially look at the mobility of the children in different environments; at home (5m), at school (50m) and in the community (500m). The completion of these distances is rated from one to six, with one being completion of the distance by the use of a wheelchair or buggy, and six being independent mobility on all surfaces. The tool also takes into account crawling, and if the distance is not applicable (Graham, et al., 2004).

In order to determine validity, the FMS was compared to the Rancho Scale (RS), a Child Health Questionnaire–Australian CHQ PF-50 (CHQ), and a Pediatric Outcomes Data Collection Instrument (PODCI)–version 2. Correlation for each subsection was determined using the Spearman rank correlation and significant correlation was found for each subsection with all the above mentioned tools ($P < 0.05$) (Graham, et al., 2004).

Construct validity of the FMS was found by Harvey et al (2010), where they compared the FMS scores of a care-giver in comparison to those given by the treating physiotherapist.

They found substantial agreement for all three environments, with greatest agreement for the 50m and 500m distances (weighted kappa 0.71, 0.76 and 0.74 for 5m, 50m and 500m respectively) (Harvey, et al., 2010).

The FMS has also been shown to have excellent interrater reliability as seen in the study done by Harvey et al (2010). Good interrater reliability was found over all three distances with the kappa coefficient being 0.87 for 5 m, 0.92 for 50 m, and 0.86 for 500 m.

When looking at the ability of the FMS to detect change following SEMLS, Harvey et al (2007) found a significant deterioration in the FMS at three and six months post-surgery, with a return to baseline at one year post surgery. Further improvement was seen at two years post-surgery (p= 0.05) (Harvey, et al., 2007).

From the above mentioned findings it can be concluded that the FMS is a valid and reliable tool (Harvey, et al., 2010; Harvey, et al., 2007; Graham, et al., 2004). Additionally the FMS has been shown to detect change after SEMLS and thus can be used to assess post-operative change in children with CP.

2.7 Conclusion

SEMLS has been widely researched, with a large amount of literature to support it (Thomason, et al., 2013; Harvey, et al., 2012; Rutz, et al., 2012; Godwin, et al., 2009). The quality of the research has improved immensely in recent times although there are still some limitations in the majority of the current research (McGinnley, et al., 2012). Research shows that there is a significant improvement in gait at the one-year follow-up period with results being maintained up to a five year follow-up (Thomason, et al., 2013). There is an initial deterioration in function at the six month follow-up, with return to the pre-operative function at the one year assessment (Thomason, et al., 2011). Significant changes in function are seen at the two year follow-up period, with results maintained at the five year follow-up (Thomason, et al., 2013). There is little research on the outcomes of SEMLS in developing countries where the resources available differ (Khan, 2007). The clinical picture of children with CP in developing countries is also altered due to late diagnosis and limited therapy (Khan, 2007). Further research is needed in order to determine the outcomes of SEMLS in this setting.

More than 90% of children with HIV live in sub-Saharan Africa (Donald, et al., 2015; Lowenthal, et al., 2014; Baillieu & Potterton, 2008). The advent of HAART has meant that many children with HIV are now living much longer (Lowenthal, et al., 2014). These children are also living with complications associated with HIV, such as HIVE. There is little research

that has been done in terms of the clinical presentation and management of these children (Langerak, et al., 2014). It has been found that the gait in children with CP does differ to the gait in children with HIVE. They found that children with HIVE can be divided into two groups. The first group's gait deviates slightly from normal gait. On gait analysis the second group had stiff knees and increased equinus. This is however the only study to date that has compared the gait of children with HIVE to those with CP (Langerak, et al., 2014). There is still no research on the appropriate management of these children.

The correct physiotherapy management of children with CP has been widely reported on in the literature however most of the studies conducted are of poor quality and low level of evidence (Martin, et al., 2010; Anttila, 2008). Although a highly recognised therapeutic approach NDT had very little good quality evidence to support its use in the treatment and management of children with CP (Novak, et al., 2013; Martin, et al., 2010; Anttila, 2008). Strength training and aerobic exercise have been shown to be effective in the treatment and management of children with CP, although preferred duration and intensity has not been well documented (Novak, et al., 2013; Franki, et al., 2012; Martin, et al., 2010; Anttila, 2008). There is also little research with regards to the appropriate physiotherapy intervention post SEMLS (McGinnley, et al., 2012).

Chapter Three - Methodology

This chapter contains a detailed report of the methodology used to conduct the research.

3.1 Study design

A longitudinal, single group, pre-test post-test design was used.

3.2 Location

This study was conducted at Chris Hani Baragwanath Academic Hospital (CHBAH). CHBAH is located in SOWETO, a township in the south of Johannesburg. SOWETO has a population of over 4 million people. The hospital is an academic hospital and provides a large variety of specialised services to the people of SOWETO. CHBAH also receives many referrals from the surrounding areas for patients requiring specialised care. It is the largest hospital in Southern Africa and has over 1500 beds. The paediatric services offered are vast and range from paediatric neurology, cardiology, respiratory, ICU, neonatal services, surgery as well as orthopaedics. There are two paediatric orthopaedic wards with 30 beds in each ward. All assessments were done in the neurology treatment gym of the physiotherapy department. SEMLS was provided and the research physiotherapist worked at the site. The research question evolved from outcomes of SEMLS seen at this site. CHBAH was therefore chosen as the site for the study.

3.3 Description of subjects

Children presenting with spastic diplegic CP or spastic diplegia as a result of HIVE, GMFCS II or III, who were referred to the orthopaedic clinic at CHBAH for assessment. All of the children who met the criteria for corrective surgery were considered for inclusion into the study. The children were referred by the surrounding clinics and special needs schools as well as primary health care facilities in different districts.

All children eligible for SEMLS at CHBAH who met the inclusion criteria were invited to participate. Participants were recruited during the period from 1 January 2013 until 30 May 2014. Eleven participants were recruited for the study. The small sample size was due to the small number of patients that were eligible for SEMLS. Further detail with regards to this can be seen in chapter five. Due to the high HIV rate in South Africa, many children present with spastic diplegia due to HIVE. With the advent of HAART the majority of these children present with a static encephalopathy. If HIV positive patients who are compliant on HAART

were excluded from the study it would not be a true picture of the patients seen and treated in the public South African health care setting.

3.3.1 Inclusion criteria

Children were included in the study if

1. They presented with spastic diplegic CP or spastic diplegia due to static HIVE.
2. They were GMFCS level II/III.
3. They were able to walk at least ten meters with or without an assistive device.
4. They were between the ages of six and eighteen years.
5. They were able to follow two-part instructions.
6. A care-giver was able to bring the child to weekly follow-ups at their regular place of therapy as required per the treatment protocol.

3.3.2 Exclusion criteria

Children were excluded from the study if:

1. They presented with hemiplegic or quadriplegic CP.
2. Their diagnosis was unconfirmed.
3. They were GMFCS level I, IV or V.
4. They had had orthopaedic surgery, or botulinum toxin within the last six months.
5. They were HIV positive, and had not been receiving HAART for at least one year.
6. They were HIV positive and their CD 4 count was less than 300 or they had high viral loads.

3.4 Assessment Tools

3.4.1 EVGS

Three-dimensional gait analysis is the gold standard for the assessment of gait in order to assist with the management of children with CP (Bella, et al., 2012; Maathuis, et al., 2005). As three-dimensional gait analysis was not available for the purposes of this study, a video gait analysis tool was used. The EVGS has been found to be valid and reliable (Viehweger, et al., 2010; Ong, et al., 2008). The EVGS is a 17 item assessment scale. Each item of the assessment refers to a specific part of the anatomy during gait. The scorer can score each item ranging from zero to two, with zero being within normal range for gait, and two being a large variation from normal. The lower the score, the closer that the child's gait is to the normal range (Read, et al., 2003). The EVGS was used for the purpose of this study as a

video could be taken, and assessed at a later stage. This also meant that the person assessing the video could be blinded to the HIV status of the child. (Appendix III)

3.4.2 GMFM

Gross motor function was assessed using the GMFM. This tool was selected as it is the gold standard for the assessment of gross motor function in children with CP (Debuse & Brace, 2011). The GMFM-66 was used instead of the GMFM-88 as it has been found to be the preferred tool for research purposes. This is due to the fact that it uses an ordinal scale, it takes into account items that weren't tested and it takes a shorter time to administer (Russel, et al., 2002). The GMFM measures performance on the day, not capability. Each child was given three turns to complete an item, as per the instruction manual. Each item can be scored ranging from a zero to a three. Zero was given if the child was unable to initiate the task, one if they were able to initiate the task, two if they were almost able to achieve the task, and three is they were able to achieve the task. The scores were given according to the guidelines given in the users manual. The higher the score indicates that the child has greater gross motor abilities (Russel, et al., 2002) (Appendix IV).

3.4.3 FMS

Like the GMFM, the FMS assessed the outcomes of the children following SEMLS at the activity level of the ICF. In contrast to the GMFM the FMS assessed the child's capability, rather than their once-off performance (Graham, et al., 2004). The FMS has been shown to have good construct validity (Harvey, et al., 2010) and children were scored according to parent report. The FMS assesses the ability of the child to complete three different distances, 5m, 50m and 500m. Each distance was scored according to the assistance needed to complete the distance, see appendix V. The greater the score, the less assistance required for mobility.

3.5 Procedure

3.5.1 Recruitment

Data collection occurred from January 2013 until June 2014. All the nearby schools for children with CP were contacted with regards to appropriate children for the study. The CP clinic was also screened by the physiotherapist for appropriate candidates. Candidates for the study were assessed by the orthopaedic surgeon at the Paediatric Orthopaedic Out-patients Clinic at CHBAH. The child's diagnosis was taken as per the diagnosis in the child's out-patient file. Suitable candidates for surgery were then referred to the physiotherapist at

CHBAH for screening and selection. Appropriate candidates, according to the inclusion and exclusion criteria, were invited to participate in the study. Each participant and care-giver was given a written information sheet, along with a consent and assent form (Appendix VI & VII). All forms were written in English, but verbal translation was provided if needed. All participants and care-givers were given the right to refuse to participate in the study.

3.5.2 Pre-operative management

All participants were booked for pre-operative physiotherapy appointments. Each participant received either one or two pre-operative physiotherapy sessions, depending on the time of referral to physiotherapy prior to the date of surgery. A full explanation of the surgery, hospital stay and rehabilitation process was given to the care-giver and child. All of this information was also compiled into a basic information sheet (Appendix VIII) which was given to all the care-givers. Each child underwent a thorough functional assessment, and was issued a unique Home Exercise Programme (HEP) (Appendix IX) according to his/her needs. The HEP sheet was standardized, but the appropriate exercises for each child were highlighted. All exercises given to the child were demonstrated to the caregiver.

After this session the children continued their HEP and any other regular therapy sessions, i.e. at their school, until surgery as well as after surgery. The surgical procedure, and therapy plans were communicated with the treating therapists either verbally or via a letter.

3.5.3 Surgical management

All surgeries were done by the same orthopaedic surgeon. The assistants for the surgeries varied due to staff rotation.

3.5.4 Post-operative management

All children received daily in-patient therapy post-surgery (Monday-Friday), until the date of discharge. The CHBAH treatment protocol (Appendix X) for children post SEMLS was followed for all children during their hospital stay and as an out-patient. Once discharged the children were followed-up one week post discharge at CHBAH by the physiotherapist and orthopaedic surgeon. If the child was receiving therapy at another institution prior to surgery, they continued with their therapy at that institution. The frequency of therapy varied in the different institutions. Children who received therapy at the schools received weekly therapy during the schools term. Children who received therapy at health care facilities received weekly therapy for the first six weeks, then monthly therapy after that. These children were followed up every three months by the team at CHBAH after the initial one week follow-up.

During this period the children and care-givers were encouraged to continue with their HEP on a daily basis. The HEP was adjusted according to the child's needs at each follow-up session. If surgery occurred during or close to school holidays, therapy was continued at CHBAH until schools re-opened. Children were readmitted for one to two weeks if the child was found to be non-compliant with the HEP. Therapy was not standardised in order to determine whether the therapy that the children were currently receiving was adequate, or whether changes needed to be implemented.

Re-assessment was done using the EVGS, FMS and GMFCS-66 at six months and one year post surgery. Where possible all follow-up assessments were done on the same day as the child's follow-up appointment with the orthopaedic surgeons. Any child who missed a scheduled appointment or assessment date was contacted telephonically and rebooked.

3.5.5 Measurement

The GMFCS level was allocated to the child by the operating orthopaedic surgeon and the physiotherapist at CHBAH in consultation with each other.

A full clinical assessment was done by either an orthopaedic surgeon or an orthopaedic registrar. This assessment was repeated at six months and one year post-surgery. Due to six monthly staff rotations, the children were not necessarily assessed by the same orthopaedic surgeon or orthopaedic registrar at each consultation. This assessment consisted of radiological examination as well as a clinical examination.

The radiological examination consisted of review of an AP pelvis x-ray. The x-ray was used to determine the Migration Index. The Migration Index determines the amount of subluxation that is occurring at the hip joint.

During the clinical examination the orthopaedic surgeon or registrar measured the popliteal angle, the rotational profile, active and passive joint range of motion at the hip, knee and ankle, which included identification of any fixed contractures. An assessment of their gait was also done. Each patient was also assessed by the operating orthopaedic surgeon prior to surgery.

The full functional assessment, which included the GMFM-66 and the FMS, was completed by one physiotherapist in the CHBAH physiotherapy department. The physiotherapist had five years' experience at the commencement of the study and she was NDT trained. Due to the nature of the study, the physiotherapist was not blinded to which assessment it was being done, whether it was the pre-operative or one of the post-operative assessments, or to

the HIV status and place of therapy. The GMFM-66 was completed according to the guidelines in the user's manual (Gross Motor Function Measure (GMFM88 & GMFM66) User's Manual (2002)). The FMS was completed according to care-giver report.

The video used for the EVGS was taken by the assessing physiotherapist in one of the treatment areas in the physiotherapy department at CHBAH. The video was taken with a Canon Legria HF R206 HD Camcorder. The children walked a distance of ten meters across the length of the treatment room. For each video the children had to walk from the one end of the room to the other end of the room and back, a total distance of twenty meters. At least two videos were taken of each patient, one in the coronal and one in the sagittal view. Children used appropriate walking aids during completion of the required distance. All equipment used was recorded. The children were barefoot during the video assessment.

The videos were copied onto a disk and given to a second orthopaedic surgeon, with more than five years' experience, to score according to the EVGS. The date at which the video was taken was concealed and the videos were randomised. The videos were assessed by the orthopaedic surgeon on his private computer off site.

3.6 Ethical considerations

3.6.1 Permission to conduct research

Permission to conduct research was granted by the research board of CHBAH. Selected children and their parents were given information sheets with an attached consent and assent form respectively (Appendix VI & VII). The parents of all the children consented to participate in the study.

