

EVALUATION AND ADAPTATION OF AN OBSERVATION PROTOCOL TO QUANTIFY AND DEFINE PHYSIOTHERAPEUTIC ACTIONS FOR CHILDREN WITH CEREBRAL PALSY

Lindie Dalton

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DECLARATION

I, Lindie Dalton, declare that this dissertation is my own work. It is being submitted for the degree of Master of Science (Physiotherapy) in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signed this day in Johannesburg

A handwritten signature in black ink, appearing to be 'L. Dalton', written over a rectangular box.

Signature

Date: 5 June 2017

ABSTRACT

Aim: The aim of this study was to evaluate the applicability of an existing behavioural observation tool and assess whether it could be used to quantify and define physiotherapeutic actions (PA) as implemented during treatment sessions of children between the ages of one and 16 years with a diagnosis of Cerebral Palsy (CP). If the tool was found to be unsuitable a more appropriate measure would need to be developed.

Method: This study consisted of three phases and was exploratory in nature with one phase leading to the next.

Phase 1: A panel of experts evaluated the Original Observation Protocol (OOP) by implementing it on treatment videos of children from different Gross Motor Function Classification System (GMFCS) levels, thereby testing its usefulness in a different context to its original intended purpose.

Phase 2: The OOP's content validity was evaluated with the help of the same panel of experts. The recommended adaptations were based on the feedback collected during a series of modified Nominal Group Technique (NGT) sessions.

Phase 3: The Adapted Observation Protocol (AOP) was piloted on five treatment videos, each with different GMFCS levels, by a sample group of six experienced physiotherapists (PT's). Inter-rater and intra-rater reliability were determined to start unpacking some of the psychometric properties of the AOP.

Results: Phase 1: The mutual exclusivity of the OOP was found to be unsatisfactory and hence unsuitable for use with older children within the South African context where adaptation was deemed necessary.

Phase 2: Content validity for an adapted version was established by achieving 80% agreement between the experts for the inclusion and adaptation of items from the OOP. The AOP consisting out of three sections was developed as the end result of this phase.

Phase 3: Some of the preliminary results of the psychometric properties of the AOP looked promising. In Section 3 a high to very high positive correlation were found when looking at both inter- and intra-rater reliability for relative duration of the therapeutic activities across all videos. The ICC values ranged from $\alpha = 0.68$ to

$\alpha=0.94$ for the inter-rater reliability and $\alpha=0.65$ to $\alpha=0.99$ for the intra-rater reliability with a confidence level of 95%. In contrast, the incidence of therapeutic activities scored in Section 3 had slightly lower correlation, ICC ranging from $\alpha=0.43$ to 0.76. In Sections 1 and 2 a negligible to moderately positive level of correlation was predominantly observed. This might be ascribed to a lack of training amongst other reasons.

Conclusion: Further research is needed to develop the psychometric properties of the AOP. However, it does have the potential to be a tool that defines and quantifies therapeutic input in children with CP and an invaluable free resource that can be implemented across a variety of practice settings within South Africa.

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LIST OF ABBREVIATIONS

AOP	Adapted Observation Protocol
CCD	Client-Centred Services
CE	Conductive Education
CFCS	Communication Function Classification System
CP	Cerebral Palsy
DOH	Department of Health
EI	Early Intervention
FCS	Family-Centred Services
GMFCS	Gross Motor Function Classification System
HIV	Human Immunodeficiency Virus
HGR	Hypothesis-generating research
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health Children and Youth version
MACS	Manual Ability Classification System
MRI	Magnetic Resonance Imaging
MTSCI	Motor Teaching Strategies Coding Instrument
NDT	Neurodevelopmental Therapy
NGT	Nominal Group Technique
OOP	Original Observation Protocol
PA	Physiotherapeutic Actions
PT	Physiotherapist
RCTs	Randomised Controlled Trials
TIP	Tone Influencing Patterns
TQQ	Ten-Question Questionnaire
WITS	University of the Witwatersrand

DEFINITION OF TERMS

Evidence Alert Traffic Light system: This system is a three-level colour coding system that provides a user-friendly research implementation structure. This enables stakeholders to use common terms to more readily decide on a course of action when putting into practice the clinical evidence (Novak et al., 2013).

Model of qualitative hypothesis testing research: This research method is where a set of data is explored to identify relationships and patterns in order to test a hypothesis (Trochim, 2006).

The Occupational Performance Process: The Occupational Performance Process Model is an intervention model for occupational and physiotherapists. According to this model the initial three stages of assessment, comprises data collection, prioritization of concerns and identification of relevant theory, followed by assessment of body function, activity and participation. Then after the personal and environmental factors are identified a plan is negotiated and ultimately implemented. This is followed by an evaluation of the whole process after which, depending on the outcome, the client might be discharged or the whole process might restart at step two (Dodd et al., 2010)

Observational Protocol: This is a format developed in an attempt by Blauw-Hospers et al. (2010) to objectively capture the physiotherapeutic actions that might be implemented by a physiotherapist during a treatment session for infants. The psychometric properties of this Observation Protocol in terms of its completeness, mutual exclusiveness, reliability, and construct validity were assessed. The Observation Protocol contains three levels of observation. The first level consists of eight mutually exclusive main categories. The second level consists of the subcategories of the main techniques. For example, the main category 'facilitation techniques' consists of the following subcategories: handling, pressure techniques, transitions, and support devices. The third level of the protocol entails concrete PA: for example, "in the supine or sitting position, the shoulders of the infant function as a key point. It is observed that the therapist guides the shoulders of the infant into protraction to control the infant's movements and to facilitate hand-on-hand contact and symmetry" (Blauw–Hospers et al. 2010).

Physiotherapeutic actions: Set of actions that comprise a physiotherapeutic treatment session with the aim of improving function (Blauw et al.,2010)

Tab-Overview of the Observer: This document is a guide on how the original Observation Protocol was formatted in the Observer software. It was supplied by Ms. Anna Schmidt who has completed her masters research on the Observation Protocol following the Blauw-Hospers et al. (2010) study. The Tab-Overview of the Observer has not been published.

CHAPTER 1

INTRODUCTION

Motor disabilities in children are most frequently the result of Cerebral Palsy (CP) (Cans, 2000). These motor disabilities can have a severe impact on any country's economy especially when considering that the estimated lifetime cost for persons born with CP in the United States in the year 2000 is 11.5 billion dollars (Honeycutt et al., 2004).

According to Bax et al. (2005) and Odding et al. (2006) the estimated prevalence of CP, in well-resourced countries, for the general population is 2/1000. This worldwide prevalence of 2.11 per 1000 live births was once again confirmed by Oskoui et al. (2013). We therefore see that, although developments in prenatal and perinatal care have improved the survival rate of at-risk preterm infants, they have had no effect on the prevalence of CP. However, at 40-100 per 1000 live births the prevalence rates for CP are significantly higher in premature babies and babies of low to very low birth weight compared to normal birth weight babies (Cans, 2000).

Unfortunately epidemiological studies of CP are limited in resource-constrained settings. A systematic review looking at the prevalence of CP in Africa reported wide variance in prevalence ranging from 2 to 10 per 1000 live births (Donald et al., 2014). Only two studies have explored the prevalence of CP in South Africa. The study by Couper (2002) reported a prevalence rate of 10 per 1000 and Christianson et al. (2002) showed a rate of 8 per 1000. Both these studies were particularly localised and therefore not necessarily representative of greater South Africa.

Cerebral Palsy is a highly complex condition that affects the child not only on a neurological level but almost on every other biophysical and psycho-social level too (Rosenbaum et al., 2007). The effects on the child's functional level were reported on by the Surveillance of CP in Europe (SCPE) (Cans, 2000). They reported that 30% of children with CP cannot walk, an equal percentage has a severe impairment in cognition, 28% have speech impairment and 12% of children are visually impaired.

CP has far reaching effects and is a persistent condition that affects an individual and their family for a lifetime as well as society as a whole (Scrutton 2004). The sphere of influence of CP further extends to the health professionals who engage with the child and family and those who research the condition. Therefore health professionals should strive to implement the most effective therapeutic modalities that minimise risk of primary and secondary complications

In systematic reviews of interventions for CP by Novak et al. (2013) and Flores-Mateo and Argimon (2007) the researchers recognized that there exists a discrepancy between research and medical practice across numerous specialties, countries and diagnoses. They further cited McGlynn et al. (2003) and Leape et al. (2003), who found that 10% to 40% of health interventions have no documented evidence and that a further 20% of interventions are essentially not effective or necessary and in some cases even unsafe. This discrepancy is also evident in the field of CP (Metcalf et al., 2001; Saleh et al., 2008). There are several reasons why professionals are reluctant to implement evidence based practice and these will be further explored in the literature review.

Since 1994, the field of CP has gone through rapid changes due to the increasing volumes of emerging evidence and changing clinical practice (Scrutton, 2004). As a result the health professional may be placed in a predicament when seeking the most appropriate intervention.

In a recent systematic review, of different types of interventions for CP, by Novak et al. (2013) the researchers attempted to give guidance to the professional when negotiating this decision making process in selecting appropriate interventions for children with CP. They endeavoured to bridge the gap between research and practice by providing comparisons of different interventions. The interventions they compared, amongst others, were: fitness training; bimanual training; constraint-induced movement therapy; context-focused therapy; goal-directed/functional training; home programmes; Bobath / Neurodevelopmental therapy (NDT); motor learning and Vojta.

The researchers used an Evidence Alert Traffic Light system to code the interventions. Sixty-four different CP interventions were reviewed across 131 intervention outcomes. The researchers found that the bulk of evidence (70%) for intervention was lower level (yellow) while 6% was ineffective (red) and that the evidence only supported 15 green light interventions (24%) (Novak et al., 2013). However this paper has been very controversial and has been critiqued by a wide variety of experts in the field of CP (Autti-Rämö et al., 2014; Fehlings, 2014; Mayston and Rosenbloom, 2014).

From the research it is clear that there is a need for a tool to describe the 'physiotherapeutic actions' (PA), a term coined by the Blauw-Hospers et al. (2010) team, that occur during a physiotherapy session. Two of the reasons why it is difficult to prove the effectiveness of intervention/ns that focus on direct intervention from the therapist are firstly that few, if any, studies describe the specific composition of the therapeutic intervention. Secondly, most approaches and therapy interventions are eclectic and therefore combine several therapy approaches.

The interventions selected by therapists should therefore be equally multifaceted and holistic. In the quest to find the most appropriate intervention it is important to be able to objectively report on what PA, comprise a typical physiotherapy session within the South African context.

The development of a tool that is able to objectively describe and quantify the PA comprised in a typical physiotherapy session (which would include elements of family-centred service (FCS), not just direct hands-on therapy may facilitate the investigation of the clinical effectiveness of therapeutic interventions. In addition it may allow comparisons between intended and actual therapeutic actions.

The possibility of objectifying and quantifying therapy intervention for infants that have a high risk of developmental disorders was investigated by Blauw-Hospers et al. (2010). The aim of their study was to define and quantify physiotherapy interventions for infants identified as being in this category of high risk. The outcome of this study was the Observation Protocol that originated from their

understanding of physiotherapy for infants and the exploration of directly observable PA.

It was suggested by Blauw-Hospers et al. (2010) that their study has only partly contributed to the process of quantifying PA. They suggested that future research in other countries should set out to replicate their study on children of different age groups and different levels of neurological impairment. The research question for this study was formulated from the above future research suggestion.

1.1 Research Question

Can PA, as practiced by a rehabilitation physiotherapist (PT) working with children with CP within the various South African settings, be defined and quantified with the aid of the Observation Protocol developed by Blauw-Hospers et al. (2010) or should a new protocol be developed?

1.2 Problem statement

Despite the fact that several attempts have been made to find the evidence for best practice when treating children with CP there is little clinical evidence for the effectiveness of treatment modalities worldwide and even more so in South Africa.

There are a variety of treatment approaches and amongst them is the very popular Bobath/NDT concept. This approach forms the most prominent part of the background knowledge and skill repertoire that PTs, with a special interest in paediatric neurology, can access as a reference base. However, it is not the only treatment approach and it is difficult to have a purist approach when analysing a typical physiotherapy session within the South African context.

It is however important to attempt to develop a method to define and quantify a typical physiotherapy session for a child with CP in South Africa because there is a paucity of research for effective treatment. This research might contribute towards identifying optimal allocation of resources when planning treatment to optimise function in this vulnerable population.

1.3 Aim of the study

The aim of this study was to evaluate an existing observation tool in order to assess whether it could be used to quantify PA for children with CP in the South African context. Should the tool not be suitable for use a more appropriate observation tool needs to be developed.

1.4 Objectives

- To determine whether the Observation Protocol developed by Blauw-Hospers et al. (2010) could be used in the South African context when treating children with CP or
- To establish to what extent it needs to be adapted to be able to quantify and define PA during a physiotherapy session.
- To develop an adapted observation tool to determine if the whole physiotherapy session can be ascribed to specific PA in order to quantify a physiotherapeutic session by establishing content validity.
- To determine the inter-rater and intra-rater reliability of the adapted Observation Protocol.

1.5 Significance of the study

It is suggested that childhood disability is an indicator of the health status of children in South Africa (Couper, 2002). Cerebral palsy is a major contributor to long-term disability among children and therefore has significant implications on the South African health system and economy.

The outcome of this study will bring us closer to being able to accurately and objectively define and quantify PA in a typical physiotherapy treatment session for a child with CP. This will facilitate comparison between different treatment approaches and allow more accurate assessment of their effectiveness. This will

not only contribute to developing an evidence base for physiotherapeutic intervention for children with CP but, in addition, will aid the decision-making processes for local health teams and more importantly possibly lead to the development of policies for best practice by Health and Social Development departments. This will potentially have far reaching effects on health and rehabilitation services, in both rural and urban areas.

It is therefore important to consider what the literature says on this subject. Chapter two presents a comprehensive discussion of the literature on the aetiology of CP, the diagnosis and classification and how it affects the individual. The medical management of children with CP is discussed as well as current research around the interventions used in this patient population.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter provides an overview of CP within the paediatric population along with a more detailed discussion on the management of this condition. The socioeconomic impact of CP and the implications on the child's development and the community as a whole will be discussed. Current research regarding treatment techniques and the development of tools to quantify and describe therapeutic interventions will be reviewed. Tools that address this within the field of physiotherapy for paediatric rehabilitation are very scarce and those available will be described. The necessary properties of a standardised observation tool for intervention are discussed.

Articles for this review were sourced from EBSCO Host (Academic Search Complete), PubMed, CINAHL, PSYCHInfo, Medline Plus and Cochrane Collaboration searches. A hand search was also conducted in the Health Sciences Library of the University of the Witwatersrand. References were downloaded into a reference manager (Endnote X5). Reference lists of appropriate articles were also reviewed for further sources.

Key words used in searches included 'cerebral palsy', 'NDT', 'Bobath', 'intervention', 'Observation Protocol', 'behavioural studies', 'developmental delay', 'neurodevelopment', 'socioeconomics in CP' and 'poverty and South Africa'.

2.2 Definition of Cerebral Palsy

Attempts to define the term 'cerebral palsy', and the way in which the different presentations can be classified, have been on-going for well over 150 years (Morris, 2007). In the 19th century the term 'Cerebral Palsy' (CP) was first used by an

orthopaedic surgeon William Little (1862), by neurologist Sigmund Freud (1897) and the physician William Osler (1889) (Scrutton, 2004).

The most recent attempt to define CP by Rosenbaum et al. (2007; p9) is the following:

“a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems.”

It is clear that the process of defining CP is ever-evolving. The chances are strong that the definition will change in the future as our understanding of CP and its causes and risk factors further develop and as more research is produced. Incidence and prevalence of CP is difficult to establish as different criteria may be used when diagnosing the condition. In the following section, the prevalence of CP globally and locally is described.

2.3 Epidemiology of Cerebral Palsy

2.3.1 Prevalence

Cerebral Palsy is considered to be the number one cause of childhood neuro-disability worldwide (Stanley et al., 2000). The global prevalence of CP has remained unchanged despite improved survival rates of at-risk preterm infants and has been estimated to be 2 per 1000 live births (Bax et al. 2005; Odding et al. 2006). This has been confirmed more recently at 2.11 per 1000 per live births (Oskoui et al., 2013). However, this relative constant trend has been contradicted for the first time been by Sellier et al. (2016) who reported a slight decrease in the overall prevalence of CP within Europe for the birth years 1980 to 2003. They reported a linear decrease from 1.90 to 1.77 per 1000 live births that is a mean decrease of 0.7% per annum. A non-statistically significant decrease of 2% per annum was also detected in the prevalence of children with moderate-to-severe CP.

These results emphasise the need for countries to set up registers for children with CP to investigate trends over time (Selliers et al. 2016). Two countries in particular have had a register for many years: Australia reports a prevalence of 2 to 2.5 per 1000 live births (Reddihough and Collins, 2003) and Sweden 2.18 per 1000 live births (Himmelman et al., 2010). Although there is definite merit in local registers there is still a call for more longitudinal and multi-centred collaborations.

The Oskoui et al. (2013) systematic review was the first to report on a global CP prevalence a meta-analysis with a very rigorous methodology. It was reported by Oskoui et al. (2013) that the highest prevalence, at 111.80 per 1000 live births, was found among children born before 28 weeks of gestation and the lowest prevalence, at 1.35 per 1000 live births, was found in children born after 36 weeks.

This particular study also looked at the correlation between birth weight and prevalence. The prevalence was the highest in children weighing 1000 to 1499g, at 59.18 per 1000 live births, and the lowest in children weighing over 2500g, at 1.33 per 1000 live births (Oskoui et al., 2013). This trend is similar to the results reported by the comprehensive review on existing databases for the prevalence of CP across 13 centres throughout Europe (Cans, 2000). A downward trend has been reported in the prevalence of CP in children with moderate to low birth weight (1500 to 2499g) and some reduction in the very low birth weight range (1000-1499g) (Sellier et al., 2016).

In contrast to well-resourced countries, data that accurately report the prevalence of childhood disability and specifically CP within low and middle-income countries is scarce. This is also true in South Africa with the prevalence differing between provinces and reportedly ranging from 33 to 64 per 1000 live births (South African Government, 1997).

A comprehensive systematic review looked at the prevalence of CP in Africa reported a wide variance in prevalence ranging from 2-10 per 1000 live births (Donald et al., 2014). A limitation of this study was that 'grey' material, including articles published in different languages, was not included. No longitudinal studies

were found and the heterogeneity in methodology limited the possibility to derive definite conclusions regarding prevalence.

Two studies examined the prevalence of CP in South Africa (SA) and reported it to be between 10 per 1000 live births (Couper, 2002) and 8 per 1000 live births (Christianson et al., 2002). However both these studies set out to describe the prevalence of childhood disability, and were not CP-specific. Furthermore, both were conducted in a small geographical area and the results cannot be extrapolated to the rest of South Africa with its diverse socio-economic and cultural settings (Christianson et al., 2002; Couper, 2002).

The prevalence of children with severe CP in Africa was found to be higher when compared to European and North American cohorts (Donald et al., 2014). Children's functional abilities were therefore more severely affected, with more co-morbidities present. This was attributed to inadequate care during birth, delayed presentation to health care services and meagre early intervention services.

Locally and globally CP is a major cause of childhood disability that has far reaching implications for an individual progressing into adulthood, the supporting family and society as a whole. Many factors can lead to an insult to the developing brain that results in CP. These and other contributing factors will be discussed in the following paragraphs.

2.3.2 Causes

Through the ages many attempts have been made to understand the causes of CP in order to decrease its prevalence. Today there remains a lack of understanding of the causes of some cerebral palsies and the aetiology for many children will always evade medicine (Sewell et al., 2014).

The causes of CP as a once-off injury to the central nervous system were summarised in a study by Fairhurst (2012). He stated that these might include irregularities in the blood supply to the developing brain during the different stages of the infant's development. This may have resulted in changes to the developing

brain's structure that in turn manifested in varied physical difficulties and clinical presentations.

It is clear from the research that there are a myriad of causes for CP. In the past genetic factors were only rarely considered to be related to CP (Hughes and Newton, 1992; Bunday and Griffiths, 1977). However recent studies (Tollanes et al., 2014) concluded that genetics forms part of environmental factors that more often play a role as a causal agent than was considered to be the case in the past. Indecision was expressed by Oskoui et al. (2013) regarding the contribution of genetic factors in the aetiology of CP and they concluded that genetic factors might either escalate or reduce the aetiology of CP.

Eighty percent of childhood CP cases in well-resourced areas and countries can be attributed to malformations of the foetal brain which can be observed by Magnetic Resonance Imaging (MRI) (Johnson, 2002; Krageloh-Mann and Horber, 2007). This refutes the perception that CP is most often caused by a difficult birth and resulting oxygen deficiency as this only occurs in 10% of cases. The remainder are caused by postnatal incidents such as near drowning accidents, premeditated injuries and acquired diseases like meningitis (only 10%) (Krageloh-Mann and Cans, 2009).

In contrast to well-resourced settings the epidemiology in developing countries can be mostly attributed to perinatal and postnatal causes (for instance cerebral malaria) (Sewell et al., 2014).

No research relating to causes of CP has been conducted in South Africa but a study of 68 children in Botswana has recently been published (Baranov et al., 2015). Botswana neighbours South Africa and has similar social characteristics. They reported different findings to those of well-resourced settings in that there was a higher incidence of associated impairments along with more adverse long-term effects for children with CP in Botswana. However, there was a degree of selection bias as this was a hospital cohort study as opposed to a community or population-based study. This might have resulted in a sample comprising more severely affected children requiring more medical intervention. Therefore these results are not truly representative of all children with CP in Botswana.

The most predominant cause of CP was found to be prematurity (21%) followed by intra-partum hypoxic events (18%). Postnatal infections caused 15% of cases while both arterial ischemic strokes as well as TORCH infections (toxoplasmosis, rubella, cytomegalovirus, herpes simplex, and HIV) each attributed to 10% of cases (Baranov et al., 2015). This confirms the findings of the systematic review by McIntyre et al. (2013), who identified 10 risk factors in term babies. Amongst these were birth asphyxia, infections and placental dysfunction. However one of the limitations of this study was that they were unable to do a meta-analysis due to a lack of uniformity of the studies.

2.3.3 Associated impairments

A study looking at children with CP in Botswana reported mental delay to be the most often associated impairment (83.8%), followed by epilepsy at 76.5% and visual impairment at 45.6%. The incidence of orthopaedic impairments was also high at 30.9 % of children having contractures and 27.9% with a scoliosis. Difficulties in hearing ability were the lowest reported associated impairment at 16.2 %. The researchers found a high proportion (41%) of Gross Motor Function Classification System (GMFCS) Level IV (more severely affected) children (Baranov et al., 2015).

2.4 Diagnosis of CP

The decision making process around best practice and future function of a child begins with an accurate diagnosis. Research suggests that there is a strong correlation between the MRI findings and the clinical findings when looking at CP (Bax et al., 2006). Results from a large cohort study indicated that brain MRI scans showed that white-matter damage of immaturity, including periventricular leukomalacia (PVL), was the most common finding (42.5%); followed by basal ganglia lesions (12.8%); cortical/subcortical lesions (9.4%); malformations (9.1%); focal infarcts (7.4%) and miscellaneous lesions (7.1%). A small number of these children (11.7%) had normal MRI findings (Bax et al., 2006).

Research suggests that neuroimaging of pathophysiology should also accompany clinical assessment for the diagnosis of CP. However both Fairhurst (2012) and Sewell et al. (2014) stressed the fact that the diagnosis of CP should not rely on neuroimaging alone and that the process of diagnosing CP should include clinical observations and the acquiring of a detailed antenatal and family history.

As early as three months it is already possible to identify children who later in life may have a definite diagnosis of CP by observing their 'general movements' while awake (Prechtl et al., 1997; Spittle et al., 2009). From their collaborative longitudinal study with large sample size, Prechtl et al. (1997) concluded that it is possible to make (as early as three months of age) an accurate diagnosis of neurological impairment when abnormal 'general movements' are observed. This can be predicted with 95% sensitivity and 96% precision. Another high powered study, utilised two standardised outcome measures and reported that the accuracy of a diagnosis rises to 100% when these findings are combined with a MRI in premature infants (Spittle et al., 2009).

It was stressed by Sewell et al. (2014) that often the comorbidities of CP, such as difficulties in feeding, are easier to pick up in young infants than the slight abnormalities of movements. They further suggested that concerns should lead to immediate referral so that a child can already be red-flagged from their first few weeks of life. In order to prevent incorrectly classifying children with CP, the leading European centres for CP will not diagnose a child with CP before the age of four (Johnson, 2002).

With CP, on-going assessments are needed as the functional abilities and clinical presentation might change despite the unchanging nature of the cerebral damage (Sewell et al., 2014). According to Leonard et al. (2011) it is therefore imperative to differentiate CP that is predominantly static in nature from neurodegenerative and metabolic disorders. These progressive diagnoses are usually identified by tell-tale signs of deterioration in motor abilities and should be confirmed with MRI.

In their systematic review Ashwal et al. (2004) concluded that MRI results are very accurate successfully identifying neurological abnormalities 86% of the time.

However, even when an MRI does not indicate an abnormality, despite the presence of clinical markers indicative of abnormal development, further investigations should be undertaken (Sewell et al., 2014).

2.5 Pathology

A simplified understanding of the pathology of CP comprises two components. The one is the 'positive' aspect that refers to hypertonia, which is the result of velocity dependent increase in the stretch reflex. The second component is the 'negative' symptoms or reduced muscle activation, which is often more incapacitating due to the resultant weakness and decreased motor control (Fairhurst, 2012).

The 'positive' symptoms occur in the descending cortico-spinal tracts where the inhibitory neurotransmitter, γ - amino butyric acid (GABA), is released at spinal level. Lesions in the upper motor neuron part of this track leads to the loss of this inhibitory function which results in the unchecked activation of the reflex arc and muscles (Fairhurst, 2012).

Another abnormal pattern of movement that might be observed is dystonia that is predominantly the result of an insult to the basal ganglia. This disturbance results in motor patterns that may be described as 'involuntary movements'. The triggering of these movements may be due to overwhelming sensory and/ or emotional input such as anticipation, angst, sudden loud sounds or distress. These motor patterns can be best described as 'fluctuating' movements of extremities through wide ranges of movement (Fairhurst, 2012).

Ataxia, the last subcategory of CP, is the rarest form and most often the result of damage to the cerebellum (Fairhurst, 2012).

The pathology behind the condition only partly contributes to the clinical picture and diagnosis. However, it is also imperative to correctly classify a child once a diagnosis of CP has been confirmed. The current thinking behind classification will be addressed in the next section of this literature review.

2.6 Classification of Cerebral Palsy

Throughout history it has been understood that there is a need to have a universal classification system for CP and that this is a complex task. The most recent change to the classification system was introduced at the turn of the century by The Surveillance of Cerebral Palsy in Europe (SCPE) collaboration (Cans, 2000). They recommended a physical classification system, where the distribution of abnormal neurological fall-out be described as simply unilateral or bilateral involvement. This group reported the prevalence of unilateral CP to be 30% and that of bilateral spastic CP to be 58% (Krageloh-Mann and Cans, 2009). The SCPE furthermore recommended that the main abnormal motor tone varieties should be divided into one of four groups, namely spastic, dyskinetic, ataxic or mixed.

More recently this was expanded on by Rosenbaum et al. (2007) who described the different components that should be considered when classifying CP. Firstly they identified that motor abnormalities should be included by noting the nature and typology of the motor disorder. Abnormal tone should be assessed, distinguishing between hypertonia and hypotonia. The existing movement disorder is also important to note, differentiating between spasticity, ataxia, dystonia or athetosis. This includes all functional motor abilities such as oromotor and speech function and the degree to which it is limiting the individual's functional abilities.

Secondly the accompanying impairments such as seizures, secondary musculoskeletal complications and hearing or vision impairments amongst others should be mentioned. The debilitating extent should furthermore be included. The inclusion of the parts of the body affected and neuro-imaging findings are important together with the timing of the injury as well as possible causes (Rosenbaum et al. 2007).

Classification and the reasoning behind it have evolved through the decades and progress has been made in standardizing and simplifying the process. However professionals realize that these physical classification systems still don't answer the

parents' probing questions about what the long-term outcome for their child will be (Sewell et al., 2014). Functional classification systems such as the GMFCS (Palisano et al., 1997), the Manual Ability Classification System (MACS) (Eliasson et al., 2006) and the Communication Function Classification System (CFCs) (Hidecker et al., 2011) have attempted to answer these questions regarding long term functional motor outcomes and are now the preferred method for classifying children with CP. These functional classification systems also indicate what the child is able to do and to what extent they are able to participate in their community and social spheres. These trends are in line with the World Health Organization's (WHO) focus on the International Classification of Functionality, Disability and Health (ICF) measures that look at "activity, participation, restrictions and limitations." (WHO, 2001)

In summary the SCPE is the most broadly used system in research studies (Cans, 2000; Bax et al., 2005; Rosenbaum et al., 2007; Krageloh-Mann and Cans, 2009). Furthermore, naming or classifying CP according to clinical subtype on its own, does not suffice and the second component of any classification system is the functional classification system where the GMFCS is universally used. The following section will look in more depth at the GMFCS.

2.7 GMFCS levels

The Gross Motor Function Classification System (GMFCS) was developed by Palisano et al. (1997). Content validity was established through the adapted nominal group consensus method followed by two rounds of the Delphi method. During the initial stages of the process there were conflicting opinions on how to distinguish between the different levels and appropriate ages for classification to be reliable. However, consensus was finally reached at 80% for all 29 of the statements. Once consensus was reached on the content of the GMFCS the inter-rater reliability was established for the classification system with a Kappa value of 0.75 when classifying the gross motor function of children between the ages of 2 to 12 years.

It was adapted in 2007 to include an adolescent age band and is now known as the Gross Motor Function Classification System Expanded and Revised (GMFCS-E&R). The GMFM was developed as a result of the need for a simplified, standardised system for the classification of the severity of dysfunction of movement in children with CP.

The GMFCS consists of five consecutive levels each giving a detailed account of the different movement capabilities of a child with CP. Each level provides a description across five age bands: less than 2 years, 2 to 4 years, 4 to 6 years, 6 to 12 years and the most recent addition of 12-18 years.

Fundamentally, the test identifies the child's ability to initiate an activity like sitting and walking, where the child might need supportive equipment such as walking frames or wheelchairs (Wood and Rosenbaum, 2000; Palisano et al., 1997). The GMFCS focuses on the child's abilities rather than limitations. Therefore if a child is able to complete activities at the level that is similar to the descriptors should be classified at that particular level.

Children with CP classified as being Level I are the least affected and have the same abilities as their peers of a similar age. However the quality of the movements might be affected as they perform the activities in a less coordinated way with less speed and balance. Children on Level V are the most affected and struggle to maintain a good head position and trunk posture in the majority of positions (See Appendix I)(CanChild). The differences between Levels I and II are not as marked as between the other levels and this is particularly evident in babies younger than two years of age (CanChild).

The GMFCS does not focus on the quality of movement. It rather focuses on the meaningful differences between the day-to-day functional limitations evident amongst children functioning at the different levels. The GMFCS enables the professional to identify the child or youth's current 'abilities and limitations' in gross motor activities. It emphasises their typical performance at school, in the community and at home and not their perceived optimal ability (Palisano et al., 2008).

It is important to bear in mind environmental factors when assessing mobility methods, for instance the distance a child might have to cover at school. In addition, personal factors such as whom they prefer to socialize with also play a role. These factors are considered when describing terms for the six to 12 year and 12 to 18 year age bands (Palisano et al., 2008).

Following on this the WHO considers measures that look at activity and participation as outcome measures to be of great value to assess interventions. A study by Fauconnier et al. (2009) indicated that the children with CP have restricted participation in life situations and that restrictions increases with the level of severity of the child's impairment, where children of Level IV and V are most restricted. Another study by Sewell et al. (2014) implemented the Activities Scale for Kids performance version (ASKp) to assess if there was a difference between an operative group and a control group for scoliosis in children with CP from GMFCS levels IV and V. They found that GMFCS levels, mobility, communication and eating did not improve. However the children from the operative group's activity and participation did improve.

Once a child with CP has been classified, their functional level has been determined and all the social and environmental factors have been considered, the team of professionals are faced with the dilemma of where to go from there.

2.8 Physiotherapy for Children with CP

In an apt comment Scrutton (2004) said that the primary predicament in the treatment of CP is: "*whether* and *what* to treat; rather than *how* to do so." By highlighting several dimensions that influence a child's function, e.g. environmental and personal factors, Morris (2007) built on this statement. However, the relationship between these factors is not fully understood and it is still a point of contention as to which of these should be addressed by a PT and at what stage.

2.9 When to treat

The focus in treating children with CP has shifted to early intervention (EI) in the past few decades (Shonkoff and Meisel, 2000; Scrutton, 2004). Early intervention is applied to children at risk of developmental disorders and those with confirmed developmental delays.

Currently the most utilised definition of EI is that given by (Shonkoff and Meisel 2000, p24):

“Early Intervention consists of multidisciplinary services provided to children from birth to 5 years of age to promote child health and well-being, enhance emerging competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning. These goals are accomplished by individualized developmental, educational, and therapeutic services for children provided in conjunction with mutually planned support for their families.”

There are two components to early intervention. In the one ‘early’ refers to early in life and the other would be during the early stages once a delay has become apparent (Blauw-Hospers and Hadders-Algra, 2005). From research it is evident that the brain has the most capacity for adaptation through neuroplasticity during the process of dendritic outgrowth where synapse formation is highly prevalent (Kolb et al., 2001). This is the phase that follows the completion of neuronal migration and occurs between 2 to 3 months before, and about 6 to 8 months after term age (Hadders-Algra, 2001).

Better outcomes regarding motor and personal skills seemed evident when interventions commenced prior to the ninth month after term when compared to programmes starting later (Shonkoff and Hauser-Cram, 1987; Sharkey et al., 1990).

