A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY IN PUBLIC HOSPITALS OF KWAZULU-NATAL

Submitted in fulfilment of the requirement for the degree:

Masters of Physiotherapy

Faculty of Health Sciences
University of KwaZulu-Natal

2015

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SUPERVISORS PERMISSION TO SUBMIT FOR EXAMINATION

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ABSTRACT

Background: Medical advances have resulted in the survival of infants born prematurely, placing them at risk and escalating the number of children diagnosed with Cerebral Palsy (CP). CP is a permanent yet changing condition and is one of the leading childhood disabilities with many physiological, mental and secondary complications requiring therapy. Physiotherapy forms an important role in the management of children with CP. However, in KwaZulu-Natal (KZN), limited rehabilitation equipment, poor provision of assistive devices and restrictions on the employment of health care professionals places major strain on the overall management of children with CP.

Aim and Objective: To determine the physiotherapy management of children with CP in KZN public hospitals, with the objective of identifying current management practices of children with CP in urban and rural public hospitals, in order to improve the management of these children with CP.

Study Design: The study was a cross sectional survey study using a self-designed open and closed-ended questionnaire based on the aim and objectives of this study. Physiotherapists (PTs) employed at various levels of public hospitals in KZN were selected to make up the study population. A quantitative approach was utilised and the sample size of the study was 152. The data collected was systematically and thematically analysed.

Results: The response rate of the study was 72 (52.6%) of which 63 (87.5%) were female and 9 (12.5%) were male. The mean age of the participants was 32 years old. Forty one (56.9%) of the PTs worked in a rural hospital while 31 (43.1%) of the participants were employed in an urban hospital. The majority 35 (48.6%) of the respondents treated one to 10 children with CP a month. A limited number of participants 25 (34.7%) used outcome measures to evaluate their children with CP. A Likert scale was used to rate the importance of the common treatment techniques and the most important treatment techniques used by the PTs in this study were postural stabilising activities 68 (94.4%), respiratory care 67 (92.9%) and positioning 67 (92.9%). Most of the participants 32 (45.0%) reported that managing children with CP in a multidisciplinary team (MDT) resulted in a

significant difference (p=0.002) between rural and urban based PTs. The Majority of the rural based PTs 39 (95.1%) predominantly managed children with CP in a MDT, while most urban based PTs 24 (77.4%) preferred an individual approach. Twenty one (51.2%) of the rural based PTs predominantly managed children with CP on a monthly basis significantly different (p=0.001) from those 19 (61.3%) of the urban based PTs in this study who managed children with CP on a bi-monthly basis. Seventy one (98.6%) of the respondents in this study included the caregiver (CG) in their management approach. Handover management 69 (97.2%) and back care techniques 64 (90.2%) were the most important CG management approaches as rated on a Likert scale. Thirty two (44.4%) of the participants reported having insufficient skills to manage children with CP, while only 12 (16.7%) participated in CP postgraduate training. Sixty three (87.5%) of the participants reported experiencing one or more challenges whilst managing children with CP; CG complications 21 (34.1%) and a lack of resources 19 (29.7%) were the most common. Fifty eight (80.6%) of the participants provided recommendations for improving the management of children with CP in KZN. The recommended suggestions provided by 19 (33.5%) of the participants were to refine the undergraduate training curriculum and to improve the accessibility of post graduate CP training.

Conclusion: The results of this study revealed that the management of children with CP in KZN encourages a MDT approach. This study found that the majority of the rural based PTs managed children with CP in a MDT on a monthly basis reflecting differently from those urban based PTs who managed children with CP individually and on a bi-monthly basis. In this study there were many challenges expressed by the PTs regarding the management of children with CP. It would therefore seem that implementing clinical protocols, procuring assistive devices and employing additional PTs and other health care professionals is a viable option in assisting those PTs already employed in the KZN public health sector. Despite these challenges the overall management of children with CP in KZN is viewed as holistic and favourable.

Keywords: Cerebral palsy, physiotherapy management, public health KwaZulu-Natal.

DECLARATION

I, Tracey-Lee White declare that:

i. This research dissertation is my own unaided work except for the assistance provided by the persons listed under the acknowledgments.

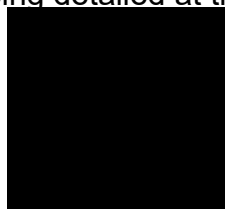
ii. The purpose for submission is for fulfilment of the requirements of the degree of Master of Science in Physiotherapy at the University of KwaZulu-Natal. This dissertation has never been submitted for any other degree purposes or examinations.

iii. In this dissertation the writing of another person's research is acknowledged and referenced appropriately. Where written sources have been quoted then:

   a) The persons whose words have been re-written in the context of the researcher's dissertation has been rightfully referenced.

   b) Where the researcher has used the particular words of the persons work within the dissertation, those words have been placed inside quotation marks and then further referenced.

iv. This dissertation does not include data, pictures, graphs and information of other people's research or that from the internet without the acknowledgement and adequate reference thereof within the reference list as well as being detailed at the source.

Signature: _____  _____

Place: University of KwaZulu-Natal

Date: 30 November 2015

ACKNOWLEDGEMENTS

The author would like to extend her sincere thanks and gratitude to all those who contributed to this project:-

- My pillar and my strength, the Lord Jesus Christ, for the wisdom and strength bestowed onto me.
- My supervisor Dr SS Maharaj for his guidance, time and patience through the duration of this study.
- Mrs Rosalind Standal my editor your on-going love for life, strength and determination despite your physical circumstances has truly amazed me.
- Mr S Singh for his assistance with the statistical analysis.
- The KwaZulu-Natal Department of Health and Health Districts for their support and permission to conduct the study.
- The KwaZulu-Natal public health physiotherapists for their compliance without whom, this study could not have been conducted.
- My working colleagues for all their support and assistance.
- My family and friends, especially Jacqui Boyd for supporting me throughout.
- To my loving parents thank you for your continuous love, support and confidence in me.
- My devoted partner, Dustin Du Plessis for your continuous encouragement and understanding of my dedication to my career, passion and love for physiotherapy. Thank you for always believing in me.

I dedicate my work to all those beautiful children with cerebral palsy I have managed.

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LIST OF OPERATIONAL DEFINITIONS OF KEY CONCEPTS

1. **Cerebral palsy-** points to a number of neurological disorders caused by lesions in the brain in the early stages of development. These lesions result in atypical development of movement and postural control. It is a non-progressive disorder, resulting in altering motor abnormalities and secondary complications (Ketelaar et al., 2001).

2. **Multidisciplinary team-** a team of individual disciplines working together to provide a patient with optimal rehabilitation services (Norrefalk, 2003).

3. **Holistic Approach-** when a patient receives a variety of treatments, including the involvement of all disciplines and family members, in order to create realistic rehabilitation measurements and objectives to achieve (Norrefalk, 2003).

4. **Physiotherapist-** is a trained individual who assists in developing and upholding a person's mobility and function. He provide his services to a vast amount of people to enhance functional and physical activity (Singh, 2013).

5. **Occupational therapist-** is an individual who has specialised in this field to assist people with mobility and cognitive disabilities. His treatment approach is through occupation by means of adapting his patients' remaining abilities, the use of modified equipment and environmental changes; all in aid of introducing and encouraging functional activities of daily living (Radomski and Latham, 2008).

6. **Audiologist-** is an expert who practises to stimulate hearing, communication abilities, and quality of life for persons of all ages, by assessing and managing the patients' hearing, auditory function, balance, and other systems (American-Speech-Language-Hearing, 2004).

7. **Speech therapist-** is an expert who assesses and manages patients with speech, language, cognitive-communication and swallowing disorders. He

treats all patients presenting with different neurological disorders and symptoms (Krigger, 2006).

8. **Caregiver-** is a person who cares for an individual's needs uniquely and ensures or seeks the provision of a reassuring and caring setting (Swafford, 2010). In this study the reference to a caregiver is a person who looks after a child with cerebral palsy.

9. **Adherence-** is defined as someone who acts strictly according to rules or his beliefs. In this study, adherence refers to partaking in a caregiving regime outside the rehabilitation setting as prescribed by a therapist (Dictionaries, 2014) .

10. **Functional ability-** is the manner in which a person is able to perform activities of daily living (Anderson et al., 2007).

11. **Public hospital-** Is a hospital that caters for the majority of South Africa's population. The most common categories in public health hospitals are district, regional and tertiary; also known as Level 1, 2, 3 Hospitals (Cullian, 2006).

12. **Urban hospital-** is a hospital situated near and in urban centres, large cities and provincial capitals (De Vries and Reid, 2003).

13. **Rural hospital-** is a hospital situated outside main urban midpoints, city centres and provincial capitals (De Vries and Reid, 2003).

14. **District hospital (Level 1)-** is a hospital that provides in and outpatient services. It is open 24hours a day, 7 days a week with an operating theatre. The majority of those using public health services will be admitted to a district hospital. Rehabilitation services are offered at this level. There are 37 district hospitals in KwaZulu-Natal (Cullian, 2006).

15. **Regional hospital (Level 2)-** is a hospital that will provide at least five specialties, mainly surgery, orthopaedics, obstetrics, medicine, paediatrics,

psychiatry and anaesthetics, to name a few. In KwaZulu-Natal there are 14 regional hospitals (Cullian, 2006).

16. **Tertiary hospital (Level 3)-** is a hospital that provides specialist and sub-specialist care. This hospital provides support to other regional hospitals. There is only 1 tertiary hospital in KwaZulu-Natal (Cullian, 2006).

LIST OF ABBREVIATIONS

Audio:	Audiologist
BFMFS:	Bimanual Fine Motor Function Scale
CFCS:	Communication Function Classification System
CG:	Caregiver
CNS:	Central Nervous System
CP:	Cerebral Palsy
CPD:	Continuous Professional Development
CS:	Community Service
DOH:	Department of Health
DSD:	Department of Social Development
FASD:	Foetal Alcohol Syndrome Disorder
GMFCS:	Gross Motor Functional Classification Scale
HEP:	Home Exercise Programme
HIV:	Human Immunodeficiency Virus
HRD:	Human Resource Development
KZN:	KwaZulu-Natal
MACS:	Manual Ability Classification System
MDT:	Multidisciplinary Team
MRI:	Magnetic Resonance Imaging
OT:	Occupational Therapist
PHC:	Primary Health Care
PT:	Physiotherapist
ROM:	Range of Movement
SA:	South Africa
SANDTA:	South African Neurodevelopmental Therapy Association
SLT:	Speech and Language Therapist
TB:	Tuberculosis
UKZN:	University of KwaZulu-Natal

CHAPTER 1: INTRODUCTION

1.1 Introduction

Cerebral Palsy (CP) is defined as a neurological impairment starting in early childhood and continuing into adulthood (Ketelaar et al., 2001, Rosenbaum and Gorter, 2011, Clover et al., 2013). CP is a permanent yet changing condition and is one of the leading childhood disabilities (Krageloh-Mann and Cans, 2009). It is a condition that affects the development of an infant or child, resulting in movement and postural disorders. CP can also be associated with perceptual complications, behavioural problems, seizure disorders, speech, communication and cognitive impairments (Laughton, 2004, Bax et al., 2005).

Medical advances have resulted in an increasing survival rate of premature and low birth weight infants, putting those infants at risk of CP, contributing to the increase in the CP population (Pharoah et al., 1990, Palisano et al., 1997). In a survey conducted by the Department of Social Development (DSD), it was reported that 28% of 130 000 children were reported to have a disability-including CP (DSD et al., 2012). In the Republic of South Africa (RSA), it is known that there is a high prevalence of CP (Mclaren, 2013). In South Africa (SA) two different findings were reported on the prevalence of CP where Couper (2002) indicated for every 1000 live births, 10 children are diagnosed with CP but Christianson (2002) reported that 80 children per 1000 live births are diagnosed with CP. The number of children with CP currently being treated in KwaZulu-Natal (KZN) has not yet been determined.

CP has many physiological, mental and secondary complications requiring therapy to help reduce and prevent associated complications. Rehabilitation improves the function, independence and activities of daily living (ADLs) of the child with CP, resulting in fewer admissions to hospitals and clinics for any secondary effects of CP (Ketelaar et al., 2001, Laughton, 2004, Bachman et al., 2010). The beneficial management of a child with CP would include the thorough intervention from a range of disciplines. A multidisciplinary team approach (MDT) is beneficial for a child with CP and Krigger (2006) reported that the ideal management for a child

with CP is a team approach that focuses on *'total patient development' which* includes the involvement of the family. Health care professionals should aim to assist the caregiver (CG) or family unit by providing therapeutic support (Thorogood and Lorenzo, 2013) to avoid any further delay in the child with CP's independence and to prevent any secondary complications associated with CP (Heller et al., 2002). The management of a child with CP should ideally be approached holistically (Krigger, 2006, Clover et al., 2013).

1.2 Background

It is reported that 6% of children living in rural KZN are disabled. Although there are limited studies on the population based prevalence rate of children with CP in developing countries, it has been found that 10/1000 children are diagnosed with CP in rural KZN. These statistics place a high demand on the service delivery of health, welfare and educational services (Khan, 2005). The knowledge and employment of health care professionals is a fundamental need in the public sector and without these services, a health care system cannot function optimally (Padarath et al., 2003). The management of children with CP is predominantly therapeutic based and in SA there is a scarcity of therapists employed within the public domain (Mclaren, 2014). In KZN 50% of therapy posts are not filled and there is no disaggregation between rural and urban therapists (Khan, 2005, Mclaren, 2014). In the South African public sector of health, it has been found that the ratio per 100 000 people to a Physiotherapist (PT) is 1.19%; an Occupational Therapist (OT) is 0.77% and a Speech and Language Therapist (SLT) is 0.08% (Mclaren, 2013).

Hospitals, rehabilitation centres and clinics dealing with the CP sector should ensure the employment of health care professionals who are predominantly trained to manage children with CP, like PT's, OT's, SLT's and Audiologists (Audios) assess and manage children with CP in a MDT approach (Mclaren, 2013). A MDT approach is vital to ensure that the adequate management of a child with CP is performed to avoid any secondary complications (Krigger, 2006, Yalcinkaya et al., 2014). However, most health care professionals cannot work in a MDT. Instead, they are forced to work on their own due to the lack of therapeutic

posts and structural constraints (Mclaren, 2014). The high case load of those patients diagnosed with Human Immunodeficiency Virus (HIV) and Tuberculosis (TB) is a devastating epidemic. Financial support is primarily provided to the HIV and TB epidemic, resulting in the limited provision of financial aid to the rehabilitation sector. This results in the limited number of therapeutic posts in the public system (Maharaj and Dunpath, 2014). The limited access to therapeutic services ultimately results in infrequent rehabilitation.

Children with CP, accessing public health services, often present with multiple impairments making it difficult for the health care professionals to address all the problems (Mclaren, 2014). In South Africa, rehabilitative services are mainly centrally located, with reference to CP clinics and therapy groups (Mclaren, 2013), but individual children with CP present differently and treatment should be patient specific (Krigger, 2006). The lack of therapy posts, the complexity of impairments of the child with CP's and the high workload from HIV and TB cases in the public sector, does not allow adequate time for comprehensive individual treatments for children with CP (Maharaj and Dunpath, 2014).

The employment of community service therapists has proven to provide relief to those public hospitals. However the lack of individual therapeutic experience and supervision often leads to feelings of incompetency to manage children with CP (Khan, 2005, Mclaren, 2014). South African health care professionals lack adequate CP training in undergraduate studies and postgraduate studies, such as Neurodevelopmental Therapy (NDT) as recommended by Mclaren (2014). However the costs and time taken off to complete these courses appears, difficult for most health care professionals to complete this postgraduate training .

1.3 Motivation for the study

CP is one of the most common and costliest childhood disorders, with the incidence of 10/1000 live births in South Africa (Couper, 2002, Raina et al., 2005, Krageloh-Mann and Cans, 2009, Papavasiliou, 2009). Motor aliments and disturbances are common in children with CP and PT intervention is an acceptable way to manage these children with CP functionally (Krigger, 2006, Thomas et al.,

2014). Many studies have addressed the importance of PT intervention in the management of a child with CP, but little is known about how PT's approach the management of children with CP in KZN public hospitals. Factors such as the colonial apartheid history, inadequate allocation of finances, and a shortage of material and human resources are a few reasons why the SA public health care system is in a state of disarray and unfortunately, rural areas are the most affected by these concerns (Sips et al., 2014). The researcher noted that the urban, larger and fully equipped hospitals were the choice of permanent employment for therapists as opposed to rural district hospitals in KZN, as therapists expressed feelings of remoteness, limited communication with experienced health care professionals, professional inadequacy and reduced support, particularly in those rural areas.

The researcher was employed in the public sector at a district hospital where only a PT and OT were employed. There were many children with CP needing rehabilitative services but because of the high patient volumes and limited staffing they received treatment once a month only. The researcher had limited supervision and professional advice while working with children with CP and at times felt inadequate managing children with CP; furthermore, there were no systems or protocols in place, regarding the management of children with CP.

The researcher had anecdotal information of other PT's who had expressed similar concerns on managing children with CP in KZN. The researcher would like to identify the managing practices of children with CP among KZN PT's, which may prove to be beneficial and lead to suitable rehabilitation programmes and policies being designed and implemented, to address the needs of these children with CP throughout KZN. This research may further highlight the need for therapeutic intervention for children with CP and possibly lead to the provision of more PT's, within the public health domain, for the efficient delivery of rehabilitation services to children with CP.

1.4 Problem Statement

Limited priority and resources are provided for disability and rehabilitation services. Rural and urban therapists face the challenges of inadequate human resources and as a result, poor service delivery occurs (Mclaren, 2013). Disability and rehabilitation services are under-developed and inaccessible to the majority of the population especially in rural areas and majority of the therapists work solely on their own and not in a MDT (Khan, 2005, Mclaren, 2013). The majority of therapists employed in the public sector are compulsory community service (CS) therapists, who are primarily placed in rural areas. The success of therapy depends a great deal on their attitudes, knowledge and readiness to conduct these services in an adequate and successful manner. In a study conducted on KZN community service therapists, the lack of support, inexperience and limited resources were a major concern for these therapists (Khan, 2005).

Currently, there are no studies published or protocols on the management of children with CP contextualised to SA and KZN to assist those PT's working in KZN public health. To date, there are no studies published on the PT management of children with CP in rural or urban hospitals in KZN. Understanding the practices and trends of the physiotherapy management of children with CP may help improve the rehabilitation of children with CP in KZN and in SA.

1.5 Research Questions

1. What is the physiotherapy management of children with CP in KZN public hospitals?
2. Is the current physiotherapy management satisfactory for a child with CP?
3. Are there any differences in the physiotherapy management of children with CP between KZN urban and rural hospitals?
4. Does the current physiotherapy management of children with CP in KZN public hospitals include a multidisciplinary team approach?
5. Is there potential for improvement(s) with the current physiotherapy management of a child with CP?

1.6 Aim and Objectives of the Study

The broad aim of this study is to determine the current physiotherapy management of children with CP in KZN public hospitals, with the objectives of identifying current management practices of children with CP, in urban and rural public hospitals, to improve the management of children with CP. The objectives of the study are:

1. To determine the current physiotherapy management of children with CP in KZN public hospitals.
2. To determine whether PTs employed in KZN public hospitals consider the current management of children with CP to be effective.
3. To determine whether there is a difference in physiotherapy management of children with CP in rural and urban KZN public hospitals.
4. To determine whether a MDT approach is included in the PT management of children with CP in KZN public hospitals.
5. To source potential improvements on the current management of children with CP in public hospitals of KZN.

1.7 Significance of the Study

The significance of this study is that if the management trends of children with CP in public hospitals are identified the results may inform clinical practice and highlight areas requiring improvements that may be developed and have a holistic effect on the management of children with CP.

The significance could potentially be:

1. Improving the knowledge of physiotherapy management of children with CP, and may include a review of, and changes to current practice.
2. An improvement in service delivery to children with CP and their families within public hospitals.
3. The research could improve the overall management of children with CP, by informing other members of the MDT.

4. Results collected can be added or compared to existing literature on the management of children with CP, with the potential of identifying the need for further research on this topic.

1.8 Outline of the Study

The research will be presented in the following six chapters:

Chapter 1- Introduction: This chapter explores the topic under analysis and describes the purpose of the study. It includes the introduction, background, motivation for the study, the problem statement, and research questions. The aims and objectives are described and the significance of the study is outlined.

Chapter 2- Literature Review: Literature pertaining to CP and the management practices of CP are addressed in this chapter. The literature on the South African health care systems and KZN DOH is explored. The aim of the literature review is to provide evidential facts and clarity on the topic being researched.

Chapter 3- Methodology: This Chapter describes the methodology used to conduct the research. It includes the study method, the study population and sample of the study. The data collection tools, data management and analysis is discussed. Ethical considerations are included.

Chapter 4- Results: The results of the study are accessible in this chapter. Tables and graphs are used with descriptive summaries under each.

Chapter 5- Discussion: The results of the study are discussed in detail and reviewed in relation to other studies and literature.

Chapter 6- Conclusion: The conclusion of the study is reflected in this chapter. Proposed recommendations for future studies and the limitations of this study are discussed.

References: This section includes all the references to literature used to formulate this dissertation.

Appendices: All appendices related to this study are included in this chapter.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

CP is a leading childhood disability affecting the lives of many families, children and indirectly, the public health care system. Creating awareness on how children with CP are managed, may possibly lead to better management interventions for these children. It is important that the basis of the term *'Cerebral Palsy'* is investigated and discussed, so that a deeper understanding is achieved.

Articles were sourced for this review using the University of KwaZulu-Natal (UKZN) online library, Pubmed, Pedro, Google scholar, Medline on Ovid, PT Journal online and other related sources pertaining to CP and the management thereof. A hand search was performed at the Westville campus library of UKZN.

Key words used in the searches included: Cerebral palsy, physiotherapy, physical therapy, rehabilitation, disability, management, perceptions, public health KwaZulu-Natal.

2.2 Cerebral Palsy

2.2.1 Definition of CP

CP is one of the known causes of disability in childhood, affecting function and typical development of the child's central nervous system (CNS) (Raina et al., 2005, Krageloh-Mann and Cans, 2009, Thorogood and Lorenzo, 2013). Bax et al. (2005) describes CP as "a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain." CP is defined by Laughton (2004) as an upper motor neuron lesion, presenting with muscle tone fluctuations and continuous primitive reflexes. CP affects the development of a child and continues into adulthood. It is continuing but flexible in movement and posture through the lifespan of a child with CP (Bax et al., 2005, Rosenbaum and Gorter, 2011).

2.2.2 Diagnosis of CP

The early diagnosis of CP is crucial to ensure that rehabilitation and adequate management proceeds promptly, to avoid any further delay and regression (Yalcinkaya et al., 2014).

The diagnosis of CP can be done in different forms. The observation of atypical tone and posture, persistent infantile reflexes, poor sucking, recurring seizures, microcephaly and hand preferences before 12 months will warrant the need for further investigations (Jan, 2006). Outcome measures are also readily available to therapists to assist in the diagnosis of CP such as the Gross Motor Functional Classification Scale (GMFCS), the Bimanual Fine Motor Function Scale (BFMFS) and the Manual Ability Classification System (MACS) (Bax et al., 2005, Krageloh-Mann and Cans, 2009).

An evaluation by MDT members including a PT, OT, SLT, ophthalmologist, Audio, orthopaedic surgeon, paediatrician, neurologist, radiologist, dentist and social worker can add value to the diagnosis and management of a child with CP (Jan, 2006). Continuous observation of the child's hearing, vision, sensory perceptions, behaviour, occurrence of seizures, physical development and intellectual abilities through-out their development may further strengthen the diagnosis of CP. Further investigations include using diagnostic outcome measures such as a Magnetic Resonance Imaging (MRI) or ultrasound (Krigger, 2006, Krageloh-Mann and Cans, 2009, Mclaren, 2013).

