

**THE PROCESS OF REHABILITATION FOR 0-6 YEAR OLD
CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL
HOSPITAL, KENYA**

By

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ABSTRACT

Introduction: Cerebral palsy is one of the leading causes of disability globally. The number of new cases of children with cerebral palsy (CP) is on the increase. Rehabilitation is the most common intervention used to help children with CP in Kenya. Early initiation of the rehabilitation process, and involvement of the family are important for optimal functional outcomes for children with cerebral palsy. This study aimed to establish the incidence of children under six years old with CP at the physiotherapy and occupational therapy department at Kenyatta National Hospital, Kenya in 2015. This was done in order to establish the need for rehabilitation services. Furthermore, the study aimed to explore and describe the direct patient process of care as part of the current rehabilitation process followed for children with CP from the age of 0 to 6 years in order to identify any room for improvement.

Study population and Methodology: Data were collected in two phases. Phase A consisted of collecting information pertaining to the number of new cases (incidence) of children with CP under six years of age in 2015 treated at the therapy (occupational and physiotherapy) departments at KNH. For this purpose, all records of children with CP under the age of six years at the rehabilitation department in 2015 were included and reviewed. For Phase B, a mixed methods approach and a parallel convergent design were used to explore the direct patient process of care component of the rehabilitation process. In Phase B, three instruments were used to collect data: 1) Data extraction sheet (to review documentation on treatment given), 2) Semi-structured interviews with caregivers of children with CP (to determine involvement in rehabilitation) and 3) Focus group discussions with rehabilitation staff (to triangulate findings). The initial review of the medical records to document the treatment provided at the therapy departments consisted of 70 medical folders that were randomly selected. System random sampling was used to select medical records for review using Slovin's formula $n = \frac{N}{1+Ne^2}$. The total numbers of available records were 360, and the sample size was 70.

Twenty parents/caregivers of children with CP were conveniently sampled and interviewed to determine their involvement in the rehabilitation process. Finally eight medical personnel were purposively sampled based on their involvement in the rehabilitation of children with CP at the hospital. Quantitative data relating to the incidence of CP in children under 6 years in 2015 were

analysed descriptively by using frequencies. Quantitative data from phase B pertaining to the process of rehabilitation were also analysed using descriptive statistics in SSP version 22. Qualitative data was analyzed by using thematic content analysis methods.

Results: The incidence of CP in children under the age of six years in 2015, at the therapy departments of KNH was 30 per 1 000 live births. Cerebral Palsy was more common amongst males than females ($p = 0.030$). A lack of multidisciplinary team approach to rehabilitation was identified in this study, as well as the limited rehabilitation techniques used during treatment of children with CP. Parents and caregivers were not effectively involved in the rehabilitation process during therapy sessions to continue the rehabilitation programme at home.

Conclusion: There is a relatively high incidence of children under 6 years with CP at this hospital, which highlights the need for the provision of early intervention and rehabilitation. There was a lack of a multidisciplinary team (MDT) approach to the rehabilitation process for young children with cerebral palsy, and limited techniques were used during therapy. Caregivers were also not sufficiently involved in the process of rehabilitation. Furthermore, there was low attendance recorded of children with CP in 2015 at Kenyatta National Hospital (KNH) in Kenya. Some of the reasons given for the low attendance at the rehabilitation clinics were the high cost of rehabilitation services charged for patients and few specialized staff assigned to the rehabilitation clinics at KNH. The rehabilitation clinics should reduce or waive their service charge for the rehabilitation of children with CP under the age of six years. This could potentially encourage earlier intervention and a more holistic approach to rehabilitation in this setting.


Keywords: Cerebral palsy, rehabilitation, children, prevalence, parents/caregivers, advice, multidisciplinary approach, devices, techniques, disability

DECLARATION

This research “The process of rehabilitation for 0-6year old children with cerebral palsy at Kenyatta National Hospital, Kenya” is my original work and has not been presented for an award of a degree or examination in any other university. Complete referencing has been made and acknowledged for all sources used and quoted.

Signature:  Date: July, 2018

Daniel Odhiambo Ngota

Dr Liezel Ennion:  Date: July, 2018

DEDICATION

This work is dedicated to my wife, Dr. Janet Auma Odhiambo, for her continuous support during the hard times of my studies. My dedication is also to our children, Richard, Robert, Ruth and Harriet, who were the source of my encouragement during my studies in South Africa.

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LIST OF ABBREVIATIONS AND ACRONYMS

ABR	Advanced Biomedical Rehabilitation
ADDM	Autism Developmental Disabilities' Monitoring
CDC	Centre for Disease Control and Prevention
CG	Caregiver
CP	Cerebral Palsy
FGD	Focus Group Discussion
GMFCS	Gross motor functional Classification Scale
KBSC	Kenya bureau of statistics census
KI	Key informants
KNH	Kenyatta National Hospital
PT	Physiotherapist
SDR	Selective dorsal rhizotomy
SCPE	Surveillance of cerebral palsy in Europe
SPSS	Statistical Package for Social Sciences
SPO	Structure, process and outcome
OT	Occupational Therapist
MCH	Maternal child health
MDT	Multidisciplinary Approach
MP	Medical personnel
USA	United States of America
UWC	University of the Western Cape
WB	Weight-bearing

CHAPTER ONE: INTRODUCTION

1.1 Background

Cerebral palsy (CP) is a common cause of physical disabilities amongst children globally (Rosenbaum et al., 2007). The Centre for Disease Control and Prevention's [CDC] (2015) population-based studies from around the world report incidence estimates of CP ranging from 1.5 to 4 per 1000 live births for children between the ages of two to six years. In the United States of America (USA) one in every 34 000 children is born with CP (Report & Baio, 2012). According to studies conducted in Africa by Donald, Samia, Kakooza-Mwesige & Bearden, (2014) the incidence of CP varies widely from country to country, from approximately 2 to 10 per 1000 live births. There are no specific statistics available for Kenya relating to CP. However, the incidence of CP seems to be increasing. This could potentially be because of a lack of maternal care during pregnancy, or the scarcity of medical facilities in rural areas. The Kenya bureau of statistics census 2009 shows that 1776064 or 4.6 % of the estimated population of 38619097 suffer from some form of disability affecting movement, sight and hearing disorders associated with conditions present in cerebral palsy.

There are mainly four types of CP, namely spastic cerebral palsy, ataxia, athetoid and mixed CP. Spastic CP is by far the most common type of CP and constitutes 70% of all cases (Rosenbaum et al., 2007). Ataxia occurs in 5% to 10% of all CP cases. A patient with athetoid or dyskinetic CP presents with both hypertonia and hypotonia and mixed involuntary movements. A patient with mixed cerebral palsy shows symptoms of athetoid, ataxic and spastic CP appearing simultaneously, each to varying degrees, and with or without certain symptoms of the other types of CP (Rosenbaum et al., 2007).

Rehabilitation can be defined as a set of interventions taken to reduce the impact of disability on an individual, optimizing independence, social participation and improved quality of life (Helander, 1999). Evaluating the process of rehabilitation is a complex task, as many factors

influence how the patient responds to rehabilitation. The patient's condition, the context and environment, the therapy received as well as the providers of the rehabilitation service all impact on the outcomes of the rehabilitation process. In order to investigate, and better understand specific aspects of rehabilitation, Donabedian's framework of structure, process and outcome (SPO) as reported on by Hoeniget al., (1999) is useful to assist. The SPO framework consists of three components, namely; the structure of the rehabilitation, the process of care and the patient outcomes (Hoenig et al., 1999).

The structure of rehabilitation refers to the rehabilitation facilities and health professionals providing the care. For this study, the specific structure will be the Physiotherapy and Occupational therapy departments at the KNH in Kenya. The process of care refers to what is actually done to the patients during rehabilitation or as they move through the health system. This can include indirect care such as rehabilitation policies or direct care such as the physical treatment techniques or interventions used on patients. This study is focused on children with CP who are less than six years of age undergoing the process of direct care by physical treatment. As explained by Hoenig et al., (1999) direct patient care can include exercises, physical modalities, education and assistive devices.

The SPO framework also included patient outcomes as a result of the structure and process of rehabilitation. Even though patient outcomes is essential when evaluating a specific rehabilitation process, patient outcomes will not be considered in this study, as it only aims to describe the process of direct patient care.

According to Szabo (2000), effective rehabilitation process for children with CP should include an holistic multidisciplinary approach, including medical therapy, physiotherapy, occupational therapy, training in communication skills and self-care skills, vocational rehabilitation, access to orthopaedic adaptive and assistive devices, and educational interventions. Early intervention in the rehabilitation process of children with CP is vital for improved functional outcomes and

independence (Rosenbaum & Stewart, 2004). There is no consensus in the literature on the definition of “early intervention” as it relates to children with CP, but it is widely accepted as therapy initiated within the first six months of life (Herskind, Greisen& Nielsen, 2015). Studies by Frederick et al., (1988) show that early intervention minimises chances of secondary complications, such as contractures, that could impact negatively on functional independence. Early intervention also assists children with CP to perform activities of daily (ADL) living more independently, leading to improved self-confidence and more active participation in society (Damiano, 2006). The different professionals who are involved in providing early interventions are: doctors, physiotherapists, Occupational therapists, Speech and language therapist, social workers, and orthopaedic technicians.

The benefits of a family-centered approach to rehabilitation in children are well documented (American Academy of Pediatrics 2003, Moore, et al., 2009). The family-centered approach is based on the understanding that a child’s primary source of support and strength in their family and important in medical decision-making (American Academy of Pediatrics 2003, Moore, et al., 2009). Yet, from personal experience, the families of children with CP are not always involved in the rehabilitation of their children in the Kenyan context. Within the Health Care Community, there has been increased emphasis on the need for user involvement within health provision (Ross, 2000). The aim of rehabilitation is to promote independence and to help integrate children with CP into societal/family activities. Parental/caregivers involvement is therefore important in the rehabilitation process for positive and sustainable self-reliance.

In developed countries, statistics show the benefits of continuing the exercises prescribed by a therapist in the home environment of children with CP, highlighting the importance of parent involvement (King & Chiarello2014). Effective Parental/caregivers collaboration with the medical personnel is fundamental to effective rehabilitation programs for children with cerebral palsy. In developed countries, parents are recognized as being the experts on the abilities and

needs of their own children (Hanna & Rodger 2002). In Kenya, it is not clear if parents are actively recognized and involved by medical practitioners in the rehabilitation of their children with CP. Parents are generally also not involved in collaborative goal setting for individual children with cerebral palsy in a large referral hospital like KNH, where there is an acute shortage of therapy staff. Family involvement in the rehabilitation process of children with cerebral palsy had not been previously explored in a Kenyan context and it has not been known how Kenyan parents have experienced family centered practices. It was therefore important to examine the family/ caregiver's involvement in the rehabilitation process of children with cerebral palsy at KNH in Kenya.