However the extensive systematic review of Blauw-Hospers and Hadders-Algra (2005) showed that the majority of articles regarding outcomes of EI had high evidence levels. However, whenever the rigour of studies increased the evidence for the effectiveness of early intervention decreased (30% of the studies showed effectiveness). However, the studies with limited methodological quality indicated better effectiveness (50% of the studies). The authors concluded that no meta-

analysis was possible as the studies were too heterogeneous. Possible contributing factors to poor outcomes were that outcome measures were not sensitive enough, looking only at quantitative changes in motor development. They suggested that future studies should rather look at qualitative changes and measures that focus on changes in functional abilities during daily life as well as participation. Other contributing factors were small sample sizes, heterogeneous conditions and severity levels as well as the ethical considerations of control groups.

The systematic review by (Donald et al., 2014) reported a lack of screening services and limited referral pathways in Africa resulting in the late diagnosis of children with CP. This and other constraints lead to a lack of early intervention in these settings. In the African context children therefore tend to receive therapeutic input much later in life.

A recent systematic review of EI with very rigorous methodology by Morgan et al. (2016) included 10 studies from level II evidence (second highest level), one study from level III, 13 studies from level IV and 10 level V studies. There were 379 infants from level II studies and 23 infants from level IV evidence, giving a total of 402 infants. In total 34 studies were included of which 10 were randomised control trials (RCT's). They concluded that although methodology of research has improved there is still a lack of high quality trials in EI. Despite this encouraging evidence was found when adaptation of the environment, child-initiated movements and task specificity were implemented.

Knowing that there are guidelines on when to start therapy, the next question that arises is “how to treat”. A vast body of knowledge on therapy approaches exists. However, only a few relevant ideas from the literature are presented in the following section.

2.9.1 Frameworks for intervention

The Occupational Performance Process Model was adapted by Dodd et al. (2010) to describe an intervention model for occupational and physiotherapists. According to this model the initial three stages of data collection, prioritization of concerns and

identification of relevant theory, should be followed by assessment of body function, activity and participation. Then after the personal and environmental factors are identified a plan is negotiated and ultimately implemented. This is followed by an evaluation of the whole process after which, depending on the outcome, the client might be discharged or the whole process might restart at step two. This process is in line with International Classification of Functioning, Disability and Health (ICF) (WHO 2001) and widens the scope of clinical reasoning beyond that of just solving the problem but rather recognises all the different components of function and their multifaceted interplay (Dodd et al. 2010).

Rosenbaum and Stewart (2004) emphasised the end result of any intervention should be to encourage participation in all areas of life and function within all possible environments, most importantly, family life. This also led to the widely cited opinion piece referred to as “The ‘F-words’ in childhood disability” where Rosenbaum and Gorter (2012) named six words that should be incorporated in all services surrounding the child with CP namely: function, family, fitness, fun, friends and future. These words were to replace the term ‘fixing’ that referred to the notion that the accurate diagnosis would dictate the correct intervention. This in turn will amend the underlying impairment in body function and structure and lead to a positive outcome for the child. They suggest that a reverse approach to the traditional medical model might lead to a better outcome for the child. So in this approach the child might perceive his improved participation as more meaningful, which might lead to an increase in activity and in turn lead to positive changes in body structure and function e.g. improved fitness (Rosenbaum and Gorter 2012).

For this to be possible a multidisciplinary team approach is essential and at the core of this team of decision-makers should be the child and the family. They are the primary experts in matters concerning their family life and it is important to gain their trust and be sensitive to their needs (Dodd et al., 2010; Fairhurst, 2012). The involvement of the child and their family within an intervention potentially has a significant influence on the therapist’s role. The key aspects of the therapist’s treatment should be that it is both child and family centred. Family-Centred Services (FCS) (Rosenbaum et.al. 1998) is based on the concept of Client-Centred Services (CCS) (term coined by psychologist Carl Rogers quoted by Di Rezze et al. 2012)

and includes supporting the family and assisting them in the identification of their strengths. This includes collaborating with parents while bearing in mind their psychosocial needs and communicating clearly in order to encourage their participation.

In a well-resourced setting the team also includes a paediatrician, neurologist, general and orthopaedic surgeons, PT, occupational therapist, speech and language therapist and psychotherapists. The team might also include a gait analysis laboratory team, orthotics specialist and nursing specialists who predominantly address the medical aspects of patient care. Ideally the team should further include professionals from the social and educational remits including awareness groups, social workers and teachers (Fairhurst 2012).

Intervention by the team should primarily focus on reducing the influence that comorbidities and secondary biomechanical changes might have on the child's overall function (Fairhurst 2012). This is especially true when considering the original cause of the disruption in function is untreatable. These comorbidities might include changes in behaviour, communication, cognition, sensation and perception (Bax et al., 2005). Management mostly involve monitoring and maintaining of joint ranges in order to limit joint deformities that are a major concern in adults with CP (Graham, 2004; Hilberink et al., 2007). Treatment for this might include soft tissue stretching and sustained limb positioning with the aid of orthotic devices (Dodd et al., 2010). If left untreated this problem can lead to complications such as hip dislocation, scoliosis, poor posture with resultant respiratory problems and ultimately excessive pain (Bagg et al., 1993 ; Graham, 2004).

Pain is an inevitable part of the child with CP's life due to the secondary changes that are synonymous with this diagnosis. Fauconnier et al. (2009) found that children with CP that have pain were less likely to participate in life situations and Dickinson et al. (2007) reported that these children had a lower quality of life. It was found by Penner et al. (2013) in their study with a very large sample group that 30,4% of children had mild/moderate pain that did not affect activity and 13.2% had moderate pain that affected some activities. A further 7.6% had moderate to severe

pain that prevented some activities and 3.6% had severe pain that affected most activities with the remainder having no pain.

In another study Findlay et al. (2016) found that pain was mostly caused by musculoskeletal deformities (24%) with the predominant cause amongst those being hip dislocations (9%). The second highest percentage of causes of pain was hypertonia (18%). They also compared the presence of pain within the different populations of children from the various GMFCS levels. They found that the percentage of participants with pain significantly increased as the severity of the impairment increased. It is therefore of great importance to recognise and manage pain appropriately. This can be particularly difficult in a child with severe CP who has difficulties in communicating amongst a cohort of other comorbidities (Fairhurst, 2012). A study of non-verbal children by Stallard et al. (2001) reported that 67% of children with CP had moderate to severe pain but hadn't receive any treatment for it.

The management of pain and the role that physiotherapy plays in this is predominantly around detecting and then, along with the rest of the team, properly evaluating it so as to detect the cause. Preventing deformities through 24-hour postural care and improved fitness are the main aims of physiotherapy as inactivity and deformities are most often the causes of pain (Edwards, 2004).

Therefore care of the paediatric patient with CP should encompass adaptation to the ever-changing secondary biomechanical changes. These changes are a result of abnormal skeletal and soft tissue growth and the professional team should focus on limiting these deformities (Mayston, 2001). Different treatment modalities should be used to ultimately prepare the child for long-term mobility using their background posture and movement as an aid rather than counteracting it. All therapies should work in complimentary ways to reduce disability and maximise potential (Dodd et al., 2010).

There are a variety of diverse physical and occupational therapeutic modalities that have been used to treat CP that focus mainly on movement. Most rehabilitation centres treating children with neurological difficulties base the treatment

approaches on the following concepts: stretching and strengthening of muscles, postural balance, neural plasticity and patterning of movement (Mayston, 2001; Fairhurst, 2012).

Contrarily, the notion that the current trend for intervention for children with CP has changed is supported by Sakzewski et al. (2009) and Love et al. (2010). According to them intervention is now based more on the principles of motor learning and administering of antispasmodic medicine to restricted areas. They stated that this differs from the past where orthopaedic surgery and so-called normalisation of movement formed the basis of care. The fact that recent research emphasises the need for approaches that address both quality of movement, to prevent secondary impairments, as well as functional tasks, in order to improve activity and movement goals was pointed out by Sorsdahl et al. (2010) when quoting Valvano (2004).

In a well-powered RCT, functional tasks were linked to better outcomes and indicated successful motor learning (Ketelaar et al., 2001). Two standardised outcome measures were used in this study, however a limitation was that the content of treatment sessions was only reported on and not observed and defined or scored in some way.

The evidence of the importance of focussing on quality of movement is limited. In a repeat measures design by Sorsdahl et al. (2010) it was suggested that there might be a link between focussing on quality of movement and a decreased incidence of secondary impairments resulting in less effort when performing certain tasks. One approach that is most often linked to quality of movement is Bobath/NDT. This approach, along with Vojta therapy and Conductive education (CE) (as advocated by the Peto Institute) also bases treatment principles on neurological adaptation and remodelling (Anttila et al., 2008).

However, some therapists stay clear of following certain approaches and would rather select elements from different modalities that complement each other. Amongst these is the use of orthotic devices including supportive devices made of neoprene, lycra or more sturdy materials such as polypropylene. Another adjunct to physical treatment is the implementation of 24-hour postural care where equipment

is utilised to support the child in a variety of biomechanically aligned positions (Fairhurst, 2012).

Another consideration to any therapy approach is whether the session will be on an individual or group basis. It was suggested by Sorsdahl et al. (2010) that group treatment in the child's familiar settings might lead to better compliance. This can be attributed to the added fun factor of groups that facilitates motor learning. These settings add elements of competition and encouragement that result in favourable levels of intensity and repetition. This study used standardised and reliable outcome measures and had a qualitative component to the study. They made some effort to quantify and describe the therapy input by videoing these sessions and analysing them with the 'Motor Teaching Strategies Coding Instrument'. The outcomes of this study also suggested that a higher intensity programme over a shorter period of time might lead to better outcomes.

This concludes this section about the frameworks and principles behind intervention strategies for treatment of CP. The next section will focus on specific and direct or 'hands-on' therapy interventions commonly used by PTs as well as the evidence for clinical effectiveness.

2.10 Clinical effectiveness of different treatment modalities

With the myriad of treatment modalities on offer for CP it is difficult to determine which ones are clinically more effective. This is despite several efforts in recent years to determine clinical effectiveness. It is stated by Autti-Rämö et al. (2014) that although RCTs are mostly considered better quality evidence there are a few aspects of RCTs that are not suitable in the CP context. RCTs are usually only run over a short space of time. This is not in line with CP as a disorder that lasts a lifetime. Furthermore in the CP context, goal setting should be individualised. As a result, a standard outcome measuring tool will not necessarily identify change (Autti-Rämö et al., 2014). Furthermore RCTs mostly focus on whether interventions work and not necessarily on the mechanism behind them. Therefore there is still a

gap in research to assess ways to improve intervention and ways to meet patients' needs. They recommended that only qualitative studies can look at patients' perceptions, ideals, prerequisites and aims as RCTs will only answer some of the questions in terms of best practice in CP.

An attempt was made to add to the clinical knowledge base of professionals in the field by Novak et al. (2013). As mentioned in the introduction Novak et al. (2013) compared the most widely used treatment modalities available within a well-resourced setting. This was done in the format of a systematic review of systematic reviews that is incidentally the highest level of intervention research evidence offered (Burns et al., 2011). For inclusion they favoured systematic reviews (74%) as reviews shed some light on discrepancies between studies but also summarise substantial bodies of evidence (Novak et al. 2013). Lower levels of evidence were included for interventions where systematic reviews could not be found. Studies that investigated care provided by either a medical practitioner or allied health professional were included. Further inclusion criteria were for study participants to be human and 25% of the participants to be children with CP.

The researchers developed a data sheet that two independent raters (a knowledge broker and a CP research expert) used to screen all the abstracts for eligibility for further review. After this the full text of all the possible eligible articles were reviewed to confirm that these studies met all the inclusion criteria. Data were then tabulated and included the following information: the authors and date of the study and the purpose and nature of the treatment implemented, the study design, the original authors' conclusions about the study results and the strength of their evidence. The evidence that fell in the lower levels was assessed using the Cochrane criteria.

The different interventions were coded using the Oxford Levels of Evidence GRADE system and supplemented with the Evidence Alert Traffic Light (EATL) system to make it more user friendly for professionals who want to interpret evidence. Another dimension was added by assigning an ICF domain to each intervention outcome.

Only 6% of the modalities were classed as 'do not do it' (red and stop) and therefore deemed to be ineffective in the field of CP. Amongst these were NDT, craniosacral therapy, hip bracing, and sensory integration.

The majority of evidence (70%) had lower level of evidence of effectiveness (yellow measures) and were subdivided into 'probably do it' and 'probably do not do it'. Amongst these interventions were: treadmill training, seating and positioning, sensory processing, electrical stimulation, CE, hippotherapy, hydrotherapy, strength training, stretching, therasuits, massage, orthoses, Vojta and whole-body vibration.

The interventions that were assigned code green or 'do it' amounted to 16% and included fitness training, casting, constraint-induced movement therapy, bimanual training, context-focused therapy, goal-directed training, hip surveillance and home programmes.

However this study is steeped in controversy that has led to a very open debate about the true nature of systematic reviews and how conclusions should be implemented. Positive feedback came from Fehlings (2014) who noted that the pure fact that the Novak et al. (2013) article has been cited so often, in a short space of time, indicated that it addressed a need. Another positive fact was that interventions were classed according to the ICF (Fehlings, 2014) (Mayston and Rosenbloom, 2014).

Critics have questioned whether conclusions could be made and distributed if all areas of expertise were not represented by the researchers (Autti-Rämö et al., 2014). They felt recommendations can't be made on the basis of clinical trials alone and agreement between clinicians and researchers, combined with clinical judgement, are essential (Autti-Rämö et al., 2014). Further critique of the EATL system included the fact that it did not consider the diversity that can occur in a group of children with CP. Diversity includes differences in age, degree of cognitive and motor function impairment and the subtypes of CP.

The fact that the EATL system seemingly doesn't allow the researcher to look at the child as a whole but compartmentalises aspects of care were endorsed by Mayston

and Rosenbloom (2014). Furthermore the Novak et al. (2013) study was criticized by Mayston and Rosenbloom (2014) in the fact that interventions were not recommended in light of the child's age, GMFCS level and type or classification of CP.

The next section explores one of the most widely used therapy approaches, namely Bobath / NDT (Baxter, 2014). This approach has been criticized through the years for its lack of evidence and was deemed as a red light (stop, 'do not do') modality in the Novak et al. (2013) study. The reason for focusing on this approach in this review is that it is the most commonly used approach used by South African therapists and that as the objective of this study is to find an appropriate observation tool for describing the content of a typical therapy session, it is appropriate to include a discussion on this approach.

2.11 Bobath/NDT

In the 1940s Karel and Bertha Bobath. developed the Bobath/NDT approach. The Bobaths analysed movement and through the use of tone-influencing patterns and therapeutic handling techniques they aimed to influence tone and facilitate more normal posture and motor behaviour (Mayston, 2001). In the late 1970's and 1980's it became the main approach to CP (Mayston 2005).

The Bobath/NDT concept was not intended to be static, but rather an evolving treatment approach based on emerging clinical evidence of therapy (Mayston, 2005). It has gradually evolved in accordance with new theories and practical knowledge. Although the basic philosophy and approach to treatment has remained the same since first being described by the Bobaths the goals, treatment techniques and applications have taken on a more functional orientation (Howle, 2002; Mayston, 2005).

Bobath/NDT as an approach is not a set of techniques that can be applied in a standardised method but rather an approach that is implemented according to principles. It is therefore dependent on the clinician's advanced skills in analysis of movement and problem solving. The level of input and perceived efficacy of the treatment is very much reliant on the therapist's handling skills and level of

experience (Butler and Darrah, 2001). This is a very important consideration in evaluating the efficacy of an intervention. The outcome might be influenced by variability in handling skills and interpretation of what the approach involves.

Bobath/NDT is implemented with different hands-on techniques that allow the child to experience more typical motor patterns. The therapist can choose to start off with the child first experiencing the movements through both the sensory and motor systems before it leads to active participation within a functional goal. The aim of the hands-on therapy is to influence tone and patterns of muscle activity. This might include maintaining biomechanical alignment and proprioceptive input through specific handling techniques. Alternatively this can be achieved by the use of supportive devices such as equipment or orthotics. The Bobath/NDT approach emphasises the role of the caregiver for carryover whereby therapy is not restricted to therapy sessions but needs to be carried over into all activities of daily life (Bly, 1991; Mayston, 2001).

Despite Bobath/NDT's past popularity it has recently become less sought after due to the deficiency of evidence (Mayston, 2016). Despite many clinical trials and comparative studies, as well as attempts by experts in the field (Raine, 2007; Raine, 2006; Mayston and Damiano, 2008; Tyson et al., 2009), the answer to the question 'What is Bobath/NDT therapy?' eludes us. In fact Mayston concluded very recently in an opinion piece (September 2016) that due to the diversity of approaches and the lack of agreement on what Bobath/NDT is, it cannot stand up to research rigors and no longer should stand as a valid therapy approach.

Mayston (2016) recommended that practitioners now shift their focus from a specific approach to the implementation of effective child-centred and FCS. This might then lead to improved activity and resultant participation of the child.

Mayston (2016) further recommended that rigorous methodologies investigating components of fidelity of treatments that allows for better description of the interventions for CP are needed. Especially when implementing the most recent knowledge about muscle physiology, neuroplasticity, biomechanics, motor learning and the ICF. Therefore not ascribing specific activities to a specific approach but

rather identifying and describing therapeutic activities that a therapeutic session might consist of that originates from those different domains.

2.12 Bridging the gap in evidence based research

It is clear that CP is a very complex condition requiring complex intervention. It was stated by Campbell et al. (2000) that complex interventions are comprised of several components and it is difficult to research each of them. This is because of problems of identifying, developing, documenting, and reproducing the intervention. These researchers proposed a process that allows for the development and evaluation of such complex interventions. This will allow researchers to more clearly define what has been achieved. Accordingly both qualitative and quantitative evidence is required to do the evaluation of this process.

Therefore the on-going controversy surrounding the role of hands-on therapy approaches for children with CP and the challenges in the quest for concrete evidence in efficacy presents an opportunity to bridge this gap. In the research it suggests that what happens within a therapeutic session is sometimes viewed as mysterious and difficult to define. This view was based on the argument that sessions are mostly individualised and can't be standardised. It seems to be a 'Black-box' that contains elusive information and this enigma needs to be unravelled by unpacking the contents of a treatment session.

2.13 Unpacking the “black box” of therapy

The theory-driven evaluation (Chen, 1990) that originated in the field of psychology might be useful in the quest to unpack the 'black box' of therapies. This might shed some light on the reason for the scarcity of clinical evidence for effective treatments in the field of CP. According to Chen (1990), theory-driven evaluations look at the mechanisms underlying the outcomes instead of just the outcomes. It evaluates both what effect the implemented intervention had on the outcome (e.g. does the implementation of NDT result in a higher score on the GMFM?) as well as the pathway along which the outcome was achieved (Chen 1990) (e.g. is a specific outcome related to the implementation of specific PA?).

Chen (1990) further stated that the theory-driven evaluation links all components: “the programme input, the contents of the programme (the “black box”), and the outcomes.” It is essential to understand the interaction between specific elements of an intervention and how they relate to outcomes in order to better formulate guidelines for physiotherapeutic modalities (Blauw-Hospers et al., 2010). These guidelines should only include the elements that have a positive outcome and omit negative ones. It should be possible to distinguish between the two by unveiling the specific elements of physiotherapy interventions (Blauw-Hospers et al. 2010).

2.14 Past studies that have attempted to unpack the “black box” of therapy for CP

Some efforts have been made to investigate the decision making process involved in choosing specific treatment techniques when treating a patient with neurological pathology such as stroke (Ballinger et al., 1999; DeJong et al., 2005; DeJong et al., 2004; De Wit et al., 2007; De Wit et al., 2006). However attempts to do this in the field of CP are scarce.

Typical therapy sessions for children with CP were examined by Embrey and Hylton (1996) to determine what it might comprise. They stated that therapists depend on prior acquired experience and theoretical knowledge that forms the basis of their mental systems or contextual frameworks. These two researchers attempted to begin to understand the movement scripts that are implemented during therapy sessions for children with CP and that are based on these mental systems. This study (Embrey and Hylton, 1996) had three experienced and three inexperienced PTs verbally report back during a retrospective, think-out-loud procedure. They reported on the intent behind the different therapeutic activities that were implemented during a pre-recorded video session. These verbal responses were transcribed and then analysed, coded and grouped. The responses were recorded for 48 sessions conducted with 18 children with CP. When analysing the data they could see how a specific movement script related to six different applied treatment

activities. This accounted for 71% of the treatment time when analysing the treatment of one experienced clinician and one child (Embrey and Hylton, 1996). They identified three 'movement scripts' that described diplegia in CP. Number one, for example, is 'Hip flexion, adduction and internal rotation in conjunction with knee flexion and foot plantarflexion'. The authors felt that these activities may help clinicians apply two therapeutic theories (motor learning and NDT) when treating such a complex and heterogeneous clinical condition as CP.

Another study by Larsson et al. (2012) looked at the perceptions PTs might have regarding different physiotherapeutic interventions for children with CP by reflecting on published research articles. The researchers used a 'phenomenographic approach' during which they identified three qualitatively different descriptive categories - A: Making it possible, B: Making it work, and C: Making it normal.

According to Larsson et al. (2012), 'Making it possible' is based on the bio-psychosocial health paradigm and is orientated towards function of the child with CP within their daily context. The PT fulfils the role of coordinator between the role players in the different environments e.g. school, family and community. The outcome is improved services that are family centred and focussed on goal setting, planning and evaluation of the intervention. The therapist seeks to empower the child and family by allowing them to be more active in the problem-solving process. 'Making it work' is based on the mixed health paradigm (biomedical and bio-psychosocial) therefore balancing impairment-focused intervention with function-focused ones. The PT fulfils the primary role of coach to the family and is the one who sets goals and plans and evaluates interventions. The last approach identified by Larsson et al. (2012) is 'Making it normal' - an impairment-based intervention. The PT fulfils the role of the expert who imposes goals, interventions and evaluation without the involvement of caregivers and children. This usually happens in the clinical setting where intervention is mostly directed towards bodily impairment and not addressing any aspects of activity and participation.

The authors suggest that the outcome of their study might enable researchers to approach the design of future quantitative and qualitative studies on physiotherapy interventions in a more holistic way that is in line with current thinking. This will also

have a positive impact on whole intervention processes where professionals can critically assess if their process of assessment, goal setting and treatment meet the expectations of FCS and motor learning strategies (Larson et al. 2012).

These articles have looked at different ways to define the qualitative content of a physiotherapy intervention session for children with CP. There is currently no generally accepted tool in the field of CP that defines and quantifies PA. The literature on this subject is also very limited. Two of the documented attempts to address this issue will be reviewed in the next section.

2.15 Quest to quantify and define rehabilitation for children with CP

Recent research has explored this conundrum of quantifying and defining interventions and assistance came from the psychotherapy domain where some efforts have been made to describe the therapy. The concept of intervention fidelity, firmly rooted in the world of psychotherapy, gave some clues on how to approach this dilemma. Intervention fidelity refers to the idea that there is a good correlation between the implementation of intervention and the intent of the therapist (Carroll et al. 2007 cited by Di Rezze et al. 2012). In other words was the treatment administered as planned? (Whyte 2003)

Moncher & Prinz (1991) (cited by Di Rezze et al. 2012) lay claim to the term 'treatment fidelity'. Ever since this claim was made methods to assess the concept of intervention fidelity have been used to verify a causal association between a defined treatment and its outcomes (Di Rezze et al., 2014). The use of this concept might support the validity of research as it permits the duplication of research methods by matching settings and samples but also correlates the theory with the intervention (Hennessey and Rumrill, 2003).

Due to the complexities of paediatric rehabilitation it has become imperative to not only define the unique features of an intervention but also consider how various interventions differ (Di Rezze et al. 2012). Also important is to identify vital features

that are nonspecific and therefore common to all interventions (Calsyn, 2000). In order to capture all these complexities fidelity measures have evolved significantly (Di Rezze et.al. 2012).

Di Rezze et al. (2012) reported in their narrative review (which is a lower level of evidence) that literature implicates two types of fidelity measures, namely specific and generic measures. A generic measure evaluates both the compliance to one intervention as well as the comparative differences with other treatments (Breitenstein et al. 2010 cited by Di Rezze et al. 2012). Occasionally generic fidelity measures will also include characteristics that are not common to a particular intervention as for instance an intervention process that might include evaluation of the child. Therefore these are well suited to assess the fidelity of more than one intervention where the features of both interventions are distinct (Di Rezze et al. 2012).

On the other hand specific measures examine the therapist's compliance to a particular treatment approach or the way in which the program was implemented. This can therefore be used in research that investigates the active ingredients of a specific intervention (Di Rezze et al. 2012). Di Rezze et al. (2012) reported on two specific fidelity measures published in the paediatric rehabilitation literature (Bayona et al., 2006; Parham et al., 2007). Both of these are related to occupational therapy and are used to report on programme evaluation (Bayona et al., 2006) and the successful provision (Parham et al., 2007) of a particular intervention. In the next sections we will look at a few examples of these types of measures.

2.15.1 Implementation Fidelity Framework (IFF)

One of these examples is the Implementation Fidelity Framework (IFF) (Carroll et al., 2007). Although this model is not specific to physiotherapy it forms the basis of what such a measure should consist.

The IFF features both moderating and mediating factors of treatment fidelity. Mediating features include only the behaviours of the therapist. Here the emphasis is on how consistent the therapist's implementation of the treatment is to that which

is expected. On the other hand moderating features of treatment fidelity look at different aspects of the treatment. This does not only look at the quality of delivery of care but also considers both the client's characteristics that are not influenced by the therapist and those which are (i.e., therapist-client interaction) (Carroll et al. 2007). A major part of paediatric rehabilitation and its successful implementation is the receptiveness of the child (0–11 years) especially and/or the parent within an intervention delivered by a therapist. Therefore treatment should always be geared towards CCS and FCS (Di Rezze et al. 2012). Hence when investigating intervention fidelity in paediatric rehabilitation both mediating and moderating factors need to be considered.

2.15.2 Motor Teaching Strategies Coding Instrument' (MTSCI)

In the Sorsdahl et al. (2010) study an adapted version of the 'Motor Teaching Strategies Coding Instrument' (MTSCI) (Larin, 2007) was used to describe the intervention implemented in their treatment sessions. In this study (Sorsdahl et al., 2010), the sessions were videoed and one of the researchers categorized the amount and type of training that was given, with the aid of the MTSCI.

The MTSCI was originally developed to address the need to quantify instructional treatment modalities implemented in the paediatric population that are based on theories and concepts of motor learning (Larin, 2007). The authors reviewed the literature in order to formulate appropriate items. Some of the psychomotor properties were tested. The inter- and intra-rater reliability, as well as content and construct validity were determined in a pilot stage. The study reported that there was a disparity between the different strategies implemented by therapists with various years of experience. They suggested that this tool might be used to assess the outcomes of motor learning teaching for trainee therapists reflecting on their intended behaviour compared with the actual implemented strategies. This tool solely focuses on therapist behaviour that is embedded in motor learning concepts. Therefore, its limitation lies in the fact that the scope is not broad enough to include other strategies. It also does not include principles that are geared towards CCS and FCS.

2.15.3 The Observation Protocol

An attempt was made by Blauw-Hospers et al. (2010) to objectively capture the PA that might be implemented by a PT during a treatment session for babies in the form of an Observation Protocol. This study was undertaken in the Netherlands and the tool was based on the theories that are most commonly used in this location, namely functional therapy and Bobath/NDT.

The authors stated that although the word 'functional' is only used in one of the approach's title it in no way implies that the latter (Bobath/NDT) doesn't address function at all. In fact, most approaches in infant care aim to improve function (Blauw-Hospers et al. 2010). Despite this, the two approaches do differ in some respects; where functional therapy focuses solely on behaviour that is self-produced by the child, Bobath/NDT has a repertoire of approaches that lead to much more direct contact between therapist and child.

The emphasis of functional therapy is reinforcement of motor behaviour that is self-produced within the context of an everyday functional task like dressing or eating (Ketelaar et al., 2001; Ekström et al., 2005). In this approach the therapist will predominantly fulfil the role of a coach who encourages the child and family's exploration of different motor behaviours to achieve motor tasks (Damiano 2006 cited by Blauw-Hospers et al. 2010). The role of a coach furthermore entails the emphasis of certain goals by the therapist. However the family then decides how best these can be incorporated in their daily lives. The authors' classified activities that mostly involved handling as Bobath/NDT, and activities that were observed as being family involvement, education and functional activities (self-produced) as functional therapy.

Various physiotherapy sessions can be compared with each other by calculating the time spent on various therapeutic activities as a percentage of the total treatment time. This helps to account for the time that was spend on a certain activity and allows for later comparisons between different treatment approaches and different severity levels or classifications.

The psychometric properties of this Observation Protocol in terms of its completeness, mutual exclusiveness, reliability, and construct validity were assessed. Videos of 42 physiotherapy sessions of infants were analysed. These infants had been identified as having a high risk of developmental disorders at the corrected ages of four and six months. The Observation Protocol that was developed classified PA into eight mutually exclusive categories. According to the authors virtually all PA during a treatment session could be classified in this way. Inter- and intra-rater agreements were satisfactory (intra-class correlations, 0.68–1.00).

The Observation Protocol contains three levels of observation. The first level consists of eight mutually exclusive main categories of PA (see Appendix II). These are: “Family involvement and educational actions, Communication, Facilitation techniques, Sensory experience, Passive motor experience, Self-produced motor behaviour, Infant is challenged to produce motor behaviour by himself, Infant is challenged to produce motor behaviour by himself; activity flows over into therapeutic handling” and the “Not specified” category.

The second level consists of the subcategories of the main techniques. For example, the main category ‘facilitation techniques’ consists of the following subcategories: handling, pressure techniques, transitions, and support devices.

The third level of the protocol entails concrete PA: for example, “in the supine or sitting position, the shoulders of the infant function as a key point. It is observed that the therapist guides the shoulders of the infant into protraction to control the infant’s movements and to facilitate hand-on-hand contact and symmetry” (Blauw–Hospers et al. 2010). While the child is in the prone, side lying, or sitting position the observer will score the measure of postural support given by the PT or caregiver as an additional variable.

In conclusion, Blauw-Hospers et al. (2010) found that it is possible to document all PA during physiotherapy sessions of infants at high risk for CP in a systematic, standardised, and reliable manner.

The Blauw-Hospers study found a great deal of diversity during treatment of children with developmental delays and concluded that this might be the result of the ever-evolving nature of different approaches. The authors acknowledged that this diversity within one country indicates the possibility of even more degrees of diversity across geographical boundaries (Blauw-Hospers et al. 2010).

Therefore, they suggested that it would be useful to investigate the applicability of this protocol elsewhere. The authors found that this protocol was useful in reflective practice. The therapists expressed their surprise at the inconsistency between their intended activities and the perceived activities once they had been categorised. They agreed with Larin (2007) that this type of practice of scoring videos can be useful in training therapists.

The authors (Blauw-Hospers et al., 2010) also suggested that this study should be replicated for a population of a different age group than the current one with various neurological fall-outs. The authors furthermore suggested that the protocol should be used to assess the relationship between the activities of which a treatment session consisted and the degree of effectiveness. They concluded that it is imperative to understand more about the content of a treatment session in order to effectively implement evidence- based therapy.

This Observation Protocol was also used in a study by Dirks et al. (2011) in order to analyse the treatment sessions of forty six at-risk infants. They aimed to quantify the differences between two treatment approaches namely "Coping With and Caring for Infants With Special Needs" (COPCA) and traditional infant physical therapy (TIP) sessions, which in the Netherlands are largely based on NDT. In this study bias was minimised by implementing block randomization and blinding of the video analysers. However only about a quarter of the infants developed CP and some of the remaining children went on to develop moderate learning and behavioural difficulties. The authors determined through their study that COPCA and TIP have very quantifiable differences.

2.16 Summary

Cerebral Palsy is the biggest cause of motor disabilities in the paediatric population in South Africa and the rest of the world. This condition is caused by neurological damage to the immature brain through a number of pathological mechanisms and results in a heterogeneous and complex clinical picture that has far reaching effects on the individual and community as a whole.

This heterogeneity and complexity of the condition, as well as logistics and ethics behind big cohort studies, has resulted in a disparity and scarcity in clinical evidence for best practice in terms of intervention and management. This is despite many attempts to try and describe and classify this population of patients more adequately. A few tools have emerged to progress in these efforts to homogenise sample groups. Research concludes that more studies are needed in different treatment modalities but that there is a need for adequate ways to describe what intervention was implemented in order to determine what specific input has led to certain clinical outcomes. Limited attempts have been made to quantify and define the intervention that has been followed in the field of neurology in physiotherapy and more specifically the field of CP.

Different approaches to intervention are followed in different countries. In South Africa one particular approach namely Bobath/NDT is popular. As stated in Chapter one, this study therefore undertakes to evaluate an existing observation tool in order to assess whether it could be used to quantify PA for the rehabilitation of children with CP in the South African context. Should the tool not be suitable for use, a more appropriate observation tool needs to be developed in order to better describe certain interventions that are implemented in clinical research.

CHAPTER 3

MEASURING INSTRUMENT

3.1 Introduction

This chapter will provide an overview of the measuring instrument, namely the Observation Protocol (Blauw-Hospers et al. 2010) that was considered for implementation to quantify and define physiotherapy intervention for an older population of children with CP. The implementation of the protocol involved not only a paper version of the items describing different PA but required specialised software that recorded the observations in real time during playback of pre-recorded video sessions. The coding with the aid of similar software to that used in the original study deemed to be more challenging than expected and had to be overcome.

3.2 Original Observation Protocol

As discussed in the Literature review (see Chapter 2) the observational protocol as developed by Blauw-Hospers et al. (2010) comprises three levels of observation. Their data indicated that the PA of the Observation Protocol could be assessed in a reliable way and a sufficient degree of mutual exclusiveness was found for the items.

Although the Observation Protocol was administered to a completely different population group the literature search did not indicate any other existing tools specifically designed to describe PA. It therefore makes sense to use this protocol as a starting point. Henceforth the terms Original Observation Protocol (OOP) and Adapted Observation Protocol (AOP) will be used to distinguish between the two versions.