2.2.3 Aetiology and Prevalence of CP

The cause of CP varies with each case of CP, dependent on the timing of insult. CNS damage can occur at any level during a child's development. Damage to the CNS can occur in the prenatal, perinatal or postnatal (acquired) phases. Prenatal risks include strokes, cerebral malformations, infections and Foetal Alcohol Syndrome (FASD). Perinatal risks include preterm births, birth asphyxia, bilirubin toxicity and CNS infections. Malaria, TB, meningitis, HIV and gastroenteritis are identified as postnatal risks (Laughton, 2004, Krigger, 2006, Toorn et al., 2007,

Mclaren, 2013). Figure 2.1 illustrates the risk factors of the possible occurrence of CP within the different phases, pre and post birth.

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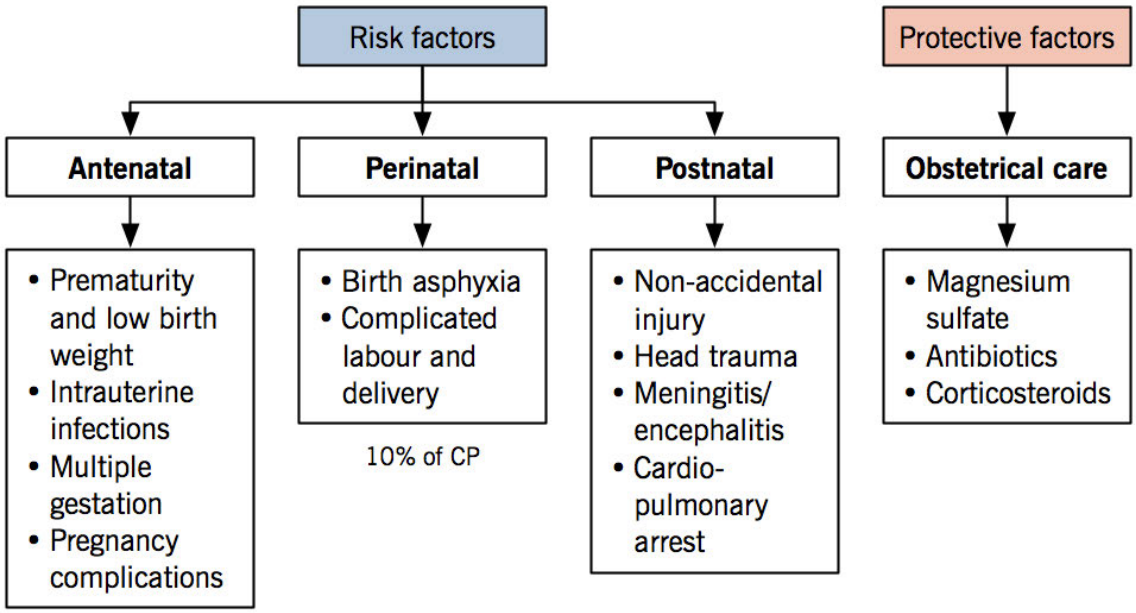

Figure 2.1: Risk factors of CP adapted from Rogers and Wong (2012-2015).

In a study done by Krigger (2006) it was reported that 10-20% of children with CP acquired insult during the postnatal phase. It has been suggested that in developed countries, CP occurs predominantly in the prenatal phase and in developing countries, the cause of CP is most likely to occur in the perinatal and postnatal phases of an infant or developing child (Toorn et al., 2007). Toorn et al. (2007) mentions that during the prenatal phase 28.9% of insult to the brain, causing CP occurs. In the perinatal phase 38% of the insult occurs and 21.1% of insult to the brain is acquired. The remaining 12% is undetermined.

The prevalence of CP is high in SA due to poor obstetric and neonatal care, restrained resources, poor education, high infection rate and malnutrition (Camp, 2014). The recorded prevalence of CP over a period of time revealed no difference between white and black racial groups (Winter et al., 2002). The absenteeism of racial heterogeneity in research doesn't warrant a solid conclusion that ethnicity has an impact on the prevalence of CP, although some studies suggest that black ethnic groups have a greater possibility of conceiving/raising children with CP, possibly due to poor socio-economic concerns (Wu et al., 2006).

Wu et al. (2011) concluded that there was no notable difference in the incidence of CP between black and white groups but a greater prevalence of CP among mothers who did not receive perinatal care. A study in Sweden concluded that there is no remarkable trend regarding gender distribution in CP (Himmelmann et al., 2010).

2.2.4 Incidence of CP

The incidence of CP varies from country to country. However, the mean ratio of children diagnosed with CP internationally is 2-3/1000 live births (Yalcinkaya et al., 2014). Toorn et al. (2007) mentioned that the incidence of CP is said to be the same in both developed and developing countries.

Mclaren (2013) noted, in her review, that the number of children with CP is not certain, but it is a known fact that the prevalence of CP is high in SA. In South Africa there are two findings that do not collaborate: Couper (2002) reported that 10/1000 children are diagnosed with CP whereas Christianson (2002) reported that 80/1000 children are diagnosed with CP. Unfortunately, these two studies were done prior to 2002 and no recent data has been collected since then.

Mclaren (2013) does point out that the limited knowledge on the incidence of children diagnosed with CP is due to a delayed diagnosis; in SA the diagnosis of a child with CP is performed during childhood and not at birth, ultimately not reflecting on the statistics of new-borns in SA.

2.2.5 Classification of CP

CP is an umbrella term categorising individual children with CP into groups according to their clinical features (Laughton, 2004), and the distribution of motor impairments of a child with CP is indicative of the sub-type of CP (Krageloh-Mann and Cans, 2009).

Children with CP, presenting with increased hypertonicity in their affected limbs, extension tremors, muscular weakness and who mobilise with a toe and scissor

gait are classified under the spastic clinical picture, making up 80% of those diagnosed with CP. The type of CP affecting 10-20% of children with CP is known as athetoid /dyskinetic CP; characterised by atypically slow, writhing movements of the extremities. Ataxic CP makes up 5-10% of children with CP with clinical features of a wide based gait, intention tremors, poor balance and co-ordination difficulties (Krigger, 2006). Figure 2.2 illustrates the classification of children with CP according to their motor aliments.

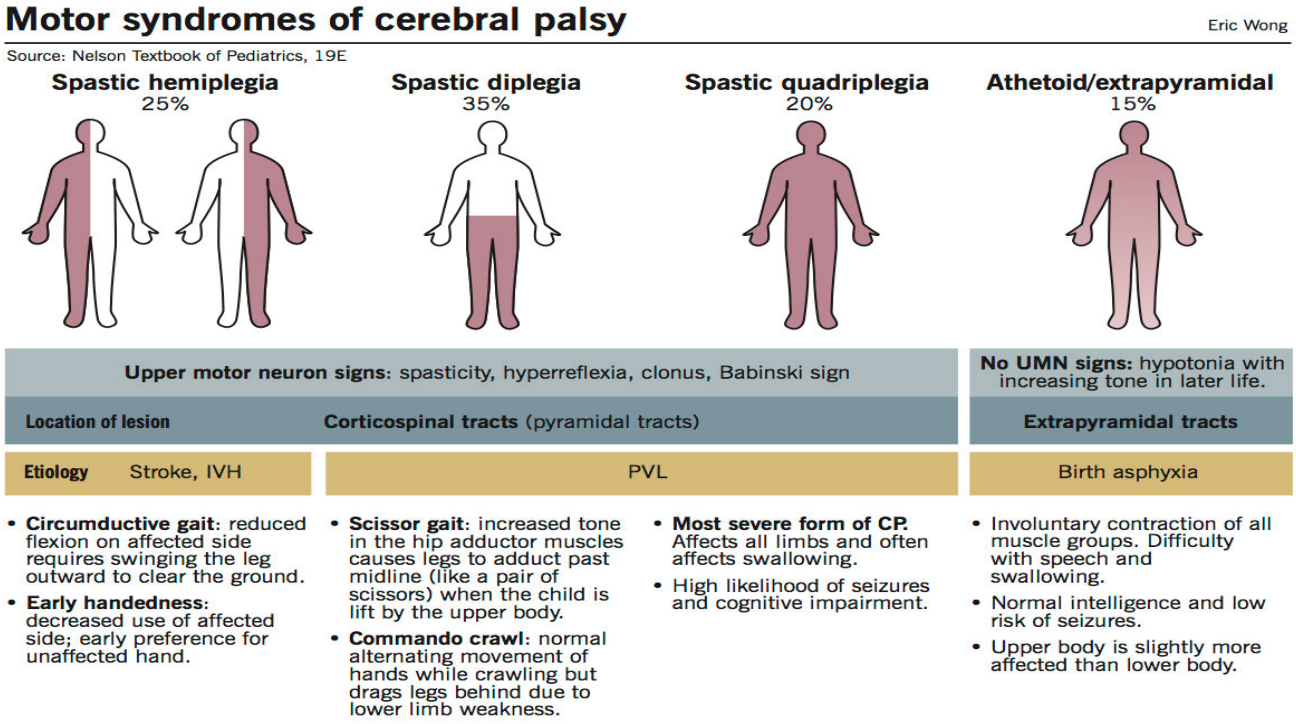

Figure 2.2: Classification of Children with CP adapted from Kliegman et al. (2011) and Rogers and Wong (2012-2015).

Children with CP are further classified by their functional motor capabilities, using objective functional scales. The GMFCS assesses the functionality/mobility or restrictions thereof of a child with CP. Two upper limb function tests have been designed: The BFMFS and the MACS (Bax et al., 2005, Krageloh-Mann and Cans, 2009). These classification systems aid health care professionals to categorise the motor function of children with CP to set realistic and appropriate treatment goals.

2.2.6 Clinical Presentation and Associated Complications of CP

CP has many effects on the body and depending on the nature and occurrence of the lesion, each child with CP will present with some sort of motor, intellectual and sensory complications, in some cases leading to a residual disability (Laughton, 2004, Krigger, 2006, Mclaren, 2013). Figure 2.3 illustrates the variation of features seen dependent on the region of the lesion to the brain.

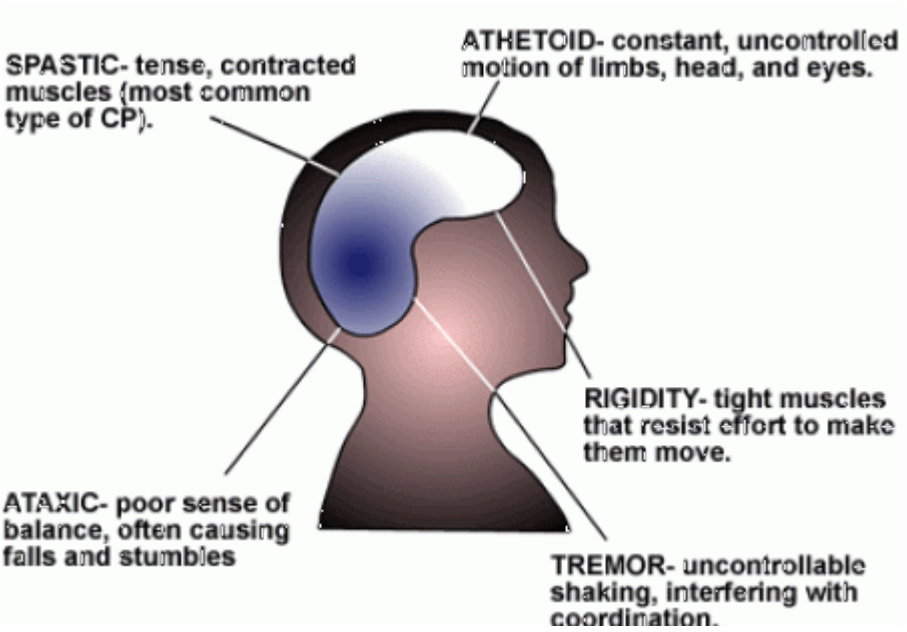

Figure 2.3: The variation of features according to the lesion in the brain adapted from Clerkship (2013).

Motor ailments of CP are often accompanied by associated impairments (Krageloh-Mann and Cans, 2009, Yalcinkaya et al., 2014). The researcher discusses these ailments in detail to emphasise the plight of children with CP.

i. Orthopaedic complications

The increased tone and spasticity in children with CP may lead to joint contractures, dislocations, lower limb deformities and shortened muscles (Jan, 2006). Fractures of the femur occur regularly in children with CP, who suffer from seizures and a Vitamin D insufficiency (Laughton, 2004).

In children with CP, who are severely affected, reduced bone density is present as limited weight-bearing through the legs occurs. The reduced bone density often

leads to fractures, osteoporosis, osteopenia, scoliosis and most detrimental of all, pain (Jan, 2006, Krigger, 2006).

ii. Respiratory complications

Chest infections are a common occurrence in children with CP, particulary whose who are affected and classified as level 4-5 according to the GMFCS (Couriel et al., 1993). Reflux and aspiration of feeds during meal times are the main reasons for respiratory complications due to poor oral motor function (Morton et al., 1999, Krigger, 2006). Pneumonia, respiratory failure and bronchiectasis are common respiratory complications that often result in the death of a child with CP. A weak cough, immobility, a poor immune system, chest wall irregularities and weak muscles predispose children with CP to respiratory complications (Couriel et al., 1993).

iii. Epilepsy

Krigger (2006) concluded that almost half the CP population suffers from epilepsy and according to Cole (2000), epilepsy is *"A symptom of an underlying brain disease or injury."* Epilepsy is common among children with CP. However, epilepsy is rarely the reason for a CP diagnosis which may lead to further motor disturbances, indicating the severity of the neurological insult (Laughton, 2004, Bax et al., 2005).

iv. Intellectual disability

An IQ score of less than 70 is conclusive of a diagnosis of an intellectual disability (Mefford et al., 2014). Difficulty in cognitive processing may be present in children with CP, leading to perceptual development and learning limitations (Laughton, 2004, Bax et al., 2005).

v. Feeding, nutrition and growth

Two types of feeding problems are identified in children with CP:

1. Problems with sucking, swallowing and chewing
2. Gastro-oesophageal reflux

These feeding complications may be a result of poor lip and mouth closure, tongue thrusting, drooling, temporo-mandibular joint contractures and incorrect positioning whilst feeding. Jan (2006) reported that on average 30% of children with CP are malnourished; vomiting, aspiration of feeds and regurgitation are complications that may occur resulting in this failure to thrive (Laughton, 2004, Bax et al., 2005, Krigger, 2006).

vi. Bladder dysfunction

Urinary tract infections, urgency and urinary incontinence are common in children with CP. An impaired motor control of the bladder muscle better known as the detrusor muscle is the main cause for bladder dysfunction (Bergendal et al., 1996, Krigger, 2006).

vii. Bowel dysfunction

Constipation and bowel obstruction often causes extreme discomfort and pain. The atypical autonomic control of the gastrointestinal system, reduced mobility, poor feeding and a limited intake of water and fibrotic foods are a few highlighted causes of constipation and bowel obstruction. (Laughton, 2004, Jan, 2006, Krigger, 2006)

viii. Hearing loss

Hearing loss is diagnosed in 18% of children with CP and an early diagnosis and intervention are critical to establish greater rehabilitation outcomes, as hearing is vitally important for speech and language development. (Laughton, 2004). Hearing impairments affects the developmental progress of a child with CP.

ix. Visual deficits

Visual deficits result in poor rehabilitation outcomes and delayed development if not diagnosed and managed early (Laughton, 2004, Jan, 2006). The visual sensory system is often compromised in children with CP and as many as 25-39% of children with CP are diagnosed with a visual impairment (Bax et al., 2005, Krigger, 2006). Glaucoma, myopia and strabismus are a few mentioned visual deficits. Damage to the occipital lobe may result in cortical visual impairments. Regular ophthalmological assessments of visual acuity and visual fields is

necessary to ensure progress in the rehabilitation outcomes (Laughton, 2004, Jan, 2006).

x. Dental Hygiene

Poor dental hygiene is a common occurrence in children severely affected by CP and appropriate dental hygiene needs to be implemented early to avoid dental complications (Botti Rodrigues dos Santos et al., 2003). There are many reasons that may attribute to poor hygiene:

1. Drooling occurs in one third of the CP population due to their inability to swallow and maintain good lip closure, resulting in an accumulation of saliva.
2. Tongue thrusting occurs as children with CP present with reduced skilled tongue movements, leading to food decay and as a result food particles are left behind in the mouth resulting in plaque formations.
3. Mouth breathing often occurs in children with CP as they respire only through their mouths. Their inability to close their mouths, results in dental caries (Botti Rodrigues dos Santos et al., 2003, Laughton, 2004, Krigger, 2006).

Many clinical manifestations occur within the diagnosis of CP and it is important to note that every case of CP will present differently, due to the timing and type of insult. The lesion to the brain is static but the clinical description changes over time (Mclaren, 2013). There are many clinical, therapeutic, pharmaceutical and surgical treatment options that need to be explored, to reduce and avoid secondary associated complications (Wade and Jong, 2000).

2.2.7 Prognosis of CP

Children have an amazing ability to learn and process new movements and sensory information. In the case of a child with CP, neuroplasticity, which is the ability of the damaged brain to formulate new connections and allow for re-learning and processing occurs. Regular therapeutic intervention encourages neuroplasticity resulting in greater rehabilitation outcomes (Jan, 2006).

As previously discussed, the degree and timing of the insult to the brain determines the prognosis of a child with CP. Children with CP who require nasogastric tube feeding, as opposed to oral feeders, have a 5-times larger mortality rate. On average the majority of those severely affected live up to only 20 years of age. Therapeutic intervention and medical advances can now prolong the survival rate of children with CP (Jan, 2006). Laughton (2004) concluded that *"It is not acceptable to say, sorry, there is nothing we can do for this child. It may not be possible to correct the brain damage, but we can provide a life that is free from pain and discomfort, by anticipating problems and managing them appropriately and by preventing complications."* Therefore the prognosis of a child with CP ultimately depends on the severity of the brain damage and the effectiveness of the management they receive once diagnosed.

2.3 Rehabilitation of CP

Bachman et al. (2010) states *"The aim of rehabilitation is to maximise function and minimise limitation of activity and restriction of participation resulting from the underlying impairment."* Treatment of a child with CP should be patient-specific as each child presents differently (Krigger, 2006, Clover et al., 2013). Rosenbaum and Gorter (2011) and Yalcinkaya et al. (2014) describes CP as "*heterogeneous"* and treatment goals should be set according to each individual child with CP. There are different approaches regarding the rehabilitation of a child with CP which need to be suitable for his age and functional ailments (Clover et al., 2013, Yalcinkaya et al., 2014). Becher (2002) encourages those who are involved with treating a child with CP to *"Focus on all developmental aspects of the child and plan interventions in relation to the most urgent needs of the child and the family."*

In the literature, four models of therapy are described; the first being an individual, one-on-one approach, the second being group centred , the third a web-based therapy training approach and the last being an individual session in the patient's familiar surroundings (Thomas et al., 2014).

Individual- based therapy should ideally take between 45-180 minutes and therapy sessions should be done 2-5 times a week. Group centred CP treatment sessions are generally outlined as follows:

1. Warm up.
2. Goal orientated activities.
3. Warm down.

These group based classes need to be small in size ranging from 4-6 children per class. It has been reported that group-based therapy sessions have shown to lead to greater rehabilitation results as it creates a social support structure; it allows for personal goal setting and leads to greater interactions resulting in overall improved participation. However, the effectiveness between individual vs. group based sessions is difficult to measure (Thomas et al., 2014). In her report, Mclaren (2013) discusses the various ways CP clinics are run in the different provinces of SA. Children with CP are categorised either according to age, location or severity of their symptoms. Some CP clinics are run weekly, monthly and even every 2 months. The use of individual assessment forms, the Communication Function Classification System (CFCS), GMFCS and MACS is widely used.

The four models of therapy discussed above can be used in conjunction with many different management approaches that there are to manage a child with CP. The first being the neurophysiological approach/ *'Neurodevelopment treatment (NDT) approach'*, a Bobath technique that focuses on inhibiting certain reflexes and postures to encourage typical patterns of movement and encourage independence in a child with CP with regard to motor-skills, ADL's, play and leisure activities (Ketelaar et al., 2001, Yalcinkaya et al., 2014).

The *'functional approach'* is an alternative approach to managing a child with CP; this method focuses on the environment and task at hand. It allows for movement exploration and encourages self-motor solutions to the new task at demand as well as adapting the environment, encouraging active motor learning (Ketelaar et al., 2001).

Constraint-induced movement therapy is a treatment approach whereby the unaffected limb is restrained and the child with CP is encouraged to use the affected limb- to help improve the functionality of that limb, working best with a child with asymmetric motor impairment (Taub et al., 2004).

The Vojta method, conductive education and sensory integration are examples of many other forms of treatment approaches that can be used. Each approach differs; however all these approaches have one common link and that is to encourage and develop the child with CP's independence (Ketelaar et al., 2001).

The assessment and management approaches of a child with CP is vast and controversial. However, it is important to note that all health care professionals are in a mutual agreement to ensure that the child with CP they are treating obtains his highest functional level, maintains a healthy social and emotional well-being and is effectively integrated into the community (Broughton, 2012). The progression of a patient leads to feelings of fulfilment not only for the therapist but for the CG (Chang and Hasselkus, 1998). Rehabilitation is becoming the conventional treatment method and is needed more now than ever in health care (Stolp, 2011). Rehabilitation of a child with CP should include a variety of health care professionals. Rehabilitation is an intricate process and is all about a MDT to ensure the child with CP receives adequate care (Wade and Jong, 2000, Krigger, 2006, Broughton, 2012).

2.3.1 Physiotherapy Management of a CP

Various children with CP may present with reduced motor control and muscle discrimination, resulting in constraints of balance, gait, fitness and functional abilities. PT's assist children with CP by decreasing the above constraints striving to optimise overall function in their physical performance (Thomas et al., 2014). A PT's objective for the treatment of a child with CP includes promoting and developing his motor skills such as using postural stabilizing exercises (de Graaf-Peters et al., 2007). Range of Movement (ROM) exercises are done to avoid contractures and to preserve the ROM of the joints and soft tissue. Muscle strengthening exercises and electrical stimulation on weakened muscles may

improve the muscle strength of a child with CP (Misbach, 2004, Krigger, 2006, Thorogood and Lorenzo, 2013, Thomas et al., 2014). In their systematic review Anttila et al. (2008) discussed the importance of PT in the management of a child with CP's *'motor disability'.* Their emphasis is placed on strength training, postural control activities and soft tissue mobilisations as the main PT intervention.

Respiratory complications occur regularly in children with CP (Couriel et al., 1993). Chest physiotherapy consisting of percussions, vibrations, postural drainage, nebulising and suctioning are performed to clear the lung secretions, to improve overall lung function and prevent any further respiratory difficulties (Hall et al., 1991, Ntoumenopoulos et al., 2002).

In the literature Grecco et al. (2013) states that the functional outcomes of a child with CP are achieved with the collaboration of PT's and therapeutic resources/approaches. The inclusion of a PT post Botox injections is one example of how the collaboration of PT with other modalities/therapies ensures a significant difference in the prognosis of a child with CP's (Thomas et al., 2014).

A PT should ideally work and consult with the caregivers and families of the children with CP. Kavlak et al. (2014) supports this statement and encourages PTs to *"Talk with parents of a disabled child before planning a specific treatment or intervention, in order to establish the most suitable programme for the child."* PTs are encouraged to train and develop the skills of the CGs so that the continuation of therapy and rehabilitation outcomes are achieved at home (Misbach, 2004).