1.2. Problem Statement

Cerebral palsy is the most common motor disability in childhood globally. Population based studies from around the world report prevalence estimates of cerebral palsy ranging from 1.5 to more than 4 per 1,000 live births. There is a perceived increase in the incidence of CP in Kenya, but no statistics to document it. Furthermore, the statistics used for incidence by CDC (2006) to calculate the extrapolated incidence of CP in developing countries such as Kenya is based on UK, US, Canada and Australian incidence rates that might differ greatly from developing countries such as Kenya. The extrapolation calculation used for the existing statistics is automated and does not take into account any other differences across various countries and regions for which the extrapolated cerebral palsy statistics refer. The extrapolation does not use data sources or statistics about any country other than its population. As such, these extrapolations may be inaccurate especially for developing country like Kenya. The incidence documented for the Kenyan context could therefore be outdated and there is a need for recent incidence or recent update for proper planning of effective rehabilitation programs.

In order to plan for and provide adequate rehabilitation services for children with CP, the incidence of CP in the specific setting had to be determined in order to describe the need. Kenyatta National Hospital was chosen as the study setting, as it is the largest referral hospital that provides services to children with CP and it is located within the capital city of Kenya.

The only intervention strategy used in Kenya for children with CP is rehabilitation. However, the rehabilitation process followed is not standardized or well documented. It is clear that early rehabilitation intervention is beneficial to children with CP and should be standard practice in the management of these children. However, there is still a lack of awareness and early intervention in some developing countries such as Kenya. In order to improve the functional outcomes and level of independence of children with CP in Kenya, the current rehabilitation process being followed for children of six years and younger with CP has to be described in order to identify any gaps or room for improvement. This might also lead to an increase of awareness about the value of early intervention for this population of children with CP and decrease the incidence.

Parents/caregivers involvement in the rehabilitation process of children with cerebral palsy is a key element in the field of medical intervention in the developed countries. However, in Kenya, there are no statistics showing how parents/caregivers are involved in the rehabilitation process of children with cerebral palsy. There is also no standardized guideline to inform the management of children with CP at KNH.

Early rehabilitation and family involvement is essential to improve functional outcomes of children with CP. The perceived growing number of children with CP in Kenya would require more rehabilitation staff and services, but without information on the need for rehabilitation, and a clear description of the services provided, rehabilitation services cannot be improved.

1.3 Research Questions

- i. What was the incidence of cerebral palsy amongst children aged six years and younger at Kenyatta National Hospital, Kenya, in 2015?
- ii. What is the process of direct patient care used by the medical personnel in the rehabilitation team at Kenyatta National Hospital, Kenya, to assist children with cerebral palsy?
- iii. What is the extent of involvement of parents/caregivers of children with Cerebral Palsy, by medical personnel during rehabilitation process?

1.4 Aims of the Study

- i. To determine the incidence of CP amongst children aged from 0-6 years in Physiotherapy (PT) and Occupational therapy (OT) departments at Kenyatta National Hospital, Kenya in 2015.
- ii. To explore and describe the process of direct patient care as part of the current rehabilitation process that was being followed for children with CP from the age of 0 to 6 years at Kenyatta National Hospital, Kenya.
- iii. To explore the extent of parental/caregivers involvement in the rehabilitation process of children with cerebral palsy.

1.5 Research Objectives

- i. To determine the incidence of new cases of CP in children aged 0-6 years in 2015 at the rehabilitation departments at Kenyatta National hospital, Kenya.
- ii. To explore and describe the process of direct patient care as part of the current rehabilitation process for children aged 0-6 years with CP in terms of a multidisciplinary approach to rehabilitation techniques used and education of caregivers.

- iii. To explore the extent of involvement of caregiver's in the rehabilitation process of children with Cerebral Palsy.

1.6 Significance of the Study

The findings of this study may advance the quality of service by the provision of holistic rehabilitation to CP children through the involvement of other approaches currently not being used in Physiotherapy and occupational therapy at Kenyatta National Hospital. The study have also highlighted some gaps in the current rehabilitation process and provided some baseline information to advocate for improvement in the rehabilitation of children with CP between the ages of 0–6 years. The study contributed to providing some insight into the incidence of new cases of cerebral palsy and the process of management used for rehabilitating children with Cerebral Palsy at Kenyatta National Hospital in Kenya. The study highlighted the importance of involving parents or caregivers on management of children with cerebral palsy. This information might be helpful to the Ministry of Health and other stakeholders supporting the health sector to plan and provide adequate allocation of funds to support rehabilitation facilities and hospitals in Kenya.

1.7 Operational Definition of Terms

The following terms are operational definitions as defined by the researcher for the purpose of the study: -

Cerebral Palsy	A disorder of movement and posture that comes as a result of damage to the part of the brain that deals with voluntary movement.
Activities of Daily Living:	These are day-to-day activities that people perform for example feeding, dressing, washing, cleaning, toileting and moving from one place to another.
Physiotherapist	Medical personnel whose job is to give exercises to those with physical disabilities.
Occupational therapist	Medical personnel whose job is to give interventions designed to achieve functional outcomes, which promote health, prevent injury or disability and which develop, improve, sustain or restore the highest possible level of motor independence.
Devices:	Equipment designed to aid or support in performing an activity.
Trans-disciplinary	Health professionals who have sufficient knowledge in different areas such as physiotherapy, occupational therapy, speech therapy and social workers who come together to assess an individual's needs.
Multidisciplinary team:	The rehabilitation team composed of doctors, physiotherapists, occupational therapists, speech therapist, social workers and other specialized medical personnel.

1.8 Outline of the Study

Chapter 1- Introduction: Chapter one presented the background to the study problem, the incidence of cerebral palsy in Europe, America, Africa and the disability that is associated with CP was highlighted. The problem statement is discussed and the terms used in the study were defined. The next chapter will provide compare other studies done in developed and developing countries.

Chapter 2 – Literature review: Chapter two provides an overview of the relevant literature pertaining to the study objectives. In this section, the literature reviewed was in alignment with the incidence of CP, rehabilitation process and techniques and education and advice given to the parents or caregivers. Relevant studies are compared or related to other studies conducted in the rest of the world and what is followed at KNH.

Chapter 3 – Methodology: This chapter involves the methodology followed for the different phases of the study. In phase A, the methods used to determine the incidence of CP in children under the age of six years in 2015 are described. The methods used to describe and explore the process of direct patient care of rehabilitation (phase B) are elaborated on. Phase B is divided into three stages, namely: 1) a review of the medical records; 2) qualitative interviews with parents and caregivers, and lastly by 3) focus group discussions with rehabilitation professionals and parents. For each phase, the research setting, study design, population and sampling procedure, instruments used in the study, sampling method, data collection and analysis are described, followed by the ethical considerations.

Chapter 4 – Results: This chapter presents the results of the analysis of the study. The chapter has been divided into the Phases in which the data was collected, namely: Phase A (Incidence) and Phase B1-3 (process direct patient care). The research findings have been presented in alignment with the research questions and the objectives of the study.

Chapter 5 – Discussion: This chapter contains a discussion of the results from the two phases of the study compared with other studies. The focus group discussion with rehabilitation personnel and parents clarifies the discrepancies between the medical records and interviews with parents, and these are also discussed.

Chapter 6 - Conclusion: Chapter six summaries the findings and limitations of the study. In addition it gives recommendations that could be used by the Ministry of Health and Kenyatta National hospital in the management of children with cerebral palsy at their rehabilitation clinics. Involvement of parents/caregivers of children with cerebral palsy should also be taken into account when designing specific rehabilitation goals for each patient. A multidisciplinary team approach should be embraced in order to improve assessment and planning of short, medium and long-term goals of children with cerebral palsy.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Cerebral Palsy is one of the most common causes of disability globally (Rosenbaum et al., 2007). Cerebral palsy has a severe impact on the lives of the affected children, their families and health sector services. In this chapter, the relevant literature pertaining to cerebral palsy and how it affects children was reviewed in alignment with the objectives of the research. The databases that were used for the literature search included PubMed, Sabinet, Ebscohost and Science direct from the University of the Western Cape Library, South Africa. The key words used in these searches were Cerebral palsy, rehabilitation, children, incidence, parents/caregivers, advice, multidisciplinary approach, devices, techniques, and disability.

2.1.1 Definition of CP

Cerebral palsy is one of the major causes of disability in the world that affects development of a child before birth, during birth or after birth (Rosenbaum et al., 2007). Cerebral palsy affects the central nervous system (CNS) that controls the fine and gross movements of the body (Thorogood and Lorenzo, 2013; Krageloh-Mann and Cans, 2009). Damage to the CNS negatively affects a child's gross and fine motor and mental development, as well as their functional outcomes and level of independence in activities of daily living (Rosenbaum and Gorter, 2011).

2.1.2 Diagnosis of CP

Early diagnosis of CP and early intervention is essential for improved rehabilitation outcomes (Yalcinkaya et al., 2014). Health professionals can make the diagnosis of CP through special investigations such as a computed tomography (CT) scan or clinically. In developing countries, CP is most often diagnosed clinically based on the delay of motor milestones and delayed reflexes in the first year of life (Jan, 2006). Relying on clinical diagnoses often delays the

diagnosis of CP, and results in delayed intervention. The clinician can only make the diagnosis based on delayed milestones, which might only become clear as late as 12 months of age, thus missing the opportunity for early intervention before the age of six months. The diagnosis of CP is made by the multidisciplinary team (MDT), which comprises a doctor or a pediatrician, physiotherapist (PT), occupational therapist (OT), speech and language therapist (SLT), a social worker, orthopaedic technician, and wheelchair technician. However, in most developing countries, the MDT is not complete but is composed of the first cadre of medical professionals.

2.2. Rehabilitation process for children aged 0-6 years with CP

A study by Paneth, Hong, & Korzeniewski, (2006) highlights that globally there is no standard rehabilitation therapy that works for all patients with cerebral palsy. Ideally, doctors must work with a team of health professionals to identify the patient's unique needs and create an individual treatment plan.

2.2.1 Rehabilitation process

The rehabilitation process followed for children with cerebral palsy include the following intervention; mobilisation, stretching, positioning, ambulation, speech therapy, provision of devices to enable functional activities, integration in special schools and vocational rehabilitation centres.

According to Donald et al., (2014), since 1948 tremendous progress has been made in South Africa in the field of cerebral palsy rehabilitation. The state subsidises voluntary associations that have been able to establish schools for children with CP equal to the best in the world, situated in various parts of the Republic of South Africa, for all population groups. Diagnostic and assessment clinics operate in many schools and centers throughout the Republic; provincial hospitals are also expanding their clinical services for CP children in South Africa. In Kenya, parents or caregivers are asked to pay for services, special schools and appliances that a child with CP may need.

Study findings by Zhang, Jia, Lilian, Li, Chen, Young, Ge and Lilian (2014) in South Africa, show that, in most advanced places in South Africa there is the use of Advanced Biomedical Rehabilitation (ABR), a life changing new technique designed specifically to address weak soft tissue and connective tissue structure. A home-based programme is taught to parents or caregivers and then practised between 30 minutes to one hour per day in a home environment through a specialised method of repetitive application of pressure by which an equal repetitive stimulation of the soft tissue is achieved. The body reacts to this stimulus by remodeling and regenerating the areas that are being addressed. Recent studies presented in 2012 at the international cerebral palsy conference in Italy have shown that (ABR) significantly improves the quality of life and function in children between the ages of five and 13 years suffering from the most severe forms of cerebral palsy. The treatment technique used in Kenya, according to this study, are basic techniques - mainly massage, stretching exercises and positioning.