3.3 The Observer XT 5.0

The Observer[®] (version 5.0; Noldus, Wageningen, the Netherlands) software programme was used by Blauw-Hospers et al. (2010) in conjunction with the OOP to classify treatment videos into different PA. This programme is specially designed for behavioural observations and allows for the quantification of the occurrence, the frequency and the duration of defined therapeutic actions. The analysis of the contents of a specific predetermined timeframe of a physiotherapy session is performed on a real-time basis. When an observer interprets the therapeutic actions observed in a specific timeframe to be described by more than one subcategory the video will need to be watched and scored multiple times. The therapist scores only one subcategory per run e.g. scoring Subcategory B5-‘Imparting Knowledge’ for the duration of the video. Then the observer will watch the video a second time only scoring the following subcategory for instance, C1-‘Handling’. This is very time consuming as the observer needs to watch the video more than once to do the analysis, however the Blauw-Hospers et al. (2010) study stated that the necessary technique could be learnt relatively quickly and reliably.

This researcher consulted with the distributors of the software and was informed that Version 5.0 (used in the Blauw-Hospers et al. 2010 study) was no longer supported by the manufacturer. The latest Version (10.0), at a cost of R50 000, was too expensive for this research budget. It was therefore not feasible to use this software during phase one and two of the study and alternative software needed to be found.

3.4 CowLog

Due to budget constraints on this research project, and the feasibility of future application, it was decided to find free and open-source software for this study. It is almost certain that costly complicated software requiring specialist input will not be appropriate or used in resource constrained clinical settings.

The open-source software, 'CowLog', which can be used to code behaviours from digital video was developed by Hänninen and Pastell (2009). The choice of the 'CowLog' software was made because it is freely available, easy to use and easy to adapt. The 'CowLog' software was originally developed for animal studies but is suitable for coding any type of subject matter from digital videos. The graphical user interface (GUI) of 'CowLog' consists of a window for playing and controlling digital video. This screen/display has different buttons that represent behavioural codes linked to behavioural observations.

A few shortcomings of CowLog compared to The Observer (Version 5.0, Noldus, Wageningen, the Netherlands) software is that CowLog only allows one option for a physiotherapeutic action to be selected per timeslot and does not allow multiple reruns on the same scoresheet. More detailed comparison was not possible due to the cost of The Observer (Version 5.0, Noldus, Wageningen, the Netherlands) software and could therefore not be purchased for trialling out.

The most recent version of 'CowLog' was downloaded for free from its homepage: www.mm.helsinki.fi/~mpastell/CowLog on the 3 August 2014.

CHAPTER 4

METHODOLOGY

Organisation of the study

The following is a brief outline of the three phases of the study.

Phase one: Five experts in the field analysed four treatment videos using the OOP to determine its relevance in the South African context (Blauw–Hospers et al, 2010). The aim was to achieve 80% consensus. Due to the iterative nature of the study, the methodology, analysis and results of each phase are presented within each phase's chapter.

Phase two: It was found that the OOP was not suitable for an older CP population, and adaptation of the Observation Protocol ensued. During this phase the content validity was determined for the AOP. This was established with the help of a panel of experts.

Phase three: Finally, a pilot study of the AOP was conducted using six PTs working in the field of CP. This was the first step towards establishing the psychometric properties of the adapted protocol; namely the reliability, completeness, mutual exclusivity and construct validity. The same procedure, as applied in the development of the original protocol, was followed. Figure 1.1 below outlines the steps followed in the study.

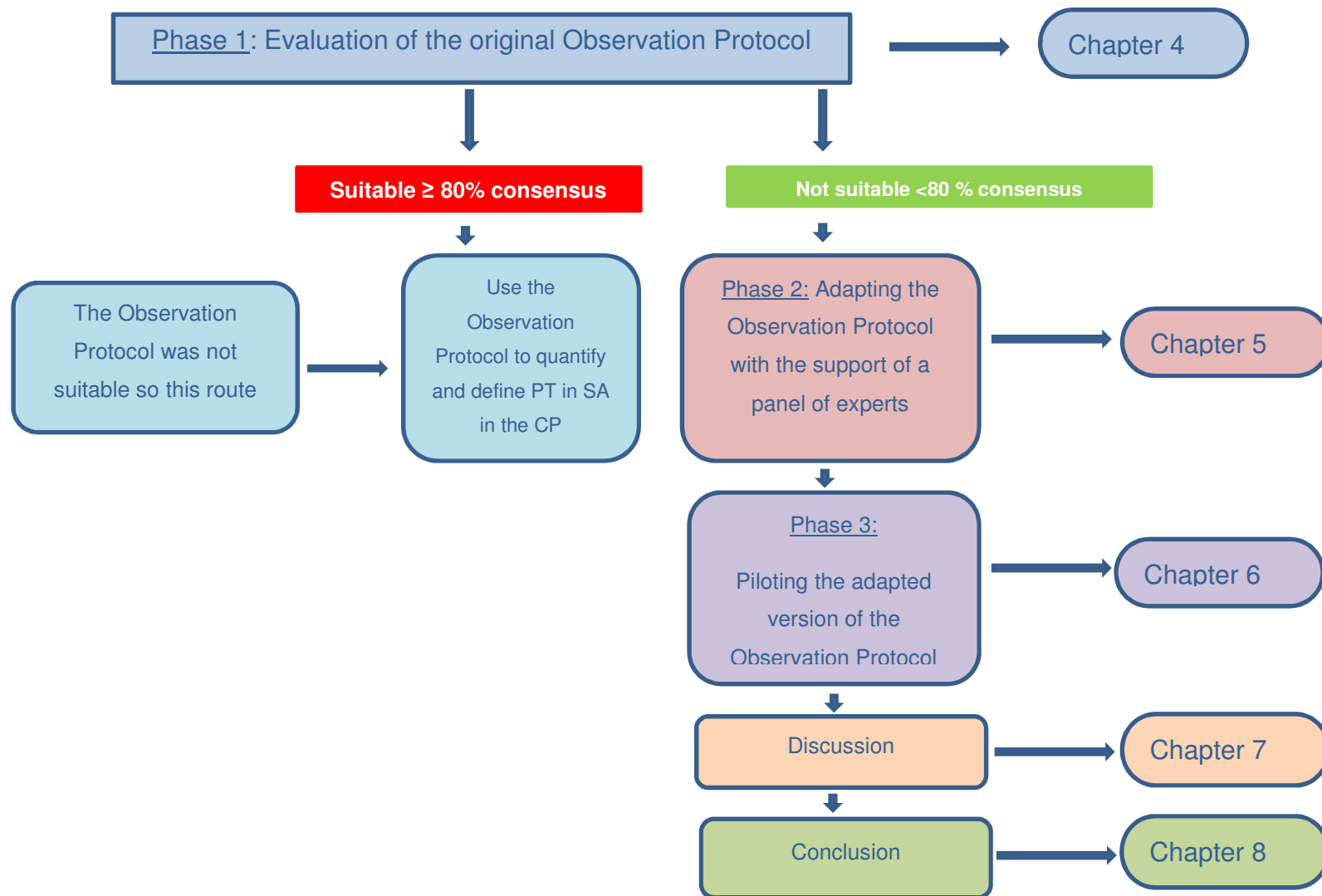


Figure 4.1 Diagram depicting the organisation of the dissertation

PHASE 1: EVALUATION OF THE ORIGINAL OBSERVATION PROTOCOL

The first step was to establish whether the OOP (see Appendix II) could be applied in a physiotherapy session, within the South-African context, in a CP population between the ages of one and 16 years (opposed to the the Blauw-Hospers study that only included infants under one year of age). The methodology and results for this phase will be presented in this chapter.

The objectives of Phase One were to:

- Determine whether the Observation Protocol developed by (Blauw-Hospers et al., 2010) could be used in the South African context when treating children with CP.
- If found unsuitable: Ascertain to what extent it needed to be adapted to be able to quantify and define therapeutic actions during a physiotherapy session with the targeted population of CP children.

4.1 Location

The nominal consensus groups were conducted at the therapy centre of a non-profit organization.

4.2 Ethical Considerations

Ethical clearance for all phases of this study was obtained from the Committee for Research on Human Subjects at the University of the Witwatersrand (Clearance certificate M120827) (See Appendix III).

Permission to conduct the study was obtained from the chairperson of the board of Malamulele Onward, a non-profit organisation, in order to use their facilities to conduct the nominal consensus groups and analyse the videos (See Appendix IV).

The study was explained to each member of the panel of experts and a written information sheet was provided. Informed, written consent to take part in the video

scoring was obtained from each member of the panel of experts prior to them being enrolled in the study. They were given the opportunity to ask questions before giving their consent (See Appendix V).

4.3 Study design

In this phase of the study a non-experimental, descriptive design was used. The aim was to investigate the suitability of an existing Observation Protocol and the possible adaptation of the tool for implementation on an older CP population.

4.3.1 Study participants

Five experts were approached to take part in this first step of evaluating the OOP. They were purposively selected, based on their expertise in the field of paediatric neurology physiotherapy.

Study participants were considered to be experts if they met all the following criteria (Hilburn, 2010):

- a) Had a physiotherapy qualification
- b) Had a minimum of 10 years' experience in paediatrics
- c) Were currently practicing in the field of paediatrics
- d) Were preferably involved in research/were familiar with the processes of research
- e) Were familiar with the administration of standardised assessment tools

The PTs were working in the following settings: four in private paediatric practice and one at a paediatric NPO specialising in the care of children with CP. Four of the study participants were Bobath/NDT tutors, i.e. they trained therapists on the 8 week Foundation Paediatric Course. Bobath/NDT has until very recently been one of the only post-graduate courses in South Africa. Extensive training and relevant experience is a prerequisite to qualify as a tutor. It is also expected to keep abreast with current clinical evidence and trends in this field.

4.4 Measurement tool

4.4.1 Original Observation Protocol

Dr. Mijna Hadders-Algra (see appendix VI), who was part of the original team who developed the Observation Protocol (Blauw-Hospers et al., 2010), was contacted in order to gain insight into the content and application of the OOP. Additional unpublished material was obtained, supplementary to the implementation of the Observation Protocol into The Observer[®] XT 5.0 software (Appendix VIII).

4.5 Procedures

Informed consent was obtained from each member of the panel of experts to participate in the study. The layout and content of the OOP (Blauw-Hospers et al. 2010) was explained to the panel.

In preparation for this session the researcher analysed four, 30-minute long treatment videos splitting each video into specific timeslots. Each timeslot represented the beginning and end of one observed therapeutic activity. Pre-recorded treatment videos of older children with CP were used for this phase of the study. These videos were originally recorded for teaching purposes and appropriate consent had been obtained. The videos were taken during therapy demonstrations on Bobath / NDT training courses, in order to have visual training material on future Bobath / NDT courses. The treating physiotherapists were all senior Bobath/NDT tutors and the caregivers were present in all but one of the sessions.

The reason for choosing videos made during training courses for the purposes of teaching is that it was assumed that in this setting, the treating therapist was most likely to use therapeutic actions which could be easily be categorized and described.

Videos of children between the ages of one and 16 years of age (Individual ages were 18 months, two, three and fourteen years), with different classifications were used, namely GMFCS level II, III, IV and V.

GMFCS Level I was excluded for several reasons:

- The authors of the GMFCS (Palisano et al., 1997) (CanChild) stated that there are fewer distinctions between Levels I and II than between the other levels. They stated that this is more evident in infants younger than two years of age.
- Children with a GMFCS level I are very dissimilar to infants in function and their treatment most likely needs descriptors that are not included in the OOP (Blauw-Hospers et al., 2010) that was developed for infants.
- To restrict the time the experts might spend on analysis to a maximum of two hours.

One subcategory from the Observation Protocol was assigned by the researcher to each selected timeslot and the panel was asked to indicate whether or not they agreed with that specific selection (see Appendix X). If they disagreed they were to indicate which, if any, of the other subcategories they felt more accurately described that particular timeslot. The experts also indicated whenever they didn't agree with the beginning or end of the therapeutic activity assigned to a certain timeslot.

A training session followed during which the researcher and panel of experts analysed a video of a physiotherapy session together. Scoring was done together so that the panel of experts could familiarise themselves with the process.

However, after the training session, the panel felt that the results might be too ambiguous when done in this way. The scoring sheets were then changed to only include the allocated timeslots and thus left as an open-ended question. In this way the experts were allowed to decide which subcategory adequately described the timeslot. If none of the subcategory options were applicable they could suggest a more appropriate descriptor. Experts were allowed to choose more than one subcategory in order to give an indication of the mutual exclusiveness of the subcategories.

In addition, the panel was requested to fill in a short questionnaire (see Appendix X). This was to indicate if they were of the opinion that the Observation Protocol could be applied successfully in older children within the South African context. The experts were given two months to complete the scoring of the videos and the questionnaire. A follow up was done after one month, via e-mail and telephonically, to ensure that they were able to finish it on time.

4.6 Statistical analysis

4.6.1 Methodology

The data obtained through the questionnaire was viewed as qualitative information that was changed into binary information, with 1 being an occurrence of a subcategory and 0 being a non-occurrence. Therefore although the data was qualitative in nature, quantitative evaluation methods were used to analyse it. The hypothesis testing method and therefore quantitative evaluation methods were used to analyse the data.

The Hypothesis statement was: PA's, as practiced by South African PTs working with children with CP, can be defined and quantified using the OOP (Blauw-Hospers et al., 2010).

To prove this hypothesis the researcher identified two testing criteria that could be investigated through analysis of the data. The two areas being:

1. The mutual exclusivity and the consistency with which mutual exclusivity occurred.
2. Correlation between the selections of experts from the panel.

The researcher evaluated the relationship between the various study participants per time slot, disregarded the inter relationship between the various time slots and interpreted each action as an independent action.

The study participants were allowed to allocate more than one subcategory per timeslot that in their opinion described the therapeutic activity adequately. This is in accordance with the procedures that the Netherlands teams (Blauw-Hospers et al., 2010; Dirks et al., 2011) implemented in their studies as more than one therapeutic activity can happen simultaneously. If only one subcategory has been selected per activity it will indicate mutual exclusivity. If mutual subcategories are selected, it indicates mutual inclusivity.

The data was analysed using Microsoft® Excel 2013 (Excel) with internal built-in formulas. Calculations to indicate mutual exclusivity are presented in Appendices XIII and XIV.

4.6.2 Method for evaluating mutual exclusivity

Each video was divided into timeslots which were presented on a horizontal bar, with subdivision for each expert's response indicated in different colours under the bar (see Appendix XIII). On a vertical bar all the possible categories and subcategories from the Observation Protocol were indicated. Each expert's selections were indicated with a numerical '1' in each particular timeslot. When a timeslot per expert indicated a number higher than one, mutual exclusivity was rejected. After all the columns were summed, a total percentage of mutually exclusive observations were calculated per video.

4.6.3 Method for evaluating correlation

During the correlation calculations represented in Appendix XIV each video was divided into timeslots which were presented on a vertical bar with subdivision for each expert's response indicated in different colours. On a horizontal bar all the possible categories and subcategories from the Observation Protocol were indicated. Each expert's selections were indicated with a numerical '1' in each particular timeslot. Pearson product-moment correlation coefficient was used to calculate correlations. The correlation coefficients were totalled into five subdivisions ranging from 0.5 to 1 and depicted in a tabular format. Table 4.1 below depicts the values for interpreting the correlation coefficient (Mukaka, 2012).

Table 4.1 Correlation Coefficient Interpretation (Mukaka 2012)

Size of correlation	Interpretation
.90 to 1.00 (-.90 to -1.00)	Very high positive (negative) correlation
.70 to .90 (-.70 to -.90)	High positive (negative) correlation
.50 to .70 (-.50 to -.70)	Moderate positive (negative) correlation
.30 to .50 (-.30 to -.50)	Low positive (negative) correlation
.00 to .30 (.00 to -.30)	Negligible correlation

In this case Fleiss Kappa was suitable, due to the fact that five study participants evaluated the different videos. One of the major concerns was that Fleiss' Kappa and Cohen's Kappa both require mutually exclusive categories.

Therefore, only the timeslots that did meet the mutually exclusive criteria were considered for Fleiss Kappa statistical analysis. They were grouped together because the activities are considered independent and the activities per timeslots are seen as an action to which the Observation Protocol can be applied.

Landis and Koch (1977) derived a table (see Table 4.2) for interpreting the κ value. This is just an indicator to analyse whether there is any consistency between the various study participants.

Table 4.2 Landis and Koch (1977) interpretation table for k-value

κ value	Interpretation
<0	Poor Agreement
0.01 – 0.20	Slight Agreement
0.21 – 0.40	Fair Agreement
0.41 – 0.60	Moderate Agreement
0.61 – 0.80	Substantial Agreement
0.81 – 1.00	Almost Perfect Agreement

4.7 Results

Table 4.3 below illustrates the total number of observations across the four videos that were rated as well as the percentage of observations where mutual exclusivity was achieved.

Table 4.3 Mutual exclusivity of observations

	Mutually Exclusive	Total Observations	% Mutually Exclusive Observations
Video 1 GMFCS V	102	205	50%
Video 2 GMFCS II	63	115	55%
Video 3 GMFCS III	103	165	62%
Video 4 GMFCS IV	89	200	44%

As table 4.3 shows, the highest percentage of mutual exclusivity observed was only 62%. It can therefore be concluded that the mutual exclusivity principle of the Observation Protocol developed by Blauw–Hospers et al (2010) is not reasonable and therefore rejected.

Table 4.4 depicts the correlation between the responses of the various study participants and expresses it in values between -1 (total disagreement) and 1 (total agreement).

Table 4.4 Example of the correlation coefficient between study participants for one timeslot

	Participant 2	Participant 3	Participant 4	Participant 5
Participant 1	0.69	0.34	0.46	0.46
Participant 2		0.55	0.69	0.69
Participant 3			0.34	0.34
Participant 4				0.46
Participant 5				

Based on the correlation coefficient interpretation table of Mukaka (2012) the various measurements were categorised into three correlation coefficient intervals which are illustrated in Table 4.5

Table 4.5 Average percentage correlation achieved over the four videos

	Correlation coefficient interval classification			Total
	1- 0.9	0.9-0.7	0.7-0.5	
Video 1	9.4%	1.1%	17.4%	28%
Video 2	11.7%	0.4%	28.7%	41%
Video 3	4.9%	0.9%	13.6%	19%
Video 4	8.3%	3.5%	15%	27%

Table 4.5 illustrates the percentages for each correlation coefficients interval. For example in Video 1, only 9.4% of the timeslots had correlation coefficients that fell in the interval 0.9 to 1 (the highest positive correlation). Only correlation coefficients greater than 0.5 were considered as an acceptable positive correlation (Mukaka, 2012). In video 1 only 28% of the timeslots had a positive correlation. The percentage of timeslots that had a positive correlation went as low as 19% in video 3. This indicates that there was a negligible to low positive correlation (Mukaka, 2012) between the study participants using the Observation Protocol (Blauw–Hospers et al. 2010).

The Fleiss Kappa κ value was calculated as 0.17 (see appendix XV), which indicates a slight agreement according to Landis and Koch (1977) (Table 4.1). This result is in line with the correlation coefficient that was calculated, where there was some correlation between the study participants. However, it was not enough to conclude that the Observation Protocol (Blauw-Hospers et al., 2010) can be used to define and quantify physiotherapeutic actions, as practiced by South African PTs working with children with CP.

Table 4.6 below lists the subcategories that were selected most frequently by study participants in a particular video.

Table 4.6 Most frequently selected subcategories in each video

Video	Highest Ranked Subcategories for each video				
Rank	1 st	2 nd	3 rd	4 th	5 th
Video 1 GMFCS V	E – Passive motor experience 30%	C4- support devices 14%	D- Sensory experience 9%	A1- Family members participating in guidance of infant 8%	C1- Handling 8%
Video 2 GMFCS II	C1- Handling 36%	I- Not specified 12%	C3- Transition 10%	H1- Infant is challenged to produce motor behavior by him/herself; activity flows over into therapeutic handling With little variation 9%	C4-support devices 8%
Video 3 GMFCS III	C1- Handling 28%	C4- support devices 11%	D- Sensory experience 10%	I-Not specified 9%	H1 Infant is challenged to produce motor behavior by him/herself; activity flows over into therapeutic handling With little variation 8.7%
Video 4 GMFCS IV	C1-Handling 34%	G1 Infant is challenged to produce motor behavior by him/herself; infant is allowed to continue activity by her/himself. With little variation 13%	H1 Infant is challenged to produce motor behavior by him/herself; activity flows over into therapeutic handling. With little variation 12%	H2 Infant is challenged to produce motor behavior by him/herself; activity flows over into therapeutic handling. With large variation 9%	D- Sensory experience 8%

4.7.1 Interpretation of data

Based on the analysis, the stated hypothesis was rejected and it was accepted that the Observation Protocol (Blauw-Hospers et al., 2010) is not adequate to quantify and define physiotherapeutic actions as practiced by PTs working with children with CP within the South African context. A new protocol based on the input received from the various study participants and experts in this particular field of physiotherapy had to be developed. The development of the new protocol is the subject of Chapter Five.

From Table 4.6 it is apparent that the treatment session for more involved children involves more passive experiences of movement. Furthermore it is apparent that the treatment for children of a higher level of functioning entails more practice of transitions.

4.8 Analysis of the Questionnaire

4.8.1 Methodology of the Questionnaire

Along with rating the videos, the panel of experts was requested to complete a questionnaire (Appendix XI) to comment on their experience of using the Observation Protocol and recommended changes. Content analysis was done to group similar comments together and to determine the percentages of study participants who agreed to the change for each specific subcategory or category.

4.8.2 Results of the Questionnaire

Table 4.7 contains the comments of the panel of experts in response to the question: *“If none of the subcategories adequately describe the therapeutic activity, in your opinion, state in one sentence an alternative descriptor”* (see Appendix X).

Table 4.7 Comments of the panel of experts for suggested adaptations

Subcategories from the Observation Protocol	% of agreement to change	Suggested adaption
A1 Family members participating in guidance infant A2 Role of caregiver	20%	• “Not sure how to differentiate between these two”
A.3 Infant dressing	80%	• “Only mentions infant being dressed needs to include child doing the activity themselves” • “Child putting splints on is not a therapeutic activity as it is preparation for standing” • “Sometimes dressing is the context of therapy and leads to therapeutic activity”
B Communication	40%	• “All these communication categories should be adapted to include communication with a child which is sometimes different to that of communication with an infant or a caregiver” • “Visual demonstration should be mentioned as an example”
C1 Handling	80%	• “Too limited in examples” • “Needs a more specific descriptor” • “Needs to include rotation, elongation, dissociation” • “Needs to include terms like “using gravity” “therapist is positioning the child”

		• “Should include mobilising one part/side of the body against the other” • “Need to include moving trunk over base of support (BOS) and movement within BOS” • “Need to include the use of proximal and distal key points” • “Handling might look passive but the handling is enabling/facilitating muscles to work in different synergies, handling makes it impossible for the child to move in a typical pattern and gives sensorimotor experience of new and different ways of moving” • “Age of child and level of child affects the type of handling” • “The words guiding/facilitation of movement should be included in the description.” • “Important to include weight bearing over a distal key point as an example.”
C2 Pressure techniques	60%	• “Not descriptive enough, therapist is not applying pressure she is mobilising.” • “Need to include terms like ‘hoovering’ and loosening.” • “Need to include pressure in a <u>diagonal</u> direction to connect shoulder and pelvic girdle.”
C3 Transition	80%	• “Not descriptive enough; doesn’t mention weight shift.” • “Needs an active transition descriptor.” • “Is this category needed?” • “Need to differentiate whether child is actively participating or if child is ‘done to’ i.e. therapist is doing all the movement There is no category for holding whilst carrying the child in a specific therapeutic way to influence the tone.”
D Sensory experience	20%	• “Need to include category for vestibular, proprioceptive and tactile input.”
E Passive motor experience	100%	• “Descriptor is too passive as this need to include preparation techniques.” • “Agree with the heading but not the examples given.” • “Needs subcategory for muscle releasing techniques.”

		• “Needs subcategory for spinal mobilisation.” • “Can this be better explained with a heading: “Specific handling techniques to loosen/prepare”?” • “Should it not include rocking movements as example of how to loosen the body?” • “Passive movement should lead into activity otherwise not effective.”
G-Challenged to produce motor behaviour by him/herself; infant is allowed to continue activity by her/himself G1: Little variation G2: Large variation	100%	• “Not descriptive enough.” • “Needs to be adapted to children.” • “Not clear what is meant with little and large variation.” • “Is a better descriptor: ‘Handling that alters the child’s typical way/pattern of movement or increasing the varieties of movement’ – facilitation might be different for each child but similar for different GMFCS levels.” • “Is this appropriate for children or would you rather instruct them?”
I -Not specified	60%	• “Comforting the child should not be here but under communication.” • “Example for change of position and environment should rather be classed as a separate category? As this is important context.” • “Example should include allowing the child a break.”
General		• “Need a category that explains that the therapist is using patterns (TIP’s) and/or biomechanical alignment.” • “Need a category where the child is prompted with verbal cues and cognition is used to facilitate movement.” • “Need to add the context of the treatment.” • “Category needed for re-evaluating/ reassessment to observe change although this is listed as example under B4 the descriptor’s wording is not clear enough.” • “Need category for comforting the child.” • “Need to address child’s level of participation and

		interaction.” • “Need category for hand over hand facilitation of the carer.” • “Suggestion: Less categories will be more user friendly, make it easier to implement for proper use.” • “Can therapy be seen in terms of ICF?” For example: Impairment; anything that directly involves the Musculoskeletal system. Activity; Any functional activities. Participation; Include communication and choice making.” • “Need a category for setting up equipment.” • “Should support given be classed for each activity as it typically changes throughout a session, how can it only be captured once?” • “There is no category for when the child pushes back and the therapist doesn’t interfere but only waits for the child to come back”. “Specific training in using the tool is very important.”
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Table 4.8 Opinions from experts about mutual exclusivity of the subcategories and categories

Categories	Comments
Family involvement C Handling D Sensory involvement H Infant is challenged to produce motor behaviour by him/herself; activity flows over into therapeutic handling G Infant challenged to produce motor behaviour independently; infant is allowed to continue activity.	•“A1- Family members participating in guidance infant” and A2 –“Role of caregiver” are difficult to differentiate between.” •“Sometimes very subtle changes in the handling of therapist and difficult to differentiate between H and C1.” •“Difficult to differentiate between C1 (Handling) and D as the handling generates a sensory experience.” •“Difficult to differentiate between H1 (little variation) and G1 (little variation), what comes first, the handling then the activity? It can go on in circles.”

4.8.3 Discussion of the results of questionnaire

All the study participants were of the opinion that the observational tool did not adequately and accurately describe all the aspects of the therapeutic activities that were observed in the videos. This confirms the statistical analysis.

Eighty per cent of the experts agreed regarding *“The amount of support given throughout each session by the therapist to the child”*. This is scored as a once-off

event and is not related to a specific timeslot but rather as a general impression for each video. However, the panel of experts didn't find it to be relevant when scored solely as a once-off event during the whole video but rather felt that it will change for each therapeutic activity and should be able to be scored throughout.

Option A.4.1- '*The extent of interference by the physiotherapy or the caregiver with infant's activities*' and A.4.3 – '*Caregiver coaching*', were never selected as options throughout the four videos. This might be attributed to the fact that all the videos were made for the purpose of training of a therapist, although parents were present in all the sessions. All the sessions were with children who were older than one year of age and the instructions were directed to them rather than to a caregiver.

The panel was also of the opinion that the protocol needed to be adapted to adequately describe all the therapeutic activities when treating a child older than one year of age. They concluded that the categories H1, H2, C, E needed to be either expanded upon or adapted by using different terminology (see Appendix II).

The panel stated that children from GMFCS Level V need lots of 'handling and preparation' during treatment and that the only option in the Observation Protocol that might describe this therapeutic activity is E. E is described as 'passive motor experience' and the panel agreed that this was not sufficiently descriptive to explain the complexity of what a skilled therapist is doing.

When watching the video of the child from GMFCS level IV, the panel noted that the choice of categories was limited and did not explain in depth what the therapist was doing. In this video they perceived that most of the therapy was "*getting the child to actively move in new ways and with new muscle synergies.*" They were not convinced that the given categories covered this adequately.

This was also the case for the GMFCS level III video. In this video a big part of treatment was "*handling the child in a certain way to get her to use her muscles in new ways*". Therefore the panel was of the opinion that some "*sensorimotor learning as well as therapeutic handling happened, paying particular attention as to HOW the child was performing the movement.*" Once again they found that the

Observation Protocol described these therapeutic activities to a certain extent but that the handling component was not detailed enough.

In the analysis of the GMFCS level II video the therapist gave the child a great deal of verbal instruction for optimising movement and self-initiated activity. This was not covered as a subcategory in the tool as it was designed for treatment in infants only. In this treatment a member of the panel stated that: *“the child was often doing a particular movement actively, but the therapists’ hands guided the quality of the movement – I don’t think this choice or category was adequately covered.”*

4.9 Conclusion

There was moderate agreement amongst the panel of experts as to which category adequately described a specific therapeutic activity. The panel was of the opinion that the Observation Protocol more adequately described the treatment sessions for the higher functioning children, GMFCS levels II and III, although some categories needed to be more detailed. They did concur that the handling for more involved children at level IV and V needed to be more specific to portray the complexity of the facilitation techniques that the therapists implemented. The data analysis indicated that the Observation Protocol needed adaptation to be more applicable to the treatment of children with different GMFCS levels.

CHAPTER 5

PHASE 2: ADAPTATION OF THE ORIGINAL OBSERVATION PROTOCOL

The next steps involved the adaptation of the OOP and the establishment of the content validity.

The objectives of this phase were to:

- establish the content validity of the OOP during a series of modified nominal group sessions.
- adjust the observational protocol based on recommendations made by the panel of experts.

5.1 Procedure

5.1.1 Drafting of a provisional Adapted Observation Protocol

The researcher drafted a provisional adapted version of the Observation Protocol (Appendix XVI). This was based on the feedback from the panel of experts, obtained from the questionnaires in the evaluation phase of the OOP (first phase of the study) as well as details from the unpublished *Tab-Overview of the Observer* (Appendix VIII). The *Tab-Overview of the Observer* clarified the implementation of the original protocol and contained some changes introduced by the Blauw-Hospers development team since 2010.

The changes were printed in different colours for clarity to enable study participants to give their opinion on whether or not they were appropriate. Red indicated the changes added by the researcher based on the feedback from the first phase of the study. Green indicated new additions added by the Blauw-Hospers team since 2010 but their appropriateness was questioned by the researcher (Appendix XVI). The researcher directed specific questions to the panel using comment boxes.

5.1.2 Nominal Group Technique

A panel discussion was conducted involving the same five experts in the field of paediatric rehabilitation who were involved in the first phase of the study. The Nominal Group Technique (NGT) was used in order to facilitate discussion and obtain consensus (Fink et al., 1984; Potter et al., 2004). This technique was slightly modified in the voting process as no ranking occurred but voting occurred for each item inclusion as well as questions addressed to the panel.

A letter of invitation outlining the proposed session and inviting them to participate was sent to each panel member. Each member gave consent for their participation and for the discussion to be videotaped (see Appendix XII). The NGT were conducted in two rounds. Following the first round the researcher made the suggested changes and then met with the group a second time.

The same format was followed during both rounds. Only when 80% agreement was reached did the group move on to the next point. Agreement was often only reached after considerable discussion and debate which continued until agreement was achieved. All participants were very vocal and no participant dominated the discussion. Both rounds of NGT sessions were videotaped (as recommended by Potter et al. 2004) to provide augmented clarity and in-depth explanation of results during later analysis. Each session lasted approximately two and a half hours.

During the discussions the panel discussed different treatment scenarios where they would theoretically test the adaptations. These scenarios were based on clinical experience as well as examples recalled from the videos used for analysis during the first phase. They added terms and examples that they considered more appropriate in describing the specific items to assist in implementation of the tool in a clinical setting.

The NGT protocol was followed and the following points were addressed:

- 1) Appropriateness of each category and subcategory selected (the subcategory itself and its wording).

- 2) Categories and subcategories which needed to be removed due to repetitiveness.
- 3) Alternative categories and subcategories to be included.
- 4) More examples under the categories and subcategories to clarify the particular category or subcategory.

Each participant was provided with the proposal for the study, a copy of the OOP (see Appendix II), the *Tab- Overview of the Observer* (see Appendix VIII and the Definitions of terms) and the first adapted version of the Observation Protocol (see Appendix XVI).

In line with the guidelines for NGT (Potter et al. 2004), the following steps were followed:

1. Introduction and explanation: The study participants were welcomed and the study and its aims outlined. The panel was also briefed on the procedures of the modified nominal consensus group technique.
2. Generation of ideas: The study participants were given 30 minutes to read through the documents. During this time study participants were encouraged to write down all ideas that came to mind when considering the question as well as any further comments and questions they might have. During this period, study participants were asked not to consult or discuss their ideas with one another.
3. Sharing of ideas: Study participants were then invited to share the ideas they had for each category and subcategory. The process continued until all the ideas were presented. The panel did not debate the items at this stage but each participant wrote down any new ideas. This process enabled all study participants to make an equal contribution and provided a written record of all the ideas that were generated by the group.
4. Group discussion: Study participants requested clarification if they were uncertain about any of the ideas their colleagues had generated. The researcher read out each one of the original categories and subcategories, followed by the comments that were presented in the feedback as well as the clarifiers from the *Tab- Overview of the Observer*. Time was allowed for discussion and questions concerning each specific item. Members then

offered alternative wording and definitions for that specific item and commented on the appropriateness of the specific item.

5. Voting: Every member of the group's opinion and comments were heard.

Voting was not anonymous but indicated by show of hands. This was done because of time and logistical constraints. Only when there was 80 % consensus, did the discussion move forward.

5.2 Data analysis

The NGT is seen as an exploratory process and the fact that consensus has been obtained indicates a starting point for further testing and validation rather than a destination to the 'correct' answer (Jones and Hunter 1995; van de Ven and Delbecq 1972 cited by Potter et.al. 2004). Data analysis for the NGT is described as a mixed method approach as a combination of both qualitative and quantitative analysis should be used to report results.

5.3 Results

The NGT has been used in the field of paediatrics to develop content validity for outcome measures (Boyce et al., 1993; Palisano et al., 1997; Palisano et al., 2008), where consensus was defined as 80% of study participants being in agreement. Therefore 80% agreement was also used in this study during each round. All concerns were discussed and appropriate changes suggested by study participants. There was 80% agreement for all four the objectives at the end of each session. The concerns and discussions that were raised in order to arrive at an agreement are outlined in 5.2.1.