2.3.2 Multidisciplinary Team Management Approach of CP

Patricks et al. (2001) noted that the management of children with CP is at times individual, perhaps due to the complexity of the diagnosis. However, health care is moving away from the typical medical approach, ensuring the inclusion of both psychological and sociocultural aspects (Wade and Jong, 2000). A MDT approach is ideal and proposed by most literature to ensure that the child with CP receives suitable and beneficial management. The inclusion of a MDT team is ideal however a MDT approach may not always be suitable due to time constraints and

lack of human resources (Nolan et al., 2000, Calis et al., 2008, Papavasiliou, 2009).

Team work is essential in rehabilitation and health care professionals must work together in order to set and achieve goals to ensure the thorough management of the child with CP is accomplished (Wade and Jong, 2000). A MDT approach should address the physical, mental and emotional necessities of the child with CP and not simply focus on the syndrome or disease (Yalcinkaya et al., 2014).

Many health care professionals make up a MDT. Doctors, orthopaedic surgeons, nurses, paediatricians, caregivers, neurologists, dieticians, SLTs, OTs and Audios are those health care professionals who make up a vital and functioning MDT for the management of a child with CP (Desloovere et al., 2007, Calis et al., 2008). There are policies and legislations in place to ensure that the rights of children with disabilities are meet. However these policies are failing our children with CP and it is the duty of our health care professionals to advocate and ensure that their health, well-being, social support systems and scholastic needs are being met (Camp, 2014). One of the vital members of a rehabilitation MDT, who treats a child with CP, is a PT.

Physiotherapists work in collaboration with other health care professionals and as mentioned above the involvement of all health care professionals is essential to ensure the adequate management and progression of the child with CP occurs. The adequate management of a child with CP should begin with a confirmed diagnosis, the cause of insult, type of CP and severity of the disorder. The associated problems need to be identified and short and long term goal planning need to be implemented to ensure the success of the rehabilitation programme (Mclaren, 2013). Physiotherapy services are vital in the management of CP with the involvement of as many MDT members as possible.

i. Occupational Therapy

An OT focuses his rehabilitation management on improving ADL's (dressing, feeding, toileting, cleaning, and transfers), upper limb extremity function, scholastic training and skills development. He provides the provision of assistive

devices and environmental modifications to encourage as much independence in the life of the child with CP (Misbach, 2004, Krigger, 2006, Sakzewski et al., 2013, Thorogood and Lorenzo, 2013).

ii. Speech and language therapy

A SLT manages a child with CP by managing associated problems such as dysphagia, drooling and dysarthria. SLT helps improve the communication and swallowing complications of a child with CP (Misbach, 2004, Krigger, 2006, Thorogood and Lorenzo, 2013).

iii. Audiology

An Audio evaluates and diagnoses the hearing loss or vestibular disorder of a child with CP. Upon his assessment findings he can prescribe the correct hearing aid, monitoring of the hearing impairments, hearing rehabilitation and provide assistive listening devices. An audiologist will assist the CG's and family by educating them on how to operate the hearing aid, how to provide strategies of communication and how to adjust the environment to encourage better expressive and receptive communication in the child with CP. Additionally, balance therapy may be provided to a child with CP with vestibular impairments (American-Speech-Language-Hearing, 2004).

iv. Medical officer

Rosenbaum (2003) reports that "D*octors are people who will listen, support, advocate and be there when the challenge arises."* A doctor's role in CP is to provide guidance, education and treatment options on the initial diagnosis of CP. A doctor ensures all immunizations are up to date and monitors the development of a child with CP (Jan, 2006). Modern health care services are now encouraging doctors to divulge appropriate information, empower the parents and support the parents psychologically. Furthermore, doctors and the CG's of children with CP have to work together (Rosenbaum, 2003).

v. Nurse

Literature lacks the definition of the direct role of a nurse in the management of a child with CP. However, nurses are essential members of the MDT (Olsson and

Gullberg, 1991, Crossan and Robb, 1998). In general, nurses fulfil a much needed role and provide services to those who need their care. A nurse is defined as an individual who observes and monitors his patients, to ensure effective management. A nurse cares for the sick and advocates for a safe, clean and healing environment (Crossan and Robb, 1998).

vi. Dietician

Feeding difficulties occur in children with CP and the role of the dietician is to ensure that these children with CP grow and are well nourished (Hawdon et al., 2000). In a study done by Dahl and Gebre-Medhin (1993) wastage of food, low calorie intake and feeding difficulties were common occurrences in children living with CP and as recommended by Baer et al. (1991) regular nutritional screening and follow up treatments are needed to monitor and treat those complications.

vii. Orthopaedic surgeon

A variety of surgical operations can be performed on a child with CP, by an orthopaedic surgeon. These surgeries are preformed to improve the effects of secondary orthopaedic complications such as contracted or dislocated joints. Dorsal rhizotomies, abduction bracing, soft tissue releases, reconstructive femoral/ pelvic osteotomies and salvage procedures are all common orthopaedic procedures performed to decrease spasticity and increase the ROM (Harryman, 1992, Steinbok et al., 1997, Jan, 2006, Krigger, 2006). PTs are required to provide pre and post-surgical management and advice so to ensure greater outcomes of the surgical procedure at hand is achieved (Harryman, 1992, Steinbok et al., 1997).

viii. Psychologist and Social worker

Children with CP are often ridiculed, teased and rejected from society ultimately leading to depression and feelings of isolation (Marx et al., 2011, Parkes et al., 2011). The stresses and burdens of having a child with CP are often felt by a CG of a child with CP. The social and emotional well-being of the CG and child with CP is just as important as their physical being and the intervention of a psychologist is greatly sort after to deal with these depressive symptoms (Krigger, 2006, Marx et al., 2011).

Financial constraints are paramount in children with CP, especially within the SA rural context. Poor socio-economic constraints are a common occurrence in South African rural areas and CG's with children with CP are mostly affected (Broughton, 2012). CG's face a major financial burden and the role of the social worker is to ensure that CG's are informed of the availability of social and disability grants (Saloojee et al., 2007).

ix. Paediatrician

A paediatrician should be consulted primarily to discuss the diagnosis and the management options of the child with CP, with the CG (Baird et al., 2000, Jan, 2006). Pharmaceutical prescriptions can be made by a paediatrician and in most cases of CP, Baclofen is a common oral medication prescribed to reduce spasticity in the extremities of children with CP. These medications can prevent or delay the onset of contractures caused by spasticity of the joints (Krigger, 2006)

x. Neurologist

Neuroimaging, MRI's and CT scans are performed to diagnosis CP. A neurologist is a professional individual who will request, analyse and diagnose these images (Krigger, 2006). The use of Botulinum toxin (Botox), administrated by a neurologist, is one of many options on how to address spasticity in children with CP (Jan, 2006, Krigger, 2006). The pharmaceutical approach only alters the chemical composition of the body and to ensure the long term benefits of administrating Botox are achieved, Thomas et al. (2014) encourages the involvement of a PT to reassure the success and increase the overall activity level of the child with CP.

xi. Dentist

Research has shown that children with CP are more likely to develop dental complications. The build-up of plaque, dental decay, drooling, mouth breathing and malocclusion of teeth are a few mentioned dental hygiene complications. These dental hygiene complications require the early intervention of a dentist or dental technician to prevent further deterioration and decay (Botti Rodrigues dos Santos et al., 2003).

xii. Ophthalmologist

Ocular impairments are often diagnosed in children with CP. The early diagnosis and intervention is vital and a full ophthalmological assessment should be done regularly (Black, 1982). It was reported by Gaston (1985) in his study that the services provided by the ophthalmologist was valued. An ophthalmologist needs to undertake ocular motility, visual acuity and visual field assessments, ideally from birth, or when the diagnosis takes place. The ophthalmologist is responsible for providing specific visual care to these children with CP so that greater ocular/visual outcomes can be achieved (Gaston, 1985).

2.3.3 Inclusion of the CP Caregiver in the Management Approach

A child with CP requires continuous care and maintenance through his life span. It is the responsibility of the CG to provide a 24 hour care regime for children with CP (Mclaren, 2013). When a child is diagnosed with CP, the typical caregiving/parenting regime for young children is drastically altered and a higher demand is placed on the CG (Brehaut et al., 2004, Raina et al., 2005). The CG is challenged with having to maintain a typical lifestyle, whilst caring for the disabled child (Raina et al., 2005). PT's provide training to the CG's on how to manage and treat their children with CP (Misbach, 2004). In her study, Misbach (2004) reported that of all the rehabilitation staff, 36% of the physiotherapists provided training to CG's, including education on CP, physical handling, ROM activities and ADL promotion.

Caregivers are the back bone and the ultimate deciding factor of the progression or regression of a child with CP (Parkes et al., 2011, Mclaren, 2013). Financial constraints are a serious concern for CG's and Misbach (2004) reports that although rehabilitative services are available, most cannot access these services due to their financial constraints. Social and disability grants are available to the CG's of children with CP to assist with their financial burdens. However, CG's are seldom educated on how to access these grants (Saloojee et al., 2007). CG's in rural South African areas are faced with constraints in accessing these services due to the lack of transportation and poor-socioeconomic complications (Krigger,

2006, Mclaren, 2013). This lack in transportation and poor socioeconomic resources result in the child with CP and CG receiving a monthly follow-up, one treatment a month, and this is not enough (Trahan and Malouin, 2002). Therapists are then required to address the needs of the child with CP and CG in one session and hope that the carry-over management is done at home until the next follow-up date.

These continuous constraints may impact the CG-therapist relationship altering the steady progress of the child with CP (Murphy et al., 2007). CG's are at higher risk of poor physical and emotional well-being and suffer greater stress levels than those CG's who do not care for disabled children (Kerssens et al., 1999, Parkes et al., 2011). Therapists are therefore encouraged to include and target the CG equally ensuring his well-being (Brehaut et al., 2004, Raina et al., 2005, Saloojee et al., 2011). The progression of a patient leads to feelings of fulfilment, not only for the therapist but for the CG (Chang and Hasselkus, 1998). Recent studies have shown that the inclusion of CGs in the rehabilitation management programme has led to greater compliance from the CGs and an overall improvement in the child with CP's progression (Rosenbaum, 2003). Therapists integrate the CG's into the child's rehabilitation programme by actively including the CG's from the beginning in the decision making, establishing therapeutic goals and treatment plans ensuring that responsibility is not shifted onto the therapist, but the CG (Rosenbaum, 2003, Raina et al., 2005).

2.3.4 Equipment and Assistive Devices needed for the Management of CP

Sufficient information on the type of assistive devices needed for adequate management of children with CP is broadly available in the literature. However, limited research is available on what rehabilitative equipment is needed within a rehabilitation centre for the effective management of children with CP. In their study conducted in the Western Cape, Rhoda et al. (2009) investigated what equipment therapists had in their rehabilitation departments. Equipment such as a Bobath/low plinth, weights, therapy mats, suction machines, nebulisers, stairs, suspension therapy, wall bars, mirrors and electrotherapy machinery was available, however not all this equipment was *"Equally available"* in all therapy

departments. Surprisingly the reported inconsistency or lack of equipment has been reported not to interfere with the rehabilitation outcomes (Rhoda et al., 2009).

The correct provision of assistive devices is essential to maintain a functional posture, to provide adequate mobility and to encourage everyday activities in the lives of children with CP. The list of assistive devices required by a child with CP is dependent on the severity of the condition and clinical picture. The State has a tender whereby therapists can order assistive devices and administer accordingly. Assistive devices available on the tender include the following; wheelchairs, buggies, standing frames, side-lyers, walking frames, crutches, ADL utensils and communicative instruments (Mclaren, 2013).

The delayed administration, poor funding and limited or no stock of therapeutic devices is a common occurrence in the SA government health sector. In the rural context, these assistive devices issued become a transportation burden as the shape and size of these devices limit transportation and unfortunately, results in poor treatment compliance once dispensed (Mclaren, 2013). The lack of equipment, assistive devices and resources ultimately affects the children with CP and their CGs. These children with CP need to be referred to other hospitals to receive adequate services, which is financially and time restraining (Misbach, 2004).

Issuing of Orthotic devices is a norm in therapeutic rehabilitation. Orthotic devices provide assistance in improving gait, increasing endurance and reducing the formation of contractures, ensuring the management or prevention of associated orthopaedic problems. Orthotic devices include braces, mobility devices, splints and most commonly, ankle-foot orthoses (AFO) (Jan, 2006, Krigger, 2006, Thorogood and Lorenzo, 2013). The responsibility lies within the therapist to measure and provide the children with CP with the correct devices.

2.4 KwaZulu-Natal Public Health Care System

According to the KZN Department of Health (DOH) website, KZN has 11 Health Districts: Amajuba, Ethekwini, Harry Gwala, Ilembe, Ugu, Umgungundlovu, Umkhanyakude, Umzinyathi, Uthukela, Uthungulu and Zululand Health Districts. KZN has a total of 62 hospitals, of which 37 are district hospitals, 14 are secondary hospitals and 1 tertiary hospital (Cullian, 2006).

Hirschowitz and Ngwane (1998) concluded that KZN is mainly a non-urban area making up 21% of South Africa's population of which 6% have a disability. It has an 8% geographical area and is heavily populated with an average of 95 people per square metre. A population percentage of 67% live in non-urban areas in KZN and it has been stipulated that unemployment is higher in these areas.
In KZN 71% of the population use public health services and the majority of these people are from rural areas. In rural households, 66% of those people living there have to travel a minimum of 5kms to access health services as the majority of the public health services are based within a rural environment (Hirschowitz and Ngwane, 1998).

2.4.1 Constraints on Rehabilitative Services in KwaZulu-Natal Public Health Hospitals

South Africa has an already weakened health care system and is struggling to deal with the extreme burden of health issues. Many factors, such as the colonial and apartheid history, inadequate allocation of finances and the shortage of material and human resources are a few reasons why South Africa's public health care system is in such a shambles. Unfortunately, rural areas are the most affected by these concerns (Vawda and Variawa, 2012, Sips et al., 2014). The lack of a CP database was reported by Mclaren (2013) as concern as there is no means to contact or follow up on children with CP, once they default therapy. She concluded that no formalised management of children with CP protocol or clinical procedures, contextualised to SA, has been designed, often leaving the therapists in the dark. To the best of the researcher's knowledge there is only one report on the rehabilitation of children with CP in KZN. The constraints on rehabilitative

services in KZN is limited and because physiotherapy is categorised under rehabilitation, this topic needs to be explored to understand the plight of those PTs working in the KZN public Health sector.

Government‘s disinterest and poor coordination of rehabilitation services result in the poor development of rehabilitation services country wide (Binken and Concha, 2009). There are many factors that ultimately affect the priority of rehabilitation in South Africa, one being the HIV and TB epidemic. Maternal and child care are ranked as one of the highest priorities second to HIV and TB (Cullian, 2006, Vawda and Variawa, 2012, Sips et al., 2014). Rehabilitation services are not listed as a high priority in comparison to the other health services such as reproductive health, chronic diseases, trauma and mental health (Misbach, 2004, Binken and Concha, 2009). However, rehabilitative services are directly or indirectly involved in almost all health programmes in South Africa (Misbach, 2004). Excessive spending by the Government on other so-called priorities ultimately leads to budget cuts and constraints on rehabilitation programmes (Sips et al., 2014). These constraints on the rehabilitation budget result in the loss of much needed therapy posts, ultimately leading to limited human resources (Misbach, 2004). Early identification and treatment to prevent further disability in children with CP are important (Misbach, 2004).The role of Health care professionals is to integrate children with CP into society successfully and Government needs to recognise that children with CP and other people with disabilities have the right to these services and resources (Binken and Concha, 2009).

i. Rural vs. Urban

Children with CP, living in rural areas have fewer prospects of receiving quality rehabilitation care than those living in urban areas. These differences can be due to the structural constraints in the public health sector. Those living in rural areas have very limited access to rehabilitation services as rehabilitation services are underdeveloped and not easily available (Binken and Concha, 2009, Vawda and Variawa, 2012, Mclaren, 2013). Therapists prefer to seek employment in urban and well-equipped hospitals and so rural areas are further under-serviced (Khan, 2005).

ii. Caregivers' beliefs, handover and understanding

PT's working in the public health sector are often faced with cultural beliefs and negative communal attitudes towards people with disabilities. Children with CP are found and managed far too late as families hide them away, afraid of the cultural beliefs and the negative stigma of the child's disability (Mclaren, 2013). CG's often seek the services of a traditional healer even when health care services are available or provided (Ross, 2007). This delay in physiotherapy services ultimately results in poor outcomes and frustrated family members, patients and therapists.

Cultural and language barriers are experienced 80% of the time during clinical interviews and treatment sessions. At times, there is a lack of understanding by the CG on the diagnosis and prognosis of the child with CP, leading to unrealistic expectations, resulting in poor compliance (Jacobs et al., 2006, Mclaren, 2013).

iii. Poor human resources, limited supervision and poor undergraduate and postgraduate CP training

Rehabilitation services according to Binken and Concha (2009) are *"Simply not available to a large number of South Africans."* Why? Services at a Primary Health Care (PHC) level are poor and inadequate due to the high case load of patients and inadequate staffing (Misbach, 2004, Vawda and Variawa, 2012, Mclaren, 2013). Children with CP receive on average a 45 minute treatment, once to twice a month and this is not enough as limited progress can be achieved in this time (Mclaren, 2013). In 2008, 217 PTs were employed in KZN and a total of 214 posts were frozen while 9 posts remained vacant (Directorate, 2008). This is a shocking number when the total population in KZN was 8 572 302 in 2006 and in 2011 the population grew to 10 267 300 (Africa, 2011). As mentioned previously the ratio of patient:therapist is appalling and this lack in human resources is detrimental to those children with CP needing rehabilitative services (Binken and Concha, 2009). In the Western Cape, it has been reported that the ratio of therapist to population is 1:139 189 in comparison to the expected ratio of 1:30 000. Budget constraints, limited planning and the lack of urgency are some of the many reasons for the lack in human resources (Misbach, 2004). Successful rehabilitation programmes require functioning systems, effective mentoring, supervision and adequate referral systems. Supervision is important for

professional development. It has been reported as poor and not effectively addressed in the public health care system (Kilminster and Jolly, 2000, Misbach, 2004).

In South Africa rehabilitation services are not seen as a priority and so there is a shortage of rehabilitation therapists in rural and underserviced areas. To ensure these areas are serviced, community service therapists are often placed within these areas. In her study Khan (2005) reported on the perceptions of the attitudes to compulsory community service programme. She found that CS therapists expressed their concerns of limited support, lack of resources, weak supervision and poor in-service training from experienced staff members. They reported feelings of remoteness and *'not feeling like a professional',* especially in the rural context. In another article that reviewed the experiences of PTs during a CS year, Mostert-Wentzel et al. (2013) found that these CS PTs felt unprepared, and inadequately trained for CS and they raised concerns of receiving little to no supervision. CS therapists have limited experience in CP as undergraduate training doesn't prepare them adequately (Mclaren, 2013). The revision of the CP curriculum at an undergraduate level should be carefully reinvestigated and considered as well as skills required to work in a community setting (Mostert-Wentzel et al., 2013).

In RSA, continuing professional development (CPD) training is available. CPD training and monitoring is a means to ensure that therapists are kept up-to date within their scope of practice. However CPD training is time-consuming, and expensive and due to poor human resources, a staff shortage occurs when a staff member attends training (Maharaj, 2013). When managing and treating children with CP, Mclaren (2013) recommends that therapists should ideally be NDT trained. Poor PT undergraduate training has been reported by Mclaren (2013) consisting mainly of theoretical information on CP but limited practical/hands-on skills. She reported that many therapists employed in state institutions felt *'under-qualified'* when managing children with CP. The South African Neurodevelopmental Therapy Association (SANDTA) provides CP training services to therapists. They offer the following courses:

1. A 1 Week NDT Cerebral Palsy Introduction course.

2. An 8 Week Basic NDT/Bobath Paediatric Training course.
3. Advanced Bobath/ NDT Paediatric course.

These courses, however, are time-consuming and very costly. They are very seldom hosted in a rural area and so the majority of therapists working in rural areas cannot attend these informative courses (Mclaren, 2013). According to the incomplete data collected by Mclaren (2013) only 1 PT in KZN public health is NDT trained.

iv. Co-ordination of rehabilitation services

"Co-ordination within rehabilitation at any level within the health sector is problematic," as reported by Misbach (2004) resulting in the majority of therapists working solely on their own and not in a MDT (Misbach, 2004, Atwal and Caldwell, 2005, Mclaren, 2013). Misbach (2004) informs us that the services of two or more individual disciplines complement each other. Therapists need to work together to encourage adequate services are provided to the children with CP by all disciplines; however, this is not being done, due to the lack of coordination and supervision of these systems.

2.5 Summary of the Literature Review

The literature discussed has revealed that CP is a serious issue, internationally and in South Africa. The management and treatment options for children with CP by health care professionals, including PT's, are discussed in detail.

Although a variety of treatment approaches have been explored and the roles of therapists, caregivers, and parents have been confirmed. There seems to be a lack of information regarding the PT management and treatment of a child with CP in both the rural and urban sectors, with Mclaren (2013) recommending that more studies need to be done on the management of CP with a database required to ensure uniformity in the overall management of children with CP.

From the above, it is evident that there is a gap in the literature on the management approaches of the child with CP by PT's employed within the public

health sector, which needs to be explored. The topic *'Cerebral Palsy'* is widely researched and literature highlights the complex nature of CP but with limitations. In the literature, it is evident that there is a lack of research conducted on this topic in KZN. It is particularly evident that there is limited research available on the PT management of children with CP, in KZN. Therefore this study was designed to determine the management of children with CP, by PTs in public health hospitals of KZN.

CHAPTER 3: METHODOLOGY

3.1 Introduction

In this chapter, the methodology used to conduct the study will be discussed with reference to the design, study population and sample of the study. This chapter describes the data collection tool used, data management, data analysis, and the reliability and validity of the study. Ethical considerations and confidentiality are reflected. The study was conducted from January 2013 to September 2015.

3.2 Ethical Considerations

Ethical clearance was obtained from the Humanities Social Sciences Research Ethics Committee (HSSREC) of UKZN (HSS/0174/015M) (Appendix B) which follows the Declaration of Helsinki. Permission for the use of the public hospitals in KZN was obtained from the KZN DOH National Health Research Division (NHRD) (Appendix A). Permission to gain access to the relevant database of names, email addresses and contact details of potential participants from all 11 districts was obtained from the individual District Managers (Appendix C1-11). Participants received adequate information pertaining to the research and their involvement (Appendix D1 and E). Participants were requested to sign consent forms after reading the details of the study (Appendix D2). The personal details of the participants were not used. To ensure confidentiality and anonymity, each participant was allocated a code number on the consent and questionnaire forms with no direct reference to his identity. All participants were informed that their participation was voluntary and they were allowed to withdraw from the study at any-time. No incentives were provided to those who participated in the study.

3.3 Study Design

The study was a cross-sectional survey of a self-designed questionnaire to meet the objectives being researched. Quantitative data was collected with the use of a self-designed open and closed-ended questionnaire, based on the aim and objectives of the study. The use of a questionnaire for research purposes is an

effective means of collecting data. Questionnaires are used to facilitate the collection of data in a uniform manner. As there are limited studies on this topic, the researcher formulated a self-designed questionnaire based on the aims and objectives of the study (Rattray and Jones, 2007).