On the contrary, side, findings by the National Council for Persons with Physical Disabilities in South Africa (2014) show that children with cerebral palsy living in poor and rural areas in South Africa are a particularly neglected and underserved group. Although they qualify for government assistance in the form of a “care dependency grant”, this money is usually a source of income for the family and not all the money is spent on the child. Families and caregivers have little or no access to support services, such as peer support groups and networks. Corroboration has shown that less than 30% of children in South Africa with CP, who need rehabilitation, actually receive it. Not only is transport to a hospital costly because of the distances involved, but also the hospitals do not have sufficient therapists to treat the children. In addition, those therapists who are available may have little or no experience in working with children with cerebral palsy. Furthermore, the lack of financial resources at hospitals means that there are long waiting lists for basic equipment such as wheelchairs, buggies and standing frames. As a result, children up to the age of 14 years are still being carried on their mothers’

backs. Generally, there is a severe lack of rehabilitation therapists in South Africa for managing CP. The public sector and up to 38% of the country's population live in rural areas and are mainly dependent on clinics at Primary Health Care level. Given the resource-poor situation, all aspects pertaining to the care and rehabilitation of children with cerebral palsy are often severely neglected. Lack of resources is a common challenge to parents in the rural and urban areas of Kenya. The high cost of the service charge to parents from low-income areas within the urban areas can affect the effective follow-up of treatment.

Basic care of children with CP in African countries is limited by the poor availability of diagnostic facilities or medical personnel with experience and expertise in managing cerebral palsy (Kristen, Donald, Angelina et al., 2014). The lack of available staff is exacerbated by lack of available interventions such as medications, surgical procedures, or even regular therapy input. The MDT is not often complete due to a lack of staff assigned to the rehabilitation clinics at Kenyatta National Hospital.

2.2.2 Physiotherapy & Occupational Therapy

A study conducted by CDC (2012) in four African countries, reveals that, for the first one to two years after the birth of a child with cerebral palsy, both physical and occupational therapists should provide support with issues such as head and trunk control rolling and grasping displayed by children with cerebral palsy. At a later stage both types of therapist are involved in wheelchair assessments. Braces or splints may be recommended for the children with cerebral palsy. Some of these support devices help with functions such as improved walking; others may stretch stiff muscles to help prevent rigid muscles (contractures). Children with severe contractures or deformities who may need surgery on bones or joints in the arms, hips or legs to attain correct positions, are referred to hospitals in the capital cities to be operated on by orthopaedic surgeons. The surgical procedures are used to aid in lengthening muscles and tendons that are proportionally too short because of severe contractures.

The approach of the rehabilitation process for CP children regionally is planned according to the needs of every child, Donald et al., (2014). Similarly, the rehabilitation process in Kenya follows global and regional trends as indicated by Hong, & Korzeniewski, (2006) & Donald et al., (2014).

A study by Kate (2006) indicates that an inter-disciplinary approach that integrates the expertise of all the rehabilitation team members, namely: physiotherapists, occupational therapists, orthopaedic technicians and doctors, in the rehabilitation process of CP children, provides the most optimal functional outcomes. A range of rehabilitation techniques such as passive and active movements and stretches, postural correction, weight-bearing (WB) and functional activities are recommended to address the functional impairments suffered by children with CP (Pin, 2007). The frequency vary for different patients; newly diagnosed children with CP 4 to 6 times in a month for the first three months. Duration of service for each patient is thirty minutes. Very little is known about the use of a multidisciplinary approach in the Kenyan context, particularly with children with cerebral palsy between 0-6 years.

2.2.3 Medical Intervention

A study by conducted by Rosenbaum, Walter, Hanna, Palsino, Russel&Raina (2002) shows that in America, a wide variety of medications, are used to reduce symptoms and address complications in children with cerebral palsy. Children who experience seizures, spasticity and unwanted (involuntary) uncontrolled movements, such as athetoid and chorea for example, are often prescribed drugs to minimise these movements. Some medications are also used to relax muscles, increase comfort and facilitate better posture. Medications are often prescribed to improve associated conditions such as epilepsy (Kramer & Hinojosa, 2010). Many drugs prescribed to children with CP aid in digestive problems, breathing difficulties, skin conditions and behavioural or learning issues (Palisino&Murr, 2009). When choosing prescriptions, doctors and parents consider the benefits as well as the short and long-term side effects.

Children with generalised spasticity are given oral muscle relaxants that may relax stiffness and contracted muscles. The drugs include diazepam (valium), dantrolenedantrium and baclophenac. Based on the established goals, botulinum toxin-A (Botox) injections directly into the muscle, nerve or both can also assist in reducing spasticity. Botox injections may also help to prevent drooling.

2.3. Incidence and Etiology of Cerebral Palsy

In 2008 the WHO reported that the global incidence of CP was between 10 and 40 per 1000 live births (WHO, 2008). According to a study by the CDC (2015), there is a variation of incidence of CP globally, and there is a marked difference in the incidence rate of CP between developed and developing countries. A study conducted by Rice (2009) found that the incidence of CP is 1.5 to 4 percent of live births in the United States of America.

A report from the Autism and Developmental Disabilities Monitoring Network (ADDM) (2012) revealed that in Hong Kong the incidence of CP was 1.3 per 1000 children. The age-specific incidence rate per year varied from 1.04 to 1.50 per 1000 children. A study conducted by CDC (2009) in Europe, found that the average incidence of CP in 2004 was 3.3 per 1000 children. According to the surveillance of cerebral palsy in Europe (SCPE), the incidence of CP in Europe is 2 per 1000 live births. For pre-term babies, the incidence of CP in Europe and Australia ranges from 35.0 to 79.5 per 1000 live births for children born at 28 to 31 weeks gestation. For full-term pregnancies the incidence was reduced to 1.1 to 1.7 per 1000 live births (Toorn et al., 2007).

In studies by Donald, Samia, Kakooza-Mwesige& Bearden (2014) the incidence of CP in Africa is reported to be higher than in most developed countries and varies from 2–10 per 1000 live births from country to country (Table 1). According to the CDC (2008), South African studies also indicate a high incidence rate for CP between 1% and 8% of the population.

Table 1: Extrapolated statistics by country for incidence of cerebral palsy in Eastern African countries (CDC, 2006)

Country/ Region	Extrapolated Incidence (Warning)	Incidence per 1000 people	Population Estimated Used
Ethiopia	2098	0.029	71336571 ²
Kenya	970	0.029	32982109 ²
Somalia	244	0.029	8304601 ²
Tanzania	1060	0.027	36070799 ²
Uganda	776	0.029	26390258 ²

Source: Centre for Disease Control and Prevention (2006)

The extrapolation used in the table does not use data sources or statistics about any country other than its population. As such, these extrapolations may not be highly accurate. The figures only give a general indication as to the actual prevalence or incidence of cerebral palsy in that region.

In Kenya, as in other African countries, statistics by CDC (2006) reveal that there are warning signs of 970 children having cerebral palsy in a population of 32982 109². While the reviewed literature gives a general incidence for all children with cerebral palsy, the current study specifically determines the incidence of existing cases in children aged between 0-6 years at Kenyatta National Hospital, which is a gap to be bridged. Incidence, usually expressed as a number or ratio, is the total number of people with cerebral palsy in a certain place.

A study done by Krigger (2006), reported that in developing countries 20-30% of acquired brain damage occurred during the postnatal phase. The risk factors for CP are well known and include preterm delivery or infants born with a low birth weight, traumatic brain injury in infants and brain infections (Krigger, 2006). After-birth risks predisposing a child to CP are

malaria, meningitis, head injuries or infection in the brain (Mclaren, 2013; Laughton, 2004; Krigger, 2006).

In developing countries such as South Africa, some of the common perinatal causes of CP include asphyxia during delayed or complicated labour and infections (frequently tuberculosis and meningitis associated with HIV), while head injuries are the most common postnatal cause of CP (Mclaren, 2013; Laughton, 2004; Krigger, 2006).

2.3.1 Classification of CP

CP has different presentations according to the clinical feature of each type (Laughton, 2004). The three main types of CP include spastic, athetoid and ataxic CP (Krigger, 2006). The spastic type of CP is the most common, and affects 70% of children with CP, who present with spasticity of the limbs and trunk. Athetoid/dyskinetic CP affects 15-20% of children with CP and is characterised by slow, writhing movements of the upper and lower limbs. Ataxic CP is less common but presents in 5-10% of children with CP and includes clinical features of an unstable gait pattern with a wide base of support, tremor, poor balance and co-ordination difficulties (Krigger, 2006).

2.3.2 Clinical presentation of a child with cerebral palsy

The nature and occurrence of CP depends on the area of the brain that is affected. The lesion to the brain affects different parts of the body. The lesion may affect the sensory or motor cortex of the brain, which will result in different clinical presentations and associated secondary complications (Mclaren, 2013; Krigger, 2006; Laughton, 2004).

Cerebral palsy presents differently in each type of CP diagnosed. The area of the brain that is damaged presents different complications. Research done by Christensen et al., (2014) in three states of the United States of America, reveals that children with cerebral palsy may have difficulties in the areas of motor functioning, communication disorders, hearing impairments, intellectual deficits, seizure disorders and perceptual difficulties. These complications are

common to both developed and developing countries. Research by surveillance of cerebral palsy in Europe (Johnson, & Ann, 2002) shows that 41% of children with CP are restricted in their gross motor movements and 31% need to use assistive devices for their disabilities. The challenges affecting CP children are common worldwide, although in developing countries delayed rehabilitation intervention may cause severe complications such as contractures, an inability to walk and inability to perform activities of daily living independently (Best, Heller & Bigge, 2005). It is therefore important that the rehabilitation processes in practice be examined for better intervention strategies.

The most commonly associated complications are as follows:

I. Orthopaedic complications

Children with severe CP are often unable to bear their full body weight through their lower limbs, resulting in reduced bone density. Reduced bone density can lead to secondary complications such as fractures, osteoporosis, scoliosis and pain (Jan, 2006; Krigger, 2006).

II. Respiratory complications

Respiratory complications are a common occurrence in children with CP. Children with gross motor function classification scale (GMFCS) levels of 4 to 5 are more affected than those with classification below level 4 (Couriel et al., 1993). Reflux and aspiration of food during meal times due to poor oral motor function, is the most common cause of respiratory complications among children with CP (Morton et al., 1999; Krigger, 2006). Other complications are pneumonia, bronchitis and respiratory failure, which at times can result in the death of a child with CP (Courielet al., 1993)

III. Epilepsy

Krigger (2006) indicates that nearly half of all people with CP suffer from epilepsy. Epilepsy is associated with trauma or disease affecting the brain (Cole, 2000). Even though epilepsy is common, early diagnosis is challenging, due to the existing neurological injury to the motor

part of the brain (Laughton, 2004).