3.6.2 Ethical clearance

Application for ethical clearance was made to the Human Research and Ethics Committee (Medical) of the University of the Witwatersrand and approval was granted (Clearance number M120907) (Appendix X).

3.7 Statistical Considerations

The primary objective is to determine the gait pattern and functional level of children post SEMLS and compare this to their pre-operative function. With this data, the aim was then to determine whether the outcomes of SEMLS in developing countries are similar to those seen in developed countries. The secondary objectives being to describe the outcomes of SEMLS in children with spastic diplegia as a result of HIVE as well as in children with spastic diplegic

CP. A further objective was to discuss other factors that may influence the outcomes of SEMLS. The outcomes were measured according to gait parameters, gross motor function and functional gait using the EVGS, GMFM and FMS.

3.7.1 Data Analysis

Due to the small sample size, the data was not analysed statistically. For the purpose of this study, the data was analysed descriptively, using the Minimum Clinically Important Difference (MCID) as per the literature to determine whether the results showed clinical significance.

Chapter Four - Results

The results obtained during this study can be found in the chapter below.

4.1 Demographics

The table below (Table 4.1) describes the age at all assessments, as well as the gender, GMFCS level, HIV status and place of therapy for all patients. All participants were referred to the CHBAH paediatric orthopaedic clinic and accessed public health care.

Eleven children were recruited to the study. One child was lost to follow-up. The child attended one post-operative physiotherapy appointment after rescheduling, and then she defaulted. Her primary care-giver had no personal cell-phone and needed to be contacted either via the child's father or her neighbour. This was very difficult, as the primary care-giver was often not with these two people when they were contacted. After numerous phone calls, a follow-up assessment appointment was made, and confirmed the day before. The child and her care-giver did not attend the clinic or the physiotherapy appointment. The therapist was unable to contact her to determine why they did not attend the appointment.

Table 4.1 Age, gender, GMFCS level, HIV status and place of therapy for all particpants

Number	Age pre-operatively	Assistive devices	Gender	GMFCS level	HIV	Place of therapy
1	8yrs 3m	Bilateral AFOs*	M	2	-ve	CHBAH
2	8yrs 9m	Left AFO*	M	2	-ve	Vanderbijl-park Hospital
3	11yrs 0m	Rollator, knee brace	F	3	-ve	Hope School
4	11yrs 1m	Bilateral AFOs*	M	2	-ve	Klerksdorp Hospital
5	12yrs 0m	Elbow crutches^	F	2	-ve	Hope School
6	14yrs 5m	Bilateral GRAFOs*	F	2	-ve	Germiston Hospital
7	6yrs 6m	Bilateral AFOs	F	2	+ve	Private Therapist
8	8yrs 0m	Bilateral AFOs, rollator^, crutches	F	3	+ve	Hope School
9	8yrs 1m	AFOs, rollator	M	3	+ve	Isibeleni School
10	10yrs 7m	AFOs, crutches^	F	3	+ve	CHBAH

AFO- Ankle Foot Orthosis.
GRAFO – Ground Reaction-force Ankle Foot Orthosis
*Not compliant with use
^progressed to the use of another or no device.

All demographics for the participants can be seen in the table above. With regards to the children who were HIV positive, the mean baseline CD4 count was 1757.25 (Range 795 - 3024). Two of the baseline viral loads were not detectable, one specimen was rejected, and one was 540.

Most of the children were admitted the day before surgery. The mean length of stay was 8.63 days and the standard deviation was 3.15.

Five children attended physiotherapy within the government health care setting, either at a clinic or at a hospital, four children attended special needs schools in Gauteng where they received physiotherapy, and one child received therapy from a volunteer physiotherapist in the community. Children receiving physiotherapy at the schools had weekly physiotherapy, except during school holidays. Children receiving therapy in the government health care setting or the community received weekly physiotherapy initially for six weeks, then monthly therapy there-after.

The mean age of the children in this study at the time of surgery was nine years and ten months, with a standard deviation of two years and four months. The ages ranged from six

years six months to fourteen years five months. The average time to first follow-up was six months and thirteen months at the second follow-up appointment.

Three children had previously received Botulim Toxin more than six months prior to the surgery. No children had previously had any surgical intervention.

4.2 Surgical procedures

The surgical procedures performed are summarised in table 4.2 below.

Table 4.2 A summary of the surgical procedures performed per patient

Patient	Number of procedures	Adductor release	Hamstring release	VDRO	Semi-T transfer	Strayer	Psoas release	Rectus femoris release	MTP fusion
1	8	B	B	B	B				
2	5		B	B		L			
3	7	B	B			L	B		
4	4		B	B					
5	6	B	B	B					
6	8	B	B		B				B
7	8	B				B	B	B	
8	6		B	B		B			
9	8		B	B	B		B		
10	7		B	B	B	R			

B- Bilateral; R-Right; L-Left
VDRO-Varus Derotation Osteotomy, Semi-T- Semi Tendinosus, MTP- Metatarsal Phalangeal

The table above (Table 4.2) indicates the number and type of surgical procedures that the patients underwent. A total of 67 surgical procedures were performed, with an average of 6.7 procedures per patient. The most common procedure was the hamstring release in nine of the ten patients, all were done bilaterally, followed by the Varus Derotation Osteotomy (VDRO) in seven patients, which were again all bilateral.

There was only one adverse event noted from the surgery. Patient number three's left femoral nerve was partly cut during an over the brim psoas lengthening. The nerve injury resulted in a partial loss of sensation in the leg, generalised weakness, especially with regards to hip flexion and knee extension and severe pain. These factors all contributed to deterioration in her class work and difficulty concentrating at school. A repair was done and she was given a TENS machine to manage her pain. At the one year follow-up period her pain was being fully managed with a TENS machine and some of her sensation had returned to her leg. She still had generalised weakness in her leg and was using a brace to assist with ambulation at the one year follow-up assessment.

Two children have undergone a second surgery for removal of their blade plates. To date no children have required any further surgical correction or Botulim Toxin.

4.3 Gait analysis

The pre and post-operative EVGS scores are presented in the table below (Table 4.3.1).

Table 4.3.1 A comparison of pre-operative and post-operative EVGS scores

	Pre-operative		Six months post-operative		One year post-operative	
	Right	**Left**	**Right**	**Left**	**Right**	**Left**
1	11	20	2	18	4	16
2	14	23	9	12	12	10
3	21^	23^	a*	a*	a*	a*
4	13	4	9	1	8	10
5	15	14	15	17	15	14
6	14	12	9▫	11▫	8▫	11▫
7	14	23	14	15	15	13
8	22^	24^	13^	28^	17▫	8▫
9	19^	17^	18^	17^	20^	21^
10	22	23	16	19	19	22
Mean	16.00	17.78	11.67	15.33	13.56	13.78
Standard deviation	4.00	6.74	4.90	7.26	5.81	4.97

*Use of a brace during gait
^The use of a reverse walker or rollator
▫The use of crutches
a- No result

In order to complete 10m for the gait analysis, pre-operatively three children used rollators and the remaining seven children were able to complete this distance independently. Videos were scored without the use of splints, namely ankle foot orthosis (AFO's). Six months post operatively two children were still using a rollator and one child was now using crutches. This changed at one year post-operatively as one child had progressed from using a rollator to using crutches for this distance. The orthopaedic surgeon was unable to score the videos for child number three post-operatively, as she was using a brace for gait, and this would significantly alter her score.

When using the EVGS the greater the score, the more that the child's gait deviates from the normal. A score of zero would indicate a normal gait pattern in that leg, however as all children in the study have spastic diplegia, where both lower limbs are involved, it is not expected to get a score of zero for any of the assessments. The mean scores for each leg decreased at both the six month and one year post-operative and therefore improvement was seen in the gait pattern at each assessment.

The mean score per child for the three assessments were 33.78, 27.00 and 27.33, going from pre-operative to the final assessment. All scores for child number three were excluded from the analysis. The change in the means from the pre-operative to the six month post-operative assessment was 6.78, with little further change in the mean at the one year post-operative assessment. Pre-operatively the scores per leg ranged from four to twenty four.

The ranges for the six month and one year post-operative assessments were two to twenty eight and four to twenty two respectively.

The average change in the EVGS scores at each follow-up are represented in the table below (Table 4.3.2).

Table 4.3.2 A summary of the average change in the EVGS scores

	Change from pre-operative to six month post-operative scores	Change from six month post-operative to one year post-operative scores	Change from pre-operative to one year post-operative scores
Total	**6.8**	**-0.3**	**6.5**
Foot	1.2	0.9	2.2
Knee	3.4	-0.9	2.5
Hip	0.9	0.3	1.2
Pelvis	0.3	-0.3	0.0
Trunk	0.9	-0.3	0.6

The mean change in the score per child from the pre-operative assessment to the six month post-operative assessment was 6.8 and change was seen at all joints that were assessed. There was a small overall deterioration of 0.3 from the six month to the one year post-operative assessment, with the change at the one year post-operative assessment in comparison to baseline being 6.5. The greatest change at the six month post-operative assessment was seen at the knee, followed by the foot. The most deterioration from the six month to the one year post-operative assessment was seen at the knee, followed by the trunk and pelvis. The change in the knee range during gait corresponds with the change in the popliteal angle at each assessment. The mean popliteal angles for the pre-operative, six month and one year post-operative assessments were 48.75, 26.75 and 29.75 respectively.

Looking at the change from the initial assessment to the one year post-operative assessment, there was an overall improvement seen at every joint, except at the pelvis where the scores remained the same.

4.4 Functional outcome measures

4.4.1 GMFM-66

The GMFM-66 scores are represented in the table below (Table 4.4).

Table 4.4.1 A comparison of pre-operative and post-operative GMFM-66 scores

	GMFM-66		
	Pre-operative	**Six months post-operative**	**One year post-operative**
1	69.63	72.16	74.16
2	80.93	79.11	92.05
3	50.09	44.56	46.5
4	82.99	89.7	92.05
5	71.22	61.51	65.33
6	76.75	69.63	74.16
7	72.63	69.63	70.04
8	52.09	53.38	55.15
9	50.85	50.62	53.86
10	69.63	67.75	75.34
Mean	**67.68**	**65.81**	**69.86**
Std dev	**12.35**	**13.65**	**15.24**

Scores improved
Scores decreased

The GMFM-66 has no normative values to which it can be compared to, however the higher the GMFM-66 score the more functional the children are. After the age of seven years, due to a plateau in function, there is usually a plateau in the GMFM-66 score. This score can however change after an intervention.

The GMFM-66 scores ranged from 44.56 to 92.05 over the three assessments. There was a 2.77% decrease in the mean GMFM scores at the six month follow-up assessment. The scores did however increase by 6.71% from the six month to the one year follow-up assessment. This indicates in an overall improvement of 3.23% from the pre-operative GMFM scores to those at the one year follow-up assessment. Six patients GMFM scores improved in comparison to baseline at the one year follow-up assessment, and four scores decreased.

The cadence of the children was assessed at each follow-up. The mean cadence at the pre-operative, six month post-operative and one year post-operative assessments were 0.57m/s, 0.50m/s and 0.65m/s respectively

4.4.2 FMS

Below is a table comparing pre-operative and post-operative FMS scores.

Table 4.4.2 A comparison of pre-operative and post-operative FMS scores

	Pre-operative			Six months post-operative			One year post-operative		
	5m	50m	500m	5m	50m	500m	5m	50m	500m
1	6	6	6	6	6	N	6	6	N
2	6	6	6	6	6	6	6	6	6
3	C	1	1	1	1	1	1	1	1
4	6	6	6	6	6	6	6	6	6
5	5	5	5	3	3	3	5	4	3
6	6	6	5	6	6	5	6	6	5
7	5	5	5	5	5	5	5	5	5
8	2	2	2	C	2	2	3	3	3
9	C	1	1	C	1	1	2	1	1
10	5	4	N	5	3	N	5	3	3

What is important to note about the above table is the change in assistance needed during gait. One of the aims of the surgery is to maintain the children's current ability to walk into adulthood, or to improve their current mobility. An increase in the FMS scores will indicate that the child is using less assistance for mobility and therefore an improvement has been seen.

The change in the FMS at each follow-up is represented in the graph below (Graph 4.4).

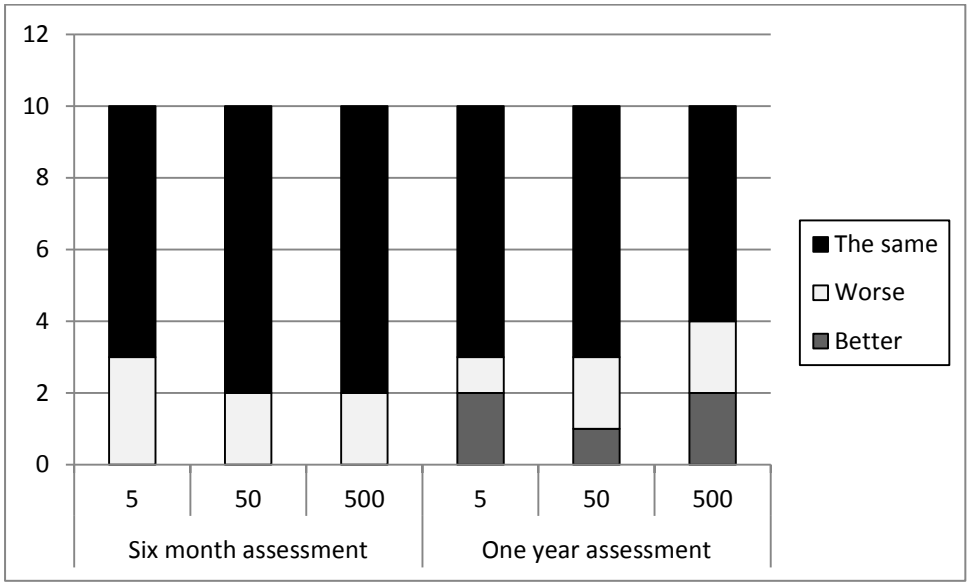


Figure 4.4 Changes in FMS scores for the 5m, 50m, and 500m distances at the six month and one year follow-up.

At the six month follow-up assessment, there was an overall decline in functional mobility, with one to two children needing more assistance during gait for each distance. At the one year follow-up period, some of the children were starting to mobilize with less assistance, and therefore improvement was seen.

4.5 HIVE and CP

All children in the study who were HIV positive presenting with HIVE, were receiving HAART and had a history of compliance prior to participation in this study.

Demographics for each group can be seen in the table below (Table 4.5.1).

Table 4.5.1 Age, gender and GMFCS level for the CP group and the HIVE group

	Age Mean (Std dev)	Gender	GMFCS level
CP (n=6)	10 yrs 11 months (26.97)	F=3 M=3	II=5 III=1
HIVE (n=4)	8 yrs 4 months (32.71)	F=3 M=1	II=1 III=3

The above table highlights that the CP group had more children of a lower GMFCS level than the HIVE group. The GMFCS levels of each group links with the pre-operative EVGS and GMFM-66 scores of each group. The CP group had mean scores of 30.66 and 79.14 for the EVG and GMFM respectively, whereas the HIVE group mean scores were 41 and 69.3.