3.4 Study Setting

The study population comprised of PT's employed in KZN public hospitals. These hospitals included district (Level 1), secondary (Level 2) and tertiary (Level 3) hospitals. KZN has 11 health districts: Amajuba, Ethekwini, Harry Gwala, Ilembe, Ugu, Umgungundlovu, Umkhanyakude, Umzinyathi, Uthukela, Uthungulu and Zululand health districts (Health, 2015). KZN has a total of 62 hospitals, of which rehabilitation services are only provided at the 37 district hospitals, the 14 secondary hospitals and 1 tertiary (Cullian, 2006).

A total of 10 hospitals was excluded from the study as the contacted participants reported that they did not treat children with CP within their facility. Those representatives who responded stated that their hospitals catered for psychiatric special need patients or spinal cord injured patients and no children with CP were being managed at their facilities. The total number of physiotherapists employed at these facilities was unknown.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion criteria

Participants were included in the study if they satisfied the following criteria:

- A degree in physiotherapy
- Registered with the Health Professions Council of South Africa (HPCSA).
- Employed at a public health hospital in KZN.
- Managed a child with CP.

3.5.2 Exclusion criterion

Participants were excluded from the study on the basis of the following criterion:

- Physiotherapists employed in public hospitals not managing children with CP in KZN.

3.6 Study Population and Sampling

PTs employed at all levels of public health hospitals in KZN were invited to participate in the study. To identify significance variances, interfaces and relationships of the study, a sample size needed to be identified (Bartlett et al., 2001). Based on a statistical analysis, the sample size n=152 would be valid for the study. The sample size (n= 152) was calculated using a formula as represented in figure 3.1.

$$n = \frac{X^2 * N * P * (1-P)}{(ME^2 * (N-1)) + (X^2 * P * (1-P))}$$

Where:

n = sample size

X^2 = Chi – square for the specified confidence level at 1 degree of freedom

N = Population Size

P = population proportion (.50 in this table)

ME = desired Margin of Error (expressed as a proportion)

Figure: 3.1. Formula used to determine the sample size of the study

Hospitals were identified using a public health register sourced from the KZN DOH. A contact database of hospitals and individual therapists was formulated by the researcher with the assistance of the individual District Rehabilitation Coordinators. A Microsoft Excel spread sheet was used to formulate this database owning to frozen posts and posts not being filled, especially in rural-based hospitals, a total of a 137 potential participants' contact details were captured.

The contact details captured were used to forward the questionnaires to all 137 potential participants via email. The researcher attended the KZN PT forum meeting and hand delivered questionnaires to those who attended. They were requested to return the questionnaires via pre-paid postage. The researcher hand delivered questionnaires to hospitals where there was a poor response or where a limited contact database was provided. To avoid any duplicate returns of

questionnaires, participants were requested not to complete the questionnaire if they had already done so. The researcher requested that completed questionnaires be returned via pre-paid postage provided.

The study received 72 completed questionnaires, of which 41 respondents practiced in the rural sector and 31 in the urban sector. The response rate was 52.6%. The researcher received a total of 45 responses from potential participants who were not interested in the study, 6 participants had invalid contact details and 1 participant was on extended sick leave.

3.7 Pilot Study

A pilot study was conducted, prior to the study to refine the questionnaire further. As the questionnaire was self-designed and had not been validated in any previous studies, it was tested through the conduction of a pilot study to sharpen up the wording and content as desired by Rattray and Jones (2007) . The aim of the pilot study was to analyse the usability and ensure that questions were relevant and grammatically correct.

The researcher randomly selected 20 participants from the contact database. Information documents and consent forms were sent to potential pilot study participants (Appendix G1-2). A total of 7 participants responded; their results were not included in the final outcome of the study. The pilot study allowed the participants to comment and this was done via a feedback form (Appendix H). Minor modifications were done to the questionnaire, prior to the study, which included the adjustment of numbering and grammatical errors to ensure that the questionnaire was comprehensible, as requested by the pilot study group. Following the pilot study the final questionnaire was designed and returned to those 7 pilot study participants for final analysis. No further adjustments were requested.

3.8 Data Collection Tool

3.8.1 Questionnaire

Questionnaires are used to facilitate the collection of data in a uniform manner. As there are limited studies on this topic, the researcher used a self-designed questionnaire based on the aim and objectives of the study (Rattray and Jones, 2007). A three-section questionnaire was designed using Microsoft Word with open and closed ended questions to evaluate the management approach of children with CP in KZN public health hospitals.

The 3 sections of the questionnaire comprised:

- Section A- Physiotherapists Profile and Demographic Information.
- Section B- The Physiotherapy Management of Children with Cerebral Palsy Children in KwaZulu-Natal Public Hospitals.
- Section C- KwaZulu-Natal Public-Employed Physiotherapists' views on the Management of Children with Cerebral Palsy.

The close-ended questions required the participants to select either one or various options. The open-ended questions required the participants to record their views by writing or typing their answers in the fields provided. Rattray and Jones (2007), encourages both the use of open and closed-ended questions to ensure a greater response and avoid incomplete data collection.

3.9 Data Collection Procedures

The questionnaire was emailed, hand delivered at meetings and at hospitals (Appendix F). Participants were able to access the questionnaire in one of the three ways; by email (where computer and internet services were available), in person at meetings or within their hospital setting. Participants who received hard copied questionnaires received self-addressed envelopes and pre-paid postage to return the questionnaires to the researcher. The researcher also arranged to collect completed questionnaires from various hospitals. As mentioned above to follow up on non-respondents, each questionnaire was coded that matched a master list of names. Every 2 weeks, a questionnaire was emailed to non-respondents. A contact database of the individual physiotherapy departments was

formulated and telephone calls were made and emails were sent with a request to encourage the potential research participants to complete the questionnaire, emphasizing the importance of the study to the profession of PT and CP body of research.

3.10 Data Management and Confidentiality

The questionnaires collected were coded with no names or reference to the individual participant or hospital to ensure confidentiality. Data collected was only accessible by the researcher via a password and username. The Questionnaires and consent forms received via post or collected in person at the PT forum meeting and in person were stored systematically in waterproof boxes in a safe. The researcher used a personal post office box and computer to receive completed questionnaires. Questionnaires returned via email were stored both on the researcher's personal computer and external hard drive to which only the researcher had pin access too. This data is only accessible by the researcher with the use of an access pin. Once the researcher had collected all the information needed, only the relevant information was shared with the supervisor and statistician for analysis. The data that was captured was stored and will be kept for a period of five years and destroyed thereafter.

3.11 Data Analysis

The completed questionnaires were systematically entered into a Microsoft Excel 2000 spread sheet. The data recorded was sent to the statistician who used a Statistical Package for Social Sciences SPSS Version 23 for analysis.

Data was described at each point using descriptive statistics. The demographic data was analysed using frequency tables. The significance was set at $p < 0.005$; the Pearson's Chi Square test was used to test association between rural and urban management approach characteristics. Frequency tables and graphs were used to analyse the management approaches, equipment used and assistive devices available.

The open ended questions were subjected to qualitative analysis. The researcher analysed the data using a thematic analysis approach. According to Braun and Clarke (2006), thematic analysis is the foundational method for qualitative analysis which can provide a thorough report of the data collected. Thematic analysis concentrates on and identifies common or similar themes and patterns that form a collective expression for systematic and non-biased analysis (Nyagah and Frantz, 2006). All data collected was analysed into themes, grouping the participant's perceptions and allowing for a systematic analysis. An independent research associate was requested to validate these themes to ensure that the researcher was not biased.

3.12 Reliability and Validity

A self-administered questionnaire was used. To ensure validity and reliability of the study, a pilot study was conducted with an option to return a feedback form (Appendix H). The information and feedback provided from the pilot study allowed the researcher to alter the questionnaire accordingly. The altered questionnaire was re-sent for further feedback to the pilot study participants to ensure face validity was obtained.

The researcher consulted independent research associates, academics and similar published questionnaires to analyse the questionnaire and questions expressed to ensure content validity of the study as recommended by Huijbregts et al. (2002). Once data was captured the researcher formulated themes and categories for analysis and a discussion, to avoid bias behaviour, the researcher consulted fellow researchers to compare themes generated.

CHAPTER 4: RESULTS

4.1 Introduction

This Chapter presents the results of the study with respect to the study objectives. A total of 72 (N=72) completed questionnaires were returned, yielding a (52.6%) response rate from which data was analysed.

4.2 Demographic Characteristics

As shown in Table 4.1 of the 72 responses, 43 (59.72%) were aged between 22-30 years and 23 (31.94%) were aged between 31-40 years old. The mean age was 32 years old. Sixty three (87.5%) were female. The majority of the respondents 33 (45.1%) had 1-5 years of experience and most of the participants 52 (72.2%) had completed their undergraduate training at the University of KwaZulu-Natal while 41 (56.9%) worked in the rural sector. Only 12 (16.7%) had completed any postgraduate training in CP. Most of the study participants 29 (40.8%) were employed in the Ethekwini Health District while the majority, 20 (27.8%) of the respondents were ranked as junior PTs.

Table 4.1 Socio-demographic data. (N=72)

Category	Variable	N (%)
Age of respondents	22-30	43 (59.8)
	31-40	23 (31.9)
	41-50	6 (8.3)
Gender	Female	63 (87.5)
	Male	9 (12.5)
Years of experience	1-5 years	33 (45.1)
	6-10 years	25 (35.2)
	11-15 years	8 (11.3)
	16-20 years	1 (1.4)
	21-25 years	4 (5.6)
	26+	1 (1.4)
Place of undergrad training	University of KwaZulu-Natal	52 (72.1)
	University of Cape Town	7 (9.7)
	University of Witwatersrand	4 (5.6)
	Stellenbosch University	4 (5.6)
	University of Limpopo	3 (4.2)
	University of Pretoria	1 (1.4)
	Other	1 (1.4)
District of employment	Ethekwini	29 (40.8)
	Ugu	10 (12.7)
	Harry Gwala	6 (8.5)
	Umgungundlovu	6 (8.5)
	Uthukela	6 (8.5)
	Amajuba	4 (5.6)
	Umkhanyakude	4 (5.6)
	Ilembe	3 (4.2)
	Uthungulu	3 (4.2)
	Zululand	1 (1.4)
	Umzinyathi	0 (0.0)
Sector of employment	Rural	41 (56.9)
	Urban	31 (43.1)
Status of employment	Community service PT	15 (20.9)
	Junior PT	20 (27.8)
	Senior PT	14 (19.4)
	Chief PT	14 (19.4)
	Assistant director of PT	9 (12.5)
Cerebral palsy postgrad training	No	60 (83.3)
	Yes	12 (16.7)

4.3 Objective 1. To Describe the Current Physiotherapy Management of Children with CP in KZN Public Hospitals.

i. Supervision of management of children with CP

In the study only 20 (27.8%) received supervision while managing children with CP. Those PTs who received supervision, received it majority from a Chief PT 7 (28.6%) followed by the Director of PT 5 (23.8%) and a Medical manager 4 (19.0%). Of those 52 (72.2%) who didn't receive supervision the reasons for no supervision was established with majority reporting that no supervisory physiotherapy posts were available 16 (18%) followed by no funding for posts 12 (19.2%).

ii. Management approach

In the study the majority of the participants 35 (48.6%) treated on average 1-10 children with CP a month (Table 4.2). Thirty one (43.1%) of the study candidates treated children once a month and 43 (56.9%) of the study participants spent on average, approximately 0-30 minutes treating children with CP.

Table 4.2 Number of children with CP treated in a month (N=72)

Number of Children	N (%)
1-10	35 (48.6)
11-20	17 (23.6)
21-30	10 (13.8)
31-40	4 (5.6)
41-50	1 (1.4)
51-60	3 (4.2)
61-70	1 (1.4)
71+	1 (1.4)

Only 25 (34.7%) of the respondents used standardised CP outcome measures and the most common forms used were self-developed PT assessment forms, 18 (72.0%), followed by GMFCS 4 (16.0%) and Bobath/NDT influenced outcome measures 3 (12.0%) (Figure 4.1).

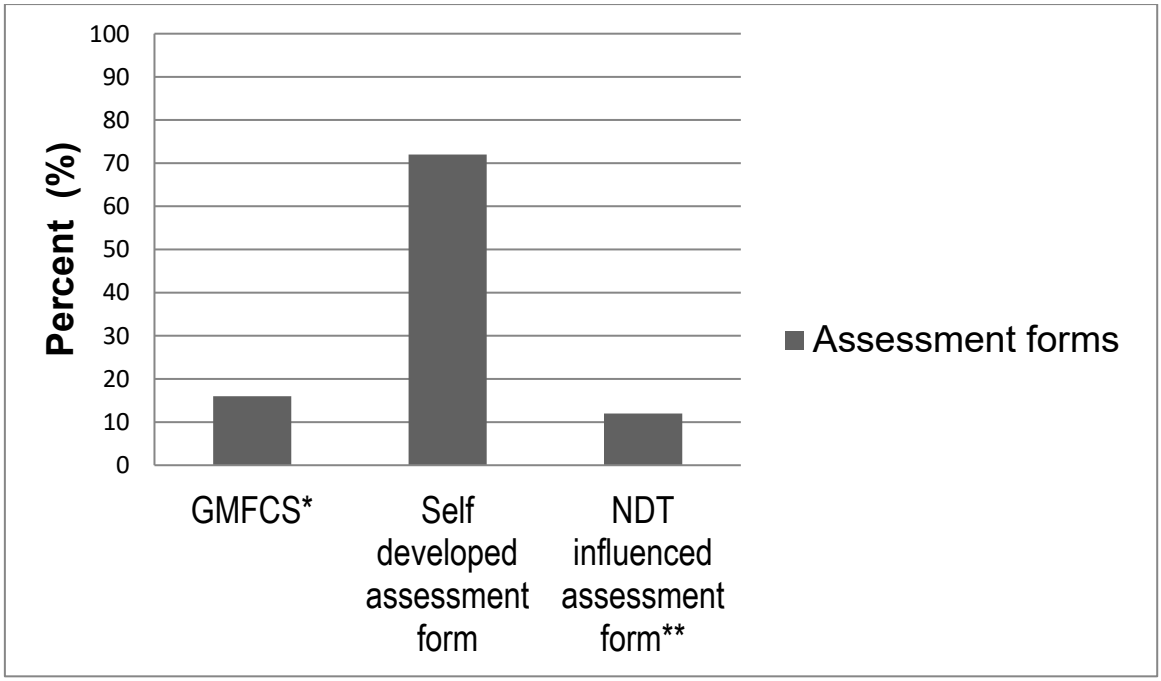

Figure 4.1 Type of outcome measures used

*GMFCS = Gross Motor Functional Classification Scale
**NDT = Neurodevelopmental Therapy

A Likert scale ranging from one (i) (minor importance) to five (iv) (major importance) was used to capture the importance of the common treatment techniques, modalities and theories used when managing children with CP. The most important treatment techniques/theories/modalities as reported by the participants were postural stabilizing activities 68 (94.4%) followed by respiratory care 67 (92.9%) and positioning 67 (92.9%). The least important treatment technique/theory/modality was constraint induced therapy 21 (28.2%) (Table 4.3).

Table 4.3 The importance of different treatment techniques by PTs managing children with CP (N=72)

Treatment techniques	Likert Scale			
	5-4	3	2-1	N/A
	Major importance N (%)	Moderate importance N (%)	Minor importance N (%)	N/A N (%)
Passive mobilizations	58 (80.2)	11 (15.5)	3 (4.2)	0 (0.0)
Milestone progression	65 (90.3)	4 (5.6)	2 (2.8)	0 (0.0)
Sensory stimulation e.g. Visual/tactile/auditory stimulation	60 (83.3)	9 (11.1)	2 (2.8)	1 (1.4)
Constraint Induced Therapy	13 (18.3)	11(15.5)	21 (28.2)	27 (38.0)
Neuro-Developmental Therapy (NDT) Approach	55 (76.1)	9 (12.7)	3 (4.2)	5 (7.0)
Feeding and swallowing management	52 (71.8)	8 (11.3)	5 (7.0)	7 (9.7)
Soft tissue mobilisations	42 (58.3)	13 (18.1)	13 (18.1)	3 (4.2)
Stretching	61 (84.5)	7 (9.9)	3 (4.2)	1 (1.4)
Production of splints	31 (41.7)	16 (22.2)	9 (12.5)	16 (22.2)
Positioning	67 (92.9)	1 (1.4)	3 (4.2)	1 (1.4)
Nutrition	51 (70.4)	9 (12.7)	4 (5.6)	8 (11.3)
Activities of Daily living	60 (83.1)	9 (12.7)	2 (2.8)	1 (1.4)
Issuing assistive devices	62 (85.9)	6 (8.5)	0 (0.0)	4 (5.6)
Gait re-education	58 (80.3)	7 (9.9)	2 (2.8)	5 (7.0)
Standing activities	65 (90.0)	3 (4.3)	2 (2.9)	2 (2.9)
Communication	51 (70.5)	14 (19.7)	2 (2.8)	5 (7.0)
School assessments	37 (51.4)	13 (18.1)	4 (5.6)	17 (23.6)
School placements	38 (52.1)	13 (18.3)	4 (5.6)	17 (23.9)
Wheelchair positioning	60 (83.1)	3 (4.2)	2 (2.8)	7 (9.9)
Postural stabilizing activities	68 (94.4)	2 (2.8)	0 (0.0)	2 (2.8)
Range of movement activities	66 (91.5)	2 (2.8)	1 (1.4)	3 (4.2)
Social welfare e.g. grant applications etc.	44 (60.5)	9 (12.7)	3 (4.2)	16 (22.5)
Respiratory care	67 (92.9)	4 (5.6)	0 (0.0)	1 (1.4)
Education on cerebral palsy to the caregiver e.g. Cause, effects, management options etc.	60 (83.4)	3 (4.2)	0 (0.0)	2 (2.8)

*N/A= Not Applicable

In the study, only 26 (36.1%) of the study participants reported taking part in CP clinics. Of these, 26 (36.1%) the majority, 11 (44.0%) managed their children with CP in MDT followed by individual management approaches 7 (26.0%) and group based 6 (22.0%). The commonest organisational strategy was a random selection

into groups 9 (35.5%). Most participants 19 (73.2%) hosted their CP clinics in the PT department.

iii. Availability of therapeutic equipment

In the study, the majority of the respondents reported that their departments were mainly equipped with therapy mats 70 (97.2%), pillows 70 (97.2%), towels 69 (95.8%), low plinths 67 (93.1%) and parallel bars 63 (87.5%), with an equipment limitation on weighted vests 71 (98.6%), hammocks 69 (91.1%) and soft tunnels 56 (77.8%) (Table 4.4).

Table 4.4 Availability of therapeutic equipment (N=72)

Equipment	Yes N (%)	No N (%)
Low plinth	67 (93.1)	5 (6.9)
High plinth	62 (86.1)	10 (13.9)
Therapy mats	70 (97.2)	2 (2.8)
Adjustable paediatric standing frame	35 (48.6)	37 (50.0)
Wedges	58 (80.6)	14 (19.4)
Therapy blocks	28 (38.9)	44 (61.1)
Therapy bench	22 (30.6)	50 (69.4)
Parallel bars	63 (87.5)	9 (12.5)
Suspension frame	17 (23.6)	55 (76.4)
Massage oils	63 (87.5)	9 (12.5)
Towels	69 (95.8)	3 (4.2)
Pillows	70 (97.2)	2 (2.8)
Screens	60 (83.3)	12 (16.7)
Dispensable foam, fabric and cushions required for wheelchair positioning	25 (34.7)	47 (65.3)
Tactile toys e.g. bean bags/ fabric booklets/ rice box etc.	67 (65.3)	25 (34.7)
Visual toys e.g. mirrors/ tinsel/ lights etc.	58 (80.6)	14 (19.4)
Auditory toys e.g. noise making books/puzzles/keyboards/ whistle etc.	53 (73.6)	19 (26.4)
Therapeutic stairs	38 (52.8)	34 (47.2)
Balance/equilibrium board	53 (73.6)	19 (26.4)
Climbing wall	21 (29.2)	51 (70.8)
Rollers	54 (75.0)	11 (25.0)
Soft tunnel	16 (22.2)	56 (77.8)
Large therapy balls	61 (84.7)	11 (15.3)
Small therapy balls	55 (76.4)	17 (23.6)
Scooter board	60 (83.3)	12 (16.7)
Hammock	3 (4.2)	69 (95.8)
Weighted vest	1 (1.4)	71 (98.6)
Nebuliser	51 (70.8)	21 (29.2)
Suction machine	55 (76.4)	17 (23.6)
Cerebral palsy information pamphlets	55 (76.4)	17 (23.6)

Most participants, 48 (66.7%) reported that they thought their departments were equipped adequately. However, 51 (70.8%) reported that there was insufficient stock of assistive devices for children with CP. The participants 21 (29.2%) who reported having sufficient stock; buggies 8 (35.8%) and wheelchairs 8 (35.8%) were among the most distributed assistive devices with reference to other 2 (11.3%) being Ankle Foot Orthoses (AFO's), crutches, drooling cuffs and picture/electronic communicative devices. (Figure 4.2)

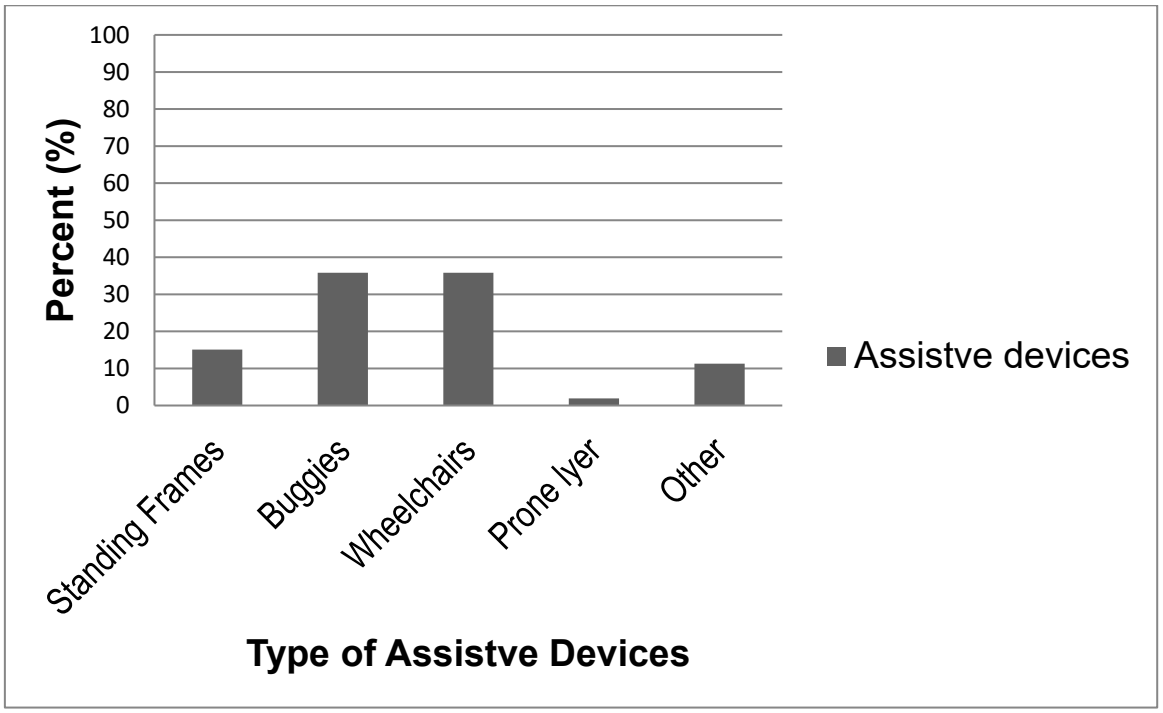

Figure 4.2 Availability of assistive devices

4.4 Objective 2. To Determine if Physiotherapists Employed in KwaZulu-Natal Consider the Public Hospital Management of Cerebral Palsy Effective.