IV. Intellectual disability

Children with cerebral palsy have intellectual disability due to brain damage. A study by Mefford et al., (2014) shows that 70% of CP children have IQ scores of less than 70, indicating some form of intellectual disability. Children born with cerebral palsy can have moderate to severe brain damage, which predisposes them to a low IQ score. The impairment resulting from brain damage causes children with CP to have difficulties in cognitive processing, leading to perceptual development and learning limitations (Laughton, 2004; Bax et al., 2005).

V. Feeding, nutrition and growth

According to Jan (2006), 30% of children with CP suffer from some form of malnourishment. Malnourishment occurs due to some of the challenges that children have with feeding. Complications in feeding of children with CP may be due to poor lip and mouth closure, tongue thrusting, drooling, temporo-mandibular joint contractures or incorrect positioning during feeding. Vomiting, aspiration of food and regurgitation are other complications that may occur that can result in malnourishment (Laughton, 2004; Krigger, 2006).

VI. Bladder dysfunction

Urinary incontinence or urinary retention and urinary tract infections are common in CP children. A deficit in the motor control to the bladder muscle (detrusor muscle) is the main cause of bladder dysfunction (Krigger, 2006).

VII. Hearing loss

Hearing loss is one of the complications that are diagnosed in 18% of children with CP at an early age. The involvement of a speech and language therapist in the rehabilitation process improves the outcomes of the treatment of hearing and speech during the development of children with CP (Laughton, 2004). Hearing impairments affect the developmental progress of children with cerebral palsy.

VIII. Visual deficits

Low vision results in poor rehabilitation outcomes and delayed development if not diagnosed and managed early (Laughton, 2004; Jan, 2006). The ophthalmic sensory system is often reduced in CP children, which accounts for 25-39% of diagnosed visual impairments (Kriger, 2006). Cortical visual impairment is caused by damage to the occipital lobe that may result in cortical visual impairments (Jan, 2006; Laughton, 2004).

IX. 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 contribute to poor hygiene, including drooling of saliva due to the inability to swallow, thrusting of the tongue and breathing through the mouth.

2.3.3 Prognosis of CP

Every case of CP presents differently and requires different approaches to rehabilitation treatment (Mclaren, 2013). “There are many clinical, therapeutic, pharmaceutical and surgical treatment options that need to be explored to reduce and avoid these secondary associated complications (Wade & Jong, 2000)”. Children with CP suffer a permanent injury to the brain, and rehabilitation is essential to improve functional outcomes for these children. The aim of rehabilitation is to enhance the functional levels and improve the activities of daily living. For children with CP, the damaged brain has the ability to formulate new connections that allow processing and re-education of functional motor tasks. This process is often referred to as neuroplasticity. A study by Jan (2006) showed that frequent therapeutic intervention in children with CP encourages neuroplasticity resulting in greater rehabilitation outcomes.

Medical advances have prolonged the lives of children severely affected with CP. Until recently, the average life expectancy of a person with severe CP was only 20 years of age (Jan,

2006). However, ultimately the prognosis of a child with CP largely depends on the severity of the brain damage and the effectiveness of the intervention they receive once diagnosed.

2.4 Parental involvement in the rehabilitation process of children with Cerebral Palsy

Studies carried out by Jelinsky, Autti-Ramo, Brogren&Carlberg (2012) states that in order to make paediatric rehabilitation care more effective, the rehabilitation care needs to be more family centered. Parents and families of children with disabilities should be able to express their family needs and be given opportunities to take part in decision-making. An important factor in doing this is the process of empowerment that involves access to health information, which is critical for decision-making.

Sloper, (1992) in her study on service needs of families of children with severe disabilities showed that a considerable part of the unmet needs of families had to do with provision of information to family members of children with disabilities. She also showed that families with the highest levels of unmet needs also had the highest stress level, which affected the effectiveness of rehabilitation to their children. King, King & Rosenbaum (2001) in agreement supports this finding in her literature that information exchange between medical personnel and family members of children with cerebral palsy appeared to be strongly associated with general satisfaction as well as with adherence to the therapy.

In the Dutch, therapy setting, parents often have only once in a while face-to face contact with therapists. (Krujsen-Terpstra, Verschuren, Kotelaar, Riedijk, Goter, Jongmans&Boije 2014). The absence of parents during their child's therapy makes it more difficult for therapists to fine-tune the treatment to the parent's needs. Involvement of parents in the rehabilitation of their children helps to support parents in their empowerment process and in shifting roles leading to establishment of partnership with the parents.

In Netherlands, physical and occupational therapy for young children with Cerebral Palsy is typically provided in rehabilitation centers often without the parents being present during therapy

(Kruijssen-Tepsterant et al.,2014). According to Joseph Williams, Elywn& Edwards (2014), although many patients generally perceive the professionals to be experts and are only partially involved in the treatment they are given, the involvement of parents into full partnership to their children's rehabilitation empowers them and motivates them for effective outcome of the therapies.

Miller, Gordon, Danielle & Diller (1992), compared mothers of children with disabilities amid mothers of children without disabilities. The findings showed that mothers of children with disabilities showed depressive symptomology. He also found out that an emotion focused coping style of the mothers was related to high stress levels. However, the most interesting part of his study for the present review is that Miller asked parents to describe the most stressful situations related to their children with disabilities and surprisingly about 33% of the stressful situations that were described involved lack of involvement of parents to their children's treatment by the medical professionals. Thus, treatment appeared to be one of the most common stress factors for mothers with children with disabilities.

According to the reviewed literature, achieving family-centered care is often found to be a challenge in practice in both the developed and developing countries. However, the importance of parental involvement in the rehabilitation of children with cerebral palsy is widely acknowledged in the literature on Family-Centered Care. Parents of children with cerebral palsy can benefit a lot from information on their child's rehabilitation process and the available support services for their children.

Summary of chapter two: Chapter two presents the literature review of similar studies that were conducted in other countries. The incidences of Cerebral Palsy in Africa are reported to be higher than most developed countries. However, the extrapolation does not use from any specific African country other than its population that could be inaccurate.

The process of rehabilitation in PT and OT departments at KNH involves the use of limited rehabilitation techniques such as massage, stretching and positioning. In other countries, more techniques are used in combination with adjunct treatment such as weight jackets and drug administration such as Botulinum-A injection. The literature highlights that there is a vast difference in the incidence of CP in countries such as the USA and in Europe, where the incidence rate is between 1.5-3per 1000 live births, while in African countries it varies from 3-10per 1 000 live births. According to reviewed literature, in developed countries there is sophisticated equipment for managements of children with Cerebral Palsy. Family involvement in the rehabilitation process of children with cerebral palsy was found to be minimal in both developed and developing countries.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents the methodology that was employed in conducting the study. It includes aspects such as research setting, research design, study population, sampling techniques, research instruments, and procedure for data collection, data analysis, presentations and ethical considerations.

3.2 Research Setting

The study was conducted in the physiotherapy and occupational therapy departments at Kenyatta National Hospital (KNH), which is the largest teaching and referral hospital in Kenya. The hospital has a 2000 bed capacity, 50 wards and 24 theatres and attends to 30000 patients daily (Kenyatta National Hospital, 2015). The hospital provides medical and surgical services and has specialised units such as neonatal that is part of maternity ward, cardio-thoracic, burns, renal and oncology.

The rehabilitation departments serve between 100-150 patients daily with different types of disabilities or injuries. These two departments were specifically selected to recruit children with CP, as all children with CP that are identified at the outpatients department are referred to either the Physiotherapy or Occupational therapy departments for further management. The two departments have an independent medical records section, which made it easier to access the medical files. The departments serve both children and adults. Other rehabilitation services provided at the facility include the provision of mobility and assistive aids, and orthotic devices for people with disabilities, and clubfoot services. The OT department also provides speech therapy services to children with cerebral palsy who have speech problem. The facilities, through government funding, procure imported workshop machinery and materials for making orthotic devices. The population that mostly accesses these services is children with CP, whose

families live in low-income residential estates in the city, and by those children referred for specialized management from other parts of the country.

3.3 Research Design

This study used a quantitative approach and a cross sectional descriptive study design to collect data on the incidence of CP in Phase A. For Phase B, a mixed method, convergent parallel design, which uses both quantitative and qualitative approaches were employed to describe the process of direct patient care, and family involvement (Creswell, Klassen, Clark & Smith, 2011). A quantitative approach involves the use of numbers to collect information, which is then evaluated, using statistical analysis that offer the opportunity to dig deeper into data and look for greater meaning (Oso&Onen, 2008). A mixed methods approach allows the researcher to gain a deeper and more holistic understanding of the problem under study, by benefitting from the strengths of both quantitative and qualitative approaches (Creswell, Klassen, Clark & Smith, 2011). Employing both approaches enhanced integrity of the findings. When used along with a quantitative approach, a qualitative approach assist in the interpretation of findings and in a better understanding of the complex reality of a given situation and the implication of quantitative data (Bryman, 2006).

3. 3.1 Phase A: Incidence of CP in children under six years at KNH

In order to determine the incidence rate of children with CP during a specific year, the total number of children under the age of six years who were potentially at risk for having CP, had to be determined. The incidence proportion method was used to determine average risk. The actual number of children with CP, who were under six years of age in that year, was then expressed as a number per 1000 live births of the total population at risk for this condition (Bonita, Beaglehole & Kjellstrom, 2006). This ratio provides valuable information to different stakeholders regarding the magnitude of a certain condition or problem. For this study the total number of children under six years who were born in maternity unit at KNH over the period of

01/01/2009 – 31/12/2015 constituted the “at risk population”. The total number of new cases of children under six years with CP reported at physiotherapy and occupational therapy departments during the same period was used to calculate the ratio. This ratio should be interpreted with caution, as it does not represent the whole catchment area of KNH, as there are other health facilities around Nairobi in which children with cerebral palsy are born and referred to PT and OT departments.