A comparison of the results of the outcomes measure for each group can be seen in the table below (Table 4.5.2).

Table 4.5.2 Pre-operative and post-operative scores between the CP and HIVE group

		EVGS	GMFM-66	FMS
Change from pre-operative to six month post-operative scores	CP	7.40	-2.49	-6
	HIVE	6.00	-0.95	-3
Change from six month post-operative to one year post-operative scores	CP	-1.00	4.60	3
	HIVE	0.50	3.25	10
Change from pre-operative to one year post-operative scores	CP	6.40	2.11	-3
	HIVE	6.50	2.30	7

Overall change in the EVGS for both the CP and HIVE group were similar when looking at both the EVGS and GMFM. With regards to the EVGS the CP group had a larger initial improvement (7.4), with a deterioration of one at the one year post-operative assessment. The HIVE group showed continued improvement up to the one year follow-up period, with the greatest change of six occurring at the six month follow-up.

In terms of function both groups had an initial deterioration in their GMFM-66 scores, with the change in the mean scores for the CP group and the HIVE group being 2.49 and 0.95 respectively. There was an increase of 2.11 (2.93%) for the CP group and 2.3 (3.75%) for the HIVE group from the initial assessment to the one year follow-up assessment.

Looking at the functional gait of the children, the CP group had an overall decrease in functional gait of six as measured on the FMS, but with improvement seen from the six month post-operative assessment to the one year post-operative assessment of three. The HIVE group also had an initial deterioration in functional gait however there was an overall improvement of seven at the one year post-operative follow-up period.

4.6 Place of therapeutic intervention

Baseline demographics for each group can be seen in the table below (Table 4.6.1).

Table 4.6.1 Age, gender and GMFCS level for the children attending therapy at a school and those attending therapy at a health care facility

	Age Mean (Std dev)	Gender	GMFCS level
Schools (n=4)	9yr 9months (24.46)	F=3 M=1	II=1 III=3
Health care facilities (n=6)	9yr 11mo (33.02)	F=3 M=3	II=5 III=1

The pre-operative functioning of the two groups is depicted by the pre-operative EVGS and GMFM-66 scores. The schools group had a lower pre-operative functioning with a mean EVGS score of 38.75 and a mean GMFM-66 score of 56.06. The mean EVGS score for the health care facilities group was 32.17, with the mean GMFM-66 of 75.43.

Results of the outcomes measure for each group can be seen in the table below (Table 4.6.2).

Table 4.6.2 Pre-operative and post-operative scores between the children attending therapy at the schools and those attending therapy at the health care facilities

		EVGS	**GMFM-66**	**FMS**
Change from pre-operative to six month post-operative scores	Schools	1.00	-3.55	-7
	Health care facilities	9.70	-0.76	-2
Change from six month post-operative to one year post-operative scores	Schools	4.30	2.69	10
	Health care facilities	-2.70	4.97	3
Change from pre-operative to one year post-operative scores	Schools	5.30	-0.85	3
	Health care facilities	7.00	4.21	1

The health care facilities group showed a large overall change in the GMFM and the EVGS. The schools group had a larger change with respect to the FMS.

4.7 Conclusion

As determined by using the EVGS all children had a gait pattern that deviated from the normal gait pattern. The variation of the deviation of the gait pattern was vast, with the EVGS scores per leg ranging from two to 23, with the highest possible score being 34 per leg.

Pre-operatively the children in the study had moderate to high levels of gross motor function, with a mean GMFM-66 score of 67.68 and the majority of the children participating in the study walked independently prior to the surgery in the home, school and the community as assessed by the FMS.

There was an overall improvement in the gait pattern of the children post-operatively, and the improvement continued until the one year follow-up. In contrast there was an initial deterioration in function, as measured by the GMFM-66 at the six month follow-up, but there was improvement in function at the year follow-up period. Similarly there was a deterioration seen in functional gait at the six month follow-up, with some improvements seen at one year. Some children were however, still needing more assistance for gait than pre-operatively.

Both the CP group and the HIVE group had similar outcomes as described for the group as a whole. The only difference seen was that there was initially a large change in the gait in the CP group at the six month assessment, with a small decline in the EGVS seen at one year. The CP group also still required more assistance for gait at the one year follow-up assessment than pre-operatively.

The schools and the health care facilities group both showed overall improvement in all areas, except for the GMFM-66 scores of the schools group which was still lower than the pre-operative scores.

Chapter Five - Discussion

5.1 Gait

Using gait analysis to determine outcomes post SEMLS, shows an improvement in gait up to the one year follow-up period (Gorton III, et al., 2009).These results have been found to be maintained up to the five year follow-up period (Thomason, et al., 2013). This study yielded similar results with an improvement of the mean EVGS scores at the one year follow-up. The mean change in EVGS was 6.4 from the pre-operative assessment to the one-year follow-up, with a deterioration of 0.3 from the six month to the one-year follow-up assessment.

Regarding the EVGS scores, Gupta & Raja (2012) reported that for a large effect size of 1.15 and 1.22 at the six month and one year follow-up assessments respectively, the minimum clinically important differences (MCID) are 11 and 15. According to this, the change in gait in this study is not clinically significant. It has been reported that a medium effect size is 0.5 with a large effect size being anything above 0.8 (Offinger, et al., 2008). With this in mind it needs to be questioned whether a smaller change in EVGS will still show a difference clinically. Further investigations need to be done to determine the change in EVGS for an effect size of 0.8 and 0.5.

Gupta & Raja (2012) also found a change of 12.08 from the pre-operative assessment to the six month post-operative assessment and a small improvement of 1.18 from the six month to the one year post-operative assessment. The initial change in their study was almost double the change seen in this study. A deterioration of 0.3 was seen in this study from the six month to the one year post-operative assessment which also contrasts to Gupta & Raja's (2012) findings.

There were some differences in this study in comparison to the study by Gupta & Raja (2012) that may account for the differences in results. The mean number of procedures per patient was 3.7, and some of the children underwent single level surgery, whereas the children in this study all received multilevel surgery with a mean of 6.7 procedures per child. Therefore the children would have required a shorter recovery period due to decreased intervention. Most of the procedures done by Gupta & Raja (2012) were soft tissue procedures, mainly at the foot. However seven out of the ten children in this study received a VDRO, which is a bony procedure, and recovery period after bony procedures is generally longer.

Another consideration when comparing this study to the study by Gupta & Raja (2012) is that 80% of the children in their study were of GMFCS level III, whereas in the current study only 40% were of GMFCS level III. It has been documented that there is greater change post SEMLS in children who have a higher GMFCS level (Harvey, et al., 2012). Therefore the difference in pre-operative functioning could account for some of the differences in the post-operative change in the EVGS when comparing the two studies.

Post SEMLS there is a larger improvement in gait from the pre-operative assessment to the six month follow-up period, with small improvements continuing to the one year follow-up (Gupta & Raja, 2012). The result of this study showed a small deterioration from the six month follow-up assessment to the final assessment at one year. This deterioration was seen at the knee, followed by the trunk and pelvis. The research shows improvements in gait parameters at all joints except at the pelvis, but only with regards to pelvic tilt, at short-term follow-up of one year. There was no significant deterioration in these parameters at mid to long term follow-up (Thomason, et al., 2013; Rutz, et al., 2013).

The deterioration in gait parameters in this study may be attributed to the limited therapeutic intervention. There is little evidence in the literature with regards to the correct amount of therapeutic intervention post SEMLS (McGinnley, et al., 2012). Thompson et al (2013) reported that the children in their study received regular physiotherapy immediately after the surgery. At three months post-surgery the children then received twelve weeks of intensive physiotherapy. During this period the children received physiotherapy three times a week. Gupta & Raja (2012) did a week to ten days of intensive physiotherapy and training with regards to a HEP at either six or twelve weeks post-operatively. The children in this study did not receive an intensive block of therapy after twelve weeks, and training on the home-exercise programme was limited. It is possible that the therapy programme, although relatively effective, as the children did improve post SEMLS, needs to be changed to include a block of intensive therapy for four weeks at three months post-surgery.

Deterioration seen in the knee could be associated with the decreased compliance in the use of assistive devices. When available children received key stone splints, to wear over the knee at night to maintain hamstring length. Compliance with these was poor by the end of the study. The children, except those attending schools, were only attending therapy once a month by the one year follow-up period, and therefore maintenance of the knee range of motion (ROM) was very dependent on the child's stretching and use of assistive devices at home.

There was also a small deterioration seen in the trunk and pelvis. With no surgeries being performed at this level, the deterioration here is most likely linked to the therapy received. It is possible that there was not enough emphasis on trunk strengthening in the rehabilitation and home exercise program given. This could have resulted in the deterioration in the trunk and pelvis during gait.

5.2 Functional outcomes

5.2.1 GMFM-66

The results of the present study revealed an initial deterioration in the function, as measured by the GMFM-66, at the six month follow-up period, with an overall improvement in function of 3.83% at the one year follow-up assessment. Due to the small sample we were unable to determine whether the results were statistically significant although Thomason et al (2011) only found a statistically significant difference in GMFM-66 scores at the two-year follow-up period.

When looking at function, cadence can also give an indication whether there was a functional change in gait. The change in the mean cadence corresponds to the changes in the GMFM-66 seen at each follow-up, with there being an initial deterioration with an overall improvement at one year.

There was a large change of 2.18 from the mean pre-operative to the mean one year post-operative GMFM-66 scores, which were 67.68 and 69.86 respectively. It has been reported that the minimum clinically important differences (MCID) for the GMFM-66 of a large effect size (0.8) is 1.3 (Offinger, et al., 2008). Therefore it can be determined that there was an observable change in function which was clinically significant.

The improvement in the mean GMFM-66 scores at the one year follow-up period is greater in comparison to the prospective study done by Thomason et al (2013). They showed a change in mean GMFM-66 scores of only 0.2 at the one year post-operative assessment, a change of 4.1 at the two year post-operative assessment and an overall change of 3.3 at the five year post-operative assessment.

The greater improvement in GMFM-66 at the one year follow-up assessment in our study could be due to the fact that these children had not reached their full functional potential prior to surgery. It has been documented that late diagnosis and limited physiotherapy is typically seen in children with CP in developing countries (Khan, 2007). Due to the plasticity of the infant brain, it has been proposed that early intervention is key to optimising function in

children with CP (Hadders-Algra, 2014). Furthermore children with CP who receive more frequent physiotherapy, with stretching and exercises present with fewer contractures and secondary complications (Knox & Evans, 2002). From this it can be deduced that children with CP who are diagnosed late and have limited access to health care facilities, including physiotherapy, are more likely to have greater contractures and secondary complications. It is therefore likely that these children did not reach their full functional potential prior to surgery.

Little research has been done in developing countries but a study in India yielded similar results. Children with untreated CP changed GMFCS level after SEMLS and intensive physiotherapy (Khan, 2007). This differs from studies in developed countries where GMFCS levels has been found to remain constant post SEMLS (Rutz, et al., 2012). Therefore it is possible that there will be a greater change in function post SEMLS in children in developing countries who have previously had limited access to health care facilities. Ongoing post-operative physiotherapy must be emphasised pre-operatively to all care-givers involved in potential SEMLS.

5.2.2 FMS

When looking at the outcomes as assessed by the functional mobility scale, an initial deterioration was seen at six months, with a return to baseline at twelve months. Similarly Harvey et al (2007) found that there was an initial deterioration in the FMS scores at three and six month assessments, with a return to previous function at one and an overall improvement seen at the two year follow-up period. At one year, over the 5m distance, two children scored better, one child scored worse, with seven children remaining the same. Over the 50m distance, one child scored better, two children scored worse and the rest remained the same. Two children scored better, two worse and six the same over 500m. When compared directly to the results from the pilot randomised control trial by Thomason et al (2011) (Appendix XI) over 5m this study yielded slightly better results with only one child scoring worse than pre-operatively, results were similar over 50m, and there were some children who improved over 500m in this study with no improvements at this distance seen in the randomised control trial.

As with the GMFM-66, the slightly more favourable results seen with regards to the FMS scores in this study could also be attributed to the fact that these children had limited access to health care facilities prior to the surgery. Another aspect to consider is whether these children were mobilizing using the correct device prior to surgery.

The FMS is a tool designed to measure performance and not capability (Harvey, et al., 2010). One's performance is directly related to the therapeutic input and resources. It was noted by the clinician that when using the FMS in this context, children used a specific device or no device for a certain distance, even if that was not the most effective device for the child over that distance. The clinician attributed this to a lack of therapeutic intervention and resources available, as well as inexperience of the treating clinician. This is illustrated in child number one. He scored highly on the FMS pre-operatively; however his GMFM-66 scores were relatively low in comparison to the group. His mother reported that he received no assistance with any distances pre-operatively, however when going very far, she would carry him on her back. It is possible that he would have been able to mobilize using sticks or crutches over 500m, however he was never advised of this or issued any devices.

Two children were non-applicable for the distance of 500m as they were carried. In this setting, wheelchairs are not readily available to children who require them only for longer distances. Another challenge with utilizing a wheelchair for mobility in the community is that public transport is often inaccessible to patients in wheelchairs, which results in patients either having to use private transport which is costly. This then leads to the alternative and the children are carried by their mothers. This mode of assistance was not accounted for within the FMS and it can be assumed that in a developed country, they would have either been using a wheelchair or at least crutches for this distance. The use of an alternative device would have altered their FMS scores. The children in this study were issued the appropriative assistive devices, if available, after the surgery, resulting in the child being able to complete the distance post-operatively. Therefore some of the change in FMS scores could be attributed to the correct device being issued post operatively.

5.3 HIVE and CP

There is very little research with regards to the management of the complications associated with HIV. In this study clinicians sought to determine the outcomes post SEMLS in children with CP and HIVE in a developing country.

Looking at the EVGS, both groups improved at the one year follow-up assessment, with the change in the mean scores being very similar. The CP group showed greater improvement at the six month assessment than the HIVE group with deterioration seen at the one year assessment. The HIVE group continued to improve up until the final assessment. The reason for the deterioration of the EVGS in children with CP is unclear. It is possible that this group was less compliant with the use of assistive devices and the home exercise programme.

With the MCID of the GMFM-66 being 1.3 (Offinger, et al., 2008) both groups showed a meaningful clinical change in the GMFM-66 scores at the one year follow-up assessment. The CP group had an overall improvement of 2.11 and the HIVE group had an improvement of 2.3. As discussed earlier these results are better than those seen in other studies and the results are similar between the two groups. The HIVE group showed less deterioration in function at the six month follow-up assessment. With the limited understanding of the appropriate medical and therapeutic intervention for children with HIVE (Langerak, et al., 2014) this population of children has previously received limited therapy. With the limited therapy comes a change in the clinical picture and more potential for change post intervention as discussed above (Khan, 2007). These factors may have contributed to the smaller initial decrease in function seen in the HIVE group post SEMLS.