In this study most of the PT's 32 (44.4%) reported that they *'sometimes'* felt adequate and equipped with the sufficient skills to treat a child with CP. In this study only 12 (16.7%) PT's from this study completed postgraduate training. Of the 12 (16.7%) the majority 3 (28.6%) completed the one week Paediatric NDT course, followed by 2 (14.3%) that attended the eight week Paediatric NDT course.

Those respondents 60 (83.3%), who did not attend CP postgraduate training, cited the main reasons as: no funding 19 (31.3%), followed by time constraints 14 (22.8%) and disinterest in CP 13 (20.9%).

i. The positive and negative experiences of managing children with CP

The positive experiences were divided into themes: Improving the QOL of the child with CP and CG, achieving functional goals, education, prevention of complications and interest in paediatrics. Table 4.5 lists these themes from the major contributing experiences to the minor; improving the QOL of the child with CP and CG appeared to be the most positive experience felt by the majority of the respondents 26 (36.1%).

Table 4.5 Positive perceptions of KZN PTs managing children with CP (N=72)

Theme	N (%)
Improving the QOL	26 (36.1)
Achieving functional goals	20 (26.7)
Education	9 (12.8)
Interest in paediatrics	9 (12.8)
Prevention of complications	8 (11.6)

In the study, the negative experiences felt by the respondents were categorised into the following themes: slow progression of treatment goals, CG complications, lack of resources and feelings of inadequacy. The most collective negative experience reported was the slow progression of treatment goals 25 (35.4%), followed by CG complications 21 (29.1%) and a lack of resources 10 (14.6%).

ii. Challenges faced by physiotherapists in KZN public Health

The majority of the respondents 63 (87.5%) reported experiencing one or more challenges whilst managing children with CP. Of the 63 (87.5%) the biggest challenge experienced were complications with the CG's 21 (34.1%) and limitation of resources and services 19 (29.7%) (Table 4.6).

Table 4.6 Challenges faced by PTs managing children with CP (N=63).

Theme	N (%)
Limited resources and services	19 (29.7)
• No equipment/assistive devices	9 (14.1)
• Poor staffing	4 (5.9)
• Time constraints	4 (5.9)
• Special school placements	2 (3.8)
Caregiver complications	21 (34.1)
• Non-compliance of HEP	9 (13.3)
• Unrealistic goals	2 (3.7)
• Language barrier	4 (6.7)
• Defaulting treatment	4 (6.7)
• Disinterest in CP	2 (3.7)
Infrequent visits	7 (11.1)
Late referrals	4 (6.6)
Feelings of inadequacy	12 (18.5)
• Limited undergrad training	9 (13.3)
• No postgraduate training	3 (5.2)

4.5 Objective 3. To Determine if there is a Difference in the Physiotherapy Management of Children with CP in Rural and Urban KZN Public Hospitals.

In the study, 41 (56.9%) of the respondents from rural hospitals completed the questionnaire and 31 (43.1%) from urban hospitals. Of those who were based in a rural hospital, a total of 22 (53.7%) participated in CP clinics which were significantly different (p= 0.001) from those urban based PT's. Of those who were based in a urban hospital, 4 (12.9%) out of the 31 (43.1%) participated in CP clinics.

Table 4.7 represents the comparison between rural based PTs to urban based PTs regarding the management approaches of children with CP. Participants were allowed to select more than one management approach, where a significant difference was found (p=0.001), that the majority of urban based PT's 23 (77.4%) managed children individually. A slight but significant difference was noted (p=0.002) regarding a MDT management approach where Rural based PT's 39 (95.1%) in the study managed children with CP in a MDT.

Table 4.7 Comparison of rural sector PT's and urban based PTs in relation to the management approach of children with CP (N=72).

Management approach	Rural N (%)	Urban N (%)	p value p*
Individual	13 (31.7)	23 (77.4)	0.001*
Inter-professional	4 (9.8)	8 (25.8)	0.070
MDT	39 (95.1)	21 (67.7)	0.002*

*P<0.005 is considered significant

Figure 4.3 illustrates that of those PT's working in Rural, only 13 (31.7%) received supervision and those PT's working in urban hospitals only 7 (22.5%) received supervision. There was no significant difference of supervision received between rural and urban based PT's in the study, with the p value being 0.392.

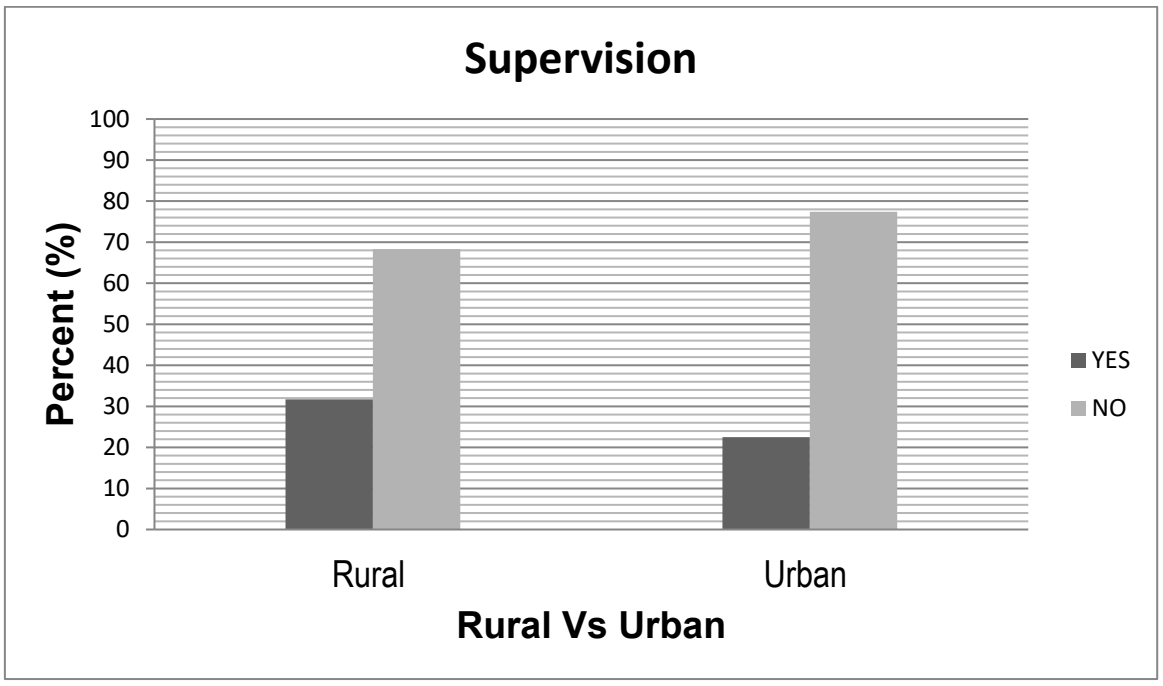

Figure 4.3 Supervision of PTs in urban and rural hospitals

The majority of rural based PT's managed children with CP on a monthly basis 21 (51.2%) which was significantly different (p=0.001) as the majority of those urban-based PTs in this study reported managing children with CP on a bi-monthly basis 19 (61.3%) (Figure 4.4). In the study the majority of both rural 19 (46.5%) and urban-based PTs 21 (70.9%) treated children with CP for approximately 0-30

minutes reflecting no significant difference where the p value was 0.052 (Figure 4.5).

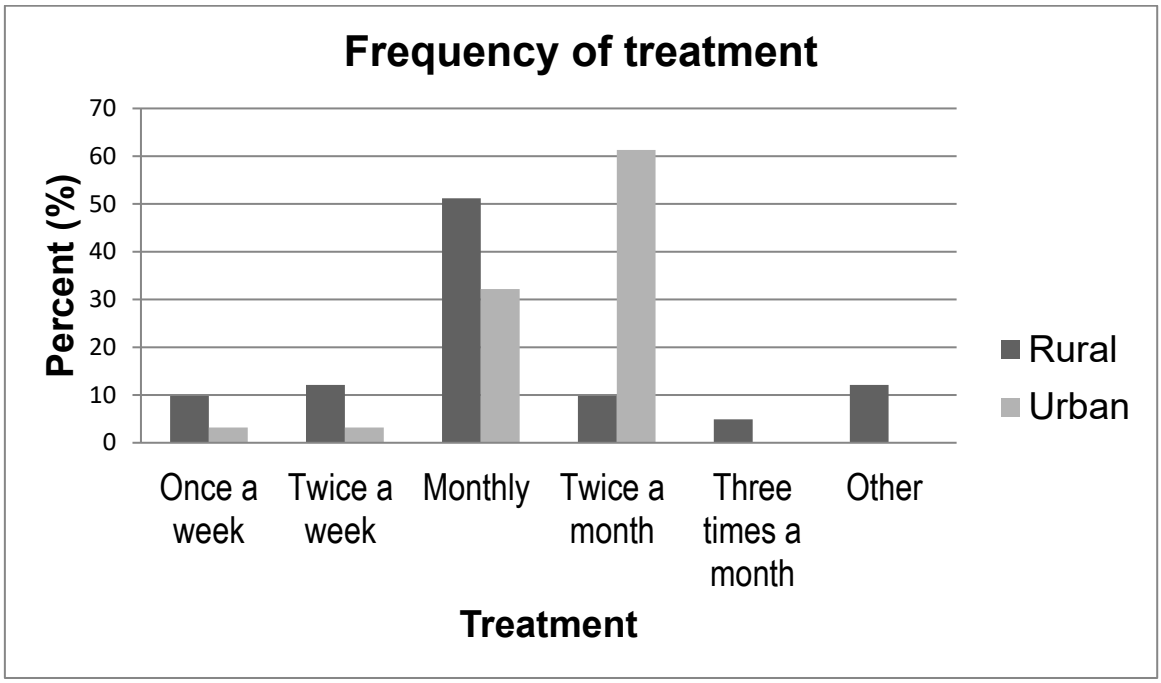

Figure 4.4 Frequency of Physiotherapy CP treatments in rural and urban hospitals

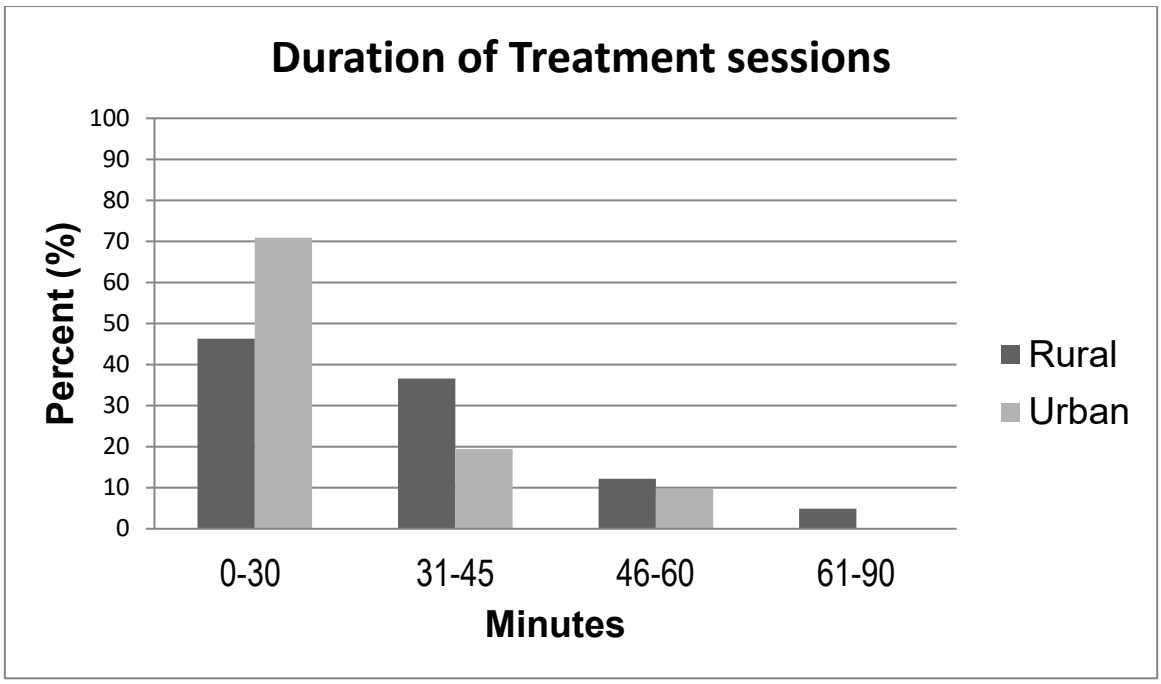

Figure 4.5 Duration of PT treatment sessions

4.6 Objective 4. To Determine if a Multidisciplinary Team Approach is Included in the PT Management of Children with CP in KZN Public Hospitals.

i. Management approach of children with CP

Of the 72 participants, 32 (44.2%) reported managing children with CP individually, 8 (10.8%) in an inter-professional team and 32 (45.0%) in a MDT approach (Table 4.8).

Table 4.8 Management approach of children with CP (N=72)

Management approach	N (%)
Individual management	32 (44.2)
Inter-professional management	8 (10.8)
Multidisciplinary Team management	32 (45.0)

ii. MDT management

Of the 32 (45.0%) who used a MDT the most common health care practitioners with whom the PT's worked with were medical officers 30 (94.4%), OTs 27 (83.3%) and SLT's 23 (70.8%). All respondents from the study reported that they referred children with CP onto other health care professionals, of which the majority of the referrals went to a medical officer 72 (100%), followed by an OT 67 (93.1%) and SLT 65 (90.3%). Those health care professionals mentioned under other (2.8%) were reported as being Audios, dentists and ophthalmologists.

iii. MDT meetings

In the study 31 (43.1%) of the PTs attended MDT meetings and those health care professionals who attended primarily were reported by the 31 (43.1%) as Medical officers 31 (100%), followed by OTs 12 (41.7%) and SLTs 11 (40.3%). Of the other 41 (56.9%) participants who did not attend MDT meetings, the restricting factors influencing the arrangement of MDT meetings were thematically analysed into the themes represented in Table 4.9.

Table 4.9 Restricting factors influencing the arrangement of MDT meetings (N=41)

Restricting factors	N (%)
No interest	14 (31.7)
Time constraints	11 (26.8)
Limited availability of health care professionals	6 (14.6)
Poor organisation and co-ordination	6 (14.6)
High workload	4 (9.8)

iv. Caregiver inclusion

Seventy one (98.6%) of the respondents considered the CG an important individual and the 71 (98.6%) research participants included the CG in the management of a child with CP in the following themes listed in Table 4.10. Research participants were allowed to provide more than one answer.

Table 4.10 PT inclusion techniques of the CG (N=71)

Inclusion techniques	N (%)
Education	51 (71.8)
Active participation	26 (36.6)
Personal goal identification	10 (14.1)
Counselling	5 (6.7)

In this study, all the participants reported challenges experienced whilst including the CG in their management approach. Thirty six (50%) of the PT's reported that cultural beliefs were a serious challenge followed by the CGs' disinterest in therapy services 35 (48.6%) and 21 (29.2%) reported that the lack of understanding was challenging at times. The least challenging experience was language barriers 16 (22.0%) (Figure 4.6).

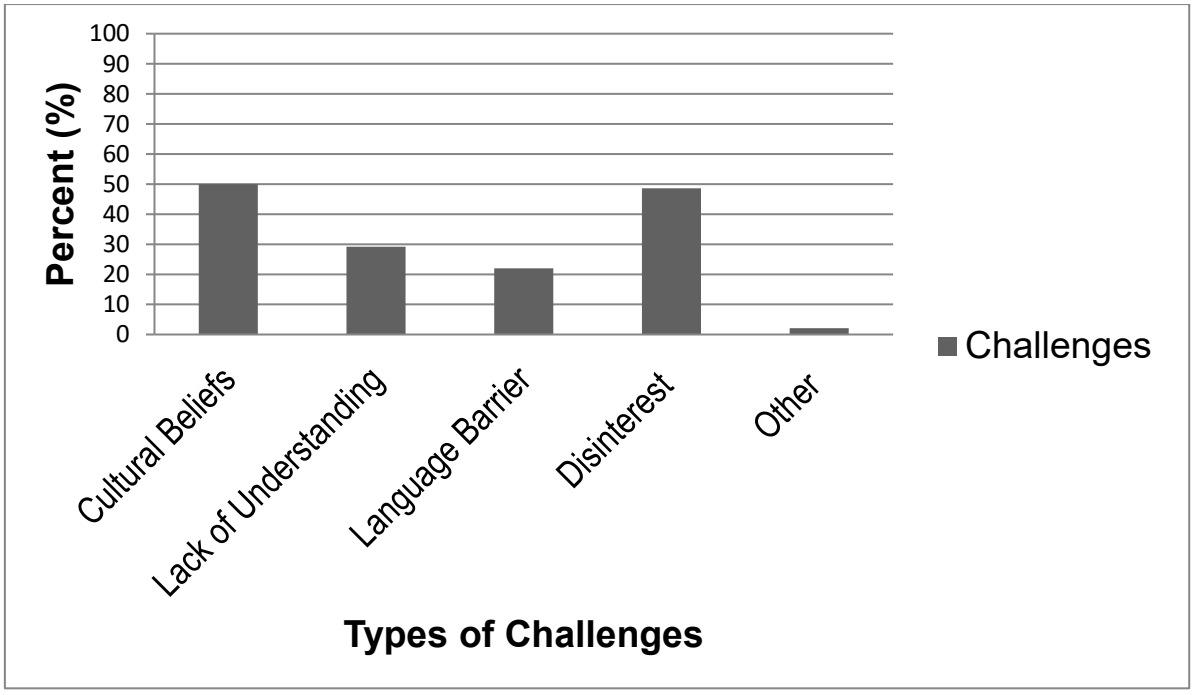

Figure 4.6 Challenges experienced by the PTs managing children with CP

A Likert scale ranging from 1 (minor importance) to 5 (major importance) was used to capture the importance of the management theories when including the CG in the management of children with CP approach (Table 4.11). Of the 71 (98%), handover management techniques 69 (97.2%) was the most important theory in the inclusion of a CG.

Table 4.11 Importance of management theories in CG handover management of children with CP (N=71)

No.	Theory	Likert			
		5-4	3	2-1	N/A
		Major importance N (%)	Moderate importance N (%)	Minor importance N (%)	N/A N (%)
1.	Handover management techniques	69 (97.2)	1 (1.4)	0 (0.0)	1 (1.4)
2.	CG back care techniques	64 (90.2)	5 (6.9)	2 (2.8)	0 (0.0)
3.	Social Welfare and needs	61 (86.1)	7 (9.7)	1 (1.4)	2 (2.8)
4.	Issuing educational pamphlets	58 (82.0)	7 (9.7)	5 (6.9)	1(1.4)

4.7 Objective 5. To source potential improvements on the current management of children with CP in public hospitals of KZN.

i. Recommendations by PT's in KZN public health to improve the management of children with CP

In the study, 58 (80.6%) participants provided recommendations to improve the management of children with CP in KZN public health. These recommendations were categorised into 9 themes: training, improving availability of assistive devices and rehabilitation equipment, CG involvement, the early referral of children with CP, encourage a MDT approach, block therapy, CP clinic rehabilitation centre development, a database collaboration and employing translators. Table 4.12 illustrates these themes with improving the skills of PTs (33.5%) being the major recommendation provided.

Table 4.12 Recommendations by PT's to improve the management of children with CP in KZN public health (N=58).

Themes	N (%)
Training	19 (33.5)
• Undergrad training	5 (7.8)
• Postgrad training	13 (22.8)
- Government to pay	7 (12.6)
- Time off	3 (5.1)
- In KZN	3 (5.1)
• In-service training	1 (2.9)
Improving availability of resources	15 (25.6)
• Assistive devices & rehabilitation equipment	10 (17.8)
• Staffing	3 (5.9)
• Transportation	1(1.9)
CG involvement	10 (16.6)
• Education	4 (6.9)
• Home visits	1 (1.9)
• Support groups	5 (7.8)
Early referral	3 (5.9)
MDT approach	3 (5.9)
Block therapy	2 (2.9)
CP clinic Rehabilitation centre development	3 (5.8)
Database collaboration	2 (2.9)
Employing translators	1 (0.9)

CHAPTER 5: DISCUSSION

5.1 Introduction

Inadequate service delivery is failing the children with CP of KZN. It has become increasingly evident that a lack in human resources, limited equipment and resources, are ultimately affecting the service delivery of PT's in KZN, both within the rural and urban setting. The aim of the study was to investigate the current PT management of children with CP, in KZN public hospitals, with the objectives of identifying current management practices of children with CP in urban and rural public hospitals to improve the management of children with CP. The results are discussed in relation to the objectives and to other studies conducted internationally.

5.2 Socio-demographics Characteristics of the Participants

In this study the majority of the respondents was female, physiotherapy is predominantly a female occupation and may be the reason for the high female sample size (Johansson, 1999). Most of the participants graduated from the University of KwaZulu-Natal and perhaps, the high sample size of UKZN PT's may be due to the demographical nature of the study. The majority of the participants, 41 (56.9%), were employed at a rural hospital, supporting the literature of Hirschowitz and Ngwane (1998), stating that KZN is mainly a non-urban area.

5.3 Objective 1. To Describe the Current Physiotherapy Management of Children with CP in KZN Public Hospitals.

i. Supervision of PT's

PT's are professional clinicians and are capable of working independently. However, inexperienced and newly qualified PTs should ultimately receive supervision and guidance while working. In this study, only 20 (27.8%) of those PT's managing children with CP, received supervision. Supervision is critically important to enhance skill development, clinical understanding and reasoning (Kilminster and Jolly, 2000). Kilminster and Jolly (2000) state that effective

supervision requires time and appropriate staffing and this is just not viable in SA due to the lack of employed health care professionals as mentioned by Mclaren (2013). No funding and no posts available for health care professionals were highlighted as reasons for the limitation on PT supervision as jointly stressed by Mclaren (2013) and Misbach (2004) that government's budget constraints and disinterest in therapy services have resulted in inadequate staffing directly affecting the PT supervision.

ii. Management approach of children with CP

Although the management of CP is widely researched, nationally limited research has been reported on the management of children with CP by KZN PTs, making it difficult to compare the results of this study to other research. Regarding the management approach, majority of the participants in this study mentioned that they encouraged a MDT approach as discussed later on in objective 4. To analyse the management approach of children with CP further, the majority of PTs in this study, reported managing on average one to 10 Children with CP a month. The demand of one to 10 children with CP seems possible, however this does not correlate with the incidence of CP as reported by Christianson (2002) that 80/1000 children in SA are diagnosed with CP and it is known that only (30%) of children with disabilities are receiving public health services (Couper, 2002). The possible reason may be due to the poor response rate, despite the researcher's best efforts.

In the study, respondents reported managing children with CP predominantly, on a monthly basis. According to Mclaren (2013), a programme of monthly treatments is not desirable, nor effective. There are many factors described by Sips et al. (2014), Mclaren (2013) and Misbach (2004) as to the reasons why monthly treatments are only possible. These are: inadequate staffing, high patient volumes and financial constraints faced by CP CG's to attend regular therapy.