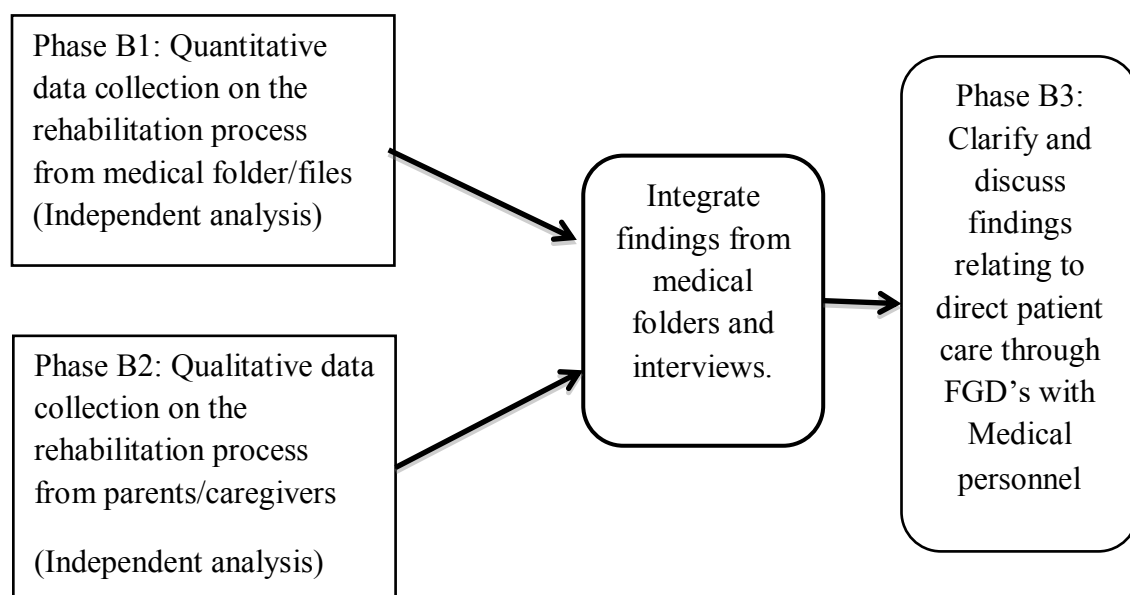


Figure 1: Mixed methods convergent parallel design

3.3.2.PhaseB: Direct process of care for children under six years with CP

The research design was a mixed method convergent and parallel designed. The quantitative study was done by retrospective records review. The researcher collected quantitative and qualitative data separately during the same phase of the research process (see Figure 1), after determining the incidence of CP in PT and OT departments at KNH in 2015. The data were compared and integrated by triangulating the findings from the quantitative (Phase B1) and qualitative (Phase B2) phases. Random sampling was used to collect the quantitative data. The medical records of CP patients attending the rehabilitation clinic in 2015 were retrieved from the records department. The qualitative data were collected from the parents/caregivers of

children with CP under the age of six years. The two sets of data were analysed independently and then compared and integrated in order to triangulate between the accounts of the parents/caregivers on the process of direct patient care reported by the caregivers and what was documented in the folders. In the next qualitative phase, a focus group discussion (FGD) with the medical rehabilitation personnel and parents served to clarify any gaps that existed between the information obtained from the parents/caregivers, and the documentation of the treatments given in the records (see Figure 1 above).

3.3.3 PHASE A: Incidence of cerebral palsy

3.3.3.1 Study Population and sampling

The study population consisted of the total number of live births (89 285) in the KNH maternity ward between 2009 and 2015, and the total number of new cases of children aged less than six years with cerebral palsy (2657) in 2015. The doctors or pediatricians did the diagnosis at birth in maternity ward or during subsequent visits by children who are under five years at the maternal child health clinic (MCHC). The total population of live births was used as the “at risk population” to determine the incidence of children with CP who were six years and younger in 2015. The incidence rate was obtained by dividing the total number of children with CP by the total number of live births obtained at Kenyatta National Hospital (table 2).

$$\text{“Incidence”} = \frac{\text{Number of children with CP}}{\text{Total number of live births 2009–2015}}$$

3.3.3.2 Inclusion Criteria

- i. Medical folders of new cases of children with cerebral palsy who were aged 0-6 years in 2015 and received rehabilitation services in PT and OT at Kenyatta National Hospital.
- ii. All children who were born in the maternity ward from the years 2009-2015 at Kenyatta National Hospital.

3.3.3.3 Sample Size Determination

The “at risk population” for this study was based on the methodology followed by Stromme et al., (2007) in order to determine the incidence of childhood encephalopathy in a defined age group. In the study conducted by Stromme et al., (2007), the population “at risk” was determined using the total number of live births in the observation period. In the current study, there was a total number of 89 285 live births recorded between 2009 and 2015 in the medical records of the maternity ward at Kenyatta National Hospital. All children who are diagnosed with CP at KNH are referred to the Occupational and Physiotherapy departments. The records from the rehabilitation clinic were thus used to determine the total number of new cases of children with CP under the age of six years during the same period. The total number of new cases that reported to the therapy departments in the period of observation was 2657. A total of 20 parents/caregivers of children with cerebral palsy were conveniently sampled to participate in interviews, and 12 medical personnel were purposively recruited based on their involvement in the rehabilitation of children with CP.

3.3.3.4. Instruments for Data Collection

A self-developed data extraction sheet using a template from Cochrane consumer and communication group (2009) was used to collect information on live births from 2009-2015 and the number of new cases of children with CP in 2015.

3.3.3.5 Procedure for data collection

The researcher contacted, in person, the officer in charge of the registry office for the medical records of the maternity ward after obtaining clearance to conduct the study. The records of all the files of all children born (live births) at KNH between the years 2009-2015 were obtained. The results were filtered to male and female children. According to Creswell, J. W., & Plano Clark, V. L. (2011), sampling of new cases was based on the age of the children (under six years) so it can be considered purposive sampling. The new cases of children with CP were

selected from the records in the Physiotherapy and Occupational therapy departments between 2009 and 2015. The data was collected using the information obtained from the files, and data was extracted and manually entered on the data extraction sheet.

3.3.3.6 Data Analysis

The demographic data of new cases of children with CP under six years were analysed descriptively using independent t-test in SPSS version 22 to differentiate between males and females. Johnson & Christensen (2008) define data analysis as creating meaning out of new data. Data analysis is a process that involves data collection, data entry and storage, segmenting, coding and developing category systems and identifying relationships such as themes, patterns, and hierarchies. It involves constructing diagrams, tables, graphs, and finally corroborating and validating results (Table 2), and is used to interpret and make sense of research findings.

3.3.4 PHASE B: Process of direct patient care in rehabilitation

Phase B1: Quantitative Medical records review

3.3.4.1 Study Population

The study population consisted of a total of 252 medical folders of children aged less than six years with CP who received rehabilitation in PT and OT departments at KNH in 2015. This year was chosen as contrary to other years, services were not interrupted by any strikes of medical personnel.

3.3.4.2 Inclusion Criteria.

- i. All medical files of children with cerebral palsy who were 0-6 years old in 2015 and received rehabilitation services at KNH
- ii. All the files with complete information of children with CP attending rehabilitation in 2015 at KNH

3.3.4.3 Sample Size Determination

To determine sample size for the medical records review, Slovin's formula was used (Slovin, 1960). Slovin's formula is used to calculate a sample size that is representative of the population under study. In this case the population was children under six years of age with CP who received therapy at KNH in 2015. The Slovin's formula is: $n = \frac{N}{1+Ne^2}$; where n is sample size, N was total population, and e was the degree of error. On average, approximately 360 CP children attended therapy per year, of which an estimated 70% was under the age of six years. The estimated sample size at a confidence level of 95% and with a total population of 252, corresponding to the number of folders, was used in the Slovin's formula. An ideal sample size of 70 records was generated from the formula.

3.3.4.4. Sampling Technique

The medical files for the records review were selected using systematic simple random sampling. Simple random sampling is employed to avoid selection bias (Creswell et al., 2011). When a simple random sampling method is used, every member (or in this case folder) has an equal chance to be selected, making it more likely to be representative of the study population. The database of all the records at the rehabilitation department at KNH that referred to children with cerebral palsy was scrutinised to sample files of children with cerebral palsy aged six years or younger. Random sampling was achieved by retrieving every third file from the list of medical folders that met the inclusion criteria.

3.3.4.5. Instruments for Data Collection

A data extraction sheet (Appendix L) was used to extract the relevant information from the medical records. The data extraction sheet was developed based on the literature on techniques used for the treatment of CP (Bower, 1999; King, Rosenbaum & King, 1996). The age of the patient recorded on the data extraction sheet was the age documented in the file at initiation of therapy at the rehabilitation department. The data extraction sheet consisted of seven sections.

The sections captured data relating to 1) the patient demographics, 2) assessment of milestones at initiation of therapy, 3) the physiotherapy techniques used during the treatment of the patient (throughout the folder), 4) any assistive devices being issued, 5) medical interventions, 6) education and advice to the caregiver and lastly, 7) involvement of the members of the multidisciplinary team. Two experts in the field of rehabilitation reviewed the data extraction sheet for face and content validity. Some of the strengths of a retrospective records review is that documents are stable and can be reviewed repeatedly. Records review in this study involved examining the medical files of children born with Cerebral Palsy from 2009 to 2015 and treated at Kenyatta National Hospital, in order to retrieve information regarding the process of direct patient care.

3.3.4.6. Procedure for Data Collection

The assistant medical records officer was assigned to assist the researcher and the research assistants with information and with the data management process at Kenyatta National Hospital. The researcher accessed the records of patients with CP who visited KNH from 2009 to 2015 from the records department. The researcher accessed the electronic database to retrieve all records from 2009 to 2015 with the help of the records personnel. These records were filtered by diagnosis to identify only patients with cerebral palsy. The records of patients with CP were filtered again to include only patients with a date of birth not later than the 01/01/2009. This then provided the final number of children with CP who were six years and below and those who attended the rehabilitation services at KNH in 2015. These records were then reviewed and the relevant data relating to the direct process of care was extracted by the researcher and captured on the data-capturing sheet (Appendix L).

3.3.4.7 Data Analysis

Quantitative data was coded and analysed descriptively as means and standard deviations using the statistical package for social science (SPSS) version 22. Data were presented in tables and figures.

3.3.5 Phase B2: Qualitative interviews with parents/caregivers

An interview is a method of asking key participants questions orally. In this study In-depth interviews were conducted with parents of children with cerebral palsy. An in-depth interview is a dialogue between an interviewer and interviewee. The goal of interview is to elicit rich, detailed material that can be used in analysis (Lofland, Anderson,&Lofland, 2006). The interviews were conducted face to face. The dynamics of interviewing were similar to a guided conversation. The interviews enabled the researcher to seek an understanding of the parents/caregivers perspectives or situation through face to face encounters.

3.3.5.1 Study Population and sampling

The total study population comprised a list of 30 parents/caregivers who regularly attended rehabilitation with their children in PT and OT departments at KNH and were willing to participate.

3.3.5.2 Inclusion criteria

- i. Parents of children with cerebral palsy who were 0-6 years old who were attending rehabilitation services in PT and OT departments on a regular basis.
- ii. Parents/caregivers with CP children who had attended at least four follow-up visits in PT and OT rehabilitation departments.

3.3.5.3 Sample size determination and sampling technique

In accordance with recommendations for qualitative interviews as is indicated by Creswell (2013), a total of 20 caregivers/parents of children with CP were randomly selected to participate in this study. Participants were sampled from a master frame consisting of newly

initiated caregivers/parents who were consistent in their follow-up visits and follow-up appointments for more than four times in a month. The inclusion of the caregivers/parents was based on their willingness to participate in the study (Teddlie & Yu, 2007).

3.3.5.4 Instruments for Data Collection

The instrument of data collection that was used was a semi-structured interview guide (Appendix H). Qualitative questions are open-ended whereby a respondent provides a response in her/his own words (Legard, Keegan & Ward, 2003). Semi-structured interviews included an outline of topics or issues to be covered, but the interviewer was free to vary the wording and order of questions (Oso & Onen, 2008). The semi-structured interview guide was developed by the researcher, and was used based on the modified questions from a similar study (Fredericks & Visagie, 2010). The interview guide consisted of three pre-determined themes, namely: 1) the use of a holistic multidisciplinary approach, 2) activities and techniques used during treatment sessions and 3) parents/caregivers involvement in rehabilitation process.