The limited therapeutic intervention and by association the limited access to assistive devices is most likely also a contributing factor for the HIVE group having a greater improvement in FMS score at both the six month and one year post-operative follow-up.

In order to fully understand the outcomes of this study in children with CP and those with HIVE, it is important to discuss the different aspects that may have affected the outcomes. Two of these aspects are age and pre-operative functional level.

The age of the children in this study ranged from six years six months to fourteen years five months. Due to the plateau in function of children with CP from the age of between six and seven years and the musculoskeletal changes that occur as a child reaches puberty, SEMLS is only done on children older than six years of age (Narayanan, 2012). The CP group mean age was two years seven months older than the HIV encephalopathy group. It has been documented that older children tend to have better functional outcomes after SEMLS (Svehlik, et al., 2011). The larger mean age of the CP group could possibly have resulted in the CP group having better outcomes than the HIVE group.

The HIVE group had a lower initial GMFM-66 score of 61.3 in comparison to that of the CP group. There is a documented ceiling effect of the GMFM-66 as well as the FMS (Harvey, et al., 2012; Debuse & Brace, 2011) and therefore the higher the child's GMFCS level the less potential there is for change. This would then result in the HIV group having more potential for change as a result of this its lower pre-operative function.

When looking at the two groups, one can see that they both had favourable outcomes post SEMLS. Although the groups are small and no deductions can be made with regards to the population, this study has given an indication that SEMLS could be a viable option in the

treatment and management of children with CP and those with HIVE. It has opened the door for further research to be done in the area.

5.4 Place of Therapeutic Intervention

All the children in the current study continued to receive physiotherapy at the facility that they were receiving physiotherapy at prior to surgery, or were referred to their local health care facility for physiotherapy. The aim of this was to look at the outcomes of children receiving therapy at schools and those receiving therapy in health care facilities.

With the overall greater improvement in the GMFM and the FMS seen in this study in comparison to the literature, although small, this study can serve as a step forwards in determining an effective physiotherapy program post SEMLS in this setting. With the majority of the therapy intervention consisting of a prescribed, progressive, home-based exercise programme as issued by the physiotherapist, it can be concluded that home-based exercise programs should be explored more with regards to treatment of children post SEMLS. This approach is supported in the literature which states that exercise programmes, including home-based exercise programmes, are effective in the management of children with CP. (Novak, et al., 2013).

The children, who received therapy at the schools, received more regular therapy. The children at the schools received therapy weekly, whereas the children at the health care facilities received therapy only once a month by the one year follow-up assessment. Based on the increased therapy received at the schools, this group would be expected to have greater outcomes. The outcomes for the two groups were similar, but the small sample size means that no conclusions can be made with regards to the reasons for this.

The change in the mean of the EVGS scores at the six month assessment was far greater in the health care facilities group. The schools EVGS did continue to improve, but the health care facilities group mean score deteriorated up to the final assessment. Again a possible contributing factor to this could be that the children in the health care facilities group had received less therapy pre-operatively, and therefore had not reached their full potential prior to surgery. The improvement in the EVGS scores in the schools group from the six month to the one year post-operative assessment could be contributed to persistent interaction with the children, and more consistent stretching of the appropriate muscles during therapy. The health care facilities group showed deterioration in gait parameters which could be linked to the lack of consistent stretches and use of assistive devices as their supervision was limited. This is highlighted by the fact that deterioration in the EVGS scores occurred at the knee and

foot from the six month to the one year assessment. These are the joints where assistive devices such as knee splints and AFO's are used to maintain ROM.

When looking at the specific joints on the EVGS for the schools group, deterioration was seen at the trunk and pelvis. As there were no surgical procedures done at these levels, deterioration in these areas could be related to the focus of the therapeutic intervention. It is possible that more emphasis was placed on the maintenance of lower limb ROM than on the maintenance of overall strength.

The health care facilities group did much better when looking at the GMFM-66 scores. They only had a limited decrease in function initially, with a large overall change in function at the final assessment. As per the GMFM-66 the schools group did not return to their pre-operative function at the one year assessment. This is worse than results seen in the literature, where children usually return to their pre-operative function at the one year follow-up assessment (Thomason, et al., 2013). One of the contributing factors to this decline is that patient number three who had the complication in surgery, fell into the schools group. Due to the small sample size and only four children attending therapy at schools, it is likely that her outcome greatly affected the overall picture. If the GMFM-66 scores of this child are removed, the mean scores of the rest of the group returns to baseline at the one year follow-up assessment.

Another aspect to consider in terms of the decreased functional change in the schools group in comparison to the health care facilities group is that it is possible there was limited focus on functional ability in therapy at the schools, with more focus on maintenance of ROM.

When comparing these two groups there is an apparent difference in the functional ability pre-operatively and this could also have had an effect on the outcomes. As stated above the greater the child's GMFCS level the less potential there is for change. This contrasts to the findings in this study as the schools group showed less change however the schools group had an overall lower GMFCS level than the health care facilities group.

Despite the small sample size in the schools group the results of this study highlights some important factors with regards to the type of therapeutic intervention children with CP and HIVE are receiving. Using the ICF as a guideline, treatment should be aimed at change at the activities and participation levels, and not merely at the body structure and functioning level. The lower limb ROM was maintained in the children at the schools. However there was no functional improvement at one year, whereas the other children showed a clinically significant improvement at one year post surgery. There was also deterioration in the trunk

and pelvis as seen during gait analysis, which contrasts to the literature (Thomason, et al., 2013; Rutz, et al., 2013). With the therapy being done in the schools being based mainly on therapeutic approaches such as NDT, and as seen in the literature there is very little evidence to support the use of therapy in the management of CP (Novak, et al., 2013), it needs to be considered whether the therapy received at the schools is the most effective intervention or whether a physiotherapist prescribed home-based exercise programme is more effective as the literature shows strong evidence for the effectiveness of home-based exercise programmes in the management of children with CP (Novak, et al., 2013). In order to maintain ROM in the group attending therapy at the health care-facilities, wearing of the assistive devices should be added into the home-based exercise programme. Further research is needed in this area as no conclusions can be drawn from this study.

5.5 Limitations of the study

5.5.1 Small sample size

The small sample size proved to be a great limitation of the study. The small number of children meant that a result from one patient, for example child number three who had a complication in surgery, could easily skew the results. Furthermore this also meant that statistical analysis was not possible.

Historically, there was little orthopaedic management of children with CP in the public health care setting, in particular at Chris Hani Baragwanath Academic Hospital. This coupled with the fact that, due to the high volumes of patients, there is no physiotherapy service provided to children with chronic disabilities over the age of six years, meant that many children with CP no longer access public health care as there was no service previously available to them. Therefore the number of children with CP attending the orthopaedic clinic at CHBAH for assessment was limited. As the service continues to grow, there should be more and more children who fit the criteria for orthopaedic management at CHBAH.

The limited physiotherapy service available for children with CP in the public health care sector is another contributing factor to the small sample size. Many of the children, who were assessed for surgery, were found to be too weak for surgery. These children either received botulinum toxin, or a physiotherapy strengthening programme for possible re-assessment for surgery in six months to a year. Child nine was previously assessed, received Botulinum toxin and physiotherapy, and a year later was stronger and an appropriate candidate for surgery. It is predicted that as the service continues to grow, more patients will be appropriate candidates for surgery.

The number of children with spastic diplegia associated with HIV encephalopathy was less than the number of children with spastic diplegic CP. In order to make a proper comparison, these numbers should have ideally been equal. Since the advent of HAART, children with HIV have an increased life expectancy (Lowenthal, et al., 2014) and with that has come a group of children with medical and rehabilitation needs that have not been previously investigated. There has been no research on the orthopaedic management of these children, and therefore the guidelines for inclusion were unknown. Consequently it was difficult to ascertain which of these children were good candidates for surgery and as research continues better guidelines will be established.

5.5.2 Short follow-up period

According to the research, changes in gait post SEMLS occur at one year follow-up, with changes in function occurring at the two-year follow-up period (Thomason, et al., 2011; Rodda, et al., 2006). Although this study had better than expected outcomes in function at the one year follow-up period, in order to properly understand the outcomes of the study, these children need to be followed up for at least two years, but ideally five years post-surgery (Bischof, 2010). As this was the first study of its kind in South Africa, a one year follow-up period was used to determine the outcomes post SEMLS in comparison to studies done in developed countries. The same time frame was used in the pilot randomised control trial conducted by Thomason et al (2011). This study has given a good indication that the results of SEMLS in children with spastic diplegia in the public health care setting in a developing country are favourable, and has opened the door for further research in the area.

5.5.3 Study design

Despite randomised control trials (RCT) being the gold standard with regards to the methodology for high quality research, there has been debate as to the ethical considerations pertaining to conducting a RCT on the outcomes of SEMLS. Although this study was not a RCT, it is a prospective study which has been suggested in the literature as an appropriate way in which to conduct research in order to determine the outcomes of SEMLS.

The use of blinded assessors is ideal when conducting research. When this is not possible, as in this study, it is preferential to have an independent assessor. Unfortunately, due to the study being conducted in a busy clinical setting, with high case loads and physiotherapists with limited clinical experience it was not possible to get an independent physiotherapist to conduct the GMFM and the FMS. Due to the nature of the video analysis, it was possible to

get an independent assessor, who was blinded to the date of assessment as well as HIV status and place of therapy.

The availability of space in which to conduct the research was limited, and all assessments were done in the neuro physiotherapy gym. As this is a busy treatment area there were often other people in the room during the assessment. This resulted in the inability to remove extra clothing for the videos, which made analysis of the videos challenging.

5.5.4 Omission of assessment of quality of life indicator in the outcome measures

The latest research regarding SEMLS has highlighted the importance of using the ICF framework when selected appropriate outcomes measures (McGinnley, et al., 2012). With this in mind, this study used outcome measure at the body, structure and functioning level, as well as at the activity level. However there was no outcome measure that assessed quality of life. Research shows a change in quality of life post SEMLS (Thomason, et al., 2011) at the two year follow-up period, and therefore in follow-up studies, a quality of life measure should be included.

5.6 Strengths of the study

McGinley et al (2012) suggest considerations to be taken into account when conducting research on SEMLS. According to those guidelines the strengths of this study are as follows;

- Detailed inclusion and exclusion criteria.
- All patients had spastic diplegia and were of GMFCS level II and III.
- All previous orthopaedic intervention, and botulinum toxin administration, was mentioned.
- It was a prospective study.
- There was adequate reporting of surgical procedures, post-operative length of stay, physiotherapy protocol and orthotics used.
- Outcomes measures used were on different levels of the ICF and included the GMFM-66 and a gait measure, and the administration of these was mentioned in detail.
- The gait analysis was done by a blinded independent assessor.
- All adverse events and additional surgical procedures were mentioned.
- Results were related to the MCID.
- It is the first study comparing the outcomes of children with CP to those with spastic diplegia as a result of HIVE.

5.7 Suggestions for further research

The results of this study have yielded the following recommendations for further research:

- The children in this study should be followed up for five years in order to determine the long term outcomes of SEMLS in developing countries.
- Further studies should be conducted to determine the effect that differing physiotherapy intervention will have on the outcomes of SEMLS. Possibly with a weekly physiotherapy group and home exercise programme group with monthly check-ups
- Further studies need to be conducted with a larger sample size looking at the outcomes of children with HIVE post SEMLS.
- A similar study with a larger sample size, at more than one institution needs to be conducted with at least a two year follow-up period.

The conclusions drawn from this study will be presented in chapter six.

Chapter Six – Conclusion

This study is important as it is a step towards increasing the understanding with regards to the outcomes of SEMLS in developing countries. It is also the first study to lookat the outcomes of SEMLS in children with spastic diplegia as a result of HIVE.

The results of this study reveal that there are favourable outcomes of SEMLS in children in developing countries. Children in this study did not show clinically important changes in gait, however clinically important changes were seen in function at the one year follow-up period. The change in function seen was greater than in previous studies. This could be due to the fact that due to limited access to health care facilities prior to surgery many of these children (especially those from health care facilities without access to specialised CP schools) had not reached their full functional potential.

The children with HIVE showed favourable results. This was seen both in the gait assessment as well as functional changes. As the first study of its kind, it has opened the door for further research in the field to compare the two groups. Further research is needed with larger comparison groups as well as a longer follow-up period.

When looking at the two therapy groups, each group did better in a specific assessment. The schools group had favourable outcomes in terms of the gait parameters and the health care facilities group had good functional outcomes. Further research needs to be done in order to optimise outcomes. Guided by the outcomes of this study it is suggested that a combination of the two therapeutic approaches should be investigated.

The outcomes of SEMLS in children with CP in developing countries are similar to the outcomes seen in developed countries. Furthermore children with HIVE had similarly positive outcomes to children with CP. This evidence reinforces the importance of further research in order to fully understand the practice of treating children with spastic diplegia, either with CP or HIVE, in developing countries through the use of SEMLS and regular physiotherapy at follow-up.

Chapter Seven - References

Anttila, H., 2008. Effectiveness of physical therapy interventions for children with cerebral palsy: A systematic review. *Biomedical Central Paediatrics,* 8(14).

Badr, L. K. & Purdy, I., 2006. Brain injury in the infant, the old, the new and the uncertain. *Journal of Perinatal and Neonatal Nursing,* 20(2), pp. 163-175.

Baillieu, N. & Potterton, J., 2008. The extent of delay of language, motor, and cognitive development in HIV-positive infants. *JNPT,* 32(3), pp. 118-121.

Beckung, E., Carlsson, G., Carlsdotter, S. & Uvebrant, P., 2007. The natural history of gross motor development in children with cerebral palsy aged 1 to 15 years. *Developmental Medicine and Child Neurology,*49(10), pp. 751-756.

Bella, G. P., Rodrigues, N. B. Valenciano, P. J., Silva, L.M., Souza, R.C., 2012. Correlation among the visual gait assessment scale, Edinburgh visual gait scale and observational gait scale in children with spastic diplegic cerebral palsy. *Revista Brasileira de Fisioterapia,* 16(2), pp. 134-140.

Bell, K., Ounpuu, S., Romness, M. & DeLuca, P., 2002. Natural progression of gait in children with cerebral palsy. *Journal of Paediatric Orthopaedics,* 22(5), pp. 677-682.

Bischof, F., 2010. Single event multilevel surgery in cerebral palsy: a review of the literature. *South African Orthopaedic Journal,* pp. 30-33.

Lofterød, B., Terjesen, T., Skaaret, I., Huse, A., Jahnsen, R., 2007. Preoperative gait analysis has a substantial effect on orthopedic decision making in children with cerebral palsy. Comparison between clinical evaluation and gait analysis in 60 patients. *Acta Orthopaedica,* 78(1), pp. 74-80.