5.3.1 Changes to the Adapted Observation Protocol

The following section describes changes to the observer protocol as a result of the panel discussions. The panel discussion surrounding each change is summarised in order to explain the panel's thinking behind the suggested changes. These

explanations also serve to highlight the complexity of designing a tool that accurately captures a therapist's actions during a treatment session.

Figure 5.1 depicts a summary of the outline of the AOP.

Section 1 <i>Position/ Transition</i>	Section 2 <i>Context of functional activity/task</i>	Section 3 <i>Therapist interactions</i>		
		<i>Subsections</i>	Categories and subcategories with modifiers	Qualifying examples
		<i>Hands-on techniques</i>		
		<i>Hands-off techniques</i>		
		<i>Communication</i>		

Figure 5.1 Outline of the adapted version of the Observation Protocol

From Figure 5.1 it can be seen that three sections were identified: (1) 'Position/Transition', (2) 'Context of functional activity/task' and (3) 'Therapist interactions'. The latter section had three further subsections: (i) 'Hands-on techniques', (ii) 'Hands-off techniques' and (iii) 'Communication'. The three subsections were then divided into categories and subcategories with modifiers, followed by qualifying examples (See appendix XVII for the changes that were proposed).

All the subcategories were classed as categories in the original version and the changes suggested by the panel are discussed in the following paragraphs.

5.3.1.1 Discussion of the category 'Position'

The panel agreed it was important to document the variety of positions in which a child might be treated as this adds depth to the description of a session. However they felt that reporting on the duration of each position would have no added benefit. It would therefore suffice to document only the incidence of change of position. They felt that most of the detail about 'how' it is done should be omitted

from this section because the list could become exhaustive. The detail of the quality of the movement however would then be captured in the following '*Therapist activities*' section.

The panel felt that the information gained from this section might provide insight into the approaches of different therapists when handling children from different GMFCS levels. A novice therapist may for example stay clear from treating a child of GMFCS level IV or V in standing and opt only for supine.

The heading '*Positions*' was therefore expanded to include the original separate category of '*Locomotion*' and was replaced with the heading '*Positions/Transitions*'.

5.3.1.2 Discussion of the category: '*Situation of treatment session*'

The panel felt that this section further added to the multi-dimensionality of this tool as a descriptor, but queried the wording of the heading. 'Goal' was suggested as an alternative but was vetoed as the consensus was that only an interview with the therapist themselves can truly reveal the goal of a treatment session.

An example given by one of the experts clarified this point - where the therapist's goal for a session might be improving hand function. The therapist might decide to address this through a variety of options from this category, i.e. First opting to use 'making a fruit salad' then 'building a puzzle', followed by 'tying shoelaces'. In this case the situation or context has changed three times but the goal remained the same. In the end the panel opted for the wording 'Context of treatment session'.

Some panel members felt that goal setting is such an important part of therapy that it needs to be quantified in some way. However in the end all five members concluded that the tool is an objective measure of observable actions during a treatment session and should be differentiated from intended actions and efficacy. It was also agreed that the terms 'passive and active' be replaced with 'engaged' as this was regarded as one of the lowest functional levels of participation.

5.3.1.3 Discussion of the category: '*Neuromotor actions*'

The researcher questioned the panel on whether this category should be split into two with an additional heading of '*Musculoskeletal actions*'. This was based on the idea that the secondary changes that occur during a child's lifespan are mostly musculoskeletal (Fairhurst, 2015) in nature and should therefore be addressed during a treatment session. Following discussion, this suggestion was vetoed and remained as '*Neuromotor actions*'.

5.3.1.4 Discussion of the categories: '*Preparatory actions*' and '*Facilitation techniques*'

The panel defined facilitation as 'enabling or making it possible'. They further agreed that one should be careful to separate these two actions as they often happen simultaneously or the one often immediately follows the other. They should not be viewed as rigid sequential actions. The panel initially felt that the words '*Preparatory actions*' were too limiting but could not agree on an alternative. Instead it was agreed that the modifiers should be expanded in order to clarify this category.

5.3.1.5 Discussion of the category: '*Pressure techniques*'

The panel felt that the term '*Pressure techniques*' was restrictive and that it should be replaced by '*Proprioceptive techniques*'. This was defined as an activity where the input is sensory in nature with the aim of a motor outcome. It was decided that all supportive devices for instance using a walking frame or splints would be excluded as examples. The wording of the modifiers and examples were further refined.

5.3.1.6 Discussion of the categories: '*Sensory experience*' and '*Passive motor experience*'

The researcher queried the usefulness of the subcategory '*passive motor experience*' and whether or not it should be excluded altogether. The panel's opinion was that an evaluation tool should be able to reflect all aspects of a

treatment session. Including these categories would make it possible to quantify and describe treatment sessions employing a more passive approach.

The panel agreed that the term '*Sensory experience*' was not useful to include in the remit of a PT and should be replaced by '*Passive sensory motor experience*'. One of the experts qualified this statement by elaborating: 'A PT mostly uses a sensory experience to produce a motor control outcome.' For instance the vestibular system can be stimulated in order to have better head control, or the tactile system can be stimulated by brushing a hand with a soft toy in order for the child to have a motor response namely, reaching for the toy. It is not in the scope of practice of PTs give sensory input merely for the sake of a sensory experience.

5.3.1.7 Discussion of the category: '*Self-produced motor behaviour*'

The panel felt that it was important to capture whether a therapy session remained passive or whether it led to activity. Furthermore, they suggested the inclusion of three different '*Self-produced motor behaviour*' subcategories, each with different modifiers. The panel also felt that the modifiers 'little and large variation' should remain to capture a variety of options that the PT might introduce. The panel further suggested the removal of the words '*interference of PT/CG*' and replacement with '*guidance from PT/CG*'.

5.3.1.8 Discussion of the category: '*Caregiver coaching*'

The panel felt that this should be changed to '*Caregiver training*' as this was more descriptive of any activities entailing the handover of handling skills. It was moved from its original category of '*Communication*' to a subcategory under '*Hands-on technique*' as this was considered an important aspect within South African practice.

5.3.1.9 Discussion of the category: '*Communication*'

The panel felt that several of the categories from the original protocol were repetitive and should be merged under the heading of '*Communication*'.

'Comforting' was replaced with *'Responding to child's emotional/psychological/social/behavioural needs'*. Six other subcategories were identified and adapted a little to be classed under *'Communication'*.

5.3.2 Final adaptation

Following the second round of discussions, the suggested changes were made to the Observation Protocol (See Appendix XIX). This version was then e-mailed to all five experts for their opinion and followed up telephonically one week later. All the panel members were of the opinion that no further changes were needed at this stage and that the new format was more concise.

5.4 Summary

The panel of experts discussed the content of a tool that would best describe all the possible components of a physiotherapy session for a child with CP within South African practice where the therapy approach is eclectic and not specific to one particular approach. The panel had to be reminded throughout the process that they were looking at the “what is done” and not the “why it is done”. Throughout the process, the panel was careful to avoid jargon that might be linked to a particular approach i.e. tone-influencing patterns linked to NDT/Bobath.

In summary the main differences between the OOP and the AOP is that three main sections have been added namely: (1) 'Position/Transition', (2) 'Context of functional activity/task' and (3) 'Therapist activities'.

Under Section 1 'Position/Transition' the following categories were added: Lying, sitting, and half kneeling with all the different varieties of these positions that might occur as subcategories.

Under Section 2 'Context of functional activity/task' the following five categories were added: 'Home related activities, Participating in leisure activity, Mobility in the community, Selfcare/grooming,' and 'No specific functional activity identified'. As subcategories the child's degree of engagement was added. The examples were

also expanded on to be more inclusive where for instance personal hygiene and eating were included.

Under Section 3 three further subsections were added namely: (i) 'Hands-on techniques', (ii) 'Hands-off techniques' and (iii) 'Communication'. Although communication was part of the OOP it was completely changed to now include the five categories namely: 'Instruct the child/infant/caregiver, Responding /adopting to the Child's emotional/psychological/ Social/behavioural needs, Provide verbal feedback to the child or caregiver, Educational information exchange' and 'Non specific communication'.

The 'Hands-on techniques' has seven categories added namely: A - Preparatory actions, B - Facilitation techniques, C - Proprioceptive techniques, D - Self-produced motor behaviour, E - Passive experience of movement, F - Caregiver training and G - Non-specific hands-on techniques.

Furthermore the category : A - Preparatory actions had three subcategories added namely A1 Soft tissue release , A2 Mobilization of specific joints and A3 Therapist moves child's limb or limbs , A4 Prolonged and sustained handling, A5 Sensory input. While under B - Facilitation techniques have three subcategories namely B1 Manual Biomechanical alignment of limbs, B2 Manual directional handling by the PT to distal/peripheral body parts and B3 Manual directional handling to proximal body parts of the child. Lastly two subcategories were added to C - Proprioceptive techniques namely: 'C1 - Proprioceptive input directly to the body' and 'C2 - Proprioceptive input via a piece of equipment'.

Lastly the categories that were added to the 'Hands-off' Section were: H – 'Self-produced motor behavior with no guidance from PT/CG, I - Self-produced motor behavior with guidance during the activity in order to explore alternatives' and 'J - Repetition of a successful activity allowed'. Lots off detail was added under the examples in order to really allow an observer to differentiate between the different categories and subcategories.

The following chapter explores the implementation possibilities of the adapted tool through piloting the AOP.

CHAPTER 6

PHASE 3: PILOTING THE ADAPTED OBSERVATION PROTOCOL

The final step of the study involved the piloting of the AOP followed by establishing the inter-rater and intra-rater validity.

The objective of this phase was:

- For a panel of experienced PTs to pilot the AOP in order to begin the process of establishing inter-rater and intra-rater reliability.

6.1 Study design

This phase was a preliminary study of the feasibility and acceptability of the AOP for implementation in CP population within the South African context. Both qualitative and quantitative data analysis methods were used.

6.1.1 Ethical Considerations

The videos used for the study participants were recorded during an outreach programme run by Malamulele Onward, a non-profit organisation. These particular videos were decided upon as they were recorded when an opportune time to video a number of therapists treating a variety of children with CP in one week at one location presented itself. Appropriate consent was obtained from the organization to use the videos for research purposes. The organization had obtained informed consent from the parents prior to the videos being made.

The study was explained to each member of the pilot group and a written information sheet provided. Informed, written consent for participation in the video scoring was obtained from each participant prior to being enrolled in the study. Study participants were given the opportunity to ask questions before giving their consent (See Appendix XX).

6.1.2 Study participants

A group of six experienced PTs were approached to take part in piloting the AOP. None were involved in the previous stages of the study. Each PT had at least four years postgraduate experience in paediatric neurology and had been involved in postgraduate research in some way. Four of the PTs worked in private practice settings whilst two worked at schools for learners with special needs. All six the physiotherapists have completed the postgraduate eight week paediatric NDT course during the last 10 years.

6.1.3 Location

The PTs involved in the piloting of the AOP attended a training session in the Physiotherapy Department of the University of the Witwatersrand while the actual analysis was done in their own homes.

6.2 Measurement tool

6.2.1 Adapted Observation Protocol

Every category, subcategory, modifier and example of the AOP (Appendix XX) was discussed and explained to all the study participants.

6.2.2 ‘CowLog’

The study participants were instructed on the installation and use of the ‘CowLog’ software. The developers of ‘CowLog’ suggested that the tabs remain numbered (1-24) to simplify the input windows (See Figure 6.1) and the related categories and subcategory codes to be indicated on a separate piece of paper. The researcher felt that constantly referring back to a piece of paper whilst evaluating a video would be both time consuming and distracting. Therefore the buttons on the formatted window were pre-programmed with a shortened code (e.g. B = Facil tech, N = educate) to indicate the main categories and then the corresponding letters (A1, B3

etc.) to indicate the subcategories (Fig.6.1). This made it easier for observers to view all the different options with one glance and therefore improve the time efficiency.

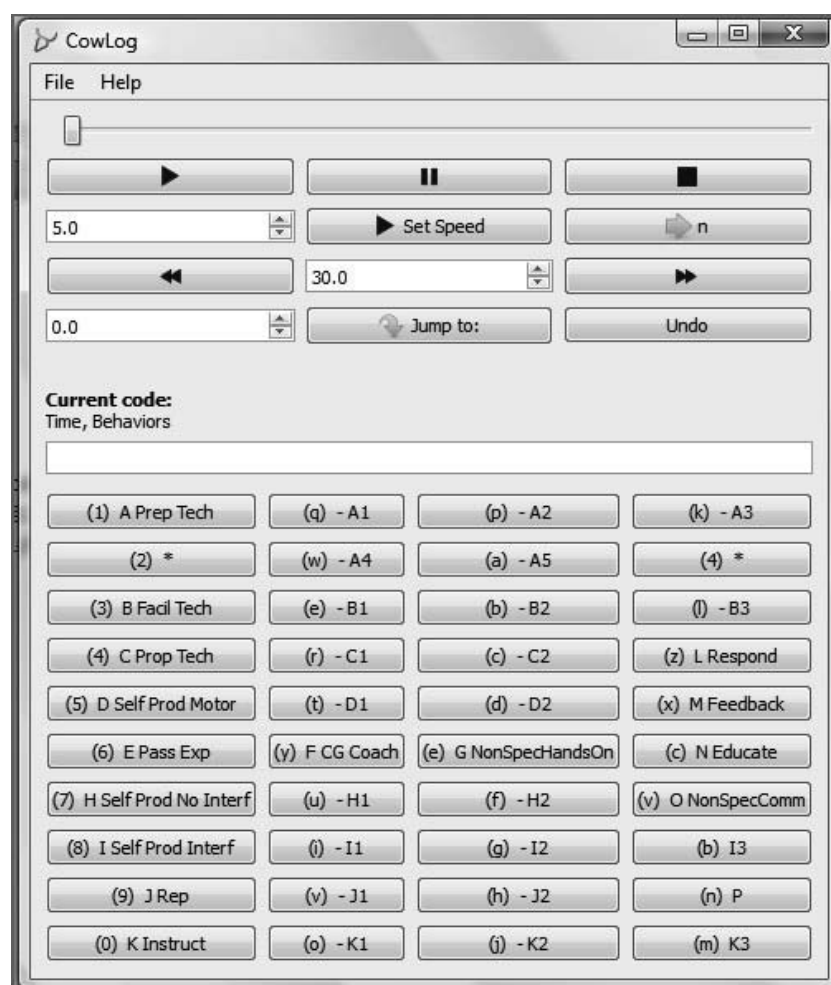


Figure 6.1 Custom 'CowLog' Input Window with the different tab selections

'CowLog' software captures behavioural categories and subcategories. For this study, the selection of a main category of behaviour paused the video and allowed the selection of one or more subcategory options corresponding to the selected category.

'CowLog' software allows the video to skip 30 seconds forward or backward or plays the video at various speeds to find a specific timeslot in the video. To undo a coding error, the undo button should be selected which will delete the last code and timeslot entered. The 'CowLog' software does not allow for more than one behavioural code to be allocated to a certain timeslot.

6.3 Procedures

During the training session, details of the study were discussed and information sheets detailing the methodology of the study provided to the study participants. Study participants also received both hard and soft copies of the protocol. All five videos were saved on each participant's computer and they were instructed to delete the videos after the second round of scoring.

For this stage of the study, five treatment videos of children with CP between the ages of one and 16 years of age, with different GMFCS levels (i.e. I, II, III, IV and V) were used. The ages of the children from the different GMFM levels were eight (GMFCS I), five (GMFCS II), six (GMFCS III), 15 (GMFCS IV) and four (GMFCS V). These treatments were taken on an outreach where the focus was on intensive therapy and the videos were specifically recorded for this study. The carers were all present during the sessions. The treating therapists were all experienced in the rehabilitative care of children with CP and came from a variety of backgrounds (school, private practice, hospital, NPO). They all have completed the paediatric NDT course and three of the treating therapists were senior lecturers in Bobath/NDT. Therefore the choice of videos reflected current South African practice.

Study participants had to score all five videos twice, with a minimum gap of two weeks between each round. The study participants were instructed to fill in a questionnaire (Appendix XXI) only once both the rounds were completed.

6.5.1 Training of study participants

The training session on the implementation of the AOP and the operation of the 'CowLog' software lasted two hours. The study participants were instructed to select the button on the 'CowLog' screen representing the specific behaviour observed. Then only select another button (representing a different code) at the start of a different behaviour. 'CowLog' then captured the timeslot, as well as the code linked to the button, in an Excel spreadsheet. The study participants were instructed to only score an observed activity if it had occurred for longer than two seconds.

A sample 30 minute long video was viewed and scored as a trial, to familiarise everyone with the process. During the scoring of the video the options were not discussed in detail to prevent bias.

6.4 Data

6.4.1 Data collection

For Section 1 and Section 2 of the AOP only the incidence (indicated by a single tick if it had occurred during the whole duration of the video) was scored and this was done separately on a tick sheet for each video. For Section 3 both the incidence and duration for each subcategory was scored with the use of the 'CowLog' software.

According to Blauw-Hospers (2010) activities occurring simultaneously could be scored through multiple runs of the video with the use of Noldus software. However the 'CowLog' software does not allow for multiple runs of one video on the same data sheet. Therefore in order to simplify the data, make the AOP more user-friendly and improve on the mutual exclusiveness of the OOP, the researcher differentiated between different activities by writing clear definitions into the qualifiers and included elaborating examples.

The captured data, in Excel spread sheet format, was then used to calculate the duration and frequency of each of the behaviours. The developers of the original protocol differentiated between 'behavioural states' (the user will capture incidence/frequency and duration) and events (behaviours where only the incidence/frequency are recorded). This differentiation only occurred at the analysis stage. In this study the relative duration (duration of an activity as a percentage of the total treatment time) for a specific category or subcategory was calculated.

6.4.2 Data analysis

The objective of this phase was to establish inter- and intra-rater reliability. For Sections 1 and 2 the Pearson product moment correlation coefficient was calculated to investigate the correlation between study participants. The agreement level between Rater 1 and Rater 2 was established followed by Rater 1 and Rater 3 and so forth. This process were repeated for all six of the study participants after which the number of occasions that different levels of agreements were reached were clustered together according to Mukaka (Table 4.1) and calculated as a percentage.

For Section 3 the durations and frequencies of the therapeutic activities scored in the tool were averaged to present summary data. To compare the use of the tool intra-rater reliability was calculated per participant after a two-week break for each video. Participants were requested to e-mail the results in excel spreadsheet form to the researcher after which they were requested to delete the file from their hard drive. Interclass correlation was also calculated across the scores between the two rounds. The Cronbach's alpha was calculated to evaluate inter-rater and intra-rater reliability.

Study participants were instructed to allow the initial 60 seconds of each video to lapse as this timeframe usually involves some form of preparation for the session. This was in line with other studies (Blauw-Hospers et al. 2010). However, not all the study participants adhered to this and hence during the data analysis stage all the data was configured to start at 70 seconds. Study participants were instructed to stop rating after 1200 seconds. This amounted to a total duration of 1130 seconds per video. All scored timeslots of less than two seconds were erased in order to clean the data as this was the definition of an action and had to occur for more than two seconds.

6.5 Results

6.5.1 Inter-rater reliability

This section presents the results of the correlation between the study participants. The percentage of occasions as well as the degree of agreement that were reached in Sections 1 and 2 is depicted in Table 6.1 and 6.2 (Mukaka 2012). For clarity sake the GMFCS level corresponds to the number of the video, GMFCS level I is video 1.

Table 6.1 Percentage of occasions where study participants reached a certain level of agreement in Section 1

Video number Correlates to GMFCS level	.90 to 1.00 Very high positive correlation	.70 to .89 High positive correlation	.50 to .69 Moderate positive correlation	.30 to .49 Low positive correlation	.00 to .29 Negligible positive correlation	-.01 to -.30 Negligible negative correlation
Video 1 GMFCS I Aged 8	20%	20%	46.7%	6.7%	6.7%	-
Video 2 GMFCS II Aged 5	-	6.7%	26.7%	40%	26.7%	-
Video 3 GMFCS III Aged 6	-	-	33.3%	26.7%	26.7%	13.3%
Video 4 GMFCS IV Aged 15	20%	53.3%	26.7%	-	-	-
Video 5 GMFCS V Aged 4	-	13.3%	60%	26.7%	-	-

In Section 1 in the majority of videos (4/5) only a low to moderate positive correlation was achieved. In Video 4, a more than average percentage (53.3%) of occasions had high positive correlation and a further 20% of occasions were ranked in the very high positive correlation interval.

Table 6.2 Percentage of occasions where study participants reached a level of agreement in Section 2 according to Mukaka (2012)

Video number	.90 to 1.00 Very high positive correlation	.70 to .90 High positive correlation	.50 to .70 Moderate positive correlation	.30 to .50 Low positive correlation	.00 to .30 Negligible positive correlation	.00 to -.30 Negligible negative correlation
1	20%	26.7%	33.3%	13%	-	-
2	6.7%	13.3%	33.3%	33.3%	13.3%	-
3	6.7%	-	40%	13.3%	20%	20%
4	13.3%	13.3%	20%	6.7%	46.7%	-
5	-	-	-	26.7%	13.3%	60%

For Section 2 (Table 6.2) a more negative correlation trend was noted, where only in Video 1, moderate to high and very high correlations were achieved. Three out of the five videos had only negligible to moderate positive agreement with Video 5 actually having a negative correlation.

Table 6.3 depicts the Intraclass Correlation Coefficient (ICC) as Cronbach's Alpha values for the relative duration of each subcategory from Section 3, for the first and second round of each video to establish inter-rater reliability between all six study participants.

Table 6.3 Inter-rater reliability for relative duration of a therapeutic action

First Round	Intraclass Correlation ^b Average measures	95% Confidence Interval		Second Round	Intraclass Correlation ^b Average measures	95% Confidence Interval	
		Lower Bound	Upper Bound			Lower Bound	Upper Bound
Video 1	.81	.67	.90	Video 1	.68	.46	.83
Video 2	.91	.84	.95	Video 2	.93	.88	.96
Video 3	.87	.77	.93	Video 3	.89	.81	.94
Video 4	.76	.59	.87	Video 4	.71	.50	.84
Video 5	.91	.84	.95	Video 5	.94	.90	.97

According to Mukaka (2012) (Table 4.1) the average correlations for Videos 2 (GMFCS II age five) and Video 5 (GMFCS V age four) have a very high positive correlation during both rounds. Video 1 round 1, and Videos 3 (GMFCS III age six) and 4 (GMFCS IV age 15) during both rounds had a high positive correlation. However during the second round, Video 1 only had a moderate correlation. It may seem that one can conclude that the highest correlations were found in the videos for the children with the lowest ages.

Below in table 6.3 the values for ICC (Cronbach's Alpha) for the frequency that a subcategory was selected during the first and second round for each video to establish inter-rater reliability between the six study participants are depicted for Section 3.

Table 6.4 Inter-rater reliability for the frequency of a therapeutic action

First Round	Intraclass Correlation^b Average measures	95% Confidence Interval		Second Round	Intraclass Correlation^b Average measures	95% Confidence Interval	
		Lower Bound	Upper Bound			Lower Bound	Upper Bound
Video 1	.59	.25	.81	Video 1	.68	.38	.86
Video 2	.49	.19	.74	Video 2	.46	.11	.72
Video 3	.70	.46	.85	Video 3	.76	.58	.88
Video 4	.60	.24	.79	Video 4	.43	-.01	.72
Video 5	.60	.31	.80	Video 5	.67	.39	.84

Regarding the frequency of agreement of the selection of subcategories the average ICC was less positive. It can be seen that only Video 3 had a high positive correlation in both rounds. Moderately positive correlations were obtained for both Video 1 and Video 5 during both rounds and Video 4 only during the first round.

6.5.2 Intra-rater reliability

When considering the intra-rater reliability between the two rounds per video the following results as tabulated in Table 6.5 were obtained when comparing relative duration of subcategories selected.

Table 6.5 Intra-rater reliability comparing relative duration of PA

Participant number	<i>Intraclass Correlation^b</i>				
	<i>Average measures</i>				
	Video 1	Video 2	Video 3	Video 4	Video 5
Participant 1	.75	.45	.75	.65	.86
Participant 2	.97	.85	.97	.95	.95
Participant 3	.72	.82	.72	.93	.92
Participant 4	.92	.95	.92	.76	.96
Participant 5	.97	.99	.97	.99	.92
Participant 6	.84	.96	.84	.87	.92

It can be seen from the results that Participant 5 was the most consistent with a very high positive correlation in each video between the two rounds. Study Participants 2 and 4 only had very high correlation for four of the videos and Participant 6 had a very high positive correlation for only two of the videos. These three study participants had a high positive ICC for the rest of their videos. Participant 1 was the least consistent with one low, one moderate, two high and one very high positive correlation.

6.6 Analysis of the Questionnaire

6.6.1 Methodology of the Questionnaire

In addition to rating the videos, study participants were requested to complete a questionnaire (Appendix XXI) on their experience of using the AOP. The results were obtained through content analysis. Similar comments were grouped together and main themes are discussed in detail in the following paragraphs.

6.6.2 Results of the Questionnaire

6.6.2.1 User friendliness of the AOP

All five study participants reported that it initially took a long time for them to familiarise themselves with all the different categories and subcategories and found it time consuming. Three out of the five study participants felt that the examples were adequate and the subcategories were well explained. The other two reported that more examples were needed but also realised that this list is not exhaustive and would make the document even longer.

Three out of the five study participants reported that they often felt that more than one activity was happening simultaneously and they couldn't score this. Comment by one of the study participants was that "this is a more structured approach to exactly what therapy techniques are being used".

6.6.2.2 Mutual exclusivity

Study participants found the following categories confusing due to their similarity (see Table 6.6).

Table 6.6 Mutual exclusivity

Categories	Description	% of study participants reporting on particular categories' mutually inclusivity
A4 and A5	A4 Prolonged and sustained handling that enables the child to "let go of their atypical strategies of movement". A5 Sensory input (i.e. vestibular/visual/tactile input) to improve body awareness and produce motor activity.	20%
A3 and B	A3 Therapist moves child's limb or limbs through small or large range of movement through different planes and directions in a repetitive way until a change of quality in muscle activity is observed B FACILITATION TECHNIQUES	20%
B2 and B3	B2 Manual directional handling by the PT to distal/peripheral body parts of the child that promotes active weight shifting over a BOS/into a new BOS B3 Manual directional handling to proximal body parts of the child to activate appropriate muscles /change synergies of coordination/ change motor activity	20%
A1, A2 and C1	A1 Soft tissue release A2 Mobilization of specific joints C1 Proprioceptive input directly to the body	20%
I1	I1 Verbal prompting K1 Instructing	20%
B and D1	B FACILITATION TECHNIQUES D SELF-PRODUCED MOTOR BEHAVIOUR with guidance from PT/CG at the beginning, during an activity or a component of an activity, D1 Little variation	40 %
D2 and E	E PASSIVE EXPERIENCE OF MOVEMENT D SELF-PRODUCED MOTOR BEHAVIOUR with guidance from PT/CG at the beginning, during an activity or a component of an activity, D2 Large variation	20%
F, K and N	F Caregiver training K Instruction N Education	40%

6.6.2.3 Relevance

The study participants were asked how applicable they found the AOP to the different GMFCS levels. Table 6.7 summarises their responses.

Table 6.7 Percentage of agreement on the relevance of the AOP for each GMFCS level

GMFCS level		% of study participants agreeing on relevance
GMFCS level I	(VIDEO 1)	100%
GMFCS level II	(VIDEO 2)	100%
GMFCS level III	(VIDEO 3)	83%
GMFCS level IV	(VIDEO 4)	67%
GMFCS level V	(VIDEO 5)	50%

In the following chapter all results are discussed.

6.7 Logistic problems encountered

In this paragraph the problems encountered during Phase 3 are discussed. The 'CowLog' software occasionally had a form of malfunction and participants in the study reported that the time cursor would get stuck from time to time making them unable to move it backwards and forwards. This affected the correctness of the coding as participants occasionally, instead of undoing an error, only amended their selection by immediately selecting the alternative desired subcategory. The study participants also reported that it would be useful if 'CowLog' would allow the participant to pause the rating process and complete it at a later stage

Also due to the nature of the videos themselves, filmed in a busy and noisy hall with 10 therapists treating children simultaneously, the sound quality wasn't always good. The video cameras were set up on tripods and often this blocked the view of the observer due to the angle. Most study participants indicated that in these circumstances, where only the therapist's instructions could be heard and the

visuals didn't clearly indicate physical contact, one of the communication categories were scored.

The observation, interpretation and classification of communication was the biggest challenge for the study participants and this was exacerbated by the fact that the 'CowLog' software did not allow multiple reruns on one scoring sheet for the same video. The scoring of the activities around the issuing and implementation of equipment was also a repeated point of contention and was regularly raised in feedback.

Study participants also often reported that two or more activities happened simultaneously and there was no way for them to indicate this. However this lack of mutual exclusivity was not truly reflected in the data. The results from Table 6.6 were not consistent as only two study participants agreed on two occasions that two particular subcategories were too closely related and could therefore be confusing. The study participants' confusion on some subcategories might be attributed to a lack of training and the sparse number of examples in those particular subcategories in the videos.

6.8 Summary

During the three phases of this study more difficulties were encountered than anticipated. The work was explorative and the results of each phase led to the next. Only afterwards did some steps that might have simplified the process become apparent.

The results from Phase 1 indicated that the OOP would need to be adapted to be more useful in the context of rehabilitation for older children with CP. The results of Phase 2 indicated in what manner the protocol should be adapted and in Phase 3 some preliminary implementation highlighted logistic considerations when applying this protocol, as well as suggestions for future studies to refine it.

In chapter 7 all the results are discussed in more detail.

CHAPTER 7

DISCUSSION

7.1 Introduction

In rehabilitative research it is becoming increasingly important to define the intended intervention and investigate whether it was implemented as the therapist intended (Whyte and Hart, 2003) to improve research rigor. However this has only been done to a limited extent in the field of paediatric rehabilitation. Blauw-Hospers et al. (2010), Dirks et al. (2011) and Di Rezze et al. (2014) amongst others have investigated this. The current study has attempted to establish whether an Observation Protocol developed for use by therapists treating young infants in the Netherlands might be applicable to the CP population of children within the different settings in South Africa.

In this chapter the results and main outcomes of Phase 1, 2 and 3 will be discussed. Limitations of the study as well as recommendations for clinical practice and for future research will be presented.

7.2 Discussion of the main findings of each Phase

7.2.1 Phase 1: Evaluation of the Original Observation Protocol

During the first phase of the study the OOP was evaluated by a panel of experts who concluded that it needed to be adapted to suit an older population of children with CP in the different rehabilitation settings in South Africa. They also determined that the mutual exclusivity was lacking when applying it to this particular population. The conclusion that it needed adaptation was not surprising as the OOP was designed for infants at high risk of developmental disorders and therefore without a confirmed diagnosis of CP. It was originally anticipated that the treatment of older children would need descriptors that define higher functioning levels. It was also expected that the OOP would lack descriptors that define hands-on treatment,

describe facilitation of movement and the handling of more severely affected children and this was indeed the case.

7.2.2 Phase 2: Establishing content validity

During the second phase the original protocol was adapted and content validity was established with the support of the ideal number of experts, namely five (Lynn, 1986), as this offered a sufficient degree of control over chance agreement. The content validity was established through a two stage process where the items were first developed and then judged by the panel during a NGT (Lynn, 1986).

It was confirmed during this phase that the physiotherapy treatment for children with CP is multidimensional and far too complex to analyse with only the aid of a post intervention interview, conducted with the treating therapist, and a tick list similar to that used in Embrey and Hylton (1996) or Larsson et al. (2012).

It also became more evident that not having access to the Noldus software, that enables the retrospective analysis of videoed PT sessions, complicated the process of scoring and interpretation of PA. It was vital to the success of this study to source software that was cost-effective, user friendly and easily accessible to make it possible for future follow-up studies and regular clinical applications. In future it would be ideal if more reliable but free and accessible software could be developed in collaboration with software developers or even IT students.

During Phase 2, similar to the findings in Embrey and Hylton (1996), the experts depended on prior acquired experience and theoretical knowledge that formed the basis of their contextual frameworks. They also recalled examples from the videos that had been viewed during Phase 1 in order to include all possible PA that might be included in a physiotherapy session. They often found it challenging to stay clear of specific terms and remain as generic as possible in their approach in order to encompass all possible PA that were in line with current thinking and might possibly be implemented in rehabilitation of children with CP. It was also challenging to word and class activities in a manner that guaranteed mutual exclusiveness.

The main categories that were adapted were 'Neuromotor actions', 'Preparatory actions', 'Facilitation techniques', 'Pressure techniques', 'Self-produced motor behaviour' and 'Communication'. The study participants succeeded in approaching the subject matter in a holistic way that allowed for the analysis of treatment sessions that met the expectations of FCS and motor learning strategies as suggested by Larson et al. (2012).

7.2.3 Phase 3: Preliminary study to investigate some of the psychometric properties of the AOP as well as the relevance for clinical implementation

During the final phase of the study the three adapted sections of the Observer Protocol were evaluated for their psychometric properties and their relevance to the target population for which they were adapted. Section 1 and 2 consisted of adaptations that were made to the OOP but also incorporated additional components that fulfilled the criteria of FCS (Rosenbaum et al.1998) and the ICF (WHO 2001). Section 3 consisted of adaptations to the OOP that allowed the observer to score the PT's hand-on, hands-off and communication actions.

7.2.3.1 Correlation for Sections 1 and 2

On average only a negligible to moderately positive level of correlation was found between the study participants (Table 6.1 and Table 6.2). This was an unexpected outcome and the reason for this moderate correlation was difficult to conclude. It was anticipated that these two sections would be self-explanatory and have such limited options that the inter-rater reliability should have been considerably better. This moderate correlation may be ascribed to the need for better examples and item descriptors as well as a more detailed training for prospective observers.

One of the reasons ascribed to Section 2's less desirable correlation might be the fact that the study participants reported that they needed to have a pre-knowledge of the intended goal in order to more accurately implement the analysis (see paragraph 7.5.2 for further detail on goal-setting).

In these two sections only inter-rater reliability was tested and not intra-rater reliability. This is an oversight and therefore something requiring future investigation.