3.3.5.5 Procedure for Data Collection

After obtaining permission from relevant authorities, the researcher recruited two research assistants who were fluent in both English and Kiswahili languages to assist during the interviews with the parents/caregivers of children with cerebral palsy. The researcher had briefed the research assistants on areas to pay attention to and record during rehabilitation interviews. Parents/ caregivers were invited during their visit at the rehabilitation department for therapy, and an appropriate appointment time for the interview was then arranged via telephone. The researcher conducted the semi-structured interview in English and Kiswahili, depending on the language of the participant, in a quiet office and it was audio-recorded. At the appointment with the caregiver, the first research assistant explained the study objectives to the participants and obtained informed consent in writing prior to data collection. The second research assistant controlled the audio recorder during interview. Each interview lasted a

maximum of 45 minutes. The data reached saturation when the participants started to repeat the same answers and no new information was obtained through the interviews.

3.3.5.6 Data Analysis

The audio recordings were transcribed verbatim and translated back from Kiswahili to English where necessary. A professional translator performed the translation of the interview guide from English to Kiswahili, which is one of the widely spoken official languages in Kenya. Another independent translator translated the Kiswahili version back to English and the two versions were compared for reliability. No changes were required after the comparative translations. The translated transcripts were then coded and categorised within three pre-determined themes: 1) the use of an holistic multidisciplinary approach, 2) activities and techniques used during treatment sessions and 3) parental involvement in order to describe the rehabilitation provided at PT and OT departments.

3.3.6 Phase B3: Focus group discussions

A focus group discussion is a form of interview where the researcher is on interaction within a group, discussing a particular topic of interest. A focus group discussion represents a small group of people chosen to represent a group of respondents. Focus Group Discussion is a good way to gather together people with similar experiences to discuss a specific topic of interest (Colucci, 2007). Focus Group Discussion can reveal a wealth of detailed information. Two focus group discussions were carried out, one with 8 medical personnel and 8 parents of children with cerebral palsy. The main objectives of the focus group discussions were, the process of rehabilitation and the parental involvement during rehabilitation process.

3.3.6.1 Study Population, sample size and sampling technique

A total of 12 health professionals were involved in the rehabilitation of children with CP at KNH at the time of data collection. An ideal sample size of 6-12 participants is recommended in the literature to participate in an FGD by Tashakkori& Creswell, (2007); eight medical

personnel were thus purposively selected to participate in phase A3 of the study. The population of eight medical personnel was purposively recruited (Tongco, 2012), to represent the different cadres of medical personnel working with children with CP at KNH, namely: medical doctors, physiotherapists, occupational therapists, speech therapists, social workers, speech and language therapists. Eight parents were selected based on their regular attendance at the PT and OT and their willingness to participate in the discussion.

3.3.6.2 Inclusion Criteria

- i. Medical personnel involved in the rehabilitation of children with cerebral palsy who were receiving services at KNH.
- ii. Parents who have been attending rehabilitation treatment regularly at PT and OT departments and are willing to participate in the study.

3.3.6.3 Instruments for Data Collection

During Phase A3, a focus group discussion was conducted with the eight medical personnel from different medical professions working actively with children with CP at Kenyatta National Hospital. The FGD was voice-recorded. A focus group discussion is a form of group interviews where the researcher interacts with a group, discussing a topic of interest (Colucci, 2007). In a focus group discussion, the participants are asked to give their opinions about a particular subject (Stewart, Shamdasani & Brook, 2007). In this FGD, the topic of interest was the process of direct patient care as part of rehabilitation of children aged 0-6 years with cerebral palsy. Qualitative and quantitative data was compared and then integrated by using triangulation with the data obtained from the caregivers and medical folders.

3.3.6.4 Procedure for Data Collection

After permission was obtained to conduct the study, an appropriate time to conduct the FGD was made with the respective health professionals. Appointments were made by telephone and verbally during working hours. A quiet room was prepared outside of the rehabilitation clinic.

The participants signed an informed consent form and a focus group discussion binding form before the discussion commenced. An identification number was given to each participant. A professional translator performed the translation of the opening and the probing questions used in the FGD, from English to Kiswahili for those who could not speak English. Both English and Kiswahili are widely spoken languages in Kenya. Another independent translator translated the Kiswahili version back to English and the two versions were compared for reliability. The information obtained from the medical personnel was recorded using a voice recorder then translated verbatim by the first research assistant and read to the participant to confirm the verity of the translation. During FGDs with the medical personnel, the researcher moderated the discussion while a research assistant took notes. The second research assistant operated the voice recorder.

3.3.6.5 Data Analysis

Qualitative data was analysed using thematic content analysis to determine the themes, trends and opinions expected, considering the range and diversity of participants' experiences. Braun & Clarke (2006) have identified six phases to follow in the use of thematic data analysis. Data for this study was analysed using the six phases, which included familiarisation with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes and producing a final report. Themes were coded according to the process and management of children with cerebral palsy of 0-6 years at Kenyatta National Hospital.

Once both the qualitative and quantitative phases of phase A1 of the study were completed and analysed, the qualitative data from the parents/caregivers were integrated with the quantitative data obtained from the records review and compared for any discrepancies. These findings were merged in order to describe accurately the current involvement of the multidisciplinary team, activities and techniques used in rehabilitation and the education and advice that were given to caregivers at the rehabilitation facility. Any discrepancies that arose between the

medical folders and the information provided by the caregivers was discussed and clarified in the FGD with the health professionals by triangulation.

3.4 Trustworthiness of Qualitative Data

The researcher sampled a representative sample of the key informants and a relatively large sample of caregivers to ensure credibility. The research assistant took field notes and audio taped the focus group discussion with the caregivers to check that it corresponded with the data after the interview. Member checking was done after completion of transcripts by giving the participants the data to confirm its credibility. **Transferability** involved documentation of sufficient details describing the process during data collection that would ensure the transferability of the study. To ensure **dependability**, the researcher was to account for every change in context in which the research occurred. To address **conformability**, the credibility of the findings after analysis of the raw transcripts was available to an independent reviewer to analyse and to confirm the themes through a process of peer review (Creswell et al., 2011). The findings of this study were only generalized to Kenyatta National Hospital.

3.5 Ethical Statement

Ethical clearance was obtained from the University of the Western Cape Senate Higher Degrees Ethics Committee (HS/16/2/14). Approval to conduct the study in Kenya was requested from Kenyan authorities, viz. the National Commission for Science, Technology and Innovation (NACOSTI/P/17/23228/15591), Kenyatta National Hospital/University of Nairobi research committee (P529/07/2016), and Head of Rehabilitation Services KNH (Physiotherapy/6/2017). This study would not directly benefit the participants immediately, but would lead to identifying potential gaps, which might result in the improvement of the rehabilitation of children with CP in KNH. Participants' confidentiality was ensured. Each member who participated in the FGD signed an FGD confidentiality binding form wherein they agreed to keep confidential the information shared in the group. To protect identity, pseudo numbers were

allocated to participants during the analysis of the data and the writing of the thesis. The participants' right to withdraw from the study, without any negative consequences at any time, was guaranteed. An information sheet was provided to all participants, explaining the purpose of the study, and a consent form was signed prior to participation in the study. The questionnaires were locked in a cabinet in the researcher's office, and electronic data was stored on a password-protected computer. Participants as well as the relevant institutions were informed of the outcomes of the study.

Summary of chapter three: This chapter covered the methodology used in the study. The research setting was at Kenyatta National Hospital in Kenya. The study design was mixed method parallel and convergent design. The population of the participants was 70 medical folders and 20 parents/caregivers randomly selected; eight medical personnel who were purposively selected, participated in focus group discussions based on their involvement in the rehabilitation process. Eight parents selected based on their attendance at rehabilitation departments and their willingness to participate in focus group discussion. The data was collected by information obtained from the files using a data extraction sheet, an interview guide and focus group discussions.

CHAPTER FOUR: RESULTS

4.1 Introduction

The study results are presented in this chapter. The chapter is divided into sections and sub-sections and the research results have been presented in line with the research questions and the study objectives. In phase A, the information on the incidence rate of CP is presented. Phase B presents the information relating to the process of rehabilitation followed for children under six years with cerebral palsy. Data were collected from three sources during phase B and were presented under three subheadings, namely: Phase B1 Medical record review on the process of direct patient care in rehabilitation; Phase B2 Data from interviews with parents/caregivers, and Phase B3 Focus group discussions with medical personnel and parents.

The information on the incidence rate of children with cerebral palsy was obtained from the ratio of numbers of live births at the KNH maternity ward from 2009 to 2015 and the number of children with cerebral palsy who were treated at the rehabilitation clinic in 2015. Data for Phase B1 (the process of direct patient care followed in this setting) was determined by extracting relevant information from 70 medical folders of children with cerebral palsy under the age of six years. The process of direct patient care was described in terms of: 1) Multidisciplinary team approach to rehabilitation, 2) Techniques used and 3) Involvement / education of parents and caregivers. The results were presented descriptively. Data for Phase B2 were obtained from interviews with 20 parents/caregivers of children with cerebral palsy under the age of six years. In Phase B3, FGDs with the medical personnel working at KNH were used to clarify any gaps in the process of care between the medical records (PhaseB1) and the interviews with parents or caregivers (Phase B2).

4.2. Phase A: Incidence of children under the age of six years with CP in 2015

The incidence rate of children with CP below six years was 30 per every 1000 children under the age of six years in 2015. The number of new case for each year from 2009 – 2015 had to be determined in order to calculate the total number of children who would be under six years of age in 2015. Table 2 below shows the total number of live births of children at KNH from 2009-2015. The total number of live births is considered the population “at risk”. The total number of children with CP constituted the total population of children (under six years of age) that were diagnosed with cerebral palsy in between 2009 and 2015 (thus being six years and younger in 2015) at the rehabilitation clinic.

$$\text{“Incidence”} = \frac{\text{Number of children with CP}}{\text{Total number of live births 2009–2015}} = \frac{2\,657}{89\,285} = 3\% \times 10 = 30 \text{ per 1000 live births at}$$

KNH.

There was a statistically significant difference in the incidence of CP between males at 36 per 1000 and females at 25 per 1000.

Table 2: Incidence of CP in children under six years per 1000 live births at KNH

Period 2009 – 2015	Males	Females	Total
At risk population (live births at KNH)	39701	49584	89285
Total number of new CP cases at KNH under six years in 2015	1430	1227	2657
Incidence ratio per 1000 of live births at KNH (percentage)	*36 per 1000 (3.6%)	*25 per 1000 (2.5%)	30 per 1 000 (3%)

**Statistically significant difference in incidence between genders (P = 0.0305)*

Source: Health Information department as at 3/4/2017 unpublished data.

4.2.1. Number of new cases of children with cerebral palsy per year

According to the available records at Kenyatta National Hospital, over the period of six years there was a general decline in the incidence of children aged 0-6 years with cerebral palsy. A spike was documented in the year 2012; thereafter there was a steady decline in the incidence (Figure 2). Numbers of new cases of children with CP ranged between 285 in 2015 to the highest number of 445 in 2012.