Chrysagis, N., Skordilis, E. K., Stavo, N., Grammatopoulou, E., Koutsouki, D., 2012. The effect of treadmill training on gross motor function and walking speed on ambulatory adolescents with cerebral palsy: a randomised controlled trial. *American Journal iof Physical Medicine and Rehabilitation,* 91(9), pp. 747-760.

Debuse, D. & Brace, H., 2011. Outcome measures of activity for children with cerebral palsy: a systematic review. *Pediatric Physical Therapy,*23(3), pp. 222-231.

Donald , K. A., Walker, K. G., Kilborn, T,, Carrara, H., Langerak, N. G., Eley, B., Wilmhurst, J. M., 2015. HIV Encephalopathy: pediatric case series description and insights from the clinical coalface. *AIDS Research and Therapy,* 12(2), pp. 1-10.

Dzienkowski, R. C., Smith, K. K., Dillow, K. A. & Yucha, C. B., 1996. Cerebral palsy: a comprehensive review. *Nursing Practitioner,* 21(2), pp. 44-48.

Franki, I., Desloovere, K., De Cat, J., Feys, H., Molenaers, G., Calders, P., Vanderstraeten, G., Himpens, E., Van den Broeck, C., 2012. The evidence base for physical therapy techniques targetting lower-limb function in children with cerebral palsy: a systematic review using the International Classification of Functioning, Disability and Health as a conceptual framework. *Journal of Rehabilitation Medicine,* Volume 44, pp. 385-395.

Friedman, B-C. & Goldman, R. D., 2011. Use of botulinum toxin A in management of children with CP. *Canadian Family Physician,* Volume 57, pp. 1006-1008.

Godwin, E., Spero, C. R., Nof, L., Rosenthal, R. R., Ecthernach, J. L., 2009. Cerebral palsy and single-event multilevel sugery; Is there a relationship between level of function and intervention over time?. *Journal of Paediatric Orthopaedics,* Volume 29, pp. 910-915.

Gorton III, G. E., Abel, M. F., Offinger, D. J., Bagley, A., Rogers, S. P., Damiano, D,. Romness, M., Tylkowski, C., 2009. A prospective cohort study of the effects of lower extremity surgery on outcome measures in ambulatory children with cerebral palsy. *Journal of Paediatric Orthopaedics,* 29(8), pp. 903-909.

Govender, R., Eley, B., Walker, K., Petersen, R., Wilmshurst, J. M., 2001. Neurologic and neurobehavioral sequelae in children with Human Immunodeficiency Virus (HIV-1) infection. *Journal of child neurology,* 26(11), pp. 1355-1364.

Graham, K., 2005. Classifying cerebral palsy. *Journal of Paediatric Orthopaedics,* 25(1), pp. 127-128.

Graham, K., Harvey, A., Rodda, J., Nattrass, G. R., Pirpiris, M., 2004. The Functional Mobility Scale (FMS). *Journal of Pediatric Orthopaedics,* 24(5), pp. 514-520.

Gupta, S. & Raja, K., 2012. Responsiveness of Edinburgh Visual Gait Score to orthopaedic surgical intervention of the lower limbs in children with cerebral palsy. *American Journal of Physical Medicine and Rehabilitaton,* 91(9), pp. 761-767.

Hadders-Algra, M., 2014. Early diagnosis and early intervention in cerebral palsy. *Frontiers in Neurology,* Volume 5, pp. 1-7.

Hannah, S. E., Bartlett, D. J., Rivard, L. M. & Russell, D. J., 2008. Reference curves for the gross motor function measure: percentiles for clinic description and tracking over time for children with cerebral palsy. *Physical Therapy,* 88(5), pp. 598-607.

Harvey, A., Graham, K., Morris, M. E., Baker, R., Wolfe, R., 2007. The functional mobility scale: ability to detect change following single event multilevel surgery. *Developmental Medicine and Child Neurology,* Volume 49, pp. 603-607.

Harvey, A., Baker, R., Morris, M. E., Hough, J., Hughes, M., Graham, K., 2010. Does parent report measure performance? A study of the construct validity of the Functional Moblity Scale. *Developmental Medicine & Child Neurology,* Volume 52, pp. 181-185.

Harvey, A., Morris, M. E.,. Graham, K., Wolfe, R., Baker, R., 2010. The reliability of the functional mobility scale for children with cerebral palsy. *Physical & Occupational Therapy in Pediatrics,* 30(2), pp. 139-149.

Harvey, A., Rosenbaum, P., Hanna, S., Yousefi-Nooraie, R., Graham, K., 2012. Longitudinal changes in mobility following single-event multilevel surgery in ambulatory children with cerebral palsy. *Journal of Rehabilitation Medicine,* Volume 44, pp. 137-143.

Hayes, C., 2012. Cerebral palsy: classification, diagnosis and challenges of care. *British Journal of Nursing,* 19(6), pp. 368-373.

Hilburn, N., Potterton, J. & Stewart, A., 2010. Paediatric HIV encephalopathy in sub-Saharan Africa. *Physical Therapy Reviews,* 15(5), pp. 410-417.

Khan, M. A., 2007. Outcome of single-event multilevel surgery in untreated cerebral palsy in a developing country. *Journal of Bone and Joint Surgery [Br],* 89-B(8), pp. 1088-1091.

Knox, V. & Evans, A. L., 2002. Evaluation of the functional effects of a course of Bobath therapy in children with CP: A preliminary study. *Developmental Medicine and Child Neurology,* Volume 40, pp. 447-460.

Langerak, N. G., DuToit, J., Burger, M., Cotton, M. F., Springer, P. E., Laughton, B., 2014. Spastic diplegia in children with HIV encephalopathy: First description of gait and physical status. *Developmental Medicine and Child Neurology,* Volume 56, pp. 686-694.

Lowenthal, E. D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., Ferrand, r. A., 2014. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: A review of emerging challenges. *Lancet Infectious Diseases,* 14(7), pp. 627-639.

Luca, P. A. D., 1991. Gait analysis in the treatment of the ambulatory child with cerebral palsy. *Clinical Orthopaedics and Related Research,* Volume 264, pp. 65-75.

Lukban, M. B., Rosales, R. L. & Dressler, D., 2009. Effectiveness of botulinum toxin A for upper and lower limb spasticity in children with cerebral palsy: a summary of evidence. *Journal of Neural Transmission,* Volume 116, p. 319–331.

Maathuis, K., van der Schans, C. P., van Iperen, A., Rietman, H. S., Geertzen, J. H. B., 2005. Gait in children with cerebral palsy. Observer reliability of the Physicians Raitng Scale and the Edinburgh Visual Gait Analysis Interval Tesing Scale. *Journal of Paediatric Orthopaedics,* 25(3), pp. 268-272.

Martin, L., Baker, R. & Harvey, A., 2010. A systematic review of common physiotherapy interventions in school-aged children with cerebral palsy. *Physical & Occupational Therapy in Paediatrics,* 30(4), pp. 294-312.

Mayston, M., 2001. People with cerebral palsy: effects of and perspectives for therapy. *Neural Plasticity,* 8(1), pp. 51-66.

Mayston, M., 2008. Bobath Concept: Bobath @50: mid-life crisis -what of the future?. *Physiotherapy Research International,* 13(3), pp. 131-136.

McDowell, B., Kerr, C. & Parkes, J., 2007. Intraobserver agreement of the Gross Motor Function Classification System in a population of ambulant children with cerebral palsy. *Developmental Medicine and Child Neurology,* Volume 49, pp. 528-533.

McDowell, B., 2008. The Gross Motor Function Classification System-Expanded and revised. *Developmental Medicine and Child Neurology,* Volume 50, p. 725.

McGinnley, J., Dobson, F., Ganeshalingam, R., Shore, B. J., Rutz, E., Graham, K., 2012. Single-event multilevel surgery for children with cerebral palsy: a systematic review of the literature. *Developmental Medicine and Child Neurology,* Volume 54, pp. 117-128.

Mitchell, C., 2006. HIV-1 encephalopathy among perinatally infected children: Neurolopathogenesis and response to Highly Active Antroretroviral Therapy. *Mental Retardation and Developmental Disabilities Research Reviews,* Volume 12, pp. 216-222.

Mitchell, W., 2001. Neurological and developmental effects of HIV and AIDS in children and adolescents. *Mental Retardation and Developmental Disabilities Research Reviews,* Volume 7, pp. 211-216.

Morris, C. & Bartlett, D., 2004. The Gross Motor Function Classification System: impact and utility. *Developmental Medicine and Child Neurology,* Volume 46, pp. 60-65.

Morris, C., 2008. The Gross Motor Function Function Classification System- Expanded and Revised. *Developmental Medicine and Child Neurology,* Volume 50, p. 725.

Mutlu, A., Krosschell, K. & Spira, D. G., 2009. Treadmill training with partial body-weight support in children with cerebral palsy: a systematic review. *Developmental Medicine and Child Neurology.,* Volume 51, pp. 268-275.

Narayanan, U., 2012. Management of ambulatory cerebral palsy: an evidence-based review. *Journal of pediatric orthopaedics,* 32(2), pp. 172-181.

Nixon, S.,Forman, l., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H., 2011. Rehabilitation: A crucial component in the future of HIV care and support. *The Southern African Joural of HIV Medicine,* 12(2).

Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Wilson, S., Goldsmith, S., Stumbles, E., 2013. A systematic review of interventions for children with cerebral palsy: a state of the evidence. *Developmental Medicine and Child Neurology,* Volume 55, pp. 885-910.

Offinger, D., Bagley, A., Rogers, S., Gorton, G., Kryscio, R., Abel, M., Diamano, D., Barnes, D., Tylkowski, C., 2008. Outcome tools used for ambulatory children with cerebral palsy: responsiveness and minumum clinically important differences. *Developmental Medicine and Child Neurology,* 50(12), pp. 918-925.

Ong, A. M., Hillman, S. J. & Robb, J. E., 2008. Reliability and validity of the Edinburg Visual Gait Score for cerebral palsy when used by inexperienced observers. *Gait and Posture,* Volume 28, pp. 323-326.

Palisano, R., Rosenbaum, P., Bartlett, D. & Livingston, M. H., 2008. Content validity of the expanded and revised Gross Motor function Classification System. *Developmental Medicine and Child Neurology,* Volume 50, pp. 744-750.

Patel, K., Ming, Xue, Williams, P. L., Robertson, K. R., Oleske, J. M., Seage, G. R., 2009. Impact of HAART and CNS-penetrating antiretroviral regimens on HIV encephalopathy among perinatally infected children and adolescents. *AIDS,* 23(14), pp. 1893-1901.

Potterton, J., Stewart, A., Cooper, P. & Becker, P., 2010. The effect of a basic home stimulation programme on the development of young children infected with HIV. *Developmental Mdeicine and Child Neurology,* 52(6), pp. 547-551.

Potterton, J. & Van Aswegen, H., 2006. Paediatric HIV in South Africa: An overview for physiotherapists. *South African Journal of Physiotherapy,* 62(1), pp. 19-22.

Read, H. S., Hazelwood, E., Hillman, S. J., Prescott, R. J., Robb, J. E., 2003. The Edinburgh Visual Gait Score for use in cerebral palsy..*Journal of Paediatrics Orthopaedics,* 23(3), pp. 296-301.

Rodda, J., Graham, K., Nattrass, J., Galea, M., Baker, R., Wolfe, R., 2006. Correction of severe crouch gait in patients with spastic diplegia with the use of multilevel orthopaedic surgery. *Journal of Bone and Joint Surgery,* 88(A), pp. 2653-2664.

Rosenbaum, P., Dan, B., Leviton, A., Paneht, N., Jacobsson, B., Goldstein, M., Bax, M., 2005. The proposed definition and classification of cerebral palsy, April 2005. *Developmental Medicine and Child Neurology,* Volume 47, pp. 571-576.

Russel, D., Avery, L. M., Rosenbaum, P. L., Raina, P. S., Walter, S. D., Palisane, R. J., 2000. Improved scaling of the Gross Motor Function Measure for children with cerebral palsy: evidence of reliability and validity. *Physical Therapy,* 80(9), pp. 873-885.

Russel, D. J., Rosenbaum, P. L., Avery, L. M. & Lane, M., 2002. *Gross Motor Function Measure (GMFM-88 & GMFM-66) User's mannual.* Plymouth: Mac Keith Press.

Rutz, E., Baker, R., Tirosh, O. & Brunner, R., 2013. Are results in single event multilevel surgery in cerebral palsy durable?. *Clinical Orthopaecis and Related Research,* Volume 471, pp. 1028-1038.

Rutz, E., Tirosh, O., Thomason, P., Barg, A., Graham, K., 2012. Stability of the Gross Motor Function Classification System after single-event multilevel surgery in children with Cerebral Palsy. *Developmental Medicine and Child Neurology,* Volume 54, pp. 1109-1113.

Sheean, G., 2002. The pathophysiology of spasticity. *European Journal Of Neurology,* 9(1), pp. 3-9.

Shula, P. & Rihtman, T., 2008. Participation of children with cerebral palsy in leisure activities supports the current ICF health paradigm. *Developmental Medicine and Child Neurology,* Volume 50, p. 726.

Svehlik, M., Steinwender, G., Kraus, T., Saraph, V., Lehmann, T., Linhart, W. E., Zwick, E. B., 2011. The influence of age at single-event multilevel surgery on outcome in children with cerebral palsy who walk with flexed knee gait. *Developmental Medicine and Child Neurology,* Volume 53, pp. 730-735.

Thomason, P., Baker, R., Dodd, K., Taylor, N., Selber, P., Wolfe, R., Graham, K., 2011. Single-event multilevel surgery in children with spastic diplegia; a pilot randomised controlled trial. *The Journal of Bone and Joint Surgery,* 93-A(5), pp. 451-460.

Thomason, P., Rodda, J., Sangeux, M., Selber, P., Graham, K., 2012. Management of children with ambulatory cerebral palsy: an evidence-based review. Commentary by the Hugh Williamson Gait Laboratory staff. *Journal of Pediatric Orthopaedics,* 32(2), pp. 182-186.

Thomason, P., Selber, P. & Graham, K., 2013. Single event multilevel surgery in children with bilateral spastic cerebral palsy: a 5 year prospective cohort study. *Gait and Posture,* Volume 37, pp. 23-38.