A limited number of PT's in the study reported using standardised outcome measures and of those 24 (34.7%) PT's, the majority 17 (72.0%), used self-developed assessment forms. The effective assessment of a child with CP is vitally important, so that PT's can establish goals, treatment plans and record the

progression of therapy (Krigger, 2006). Perhaps a possible explanation for this limited use of outcome measures, in the management of children with CP, is that the completion of outcome measures can be tedious and time consuming, and perhaps the high patient volumes experienced and as mentioned by Misbach (2004), health care professionals in RSA do not have the adequate time to evaluate and manage children with CP, effectively.

The common treatment techniques in managing children with CP were surveyed in the study. Of the 25 proposed treatment techniques/theories, four major treatment techniques were commonly practised. Postural stabilizing activities were the most common treatment techniques, similarly supported by the findings of de Graaf-Peters et al. (2007). Respiratory complications, mentioned in the literature review, easily arise in severely affected children with CP and chest physiotherapy is an effective means of improving lung and respiratory function and as highlighted by the PT's in the study, the second most important treatment theory, supporting the findings of Hall et al. (1991) and Ntoumenopoulos et al. (2002).

Positioning of a child with CP was rated one of the major important treatment techniques. A possible explanation for this as, reported by Krigger (2006), may be that inadequate positioning of a severely affected child with CP can result in many complications mainly: respiratory complications, orthopaedic impediments and bladder and bowel dysfunctions. The avoidance of these complications and clinical manifestations are what PT intervention strives to adhere to by improving the functionality and physical performance of a child with CP, as supported by Thomas et al. (2014) .

The PT's indicated that constraint-induced movement therapy was viewed as a treatment theory of minor importance, suggesting that other theories are predominantly of greater importance. However, constraint-induced movement therapy as mentioned by Taub et al. (2004) demonstrates remarkable benefits of improved motor skills and that perhaps, PT's in KZN have not received adequate training on this specific treatment approach. Constraint-induced movement is therapy predominantly a treatment associated with children with CP, affected unilaterally, such as in the case of spastic hemiplegia, making up (25%) of the CP

population as represented in Figure 2.2 in the literature review. (Taub et al., 2004) This suggests that PT's from the study do not treat a limited number of spastic hemiplegic children with CP.

Thomas et al. (2014) suggest that CP clinics contribute to an empowered social support structure. Patients and CG's are able to meet and allow for similar interaction, contributing to improved therapy participation. However, very little evidence is available to report on the effectiveness of CP clinics, in this study. Only 25 (36.1%) of the participants reported taking part in CP clinics, suggesting that the PT's feel strongly that individual therapy is best suited as supported by (Mclaren, 2013).

iii. Availability of resources and assistive devices

In this study, the majority of the respondents, 48 (66.7%), indicated that their departments were adequately equipped with enough equipment to manage children with CP. Assistive devices are needed for the management of children with CP, to ensure the maintenance of adequate positioning, to encourage mobility, communication and an overall improvement in the QOL (Mclaren, 2013). However, the high percentage of the study participants, 50 (70.8%), showed that there was insufficient stock of assistive devices to dispense to the children with CP, in KZN public health. This corresponds with the literature, that the limitation and delay of obtaining assistive devices is a common occurrence in SA (Mclaren, 2014). Government's low priority regarding the development of rehabilitation services places budget constraints on the rehabilitation services and ultimately, effects the procurement of assistive devices (Misbach, 2004, Mclaren, 2013).

5.4 Objective 2. To Determine if PTs Employed in KwaZulu-Natal Consider the Public Hospital Management of CP Effective.

Of those PTs in the study, only 26 (36.1%) reported feeling adequate in managing children with CP. While there are many factors that may affect a PT's feelings of inadequacy, research has shown that those individuals, who take part in learning activities, significantly enhance their skills (Maharaj, 2013). It is suggestive that those feelings of inadequacy are resolved when partaking in CPD activities. In the

study, only 12 (16.7%) of the study participants reported attending CP postgraduate courses and the reasons for attending no CP postgraduate courses were explored further. In the survey no funding 19 (31.3%) and time constraints 14 (22.8%) were the main reasons cited for this limitation of CP postgraduate training supporting Mclaren (2013) argument that CP training offered in SA is time-consuming and very costly. It is suggested that PT's working directly with children with CP should accept ownership and partake in CP training.

i. The positive and negative experiences of managing children with CP

In this study the positive and negative experiences reported by the respondents were categorised into themes. The majority of the respondents 26 (36.1%) reported that improving the QOL of a child with CP and CG was the most positive and rewarding experience, followed by 19 (26.7%) of the PT's reporting that achieving functional goals was rewarding and as one respondent, coded (NM2), reported:

"When one can see the quality of life of the child has improved after attending therapy because the family understands the condition better and therefore the child is looked after. When a child shows improvement and the CG cannot wait to show the therapist because they are so proud of the child." (NM2)

Literature supports this statement as the research shows evidence that a strong sense of fulfilment is expressed when therapists achieve maximum functional recovery (Chang and Hasselkus, 1998).

Participants expressed several negative experiences when treating children with CP as shown in the results; however two common themes were highlighted. Twenty five (35.4%) of the participants expressed their negativity to the plateau or slow progression of their children with CP and 20 (29.1%) respondents expressed their frustrations towards CG's, one participant coded (H1), in particular, described their frustrations by revealing that:

"As CP is a chronic disorder, the progress of the child is slow especially when CGs do not do daily exercises as much as they should. This is frustrating as it feels as if treatments are not helping." (H1)

Similarly in a study done by Chang and Hasselkus (1998), they reported that therapists mainly expressed irritation and dissatisfaction when their patients treatment progress plateaued, when a poor compliance of the rehabilitation regime was reported and when unrealistic goal outcomes were expressed by patients and CG's.

ii. Challenges faced by physiotherapists in KZN public Health

The researcher found that there were many challenges faced by the PT's within KZN public health sector; however these challenges were similarly expressed as the negative experiences of working with children with CP as discussed above. A few participants 5 (6.6%) reported that the late referral of children with CP was a challenge. To consider why the delayed referral of children with CP occurs, cultural beliefs of the CG's need to be explored. As previously discussed cultural beliefs play a large role in the early management of a child with CP as portrayed by Mclaren (2013). PT's in public health are continuously challenged with cultural and negative beliefs towards those who are disabled and so often these children receive delayed treatment. The delay of treatment can be detrimental as the secondary effects may have already manifested resulting in limited and poor therapy goal outcomes.

5.5 Objective 3. To Determine if there is a Difference in the Physiotherapy Management of Children with CP in Rural and Urban KZN Public Hospitals.

In the study, the majority of the respondents, 41 (56.9%), were employed in a rural hospital. KZN is predominantly a rural area, as noted by Hirschowitz and Ngwane (1998) and may be the reason for a higher response rate from PT's working in a rural hospital.

The most common management approach adopted by rural based PT's was a MDT approach supporting the literature of Nolan et al. (2000), Calis et al. (2008) and Papavasiliou (2009) that a MDT approach is most beneficial. The urban based PT's from the study, reported working individually, suggesting that high patient volumes, poor staffing and co-ordination difficulties are affect their management approach as suggested by Misbach (2004).

PT's employed in the rural sector, mainly managed children with CP on a monthly basis compared to urban based PTs who managed children with CP on a bi-monthly basis. This is perhaps because of the demographical and complexity of the location. KZN is predominantly a rural area (Hirschowitz and Ngwane, 1998) and CG's and children with CP, living in rural areas, cannot access these services as readily as those in urban areas. According to the literature, children with CP in rural areas have limited transportation options and poor socio-economic factors place a limitation on regular therapy visits (Trahan and Malouin (2002), Krigger (2006), Mclaren (2013)). The researcher found that mainly rural based PTs 22 (53.7%) participated in CP clinics.

In this study, rural based PT's spent more time managing children with CP than urban based PT's. It is evident from the study that PT's working in a rural sector hospital are required to manage and address the needs of the child with CP and CG in one session and so highlights the need to question why PT's in rural based hospitals, spend more time managing these children with CP and participating in CP clinics . Although Khan (2005) reports that most therapists seek employment in urban sector hospitals, a higher patient volume is experienced in these urban-based hospitals, suggesting a significant reason for the limited amount of time spent treating children with CP, compared to rural-based PT's.

5.6 Objective 4. To Determine if a Multidisciplinary Team Approach is Included in the Physiotherapy Management of Children with Cerebral Palsy in KZN Public Hospitals.

i. Management approach of children with CP

This study revealed that 32 (44.1%) of physiotherapists work individually, 8 (10.8%) in an inter-professional team and 32 (45.0%) within in a MDT. The beneficial effects of individual and inter-professional team management is apparent; however, children with CP require the services of all therapies and health care professionals and in most of the literature, research has stipulated that the most effective management of a child with CP is achieved when it is done in a MDT approach (Nolan et al., 2000, Jan, 2006, Calis et al., 2008). CP is a complex condition and because of this complexity, some literature will support individual management of children with CP as essential (Patricks et al., 2001). Papavasiliou (2009) however states*, "The current treatment recommendations call for a comprehensive team evaluation after which a treatment plan is generated."* As there are no studies focusing on the MDT approach of management of children with CP in KZN, it is difficult to compare any trends within the province. A 100% MDT approach may not be implemented in all hospitals in KZN due to research-based opinions such as ineffective collaboration of team work, staff constraints and lack of interest (Atwal and Caldwell, 2005).

Many of this study participants 32 (44.1%) work individually, which is in keeping with a study conducted by Atwal and Caldwell (2005) that the reasons for working individually and not in a MDT is due to the difficultly of a reliable commitment and effective coordination from other health care professionals. Mclaren (2013) and Misbach (2004) reported that the majority of health care professionals work on their own as there are limited organisational skills, poor coordination and lack of interest within SA Health Department. Poor human resources may also be a deciding factor for these participants to work independently as rehabilitation services according to Binken and Concha (2009) are *"Simply not available to a large number of South Africans."* Although the reason(s) for limited MDT team management was not explored in the questionnaire, literature has mentioned that

professional jealousy, poor communication and role restrictions may be contributing factors for a limited MDT management (Atwal and Caldwell, 2005).

In this study the PT's 32 (45.0%) who worked in a MDT team, included most commonly an OT and SLT in their management of children with CP. Literature stipulates that the collaboration of an OT and PT has direct and positive advances on the progression of a patient and supports the union of an OT and PT (Atwal and Caldwell, 2002).

ii. Referral to other MDT members

Participants in the study revealed that they refer children with CP to other health care professionals. This is positively viewed and supported by the literature that all health care professionals should work within a team ensuring that the child with CP benefits from a holistic management approach instead of an individual approach (Patricks et al., 2001, Papavasiliou, 2009).

iii. MDT meetings

This study revealed that 31 (43.1%) of the study participants attended MDT meetings. In the literature, it states that MDT meetings are vitally important and the effective coordination of a MDT team and meetings will only be operational by adequate organisation (Atwal and Caldwell, 2005). The reasons for the absence of MDT meetings were further explored and categorised into themes:

1. Time constraints- MDT meetings could not take place as there was limited time to organise and coordinate these meetings. Time constraints are a direct result of poor human resourcing and high work load (Mclaren, 2013).
2. Limited availability of health care professionals- MDT meetings could not take place as there was limited or no staff to allow for MDT meetings. Poor human resources are a major issue in South Africa especially within the rehabilitation context (Directorate, 2008, Binken and Concha, 2009, Mclaren, 2013).
3. No interest and poor priority- CP and rehabilitation is simply not a priority in SA. Government's priorities lie within the HIV and TB epidemic and so rehabilitation falls victim to all the other health services (Cullian, 2006, Binken and Concha, 2009, Vawda and Variawa, 2012, Sips et al., 2014)

4. High workload- one participant coded (AL3) reported that:

> "T*here is not enough time in the day to sit in MDT meetings and discuss Children with CP*." (AL3)

The demand of high patient volumes and limited staffing is the result of limited MDT meetings which Mclaren (2013) found was one of the many factors affecting the overall management of children with CP.

Studies show that when MDT meetings do not take place, health care professionals are indirectly interfering in the quality of health care, and progress of those patients and to prevent this, effective communication is a necessity (Atwal and Caldwell, 2005). Government needs to take better steps to ensure the employment of health care professionals, to advocate for the enhanced management of children with CP because according to the legislations and policies of our country ever child with a disability has the right to effective health care services (Papavasiliou, 2009).

iv. Caregiver inclusion

A CG is important in the management of a child with CP. CG's are responsible for ensuring the continuation of therapeutic management at home. In the study it was revealed that 71 (99%) of the participants considered the CG an important individual and included the CG in their treatment plans. This supports the findings of Misbach (2004) that PT's promote effective management of children with CP by including the CG in their treatment plans. According to evidence-based research a family-centred approach is best. The effective coordination between a CG and therapist is important and literature encourages health care professionals to include the CG and family in all aspects of the management approach as done by the PTs in this study (Palisano, 2006). The inclusion of a CG in the treatment approach is vital as already concluded by the majority of the participants. In the study, the question on how PT's included the CG's resulted in 4 major themes. The most common are listed followed by the least common. Majority of the participants reported including in managing the child with CP as follows:

1. Education- PT's educated the CG's on CP, the importance of performing a home exercise programme (HEP), different positioning and functional activities to perform at home, oral hygiene, safe feeding, carrying and the correct usage of assistive devices which were a few of the educational topics that the PT's discussed in each theme supporting Palisano (2006) role of a PT; that a PT's role in education is to provide CG's with information, ideas on how to manage symptoms and to provide functional activities to improve the QOL and function of a child with CP at home . Similarly supported by Saloojee et al. (2011) they describe the necessity of education on the condition of the child with CP and the provision of supportive services.
2. Active participation- in the study, 26 (36.6%) of the PT's included the CG by actively getting them to be hands on, so to ensure they understood what was expected of them. One participant coded (M4) reported that it *"Encourages responsibility."* Supporting this statement, in their study Saloojee et al. (2011) reported that CGs gained greater insight on the condition and appreciated being taught how to execute specific hands-on techniques.
3. Establishing personal priorities, needs and goals- Palisano (2006) encourages service providers to investigate primarily the concerns and needs of the family and CG and to shape a treatment plan around those priorities and needs. Despite the high level of CG disinterest towards therapy, many PT's encouraged the CG's to take the time to express their concerns, goals for their children and any other problems concerning their children. As one participant coded (MAN1) reported:

   "Caregivers set goals with the therapists, No caregiver, no treatment, and no point!" (MAN1)

   This inclusion strategy is supported by Saloojee et al. (2011) as they report that the identification of a CG's concerns will ultimately lead to greater compliance and satisfaction of the CG .
4. Counselling- Seven (6.7%) of the PTs reported providing counselling services to their CG's. The importance of effective counselling by health

care professionals is most definitely needed by CG's as literature discusses that CG's experience both negative emotional and physical effects (Raina et al., 2005, Murphy et al., 2007) . In some cases, therapists need to provide services of emotional support and assist the CG in feeling adequate and competent just as much as the provision of clinical and technical services (Hartley et al., 2005, Murphy et al., 2007, Saloojee et al., 2011), perhaps the challenges faced by PT's while working with CG's does not allow for this open transparency and provision of counselling to CP caregivers.

The most important approaches of CG training felt, by the participants, were ensuring handover management techniques were done with the CG and teaching appropriate back care techniques. Handover management techniques were portrayed as greatly important supporting the work of Saloojee et al. (2011) that South African CG's expressed the need for practical handover skills and health care providers should address this need thoroughly. Back pain is one of the largest health problems in people worldwide (Kerssens et al., 1999). The physical well-being of a CG is continuously comprised, especially when looking after a disabled child (Raina et al., 2005). CGs reported that the lifting and transferring of their children with CP often lead to back and shoulder pain (Murphy et al., 2007). Back care is very important and while handover management techniques on how to ensure functionality of a child with CP is important; the CG's and their backs are just as great a concern to PT's. There is limited research on the incidence of back pain in CGs of children with CP in SA. However, in Canada, it was reported that up to 35% of the CGs complained of back pain and in America up to 70% of CGs reported lower back pain (Brehaut et al., 2004, Murphy et al., 2007) . Of the participants, 64 (90.2%) showed concern for the importance of back care techniques in the inclusion strategy of the CG and this supports the literature that the CG's well-being is vitally important (Brehaut et al., 2004). If PT's educated and encouraged the physical well-being of CG's, it would ultimately lead to improving and ensuring the sustainable care of a child with CP by his CG (Murphy et al., 2007).

Only one individual coded (CW4) did not include the CG in the treatment approach because:

"*The CG frustrates me, they never do the exercises anyway, and so what is the point." (*CW4)

The non-compliance by CG's can be a frustrating process and delay the therapy outcome, but to consider why there is non-compliance by CG's, PT's need to understand the reasons for non-compliance and work around these challenges to ensure adequate and effective compliance is restored. In the study many challenges were expressed by the PT's while including the CG in the management of children with CP process. The most common challenges, as indicated by the statistics, were cultural beliefs 36 (50.0%). South Africa is a diverse nation with many cultural beliefs. The majority of South Africans seek the services of traditional healers, primarily before consulting the western style of medicine. The services that they receive included the use of prayer, rituals and digestion of natural medications (Ross, 2007) . These actions often result in PT's seeing children with CP later on delaying the rehabilitation outcomes. In South Africa, cultural beliefs and negative communal attitudes towards people with disabilities is a common occurrence. Children with CP are found and managed far too late as families hide them away, afraid of the culture beliefs and negative stigma of the child's disability (Mclaren, 2013).

Language barriers and lack of understanding by CG's were predominantly major challenges for PT's, in this study. Language barriers are experienced 80% of the time during clinical interviews and treatment sessions. At times there is a lack of understanding by the CG on the diagnosis and prognosis of the child with CP, resulting in unrealistic expectations (Mclaren, 2013). Those who cannot understand English will have difficulty accessing health care services. The interaction between a health care professional and family/patient is vitally important and according to the results collected, language barriers is a serious challenge faced by the PTs in KZN. The Literature stipulates that those patients who have limited English language skills are less likely to receive the adequate health services they seek. Limited language skills may result in poor

understanding and patients and CG's are less likely to comply with treatment regimens prescribed (Jacobs et al., 2006), as expressed in the study.

5.7 Objective 5. To source potential improvements on the current management of Children with CP in public hospitals of KZN.

i. Recommendations by physiotherapists in KZN public health to improve the management of children with CP

The open ended questions allowed for participants to report on any recommendations they felt they had regarding the management of children with CP in KZN. There were many recommendations reported by the respondents, one being training. The majority of the respondents 32 (44.4%), reported feeling inadequate in managing a child with CP and that greater emphasis on CP postgraduate training in the KZN area needed to be addressed as participant coded (Ad10) said:

"Make the training for PTs more accessible so that they are confident when treating Children with CP." (Ad10)

A similar report by Mclaren (2013) concluded that most of the CPD courses take place in urban areas and so many PT's cannot attend the training. This was similarly mentioned by participant coded (*KEH2):*

"PTs find CP challenging because of the lack of knowledge. If PT's get empowered the patients will be empowered." (KEH2)

The ownership is on each PT to empower himself by taking part in compulsory CPD training. However, CPD training is expensive and time consuming (Maharaj, 2013) and as recommended by the PT's in this study government should allocate and ensure adequate funding for Human Resource Development (HRD) in CP. A few participants reported that their undergraduate training was inadequate and did not satisfactorily aid them with the skills needed to manage a child with CP effectively as supported by (Mclaren, 2013).

Respondents reported that improving human, financial and equipment resources will help improve the management of children with CP. The adequate provision of assistive devices is required and supported by (Mclaren, 2013) . Assistive devices encourage functionality and prevent complications, which indirectly will result in fewer admissions and reduce the costs of medical expenses for the government (Misbach, 2004).
In the study, participants recommended that CG's need to be educated effectively and thoroughly as one participant coded (NM1) reported:

"More emphasis needs to be put on the CG and community to make sure they have adequate insight on the condition." (NM1)

Further recommendations, of establishing CG support groups, were expressed and the literature supports this as social support and interactions have direct and positive effects on treatment participation (Thomas et al., 2014). The researcher found in this study that participants reported that an early referral system of children who are at risk of a CP, diagnosis needs to be effectively implemented in all hospitals. One study respondent coded (Ad5) stated that we need to:

"Refer patients on day 1 of birth if the APGAR scores are low so that patients can be monitored accordingly to developmental milestones and treated at an early age if problems appear."(Ad5)

The early identification and management of children with CP can result in fewer secondary effects requiring hospitalisation. Health care professionals need to refer children earlier then later so that intervention may begin (Mclaren, 2013).

CHAPTER 6: CONCLUSION

In this chapter the main findings are concluded. A summary of the clinical implications are reported and the limitations and recommendations are discussed.

6.1 Overview

CP is a complex condition and every child with CP has the right to effective and adequate health care services. As a PT employed at a government hospital in KZN, the researcher noted the frustrations of PT's whilst managing children with CP. There are many international and local studies in the area of CP; however limited studies have been undertaken in KZN on the PT management of children with CP. The aim of the study, was therefore to determine the current PT management of children with CP in KZN public hospitals with the objectives of identifying the current management practices of children with CP in urban and rural public hospitals, in order to improve the management of children with CP.

KZN is the second most populated province in SA, and with this, comes the burden of the highest HIV and TB incidence in the country. This burden directly affects PT's working in the public health sector by increasing the patient workload. Although no PT:patient ratio has been established, PT's in KZN are tasked to provide physiotherapy services to a large population. This indirectly affects the management of children with CP as PT's are overwhelmed by this high work load. As in the case of this study, a limited number of respondents 25 (34.7%) revealed using standardised outcome measures; standardised assessments forms are important to establish short and long term goals these time constraints limit the adequate assessment of a child with CP. Government, the KZN DoH and Universities should encourage those PT's to familiarise themselves with or seek training on the CP specific outcome measures to establish realistic goals for their children with CP.

South Africa is a developing country and PT's may not always have access to assistive devices which is detrimental in the case of a child with CP. In this study a high number of respondents 51 (70.8%) reported that insufficient assistive devices

was a concern. Although the KZN province has taken great lengths to improve the public health sector, rehabilitation services still seem to be a low priority and there is a high need for the Government and KZN province to formulate policies to ensure greater organisational strategies are implemented, to advocate for the employment of more health care professionals and ensure the effective procurement of therapy equipment and assistive devices.

The overall management of children with CP across this study, reflected different management approaches. Individual and inter-professional management approaches were used by KZN PT's. However a MDT management approach was concluded to be predominantly the most common approach, which correlates to those of other countries. There is however a need to identify measures to ensure the adaptation of a MDT approach occurs throughout the entire province. A significant difference in the management approaches by rural and urban-based PT's was evident. PT's in rural areas adopted a MDT approach whilst urban-based PT's preferred individual management of their children with CP. KZN is predominantly a rural area, resulting in poor access to health care. The inadequate transportation system and poor socio-economic factors revealed that PTs working in rural areas could only manage children with CP on a monthly basis, while those in urban areas managed children with CP predominantly bi-monthly.

PT's in this study, predominantly managed children with CP for a period of 0-30 minutes. A thirty minute treatment can be beneficial to children with CP. However, in this study, rural-based PT's predominantly treated children on a monthly basis and urban based PT's on a bi-monthly basis. According to the literature monthly rehabilitation visits are not sufficient to achieve short and long term goals. As mentioned previously, KZN is largely a rural-based area, making health care services inaccessible at times. Transportation and socio-economic burdens of the CP population have a direct effect on the frequency of PT sessions. It is therefore understandable why PTs manage children with CP on a monthly or bi-monthly basis. This suggests that Government and the KZN province should formulate better strategies so that children with CP and their CG's can access regular PT and other health care services.