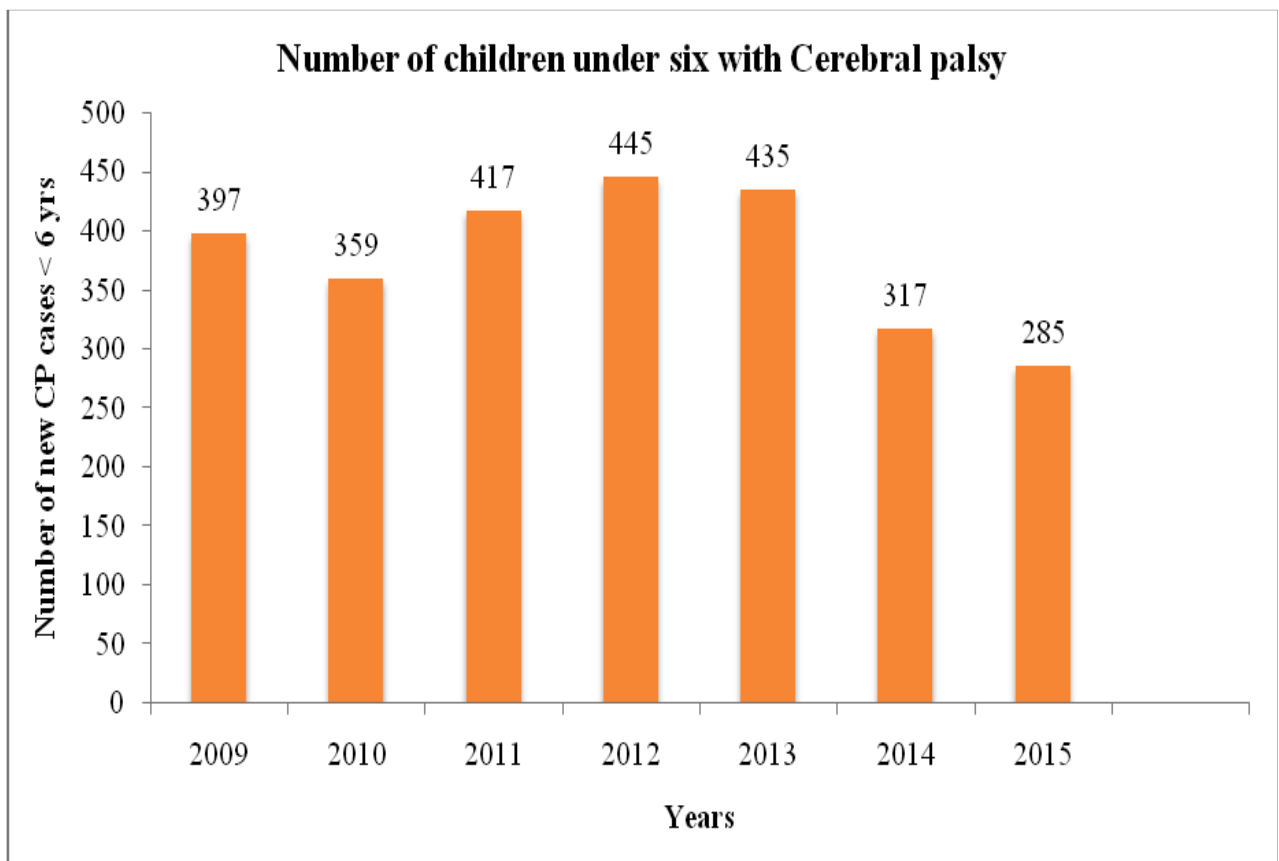


Figure 2: Number of new cases of children under six years with cerebral palsy per year at KNH rehabilitation departments, 2009-2015 at date of admission.

4.2.2 Proportion of children with cerebral palsy by gender from 2009-2015

With the exception of 2011 and 2014, when there were more females than males with CP, there were consistently more new cases of males with CP between 2009 and 2015. Overall, males accounted for the majority (53.8%) of cases (Table 3). The reduced incidence of children with

cerebral palsy in 2014 and 2015 could be attributed to devolve rehabilitation services in forty seven counties in Kenya.

Table 3: Proportion of children with cerebral palsy by gender and year in rehabilitation departments at KNH, 2009-2015

Year	Male n (%)	Female n (%)	Total Patients
2009	215(54.2)	182(45.8)	397
2010	189(52.6)	170 (47.4)	359
2011	172(41.2)	245(58.8)	417
2012	240(53.9)	205(46.1)	445
2013	290(66.7)	145(33.3)	435
2014	142(44.8)	175(55.2)	317
2015	182(63.9)	103(36.1)	285
Overall	1430 (53.8)	1227 (46.2)	2657

4.3 Phase B1: Process of rehabilitation followed for children 0-6 years with cerebral palsy in PT and OT at Kenyatta National hospital based on medical folders

4.3.1 Demographic information and clinical characteristics of children with cerebral palsy from medical folders

The process of rehabilitation followed was determined by the information documented in 70 randomly selected medical folders of children with CP under the age of six years on admission to therapy. The demographic details captured in these medical folders were also extracted. The majority of children (97%, n=68) diagnosed and treated in PT and OT departments with CP were 0-3 years of age on admission. Of the total sample, 51.4% (n=36) were males and 48.6% (n=34) were female. With the exception of a few cases where spastic cerebral palsy was documented in the folder, the type of cerebral palsy was generally not documented (Table 4).

To calculate the mean, range and standard deviations, months was used because the study aim was to explore and describe rehabilitation process of children between 0-6 years in 2015. The mean age of children who were born in 2015 was 13.1 months. The range age of children in this study ranged from one month to 59 months. The standard deviation was 11.4 months.

Table 4: Demographic information and clinical characteristics of children with cerebral palsy from medical folders (N=70)

Child characteristics	Frequency	%
<i>Age at admission (Mean 1.5 years, SD +- 1 year)</i> (N = 70)		
<i>Range 1 – 6 years</i>		
Age-groups		
0-3	68	97.1
4-6	2	2.9
Sex		
Male	36	51.4
Female	34	48.6
Type of CP		
Spastic	3	4.3
Ataxic	0	0
Athetoid	0	0
Mixed	0	0
Missing scores	67	95.7

4.3.2 Demographic distribution by Ethnicity

The demographic distribution of CP children based on ethnicity showed that 53% (n=37) were Kikuyu, Luya 13% (n=9), Kamba 9% (n=6), Meru 7% (n=5) and Somali 6% (n=4). The rest of the ethnic groups were 1% each (Table 5).

Table5: Distribution of children with CP by ethnicity

Ethnicity	Frequency (N = 70)	Percent
Arab	1	1.4
Embu	1	1.4
Kalenjin	1	1.4
Kamba	6	8.6
Kikuyu	37	52.9
Kisii	2	2.9
Luhya	9	12.9
Luo	3	4.3
Meru	5	7.1
Nubian	1	1.4
Somali	4	5.7
Total	70	100

4.4 Highest functional milestones assessed among children with CP in rehabilitation clinics, KNH 2015

Table 6 presents the outcome of the highest functional milestones achieved on admission, of children with CP who attended the rehabilitation clinic at KNH in 2015. The Mean age of children being admitted to therapy was one year. Children with cerebral palsy were able to achieve the following milestones as assessed on admission: 47% (n=33) had head and neck

control, 44% (n=31) could reach objects with their hands, 40% (n=28) could roll from side to side, 16% (n=11) were able to sit, 13% (n=9) were able to crawl and 10% (n=7) could stand. This trend was expected because the majority of the children were between 0-3 years (Table 6) with cerebral palsy that delayed their functional milestones.

Table 6: Highest functional milestones achieved among children with CP on admission to the rehabilitation clinic at KNH in 2015 (N=70)

Activities	Yes n (%)	No n (%)
Head control	33(47.1)	37(52.9)
Neck control	33(47.1)	37 (52.9)
Reach objects with hands	31(44.3)	39(55.7)
Rolling	28(40.0)	42(60.0)
Sitting	11(15.7)	59(84.3)
Crawling	9(12.9)	61(87.1)
Standing	7(10.0)	63(90.0)
Walking	1(1.4)	69(98.6)

4.5 Multidisciplinary Team

A multidisciplinary team is made up of medical professionals who are involved in the rehabilitation of children with CP at KNH. The MDT comprises of a doctor, physiotherapists, occupational therapists, speech therapist and a social worker. The orthotist and a wheelchair technician are involved if needs are identified. The data from the medical files indicated that 64% or (n=45) of the children were attended to by a doctor of whom 17% (n=12) were referred to a physiotherapist. The doctor referred 81% (n=57) to the occupational therapist for further interventions. The Occupational therapists are responsible for re-education of fine movements in children at initial stage of treatment. Lastly, only 3% (n=2) of the parents/caregivers were

referred to a social worker for guidance. The speech therapist received one referral from a medical doctor or from other members of the rehabilitation team (Table 7). Some patients are referred from maternal child health clinics (MCH), self-referral or by community health workers. The physiotherapist and occupational therapist working with children with CP have attended short courses on management of children with cerebral palsy.

Table 7: Involvement of the multidisciplinary team in rehabilitation process of CP children at KNH, Kenya (N=70)

Multidisciplinary team involvement	Yes n (%)	No n (%)
Doctor	45(64.3)	25(35.7)
Physiotherapist	12(17.1)	58 (82.9)
Occupational therapist	57(81.4)	13(18.6)
Social worker	2(2.9)	68 (97.1)
Speech therapist	1(1.4)	69(98.6)
Orthotist	0(0.0)	70(100.0)
Wheelchair technician	0(0.0)	70(100.0)

4.6 Rehabilitation techniques used for treatment of children with CP enrolled at KNH

A wide range of interventions was utilised in the physical therapy management of children with cerebral palsy at Kenyatta National Hospital. The medical files showed that 97% (n=68) of children aged between 0-6 years had received passive stretching; sixty-nine percent (n=48) had received active stretching. A total of 94% (n=66) were given advice on positioning while 87% (n=61) were trained on how to do balance and coordination exercises. Massage was the most frequently used treatment method at 90% (n=63) while 66% (n=46) had received training on how to use a corner chair for sitting children with cerebral palsy. Hippo therapy and hydrotherapy were not used at all (Table 8).

Table 8: The rehabilitation techniques used for children with CP enrolled at KNH

Physical therapy	Yes n (%)	No n (%)
Passive stretching	68(97.1)	2(2.9)
Active stretching	48(68.6)	22 (31.4)
Positioning	66(94.3)	4(5.7)
Balance & coordination	61(87.1)	9(12.9)
Chest physiotherapy	6(8.6)	64(91.4)
Massage	63(90.0)	7(10.0)
Sitting on a corner chair	46(65.7)	24(34.3)
Hippo therapy	0 (0.0)	70 (100.0)
Hydrotherapy	0 (0.0)	70 (100.0)

4.7 Medical interventions

In the rehabilitation departments, 53% (n=37) of the children were given medication or drugs for CP-related illness. The medicine given was mainly drugs to reduce spasticity before therapy e.g. baclofen, valium or tramadol; anticonvulsant drugs like Neurontin or anti-inflammatory e.g. aspirin or corticosteroid. There was no indication that surgery; botulinum-A injection or electrical stimulation was not used for treatment at the rehabilitation clinic (Table 7).