7.2.3.2 Correlation for Section 3

Section 3 had high to very high positive correlations when looking at both the inter- and intra-rater reliability for relative duration of the therapeutic activities across all videos. The ICC values ranged from $\alpha = 0.68$ to $\alpha = 0.94$ for the inter-rater reliability (Table 6.3) and $\alpha = 0.65$ to $\alpha = 0.99$ for the intra-rater reliability (Table 6.5) with a confidence level of 95%. In only one incident did Participant 1 in Video 2 achieve a very low ICC of $\alpha = 0.45$ and can therefore be viewed as an outlier. This result was similar to the outcome of Blauw-Hospers et al. (2010) where the ICC for the relative duration of therapeutic actions ranged from $\alpha = 0.76$ to 1.00 for inter-rater reliability and $\alpha = 0.69$ to 0.99 for intra-rater reliability.

However, the inter-rater reliability in that study was only assessed between two study participants and the intra-rater reliability was only assessed for one of the study participants. The fact that six study participants participated in the current study therefore adds depth to the analysis.

However when looking at inter-rater reliability for the frequency of actions observed (as opposed to relative duration of actions), significantly lower correlation was found with ICC ranging from $\alpha = 0.43$ to 0.76 (Table 6.4). This discrepancy might be attributed to the fact that some of the study participants neglected to press the button relating to a specific code only once as the activity commenced. Following this it is not necessary to select the same category again for the whole duration of that specific activity. However, some study participants repeatedly selected a particular subcategory in succession with intervals of up to 30 seconds and this affected the frequency measures between study participants for the same videos. More training is needed to allow the frequency between study participants to be correlated in a similar manner to the duration correlation already observed. There was a two-week time lapse between ratings so as to prevent the study participants from recalling previous selections.

The close intra-rater agreement showed the usability of the AOP. Some correlations were not as strong as anticipated. Nevertheless, the process of completing Phase 3 led to further significant modification of the AOP and served as a valid launching pad for future research and preparation for prospective phases.

7.3 METHODOLOGICAL CONSIDERATIONS

7.3.1 Logistical problems encountered

One of the biggest challenges of this study was to find appropriate software that would enable successful scoring and analysis of the videoed treatment sessions. After extensive consultations, enquiries and searches, the 'CowLog' open-source software was found. However the implementation of this was not without its problems. Computer compatibility, training and operational issues were rife throughout the process. The 'CowLog' was deemed to be a viable option in the end that allowed the capture of different behavioural codes in real-time and produced data in the form of Excel spreadsheets. However the 'CowLog' software did not allow for more than one behavioural code to be allocated to a certain timeslot and this was somewhat problematic when implementing the AOP.

7.3.2 Panel of experts

It might have been restrictive that all of the members of the panel of experts have been extensively involved in Bobath/NDT in the past and no other treatment modalities were represented.

However until recently this approach has been the only post-graduate modality available for PTs in South Africa and forms the basis of neurodevelopmental teaching at tertiary level. Although these therapists were NDT trained they are not unaware of other modalities that are physiotherapy specific like musculoskeletal treatment techniques and general muscle strengthening which is taught at universities in South Africa. The broad base knowledge of undergraduate studies should therefore offset this possible bias.

As more therapists are trained in other modalities, representatives of other approaches should also be involved in future implementation tests of the AOP to determine true applicability within the different settings in South Africa.

It may also have been beneficial to add a step into the research where the expert panel trialled the AOP by analysing videos prior to the pilot study. This could have led to better refinement of the protocol, prior to Phase 3, and possibly better results in the tests for reliability as it would have added clarity to the protocol.

Treatment of the child with CP is implemented globally as a multidisciplinary approach (Shonkoff and Meisel, 2000; Fairhurst, 2012). During this study it once again became evident that components of rehabilitation of children with CP are intricately intertwined and it is difficult to be a purist. This was especially evident whenever communication occurred. However, even looking at only one discipline, namely the physiotherapy related actions, proved highly complex. It becomes even more intricate to try and analyse more than one discipline. Despite this it would be of benefit if future studies would include experts from other disciplines to assess the relevance of the AOP to actions that might be related to their profession. In the process the AOP can be assessed as an observation measure for therapy of children with CP in general.

7.3.3 Difficulties encountered with the ‘*Communication*’ subsection

Communication forms such an integral part of the successful implementation of paediatric therapy and should therefore not be seen as a separate entity from the traditionally viewed PA but rather as a prerequisite for FCS and CCS (Rosenbaum et al. 1998). The receptiveness of a child and/or the parent during intervention determines its success and communication forms the basis of this interaction (Di Rezze et al. 2012). Indeed several studies have reported a perceived link between the child’s adherence to therapy and possible outcomes based on communication (Braswell et al., 1985).

During Phase 3 the scoring of the subsection 'Communication' was deemed problematic by most of the study participants. This was mostly attributed to the fact that the participants were restricted in their options where they had to prioritise one behaviour over the other despite them possibly coinciding. This was due to the limitations of the software and therefore, to simplify the statistics, the prioritisation was based on very detailed prescriptors written into the AOP so as to direct an observer. Subsequently, the study participants reported that they often struggled when observing communication coinciding with another activity and were often inclined to want to score both. It might therefore be a limitation of the study.

However, for future reference this dilemma can be overcome by: firstly scoring all the communication episodes throughout a session in an initial round and then scoring all the hands-on and hands-off activities during a second round.

In the South African context communication often happens with the help of an interpreter. This interaction has a significant influence on a treatment session and the therapist's rapport with the child. In the video analysis there were often long periods of interruption as the therapist was waiting for the interpreter's response. During this period the therapist often then refocused on the child and continued with some form of intervention. This resulted in the need to state that there should be an exclusion from the qualifier that '*Hands-on*' or '*Hands-off techniques*' take precedence over '*Communication*'. Therefore when communication coincides with a '*Non-specific hands-on*' or '*Non-specific hands-off activity*', '*Communication*' will once again take precedence.

An interpreter was not used with the OOP as only families who had a good understanding of the Dutch language, were included (Dirks et al. 2011). Due to communication being such an important, though complicated, aspect of treatment the use of an interpreter for communication should be investigated in future studies. The subcategories and modifiers explaining this aspect of communication might need to be investigated further and expanded on.

The same predicament occurred when a therapist multi-tasked. She might have talked while doing another activity that did not require devoted attention e.g.

unpacking pencils while talking with a parent. It was often observed that the concurrence of communication and a physical activity resulted in the loss of specificity of the physical activity and communication became the main focus. For instance a therapist's handling will have directionality but the moment she starts talking to the mother her handling changes and the hands may only rest on the child. However this communication whilst handling should not be confused with category F- 'Caregiver training of hands-on technique' where the therapist's hands will remain on the child while talking and will maintain directionality.

A third scenario is where communication is used in a functional context e.g. when a child is instructed to shout: "Hip-hip hoorah!" whilst the therapist is manually facilitating activation of abdominals and the 'Hands-on technique' then takes precedence.

In the Dirks et al. (2010) study the researcher used time spent on communication as a distinguisher between two modalities, namely NDT and COPCA. Although equal time was spent on communication it was spent in different ways. In future research it would be important to compare time spent on the different domains of communication within different settings e.g. private versus public services. The researcher came across specific discrepancies when analysing the communication selections for certain timeslots. This might be ascribed to the incorrect interpretation of the therapeutic activity descriptors by some of the study participants and might have been prevented if more in depth training was done.

An example to illustrate this point: In Scenario 1 a therapist's hands rested on the child to support him while prone on the ball. This was done while verbally instructing the child to reach for the beanbag. Her handling had no perceived directionality while only resting on the child to prevent him from falling. This should be classed as **G** – '*Non-specific hand-on techniques*' (see Appendix XIX).

Despite this some study participants selected one of the facilitation techniques such as D, where the activity is self-produced with interference from the therapist. However, the therapist in this instance arguably did not interrupt the sequence of movement to correct it but only maintained the child safely on the equipment, which

didn't require specific handling skills. Category E does not apply either as the child was not moved on the ball in order to primarily passively experience the movement.

Some study participants classed it as one of the '*Hands-off*' techniques i.e. I 1 – '*Verbal prompting under SELF-PRODUCED MOTOR BEHAVIOR.*' However this is in direct contrast to the definition of hands-on activities as the therapists hands were in this instance in contact with the child.

Some study participants selected K1-'*Giving verbal instructions*', category '*Communication*', which is also not appropriate as the qualifier for communication states the contrary, namely: '*Communication is scored when there is only information given without directly leading to motor activity. So either communication or a hands-on or hands-off technique occur and they can't be scored simultaneously.*' Throughout the videos, the majority of discrepancies occurred when the treating therapist was communicating whilst simultaneously doing a hands-on or hands-off activity.

Communication during a therapy session cannot be judged a non-essential element of therapy and every effort should be made to accurately analyse and quantify its presence in a treatment session.

7.3.4 Difficulties encountered when observing the use of equipment

Study participants also struggled to score the following scenario: The therapist used wedges on both sides of the child's trunk to support the child while her hands were on the equipment. Arguably this can be classified as C2 – '*Proprioceptive input via a piece of equipment*' which is indeed the case until the PT removes her hands from the equipment. The child is still benefitting from the equipment's support but there is no way of documenting how that equipment is used.

Some study participants in Phase 3 suggested the need for a separate category that describes the use of equipment. However the panel of experts, during the

establishment of the content validity phase, repeatedly stated that the use of equipment was not an objective of this protocol as the focus was mostly on direct contact or hands-on therapy. In this case the researcher felt that the subcategory H1- 'Adapting the environment' was representative of this activity. However, it was deemed necessary that the modifiers and examples for this category should be expanded on to include equipment such as a wedge. This can also be used if the child is placed in a supportive chair.

However this activity should not be confused with an activity where the PT is showing the parent how to place the child in the chair. Then it would be more appropriate to use F – '*Caregiver training*'. This is in contrast to when the therapist is only placing the child in the equipment to see if it fits, then G – '*Non-specific hands-on*' activities should then be selected. In the case of adaptation of equipment, P- '*Non-specific hands-off* activities' is suitable.

It was therefore decided that, although there is not a specific category for equipment, the use and implementation of equipment could be accurately quantified within one of the categories. However, if a future study wants to compare the use of equipment to another modality the detail will be lost during the implementation of the AOP and it is therefore a limitation of the measure in its current format.

7.4 Key findings from this study

7.4.1 Mutual exclusivity

The conclusion of Phase 1 to adapt the OOP was largely based on the rejection of the claims of mutual exclusivity made by the original authors ((Blauw-Hospers et al., 2010) after evaluation. During Phase 3 the mutual exclusivity of the AOP was investigated differently to that of the OOP (Blauw-Hospers et al. 2010). The reason for this was that the 'CowLog' software did not allow simultaneous selection of more than one subcategory. A similar step to that done in Phase 1 of this study, with preselected timeslots, might have been repeated for improved research rigor. However the piloting of the new software simultaneous to the AOP was prioritised. Following the adaption and during the implementation phase of the AOP some degree of mutual exclusivity was attained between different categories and

subcategories by establishing good inter-rater reliability for Section 3. This was despite feedback from study participants who reported the contrary. The possible inclusion of an option that stated that none of the mentioned examples adequately describe a particular action might have resulted in a different outcome.

The mutual exclusivity for Sections 1 and 2 is in need of further investigation as the inter-rater reliability was less than desirable. Extra training of the study participants and more detailed examples might also have improved the study participants' confidence in their choices. Therefore, in future it would be beneficial to revisit the mutual exclusivity of the subcategories of the AOP before any definite conclusions are made especially for those subcategories mentioned during Phase 3 in Table 6.5.

One of the strengths of this study is that more study participants were used than in previous studies (Embrey and Hylton, 1996; Blauw-Hospers et al., 2010) resulting in improved evidence of mutual exclusivity.

7.4.2 Including components recommended by other studies recommended

Carroll et al. (2007) recommended, after their investigation into intervention fidelity in paediatric rehabilitation that both mediating and moderating factors need to be considered. However the AOP predominantly assesses the mediating features (i.e. the behaviours of the therapist) of an intervention apropos the aim of this study. This results in the main focus being how consistent the therapist's implementation of the treatment is compared to that which is expected (Carroll et al., 2007). However the child's participation and interaction with the therapist gives an indication of the success with which the intervention has been implemented and received (Rosenbaum et al. 1998; Di Rezze et al. 2012). Moderating components (both the client's characteristics that are not influenced by the therapist and those which are i.e. therapist-client interaction) are beyond the scope of this study and future research should investigate and incorporate these.

Larsson et al. (2012) identified three qualitatively descriptive categories that form the basis of different therapy approaches in order to incorporate strategies that makes it FCS and are geared towards motor learning that also relates to the ICF. It makes sense that a measure that evaluates intervention should analyse these domains. Table 7.1 indicates which categories were intended to meet the requirements of a certain domain.

Table 7.1 Items of Section 3 related to Larsson et al. (2012)

'Making it normal'	'Making it possible'	'Making it work'
A PREPARATORY ACTIONS	N ' <i>EDUCATIONAL INFORMATION EXCHANGE</i> '	D SELF-PRODUCED MOTOR BEHAVIOUR with guidance from PT/CG at the beginning, during an activity or a component of an activity
B FACILITATION TECHNIQUES		F CAREGIVER TRAINING
C PROPRIOCEPTIVE TECHNIQUES		H SELF-PRODUCED MOTOR BEHAVIOR with no guidance from PT/CG and child is allowed to continue with activity
E PASSIVE EXPERIENCE OF MOVEMENT		L RESPONDING /ADOPTING TO THE CHILD'S EMOTIONAL/PSYCHOLOGICAL/ SOCIAL/BEHAVIOURAL NEEDS
		M PROVIDE VERBAL FEEDBACK TO THE CHILD OR CG

Section 1 – '**POSITION/CHANGE OF POSITION OF CHILD DURING SESSION**' was included to capture information related to activities that the therapist might include in the treatment in order to address activity limitations. Section 2– '**CONTEXT OF FUNCTIONAL ACTIVITY/TASK FOR PARTICIPATION IN LIFE SITUATION**' was included to capture some elements of when participation restrictions are addressed and in so doing applying the '*making it possible*' approach in treatment sessions.

The communication subsection of the AOP was adapted to incorporate two of these domains. The subcategory of K1- '*Verbal instruction about alternative ways to*

achieve best performance’ falls into the domain of ‘*Making it normal*’. K2 – ‘*PT gives hints, provide a suggestion /cues (indirect)*’, K3 – ‘*Giving non-verbal instruction i.e. Visual input, sign language and visual cards*’ and falls into the domain of ‘*Making it work*’.

Originally it was decided not to include a category that looks at adapting the environment and supplying equipment. This might have been a limitation and would have allowed the capture of activities that related to the ‘*Making it work*’ approach. This decision was made so as to keep the AOP as compact as possible and analyse only direct and child related PA.

Although some effort has been made to incorporate all three of these domains this still need further exploration, especially in areas that might apply the ‘*Making it possible*’ approach and more specifically aspects of evaluation and goal-setting.

7.5 Implications for clinical practice

7.5.1 Analysis of videos from different GMFCS levels

In Africa, and more specifically South Africa, there is a higher prevalence of children from GMFCS Levels IV and V. Therefore they are more severely affected and are only seen later in life which may change the dynamic of their treatment (Donald et al. 2014). During Phase 1 the researcher expected treatment of the lower functioning children (GMFCS level IV and V) to be similar to that of an infant but the opposite became evident. This might be due to the level of severity of infants for which this Observation Protocol was originally developed. Neither of the previous studies that used the OOP included children from different GMFCS levels (Blauw-Hospers et al. 2010, Dirks et al. 2011). In fact the Dirks et al. (2011) study excluded children with severe congenital anomalies and only a quarter of the children later received a confirmed diagnosis of CP which indicates that less severe children were included in that study.

Interestingly, during both the evaluation stage of the OOP and the piloting of the AOP, there was the notion that the categories and subcategories didn’t adequately

describe the sessions involving children from these levels. During Phase 3 the question was posed to the study participants: “Did you find that the adapted observational protocol could adequately describe the treatment of a child with GMFCS level I, II, III, IV and V?”

There was a high percentage agreement for GMFCS levels I, II and III. GMFCS levels IV and V had lower percentages of agreement, with Level V the lowest (see table 6.7). This was despite a very high positive correlation when looking at inter-rater reliability for the GMFCS level V video and a high positive correlation for GMFCS level IV video with the lowest correlation value still being as high as $\alpha=0.76$ and $\alpha=0.71$ respectively (see Table 6.3). This result was surprising and further investigation is required as the study participants were not asked to justify their choices. Only yes and no responses were included in the questionnaire and probing questions that would clarify their choices might have shed more light as to why the study participants were of this opinion.

Studies by Fauconnier et al. (2009) and Sewell et al. (2015) indicated that children with CP have limited participation in life situations and that restrictions increase with the level of severity of the child’s impairment particularly in children with Level IV and V who are the most restricted. This might shed some light on why both the panel of experts (Phase 1) and study participants (Phase 3) were of the opinion that the treatment of children from these two levels was not adequately covered. Participation of these children is sometimes very subtle to detect, with activities being limited and change very difficult to observe.

Section 1 was adapted during Phase 1 to include the descriptors of ‘*The child is engaged/active participant*’ where being ‘engaged’ is seen as an active role being played by more severely affected children. This term was not clarified during the training sessions of the study participants and this may have contributed to the poor inter-rater reliability for Section 1. Including it in the training and elaborating on this term in the protocol might have improved the results.

Future research will need to investigate exactly which components of the treatment of children from these levels were not adequately covered by the AOP. This can be

achieved by including a category that states 'No category adequately describes this action'. Then, after analysis of at least 5 videos from each of these GMFCS levels, further conclusions might be made by seeing if the inter-rater reliability for certain sections are improved and how often and in which circumstances this new category is selected.

The children's individual ages were eight (GMFCS I), five (GMFCS II), six (GMFCS III), 15 (GMFCS IV) and four (GMFCS V). From the results it seemed that there were better correlation between the raters when looking at treatments of younger children. However to test this theory, treatment sessions for children from different age brackets within each GMFM level group, should be evaluated. Seeing that a child's GMFCS level doesn't change throughout the course of their lives it is also not clear if this will really influence the degree of correlation. However the secondary changes that progressively affects the function of children with CP as they age might affect the outcome of correlation.

The observable PA for more severely affected children should be further investigated in future research as shortcomings have been evident in the preliminary results.

7.5.2 Goal setting

Goal setting is an integral part of treatment and the need to do so is well documented (Rosenbaum and Stewart 2004; Sorsdahl 2010). Some of the feedback from the study participants was that they found it difficult to allocate a category code to an observed PA without knowing what the goals were.

However, the researcher and the expert panel felt that the process of defining and quantifying a physiotherapy session should only involve the analysis of the PA and the goal of the session was not relevant for the purposes of the current study. Therefore, the objective was to focus on what the video analyser could objectively observe in each timeslot of the treatment video. No provision has therefore been made in the AOP to capture any information regarding the goal for a treatment session as the scope of this tool is currently only to report on what is being done.

However because the goal and the therapy input are so closely related it is important to investigate the inclusion of components of goal setting into the protocol. This would serve to individualize a treatment session to the needs of a specific patient.

No studies could be found that specifically investigated the relationship between the goal and the content of a physiotherapy session. However Embrey and Hylton (1996) determined the content of physiotherapy sessions by having think-out-loud retrospective interviews with the therapists who implemented the physiotherapy sessions. This was to establish the basis of the mental systems or contextual frameworks from which they selected the most appropriate treatment techniques. The aim was to determine the purpose of the therapists different therapeutic activities implemented during a pre-recorded video session.

These think-out-loud retrospective interviews might be useful in future studies to investigate the notion that pre-knowledge of the goal is a pre-requisite for more accurate analysis of the content of a physiotherapy session. This can be analysed by further investigating ICCs between the scores of an objective observer and that of the treating therapists. Both will analyse the same video by implementing the AOP. Any unsatisfactory ICCs can then be investigated by following up with in-depth interviews and/or co-coding between the two raters to determine the reason behind these discrepancies. The origin of any variations can be two-fold. It is either due to lack of knowledge of the intended goal on the part of the observer or a mismatch between the treating therapist's intent and their ability to execute the PA.

The outcome of this may shed some light on the question of whether better reliability results from pre-knowledge of the goal of treatment. The study participants during Phase 3 seemed inclined to agree with this sentiment. The predisposition is that knowing the goal will add some value, especially in Section 1, where the *'Context of functional activity/task for participation in life situation of treatment'* needs to be analysed.

In conclusion, the AOP is a tool developed as an objective measure of PA observed during a treatment session and is therefore not intended to capture intended

actions, goals or efficacy but lends itself to include these components in future after further development to enhance the tool.

7.5.3 Individual versus group sessions

The service delivery models for children with CP in South Africa are diverse. Whereby, for instance, children accessing private medical care might be seen weekly in the public sector the policy or resource constraints may dictate that a child only be seen once a month. In the public sector the sessions might differ from the private sector where the focus might be more on parent training and home programmes. Children in rural areas may have limited access to physiotherapy due to social stigma, work or financial demands including lack of funds for transport or even availability of transport (Donald et al. 2014). These are only some of the reasons for the discrepancies in care. Often for logistical reasons the therapist will opt for group classes to accommodate everyone.

Sorsdahl (2010) reported on the beneficial outcomes of group therapy sessions and no provision has been made in the current study to include components of these kinds of sessions in the protocol. However, group sessions are a common practice within the South African context, especially in the public sector, and not including them can be seen as a limitation. However, for the purposes of this study the focus has solely been on how relevant the AOP is to individual and direct contact therapy between one therapist and child or therapy involving the primary caregivers and the child. It might be useful if the instrument in the future included a component of group activities so as to evaluate the active ingredients of these as well.

7.5.4 Possible link between a specific intervention and outcomes

Blauw-Hospers et al. (2010) suggested that by revealing the actual content of a treatment session it might be possible to differentiate between potentially effective and ineffective components of treatment. Furthermore, Hennessey and Rumrill (2003) suggested that practice of treatment fidelity during research might produce

more coherence between the theory behind a treatment and the possible standardised implementation across settings.

Therefore the AOP might be useful to analyse why a certain treatment session did not result in a positive outcome for a child. However this requires the video analyser to distinguish whether the perceived therapeutic activity was executed as intended. For example, a PT is supporting a child to walk by holding the child's hand while his arms are in the high guard position. This should not be scored as B2- '*Manual directional handling by the PT to distal/peripheral body parts of the child that promotes active weight shifting over a BOS/into a new BOS*' because the PT is only holding the child's hand which requires no skill on the therapist's behalf and no weight shift occurs with the child. Neither is this D – '*SELF-PRODUCED MOTOR BEHAVIOUR with guidance from PT/CG at the beginning/during an activity or a component of an activity*' as the PT is not intervening to influence the outcome. G – 'Non-specific hands-on activity' is most appropriate. Analysis can possibly indicate that if the therapist's handling skills were less productive a large portion of time was spent on G.

Therefore, if an intervention series had a less positive functional outcome, the videos of those sessions could be analysed retrospectively to unpack the components of these sessions. Previous research it has been suggested that these fidelity processes may be advantageous to students and practitioners in learning as it may allow opportunities to review and analyse their delivery of a specific intervention (Larin 2007; Di Rezze et al. 2012).

7.5.5 The relationship between therapeutic activities for different classifications

This tool might in the future provide us with a better indication of what treatment works best in certain conditions e.g. in Video 5 a child from GMFCS level V with a diagnosis of dyskinesia was treated. The therapist had to opt for a lot of activities from A4 where the child had to "let go" of his learned movement strategies. This is opposed to a PT treating a child from GMFCS level IV with spastic hypertonia that

might spend more time on activities from the subcategories of A3, A1 and A2 where more soft tissue mobilization might occur. However, in order for a trend to be identified a much larger sample size needs to be investigated.

7.5.6 Differentiating between different treatment modalities

The AOP was developed to be more in line with generic fidelity measures (see paragraph 2.11.2) although limited non-specific components were included, namely the section 'Context of therapy' and the category 'Communication'. According to Di Rezze et al. (2012) generic measures can be utilised to investigate the fidelity of two or more well defined interventions.

The authors of the OOP (Blauw-Hospers et. al 2010) classified activities that mostly involved handling as Bobath/NDT and activities observed as family involvement, education and functional activities ('self-produced') as functional therapy. However, the panel of experts challenged the above classification and said that they believed that all handling actions and approaches have the aim of function even though they might not occur in the context of functional tasks. They stated that each session would be tailored to that specific child's functional level. The functional level of a child of level IV and V is by definition very limited. A treatment session might be perceived as predominantly 'handling by the therapist' but in effect enabled the child to reach their highest functional level e.g. a therapist might supply full thorax support, with the child in sitting, to enable active head control in order to facilitate looking at a book.

Therefore, these categories of family involvement, education and functional activities ('self-produced') were still included in the AOP as the experts felt that these should all be part of a typical therapy session within the South African context. These categories are also prerequisites for CCS and FCS (Rosenbaum et al. 1998) and their inclusion is imperative in all aspects of paediatric rehabilitation.

During the first phase of this study the panel of experts were unanimously of the opinion that implementing this tool to distinguish between different approaches is not useful and it should not be used for that purpose. The reasoning for this was the

consensus that in the developing phase one should stay completely clear of specific approaches and rather develop a measure that is more generic encompassing principles of treatment that are most often implemented. Therefore, it would be possible for future use to apply the protocol in distinguishing between different treatments similar to previous research (Blauw-Hospers et al. 2010; Di Rezze et al. 2012) and this should be investigated. This will involve quantifying the time spent on each of the subcategories e.g. caregiver training or communication and comparing that to different approaches.

7.6 Implications for future research

7.6.1 Suggested changes for further modification

Although the study participants from Phase 3 were not involved in any part of the development of the AOP their participation in the piloting of the adapted tool provided a unique insight into properties of the AOP and they had excellent suggestions for further modification of the tool. These suggestions have been added and indicated in red in further modification of the AOP (see Appendix XXII).

Suggested changes made by the study participants were:

- To add a subcategory called B4-*'Manual directional handling by the PT to proximal body parts of the child that produces active weight shifting over a BOS/into a new BOS'*. A gap was identified as B2 describes weight shift with handling at distal body parts and B3 is handling at proximal body parts but more specifically for facilitation of appropriate muscle synergies and activation. The numbering should furthermore be changed for clarity.
- That 'proximal body parts' should be specified in B3 and B4. These refer to the head, shoulder, thorax and pelvis.
- To add B5 where the PT positions one hand on a proximal and one on a distal part of the child's body.
- The therapist will often accompany a verbal instruction with a visual one, especially when the child's first language cannot be spoken. To standardise implementation it was decided that in future, should more than one type of

prompt occur, I2 – ‘*Visual prompting*’ should get preference and rather be scored.

- The need was identified for a category describing the activity where the therapist is only observing or analysing what the patient is doing therefore not giving feedback or responding verbally or physically but only watching what and how the child or caregiver is doing an activity. This might also include a quick gait analysis or pre- and post-testing of outcome measures. This forms part of treatment and should not be confused with a whole evaluation session. In the absence of a category like this in the current format the study participants mostly used category P- ‘*Non- specific hands-off activities.*’
- To include fitting of devices or just stabilizing a child under ‘*Non-specific handling*’.
- The activity of listening applied by the PT should also be added under ‘Communication’.
- It will be useful to colour coordinate the final version of the Observation Protocol for easier reference.
- The reason why participants were of the opinion that the AOP didn’t adequately allow the analysis of treatment sessions for children from GMFCS levels IV and V should be further investigated.

7.7 Recommendations

7.7.1 Piloting of the AOP

The characteristics of Phase 3 of this study were more in line with a preliminary study than a pilot study as both the AOP and the software tested. However, after the suggested changes recommended by the study participants the AOP is in a better state to be piloted and future research should commence there with perhaps only two observers analysing more videos from each GMFCS level. It is also recommended that co-analysis and extensive training should happen in order to achieve good inter-rater reliability.

7.7.2 Time spent on training

Only two hours were spent on training the study participants during the pilot study. This was just enough time to analyse one example treatment video and for the study participants to familiarise themselves with the 'CowLog' operations. The time was limited in order to assess whether the AOP's categories and subcategories were self-explanatory enough to guide the user. The intention was to determine whether the study participants could judge on face value which subcategory and category best described a particular therapeutic activity. During the Blauw-Hospers et al. study (2010) 40 hours were spent on training using different videos. Larin (2007) had to implement four two hour long sessions followed by discussions on the content and operational definitions prior to reaching acceptable levels of agreement for each item of the Motor Teaching Strategies Coding Instrument MTSCI-1. For future validation of this protocol it is recommended that at least 10 hours of combined video analysis should be done in order to improve correlations.

7.7.3 Sample size

The sample size of this pilot study was inadequate to draw definite conclusions about the reliability of this tool. Nunnally and Bernstein's (1994) suggested criterion for validating a scale is a minimum of 10 study participants for each scale item. This was also the standard used in the development of several other scales (Saloojee et al., 2009; Hilburn, 2010). For further validating research to be done it is recommended to use 10 videos for each category and subcategory which amounts to 320 videos. For future research it would be of benefit to include different study participants with varied experience and even therapists from other disciplines working in the field of CP. The preliminary results of implementation of the Observation Protocol, however, do look promising.

7.7.4 Group sessions vs individual sessions

The AOP has currently been developed to solely analyse aspects of individual sessions where one to one interaction occurs between the therapist, child and

carer. Considering that group sessions are an integral part of therapy further development should include categories that encompass these aspects.

7.7.5 Further recommendations

- The Observer Protocol needs further work to make it suitable for children with more severe disabilities.
- The risk is always to make such a measure too cumbersome by including too many categories and subcategories. Great care has been taken in this study to minimise the options so that they all fit in on the pre-programmed software screen. Any changes to the AOP should keep this practicality in mind.
- Goal setting and the therapist's role in setting them during intervention should be considered for inclusion in the AOP.
- The possible inclusion of moderating components should be investigated.
- Investigate if the use of an interpreter during a therapy session adversely affects the reliability with which the AOP is implemented.
- The AOP should be used firstly to only score all communication actions occurring and then a second time to look at all the other domains.

7.8 Limitations

Two studies reported on what part of the treatment time could be accounted for by implementing their particular method of quantifying and defining the treatment. Embrey and Hylton (1996) reported that 70% of the total duration was accounted for and Blauw-Hospers et al. (2010) reported that more than 90% of the treatment could be accounted for. The AOP had no category or way of indicating if no category adequately described a therapeutic activity. This might be seen as a limitation as currently this reflects that 100% of the time was allocated to a particular subcategory. Only by including such an option can one truly determine when a non-specific category was selected and whether it is attributed to ineffective handling or due to the fact that the observer couldn't find an adequate category to describe the PA. Further limitations include:

- The panel of experts and the study participants of the pilot study were all PTs and therefore not representative of a multidisciplinary approach although this was a deliberate decision to restrict the scope of the tool.
- The videos that were used to evaluate the OOP were pre-recorded for training purposes and therefore showed a variety of typical treatments consisting of different PA. However, no parents were in some of the videos.
- The videos that were used to pilot the AOP were sometimes of poor sound quality and had restricted visibility.
- Only one option for a PA observed could be selected per timeslot.
- Intra-rater reliability was not investigated for Sections 1 and 2 during Phase 3.
- No goal setting, evaluation process or specific detail about equipment use can currently be captured in the AOP.

7.9 What has been achieved?

This study has demonstrated that the content of a paediatric rehabilitation physiotherapy session within the South African context can, to some extent, be analysed in a quantitative way by means of an AOP. It was the first step in establishing a user-friendly and cost efficient method for the video-based analyses of paediatric rehabilitative therapy sessions. Free and open-source software was used instead of the very expensive and specialised Noldus software ((Blauw-Hospers et al., 2010; Dirks et al., 2011)).

The view of Campbell et al. (2000) that paediatric rehabilitation is multi-faceted and therefore complex to assess is reinforced by this study (discussed in detail in paragraphs 6.9.4, 6.9.5, 6.9.6 and 6.9.7). It will therefore, not suffice to merely analyse a treatment session by retrospectively filling in a form or ticking a list. The AOP lends itself to implementation within different clinical settings and is not restricted to a particular context.

Some effort has been made to adapt the AOP so as to make it more generic and not limited to one specific intervention as recommended by Di Rezze et al. (2014).

Both modifying and mediating features have been included as recommended by Carroll et al. (2007) in an attempt to capture more than one dimension of the treatment.

This study has succeeded to a significant degree to unpack the “The Black-box” of therapy (Chen, 1990) by defining and quantifying the PA in a reliable way in paediatric rehabilitation. Very few researchers have ventured down this avenue in the past despite the fact that research rigor has been linked to the importance of describing the content of a therapy sessions. In doing so it contributes to the body of evidence by supplying an observation tool that might shed some more light on the clinical effectiveness of different treatment modalities in the future. The application of this knowledge about paediatric rehabilitation in turn might ultimately result in improved healthcare for children with CP and their families.

7.10 Summary

This study has once again confirmed that treatment of children with CP is very complex with a myriad of nuances and influencing factors that can affect both the input and output of a session. The aim of the observation tool is not to oversimplify treatment but rather capture all the subtleties.

Although there is still a large amount of input that is required before the AOP can be used to analyse a typical physiotherapy session, involving children of all ages and with differing CP subtypes within the different clinical settings in South Africa, this study provides a starting point. The AOP now comprises several categories, subcategories and examples that have been further developed and refined. It has been demonstrated that the AOP has the potential to be used to analyse physiotherapy sessions with good inter- and intra-rater reliability.

CHAPTER 8

CONCLUSION

It is essential for clinicians to keep abreast of clinical evidence for effective treatment. However in the field of CP there is often a lack of evidence for certain treatment modalities due to the clinical diversity and the complexity of the nature of the health condition. Finding the evidence is further complicated by the lack of standardisation as well as proper definition and quantification of the therapeutic modalities. Some research has been done towards describing what the content of a rehabilitative therapeutic session might comprise. The aim of this process should not be prescriptive but rather reflective in nature.