A postural stabilizing activity was the most common treatment technique used by the respondents in this study, while respiratory care and positioning were identified as essential. Children with CP present with continuous postural restrictions and those greatly affected often acquire chest infections and orthopaedic complications, highlighting the need for these treatment techniques to improve the overall QOL of these children with CP.

All the participants, in this study, referred children with CP to other health care professionals indicating that PT's understood the importance and limitations of their scope of practice. In both international and local literature, a MDT approach is reported as ideal and the symbiotic relationship between PT and other health care professional(s) is meaningful in the management of a child with CP. CG's were seen by PT's as fundamental and the respondents expressed the need for CG's to be included in the management of children with CP. In this study the majority of the PT's reported frustrations faced when including the CG. Cultural beliefs were identified as the major challenge and in South Africa the diversity of our nation has reported to disrupt the PT management and prognosis of the child with CP. In spite of these CG challenges the management strategies adopted by the PT's in this study appear to represent a holistic management approach.

Feelings of inadequacy were noted by those PT's managing children with CP and the limitation of undergrad and postgrad CP training was the common cause. Postgraduate education is key and the development of CPD courses has made CP training possible. Although there is a selection of Cerebral Palsy CPD courses offered, high costs and time constraints resulted in a poor attendance of KZN PT's at Cerebral Palsy CPD courses. This advocates the need for specific preparation in their undergrad training, adequate mentoring once qualified and improving the availability of CPD/ postgraduate training on children with CP in KZN.

6.2 Limitations of the Study

This study had some limitations such as:

1. The sample was restricted to KZN PT's, although being a large and populated province; the findings are limited to only KZN province PT's and may restrict the transferability to other provinces.
2. Another limitation was that respondents were only from the public sector and may limit the true reflection of PT's managing children with CP in other sectors of KZN.
3. The majority of the respondents predominantly trained at UKZN and this may have skewed the information collected.

Although the findings of the study will add value to the CP and physiotherapy body of research, the limitations listed above needs to be considered in future studies.

6.3 Clinical Recommendations

This study proposes more PT's and health care professionals be employed in the public health sector. A greater emphasis needs to be placed on acquiring more equipment and assistive devices, improved accessibility to CP postgraduate training should be implemented and therefore the following clinical recommendations are suggested, based on the results of the study:

1. Government and the DoH need to implement preventative, organisational and interaction strategies such as:

- Developing an effective CP database to avoid defaulting treatment.
- Addressing staffing constraints effectively and the employing essential health care professionals.
- Facilitating CG support groups and educational sessions so that a better understanding of CP is guaranteed and the value of therapy compliance is addressed.
- Planning and procuring an adequate budget for the rehabilitation sector, to safeguard the availability of adequate equipment and resources to manage children with CP effectively.

2. Encouraging physiotherapists working with children with CP to attend CPD programmes or postgraduate courses in the field of CP with the. Government supporting the PT's financially and providing an adequate amount of study leave to attend these courses.
3. Universities training prospective physiotherapy students should consider re-evaluating their CP curriculum.
4. A structured CP procedure and policy needs to be formulated nationwide.
5. The standardised CP assessment form(s) and tool(s) need to be implemented into the rehabilitation of children with CP so that adequate planning and effective goals can be set.
6. Implementing an early referral system so that an early intervention may begin to avoid any possible cases being missed undiagnosed or left untreated.

These measures may promote the awareness of CP and encourage the prevention of the occurrence of a CP diagnosis and avoid the secondary complications that arise from poor management and delayed intervention.

6.4 Recommendations for Future Studies

Based on some of the limitations of this study, the researcher recommends the following for future studies:

1. Physiotherapists from other provinces in South Africa should be included so that comparisons of the results from the KZN study can be reviewed and analysed.
2. The use of focus groups to explore more specific management approaches of CP.
3. Collaborative exploration of the parents' and PT's views of the management approach of children with CP need to be explored.

6.5 Summary

Physiotherapy forms an important role in the management of children with CP and it is evident to the researcher that the management of children with CP in KZN

encourages a MDT approach. Although there are many challenges expressed by the PTs the overall treatment approach adopted by PTs in KZN is viewed as holistic and favourable. The researcher is of the opinion that better policies and formulations should be designed and the employment of additional PTs and other health care professionals needs to be implemented. These organisational strategies may well form an integral role in assisting those PT's already employed in the KZN public health sector and may improve the prognosis of those children with CP they manage.

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APPENDICES

Appendix A- Letter from the Department of Health

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component
10 – 103 Natalia Building, 330 Langalibalele Street
Private Bag x9051
Pietermaritzburg
3200
Tel.: 033 – 3953189
Fax.: 033 – 394 3782
Email.: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference : HRKM 124/15
NHRD: KZ_2015RP3_337
Enquiries : Mr X Xaba
Tel : 033 – 395 2805

Dear Ms Tracy-Lee White

Subject: Approval of a Research Proposal

1. The research proposal titled 'A study to determine the physiotherapy management of cerebral palsy children in KwaZulu-Natal Public Hospitals' was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken among Physiotherapist at all hospitals.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facility before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

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

Y[redacted]

D[redacted]

Chairperson, Health Research Committee

Date: 05/06/15

Appendix B- Letter from HSSREC

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

17 June 2015

Ms Tracey-Lee White 214575457
School of Health Sciences – Physiotherapy
Westville Campus

Dear Ms White

Protocol reference number: HSS/0174/015M
Project title: A Study to determine the physiotherapy management of cerebral palsy children in KwaZulu-Natal public hospitals

Full Approval – Expedited Application

In response to your application received on 16 March 2015, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yo[redacted]

.....

Dr Shamila Naidoo
On behalf of Dr Shenuka Singh (Chair)
Humanities & Social Sciences Research Ethics Committee

/pm

Cc Supervisor: Dr SS Maharaj
Cc Academic Leader Research: Prof J van Heerden
Cc School Administrator: Ms P Nene

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 3587/8350/4557 **Facsimile:** +27 (0) 31 260 4609 **Email:** [redacted]
Website: www.ukzn.ac.za

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Appendix C1- Letter of Support from Amajuba Health District

health

Department:
Health
PROVINCE OF KWAZULU-NATAL

MEMORANDUM

Tel: 034 328 7033
Fax: 03431 32123
E-mail: silindo.mhlongo@kznhealth.gov.za
www.kznhealth.gov.za

ENQUIRIES : A-S CASSIM

TO	:	MS. TRACEY-LEE WHITE SCHOOL OF HEALTH SCIENCES PHYSIOTHERAPY WESTVILLE CAMPUS UNIVERSITY OF KWA-ZULU NATAL
FROM	:	MRS A.M.E.T. TSHABALALA
		DISTRICT MANAGER
DATE	:	24/06/2015
INDEX	:	59/06/2015
REF	:	12/1
RE	:	APPROVAL TO CONDUCT STUDY AT AMAJUBA DISTRICT HOSPITALS

Dear Ms. Tracey-Lee White

I have pleasure in informing you that permission has been granted to you by the District Office to conduct research on "A Study To Determine The Physiotherapy Management Of Cerebral Palsy Children In Kwazulu-Natal Public Hospitals".

Please note the following:

1. Please ensure that you adhere to all policies, procedures, protocols and guidelines of the Department of Health with regards to this research.

2. Please ensure that this office is informed before you commence your research.

3. The District Office will not provide any resources for this research.

4. You will be expected to provide comprehensive feedback on your findings to the District Office upon completion of the study.

[redacted]
.....
SHABALALA
DISTRICT MANAGER
AMAJUBA DISTRICT OFFICE

Appendix C2- Letter of Support from Ethekwini Health District

health

Department:
Health
PROVINCE OF KWAZULU-NATAL

Postal Address: Private Bag X54318 Durban 4000
Physical Address: 83 King Cetshwayo Highway,
Mayville, Durban 4001
Tel.031 2405455: Fax. 031 2405500
Email: henry.sunpath@kznhealth.gov.za
www.kznhealth.gov.za
Enquiries: Dr H Sunpath

Date 13 July 2013

Dear Ms White

Re.: A study to determine the physiotherapy management of cerebral palsy children in KwaZulu-Natal public hospitals.

Thanks for submitting the documents in support of the above research.

The study is towards a degree in Masters in Physiotherapy

My student number is 214573457

Ethics approval has been granted from HSSREC on the 17th June 2015 ethics reference number: HSS/0174/015M.

Letter of permission from Provincial DOH has been granted on the 3rd June 2015 reference number: HRKM 124/15

Protocol and methodology for reference –received/ not received

Approval is hereby granted to conduct this research at all the relevant health care facilities that attend the cerebral palsy children located in Ethekwini district under the KwaZulu-Natal provincial DOH

Proposed start date: 01/07/2015

Proposed completion date: 30/11/2015

Please note that all research activities in the health care facility must be conducted in a way that does not interrupt clinical care. This letter serves only to support the project, however the logistical details are subject to approval by the CEO/Medical Manager /Nursing services manager.

Wishing you success in this important and relevant research.

Yours faithfully

[redacted]r. Henry Sunpath: MBBS; MFam Med; Dip HIV Man, MPH (UKZN)

Chief Technical Advisor –Clinical Governance; Ethekwini District Health Office

Appendix C3- Letter of Support from Harry Gwala Health District

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

HARRY GWALA HEALTH DISTRICT
Private Bag X502 Ixopo, 3276
111 Main Street, Ixopo, 3276
Tel.:0398348280/8200, Fax.0398342950/1301
Email.:lindiwe.zuma@kznhealth.gov.za
www.kznhealth.gov.za

Enquiries: Miss N.M. Myoli
Date: 04/05/2015
Ref :2/6/3

To: Tracey-Lee White

Dear Ms White

RE: A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CEREBRAL PALSY CHILDREN IN KWAZULU NATAL PUBLIC HOSPITALS

I have pleasure in forming you that permission has been granted to you by the district research committee to conduct research study using the physiotherapists currently employed in Harry Gwala District

Please note the following:

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

Th
Si

[redacted]

MI
CHAIRPERSON :HARRY GWALA HEALTH DISTRICT RESEARCH COMMITTEE

Appendix C4- Letter of Support from Ilembe Health District

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

ILEMBE HEALTH DISTRICT OFFICE
Postal Address: Private Bag x 10620, KwaDukuza, 4450
Physical Address: OK Mall, 36/40 Cnr Mahatma Gandi
& Chief Albert Luthuli St, KwaDukuza
Tel.:032 437 3500, Fax.: 032 551 1590
Email.:thenjiwe.thwala@kznhealth.gov.za
www.kznhealth.gov.za

Enquiries: Ms. T.Thwala
Telephone: 032 – 437 3503
Date: 29 June 2015

ATT: Ms Tracey-Lee White and Humanities Social Science Research Ethics Committee

RE: Support to conduct research study using the physiotherapists currently employed in the surrounding hospitals in ILembe District.

This confirms that the ILembe District supports the research study by Ms. Tracey-Lee White titled: *A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CEREBRAL PALSY CHILDREN IN KWAZULU-NATAL PUBLIC HOSPITALS*:

As per policy of the Provincial Health Research Committee (PHRC) you are hereby granted permission to conduct the above mentioned research once all relevant documentation has been submitted to KwaZulu-Natal PHRC inclusive of full ethical approval.

Please note the following:

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

Thanking you

[redacted]

Acting District Deputy Manager Clinical and programs
ILembe Health District

Appendix C5- Letter of Support from Ugu Health District

health

Department:
Health
PROVINCE OF KWAZULU-NATAL

UGU HEALTH DISTRICT OFFICE
Private Bag X 735, Port Shepstone, 4240
41 Bissett Street, via Main Entrance of Nelson Mandela Drive
Tel.:039 688 3000/01
Fax.:039 682 6296
Email.:comfort.nguza@kznhealth.gov.za

LETTER OF SUPPORT

To: Ms Tracey - Lee White

School of Health Sciences - Physiotherapy

RE: SUPPORT REQUESTED TO CONDUCT RESEARCH STUDY USING THE PHYSIOTHERAPISTS CURRENTLY EMPLOYED IN YOUR DISTRICT

Your application to obtain permission to conduct research study using the Physiotherapists currently employed in Ugu District dated 21 /05/2015 has reference:

Please be advised that the Senior Management at its sitting supports your application but requires to know where the pilot study will be conducted.

[redacted]

ACTING DISTRICT MANAGER

Appendix C6- Letter of Support from Umgungundlovu Health District

health

Department:
Health
PROVINCE OF KWAZULU-NATAL

UMGUNGUNDLOVU DISTRICT OFFICE
Private Bag X9124, Pietermaritzburg, 3200
171 Hoosen Haffajee Street, PMB 3201
Tel.:033 342 0932
Email: Thule.kunene@kznhealth.gov.za:
www.kznhealth.gov.za

Enquiries: Mrs. N. M. Zuma-Mkhonza
Date: 16 July 2015

ATT: MS TRACEY-LEE WHITE AND HUMANITIES SOCIAL SCIENCE RESEARCH ETHICS COMMITTEE

RE: SUPPORT TO CONDUCT RESEARCH STUDY USING THE PHYSIOTHERAPISTS CURRENTLY EMPLOYED IN THE SURROUNDING HOSPITALS IN UMKHANYAKUDE DISTRICT.

This confirms that the Umgungundlovu Health District supports the research study by Ms Tracey-Lee White titled: *A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CEREBRAL PALSY CHILDREN IN KWAZULU-NATAL PUBLIC HOSPITALS.*

As per policy of the Provincial Health Research Committee (PHRC) you are hereby granted permission to conduct the above mentioned research once all relevant documentation has been submitted to KwaZulu-Natal PHRC inclusive of full ethical approval.

Kindly note the following:

1. The research should adhere to all policies, procedures, protocols and guidelines of the KwaZulu-Natal Department of Health.
2. Research will only commence once the PHRC has granted approval to the researcher.
3. The researcher must ensure that the district manager is informed before the commencement of the research by means of the approval letter by the chairperson of the PHRC.
4. The district manager expects to be provided feedback on the findings of the research.

[redacted]MA-MKHONZA
THE DISTRICT MANAGER
UMGUNGUNDLOVU HEALTH DISTRICT
DEPARTMENT OF HEALTH KZN

Appendix C7- Letter of Support from Umkhanyakude Health District

health

Department:
Health
PROVINCE OF KWAZULU-NATAL

Umkhanyakude Health District Office
Dr C H Vaughan Williams
Medical Manager, Senior
Private Bag X 026, Jozini 3969
Tel: 035 5721327, Fax: 035 5721251
Cell: 072 584 3472
Email:hervey.williams@kznhealth.gov.za

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

15 June 2015

Dear Ms Tracey-Lee White,

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

'A study to determine the physiotherapy management of cerebral palsy children in Kwazulu-Natal public hospitals.'

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. Please ensure this office is informed before you commence your research.
3. The District Office will not provide any resources for this research.
4. You will be expected to provide feedback on your findings to the District Office.

Since[redacted]

C H Vaughan Williams
Family Physician, Umkhanyakude Health District Office

Appendix C8- Letter of Support from Umzinyathi Health District

health

Department:
Health
PROVINCE OF KWAZULU-NATAL

UMZINYATHI DISTRICT OFFICE DC 24
Private Bag X2052, Dundee, 3000
34 Wilson Street, Dundee, 3000
Tel: (034) 299 9100, Fax.: (034) 212 4800
Email: charlotte.vanross@kznhealth.gov.za
www.kznhealth.gov.za

OFFICE OF THE DISTRICT MANAGER

TO	:	*TRACEY LEE WHITE*
FROM	:	*MR. J. MNDEBELE* DISTRICT MANAGER
DATE	:	24TH JUNE 2015
RE	:	REQUEST FOR STUDY APPROVAL

Umzinyathi Health District Office supports your request to conduct research for "A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CEREBRAL PALSY CHILDREN IN KWAZULU-NATAL PUBLIC HOSPITALS".

Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.

1. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
2. Please ensure this office is informed before you commence your research.
3. The District / our facilities will not provide any resources for this research.
4. You will be expected to provide feedback on your findings to the district office.

[redacted]
District Manager
Umzinyathi District Health Office (DC24)

Appendix C9- Letter of Support from Uthukela Health District

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

UTHUKELA DISTRICT
60A Midblock, Corner Alexander Street,
Ladysmith
P/Bag X9958, Ladysmith, 3370
Tel: 036 6312202
Fax: 036 6310530
E-mail: thandeka.zulu@kznhealth.gov.za
www.kznhealth.gov.za

25 June 2015

Ms Tracy-Lee White

RE: APPLICATION FOR SUPPORT TO CONDUCT A STUDY IN UTHUKELA HEALTH FACILITIES

Please be informed that I have acknowledged your request for conducting research on "A study to determine the physiotherapy management of cerebral palsy children in KwaZulu-Natal public hospitals"

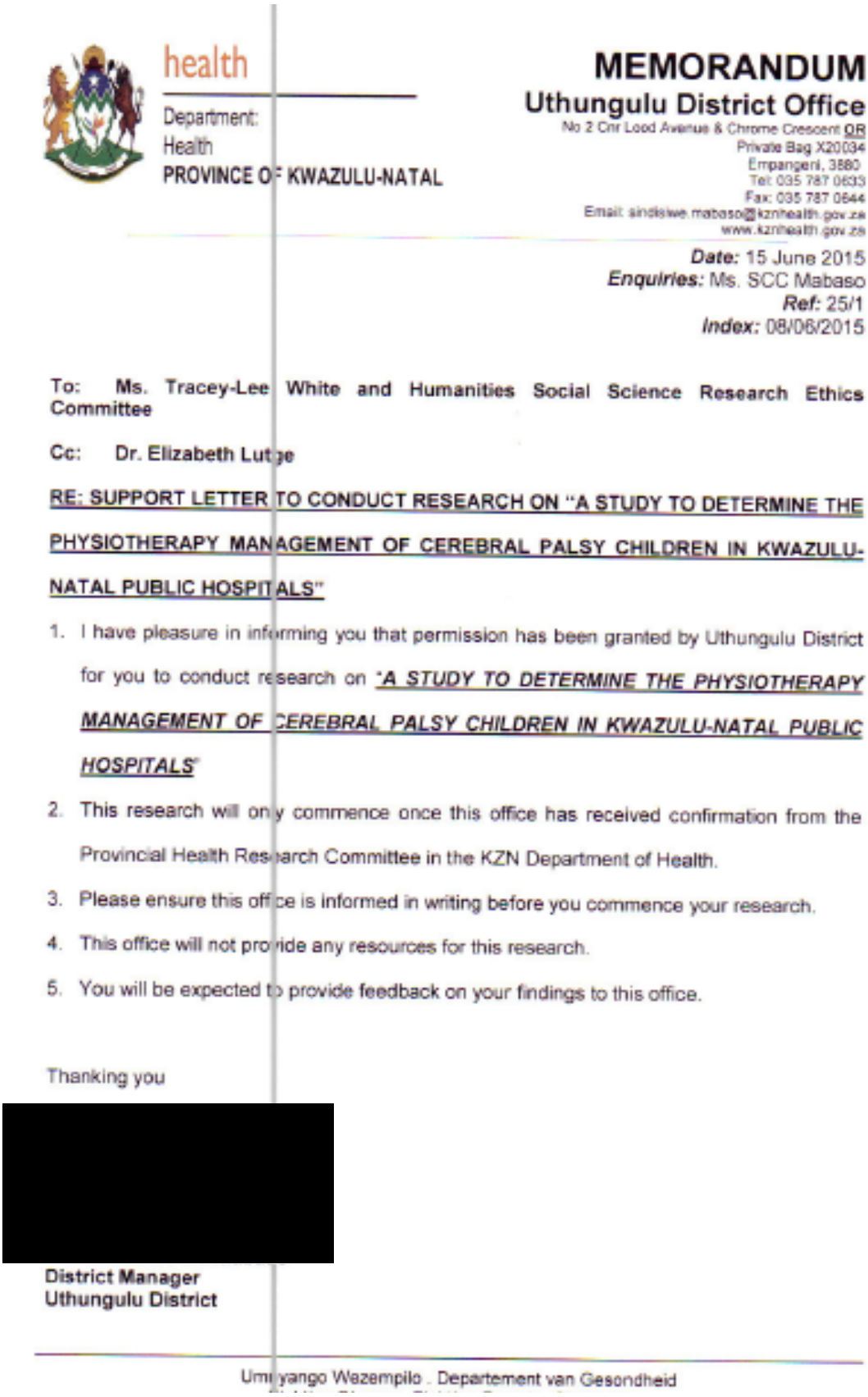
Please note the following:

1. Your letter received on 24 June 2015 refers.
2. Uthukela District must ensure adherence to all the policies, produces, protocols and guidelines of the Department of Health with regards to this research.
3. Your research will only commence once this office has received confirmation of the approval by HOD from the provincial Health Research Committee in the KZN Department of Health.
4. However your research is hereby supported.
5. I trust that you will find all to be in order.

[redacted]

DISTRICT MANAGER
UTHUKELA HEALTH DISTRICT

Appendix C10- Letter of Support from Uthungulu Health District



health

Department:
Health
PROVINCE OF KWAZULU-NATAL

MEMORANDUM

Uthungulu District Office

No 2 Cnr Lood Avenue & Chrome Crescent QR
Private Bag X20034
Empangeni, 3880
Tel: 035 787 0633
Fax: 035 787 0644
Email: sindisiwe.mabaso@kznhealth.gov.za
www.kznhealth.gov.za

Date: 15 June 2015
Enquiries: Ms. SCC Mabaso
Ref: 25/1
Index: 08/06/2015

To: Ms. Tracey-Lee White and Humanities Social Science Research Ethics Committee

Cc: Dr. Elizabeth Lutge

RE: SUPPORT LETTER TO CONDUCT RESEARCH ON "A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CEREBRAL PALSY CHILDREN IN KWAZULU-NATAL PUBLIC HOSPITALS"

1. I have pleasure in informing you that permission has been granted by Uthungulu District for you to conduct research on ***"A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CEREBRAL PALSY CHILDREN IN KWAZULU-NATAL PUBLIC HOSPITALS"***
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed in writing before you commence your research.
4. This office will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to this office.

Thanking you

[redacted]

District Manager
Uthungulu District

Umnyango Wezempilo . Departement van Gesondheid

Appendix C11- Letter of Support from Zululand Health District

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

ZULULAND HEALTH DISTRICT OFFICE
King Dinizulu Highway, Admin. Building
Tel.: (035) 874 0600
Fax. : (035) 874 0662
Email: daphne.memela@kznhealth.gov.za
www.kznhealth.gov.za

Enquiries: Mrs DT Memela
Telephone: (035) 874 0600

24 June 2015

Ms T White
Physiotherapist
Humanities Social Science Research Ethics Committee
Westville Campus
UKZN

RE: SUPPORT TO CONDUCT A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CEREBRAL PALSY CHILDREN IN KWAZULU NATAL PUBLIC HOSPITALS

I have pleasure in informing you that permission has been granted to you by the District Office to conduct *a study to determine the physiotherapy management of cerebral palsy children in KwaZulu Natal Public Hospitals.*

Please note the following:

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

[redacted]

ZULULAND HEALTH DISTRICT

Cc: Hospital Managers: Zululand District

Appendix D1- Information Document for Written Questionnaire Completion.

Information Document **No: ____**

Dear Colleague,

I, Tracey-Lee White, am enrolled as master's physiotherapy student at the University of KwaZulu-Natal. I am currently doing **"A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY IN PUBLIC HOSPITALS OF KWAZULU-NATAL".**

The aim and purpose of the study: Is to investigate the management approach of cerebral palsy children by physiotherapists in public hospitals of KwaZulu-Natal and to determine the views of those physiotherapists on the management of cerebral palsy children in public hospitals of KwaZulu-Natal.