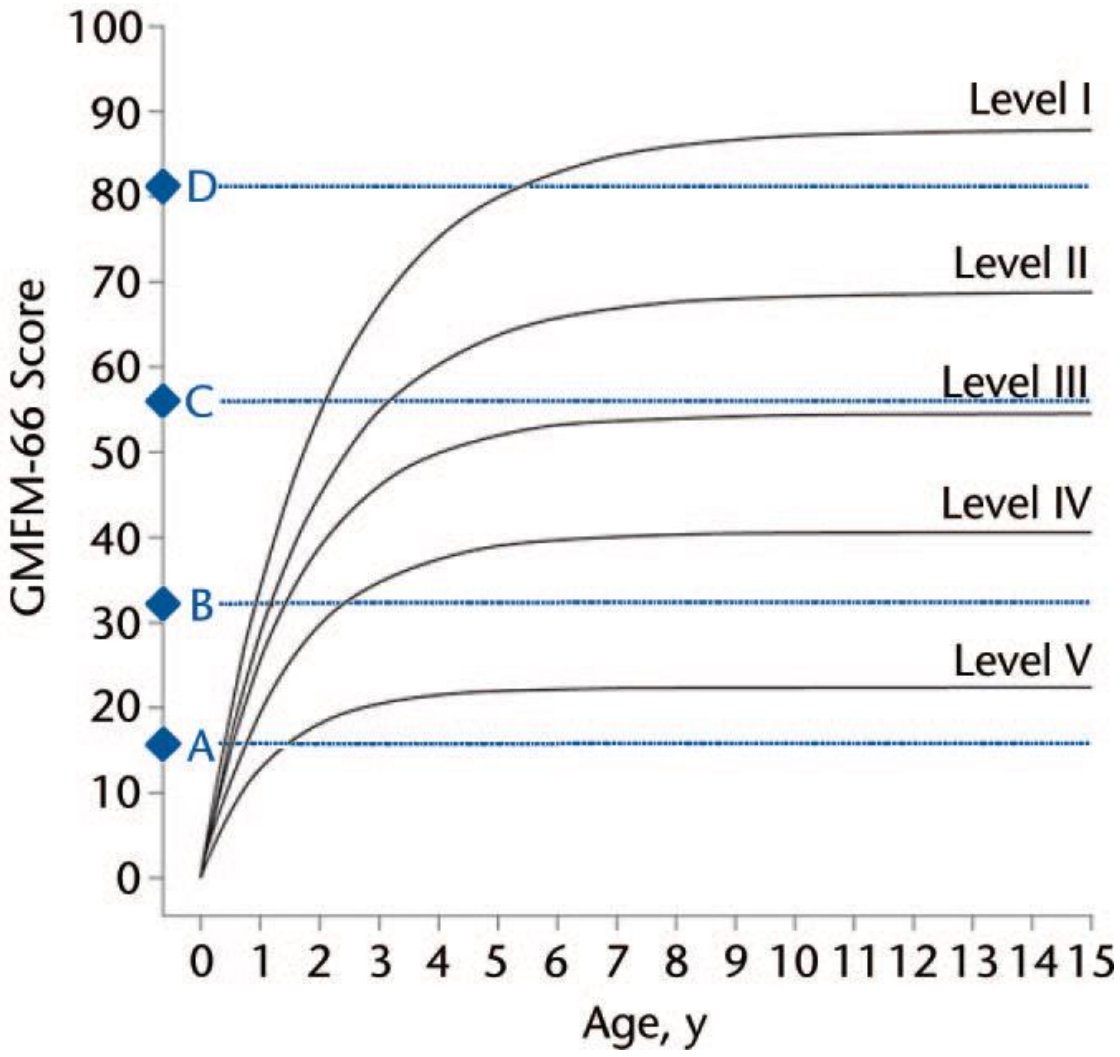
Viehweger, E., Zurcher Pfund, L., Helix, M., Rohon, M. A., Jacquemier, M., Scavarda, D., Jouve, J. L., Bollini, G., Loundou, A., Simeoni, M. C., 2010. Influence of clinical and gait analysis experience on reliability of observational gait analysis. *Annals of Physical and Rehabilitation Medicine,* Volume 53, pp. 535-546.

Willoughby, K. L., Dodd, K. J. & Shields, N., 2009. A systematic review of the effectiveness of treadmill training for children with cerebral palsy. *Disability and Rehabilitation,* 31(24), pp. 1971-1979.

Wren, T. A. L., Lening, C., Rethlefsen, S. A. & Kay, R. M., 2013. Impact of gait analysis on correction of excessive hip internal in ambulatory children with cerebral palsy: a randomised controlled trial. *Developmental Medicine and Child Neurology,* Volume 55, pp. 919-927.

Yeargin-Allsopp, M., 2011. Distribution of motor types in cerebral palsy: how do registry data compare?. *Developmental Medicine & Child Neurology ,* Volume 53, pp. 197-201.

Appendix I: Gross Motor Function Curves



(Hannah, et al., 2008)

Appendix II: Summary of the systematic reviews on the physiotherapy management of children with CP.

Study (year)	Studies reviewed (number)	Therapies investigated (number, High level of evidence(HLE))	Outcomes
Anttila et al (2008)	Published, full-length articles or full written reports of RCTs since 1990. (n= 22)	• Comprehensive physiotherapy approaches including Neurodevelopmental therapy (NDT) (n=6, HLE=1) • Upper extremity treatments (n=4, HLE=2) • Strength training programs (n=4, HLE=0) • Constraint induced therapy (n=2, HLE=1) • Cardiovascular fitness and aerobic training programs (n=2, HLE=1) • Sensorimotor training programs (n=1, HLE=0) • Balance training (n=1, HLE=0) • Therapy with animals (n=2, HLE=0)	• Limited, contradicting evidence of effectiveness of NDT. • Moderate evidence of effectiveness on hand function and ADLS. • Moderate evidence of ineffectiveness for strength training. Conflicting evidence for HEP. • Moderate evidence of effectiveness on hand function. • Limited evidence showing effectiveness at body structure and function level. • Limited evidence with short-term effects. • Limited evidence with some effectiveness at the body structure and function level. • Limited evidence with no effectiveness on muscle symmetry.
Martin et al (2011)	Published, full text articles from 1995 to October 2009 (n= 35)	• Strength training (n=16, HLE=7) • Functional training (n=5, HLE=3) • Body-weight supported treadmill training (n=6, HLE=1) • NDT (n=3, HLE=1)	• Significant improvement in strength at follow-up in the majority of the studies. • Significant improvement at the body structure and functioning as well as at the activity level. • Contradicting findings, with generally non-significant outcomes which were not sustained. • Significant improvements on the GMFM with high intensity of therapy.
Franki et al (2012)	Full text, original articles published from 1995 to December 2009 (n=83)	• Stretching (n=5, reviews=3, intervention=2) • Massage (n=4) • Strengthening (n=26, reviews=6, interventions=20) • Electrical stimulation (n=13) • Weight-bearing (n=7, reviews=1, intervention=6) • Balance training (n=6, reviews=1, intervention=5) • Treadmill training (n=13, reviews=3, intervention=10) • Endurance training (n=10, reviews=2, interventions=8)	• Weak evidence on effectiveness, with one study stating significant change at the body structure and function level. • Significant change noted at the body structure and function level in one study, and improvement at the personal level in three studies. • Isotonic strength training showed significant improvements at the body structure and function level as well as at the activity level. Functional strength training only showed significant improvement at the body structure and function level. High level of evidence was found for isokinetic strength training at all levels of the ICF. • More significant change in the body structure and function level as well as in the activity level seen when using neuromuscular nerve stimulation in comparison to threshold electrical stimulation. However one study of high level of evidence comparing the two found no significant difference. • There was a high level of evidence showing positive effects at the body structure and functioning level, but no significant change at the activity and participation level. • Improvements were noted at the body structure and functioning level as well as at the activity level in some studies. • Low level of evidence for positive effects at body structure and function level as well as at activity level • High level of evidence was found for improvements at body structure and function level, activity level, participation level and quality of life.
Novak et al (2013)	Systematic reviews published from 1935 to 2013, if no systematic reviews were found for a specific intervention, studies with a lower level of evidence were included. (n=166)	• Animal-assisted therapy (n=2, HLE=0) • Bimanual training (n=2, HLE=2) • Casting (n=14, HLE=13)	• Studies conducted were of poor quality. Some evidence to show improvement in emotional well-being and independence. “Yellow-light.”* • Studies of good quality to show improvement in hand function. “Green-light.” • Poor quality studies conducted. There is evidence to support the use of casting in the lower limbs, but not in the upper limbs or with botulinum toxin. “Green-light” for lower limbs,

		• Coaching parents (n=1, HLE=0) • Constraint-induced movement therapy (n=5, HLE=5) • Context-focussed therapy (n=1, HLE=1) • Early intervention (n=7, HLE=7) • Electrical stimulation (n=6, HLE=6) • Fitness training (n=7, HLE=7) • Goal-directed therapy (n=7, HLE=7) • Home programmes (n=3, HLE=3) • Hydrotherapy (n=3, HLE=3) • Massage therapy (n=8, HLE=8) • NDT (n=7, HLE=7) • Parent training (n=1, HLE=1) • Strength training (n=10, HLE=10) • Stretching (n=4, HLE=4) • Treadmill training (n=5, HLE=5) • Vojta (n=7, HLE=7)	"Yellow light" of upper limbs and botulinum toxin. • Very low quality evidence to show improved parent handling skills and coping. "Yellow-light." • Moderate quality of evidence to show improvement in hand function. "Green-light." • A single study of high quality showing improvement in function. "Green-light." • Studies of moderate to low quality showing improvement in motor function and cognition. "Yellow-light." • Evidence of moderate to low quality showing improvement in gait parameters and muscle strength. "Yellow-light." • Moderate quality of evidence showing improvement in aerobic fitness, activity and participation. "Green-light" for aerobic fitness, "Yellow-light" for activity and participation. • Moderate to high quality of evidence to show improvement in motor function and hand function. "Green-light" for hand function and "Yellow-light" for motor function. • Evidence of moderate quality showing improvement in the completion of functional tasks and participation. "Green-light" for functional tasks, and "Yellow-light" for participation. • Poor quality evidence to support improved vitals and gross motor function. "Yellow-light." • The studies conducted were of poor quality. There is conflicting evidence that it decreases pain, increase ROM and improves function. "Yellow-light." • Poor quality of evidence to show that it does not normalise movement patterns, it does not prevent contractures and does improve function. "Red-light" for movement patterns and contracture prevention, "Yellow-light" for improvement in function. • Evidence of poor quality to support improvement of parenting skills. "Yellow-light." • Poor quality evidence to support improvement in upper and lower limb strength. "Yellow-light." • Insufficient evidence to show improvement in muscle length and contracture prevention. "Yellow-light." • Evidence of poor quality showing improved weight-bearing and functional gait. "Yellow-light." • Poor quality evidence to show improvement in strength and movement. "Yellow-light."

*Interventions were graded according to a traffic light system. "Green-light"- do it, "Yellow-light"- probably do it, and "Red-light"- do not do it.

Appendix III- The Edinburgh Visual Gait Score

Stance					
	Flexion		Normal		Extension
Foot	2	1	0	1	2
1. Initial contact			Heel contact	Flatfoot contact	Toe contact
2. Heel lift	No forefoot contact	Delayed	Normal	Early	No heel contact
3. Max ankle dorsiflexion	Excessive dorsiflxn (>40° df)	Increased dorsiflxn (26°–40° df)	Normal dorsiflxn (5°–25° df)	Reduced dorsiflxn (10° pl–4° df)	Marked plantarflxn (>10° pl)
4. Hindfoot varus/ valgus	Severe valgus	Mod valgus	Neutral/slight valgus	Mild varus	Severe varus
5. Foot rotation	Marked extn >KPA (by >40°)	Mod ext >KPA (by 21°–40°)	SI more extn than KPA (by 0°–20°)	Mod int >KPA (by 1°–25°)	Marked int >KPA (by >25°)
Knee					
8. Knee progression angle	External, part knee cap visible	External, all knee cap visible	Neutral, knee cap midline	Internal, all knee cap visible	Internal, part knee cap visible
9. Peak extn stance	Severe flexn (>25°)	Mod flexn (16°–25°)	Normal (0°–15° flexn)	Mod hyperextn (1°–10°)	Severe hyperextn (>10°)
Hip					
12. Peak extn stance	Severe flexn (>15°)	Mod flexn (1°–15° flxn)	Normal (0°–20° extn)	Mod hyperextn (21°–35° extn)	Marked hyperextn (>35°)
Pelvis					
14. Obliquity at mid stance	Marked down (>10°)	Mod down (1°–10°)	Normal obliquity (0°–5° up)	Mod up (6°–15°)	Marked up (>15°)
15. Rotation at mid stance	Marked retraction (>15°)	Mod retraction (6°–15°)	Normal (5° retr–10° pro)	Mod protraction (11°–20°)	Severe protraction (>20°)
Trunk					
16. Peak sagittal position	Marked forward	Mod forward lean	Normal upright	Mod backward lean	N/A
17. Max lateral shift	Marked	Mod	Normal	Reduced	N/A

Swing					
	Flexion		Normal		Extension
Foot	2	1	0	1	2
6. Clearance in swing		High steps	Full	Reduced	None
7. Max ankle dorsiflexion	Excessive dorsiflxn (>30° df)	Increased dorsiflxn (16°–30° df)	Normal dorsiflxn (15° df–5° pl)	Mod plantarflxn (6°–20° pl)	Marked plantarflxn (>20° pl)
Knee					
10. Terminal swing	Severe flexn (>30°)	Mod flexn (16°–30°)	Normal (5°–15° flxn)	Mod overextn (4° flx–10° xtn)	Severe hyperextn (>10° xtn)
11. Peak flexn swing	Severely increased (>85° flxn)	Mod increased (71°–85° flxn)	Normal (50°–70° flxn)	Mod reduced (35°–49° flxn)	Severely reduced (<35° flxn)
Hip					
13. Peak flexion swing	Marked increase (>60° flxn)	Increased flexn (46°–60° flxn)	Normal flexn (25°–45° flxn)	Reduced flexn (10°–24° flxn)	Severely reduced (<10° flxn)

Appendix IV- The Gross Motor Function Measure

GROSS MOTOR FUNCTION MEASURE (GMFM)
SCORE SHEET (GMFM-88 and GMFM-66 scoring)

Child's Name: _____ ID#: _____

Assessment Date: _____ year / month / day

GMFCS Level[1]: ☐ I ☐ II ☐ III ☐ IV ☐ V

Date of Birth: _____ year / month / day

Chronological Age: _____ year / month / day

Evaluator's Name: _____

Testing Condition (e.g., room, clothing, time, others present):

_____ _____ _____

The GMFM is a standardized observational instrument designed and validated to measure change in gross motor function over time in children with cerebral palsy. The scoring key is meant to be a general guideline. However, most of the items have specific descriptors for each score. It is imperative that the guidelines contained in the manual be used for scoring each item.

SCORING KEY

0 = does not initiate
1 = initiates
2 = partially completes
3 = completes
9 (or leave blank) = not tested (NT) [used for the GMAE-2 scoring*]

It is important to differentiate a true score of "0" (child does not initiate) from an item which is Not Tested (NT) if you are interested in using the GMFM-88 Ability Estimator (GMAE) Software.

*The GMAE-2 software is available for downloading from www.canchild.ca for those who have purchased the GMFM manual. The GMFM-66 is only valid for use with children who have cerebral palsy.