This chapter presents the conclusions drawn from the study regarding the process followed, the psychometric properties of the AOP. The Blauw-Hospers et al. (2010) study concluded that it is possible to document physiotherapeutic actions for at-risk infants in a standardised and systematic way. The current study's aim was to evaluate the applicability of an existing behavioural observation tool developed in the Netherlands and assess whether this tool could be used to quantify and define PA in different clinical settings in South Africa. Treatment session of children between the ages of two and 16 years with a diagnosis of CP were considered for this purpose. This study therefore expanded on the Blauw-Hospers et al. (2010) study by extending the appropriateness of the tool to different ages and severity ranges.

Defining and quantifying PA is a valid and important quest but also a very challenging task as the population is heterogeneous and treatment often happens through a trans-disciplinary therapy approach where it is difficult to single out physiotherapeutic actions. The process of analysing therapy involves both the content (the 'score sheet') as well as the software. During the three phases of this study some ground has been covered in the mammoth task of developing the content of an Observer Protocol for children with CP where no similar tool appears to exist at the moment.

The current study explored the applicability of an existing Observation Protocol originally developed to document the specific observable therapeutic behaviours of a therapist during the treatment of at-risk infants. It was evaluated for its possible usefulness in a different context to its original intended purpose.

During the first phase of this study the OOP (Blauw-Hospers et al. 2010) lacked mutual exclusivity, with only a low percentage of correlation between study participants when implemented in a population of children with CP of varying ages within the South African context. The OOP was found to be unsuitable for use in this context and needed adaptation.

The protocol's content validity was evaluated with the help of a panel of experts. Based on their recommendations collected during a series of modified nominal consensus group sessions, adaptations were made in order to better quantify and define a physiotherapy session for children between the ages of two and 16 years with a diagnosis of CP within the South African context.

This AOP was piloted on five treatment videos, from the different GMFCS levels, with a small sample group of six experienced PT's. Inter-rater and intra-rater reliability were investigated. The preliminary outcomes for the psychometric properties look promising with a very high-to-high correlation for the relative duration of PA's selected. However the incidence of activities had a slightly lower correlation and this might be ascribed to a lack of training.

In future studies the psychometric properties should be further investigated with a larger sample group of therapists and videos. The psychometric properties have already given some indication of the potential usefulness of this protocol and with further studies including larger sample sizes this usefulness will be able to be extrapolated to the entire target population. This will allow the results of the AOP to be interpreted with confidence and accuracy.

The study participants felt the AOP needed further modification to make it more appropriate for children with more severe disabilities (i.e. GMFCS Level IV and V). More extensive training is also recommended for future video study participants to

prevent erroneous scoring and ensure correct implementation. Training times for use of the protocol need to be adapted to those implemented by other studies that also looked at therapist treatment behaviours.

The analysis of treatment videos was done with free open –source software that will enable future implementation in resource-constrained environments. However, the study participants from the pilot study reported the video analysing process to be time consuming. Reassuringly it was reported that the time spent was reduced as the study participants' grew more familiar with the options of the protocol.

Clinical applicability will rely on the amount of training that might be identified as optimal in future studies as well as its perceived usefulness. Reflective practice is a valid CPD activity and this protocol will allow a therapist to analyse perceived and intended therapeutic input versus the actual observed input. This might allow for peer reviews of treatment techniques or even training. Depending on outcomes of the psychometric modalities of future studies this protocol might contribute to the standardisation of treatment for children with CP and the influencing of government policy and funding. After further extensive testing this protocol might help unpack both effective and ineffective treatment modalities for children with CP.

This study has provided the first stage of the further development of a measure to quantify and define therapeutic input in children with CP that occurs within different settings in South Africa. With further research the AOP has the potential to be a measure that defines and quantifies therapeutic input in children with CP. The AOP has the potential to be a free resource that can be implemented across a variety of practice settings within South Africa.

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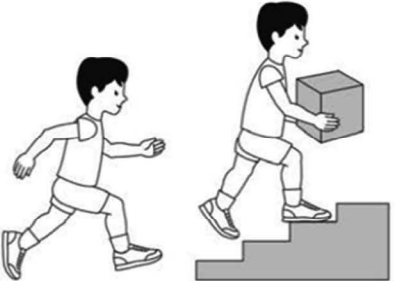
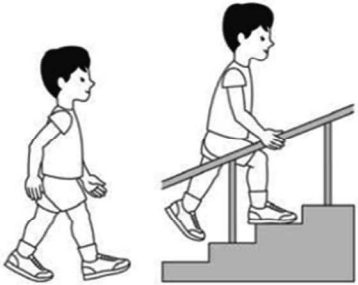
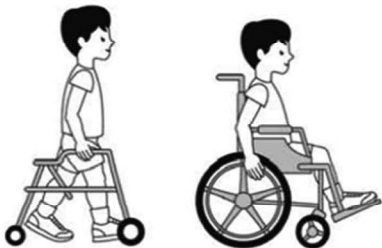
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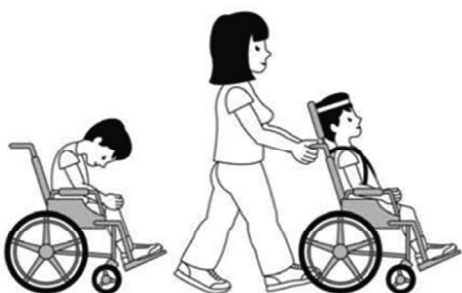
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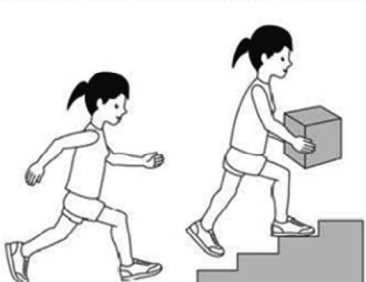
Appendix I : GMFCS E&R Descriptors

GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday (Canchild 2015)

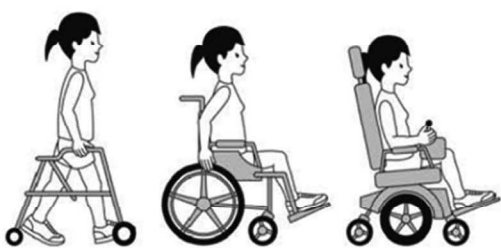
	GMFCS Level I Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited
	GMFCS Level II Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.
	GMFCS Level III Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.
	GMFCS Level IV Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

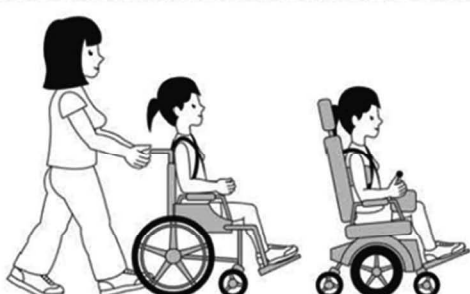
	GMFCS Level V Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.
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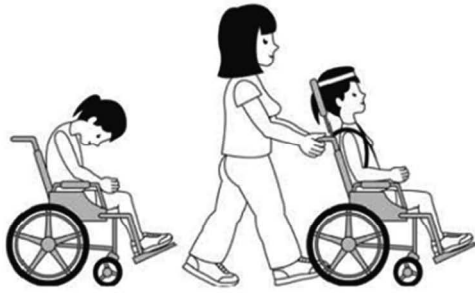
GMFCS E & R Descriptors and Illustrations for Children between their 12th and 18th birthday

	GMFCS Level I Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.
---	---

	GMFCS Level II Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.
--	--

	GMFCS Level III Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.
---	---

	GMFCS Level IV Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.
---	--



GMFCS Level V

Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

Appendix II : Original Observation Protocol

This was downloaded from a link that was provided in the Blauw-hospers (2010) article at <http://links.lww.com/PPT/A8>; the infant is challenged to produce motor behaviour by himself or herself; activity flows over into therapeutic handling.

Classification of pediatric physiotherapy actions(PA)

The PA are classified into 8 main categories that contain various subcategories (second level of observation). For each specific action one or more examples of concrete PA or caregiver actions are provided (third level of observation)

A. Family involvement and educational actions

This includes the extent to which the family is involved in the treatment of the infant and the extent of guidance, interference, coaching or training by the PT or the caregiver during the treatment session.

A.1 Family members participating in guidance infant*:

Family members involved in the treatment session.

Examples of concrete actions:

- Mother present only
- Father present only
- Both caregiver but no other family members present
- In addition to parent(s) also other family members present

A.2 Role of caregiver*: The extent to which the family is involved in the treatment.

Examples of concrete actions:

- PT performs treatment by means of handling techniques
- caregiver and PT act together in handling techniques; PT performs the treatment (hands on) while the caregiver guides the attention of the infant.
- Caregiver performs handling techniques thereby controlling the infant's actions. The PT instructs the caregiver how to handle
- Caregiver and PT act together (hands off); caregiver is playing with the child and may provide the infant with minimal support but leaves the infant always with ample opportunities for exploration. PT observes the caregiver-infant relationship and may give hints.
- Caregiver is playing with the infant (hands off) and leaves the infant with ample opportunities for exploration

A.3 Infant dressing*:

This describes the way in which the infant is dressed during the treatment session.

Examples of dressing:

- Infant is dressed
- Infant is partially dressed
- Infant is undressed (wearing underwear only)

A.4 Educational actions

A.4.1 The extent of interference by the PT or the caregiver with infant's activities

Examples of concrete actions:

- PT or caregiver interrupt PTs activities of the infant.
- PT or caregiver corrects when infant fails.
- PT or caregiver assists when infant has difficulties to perform an action

A.4.2 The extent to which the PT guides the infant activities.

Examples of concrete actions:

- PT trains motor performance at the level that is relatively too easy for the infant.
- PT provides excessive postural support or assistance.
- PT trains motor performances at the level that is too difficult for the infant.

A.4.3. Caregiver training

All actions during which the PT instructs caregivers how to handle the infant with the aim that caregivers can continue treatment strategies during daily life activities and/or in the home environment.

Examples of concrete actions:

- PT demonstrates therapeutic handling action to caregiver.
- PT demonstrates action to caregiver, variable options provided.
- PT practices with caregivers teaching them how to continue some of handling techniques in daily life at home.

A.4.4 Caregiver coaching

This includes all actions in which the PT coaches the caregiver. Coaching aims to empower caregivers so that they can make their own educational decisions during daily care activities in the home environment.

Examples of concrete actions:

- Caregiver patiently observes the infant actions
- Caregiver challenges motor performances just at the verge of infant's abilities.
- Caregiver provides as little postural support as possible – challenges postural behavior of the infant
- Caregiver tries to evoke pleasure in the infant

B. Communication

All communication between the PT and the caregiver that is related to the guidance of infant and family

B.1 Information exchanges:

All communication during which information is exchanged regarding experiences, worries and the role of the PT.

Examples of concrete actions:

- PT provides opportunity for caregivers to tell about experiences related to NICU stay, to express worries and concerns about infant and family matters.
- PT provides information about role of PT and caregiver.
- PT asks whether specific problems exist.

B.2 Content of information:

This include all communications that explain the background of the treatment strategies, including developmental education.

Examples of concrete actions:

- PT explains handling in terms of typical movement patterns, typical development, posture, muscle tone, asymmetry/symmetry and hand placing.
- PT explains the need of, variation, minimal support, exploration, trial and error, challenge, and patience.
- PT [explains the need to explore communication.
- PT discusses the application of intervention strategies into daily routines in terms of handling.
- PT discusses the application of the intervention into daily routines in terms of variation, exploration, motor challenge

B.3 Instruct:

This include all communications in which the caregiver is given assignments or hints regarding treatment strategies.

Examples of concrete actions:

- PT assigns, gives advice what to do.
- PT gives hints, provides a suggestion or clue in a very indirect way so that caregivers feel free to explore ample variable opportunities.

B.4 Provide Feedback:

All communication in which the treatment or the performances of infant and caregiver are evaluated.

Examples of concrete actions:

- PT tells the caregiver what went right/wrong.
- PT evaluates the procedure.
- PT asks and listens to the opinion of the caregiver.

B.5 Impart knowledge:

All communication that provides the caregiver with knowledge about the therapeutic actions that will be performed.

Examples of concrete actions:

- PT asks about performance action.
- PT explains the ins and outs of an action.
- PT asks about understanding.
- PT asks about ability of caregiver to perform an action and listen to caregivers comments on actions.

C. Facilitation techniques.

All therapeutic hands on actions of the PT or caregiver aiming at guidance of the movement or maintenance of the infant's posture by gently placing the hands on specific parts of the infant's body, thus providing the infant with sensorimotor experience and controlling movement output.

C1. Handling

This includes specific hands-on techniques to give the infant sensorimotor experience to improve the quality and repertoire of the infant's movements.

Examples of concrete PT/caregiver actions:

- In supine position or in sitting. Shoulders function as key point: handling hands guide shoulders of the infant in protraction to control tone and to facilitate hand-hand contact and symmetry.
- In supine position. Proximal or distal leg functions as key point: the infant's hip is passively brought into semi-flexion while adducting the leg across the midline to facilitate head righting and rolling.
- In supine position. Pelvis functions as key point: the infant's pelvis is slightly lifted to elongate the extensor muscles of the trunk and to control tone; in this way hand-foot contact and symmetry are facilitated
- In prone position. Shoulder functions as a key point, the arms are placed in puppy position to facilitate head righting, midline orientation and body-alignment.
- In sitting. Shoulder functions as key point: the shoulders are moved alternately forwards and backwards to dissociate and facilitate independent arm movements.

C.2 Pressure techniques:

All handling techniques that produce intermittent pressure to stimulate and gain control over muscle tone, posture and movement.

Examples of concrete PT /caregiver actions:

- In sitting: intermittent downward pressure on shoulders in the direction of the pelvis to facilitate extension of the trunk
- In sitting: slight intermittent pressure movements on abdominal region in direction of the sacrum to facilitate contraction of the ventral muscles.

C.3 Transition:

This includes all handling techniques that result in the change of position of the infant.

Examples of concrete PT /caregiver actions:

- From supine to side, from supine to prone, from supine to sit, from side to sit, from prone to supine, from sit to supine, etc.

C.4 Support devices:

All handling techniques that use additional devices to support the infant.

Examples of concrete / additional devices:

- Bolster or ball
- Supporting sling.

D. Sensory experience

All tactile and vestibular stimulation given to the infant during treatment - without the aim of facilitation, tapping or passive motor experience - offered to the infant to provide him/her with the perception of body awareness.

Examples of concrete PT /caregiver actions:

- Using a toy to touch the infants skin.
- Tickling.

- Tapping on muscles

E. Passive motor experience

All handling techniques induced by the PT or the caregiver in which no activity of the infant is required in the performance of the actions.

Examples of concrete PT /caregiver actions:

- Passive movements of arms.
- Repetitive movements of the upper arm towards (frontal) support surface.
- Passive rocking, small sideways movements.
-

F. Self-produced motor behavior, no interference with PT /caregiver

This includes all actions during which the infant is given ample opportunities to explore toys or other aspects of the environment or his body without interference by the PT or caregiver.

Examples of concrete PT /caregiver actions:

- Placing an infant activity play center over the infant and let the infant explore the effect of movements or arms, hands, legs and feet.
- Infant is given opportunity for spontaneous exploration with or without toy.
- Postural challenges, infant spontaneously explores postural capacities.

G. Infant is challenged to produce motor behavior by him/herself; infant is allowed to continue activity by her/himself

This includes all actions in which the infant is challenged by toys or face of PT or caregiver to experience a variety of motor activity that is continued by the infant her/himself.

G.1 Little variation:

This includes all actions in which the infant is challenged by toys or face of PT or caregiver to explore one strategy to reach and grasp, to control posture, to roll, etc.

G.2 Large variation:

This includes all actions in which the infant is challenged by toys or face of PT or caregiver the infant is challenged to explore multiple strategies to reach and grasp, to control posture, to roll, etc.

H. Infant is challenged to produce motor behavior by him/herself; activity flows over into therapeutic handling

This includes all actions in which the infant is challenged by toys or face of PT or caregiver to experience a variety of motor activity that is followed by a handling technique.

H.1 Little variation:

All actions in which the infant is challenged by toys or face of PT or caregiver to explore one strategy to reach and grasp, to control posture, to roll, etc.

H.2 Large variation:

All actions in which the infant is challenged by toys or face of PT or caregiver the infant is challenged to explore multiple strategies to reach and grasp, to control posture, to roll, etc.

I. Not specified

All time during the treatment session that cannot be classified into the eight defined categories.

Examples:

- Comforting the infant.
- Changing the treatment situation.

Postural support in prone, side and sitting position:

- No postural support:

PT or caregiver leaves it to the infant to adjust posture independently. "Hands off"

- Minimal postural support:

PT or caregiver provides as little support as possible in order to challenge postural behavior of the infant

Example of concrete action:

PT or caregiver challenges motor performance just at the verge of the infant's abilities, i.e. the infant has to 'work' to maintain balance

- Clear postural support:

PT or caregiver provides support on multiple parts of body or the trunk. Minimal active involvement of the infant to adjust posture is required.

Example of concrete action:

- PT or caregiver provides support at the neck/shoulder girdle and/or upper part of the trunk

- Full postural support:

PT or caregiver supports all parts of the body of the infant that play a role in postural adjustments. No active involvement of the infant is required.

* Independent variable: the value of this variable is supposed to not change during the course of an observation. It gives the observer the opportunity to summarize briefly important characteristics of the observation

Appendix III : Ethical Clearance Certificate



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

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Lindie Dalton

CLEARANCE CERTIFICATE

M120827

PROJECT

Evaluation and Adaptation of an Observation
Tool to Quantify and Define Bobath/Neuro
Developmental Therapy

INVESTIGATORS

Ms Lindie Dalton.

DEPARTMENT

Department of Physiotherapy

DATE CONSIDERED

31/08/2012

DECISION OF THE COMMITTEE*

Approved unconditionally

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

DATE 10/10/2012

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 IV : Permission from Chairperson of the board for Malamulele Onward

		Malamulele Onward	Possibilities for Africa's Children with Cerebral Palsy
SECTION 21 COMPANY REGISTRATION NO. 2006/032287/08 REGISTERED WITH THE DEPARTMENT OF SOCIAL DEVELOPMENT AS A NON-PROFIT ORGANISATION 056-807-NPO PUBLIC BENEFIT ORGANIZATION 930025084			
SOUTH AFRICA P.O. Box 52641 Saxonwold 2132 SOUTH AFRICA Tel: (011) 484 9456 www.CPchildren.org		Room 257 Children's Memorial Institute 13 Joubert Str Ext Braamfontein	CANADA 1268 Hillview Crescent Oakville, Ontario L6H 2C7 CANADA Tel: (905) 338 7559

1 September 2012

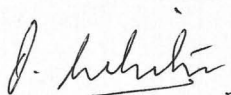
Ms. Lindie Dalton
Physiotherapist

Dear Lindie

PERMISSION TO CONDUCT STUDY

This letter serves to confirm that permission has been granted to you to conduct your study "Evaluation and adaptation of an observation tool to quantify and define Bobath/Neurodevelopmental therapy" at Malamulele Onward. Furthermore permission is granted for you to videotape therapy sessions of children attending Malamulele Onward for therapy, provided informed consent is obtained from the child's caregiver and where relevant, from the child himself/herself.

I wish you every success with this study.



JOHN WHITTER
CHAIRPERSON
BOARD OF DIRECTORS

Appendix V : Consent for evaluating the observer protocol by analysing videos

CONSENT FOR EVALUATING THE OBSERVER PROTOCOL BY ANALYSING VIDEOS RESEARCH

Evaluation and adaptation of an observation tool to quantify and define physical therapy done on a child with CP in the South African context.

THERAPIST INFORMATION SHEET FOR EVALUATING THE OBSERVER PROTOCOL BY ANALYSING VIDEOS

My name is Lindie Dalton and I am a physiotherapist completing a postgraduate degree at the University of the Witwatersrand. I am investigating a tool that might help to quantify and define physical therapy activities for children with CP. I want to see if the Observation Protocol that was developed in the Netherlands might be implemented in the South African context. I therefore need to determine if we can analyse 5 videos of treatment sessions that was done by a predominant Bobath/NDT, South African trained physiotherapist, with the help of this protocol.

I would like to invite you to take part in this study. Before you agree to take part, it is important for you to understand what the study is about, what it involves and to ask me any questions you may have.

If you agree to participate you will look at 5 treatment videos that have been premarked into timeslots by the researcher. These time slots are where the researcher perceived the start and end of a specific treatment activity. You will then need to look at the 8 domains of the Observation Protocol and indicate which one is in your opinion more applicable to describe Bobath/NDT principles and if there are any alternative activities or areas that should be included. Each tape is 30 minutes long and it should take you 45 minutes to analyse it.

All information shared within this group cannot be kept confidential or private but your name will not be used in any written documents. The tapes and information will be stored in a safe place and will be destroyed after six years or after publication of the study according to HPCSA regulations.

Participation is voluntary and if you do decide to join the discussion group, and you change your mind you can leave at any time without any consequences for yourself.

Feedback on the study will be available on request.

If you have any questions, please feel free to contact me at 0799358163. Any queries or concerns about ethics can be discussed with the Chairman of the Ethics Committee at the University of the Witwatersrand, Prof P Cleaton-Jones who can be contacted at 011 7171234.

If you agree to take part in this study, please sign the forms attached.

Lindie Dalton
Physiotherapist

RESEARCH

Evaluation and adaptation of an observation tool to quantify and define physical therapy done on a child with CP in the South African context.

THERAPIST **WRITTEN INFORMED CONSENT FORM**

I,

_____,
confirm that I have been told about the research in a language that I understand. I have also received, read and understood the written information regarding the study.

I am aware that any information I give to the researcher cannot be kept private because it is collected in a group situation and all the results will be anonymously processed.

I understand that at any stage, I may take myself out of the study. I understand that if I decide not to take part, or I change my mind, there will be no consequences for me. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.

I agree that I will volunteer to take part in this study.

Therapist's name: _____ (please print)

Therapist's signature: _____

Interviewer's name: _____ (please print)

Interviewer's signature: _____

Date: _____

Appendix VI : Letter to Dr. Mijna Hadders-Algra to request more information regarding the Observation Protocol

Mijna Hadders-Algra, MD, PhD,
Department of Pediatrics–Developmental Neurology
University Medical Center
Groningen
Hanzeplein 1
9713 GZ Groningen
The Netherlands
(m.hadders-algra@med.umcg.nl).

20 May 2014

Dear Mrs. Hadders-Algra

Re: Blauw-Hospers C.H. MSc, Dirks T PT, Hulshof L.J. MD; Hadders-Algra M, MD, PhD. Development of a Quantitative Tool to Assess the Content of Physical Therapy for Infants; Pediatrics of the American Physical Therapy Association; 2010, 22:189-198

I am a Physiotherapist and postgraduate Masters Student at the University of the Witwatersrand, Johannesburg in South Africa.

As part of my masters, I wish to undertake a research project looking into the validity, particularly the content validity and suitability of the Observation Protocol within poorly resourced settings within South Africa. I specifically want to see if this protocol can be used to define and quantify therapy as implemented by Bobath/NDT trained physiotherapists.

I would like to gain your permission for evaluating and possibly adapting the Observation Protocol.

The study consists out of three parts:

Part one will be conducted where five experts in the field will analyse five treatment videos by means of the Observation Protocol. There should be 80% consensus between the experts that 30 minute segment of a treatment sessions can be described successfully by the different items on the protocol.

Study participants will be considered to be experts if they meet the following criteria (Hilburn, 2010):

a) Have a minimum of 10 years of experience in paediatrics

- b) Have a physiotherapy qualification
- c) Are currently practicing in the field of paediatrics
- d) Are preferably involved in research

Part two: Depending on the outcome of step one, the next step will look at how to adapt the protocol. During this phase I will focus on determining the content validity of the Observation Protocol for use in the treatment of children between the ages of 2 and 14 years with a diagnosis of CP. This is a different population group from the group used for the development of the original protocol.

Part three: Will establish the psychometric properties of the adapted protocol, namely the reliability, completeness, mutual exclusiveness and construct validity following the same procedures used in the development of the original protocol.

Once this study is completed, it is a hope that the AOP will become a tool that we can use within South Africa.

If you have any further questions, please contact me.

Kind regards

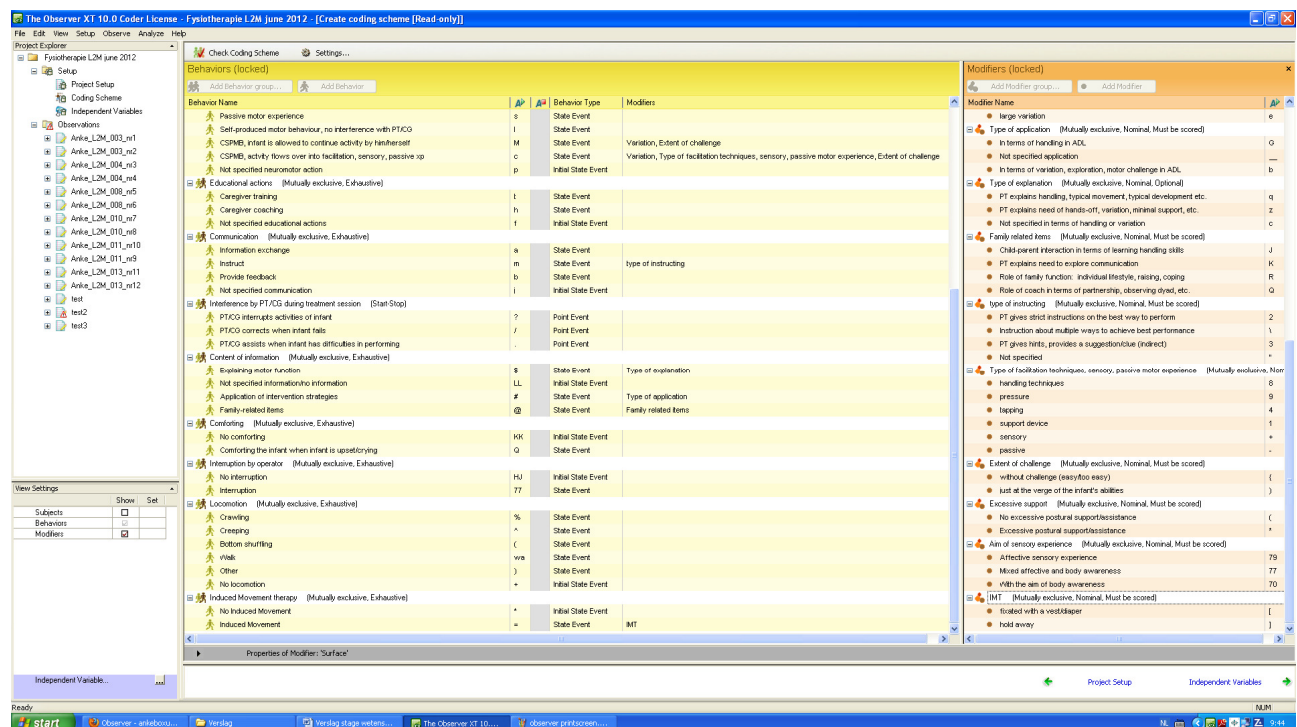
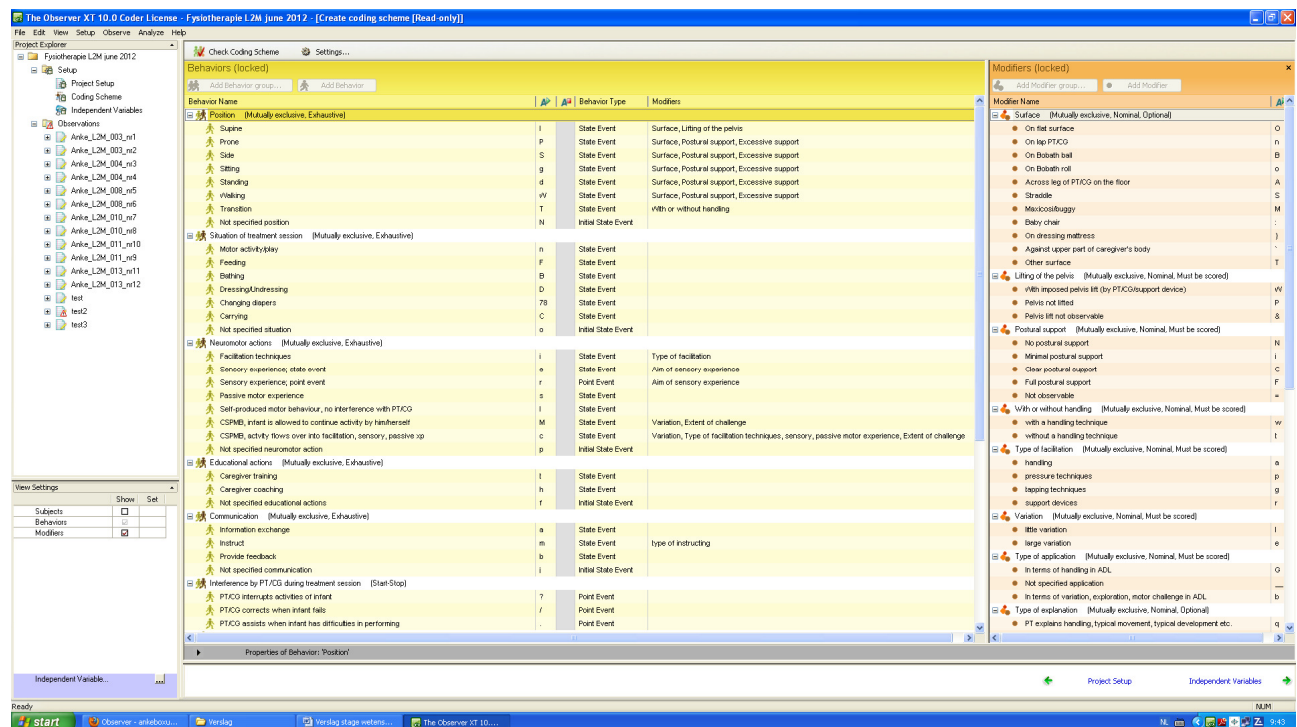
Lindie Dalton

Physiotherapist

daltonlindie@yahoo.co.uk

+27799358163

Appendix VII : Additional information on operating Noldus' Observer XT 5.0, supplied by Anna Schmidt



Browser window showing a Yahoo! Mail interface. The address bar displays <http://uk.mg41.mail.yahoo.com/neo/launch?ra>. The page title is "2535 unread - daltonlindie...". The left sidebar shows a list of folders and their counts: Drafts (166), Sent, Spam (116), Trash (69), and a list of folders including Amazon, Beth (1), BHF, BlackBerry, Career builder, CPD, Fizzy programmes, Flights (1), Follow up emails, Fotos, Groupon, Gumtree (2), Hiking, hospitality, HSBC, Huise, Huur huise, KZN, Lesotho, Lesotho outreach in ju..., Locum (2), and M2M training.

The main content area displays an email from "Ann Katrin Schmidt, M.Sc. Phys." dated 06:30 PM 2012/10/02. The email text is as follows:

Dear Lindie,

First of all I cannot tell you, if you are able to use the unpublished protocol. This might be a question you have to ask Mijna Hadders-Algra or your supervisor. As it looks like they will not have a publication about the new protocol in the near future. At the moment I have not planned to publish parts of my thesis but if so it will most probably be in German. In that case I would not interfere with the PhD students on that project.

As I understood you right you will concentrate on the evaluation of NDT. The scoring list is quite broad. The paper of Dirks et al. (2011) <Differences Between the Family-Centered "COPCA" Program and Traditional Infant Physical Therapy Based on Neurodevelopmental Treatment Principles>, describes which categories are more related to NDT or COPCA. For my thesis I scored every category but I did not use all of them for my analysis. With all those categories it takes you ages to score a tape thus I would consider to adjust the scoring list to your research question and maybe not use items directly related to COPCA.

The category A1-3 were also called independent variables. It means that you score them for the overall impression of a session. The observer has the possibility to score independent variables but we did not use that feature. We simply made an excel sheet for those items.

Send you two screen shots of the setup we have used. I guess the way the categories have been organized in the observer has not changed a lot since I have no clue how you would arrange the categories in another way. I think mainly the modifiers have been adjusted. But it is better if you'll ask those Mijna Hadders-Algra or Tineke Dirks those questions.

You can simply ignore the codes/short cuts used. They are without any order. As far as I saw how you did this it's a lot more reasonable. Obviously we are using two different versions of the observer. For each item you have to say if it is a state, point or initial event. I suspect you will find that in <properties> our version calls that <behavior type>. This is also the answer to your question on slide 5. For each set of behaviors you will have to classify an initial event. When you start an observation every set will first give you the initial event. We always used <not specified> as the initial event.

I have always set the modifier class on <none>. There you will have to put in the heading of modifier used. When you score with the observer the modifiers will automatically pop up to your behavior categories but you will have to link them first. It also means that you can use the same modifier for several behaviors for example the position. You do not have to set up the same modifier for each position separately. Supine will only be modified by pelvis tilted, support does not make any sense for supine.

In your first mail you asked which behaviors are scored simultaneously. Each set of behavior can/will be scored simultaneously. In fact you will always have to score something. That's why it is advisable to have the initial event as <none specified> whenever you cannot observe a behavior you will have to score it as <not specified>. If you classified something as a <state event> (properties) the behavior will change to that item and last until you end the sequence by choosing another behavior out of the set or the observations is finished. A <point event> will only last for a couple of seconds and the set of behavior will stay as before. That is useful for interruptions or we also used it for sensory events as often the child is touched while the neuromotor action last. In fact we use two categories of sensory events one as a state event and one as point event. As far as I know that differentiation has been added later.

Well I kind of have the feeling that I wrote down a lot of information and it might be a bit confusing. Thus I end here and looking forward to further questions.

Ann Katrin Schmidt, M.Sc. Phys.

The right sidebar contains a promotional banner for "bforex" with the text "and Get a FREE iphone 4S/ ipad*" and "Start trading! *limited time offer". Below the banner is a small image of an iPhone 4S/ iPad and the text "Lose the ads! Try Mail Plus."

Appendix VIII : Additional information and further development of the OOP that has never been published, supplied by Anna Schmidt: The Tab -Overview for the Observation Protocol.