Invitation to participation: I am inviting you to take part in the above research project.

What does the study involve?

The study involves completing a questionnaire form. This will take about 15-20 minutes of your time completing a questionnaire. You will be requested to answer every question truthfully and honestly. The initial questions asked will be based on age, gender, years of experience, and working environment. Thereafter, questions on how you manage cerebral palsy children will be asked and finally a few questions on your experiences and challenges faced while working with cerebral palsy children in KwaZulu-Natal public hospitals. The data from the questionnaire will be statistically analysed. No personal costs will be incurred by the researcher.

Are there any inherent risks involved in the study?

No, there are no risks involved in this study.

When and where will the study be conducted?

Completion of the questionnaire can be conducted at your earliest convenience

Benefits of participating in the study:

The results of the study will be available to you once the study has been completed.

Benefits of the study:

We hope that the study will create awareness on the management of cerebral palsy children in KwaZulu-Natal public hospitals.

Participation is voluntary:

Your participation is entirely voluntarily and you will be able to withdraw from the study at any time. Your views expressed will not jeopardise your profession or employment and you will not be treated unfairly in any way.

Confidentiality:

All information gathered will only be used for research purposes and will be kept strictly confidential between the researcher and supervisor. Your name will not be published and information published or presented will be grouped with other participants and will not be identifiable as each participant will be allocated a code number on the consent and questionnaire forms.

This study has been ethically reviewed and approved by the University of KwaZulu-Natal's (UKZN) Humanities and Social Science Research Ethics Committee (HSSREC) (approval number: HSS/0174/015M) and by the Department of Health. In the event of any problems or questions you may contact the researcher using the details provided below or the UKZN HSSREC, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557- Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

I humbly request your assistance to participate in the study by signing the attached consent form, answering the attached questionnaire and returning all completed documents in either one of the following options:

Option 1: In person at a physiotherapy forum meeting.

Option 2: Pre-paid postage envelope to: P.O BOX 1826
Link Hills
3652

Option3: Email- kindly attach the document and return the completed documents to: traceywhiteresearch@gmail.com

Yours faithfully

Tracey-Lee White
Masters Student-Physiotherapy
Cell: 0845894567
Email: tracey88@webmail.co.za

Dr SS Maharaj
Research supervisor
Tel: (031) 260 7817
Email: Maharajss@ukzn.ac.za

Appendix D2 - Consent Form to Complete the Written Questionnaire

Consent Form **No: _____**

My name is Tracey-Lee White and I am doing a study to determine: "The physiotherapy management of children with cerebral palsy in public hospitals of KwaZulu-Natal."

I _____ hereby give Ms T. White permission to the information I provide for research purposes only on _____ (date) at _____ (place) to take part in the study entitled: _____ and consent to participate in the study.

I understand that the study is being carried out by Ms T. White, a student at the University of KwaZulu-Natal for the requirements of a Masters in Physiotherapy Degree. I am aware that my participation is voluntary and that I may stop at any time. I understand that my stopping participation will not jeopardise my profession or occupation at my hospital of employment. I am fully informed that all information will not be disclosed to anyone else and that I will have access to information that concerns me. I agree that information obtained from this study may be published so that the finding may be of benefit to others. The study has been explained to me and I am aware that no personal costs will be incurred by Ms T. White.

_____ _____

Participant name and signature **Researcher name and signature**

Before you commence with the questionnaire please can you complete the table.

Question	YES	NO
Are you registered with the HPCSA?		
Have you obtained a physiotherapy degree?		
Have you managed a Cerebral palsy child before?		
Do you work in a Public health hospital in KwaZulu-Natal?		

Appendix E - Information and Consent Document for Online Questionnaire completion

No: _____

Dear Colleague,

I, Tracey-Lee White, am enrolled as master's physiotherapy student at the University of KwaZulu-Natal. I am currently doing "**A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY IN PUBLIC HOSPITALS OF KWAZULU-NATAL".**

The aim and purpose of the study: Is to investigate the management approach of cerebral palsy children by physiotherapists in public hospitals of KwaZulu-Natal and to determine the views of those physiotherapists on the management of cerebral palsy children in public hospitals of KwaZulu-Natal.

Invitation to participation: I am inviting you to take part in the above research project.

What does the study involve?

The study involves completing a questionnaire form. This will take about 15-20 minutes of your time completing a questionnaire. You will be requested to answer every question truthfully and honestly. The initial questions asked will be based on age, gender, years of experience, and working environment. Thereafter, questions on how you manage cerebral palsy children will be asked and finally a few questions on your experiences and challenges faced while working with cerebral palsy children in KwaZulu-Natal public hospitals. The data from the questionnaire will be statistically analysed. No personal costs will be incurred by the researcher.

Are there any inherent risks involved in the study?

No, there are no risks involved in this study.

When and where will the study be conducted?

Completion of the questionnaire can be conducted at your earliest convenience

Benefits of participating in the study:

The results of the study will be available to you once the study has been completed.

Benefits of the study:

We hope that the study will create awareness on the management of cerebral palsy children in public hospitals of KwaZulu-Natal.

Participation is voluntary:

Your participation is entirely voluntarily and you will be able to withdraw from the study at any time. Your views expressed will not jeopardise your profession or employment and you will not be treated unfairly in any way.

Confidentiality

All information gathered will only be used for research purposes and will be kept strictly confidential between the researcher and supervisor. Your name will not be published and information published or presented will be grouped with other participants and will not be identifiable as each participant will be allocated a code number on the consent and questionnaire forms.

This study has been ethically reviewed and approved by the University of KwaZulu-Natal's (UKZN) Humanities and Social Science Research Ethics Committee (HSSREC) (approval number: HSS/0174/015M) and by the Department of Health. In the event of any problems or questions you may contact the researcher using the details provided below or the UKZN HSSREC, contact details as:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557- Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

I humbly request your assistance to participate in the study by completing the questionnaire attached to this email.

By clicking on the attachment to open and complete the questionnaire, you agree to have understood all information provided to you and willingly agree to participate and give consent to use the information you provide for research purposes only.

Once you have completed the questionnaire please save your answers and return the document by attaching it to an email. Please return to traceywhiteresearch@gmail.com

Yours faithfully

Tracey-Lee White
Masters Student-Physiotherapy
Cell: 0845894567
Email: tracey88@webmail.co.za

Dr SS Maharaj
Research supervisor
Tel: (031) 260 7817
Email: Maharajss@ukzn.ac.za

Appendix F- Questionnaire: **No:_____**

QUESTIONNAIRE: A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY IN KWAZULU-NATAL PUBLIC HOSPITALS.

SECTION A: PHYSIOTHERAPIST PROFILE AND DEMOGRAPHICS

1. **Age: _____**

2. **Gender**

   - Please tick the appropriate box.

Female		**Male**	

3. **Number of years since qualification?**

   - Please tick the appropriate box.

1-5 Years		**6-10 Years**		**11-15 Years**		**16-20 Years**		**21-25 Years**		**26+ Years**	

4. **At which institution/university did you obtain your physiotherapy qualification?**

   - Please tick the appropriate box.

University of Pretoria		**University of Witswatersrand**	
University of KwaZulu-Natal		**Stellenbosch University**	
University of Limpopo		**University of Cape Town**	
Other(please specify in space provided)			

5. **In which district are you employed?**

   - Please tick the appropriate box.

Amajuba Health District		**Umkhanyakude Health District**	
Ethekwini Health District		**Umzinyathi Health District**	
Harry Gwala Health District		**Uthukela Health District**	
Ilembe Health District		**Uthungulu Health District**	
Ugu Health District		**Zululand Health District**	
Umgungundlovu Health District			

6. What is the setting of your hospital?

- Please tick the appropriate box.

Rural*		**Urban****	

* Rural = is a hospital situated outside any major urban centres, cities and provincial capitals).

** Urban = is a hospital situated near and inside urban centres (metropolis, large cities and provincial capitals.)

7. What is your current level of service/rank of employment?

- Please tick the appropriate box.

Community service PT		**Chief PT**	
Junior PT * **		**Assistant director of PT Department**	
Senior PT		**Director of PT Department**	

*** PT = Physiotherapist

8. Have you completed any post-graduate training in Cerebral Palsy?

- Please tick the appropriate box.

YES		**NO**	

a) If ***YES*** to the above question, please tick what cerebral palsy post graduate training you have completed.

- Please tick the appropriate box(es).

One Week Paediatric NeuroDevelopmental Therapy (NDT)	
Eight Week Paediatric NeuroDevelopmental Therapy (NDT)	
South African Society of Physiotherapy paediatric courses	
Malamulele Onward Training	
Shonaquip training	
Other (please specify in space provided)	

b) If you did not engage in cerebral palsy (CP) post-graduate training please indicate your reasons why?

- Please tick the appropriate box(es).

No Funding		**Unaware of CP courses offered**	
Disinterest in CP		**Time constraints**	
Other(please specify in space provided)			

SECTION B: THE PHYSIOTHERAPY MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY IN KWAZULU-NATAL PUBLIC HOSPITALS.

1. **What is the current physiotherapy management of cerebral palsy children in your department?**

   - Please tick the appropriate box(es).

Individual physiotherapy management	
Individual physiotherapy management with the assistance of the cerebral palsy caregiver	
Team management with another physiotherapist; an Inter-professional team *****	
Multidisciplinary team approach ****	
Multidisciplinary team approach with the assistance of the cerebral palsy caregiver	

**** Inter-professional team approach = a group of professionals with the same profession working together to provide a patient with rehabilitation services.

***** Multidisciplinary team approach = a team of individual disciplines working together to provide a patient with rehabilitation services.

   a) **If a *multidisciplinary team approach* is used during the management of cerebral palsy children, please specify who is involved.**

      - Please tick the appropriate box(es).

Doctor		**Psychologist**	
Nurse		**Speech Therapist**	
Occupational Therapist		**Social Worker**	
Dietician		**Neurologists**	
Other(please specify in space provided)			

2. **Is your physiotherapy management of cerebral palsy children being supervised? E.g. Chief PT supervisor etc.**

   - Please tick the appropriate box.

YES		**NO**	

- **If *YES* to question 2. Please sepcifiy who is supervising you.**
  - Please tick the appropriate box(es).

Director of PT Department		**Medical Manager**	
Assistant Director of PT Department		**Senior Physiotherapist**	
Chief Physiotherapist		**Junior Physiotherapist**	
Other(please specify in space provided)			

- **If *NO* to question 2. Why are you not receving any supervison**
  - Please tick the appropriate box(es).

No posts available		**No funding for posts**	
No candidates interested in posts		**Unsuitable candidates applying for supervisor posts**	
Other(please specify in space provided)			

3. **Approximately how many cerebral palsy children do you treat per month?**
   - Please tick the appropriate box.

1-10		**41-50**	
11-20		**51-60**	
21-30		**61-70**	
31-40		**71+**	

4. **How often do you treat the cerebral palsy children per month?**
   - Please tick the appropriate box.

Once a week		**Twice a month**	
Twice a Week		**Three times a month**	
Monthly		**Bi-monthly**	
Other (please specify in space provided)			

5. Approximately how much time do you treat each cerebral palsy child per session?

- Please tick the appropriate box.

0-30 minutes		**61-90 minutes**	
31-45 minutes		**91+ minutes**	
46-60 Minutes			

6. Do you use any standardized cerebral palsy assessment forms?

- Please tick the appropriate box.

YES		**NO**	

a) If *YES* to the above question, please specify.

- Please tick the appropriate box(es).

Gross Motor Functional Classification Scale (GMFCS)		**Self-developed assessment forms**	
Bobath/NDT influenced assessment form		**Communication Function Classification System (CFCS)**	
The Functional Mobility Scale (FMS)		**Manual Ability Classification System (MACS)**	
Other (please specify in space provided)			

7. Rate the Importance of the treatment techniques below, modalities and theories when managing cerebral palsy children.

- 1-5 (I – V) I = Least important / V = Very important.
- N/A = Not applicable.
- Please tick only one option per treatment in the appropriate box.

Treatment	**Rating**					
	I	**II**	**III**	**IV**	**V**	**N/A**
Passive mobilizations						
Milestone progression						
Sensory stimulation e.g. Visual/tactile/auditory stimulation						
Constraint Induced Therapy						

Neuro-Developmental Therapy (NDT) Approach						
Feeding and swallowing management						
Soft tissue mobilisations						
Stretching						
Production of splints						
Positioning						
Nutrition						
Activities of Daily living						
Issuing assistive devices						
Gait re-education						
Standing activities						
Communication						
School assessments						
School placements						
Wheelchair positioning						
Postural stabilizing activities						
Range of movement activities						
Social welfare e.g. grant applications etc.						
Respiratory care						
Education on cerebral palsy to the caregiver e.g. Cause, effects, management options etc.						

8. Do you participate in cerebral palsy clinics?

- Please tick the appropriate box.

YES		**NO**	

a) If *YES* to question 8. Please provide a brief overview, under the following headings spelling out the general management approach of the cerebral palsy children during the proceedings of a cerebral palsy clinic.

i. Therapy management

- Please tick the appropriate box(es).

Multidisciplinary team approach		**Group based therapy with caregivers**	
Individual therapy		**Inter-professional team approach**	
Other (please specify in space provided)			

ii. Organization strategies of cerebral palsy children in CP clinics.

- Please tick the appropriate box.

Group classification i.e all Athetoid CPs in one group		**Random selection into groups no criteria**	
Gross motor functional classification level		**Residential area classification**	
Other (please specify in space provided)			

iii. Time management e.g. is the clinic run the entire day? How long are treatment sessions etc.?

- Please specify in space below.

iv. Treatment programme of the cerebral palsy clinic e.g. 10 minutes stretching, soft tissue mobilisations, 20 minutes functional therapy, 15 minutes caregiver education etc.

- Please specify in space below.

v. Environment

- Please tick the appropriate box.

Physiotherapy department		**Outdoors**	
Recreational hall		**Paediatric units**	
Other(please specify in space provided)			

9. Do you refer cerebral palsy children to other healthcare professionals?

- Please tick the appropriate box.

YES		**NO**	

a) If *YES* to question 9. Which healthcare professionals do you refer cerebral palsy children to?

- Please tick the appropriate box(es).

Doctor		**Psychologist**	
Nurse		**Speech Therapist**	
Occupational Therapist		**Social Worker**	
Paediatrician		**Orthopaedic surgeon**	
Dietician		**Neurologist**	
Other(please specify in space provided)			

10. Do you attend multidisciplinary team meetings regarding the cerebral palsy children you manage?

- Please tick the appropriate box.

YES		**NO**	

a) If *YES* to question 10. Who attends the above mentioned multidisciplinary team meetings?

- Please tick the appropriate box(es).

Doctor		**Psychologist**	
Nurse		**Speech Therapist**	
Occupational Therapist		**Social Worker**	
Paediatrician		**Orthopaedic surgeon**	
Dietician		**Neurologist**	
Other(please specify in space provided)			

b) If *NO* to question 10. Please specify why no multidisciplinary meetings take place?

- Please specify in space provided below.

11. Please specify what available equipment you have to manage cerebral palsy children in your physiotherapy department.

- Please indicate what equipment you have available by ticking either YES/NO to the equipment option and recording how much of each item your department has.

Equipment	Yes	No	Quantity
Low plinth			
High plinth			
Therapy mats			
Adjustable paediatric standing frame			
Wedges			
Therapy blocks			
Therapy bench			
Parallel bars			
Suspension frame			
Massage oils			
Towels			
Pillows			
Screens			
Dispensable foam, fabric and cushions required for wheelchair positioning			
Tactile toys e.g. bean bags/ fabric booklets/ rice box etc.			
Visual toys e.g. mirrors/ tinsel/ lights etc.			
Auditory toys e.g. noise making books/puzzles/keyboards/ whistle etc.			

Therapeutic stairs			
Balance/equilibrium board			
Climbing wall			
Rollers			
Soft tunnel			
Large therapy balls			
Small therapy balls			
Scooter board			
Hammock			
Weighted vest			
Nebuliser			
Suction machine			
Cerebral palsy information pamphlets			

a) Is your physiotherapy department adequately equipped to treat cerebral palsy children?

- Please tick the appropriate box.

YES		**NO**	

b) Is there sufficient stock of assistive devices in your physiotherapy department to dispense to the cerebral palsy children you treat?

- Please tick the appropriate box.

YES		**NO**	

c) If *YES* to question 11. (b) Please indicate what assistive devices you have available to dispense to the cerebral palsy children you treat?

- Please tick the appropriate box(es)

Standing Frames		**Wheelchairs**	
Buggies		**Prone lyer**	
Other(please specify in space provided)			

12. **Do you consider the cerebral palsy caregiver an important individual in the treatment approach of a cerebral palsy child?**

- Please tick the appropriate box.

YES		**NO**	

a) Do you include the cerebral palsy caregiver in your treatment approach?

- Please tick the appropriate box.

YES		**NO**	

b) If *YES* to question 12. (a) How do you include the caregiver in your treatment plan?

- Please specify in space provided below.

c) Do you experience any challenge(s) when you include the caregiver in your treatment approach?

- Please tick the appropriate box(es).

Cultural Beliefs		**Language barrier**	
Lack of understanding		**Disinterest in therapy services**	
Other(please specify in space provided)			

d) If *NO* to question 12. (a) Why do you exclude the caregiver in your treatment approach?

- Please specify in space provided below.

e) Rate the importance of the theories below when including the caregiver in your treatment approach.

- 1-5 (I – V) I = Least important / V = Very important.
- N/A = Not applicable.
- Please tick the appropriate box.

Theory	Rating					
	I	II	III	IV	V	N/A
Issuing educational pamphlets						
Caregiver back care techniques						
Handover management techniques e.g. Passive mobilisations, positioning etc.						
Social welfare and needs e.g. child care disability grant (CDG) etc.						

SECTION C: KWAZULU-NATAL PUBLIC EMPLOYED PHYSIOTHERAPISTS VIEWS ON THE MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY.

1. Do you experience any challenge(s) regarding the management of cerebral palsy children?

- Please specify in space provided below.

2. Do you believe you have adequate skills and knowledge to treat cerebral palsy children?

- Please tick the appropriate box.

YES		NO		SOMETIMES	

3. What are the positive aspects of treating a cerebral palsy child?

- Please specify in space provided below.

4. **What are the negative aspects of treating a cerebral palsy child?**

   - Please specify in space provided below.

5. **Could you offer suggestion(s) to help improve the management of cerebral palsy children in KwaZulu-Natal public hospitals?**

   - Please specify in space provided below.

Thank you very much for your effort and time spent completing the questionnaire.

Appendix G1 - Information Document for Pilot Study

Information Document **No: ____**

Dear Colleague,

I, Tracey-Lee White, am enrolled as master's physiotherapy student at the University of KwaZulu-Natal. I am currently doing "**A STUDY TO DETERMINE THE PHYSIOTHERAPY MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY IN PUBLIC HOSPITALS OF KWAZULU-NATAL".**

The aim and purpose of the study: Is to investigate the management approach of cerebral palsy children by physiotherapists in public hospitals of KwaZulu-Natal and to determine the views of those physiotherapists on the management of cerebral palsy children in public hospitals of KwaZulu-Natal.

Invitation to participation: I am inviting you to take part in the pilot study of the above research project.

What does the pilot study involve?

The pilot study involves completing a questionnaire form. You will be requested to answer every question truthfully and honestly. The initial questions asked will be based on age, gender, years of experience, and working environment. Thereafter, questions on how you manage cerebral palsy children will be asked and finally a few questions on your experiences and challenges faced while working with cerebral palsy children in KwaZulu-Natal public hospitals. Once you have completed the questionnaire you will kindly be requested to complete a feedback form. The reason for this is to improve the questionnaire design and to validate the study. No personal costs will be incurred by the researcher.

Are there any inherent risks involved in the pilot study?

No, there are no risks involved in this study.

When and where will the pilot study be conducted?

Completion of the questionnaire can be conducted at your earliest convenience

Benefits of participating in the pilot study:

The results of the study will be available to you once the study has been completed.

Benefits of the pilot study:

The pilot study will help improve the design of the questionnaire and ensure that all information is understood and perceived correctly. We hope that the study will create awareness on the management of cerebral palsy children in KwaZulu-Natal public hospitals.

Participation is voluntary:

Your participation is entirely voluntarily and you will be able to withdraw from the study at any time. Your views expressed will not jeopardise your profession or employment and you will not be treated unfairly in any way.

Confidentiality:

All information gathered will only be used for research purposes and will be kept strictly confidential between the researcher and supervisor. Your name will not be published and information published or presented will be grouped with other participants and will not be identifiable as each participant will be allocated a code number on the consent and questionnaire forms.

This study has been ethically reviewed and approved by the University of KwaZulu-Natal's (UKZN) Humanities and Social Science Research Ethics Committee (HSSREC) (approval number: HSS/0174/015M) and by the Department of Health. In the event of any problems or concerns/questions you may contact the researcher using the details provided below or the UKZN HSSREC, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
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Durban
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KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604557- Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za

I humbly request your assistance to participate in the study by signing the attached consent form, answering the attached questionnaire and returning all completed documents in either one of the following options:

Option 1: In person at a physiotherapy forum meeting.
Option 2: Pre-paid postage envelope to: P.O BOX 1826
Link Hills
3652
Option3: Email, kindly attach the document and return the completed documents to: traceywhiteresearch@gmail.com

Yours faithfully

Tracey-Lee White
Masters Student-Physiotherapy
Cell: 0845894567
Email: tracey88@webmail.co.za

Dr SS Maharaj
Research supervisor
Tel: (031) 260 7817
Email: Maharajss@ukzn.ac.za

Appendix G2 - Consent Form to Participate in the Pilot Study

Consent form **No: _____**

My name is Tracey-Lee White and I am doing a study to determine: "The physiotherapy management of children with cerebral palsy in public hospitals of KwaZulu-Natal".

I _____ hereby give Ms T. White permission to the information I provide for research purposes only on _____ (date) at _____ (place) to take part in the study entitled: _____ and consent to participate in the pilot study.

I understand that the study is being carried out by Ms T. White, a student at the University of KwaZulu-Natal for the requirements of a Masters in Physiotherapy Degree. I am aware that my participation is voluntary and that I may stop at any time. I understand that my stopping participation will not jeopardise my profession or occupation at my hospital of employment. I am fully informed that all information will not be disclosed to anyone else and that I will have access to information that concerns me. I agree that information obtained from this study may be published so that the finding may be of benefit to others.

The study has been explained to me and I am aware that no personal costs will be incurred by Ms T. White.

_____ _____

Participant name and signature **Researcher name and signature**

Before you commence with the questionnaire please can you complete the table.

Question	YES	NO
Are you registered with the HPCSA?		
Have you obtained a physiotherapy degree?		
Have you managed a Cerebral palsy child before?		
Do you work in a Public health hospital in KwaZulu-Natal?		

Appendix H- Pilot Study Feedback Form

Pilot Study Feedback Form **No: _____**

1. **How long did it take you to complete the questionnaire**
   - Please tick the appropriate box.

0-10 mintues		**21-30 minutes**	
11-20 minutes		**31-40 minutes**	

2. **Did you understand all the information on the information document provided?If NO, what was unclear and needed clarification?**
   - Please specify in space provided below.

   _____

   _____

3. **Were all the questions easy to understand? If NO, what was unclear and needed clarifcation?**
   - Please specify in space provided below.

   _____

   _____

4. **Do you have any suggestions on how to improve the questionnaire? If YES, please specificy.**
   - Please specify in space provided below.

   _____

   _____

5. **Please list any any additional comments or suggestions below.**
   - Please specify in space provided below.

   _____

   _____

Thank you for taking the time to complete the feedback form.