Contact for Research Group:
CanChild Centre for Childhood Disability Research,
Institute for Applied Health Sciences, McMaster University,
1400 Main St. W., Room 408,
Hamilton, ON Canada L8S 1C7
Email: canchild@mcmaster.ca Website: www.canchild.ca

[1]GMFCS level is a rating of severity of motor function. Definitions for the GMFCS-E&R (expanded & revised) are found in Palisano et al. (2008). Developmental Medicine & Child Neurology, 50:744-750 and in the GMAE-2 scoring software. http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf

Check (3) the appropriate score: If an item is not tested (NT), circle the item number on the right column

	Item	A: LYING & ROLLING	SCORE				NT
	1.	SUP, HEAD IN MIDLINE: TURNS HEAD WITH EXTREMITIES SYMMETRICAL	0☐	1☐	2☐	3☐	1.
*	2.	SUP: BRINGS HANDS TO MIDLINE, FINGERS ONE WITH THE OTHER	0☐	1☐	2☐	3☐	2.
	3.	SUP: LIFTS HEAD 45°	0☐	1☐	2☐	3☐	3.
	4.	SUP: FLEXES R HIP & KNEE THROUGH FULL RANGE	0☐	1☐	2☐	3☐	4.
	5.	SUP: FLEXES L HIP & KNEE THROUGH FULL RANGE	0☐	1☐	2☐	3☐	5.
*	6.	SUP: REACHES OUT WITH R ARM, HAND CROSSES MIDLINE TOWARD TOY	0☐	1☐	2☐	3☐	6.
*	7.	SUP: REACHES OUT WITH L ARM, HAND CROSSES MIDLINE TOWARD TOY	0☐	1☐	2☐	3☐	7.
	8.	SUP: ROLLS TO PR OVER R SIDE	0☐	1☐	2☐	3☐	8.
	9.	SUP: ROLLS TO PR OVER L SIDE	0☐	1☐	2☐	3☐	9.
*	10.	PR: LIFTS HEAD UPRIGHT	0☐	1☐	2☐	3☐	10.
	11.	PR ON FOREARMS: LIFTS HEAD UPRIGHT, ELBOWS EXT., CHEST RAISED	0☐	1☐	2☐	3☐	11.
	12.	PR ON FOREARMS: WEIGHT ON R FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD	0☐	1☐	2☐	3☐	12.
	13.	PR ON FOREARMS: WEIGHT ON L FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD	0☐	1☐	2☐	3☐	13.
	14.	PR: ROLLS TO SUP OVER R SIDE	0☐	1☐	2☐	3☐	14.
	15.	PR: ROLLS TO SUP OVER L SIDE	0☐	1☐	2☐	3☐	15.
	16.	PR: PIVOTS TO R 90° USING EXTREMITIES	0☐	1☐	2☐	3☐	16.
	17.	PR: PIVOTS TO L 90° USING EXTREMITIES	0☐	1☐	2☐	3☐	17.

TOTAL DIMENSION A ☐

	Item	B: SITTING	SCORE				NT
*	18.	SUP, HANDS GRASPED BY EXAMINER: PULLS SELF TO SITTING WITH HEAD CONTROL	0☐	1☐	2☐	3☐	18.
	19.	SUP: ROLLS TO R SIDE, ATTAINS SITTING	0☐	1☐	2☐	3☐	19.
	20.	SUP: ROLLS TO L SIDE, ATTAINS SITTING	0☐	1☐	2☐	3☐	20.
*	21.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD UPRIGHT, MAINTAINS 3 SECONDS	0☐	1☐	2☐	3☐	21.
*	22.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD MIDLINE, MAINTAINS 10 SECONDS	0☐	1☐	2☐	3☐	22.
*	23.	SIT ON MAT, ARM(S) PROPPING: MAINTAINS, 5 SECONDS	0☐	1☐	2☐	3☐	23.
*	24.	SIT ON MAT: MAINTAIN, ARMS FREE, 3 SECONDS	0☐	1☐	2☐	3☐	24.
*	25.	SIT ON MAT WITH SMALL TOY IN FRONT: LEANS FORWARD, TOUCHES TOY, RE-ERECTS WITHOUT ARM PROPPING	0☐	1☐	2☐	3☐	25.
*	26.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S R SIDE, RETURNS TO START	0☐	1☐	2☐	3☐	26.
*	27.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S L SIDE, RETURNS TO START	0☐	1☐	2☐	3☐	27.
	28.	R SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS	0☐	1☐	2☐	3☐	28.
	29.	L SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS	0☐	1☐	2☐	3☐	29.
*	30.	SIT ON MAT: LOWERS TO PR WITH CONTROL	0☐	1☐	2☐	3☐	30.
*	31.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER R SIDE	0☐	1☐	2☐	3☐	31.
*	32.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER L SIDE	0☐	1☐	2☐	3☐	32.
	33.	SIT ON MAT: PIVOTS 90°, WITHOUT ARMS ASSISTING	0☐	1☐	2☐	3☐	33.
*	34.	SIT ON BENCH: MAINTAINS, ARMS AND FEET FREE, 10 SECONDS	0☐	1☐	2☐	3☐	34.
*	35.	STD: ATTAINS SIT ON SMALL BENCH	0☐	1☐	2☐	3☐	35.
*	36.	ON THE FLOOR: ATTAINS SIT ON SMALL BENCH	0☐	1☐	2☐	3☐	36.
*	37.	ON THE FLOOR: ATTAINS SIT ON LARGE BENCH	0☐	1☐	2☐	3☐	37.

TOTAL DIMENSION B ☐

Item		C: CRAWLING & KNEELING	SCORE				NT
	38.	PR: CREEPS FORWARD 1.8m (6')	0☐	1☐	2☐	3☐	38.
*	39.	4 POINT: MAINTAINS, WEIGHT ON HANDS AND KNEES, 10 SECONDS	0☐	1☐	2☐	3☐	39.
*	40.	4 POINT: ATTAINS SIT ARMS FREE	0☐	1☐	2☐	3☐	40.
*	41.	PR: ATTAINS 4 POINT, WEIGHT ON HANDS AND KNEES	0☐	1☐	2☐	3☐	41.
*	42.	4 POINT: REACHES FORWARD WITH R ARM, HAND ABOVE SHOULDER LEVEL	0☐	1☐	2☐	3☐	42.
*	43.	4 POINT: REACHES FORWARD WITH L ARM, HAND ABOVE SHOULDER LEVEL	0☐	1☐	2☐	3☐	43.
*	44.	4 POINT: CRAWLS OR HITCHES FORWARD 1.8m(6')	0☐	1☐	2☐	3☐	44.
*	45.	4 POINT: CRAWLS RECIPROCALLY FORWARD1.8m (6')	0☐	1☐	2☐	3☐	45.
*	46.	4 POINT: CRAWLS UP 4 STEPS ON HANDS AND KNEES/FEET	0☐	1☐	2☐	3☐	46.
	47.	4 POINT: CRAWLS BACKWARDS DOWN 4 STEPS ON HANDS AND KNEES/FEET	0☐	1☐	2☐	3☐	47.
*	48.	SIT ON MAT: ATTAINS HIGH KN USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0☐	1☐	2☐	3☐	48.
	49.	HIGH KN: ATTAINS HALF KN ON R KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0☐	1☐	2☐	3☐	49.
	50.	HIGH KN: ATTAINS HALF KN ON L KNEE USING ARMS, MAINTAINS, ARMS FREE, 10 SECONDS	0☐	1☐	2☐	3☐	50.
*	51.	HIGH KN: KN WALKS FORWARD 10 STEPS, ARMS FREE	0☐	1☐	2☐	3☐	51.
		TOTAL DIMENSION C					

Item		D: STANDING	SCORE				NT
*	52.	ON THE FLOOR: PULLS TO STD AT LARGE BENCH	0☐	1☐	2☐	3☐	52.
*	53.	STD: MAINTAINS, ARMS FREE, 3 SECONDS	0☐	1☐	2☐	3☐	53.
*	54.	STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS R FOOT, 3 SECONDS	0☐	1☐	2☐	3☐	54.
*	55.	STD: HOLDING ON TO LARGE BENCH WITH ONE HAND, LIFTS L FOOT, 3 SECONDS	0☐	1☐	2☐	3☐	55.
*	56.	STD: MAINTAINS, ARMS FREE, 20 SECONDS	0☐	1☐	2☐	3☐	56.
*	57.	STD: LIFTS L FOOT, ARMS FREE, 10 SECONDS	0☐	1☐	2☐	3☐	57.
*	58.	STD: LIFTS R FOOT, ARMS FREE, 10 SECONDS	0☐	1☐	2☐	3☐	58.
*	59.	SIT ON SMALL BENCH: ATTAINS STD WITHOUT USING ARMS	0☐	1☐	2☐	3☐	59.
*	60.	HIGH KN: ATTAINS STD THROUGH HALF KN ON R KNEE, WITHOUT USING ARMS	0☐	1☐	2☐	3☐	60.
*	61.	HIGH KN: ATTAINS STD THROUGH HALF KN ON L KNEE, WITHOUT USING ARMS	0☐	1☐	2☐	3☐	61.
*	62.	STD: LOWERS TO SIT ON FLOOR WITH CONTROL, ARMS FREE	0☐	1☐	2☐	3☐	62.
*	63.	STD: ATTAINS SQUAT, ARMS FREE	0☐	1☐	2☐	3☐	63.
*	64.	STD: PICKS UP OBJECT FROM FLOOR, ARMS FREE, RETURNS TO STAND	0☐	1☐	2☐	3☐	64.
		TOTAL DIMENSION D					

Item		E: WALKING, RUNNING & JUMPING	SCORE				NT
*	65.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO R	0☐	1☐	2☐	3☐	65.
*	66.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO L	0☐	1☐	2☐	3☐	66.
*	67.	STD, 2 HANDS HELD: WALKS FORWARD 10 STEPS	0☐	1☐	2☐	3☐	67.
*	68.	STD, 1 HAND HELD: WALKS FORWARD 10 STEPS	0☐	1☐	2☐	3☐	68.
*	69.	STD: WALKS FORWARD 10 STEPS	0☐	1☐	2☐	3☐	69.
*	70.	STD: WALKS FORWARD 10 STEPS, STOPS, TURNS 180°, RETURNS	0☐	1☐	2☐	3☐	70.
*	71.	STD: WALKS BACKWARD 10 STEPS	0☐	1☐	2☐	3☐	71.
*	72.	STD: WALKS FORWARD 10 STEPS, CARRYING A LARGE OBJECT WITH 2 HANDS	0☐	1☐	2☐	3☐	72.
*	73.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS BETWEEN PARALLEL LINES 20cm (8") APART	0☐	1☐	2☐	3☐	73.
*	74.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS ON A STRAIGHT LINE 2cm (3/4") WIDE	0☐	1☐	2☐	3☐	74.
*	75.	STD: STEPS OVER STICK AT KNEE LEVEL, R FOOT LEADING	0☐	1☐	2☐	3☐	75.
*	76.	STD: STEPS OVER STICK AT KNEE LEVEL, L FOOT LEADING	0☐	1☐	2☐	3☐	76.
*	77.	STD: RUNS 4.5m (15'), STOPS & RETURNS	0☐	1☐	2☐	3☐	77.
*	78.	STD: KICKS BALL WITH R FOOT	0☐	1☐	2☐	3☐	78.
*	79.	STD: KICKS BALL WITH L FOOT	0☐	1☐	2☐	3☐	79.
*	80.	STD: JUMPS 30cm (12") HIGH, BOTH FEET SIMULTANEOUSLY	0☐	1☐	2☐	3☐	80.
*	81.	STD: JUMPS FORWARD 30 cm (12"), BOTH FEET SIMULTANEOUSLY	0☐	1☐	2☐	3☐	81.
*	82.	STD ON R FOOT: HOPS ON R FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE	0☐	1☐	2☐	3☐	82.
*	83.	STD ON L FOOT: HOPS ON L FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE	0☐	1☐	2☐	3☐	83.
*	84.	STD, HOLDING 1 RAIL: WALKS UP 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET	0☐	1☐	2☐	3☐	84.
*	85.	STD, HOLDING 1 RAIL: WALKS DOWN 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET	0☐	1☐	2☐	3☐	85.
*	86.	STD: WALKS UP 4 STEPS, ALTERNATING FEET	0☐	1☐	2☐	3☐	86.
*	87.	STD: WALKS DOWN 4 STEPS, ALTERNATING FEET	0☐	1☐	2☐	3☐	87.
*	88.	STD ON 15cm (6") STEP: JUMPS OFF, BOTH FEET SIMULTANEOUSLY	0☐	1☐	2☐	3☐	88.

TOTAL DIMENSION E ☐

Appendix V- The Functional Mobility Scale

Rating **6**

Independent on all surfaces:

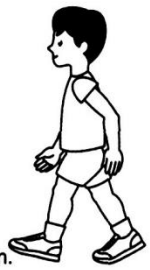
Does not use any walking aids or need any help from another person when walking over all surfaces including uneven ground, curbs etc., and in a crowded environment.

Rating **5**

Independent on level surfaces:

Does not use walking aids or need help from another person. *Requires a rail for stairs.

*If uses furniture, walls, fences, shop fronts for support, please use 4 as appropriate description.



Rating **4**

Uses sticks (one or two):

Without help from another person.

Walking distance	Rating: select the number (from 1–6) which best *describes current function*
5 metres (yards)	
50 metres (yards)	
500 metres (yards)	

Rating **3**

Uses crutches:

Without help from another person.

Rating **2**

Uses a walker or frame:

Without help from another person.

Rating **1**

Uses wheelchair:

May stand for transfers, may do some stepping supported by another person or using a walker/frame.

Rating **C**

Crawling:

Child crawls for mobility at home (5m).

Rating **N**

N = does not apply:

For example, child does not complete the distance (500m).

Appendix IV- Parent information sheet and consent form

Parent information sheet for patients undergoing surgery

PARENT INFORMATION SHEET

Dear Parent.

Hello. My name is Linda Wood and I am a physiotherapist working at Chris Hani Baragwanath Academic Hospital Physiotherapy Department. I am currently doing a study looking at the recovery of children with cerebral palsy after the operation known as single event multilevel surgery, as discussed in the pamphlet that you received. As you have already discussed with the doctors your child will benefit from this operation. As a result your child has been identified as a possible participant in our study.

Reasons for conducting the study
We would like to find out how the walking ability of children with CP improves or changes after the operation. We want to look at how your child was walking before the operation and compare this to how your child walks after the operation. All the information will be used to look at how the operation helps children with CP and whether the physiotherapy programme works well or if it needs to be changed.