	Category	Modifier	Dirks et al. 2011
Position	- Supine - Prone - Side - Sitting - Walking - Transition - Not specified position	- Lifting of Pelvis: - with imposed pelvis lift (by PT/CG/support device) - Pelvis not lifted - Surface: - on flat surface - On lap PT/CG - On Bobath ball - On Bobath roll - Across leg of PT/CG on the floor - Straddle - Maxi cosi/buggy - Baby chair - On dressing mattress - Against upper part of caregiver's body - Other surface - With or without handling: - With a handling technique - Without a handling technique	→ Postural support in... → C.3
Situation of treatment session	- Motor activity/play - Feeding - Bathing - Dressing/Undressing - Changing diapers - Carrying - Not specified situation		→ I
Neuromotor actions	- Facilitation techniques - Sensory experience (state event/point event) - Passive motor experience - Self-produced motor behavior, no interference with PT/CG - CSPMB, infant is allowed to continue activity by him/herself - CSPMB, activity flows over into facilitation, sensory, passive - Not specified neuromotor action	- Type of facilitation: - Handling - Pressure techniques - Tapping techniques - Support devices - Aim of sensory experience: - Affective sensory experience - Mixed affective and body awareness - With the aim of body awareness - Variation: - Little variation - Large variation - Extent of challenge - Without challenge (easy/too easy) - Just at the verge of the infant's abilities - Type of facilitation techniques, sensory, passive motor experience: - Handling techniques - Pressure - Tapping - Support device - Sensory - passive	→ C → C.1 → C.2 → C.4 → D → E → F → G → G.1 / H.1 → G.2 / H.2 → H
Educational actions	- Caregiver training - Caregiver coaching - Not specified educational action		→ A.4.3 → A.4.4
Communication	- Information exchange		→ B.1

	Category	Modifier	Dirks et al. 2011
	- Instruct	Type of instructing: - PT gives strict instructions on the best way to perform - Instruction about multiple ways to achieve best performance - PT gives hints, provide a suggestion/ clue (indirect) - Not specified	→ B.3
	- Provide feedback - Not specified communication		→ B.4
Interference by PT/CG during treatment session	- PT/CG interrupts activities of infant - PT/CG corrects when infants fails - PT/CG assists when infant has difficulties in performing		→ A.4.1
Content of information	- Explaining motor function - Not specified information /no information - Application of intervention strategies - Family-related items	Explaining motor function: - PT explains handling, typical movements, typical development etc. - PT explains needs of hands-off, variation, minimal support etc. - Not specified in terms of handling or variation Application of intervention strategies: - In terms of handling in ADL - Not specified application - In terms of variation, exploration, motor challenge in ADL Family-related items: - Child-parent interaction in terms of learning handling skills - PT explains need to explore communication - Role of family function: individual lifestyle, raising, coping - Role of coach in terms of partnership, observing dyad etc.	→ B.2
Comforting	- No comforting - Comforting the infant when infant is upset/crying		
Interruption by operator	- No interruption - Interruption		
Locomotion	- Crawling - Creeping - Bottom shuffling - Walking - Other - No locomotion		→ new
Induced Movement Therapy	- No induced movement - Induced movement	IMT - Fixated with a vest/diaper - hold away	→ new

Appendix IX : Attempts to implement the Observation Protocol into the Observer XT 5.0

The screenshot shows the 'The Observer - testProject(1)' window. On the left is a tree view of the project structure. The main area displays three tables for configuration:

testProject(1) - Fam involvement - Behaviors

	Name	Description	Code	Modifier Class 1	Modifier Class 2	Properties
1						
2	Role of caregiver		A2	None	None	State
3	Fam participate		A1	None	None	State
4	Infant dressing		A3	None	None	State
5	*					

testProject(1) - Behavioral Classes

	Name	Description	Type	Elements
1	Fam involvement		Nominal	Role of caregiver, Fam participate, k...
2	Communication		Nominal	Info exchange, Content of info, Ins...
3	Neuromotor activ		Nominal	Facilitation, Sensory experien, Pa...
4	Positioning		Nominal	Supine, Side, Prone
5	*			

testProject(1) - Communication - Behaviors

	Name	Description	Code	Modifier Class 1	Modifier Class 2	Properties
1						
2	Info exchange		B1	None	None	State
3	Content of info		B2	None	None	State
4	Instruct		B3	None	None	State
5	Provide feedback		B4	None	None	State
6	Input knowledge		B5	None	None	State
7	*					

Red text annotation: "This is the way we set up the behavioural classes and the behaviours"

The screenshot shows the 'The Observer - testProject(1)' window with the 'Initialize Channels (Classes)' dialog box open. The dialog box contains a table with the following data:

CLASS	BEHAVIOR
Fam involvement	Element
Communication	
Neuromotor ac	
Positioning	

Red text annotation: "When we want to start observing this box comes up. What do we need to fill into the clear box in order to proceed?"

The background shows the 'Timers' and 'Event Log' windows. The 'Event Log' window has columns for RECORD, TIME, and BEHAVIOR.

Appendix X : Initial scoring sheet for the evaluation of the Observation Protocol

EVALUATION AND ADAPTATION OF AN OBSERVATION TOOL TO QUANTIFY AND DEFINE PHYSICAL THERAPY FOR CP IN THE SOUTH AFRICAN CONTEXT

Lindie Dalton

Marksheet for analysing video material with the aid of the Observation Protocol

Thank you for being part of my expert panel and for your very important insight into this research topic.

Please indicate what category you would indicate as representative of the actions and activities that occurred during the stated timeslot. Please state if you agree or disagree with the completeness, applicability or specificity of any of the categories in the block provided. Therefore if in your opinion no other category describes the activity adequately, please state what descriptor you would suggest instead to explain the action appropriately.

Also, state if you feel the timeslots as indicated by the researcher are not accurate.

It is important to note that in observational research an activity is only noted as such if it persists for more than 2 seconds. It is therefore not necessary to note an activity unless it is sustained for more than 2 seconds.

E.g. If you observe in the video during a specific timeslot that the therapist is “Handling” the child, fill in C1. However if you perceive “handling “ as a descriptor to be vague and that it would be more beneficial to describe the action as a specific action of “Hoovering”, please add this as a comment.

Video 1: Forward the Video to the 27th min to commence

Observer name: _____

Video number:	1	Time slot: 27-31.18 min	
Suggested category number:	H1	I AGREE	I DISAGREE
<u>In the case of you disagreeing on the timeslot allocated, please state which time slots:</u>			
If none of the categories adequately describe this therapeutic activity in your opinion state in one sentence an alternative descriptor:			
Video number:	1	Time slot: 31.18 – 34.35 min	
Suggested category	G1	I AGREE	I DISAGREE

number:			
<u>In the case of you disagreeing on the timeslot allocated, please state which time slots:</u>			
If none of the categories adequately describe this therapeutic activity in your opinion state in one sentence an alternative descriptor:			
<u>Video number:</u>	1	<u>Time slot:</u> 34.35 – 34.56 min	
<u>Suggested category number:</u>	C3	I AGREE	I DISAGREE
<u>In the case of you disagreeing on the timeslot allocated, please state which time slots:</u>			
If none of the categories adequately describe this therapeutic activity in your opinion state in one sentence an alternative descriptor:			

Appendix XI : Questionnaire for panel of experts in evaluating the Observation Protocol

EVALUATION AND ADAPTATION OF AN OBSERVATION TOOL TO QUANTIFY AND DEFINE PHYSICAL THERAPY FOR CP IN THE SOUTH AFRICAN CONTEXT

Lindie Dalton

Dear Bobath/NDT trained Therapist

Thank you once again for your time and effort in implementing the observational tool in analyses of treatment sessions done by Bobath/NDT trained therapists. Can you kindly answer the following question in regards to the observational tool.

1. In your opinion would you say that the observational tool adequately and accurately described all the aspects of the therapeutic activities that were observed during the treatment sessions done by the Bobath/NDT trained therapists?

2. In your opinion do you feel that the observational tool need to be adapted in order to adequately and accurately describe all therapeutic activities of the treatment sessions done by the Bobath/NDT trained therapists?

3. If so what categories would you adapted or add?

4. Do you feel that the observational tool can accurately be implemented on a treatment session for a child older than one years of age?

5. Do you feel that the observational tool adequately and accurately described treatment activities as implemented during treatment for children with different GMFCS levels? Please explain why you say so?

5a. GMFCS level V

5b. GMFCS level IV

5c. GMFCS level III

5d. GMFCS level II

Other comments:

Appendix XII : Information sheet and consent for the discussion groups in order to adapt the Observation Protocol.

CONSENT FOR DISCUSSION GROUPS

RESEARCH

Evaluation and adaptation of an observation tool to quantify and define physical therapy done on a child with CP in the South African context.

THERAPIST INFORMATION SHEET FOR DISCUSSION GROUPS

My name is Lindie Dalton and I am a physiotherapist completing a postgraduate degree at the University of the Witwatersrand. I am investigating a tool that might help to quantify and define physical therapy activities for children with CP. I want to see if the Observation Protocol that was developed in the Netherlands might be implemented in the South African context. I therefor need to determine if we can analyse 5 videos of treatment sessions that was done by a predominant Bobath/NDT, South African trained physiotherapist, with the help of this protocol.

It was determined that the Observation Protocol in its current form needs to be adapted before it can be implemented in the South African paediatric neurology context and I therefor need to determine the content validity.

I would like to invite you to take part in this study. Before you agree to take part, it is important for you to understand what the study is about, what it involves and to ask me any questions you may have.

If you agree to participate you will be included in a discussion group together with other therapists to discuss and look at the 8 domains of the Observation Protocol and the therapeutic activities that it entails. Each discussion will take about 120 minutes. I am also asking that you give permission for the discussion groups to be videotaped.

How do I determine Content Validity?

The following is excerpts from the Thesis by Nicole Hilburn (2010) that answers this question: "Content validity is an essential step in the development of new measuring devices as it represents a beginning mechanism for linking abstract concepts with observable and measurable indicators (Wynd et al, 2003). Content validity is often the first step in examining the validity of a newly developed tool and is not determined by statistical analyses, but by practical considerations (McEwan et al, 2003; American Psychological Association, 1985)."

She further states that: "This is often carried out in consultation with a panel of experts to obtain consensus on each item, as well as the consensus on the scale as a whole (Dunn et al, 2005; Harris et al, 2003; Harris and Daniels, 1996). "

"Content validity is largely a matter of judgement, involving two distinct phases: the scale developer should enhance content validity through careful conceptualisation and domain analysis prior to item generation, and the relevance of the scale's content through expert assessment (Polit and Beck, 2006; Mastaglia, et al, 2003; Beck and Gable, 2001). "

Hilburn (2010) quotes Jones et al (2000) about the Modified nominal consensus group Technique: " it is based on the premise that 'pooled intelligence' enhances individual judgement and captures the collective opinion of experts.

Hilburn further quotes Potter et al (2004): "The aim of the NGCT is to generate information in response to a focused issue, and to facilitate discussion around this. This is done during a focused meeting, which lasts up to two hours, and consists of five to nine study participants. There are a number of advantages to this technique: minimal preparation is required by study participants, and study participants input is limited to a single meeting lasting up to two hours. Task completion and immediate dissemination of results to the group lead to greater satisfaction amongst study participants due to quick dissemination of information; and researcher-bias is minimised due to the highly structured nature of the process.

The NGCT protocol follows a number of steps as outlined below:

1. Introduction and explanation: the study participants should be welcomed, and an explanation of the purpose and procedure of the meeting should be given.
2. Generation of ideas: each participant should be provided with a sheet of paper with the question to be addressed and study participants are then asked to write down all ideas that come to mind when considering the question. During this period, study participants are asked not to consult or discuss their ideas with others. Approximately ten minutes are allowed for this.
3. Sharing of ideas: study participants should be invited to share the ideas they have generated. The process continues until all ideas have been presented. There is no debate about items at this stage and study participants should write down any new ideas that may arise from what others have shared. This process ensures that all study participants get an opportunity to make an equal contribution and provides a written record of all ideas generated by the group.
4. Group discussion: study participants are invited to ask for further explanation and detail about any of the ideas that colleagues have produced.
5. Voting and ranking: this involves prioritising the recorded ideas in relation to the original question. Immediate results are available to study participants so that the outcomes are reached by the time the meeting concludes. It is recommended that the process is recorded on videotape or audiotape (Potter et al, 2004)."

All information shared within this group cannot be kept confidential or private but your name will not be used in any written documents. The tapes and information will be stored in a safe place and will be destroyed six years or publication of the study according to HPCSA regulations, after we have written about the results of the study.

Participation is voluntary and if you do decide to join the discussion group, and you change your mind, you can leave at any time without any consequences to yourself.

Feedback on the study will be available on request.

If you have any questions, please feel free to contact me at 0799358163. Any queries or concerns about ethics can be discussed with the Chairman of the Ethics Committee at the University of the Witwatersrand, Prof P Cleaton-Jones who can be contacted at 011 7171234.

If you agree to take part in this study, please sign the forms attached.

Lindie Dalton
Physiotherapist
Full references is available on request

RESEARCH

Evaluation and adaptation of an observation tool to quantify and define physical therapy done on a child with CP in the South African context.

THERAPIST **WRITTEN INFORMED CONSENT FORM**

I, _____,
confirm that I have been told about the research in a language that I understand. I have also received, read and understood the written information regarding the study.

I am aware that any information I give to the researcher cannot be kept private because it is collected in a group situation and all the results will be anonymously processed.

I understand that at any stage, I may take myself out of the study. I understand that if I decide not to take part, or I change my mind, there will be no consequences for me. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.

I agree that I will volunteer to take part in this study.

Therapist's name: _____ (please print)

Therapist's signature: _____

Interviewer's name: _____ (please print)

Interviewer's signature: _____

Date: _____

THERAPIST **PERMISSION TO VIDEO TAPE DISCUSSION GROUPS**

I, _____, give
permission for the Video taping of the discussion group which I have agreed to participate in.

Therapist's name: _____ (please print)

Therapist's signature: _____

Date: _____

Appendix XIII : Example of Excel spreadsheet used to calculate mutual exclusivity

Timeslot	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	
A1	0	0	1	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0
A2	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
A3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
A.4.1.	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
A.4.2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
A.4.3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
A.4.4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
B1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
B2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
B3	0	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
B4	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
B5	0	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0
C1	0	0	1	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0
C2	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
C3	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
C4	1	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0
D	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
E	1	1	1	1	1	1	1	0	0	1	1	1	1	1	1	1	1	1
F	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
G1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
G2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
H1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
H2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Indecisive	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	2	1	4	2	2	1	4	2	1	1	3	2	1	1	1	1	1	2
Mutually Inclusive		103																
Total Observations		205																
% Mutually Inclusive Observations		50.24%																

	CATEGORIES PER RATER																									
	A							B					C				D	E	F	G	H		I			
Timeslot	A1	A2	A3	A.4.1	A.4.2	A.4.3	A.4.4	B1	B2	B3	B4	B5	C1	C2	C3	C4	D	E	F	G1	G2	H1	H2	I	Indecisive	
1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
	1	1	0	0	0	0	0	0	0	0	1	1	0	1	0	0	1	0	1	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	0	0	
2	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
	1	1	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	0	0	0	0	
3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
	1	1	0	0	0	0	0	0	0	0	1	0	1	0	0	0	1	0	0	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	0	0	
4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	
5	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
	1	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	

	Person 2	Person 3	Person 4	Person 5
2 Person 1	0.692219	0.472866	0.456522	0.456522
1 Person 2		0.327327	0.692219	0.692219
7 Person 3			0.472866	0.472866
2 Person 4				0.456522
2 Person 5				
2 Person 1	0.692219	0.221163	0.456522	-0.06019
1 Person 2		0.408248	0.692219	-0.04167
5 Person 3			0.589768	-0.10206
2 Person 4				-0.06019
1 Person 5				
1 Person 1	-0.04167	-0.10206	-0.06019	-0.04167
1 Person 2		-0.10206	0.692219	1
5 Person 3			-0.14744	-0.10206
2 Person 4				0.692219
1 Person 5				
1 Person 1	-0.04167	-0.04167	-0.04167	-0.04167
1 Person 2		-0.04167	1	1
1 Person 3			-0.04167	-0.04167
1 Person 4				1
1 Person 5				
1 Person 1	1	-0.07538	1	1
1 Person 2		-0.07538	1	1
3 Person 3			-0.07538	-0.07538
1 Person 4				1
1 Person 5				

	1- 0.9	0.9-0.8	0.8-0.7	0.7-0.6	0.6-0.5
Total	10	10	10	10	10
Total over	0	0	0	3	0
Total under	0	0	0	0	0
Percentage in correlatio	0%	0%	0%	30%	0%
Total	10	10	10	10	10
Total over	0	0	0	2	1
Total under	0	0	0	0	0
Percentage in correlatio	0%	0%	0%	20%	10%
Total	10	10	10	10	10
Total over	1	0	0	2	0
Total under	0	0	0	0	0
Percentage in correlatio	10%	0%	0%	20%	0%
Total	10	10	10	10	10
Total over	3	0	0	0	0
Total under	0	0	0	0	0
Percentage in correlatio	30%	0%	0%	0%	0%
Total	10	10	10	10	10
Total over	6	0	0	0	0
Total under	0	0	0	0	0
Percentage in correlatio	60%	0%	0%	0%	0%

Appendix XIV : Excel spreadsheet for correlation coefficient calculation during phase 1

Timeslots	A1	A2	A3	A.4.1	A.4.2	A.4.3	A.4.4	B1	B2	B3	B4	B5	C1	C2	C3	C4	D	E	F	G1	G2	H1	H2	I	Indecisive	P _i	
4	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	3.0	0.0	0.0	1.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.3
9	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.0	0.0	0.0	0.0	0.0	3.0	1.0	0.3
13	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.0	0.0	1.0	2.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.1
20	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	4.0	0.0	0.6
21	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	1.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	1.0	1.0	0.0	0.0	0.0	
33	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.0	0.0	4.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.6
26	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	3.0	0.0	0.0	0.0	0.0	1.0	0.0	1.0	0.3	
17	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	2.0	2.0	0.0	0.2	
Total	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.0	1.0	3.0	0.0	8.0	0.0	1.0	7.0	0.0	1.0	0.0	1.0	4.0	10.0	3.0		
P _j	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.3	0.1		

Appendix XV : Calculation of Fleiss Kappa

10	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	2
11	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	2
15	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	1
16	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	1	1
17	0	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	1	1
22	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	3
23	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0
41	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	1
Total	0	0	0	0	0	0	0	0	0	0	1	1	5	3	2	2	3	11
p _j	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.025	0.025	0.125	0.075	0.050	0.050	0.075	0.275

P 0.0875
P_e 0.1425
-
K 0.06414

Appendix XVI : The first provisional adapted version of the Observation Protocol discussed during the first stage of the Adapted Modified nominal consensus group Technique

Category	Subcategory	Modifier	Relation to original Observation Protocol
Position	- Lying	Supine: Lifting of Pelvis: with imposed pelvis lift (by PT/CG/support device) Pelvis not lifted Prone: - Imposed extention of the mid - thorax (by PT/CG/support devices) – Imposed hip extention (by PT/CG/support devices) - Imposed scapula protraction (by PT/CG/support devices) -Prone over roller with weightbearing and weightshift	- Postural support in.....
	- Sitting	Side sitting: Imposed active side flexion and abduction of the upper leg Dynamic/High/Straddle sitting: On lap PT/CG On Bobath ball On Bobath roll Across leg of PT/CG on the floor Bench Longleg sitting : Bench On lap of PT/CG On treatment mat	

Situation of treatment session		Other surface	
	- Standing	Wide leg stance with imposed biomechanical alignment (by PT/ garment/equipment/orthotics) Single leg stance with imposed weight bearing on lateral side of the foot of stance leg as well as elongation on weight bearing side of body (by PT extending/ abducting/ flexing non weight bearing leg either manually or using equipment) Walk stance with imposed biomechanical alignment (by PT/Garments/equipment)	
	- ½ kneeling	Facilitate ½ kneeling with handling techniques Facilitate ½ kneeling with use of equipment	
	Transition	- With a handling technique - Without a handling technique but rather using verbal prompts - Child self-initiated	
	Not specified position		- C3
	Motor activity/play/work/functional activity Feeding/eating/preparing food	- Child is an active participant involving facilitation or self-initiation - Child is a passive participant	
	Personal hygiene routines /toilet transfers / Dressing /Undressing/changing diapers	- Child is an active participant involving facilitation or self-initiation - Child is a passive participant	

Carrying
Not specified situation

- I

Musculoskeletal actions

Preparatory actions

Mobilisation techniques:

- Soft tissue release
- Mobilization of specific joints for better alignment
- Manual alignment of body parts to activate muscles and overcome passive insufficiencies i.e. depression of the ribcage to activate abdominals

Rythmical/reciprocal movements: that

- Includes "hoovering" of either the lower or upper-limbs mostly to reduce the non-neural component of spasticity
- Induced rotation of the pelvis
- Induced rotation of the ribcage

Replaces passive motor experience, what is motor experience is that not then sensory experience again?

Neuromotor actions

Facilitation techniques

Type of facilitation:

- C

Handling:

- Biomechanical alignment of the limb for tone influencing pattern
- placing of the limb or body part for active weight shift
- Disrupt/perturb BOS manually or with equipment to activate core muscles

- C1

Pressure techniques

- Manually: Directional to improve proprioception, body awareness and optimise muscle tone

- C2

- Support devices: Theratogs/AFO's

- C4

Tapping techniques for proprioceptive input i.e tapping with

hand on muscles in sweeping motion or tapping through a stick held in extended arms done in an intermittent manner or tapping through the joint itself.

-

Is tapping and pressure techniques the same thing?

Passive motor experience

Sensory experience (state event/point event)

Aim of sensory experience: Affective sensory experience
Mixed affective and body awareness
Body awareness

Self-produced motor behavior, no interference with PT/CG

This is accomplished through manipulation/adaptation of the environment

- F

CSPMB(Challenged self-produced motor behaviour), infant/child is allowed to continue activity by him/herself

- Little variation
- Large variation Extent of challenge
- Without challenge (easy/too easy)
- Just at the verge of the infant's abilities

- G1/H1

- G2/H2

CSPMB, activity flows over into facilitation, sensory, passive

- Type of facilitation techniques, sensory, passive motor experience:
- Handling techniques
 - Pressure
 - Tapping
 - Support device
 - Sensory
 - passive

Neuromotor actions Not specified neuromotor action

.

Educational actions

- Caregiver training: verbal information about their child's condition and strategies to handle the child
- Caregiver coaching: teaching handling techniques and use of

• A.4.3

• A.4.4

equipment to carers through demonstration and observing and giving feedback to their efforts

- Child training i.e. about their condition and why they have to do certain activities

- Not specified educational action

- Information exchange

Communication

- Instruct

Type of instructing:

• B.3

- PT gives strict instructions on the best way to perform to child or CG

- Instruction about multiple ways to achieve best performance

- PT gives hints, provide a suggestion/ clue (indirect)

Giving non-verbal cues i.e. visual input

This multiple ways as well as large and little variations I think is more related to COPCA "Coping With and Caring for Infants With Special Needs"

- Provide feedback

• B.4

- Not specified communication

What do you understand around this? Is this feedback from previous sessions or is it feedback as the treatment session unfolds?

Interference by PT/CG during treatment session

- PT/CG interrupts activities of infant

- PT/CG corrects when infants fails

- PT/CG assists when infant has difficulties in performing

• A.4.1

Content of information

- Explaining motor function

Explaining motor function:

• B.2

- PT explains handling, typical movements, typical development etc.

- PT explains needs of hands-off, variation, minimal support etc.

- Not specified in terms of handling or variation

I feel these should be included under communication and not a separate section?

Can this whole section not be included into the education section?

- Not specified information /no information

- Application of intervention strategies

Application of intervention strategies:

	- Family-related items	- In terms of handling in ADL - Not specified application - In terms of variation, exploration, motor challenge in ADL - Family-related items: - Child-parent interaction in terms of learning handling skills - PT explains need to explore communication - Role of family function: individual lifestyle, raising, coping - Role of coach in terms of partnership, observing dyad etc.
Comforting	- No comforting - Comforting the infant when infant is upset/crying	
Interruption by operator	- No interruption - Interruption	
Locomotion	Facilitation of : - Crawling - Creeping - Walking	- new - Facilitation of walking with handling techniques using proximal key points of pelvis, shoulder girdle. - Facilitation of walking with a handling techniques using proximal key points of distal key points i.e. hands or placing of feet - Facilitation of walking using equipment to optimise/facilitate biomechanical alignment or patterns of movement
	Bottom shuffling Rolling	- Facilitation using key points - Facilitation using equipment to

physically initiate the movement
- Facilitation using incentive and
verbal prompting to self-initiate

- Other

**Induced
Movement
Therapy**

- No induced movement
- Induced movement

IMT
Fixated with a vest/diaper
- hold away

▪ new

Appendix XVII : Adapted observational tool that was discussed and adapted during the second round of Adapted Modified nominal consensus group techniques

Category	Subcategory	Modifier	Example
Position/transition (Motor behaviour/ motor activity Leading to a functional activity or participation in a life situation	LYING	Supine Prone Side	
	SITTING	Side sitting High sitting Long sitting/semi-long sitting Sandwich sitting on the floor or on a bench Other varieties of sitting	
	STANDING	Single leg stance Walk stance Bear stance Upperlimb support stance Sandwich standing Other varieties of standing	
	KNEELING	½ kneeling 2 point kneeling 4 point kneeling	
	LOCOMOTION/MOBILITY	Being carried by carer with biomechanical alignment imposed Rolling Crawling Creeping Cruising Walking Transition from one base of support to a new base of support	i.e long leg sit to quadropod through side sitting Transition within BOS/weight shift

Category	Subcategory	Modifier	Example
Context of functional activity/task for participation in life situation desk (CONTEXT ACCORDING TO ICF)	PARTICIPATING IN COMMUNITY, SOCIAL AND CIVIL LIFE	-Child is engaged (the child is “with me” and have eye contact) -Action is “done to” the child (no communication)	-play with toy -do age related task at a
	PARTICIPATING IN LEISURE ACTIVITY	-Child is engaged -Action is “done to”	
	MOBILITY IN THE COMMUNITY	-Child is engaged -Action is “done to”	-i.e. being carried, transfer in and out of a car/wheelchair, walking
	SELF CARE/GROOMING	-Child is engaged -Action is “done to”	-changing diapers/ toilet transfers/dressing/ hygiene
undressing/personal			

Category	Subcategory	Modifier	Example
Hands-on techniques leading to functional activities and participation in life situations (SANDTA change quality of tone and patterns of muscle activation using minimalistic tools(i.e. hands) to bring about meaningful function. and knees in external standing	PREPARATORY ACTIONS	Mobilization techniques: -Soft tissue release - Mobilization of specific joints for better alignment - Therapist moves child/limb through small or large movement through different planes and way until a change of quality in	
	FACILITATION TECHNIQUES	- Manual Biomechanical alignment of limb/limbs to optimise the agonist and antagonist interaction - handling that promotes active weightshifting over a BOS/into a new BOS/within BOS - Manual directional	i.e supporting the hips of a diplegic manually rotation and ext in i.e placing of a hand for support in side sitting and maintaining the elbow in weight bearing position i.e. applying pressure in diagonal handling to activate muscles through the shoulder joint towards opposite hip to activate abdominals
	PROPRIOCEPTIVE TECHNIQUES	- For proprioceptive input directly to the body i.e tapping with hand on specific muscles in sweeping motion or through a joint - Proprioceptive input via a piece of equipment tapping through a stick held in extended arms done in an intermitted manner or tapping on a ball while child is holding on.	
	PASSIVE SENSORY MOTOR EXPERIENCE	- When you are giving the child a sensation of what the motion feels like(sensory experience) so that they can take over an make it part of their active motor experience. i.e rolling the child passively to experience the mvt	

	-Sensory input (i.e. vestibular/visual/tactile input) to improve body awareness and produce motoractivity	
SELF-PRODUCED MOTOR BEHAVIOUR for an activity or a component of an activity with guidance from PT/CG during the activity	- Little variation - Large variation	-PT will correct a limb position by placing the child's hand while crawling -PT will correct more than one limb during a sequence of movement i.e whilst crawling placing a hand and a foot in a hemi - This usually follows a facilitation technique therefor after a limb is placed in a weight bearing position a self-produced movement is encouraged by placing a toy at a distance for child to retrieve
CAREGIVER COACHING		Teaching handling techniques for handover and use of equipment to carers through demonstration and observing and giving efforts
NOT SPECIFIED NEUROMOTOR ACTION		

Category	Subcategory	Modifier	Example
Hands-off techniques leading to functional activities and participation in life situations toy in of	SELF-PRODUCED MOTOR BEHAVIOR no guidance from PT/CG and child is allowed to continue with activity	-Little variation (one toy is placed on one level) -Large variation (multiple toys are placed on multiple levels)	This is accomplished through manipulation/adaptation of the environment i.e. presenting/placing a different position to produce a variety of movements Through repetition strengthening occurs
	SELF-PRODUCED MOTOR BEHAVIOR With guidance during the activity in order to explore alternatives for achieving success	-verbal prompting - visual prompting	
	REPETITION OF A SUCCESSFUL ACTIVITY	-verbal prompting	

ALLOWED AND ENCOURAGED

-Strengthening occurs
- i.e child is successful in rolling a ball back to PT in prone and PT allow the activity to continue Repeated times

Category	Subcategory	Modifier	Example
Communication	INFORMATION EXCHANGE	-bidirectional -unidirectional - open dialogue	not any info ax related
	INSTRUCT THE CHILD/INFANT/CG	-Instruction about multiple ways to achieve best performance - PT gives hints,provide a suggestion /clue (indirect) - Giving non-verbal cues i.e.visual input	This is when there is only information given without a direct going over into motor activity
	RESPONDING /ADOPTING THE CHILD'S EMOTIONAL/PSYCHOLOGICAL/SOCIAL/BEHAVIOURAL NEEDS PROVIDE VERBAL FEEDBACK TO THE CHILD OR CG EDUCATIONAL INFORMATION		PT Explaining motor function PT explaining child's condition PT explains their role to play PT explains need to explore communication and child parent interaction PT explains handling, typical movement and development PT explains family related issues:raising, coping
	NON SPECIFIED COMMUNICATION		

Appendix XVIII: Adapted observational tool that was e-mailed to the panel for final feedback

Category	Subcategory	Modifier	Example
<u>SECTION 1</u>			
Position/change of position of child during session	LYING	Supine Prone Side	Score the position that the child predominantly lie in i.e. if the child is lying in a position that is in between supine or prone then see if they are more than 45 degrees Inclined towards the one or the other.
	SITTING	Sidesitting High sitting Long sitting/ 1/2long sitting	
		Other varieties of sitting	½ long sitting is the position when the one leg is bent and the other straight and can be on a bench or on the floor
	STANDING	Single leg stance Walk stance Bear stance Upper limb support stance Other varieties of standing	
	KNEELING	½ kneeling 2 point kneeling 4 point kneeling	
	LOCOMOTION/MOBILITY	Being carried Rolling Crawling	This is not just when the child is held but when they are being moved through space
		Cruising Walking Transition from one base of support to a new base of support	Classed as crawling when the action is predominantly seen as crawling, therefor at least three limbs are on the floor and that the child is on their hands and knees sit to stand i.e. long leg sit to quadropod through side sitting

SECTION 2

Context of functional activity/task for participation in life situation

HOME RELATED ACTIVITIES

Child is engaged/active participant
(the child is “with me” and have eye contact,
allows the therapeutic activity)

washing the dishes
make a sandwich
sweeping of the floor

Child is passive recipient
(Action is “done to” the child/ (no communication)

PARTICIPATING IN LEISURE ACTIVITY

- Child is engaged/active participant
- Child is passive recipient

Play
socialize

MOBILITY IN THE COMMUNITY

- Child is engaged/active participant
- Child is passive recipient

-i.e. being carried/
transferred in and out of a
car/wheelchair/walking

SELFCARE/GROOMING

- Child is engaged/active participant
- Child is passive recipient

toileting/feeding/
changing diapers/
toilet transfers/dressing/
undressing/personal hygiene

OTHER/UNSPECIFIED

e.g. massage/preparation/
teach the dystonic child to “
let go”

Category	Subcategory	Modifier	Example
HANDS-ON TECHNIQUES	A PREPARATORY ACTIONS	Mobilization techniques:	
		A1 Soft tissue release	e.g. massage
		A2 Mobilization of specific joints	
		A3 Therapist moves child/limb through small or large range of movement through different planes and directions in a repetitive way until a change of quality in muscle activity is seen	e.g. hoovering and other loosening techniques
		A4 Preparation for a diskynetic child providing stability and security that allows them to “let go of their strategies of movement” (activate their core)	e.g. Doing random movements with the limbs to eliminate anticipation - Sitting behind the child with full support and waiting for them to “let go” of their limbs
		A5 Sensory input (i.e. vestibular/visual/tactile input) to improve body awareness and produce motor activity	e.g. massage of the hemi-side - bouncing a child on a ball - rolling a child over a roller
	B FACILITATION TECHNIQUES	B1 Manual Biomechanical alignment of limb/limbs to optimise the agonist and antagonist interaction	i.e. supporting the hips and knees of a diplegic manually in external rotation and ext in standing
		B2 handling that promotes active weight shifting over a BOS/into a new BOS/within BOS	i.e. placing of a hand for support in side sitting and maintaining the elbow in weight bearing position
		B3 Manual directional handling to activate appropriate muscles /change synergies of coordination/ change motor activity	i.e. applying pressure in diagonal through the shoulder joint towards opposite hip to activate abdominals
	C PROPRIOCEPTIVE TECHNIQUES	C1 For proprioceptive input directly to the body	i.e. tapping with hand on specific

		muscles in sweeping motion or through a joint whilst that joint is weight bearing
	C2 Proprioceptive input via a piece of equipment	tapping through a stick held in extended arms done in an intermitted manner or tapping on a ball while child is holding on.
D SELF-PRODUCED MOTOR BEHAVIOUR with guidance from PT/CG during an activity or a component of an activity	D1 Little variation D2 Large variation	e.g. PT will correct a limb position: by placing the child's hand while crawling -PT will correct more than one limb during a sequence of movement i.e. placing a hand and a foot in a hemi whilst crawling This usually follows a facilitation technique: after a limb is placed in a weight bearing position a self-produced movement is encouraged by placing a toy at a distance for child to retrieve i.e. rolling the child passively to experience the mvt
E PASSIVE EXPERIENCE OF MOVEMENT	When you are giving the child a sensation of what the motion feels like (sensory experience)	
F CAREGIVER COACHING		Teaching handling techniques /facilitation techniques/use of equipment/for handover to carers through hand over hand demonstration, observing and giving feedback
G NONE SPECIFIED HANDS-ON TECHNIQUES		