What does the study entail?
Your child will be booked into two out-patient physiotherapy sessions before the date of the operation. In these sessions your child will be given a home exercise programme, which will be practiced and demonstrated during the physiotherapy appointment. We will also look at what your child is able to do and how your child walks using standard tests. The standard tests include a video assessment of your child walking. These tests will not harm your child in any way. During the therapy sessions you will also be asked to complete a questionnaire about your daily habits. After the two physiotherapy appointments your child will be given a date when they will be admitted for the operation. During the hospital stay your child will receive physiotherapy on week days. After discharge from the hospital you will have to come back a week later for a check up with the doctors and a physiotherapy appointment. Your physiotherapy appointments will then continue as needed. At six months and one year after the operation you will need to bring your child back to the hospital for a doctors appointment and so that we can complete the assessments again.

Taking part in this research study is voluntary and no person will be advantaged or disadvantaged in any way from choosing to participate or not to participate in this study.
All of your child's information will be kept confidential and no information that could identify you would be used in the research report. You may choose to withdraw from the study at any stage.

The participation of you and your child in this research would be greatly appreciated. This information is important to us at the physiotherapy department in order to provide the best service to you and your child as well as to other patients.

Thank you for your time.
If there are any questions or any other information that you may require please feel free to contact the researcher at Chris Hani Baragwanath Academic Hospital Physiotherapy Department.

Linda Wood
0711743887

CONSENT FORM

Research problem: To look at the changes in walking pattern of children with CP after the operation known as single event multilevel surgery. The assessment will be done before the operation, and at six months and one year after the operation. Standard tests will be used to see if there is any change.

I _____ understand the purpose of the study and give consent for my child _____ to participate in the research. I have read and understand the information and all my questions have been answered. I am fully aware of the procedures and the fact that the assessments will not harm my child in any way. I am aware that I may withdraw my child from the research without any prejudice towards my child or myself.

_____	_____
Caregiver	Researcher
_____	_____
Date	Date

Appendix VII- Patient information sheet and assent form

Patient information sheet for patients undergoing surgery

PATIENT INFORMATION SHEET

Dear patient.

Hello. My name is Linda Wood and I am a physiotherapist working at Chris Hani Baragwanath Academic Hospital Physiotherapy Department. I am currently doing a study to look at how children manage after they have had a surgery like the one you are going to have. If you would like to you can be a part of my study.

What you need to do to be a part of the study?
To be a part of the study you will have to do some easy exercises to see how well you can do them. We will ask your mom/dad about how you walk at home and at school and we will also take a video of you walking, so that we can have a proper look at how you walk. These tests will be done 3 times, before the operation, 6 months after the operation and 1 year after the operation.

You can decide whether you want to be a part of the study or not. If you change your mind during the study and don't want to be a part of it anymore, that is also ok. You will not be treated any differently if you decide that you do not want to be part of the study. None of the tests that we will do for the study will cause any pain.

It would really help me a lot if you decide to be a part of the study.

If you have any questions please ask me or any of the doctors.

Linda Wood

0119338309

ASSENT FORM

I _____ say that it is ok for the physiotherapists to test me for this project. I understand what this project is about and I understand what I am expected to do as a part of the study. I understand what has been explained to me about the surgery, the recovery, the importance of exercise and the tests that will be done to look at my walking. I know that taking part in the assessments for the study will not harm me in any way. I am aware that I may say that I do not want to be tested in for this study.

_____ _____

Patient Researcher

_____ _____

Date Date

Appendix VIII- Patient information sheet

SURGERY FOR CHILDREN WITH CP!

WHAT IS CP?

Cerebral palsy, or CP is the term used for children who had an injury to the brain either before birth, during birth or just after birth. The brain tells the rest of our body what to do. It helps us move, think and speak. If the brain is damaged it can effect one or more of these abilities. The brain damage is permanent, so although children with CP improve over time they will always find certain tasks difficult, like walking.

WHY DO WE DO SURGERY FOR CHILDREN WITH CP?

The damaged brain is unable to send the proper message to the muscles of the arms and legs. This results in an abnormal activity in some of the muscles. This abnormal activity can cause shortening of some muscles and the abnormal formation of some of the bones in the legs, which makes it difficult to perform activities like walking. The aim of the operation is to correct the abnormal bone formation and lengthen short muscles to help with better walking.

WHAT DOES THE SURGERY INVOLVE?

There is more than one type of operation that is usually done on children with CP to help with the walking. The surgery that will be done may be lengthening of the muscles and/or cutting and fixating the leg bone into a better position. The operation that is done will depend on what the doctors find when they examine your child. During the operation, all problems with the muscles and bones in the legs, found on assessment, will be corrected at the same time. This means that your child will only have to have to come to the hospital for one operation. the fact that they do one operation to correct all the problems means the time it will take for your child to recover from surgery will be long, often up to one year.

RECOVERY

The operation is a very big operation, and it is normal for your child to have a lot of pain after the operation. The doctors will make sure that he or she gets the proper pain medication as needed. Your child will stay in the hospital for 2-4 weeks after the operation, in order to monitor him or her and for early physiotherapy. The operation is a big operation which means that recovery is slow and your child may lose some of his or her function temporarily after the operation as his or her muscles will be very weak. For this reason your child may need a wheelchair in order to move

around at home and school for the first few months after the operation. Only after 6 months to one year will your child start to be able to complete all his or her previously achieved daily tasks. Improvement in the completion of daily tasks will only be seen after that. Recovery does differ from child to child and the type of operation will affect the length of recovery.

PHYSIOTHERAPY AFTER SURGERY

Physiotherapy plays a very important role in your child's recovery after the operation. Physiotherapy will help to strengthen the weak muscles, and will help to get your child back to his or her functioning before the operation as well as help improve the functioning from there.

The physiotherapist will see your child every week day whilst he or she is in the ward. On discharge you will continue to come for weekly physiotherapy sessions for one month. If you are managing with the home exercise programme after one month you will only need to come for monthly follow-up session to monitor your child's progress and change the home exercise programme if needed. If your child is receiving regular physiotherapy at another hospital or school, they will continue with therapy there. The therapist from CHBAH will send a letter to your physiotherapist explaining the operation and the exercises that were done in the hospital. If you are unable to attend a scheduled appointment please contact the physiotherapy department to rebook. It is also important to attend all follow-up appointments with the doctors.

Compliance with the home exercise programme and therapy sessions is essential for the best possible outcome after surgery!

ASSISTIVE DEVICES

Following surgery your child may need splints, and or walking aids. These will all be ordered by the physiotherapist if and when they are needed. It is very important to wear, use and care for the assistive device as instructed by the physiotherapist. All splints should be brought to every therapy session so that they can be checked and used during the session if needed.

Chris Hani Baragwanath Hospital Physiotherapy department

011 933 8309- Lizzy-Clerk

011 933 8818

Appendix IX- Home exercise programme sheet

HOME EXERCISE PROGRAMME!

Strengthening

1. Ly on your stomach every day for _____ while watching TV or playing a game.
2. Ly on your back, on a stable surface, i.e. the floor. Bend both knees, keeping your feet on the floor. Using your legs, lift your bum off the surface. Keep your bum up for ___sec. Repeat _____ times, _____ times a day.
3. Ly on your back, on a stable surface, i.e. the floor. Bend both knees, keeping your feet on the floor. Get someone to hold your feet flat on the floor. Try and lift your shoulders off the floor or try to touch your knees, keeping your arms in front of you. You can repeat this exercise reaching from side to side. Repeat _____times, _____times a day.
4. Sit on the floor with your legs straight in front of you. Push your knees down into the floor. Hold for _____ sec. Repeat _____ times, _____ times a day.
5. Sit on a high surface, with your feet off of the ground. Cross your arms over your chest. Lean backwards slowly without falling over and then come back up. Then repeat to your right and left. Repeat _____times, _____times a day.
6. Sit on a bench or chair with your knees bent. Lift one foot up so that your knee is straight, but do not lean backwards. Hold for _____ sec, then bring slowly down. Repeat with the other leg. Repeat _____ times, _____ times a da
7. Position yourself on the floor on your hands and knees. Your hands must be in line with your shoulders, your knees must be 10 cm apart. Keeping your body straight slowly lift up one arm to reach for an object and then slowly bring it back down. Repeat with the other side. Repeat _____times, _____times a day.
8. Position yourself on the floor on your hands and knees. Your hands must be in line with your shoulders, your knees must be 10 cm apart. Keeping your body straight slowly lift up one leg and then slowly bring it back down. Repeat with the other side. Repeat _____times, _____times a day.
9. On the floor, sit in kneeling, with your legs directly under your bum, NOT in W-sitting. Lift your bum off the floor so that your legs and trunk are in a straight line. This is known as high kneeling. Hold this position for _____ sec. Repeat _____times, _____times a day.

10. Find a big light box, and a friend. Get into high kneeling. You and your friend must sit opposite each other and each hold one side of the box. Push against each other until someone wins or your get tired. Repeat _____times, _____times a day.
11. Sit on a low chair or a bench with your feet flat on the ground. Make sure your ankles are slightly behind your knees, 10cm apart from each other. Come forwards up, over your legs in order to stand up. Make sure you are using your legs and NOT your arms to stand. Stand up straight and reach as high as your can. Slowly sit back down, again using your legs and NOT your arms. Repeat _____times, _____times a day.
12. Stand with your back against the wall. Get your heels as close to the wall as possible, and as straight as possible. Slowly bend your knees, coming down towards the floor, making sure that your knees do not come together and that your heels stay on the floor. When you can't come down any more, hold for _____ sec then slowly comes back up. Repeat _____times, _____times a day.
13. Play with a ball in standing. While you are playing with the object, make sure that you are reaching up high for the object making yourself as tall as your can, but keep your heels on the floor and your knees as straight as possible. Do not let your legs come together. Play like this for _____.
14. In standing, place your _____leg on a raised surface, i.e. a box, placing most of your weight on your _____ leg. Try and stand as straight as possible, not leaning over to one side, and not using your hands to help. Play like this with a ball for _____.
15. Stand in front of a step. Put one leg onto the step, then slowly step up using that leg. Once at the top of the step, slowly come back down. Repeat with the other side. Repeat _____times, _____times a day.

Stretching

1. Ly on your stomach, resting on your elbows every day for _____ while watching TV or playing a game.
2. Sit on the floor with your legs straight and your back against the wall. Reach forward and try to touch your toes. Hold for _____ sec.
3. Sit on the floor with your knees bent and your feet touching. Gently press your knees down towards the floor. Hold for _____ sec.
4. Stand on a step. Place one of your heels slightly off the step, pushing it downward towards the floor. Hold for _____ sec. Repeat with the other leg.

Appendix X- Chris Hani Baragwanath Academic Hospital Physiotherapy treatment protocol for SEMLS.

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Chris Hani Baragwanath Academic Hospital
Physiotherapy Department

Protocol for the management and treatment of children having SEMLS

Purpose: To establish guidelines for Physiotherapists regarding the assessment, treatment and management of children undergoing SEMLS (Single Event Multi-Level Surgery).

Procedure:

Pre-Surgery

- All patients should come for at least one pre-surgery physiotherapy session at Chris Hani Baragwanath hospital. This will help to build a relationship between the therapist and the family. This session will also enable the therapist to explain to the parents the physiotherapy requirements post surgery, as well as the home exercise programme and what to expect.
- Do not forget to explain to the child about the surgery and the fact that he/she will experience pain and be weaker, and will need to work hard with the exercises in the ward and at home.
- In the pre-surgery physiotherapy session a handout will be given to the family explaining what to expect post surgery and showing the daily exercises (see appendix1). The parents must be informed that the exercises will need to be done daily at home for optimal outcome, and that the recovery period is up to one year. The post surgery exercises should be practiced pre-surgery to help with understanding and compliance. In addition to the exercise handout, the parents will also receive a list for wheelchair hire if necessary for long distances (see appendix5).
- Included in the pre-surgery assessment should be the following outcome measures: the FMS, the Edinburg visual gait scale and the HESI (see appendices 2, 3 &4).
- Prior to the surgery, appropriate surgical appliances should be ordered and or made for the child, i.e. splints, AFO's, gaiters, abduction pillows.

- The parents must be given adequate time to ask about the surgery, and to consider the implications of surgery. Remember, it is the parents decision whether to operate or not, and the post surgery rehab will require much work and sacrifice from the family.

Post surgery (during admission in the ward)

- One of the most important aspects post surgery is to ensure that there are adequate pain control measures in place. The medication chart must be checked on a daily basis.
- All treatment must be done within pain limits, after pain medication has been administered.
- Day 1 post surgery: Check the child's chest and position him/her correctly, in supine with the knees extended and the legs abducted. No passive movements or maintenance of range to be done, as the child is usually in too much pain.
- Day 2 post surgery: Start with gentle passive movement in the hips, focusing on hip abduction and flexion, within the limits of pain. The therapist must also maintain full extension in the knees, soft splints may be required to maintain this position.
- Passive joint range and mobilization will continue until the child's pain allows 90 degrees of hip abduction and flexion, and until the doctors give orders to mobilize the child to the chair, which is normally 1 week post surgery.
- 1 week post surgery:
    - Continue to maintain passive range in the joints and length in all "at risk muscles". If necessary the child can be referred to OT for soft splints to help maintain the range, ie knee extension.
    - Active exercises can commence, but these need to be open chain exercises. Active movement must be done within pain limits.
    - The child can be mobilized to the chair daily, but not for periods exceeding 30 minutes.
    - The child must lie prone daily in the ward for at least 30 minutes, but preferably longer.
- 2 weeks post surgery:
    - Weight-bearing can commence, initially a standing frame is preferable to aim for optimal extension in standing.
    - Weight-bearing exercises can commence.
- Once the therapist is satisfied with the child's progress, and is sure that the child will not regress at home, the child may be discharged.

On discharge:

- Physio OPD appointment to be made on the same day as the doctor's follow-up appointment (about 2 weeks after discharge)
- The therapist must meet with the parents to discuss the home exercise program and pain management/positioning at home.
- The parents should be informed that the child should return to School once pain free, even if the POP's are still on.
- The family must be given the contact list for wheelchair hire.
- If the child lives out of the CHBAH catchment area or attends a School where there is a physio, the treating therapist must be contacted, an appointment made, and a referral letter written.

Follow-up at Physiotherapy:

- During follow-up, strength training must be continued.
- Follow-ups will be weekly for the first month, for children in the CHBAH catchment area, and then 2 weekly thereafter until the therapist feels that monthly appointments are suitable.
- During this period the therapist must update the home exercise program and continue to liase with the doctors about progress.

- As all children are different, the pace at which the exercises progress and the general management will depend on the individual.

Protocol generated by: Linda Hitchman

Date: August 2012

Review date: August 2013

Appendix XI- Ethical clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Linda Hitchman

CLEARANCE CERTIFICATE	**M120907**
PROJECT	The Outcomes of Single Event Multilevel Surgery in the Walking Spastic Diplegic Child Using Visual Gait Analysis
INVESTIGATORS	Ms Linda Hitchman.
DEPARTMENT	Department of Physiotherapy
DATE CONSIDERED	28/09/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 01/11/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Joanne Potterton

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix XII- FMS scores for the pilot randomised control trial by Thompson et al (2011)