Category	Subcategory	Modifier	Example
Hands-off techniques	H SELF-PRODUCED MOTOR BEHAVIOR no guidance by PT/CG and child is allowed to continue with activity	H1 Little variation (one toy is placed on one level) H2 Large variation (multiple toys are placed on multiple levels)	This is accomplished through manipulation/adaptation of the environment i.e. presenting/placing a toy in different position to produce a variety of movement pattern.
	I SELF-PRODUCED MOTOR BEHAVIOR With guidance during the activity in order to explore alternatives	I1 verbal prompting I2 visual prompting I3 auditory prompting	e.g. Child initiates an activity like walking and once they start walking he goes up onto his toes after which the therapist will tell him to walk with his heels down.
	J REPETITION OF A SUCCESSFUL ACTIVITY ALLOWED AND ENCOURAGED	J1 verbal prompting J2 visual prompting	- i.e child is successful in rolling a ball back to PT in prone and PT allow the activity to continue Repeated times Motor learning occurs Strengthening occurs Reprogramming of pathways may occur

Category	Subcategory	Modifier	Example
Communication	K INSTRUCT THE CHILD/INFANT/CG	K1 Instruction about multiple ways to achieve best performance	This is when there is only information given without a direct going over into motor activity; this is to differentiate from I and J. So either communication or a hands-on or hands off techniques occur they can't occur simultaneously
		K2 PT gives hints, provide a suggestion /clue (indirect)	
		K3 Giving non-verbal cues i.e. Visual input	
	L RESPONDING /ADOPTING THE CHILD'S		Consoling a child when they start

EMOTIONAL/PSYCHOLOGICAL/SOCIAL
/BEHAVIOURAL NEEDS

crying or finding out why they don't
want to continue with an activity

M PROVIDE VERBAL FEEDBACK TO THE CHILD OR CG

N EDUCATIONAL INFORMATION a

PT explaining motor function
PT explaining child's condition

PT explains their role to play
PT explains need to explore
communication and child parent
interaction
PT explains handling, typical movement
and development
PT explains family related
issues: raising, coping

O NON SPECIFIED COMMUNICATION

Appendix XIX : Final version of the adapted observational protocol that was used in the pilot study

SECTION	CATEGORY	SUBCATEGORY WITH MODIFIER	EXAMPLE
SECTION 1 POSITION/CHANGE OF POSITION OF CHILD DURING SESSION	LYING	Supine Prone Side	- Score the position in which the child predominantly lies i.e. if the child is lying in a position that is in between supine or prone then see if they are more than 45 degrees inclined towards the one or the other
	SITTING	Side sitting High sitting Long sitting/ ½ long sitting Other varieties of sitting	- ½ long sitting is the position when the one leg is bent and the other straight and can be on a bench or on the floor
	STANDING	Single leg stance Walk stance Bear stance Upper limb support stance Other varieties of standing	
	KNEELING	½ kneeling 2 point kneeling 4 point kneeling	
	LOCOMOTION/MOBILITY	Being carried Rolling Crawling Cruising Walking Transition from one base of support to a new base of support	- This is not just when the child is held but when they are being moved through space - Classed as crawling when the action is predominantly seen as crawling, therefor at least three limbs are on the floor and that the child is on their hands and knees. - sit to stand - long leg sit to quadropod position through side sitting

SECTION	CATEGORY	SUBCATEGORY WITH MODIFIER	EXAMPLE
SECTION 2 CONTEXT OF FUNCTIONAL ACTIVITY/TASK FOR PARTICIPATION IN LIFE SITUATION	HOME RELATED ACTIVITIES	- Child is engaged/active participant (the child is "with me" and have eye contact, allows the therapeutic activity) - Child is passive recipient (Action is "done to" the child/ no communication)	- washing the dishes - make a sandwich - do sweeping
	PARTICIPATING IN LEISURE ACTIVITY	- Child is engaged/active participant - Child is passive recipient	- Play, socialize
	MOBILITY IN THE COMMUNITY	- Child is engaged/active participant - Child is passive recipient	- being carried/ transferred in and out of a car/wheelchair/walking
	SELFCARE/GROOMING	- Child is engaged/active participant - Child is passive recipient	- toileting/feeding/changing diapers/toilet transfers/dressing/undressing/personal hygiene
	NO SPESIFIC FUNCTIONAL ACTIVITY OR TASK IDENTIFIED		- massage/preparation/teach the dystonic child to "let go"

SECTION	CATEGORY	SUBCATEGORY WITH MODIFIERS	EXAMPLE This list is not exhaustive but gives some ideas about what might be included.
SECTION3 THERAPIST INTERACTION SUBSECTION A HANDS-ON TECHNIQUES	A PREPARATORY ACTIONS	A1 Soft tissue release A2 Mobilization of specific joints A3 Therapist moves child's limb or limbs through small or large range of movement through different planes and directions in a repetitive way until a change of quality in muscle activity is observed A4 Prolonged and sustained handling that enables the child to "let go of their atypical strategies of movement " A5 Sensory input (i.e. vestibular/visual/tactile input) to improve body awareness and produce motor activity	- massage/myofascial release - OMT and other modalities - hovering and other rhythmical loosening techniques of for instance the pelvis - PT moves the child's limbs passively to swipe a ball - PT does random movements with the limbs to eliminate anticipation. - PT provides stability and security that enables the child to "let go" e.g. PT holds the child's head in sitting so that child's hands can relax next to the side of the body. - PT sit behind the child with full support and waits for the child to "let go" of their limbs - PT massages the hemi-side - PT bounces a child on a ball - PT rolls a child over a roller - This differs from E in the sense that the child's whole body moves through space and the different body parts stays relatively static in relation to each other. - PT rubs child's hand on another body part in order to open up the child's hand.
	B FACILITATION TECHNIQUES	B1 Manual Biomechanical alignment of limb/limbs to optimise the agonist and antagonist interaction	- PT supports the hips and knees of a diplegic manually in external rotation and extension in standing. - PT places the child's hand for support in side sitting whilst maintaining the elbow in weight bearing position.

		B2 Manual directional handling by the PT to distal/peripheral body parts of the child that promotes active weight shifting over a BOS/into a new BOS B3 Manual directional handling to proximal body parts of the child to activate appropriate muscles /change synergies of coordination/ change motor activity	- Therefor handling is relatively static in relation to the child's body and attempts to optimises static balance and postural control. - PT's handling is directional and produces very definite movement in relation to BOS. - PT is applying pressure in a diagonal through the shoulder joint towards opposite hip to activate abdominals - PT places her hands over lower ribcage and brings the lower ribcage down towards and over the pelvis to mobilize intercostal muscles in order to activate abdominals.
	C PROPRIOCEPTIVE TECHNIQUES	C1 For proprioceptive input directly to the body C2 Proprioceptive input via a piece of equipment	- pressure tapping with hand on specific muscles in sweeping motion or through a joint whilst that joint is weight bearing - tapping through a stick held in extended arms done in an intermitted manner or tapping on a ball while child is holding on -- A wedge/roller/ball ect. might be used to support the child. The therapists hands are therefore indirectly guiding the child and encouraging movement through manipulation of the equipment that results in proprioceptive input.

SECTION	CATEGORY	SUBCATEGORY WITH MODIFIER	EXAMPLE
	D SELF-PRODUCED MOTOR BEHAVIOUR with guidance from PT/CG at the beginning, during an activity or a component of an activity	D1 Little variation : PT will correct a limb position i.e. by placing the child's hand while crawling D2 Large variation: PT will correct more than one limb during a sequence of movement i.e. by placing a hand and a foot in a hemiplegic whilst crawling.	- This usually follows a facilitation technique: after a limb is placed in a weight bearing position a self-produced movement is encouraged by placing a toy at a distance for child to retrieve.
	E PASSIVE EXPERIENCE OF MOVEMENT	When you are giving the child a sensation of what the motion feels like (sensory experience).	- This differs from A5 in the sense that the the position of the child's different body parts changes in relation to each other. - Rolling the child passively to experience the movement - This is when the child is not taking part at all in the activity (but where it is "done" to the child)
	F CAREGIVER TRAINING	When the therapist is handing over specific handling skills to a parent or caregiver.	- Teaching handling techniques/facilitation techniques/for handover to carers through hand-over-hand demonstration, observing and giving feedback - The feedback that might spontaneously follow or coincide with the hand over hand demonstration is not the same as M (Where giving feedback is the main aim.)
	G NON-SPECIFIC HANDS-ON TECHNIQUES	The therapist is handling the child with no intention of a specific 'therapeutic' outcome.	- Putting on splints - Dressing and undressing the child if this is not done in an active activity where the child is encouraged to take part. - Therapist can support the child on the ball while they are hopping for safety precautions. - Carrying the child from one area to the Other

SECTION	CATEGORY	SUBCATEGORY AND MODIFIERS	EXAMPLE
SUBSECTION B HANDS-OFF TECHNIQUES	H SELF-PRODUCED MOTOR BEHAVIOR with no guidance from PT/CG and child is allowed to continue with activity	H1 Little variation (one toy is placed on one level) H2 Large variation (multiple toys are placed on multiple levels)	- This is accomplished through manipulation/adaptation of the environment i.e. presenting/placing a toy in different positions to produce a variety of movement pattern. - Or the therapist is asking the child to stand on a balance board and he should hit the ball with two hands.H1 the therapist only throw the ball on one plane H2 throws the ball in lots of directions and planes.
	I SELF-PRODUCED MOTOR BEHAVIOR with guidance during the activity in order to explore alternatives i.e. make corrections to biomechanical alignment	I1 verbal prompting I2 visual prompting I3 auditory prompting	- Child initiates an activity like walking and once they start walking he goes up onto his toes after which the therapist will tell him to walk with his heels down. - Or the therapist points at a the child's feet with a questioning facial expression when child is toe- walking occurs. - Or the therapist have instructed the child to stop running when he hears the whistle.
	J REPETITION OF A SUCCESSFUL ACTIVITY ALLOWED AND ENCOURAGED In order to differentiate from H and I It is important to emphasize that this is only if no corrections/guidance was needed	J1 verbal prompting J2 visual prompting	- J can only follow H and I: You therefor score either H or I with the first attempt and any successful successive sequences is J. If they child needs to be corrected it remains I. - This is repetition of an activity that was initiated in H and I and not to be confused with : completing a sequence of movements that leads to a goal e.g. crawling to a toy. - Child is successful in rolling a ball back to PT whilst in prone and PT allows the activity to continue repeatedly. - The intention is Motor-learning to occur. - The intention is strengthening through repetition. - Remodelling of motor and sensory pathways may occur.

SUBSECTION C Communication Communication is scored when there is only information exchanged without directly leading to motor activity; this is to differentiate from I and J. So either communication or a hands-on or hands-off techniques occur they can't be scored simultaneously.	K INSTRUCT THE CHILD/INFANT/CG	K1 Verbal instruction about multiple ways to achieve best performance –instructions tend to be more authoritative with limited scope for variations. K2 PT gives hints, provide a suggestion /cues (indirect) K3 Giving non-verbal cues i.e. Visual input, sign language and visual cards or home-programme is given	
	L RESPONDING /ADOPTING To THE CHILD'S EMOTIONAL/PSYCHOLOGICAL/ SOCIAL/BEHAVIOURAL NEEDS		Consoling a child when they start crying or finding out why they don't want to continue with an activity
	M PROVIDE VERBAL FEEDBACK TO THE CHILD OR CG		After a session the PT tells the child or CG what went well during the session and what can improve.
	N EDUCATIONAL INFORMATION EXCHANGE		PT explaining motor function PT explaining child's condition PT explains their role to play PT explains need to explore communication and child parent interaction PT explains handling, typical movement and development PT explores family related issues: raising, coping PT reads the file or attains other information from the child or caregiver to identify problems and determine goals
	O NON SPECIFIC COMMUNICATION	Communication not related to the therapeutic outcome might be for social reasons.	PT is talking to someone who comes into the room. Talks to a parent about what happened in the rugby over the weekend ect

	P NON-SPECIFIC HANDS-OFF ACTIVITIES	Handling not related to the therapeutic outcome might be for practical reasons.	- Fetching a toy/ball - Adapting the environment/preparing a work surface - Putting on splints - Moving with the child from one area/piece of equipment to the other
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Appendix XX : Information sheet and consent for the piloting of the adapted Observation Protocol

CONSENT FOR PILOT STUDY

RESEARCH

Evaluation and adaptation of an observation tool to quantify and define physical therapy done on a child with CP in the South African context.

THERAPIST INFORMATION SHEET FOR PILOT STUDY

My name is Lindie Dalton and I am a physiotherapist completing a postgraduate degree at the University of the Witwatersrand. I am investigating a tool that might help to quantify and define physical therapy activities for children with CP. This is phase three of the study where the adapted Observation Protocol will be piloted. During this phase inter-and intra-rater reliability will be investigated.

In the previous phases the original Observation Protocol as developed in the Netherlands has been evaluated and adapted with the help of a panel of experts to better suit the South African paediatric neurology rehabilitation context.

I would like to invite you to take part in this study. Before you agree to take part, it is important for you to understand what the study is about, what it involves and to ask me any questions you may have.

If you agree to participate you will need to evaluate five videos of 20 minutes each, during two rounds, two weeks apart.

You will also be required to fill in a questionnaire afterwards.

All data acquired cannot be kept confidential or private but your name will not be used in any written documents. All data will be stored in a safe place and will be destroyed six years or after publication of the study according to HPCSA regulations, after the results have been written.

Participation is voluntary and if you do decide to join the pilot study, and you change your mind, you can leave at any time without any consequences to yourself.

Feedback on the study will be available on request.

If you have any questions, please feel free to contact me at 0799358163. Any queries or concerns about ethics can be discussed with the Chairman of the Ethics Committee at the University of the Witwatersrand, Prof P Cleaton-Jones who can be contacted at 011 7171234.

If you agree to take part in this study, please sign the forms attached.

Lindie Dalton
Physiotherapist

RESEARCH

Evaluation and adaptation of an observation tool to quantify and define physical therapy done on a child with CP in the South African context.

THERAPIST

WRITTEN INFORMED CONSENT FORM

I,

_____,
confirm that I have been told about the research in a language that I understand. I have also received, read and understood the written information regarding the study.

I am aware that any information I give to the researcher cannot be kept private and will be anonymously processed.

I understand that at any stage, I may take myself out of the study. I understand that if I decide not to take part, or I change my mind, there will be no consequences for me. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily.

I agree that I will volunteer to take part in this study.

Therapist's name: _____ (please print)

Therapist's signature: _____

Date: _____

Appendix XXI : Feedback Sheet for Study Participants during the Final Stage of the Study

FEEDBACK AND COMMENTS REGARDING THE PILOT IMPLEMENTATION OF THE ADAPTED OBSERVATION PROTOCOL

Name: _____

Date: _____

1. Did you find this adapted Observation Protocol user friendly when analysing the treatment of the therapist? Please explain your answer.

3. What did you find most useful and least useful in the implementation of this adapted Observation Protocol?

4. Did you find that any of the Items in the adapted Observation Protocol were not adequately explained with examples ? Please elaborate which ones.

5. Did you find that any of the items were not mutually exclusive and could be misinterpreted by another ? Please state which ones.

6. Are there any treatment modalities that occurred in one of the treatment sessions that you feel could not adequately be described by the adapted Observation Protocol? What treatment modality was this and how would you describe it?

7. Did you find that adapted Observation Protocol could adequately describe the treatment of a child of :

<u>GMFCS level 1</u>	<u>(VIDEO 1)</u>	YES/NO
<u>GMFCS level2</u>	<u>(VIDEO 2)</u>	YES/NO
<u>GMFCS level 3</u>	<u>(VIDEO 3)</u>	YES/NO
<u>GMFCS level 4</u>	<u>(VIDEO 4)</u>	YES/NO
<u>GMFCS level 5</u>	<u>(VIDEO 5)</u>	YES/NO

8. Did you find the software Cowlog user friendly? Please explain your answer.

Any other comments or suggestions:

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Appendix XXII : AOP with suggested recommendations following Phase 3

SECTION	CATEGORY	SUBCATEGORY WITH MODIFIERS	EXAMPLE
SECTION 1 POSITION/CHANGE OF POSITION OF CHILD DURING SESSION	LYING	Supine Prone Side	- Score the position in which the child predominantly lies i.e. if the child is lying in a position that is in between supine or prone then see if they are more than 45 degrees inclined towards the one or the other
	SITTING	Side sitting High sitting Long sitting/ ½ long sitting Other varieties of sitting	- ½ long sitting is the position when the one leg is bent and the other straight and can be on a bench or on the floor
	STANDING	Normal/Biomechanical alignment standing Single leg stance Walk stance Bear stance Upper limb support stance Other varieties of standing	
	KNEELING	½ kneeling 2 point kneeling 4 point kneeling Other varieties of kneeling	
	LOCOMOTION/MOBILITY	Being carried Rolling Crawling Cruising Walking Transition from one base of support to a new base of support Climbing stairs Other varieties of Mobility	- This is not just when the child is held but when they are being moved through space - Classed as crawling when the action is predominantly seen as crawling, therefore at least three limbs are on the floor and that the child is on their hands and knees - sit to stand - long leg sit to quadropod position through side sitting

SECTION	CATEGORY	SUBCATEGORY WITH MODIFIERS	EXAMPLE
SECTION 2 CONTEXT OF FUNCTIONAL ACTIVITY/TASK PARTICIPATION IN LIFE SITUATION	HOME RELATED ACTIVITIES	- Child is engaged/active participant (the child is "with me" and have eye contact, allows the therapeutic activity) - Child is passive recipient (Action is "done to" the child/ no communication)	- washing the dishes - make a sandwich - do sweeping
	PARTICIPATING IN LEISURE ACTIVITY	- Child is engaged/active participant - Child is passive recipient	- Play, socialize
	MOBILITY IN THE COMMUNITY	- Child is engaged/active participant - Child is passive recipient	- being carried/ transferred in and out of a car/wheelchair/walking
	SELFCARE/GROOMING	- Child is engaged/active participant - Child is passive recipient	- toileting/feeding/changing diapers/toilet transfers/dressing/undressing/personal hygiene
	NO SPESIFIC FUNCTIONAL ACTIVITY OR TASK IDENTIFIED		- massage/preparation/teach the dystonic child to "let go"
SECTION	CATEGORY	SUBCATEGORY WITH MODIFIERS	EXAMPLE
SECTION3 THERAPIST INTERACTION SUBSECTION A HANDS-ON TECHNIQUES	A PREPARATORY ACTIONS	A1 Soft tissue release	- massage/myofascial release
		A2 Mobilization of specific joints A3 Therapist moves child's limb/ limbs or whole body through small or large range of movement through different planes and directions in a repetitive way until a change of quality in muscle activity is observed or allows child to relax and maybe bring their weight forwards or backwards	- OMT and other modalities - Mobilization of costo-vertebral joints - hoovering and other rhythmical loosening techniques of for instance the pelvis - PT does random movements with the limbs to eliminate anticipation. - Therapist might have close contact between her body and that of pt so that the movement of her body translate into child's i.e. moving rhythmically over the base of support this differs from A5 (where the whole child is rocked to experience the

		A4 Prolonged and sustained handling that enables the child to "let go of their atypical strategies of movement " no movement is induced by the therapist but the child might throw themselves back into space and the therapist have to "wait " by fully supporting the child's weight in the abnormal posture before the child can initiate a better movement pattern once the old strategies have been "let go off". Once the "holding" of the therapist goes over into child initiated movement then it is scored as D. However it remains A4 if the child only "let's go" by allowing the therapist to bring them back to midline but doesn't actively take part. A5 Sensory input (i.e. vestibular/visual/tactile input) to improve body awareness and produce motor activity	movement) - PT provides stability and security that enables the child to "let go" e.g. PT holds the child's head in sitting so that child's hands can relax next to the side of the body. - PT sit behind the child with full support and waits for the child to "let go" of their limbs - Might maintain asymmetrical sitting position to decrease the child's symmetrical pattern of pushing back - Stretching of hamstrings by maintaining the leg in extension with support on the knee and heel - This includes situations when child pushes back completely and PT allows him to remain there with full support until child initiates coming back to midline. - Maintain full support of rest of the body while letting one limb go to be more active - PT massages the hemi-side - PT bounces a child on a ball - PT rolls a child over a roller - This differs from E in the sense that the child's whole body moves through space and the different body parts stays relatively static in relation to each other. - PT rubs child's hand on another body part in order to open up the child's hand. - Rhythmically moving child through space i.e rocking - Bringing the child back in space so that he can experience reclining back in space e.g. in sitting
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	B FACILITATION TECHNIQUES The focus is here more on sustained support from therapist to really enable the movements	B1 Manual Biomechanical alignment of limb/limbs to optimise the agonist and antagonist interaction and might happen in weight bearing position B2 Manual directional handling by the PT to distal/peripheral body parts of the child that promotes active weight shifting over a BOS/into a new BOS These refer to a knee, elbow, hand or foot B3 Manual directional handling by the PT to proximal body parts of the child that produce active weight shifting over a BOS/into a new BOS. These refer to the head, shoulder , abdominals and pelvis B4 Manual directional handling to proximal body parts of the child to activate appropriate muscles /change synergies of coordination/ change motor activity or This differs from A4 where the end result is muscle activation and A4 is the end result where the child is letting go of the unwanted or excessive movements and relaxing under the therapist's hands. B5 where PT positions one hand proximal and one distal	- PT supports the hips and knees of a diplegic manually in external rotation and extension in standing. - PT places the child's hand for support in side sitting whilst maintaining the elbow in weight bearing position. - Therefore handling is relatively static in relation to the child's body and attempts to optimises static balance and postural control. - Therapist corrects the child's symmetry of LL and UL to allow them to maintain their head in midline - PT's handling is directional and produces very definite movement in relation to BOS. i.e go from prone through side sitting into high sitting on a bench with knee as key point - PT is applying pressure in a diagonal through the shoulder joint towards opposite hip to activate abdominals - PT places her hands over lower ribcage and brings the lower ribcage down towards and over the pelvis to mobilize intercostal muscles in order to activate abdominals. - Differs from A4 This is to support to one or more proximal areas in order to produce activity.
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	C PROPRIOCEPTIVE TECHNIQUES	C1 For proprioceptive input directly to the body to improve muscle activation and co-contraction C2 Proprioceptive input via a piece of equipment that is applied directly by the therapists hands that is indirectly in contact with the child	- pressure tapping with hand on specific muscles in sweeping motion or through a joint whilst that joint is weight bearing - wiping mouth in the direction of the lips in order to close the mouth - This might include approximation of joints or tapping on the tummy to improve core-activation - tapping through a stick held in extended arms done in an intermitted manner or tapping on a ball while child is holding on - A wedge/roller/ball ect. might be used to support the child. The therapists hands are therefore indirectly guiding the child and encouraging movement through manipulation of the equipment that results in proprioceptive input.
SECTION	CATEGORY	SUBCATEGORY AND MODIFIERS	EXAMPLE
	D SELF-PRODUCED MOTOR BEHAVIOUR with manual/physical guidance from PT/CG at the beginning, during an activity or a component of an activity Focus is here on self-produced activity with occasional facilitation to improve function for higher level functioning children This is different from when pt initiate and therapist only keep her hands on pt to prevent from falling as there is no directionality or correction for better function or quality of movement	D1 Little variation : PT will correct a limb position i.e. by placing the child's hand while crawling or might include tapping on the hand that the therapist want the child to move Might mean restraining a hand (preventing it from taking part in an activity by physically holding it) D2 Large variation: PT will correct more than one limb during a sequence of movement i.e. by placing a hand <u>and</u> a foot in a hemiplegic whilst crawling. Restraining a hand and foot to move	- This usually follows a facilitation technique: after a limb is placed in a weight bearing position a self-produced movement is encouraged by placing a toy at a distance for child to retrieve - The child's foot is placed (lifted up on to wheelchair step after they have attempted to do so) and kept in place in order for the child to push themselves back on the wheelchair. - If the child is starting to roll over by reaching for a toy and the therapist brings their hip slightly forward but waits for them to complete the roll it is D1 if the PT rolls the child over without waiting for initiation or completion it is E. - Therapist might be holding the rest of the child's body and then facilitate the child to move his head from left to right by turning

			a book from side to side. Active movement of one part of the body induced with variation
	E PASSIVE EXPERIENCE OF MOVEMENT	When you are giving the child a sensation of what the motion feels like (sensory experience).	- This differs from A5 in the sense that the the position of the child's different body parts changes in relation to each other. - Rolling the child passively to experience the movement - This is when the child is not taking part at all in the activity (but where it is "done" to the child) - Hand over hand facilitation of arm movement holding a cloth to wipe your face or to pick up a cup, the extremity is guided by the therapist to experience the movement - hand over hand facilitation to guide the child's hand to place a toy in the box
	F CAREGIVER TRAINING	When the therapist is handing over specific handling skills to a parent or caregiver. This differs from other hands-on activities in the way that there is clear interaction with caregiver. But the therapist's hands is either directly or indirectly on the child (i.e the therapists hands are on the CG's hands to direct them). Even if the PT is training the CG how to do a non-specific hands-on techniques like putting splints on then it is still an activity that falls in this category of specific handling training. Therefor once there is interaction with the caregiver regarding handling then it is F. However once the therapist is observing if the parent is doing it correctly it is another category	- Teaching handling techniques/facilitation techniques/for handover to carers through demonstration, observing and giving feedback might include hand-over-hand facilitation. - The feedback that might spontaneously follow or coincide with the hand over hand demonstration is not the same as M (Where giving feedback is the main aim.)
	G NON-SPECIFIC HANDS-ON TECHNIQUES	The therapist is handling the child with no intention of a specific 'therapeutic' outcome. Can only support the child i.e in walking and sitting so to prevent them from falling over.	- Putting on splints - Dressing and undressing the child if this is not done in an active activity where the child is encouraged to take part. - Therapist can support the child on the Ball while they are hopping, for safety precautions. - Carrying the child from one area to

			the other. - where the therapist is taking full support of the child's body weight to aid in transfers i.e. therapist is placing the child where the child is a passive recipient of transfer. - When the therapist is offering her hand for child to walk this is classed in this category as it is not therapeutic. - When placing the child in piece of equipment with hands still on the child.
SECTION	CATEGORY	SUBCATEGORY WITH MODIFIERS	EXAMPLE
SUBSECTION B HANDS-OFF TECHNIQUES	H SELF-PRODUCED MOTOR BEHAVIOR with no guidance from PT/CG and child is allowed to continue with activity This is a completely child initiated activity i.e child lead	H1 Little variation (one toy is placed on one level) Wedge is placed on one side of child's trunk to support H2 Large variation (multiple toys are placed on multiple levels) Two wedges or more is placed to support child in multiple levels but therapist is no longer holding on to the wedges.	- This is accomplished through manipulation/adaptation of the environment i.e. presenting/placing a toy in different positions to produce a variety of movement pattern. The environment is set-up prior to the child arriving allowing them to choose an activity and initiate and adapt it themselves.
	I SELF-PRODUCED MOTOR BEHAVIOR with non-manual/physical guidance at the beginning or during the activity in order to explore alternatives i.e. make corrections to biomechanical alignment	I1 verbal prompting - talk to patient I2 visual prompting- show pt how to do it I3 auditory prompting- patient must walk to the beat of the drum or stop when the music stops ect If more than one occurs then visual prompting is scored only to standardise implementation and as this is an observational protocol it was decided to give preference to visual prompting.	- Child initiates an activity like walking and once they start walking he goes up onto his toes after which the therapist will tell him to walk with his heels down. - Throw the ball at the child the approaching ball is an interference from the therapist - The therapist instructs the child to walk on a line by demonstrating how to do it in order for the child to follow suit. If the therapist tells the patient to walk to the end of the corridor by instructing him to complete the activity it is scored differently than when the child is asked to walk from the chair to the door and then asked to repeat it 5 times (then scored as J). - Or the therapist points at a the child's feet with a questioning facial expression when child is toe- walking occurs. - Or the therapist have instructed the child to

			stop running when he hears the whistle. This might follow an initial verbal instruction by a therapist
	J REPETITION OF A SUCCESSFUL ACTIVITY ALLOWED AND ENCOURAGED In order to differentiate from H and I it is important to emphasize that this is only if no corrections/interference was needed, therefore typically for higher functioning kids where specific strengthening exercises is done i.e quads strengthening through knee extension. Is scored after the second repetition without correction otherwise if the activity is corrected in any way by therapist it remains either I or H	J1 verbal prompting J2 visual prompting	- J can only follow H and I: You therefor score either H or I with the first attempt and any successful successive sequences is J. If they child needs to be corrected it remains I. - This is repetition of an activity that was initiated in H and I and not to be confused with : completing a sequence of movements that leads to a goal e.g. crawling to a toy. - Child is successful in rolling a ball back to PT whilst in prone and PT allows the activity to continue repeatedly. - The intention is Motor-learning to occur. - The intention is strengthening through repetition. - Remodelling of motor and sensory pathways may occur.
SUBSECTION C Communication Communication is scored when there is only information exchanged without directly leading to motor activity; this is to differentiate from I and J. So either communication or a hands-on or hands-off techniques occur they can't be scored simultaneously. Hands-on and hands-off activities related to the child, takes priority over	K INSTRUCT THE CHILD/INFANT/CG might be ways to address physical impairments, activity limitations and participation restrictions. If communication coincides with non-specific hands on or non-specific hands-off activities the communication takes president as this is mostly the reason why a therapist will multi-task where they might talk whilst doing another activity that does not involve too much concentration. Like unpacking the pencils while talking to the mum.	K1 Verbal instruction about alternative ways to achieve best performance –instructions tend to be more authoritative with limited scope for variations instructions to follow at home K2 PT gives hints, provide a suggestion /cues (indirect) “maybe you can try and get him to stand up if you hold the toy higher up?” K3 Giving non-verbal instruction i.e. Visual input, sign language and visual cards or home-programme is given, point to the object often occurs when the same language is not used. This is applicable when the child is of a lower functional level and the therapist instructs the child non-verbally or verbally and no motor activity follows from child’s side. Therefor after the instruction was given or after the therapist told the child what is going to happen e.g “we are going to sit on the ball” which is followed by the therapist placing the child on the ball.	- K1 e.g Instructing caregiver how to put splints on but therapist is not handling the child herself only parent - Activity can be classed as instructions if they have given instructions but no motor activity followed from child’s side however when the CG or parent is doing an activity with the child and the PT is giving instructions only (no hands on child or parents) then K is applicable when the PT instructs the parent. - For instance: “ when you go home I want you to sit in the side of the bed when you put your jacket on instead of on your wheelchair” or when you get out of your wheelchair in class I always want you to first put your breaks on.

communication categories. i.e if the therapist is talking in soft tone to child with dyskinesia while fully supporting child. In order for the child to let go of the predominant pattern of movement then a hands-on activity is scored. Communication is then not scored as it forms part of the hands-on activity Any of these subcategories can happen with the help of an interpreter	It is assumed that if the therapist looks at the child they are communicating to the child therefore if they are looking at the child whilst communicating and only supporting the child then it is a nonspecific hands-on technique and therefore the communication takes president where after the appropriate category should be selected under communication.	Where verbal and non-verbal is combined the non-verbal takes president for conformity.	
	L RESPONDING /ADOPTING To THE CHILD'S EMOTIONAL/PSYCHOLOGICAL/ SOCIAL/BEHAVIOURAL NEEDS	Any interaction that builds relationship between therapist and child for improved rapport and function -can happen in the form of turn taking	-Consoling a child when they start crying or finding out why they don't want to continue with an activity -Giving praise encouraging PT communicates to the child if they want more of an activity to encourages choice making and turn taking Responding to child's requests
	M PROVIDE VERBAL FEEDBACK TO THE CHILD OR CG	Communication regarding outcomes not the same as when clear instructions is given.	After a session or an activity the PT tells the child or CG what went well during the session and what can improve.
	N EDUCATIONAL INFORMATION EXCHANGE		PT explaining motor function PT explaining child's condition PT explains their role to play PT explains need to explore communication and child parent interaction PT explains handling, typical movement and development PT explores family related issues: raising,

			coping might include questioning and listening to parents input - PT reads the file or attains other information from the child or caregiver to identify problems and determine goals
	O NON-SPECIFIC COMMUNICATION	Communication not related to the therapeutic outcome might be for social reasons.	- PT is talking to someone who comes into the room. - Talks to a parent about what happened in the rugby over the weekend ect.
	P NON-SPECIFIC HANDS-OFF ACTIVITIES (This should in future be moved up and be classed as K for better readability)	Handling not related to the therapeutic outcome might be for practical reasons.	- Fetching a toy/ball - Adapting the environment/preparing a work surface - Moving with the child from one area/piece of equipment to the other i.e pushing the child whilst in chair or adapting equipment without being in contact with the child, adapting the equipment around the child. - Taking photo or video - Observing child's gait or a specific outcome measure
	Q Observation	Where the therapist is only observing to either evaluate how the child or caregiver is executing the activity and not responding either verbally or physically.	- Might observe/eye-balling the child once they are placed in the piece of equipment with making any adjustments or touching the child or producing any activity by adapting the environment. - Gait/posture analysis

Appendix XXIII : Turnitin Report

Final Document			
ORIGINALITY REPORT			
% 8	% 7	% 5	% 3
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS
PRIMARY SOURCES			
1	www.rug.nl Internet Source		% 1
2	onlinelibrary.wiley.com Internet Source		<% 1
3	Submitted to University of Witwatersrand Student Paper		<% 1
4	Submitted to Universiti Teknologi MARA Student Paper		<% 1
5	etd.uovs.ac.za Internet Source		<% 1
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Internet Source | <%1 |
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<small>Internet Source</small> | <% 1 |
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| 65 | Submitted to Indian Institute of Technology,
Madras
<small>Student Paper</small> | <% 1 |
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<small>Internet Source</small> | <% 1 |
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| 67 | Submitted to University of Stellenbosch,
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