Table 9: Medical interventions used in CP children at KNH, Kenya

Medical intervention	Yes n (%)	No n (%)
Surgery	0(0.0)	70(100.0)
Medication or drugs	37(52.9)	33 (47.1)
Botulinum-A injection	0(0.0)	70(100.0)
Electrical stimulation	0(0.0)	70 (100.0)

4.8 Education and home advice to parents and caregivers

According to the records, education and home advice regarding a rehabilitation programme was given to 91% (n=64) of parents/caregivers for continuity at home of the rehabilitation process for children with CP. There was no equipment provided for use at home or follow-up by social workers to the parents/caregivers, the children at home or in the community (Table 8).

Table 10: Education to the parents/care-givers attending the clinic at KNH, Kenya

Education and home advice to parents/caregivers	Yes n (%)	No n (%)
Education and advice given	64(91.4)	6(8.6)
Equipment available	0(0.0)	70(100.0)
Follow-up at home	0(0.0)	70(100.0)

4.9. Phase A2: Process of rehabilitation followed for children 0-6 years with CP at Kenyatta National hospital based on qualitative interviews with parents/caregivers

4.9.1 Demographics of parents/caregivers

Twenty participants recruited to participate in one-on-one interviews during the second phase of the study that involved five caregivers and fifteen parents. The majority (n=16) of the participants were between the ages of thirty to fifty years. Ninety five percent (n = 19) were female. Half of the participants (n=10) had attained secondary level education. Less than half (40%) were permanently employed, while thirty percent were unemployed.

Table 11: Social demographic information of Parents/caregivers

Variable	Frequency	Percentage (%)
Age		
< 20years	2	10
21-30	2	10
31-40	7	35
41-50	9	45
Gender		
Female	19	95
Male	1	5
Level of Education		
No Schooling	1	5
Primary	6	30
Secondary	10	50
Tertiary Education	3	15
Employment		
Not employed	6	30
Working part time	4	20
Working full time	8	40

4.10 Emerging Themes from interviews

Parents/caregivers were interviewed on the process of rehabilitation that they had experienced with their children, in order to obtain a more holistic perspective of the process. Interviews were structured into the predetermined themes of MDT, rehabilitation techniques and education of parents/caregivers. The categories associated with each theme are presented below in (Table 12).

Table 12: Emerging themes and categories

Themes	Categories
Involvement of the multidisciplinary team	Improved outcomes with early intervention from multidisciplinary team.
Rehabilitation Techniques	<ul style="list-style-type: none">• Variety of techniques used, but massage most common• Parents are “shown” some techniques to do at home
Parental involvement and home education and advice to parents /caregivers	<ul style="list-style-type: none">• No actual involvement during therapy, only observations• Home exercise programme given, but parents not adequately trained• Too little time spent with caregiver during session
Barriers to accessing rehabilitation	<ul style="list-style-type: none">• Service charge fees• Lack of family support• Other family responsibilities

4.10.1 Improved outcomes through early intervention of multidisciplinary team

Early diagnosis and treatment by the MDT positively influenced the functional outcomes of children in this study. Caregivers reported that their children's functional milestones improved after massage, stretching, training and positioning as a treatment at the rehabilitation departments. They gained better head and neck control in the first three months. They felt that the outcome was as a result of early intervention and involvement of more than one member of the team during the rehabilitation process. The respondents reported improvement with functional activities such as trunk control, and the ability of children to crawl and perform functional activities during the first year of their lives.

“After the first three months of coming to KNH with my child, I noticed some improvement. My child was able to hold his head and neck in upright position. I was happy to see the progress that gave me hope and encouragement to bring my child to the clinic according to the appointments given by the doctors (Physiotherapist and the Occupational Therapist)” (Participants 5)

“One day I had put my child to lie on the stomach while cooking. Suddenly I felt someone pulling my dress. I thought I was dreaming when I saw my child had move from where I had place him to sleep, about three meters away from where i was cooking in my house”. (Participant 16)

4.10.2 Rehabilitation techniques

All the parents/caregivers responded that the children were given stretching exercises and massage as a treatment during their appointments at the rehabilitation clinic. Other techniques used (according to the caregivers) were teaching children how to sit, how to stand on a tilting board progressing to standing on a standing board and eventually standing independently without a standing aid.

“When I took my child to the clinic, the medical personnel working in the physiotherapy department took my child from me and started to do massage, stretching and other exercises.”(Participant 18)

The most commonly reported treatment method used in the rehabilitation clinic though was massage. According to the parents/caregivers, massage was an effective method for inducing relaxation and normalising the muscle tone. They reported that they were not adequately trained to continue with other rehabilitation exercises at home, but that they were able to continue with massage at home.

“It is easy to do massage to my child at home. Stretching of the hands and the legs of my child it is not easy to do the same at home. This needs more practice and expertise. I do not have a standing frame at home. The only exercises i can manage to do is massage” (Participant 6).

4.10.3 Parental involvement and home education and advice to parents and caregivers

The parents/caregivers reported that during the treatment sessions they were shown what to do at home. However, most of them did not participate directly but watched what the therapists were doing. They also felt that they did not receive adequate training in order to continue with the therapy at home.

I just observe what the medical person was doing. He asked me? [Do you see what i am doing? He then said“ you have to do like that at home” okay]. I think time should be given for me as a parent to understand and perform exercises in their presence so that I can do it properly at home. Some doctors (PT/OT are very fast when doing demonstrations to me)”(Participant 18).

“The exercises I am asked to do at home are very difficult to do on my own. It needs more training from the doctors in order to master them. Only massage is what I do with little stretching. I need more time to practice with the Doctor before doing it at home”.

(Participant 6)

“The exercises I am asked to do at home are very difficult to do on my own. It needs more training from the doctors in order to master them. Only massage is what I do with little stretching. I need more time to practice with the Doctor before doing it at home”

(Participant 9)

“I was not given chance to practice although they spent time with my child doing different kinds exercises”. (Participant 9)

The parents/caregivers reported not having enough time with the therapists to learn the techniques.

“We were given education on how to take care of our children at home but when it came to exercises program we were not involved in practicing before going home. The therapists were in a hurry in some days they would spend a short time with our children” (Participant 5)

“I got different therapist during visit to the clinic, some were very fast in doing exercises while others were would take time with my child. The exercises are not easy and needs someone who is trained to do them very well at home. I did not have some equipment like a standing frame at home to position my child in upright position”

(Participant 15)

4.10.4 Barriers to accessing rehabilitation services

Service charge fees

The service charge fee was one of the emerging themes of challenges that prevented children accessing services that indirectly delayed improvements of a child during the rehabilitation process. The parents complained about the introduction of cost, stating that they had to pay a service charge fee to every health provider who attended to their child, which was a heavy burden on the parents. Financial implications was a common issue that emerged during interviews with parents of children with cerebral palsy, who said that transport of the children to hospital was expensive, that the purchase of assistive devices and the expense of medication was a heavy burden.

“The experience of having a child with cerebral palsy has drastically brought me down financially. At the beginning I used to hire a taxi, to bring my child to clinics, but this only lasted one year. I have exhausted all the resources I had, I stopped going to work but still I have to bring to the hospital using public service vehicles at the same time I have to meet the medical bills required. I have borrowed money from people until no one wants to lend me any money, but by the grace of God. I still find myself reaching the clinic at the appointed time with my child”

(Participant 11)

Another challenge that was mentioned during the interviews with parents was that the majority of parents/CGs said that they had no time to attend treatment due to commitments at work. Thus they were unable to keep appointments made with the therapists on the treatment programme. Most of the parents or the caregivers fall into the low-income bracket, with the majority being self-employed or working in the informal employment sector, which cannot sustain all the family’s needs. One parent lamented:

“I sell vegetables on the streets. During a good day, I am able to make a profit of Kenya shilling 300. This amount of money is not enough to feed my family. We have to do with one meal for me and my husband in order to save enough money to take our child for treatment at least once in a month instead of twice a month”. (Participant 9)

Lack of family support

Lack of support from the family was reported by parents/caregivers. Mothers are usually left with the responsibility of taking care of the family by providing all the care. Some are the head of the household and have to find money for food and carry other responsibilities. Most husbands do not give support to their spouses in taking care of a child with CP at home or to the rehabilitation clinics. The responsibility of children was left in the hands of the mothers. This provided a big challenge to achieve proper rehabilitation of a child. A number of mothers mentioned being abandoned by their husbands because they had children with cerebral palsy, which left them as the sole breadwinner of their families and the burden was overwhelming. Even the most stable families faced financial challenges and considering the reality of having a child with cerebral palsy was very difficult.

“I do not get support from the family member because some of them consider my child as a burden to them. I have to do what I can to come to make sure I bring my child to the rehabilitation clinic for treatment”. (Participant 14)

Other family responsibilities

Another issue raised by parents during the interviews was that some parents had other children who required their attention. This gave them the extra responsibility of taking care of other siblings that prevented them from taking their children for treatment at KNH. A child with CP requires a lot of time. One of the parents had this to say:

“I have other young children who i need to attend to. I am not able to spend all the time on one child because to pay for a maid to help out is very expensive. Sometimes I feel frustrated because I have to divide attention for my children”. (Participant 19)

4.11 Phase B: Findings from the focus group discussions with the Medical personnel at rehabilitation clinics

4.11.1 FGD Demographic information of participants in Focus Group Discussions

During Phase B3, FGDs were conducted with medical personnel who were directly involved with children with cerebral palsy to clarify any gaps or discrepancies between the records in the folders and the caregiver interviews that arose during the second phase of data collection. A focus group discussion was conducted with eight participants at the rehabilitation clinic. Participants included two medical doctors, two physiotherapists, two occupational therapists, one speech therapists and a social worker. Participants’ ages ranged between 30 and 45 years. The demographic details and qualifications of the participants are outlined below in (Table 13).

The table below provides information about the members of the multidisciplinary team who were involved in direct patient care as part of the rehabilitation service for children with cerebral palsy at Kenyatta National Hospital.

Table 13: Demographic Information of medical personnel

Cadre of Staff	Total	Gender		Age		Education level			Working time	
		Profession	Numbers	M	F	30-45	46-60	Dip	Degree	Msc
Doctors	2	-	2	2	-	-	1	1	-	2
Physical Therapist	2	-	2	2	-	-	1	1	-	2
Occupational Therapist	2	2	-	2	-	1	1	-	2	-
Social worker	1	-	1	1	-	-	1	-	1	-
Speech therapist	1	1	-	1	-	-	1	1	-	1

Key: M=male; F = female Dip= Diploma; Degree; Msc = Masters,

4.12 Gaps and topics to be clarified through focus group discussion

The discrepancies that emerged during analysis and comparison of Phases B1 and Phase B2 were:

- 1) The initial assessment and diagnosis of children with cerebral palsy
 - There was no specific type of cerebral palsy diagnosed during assessment.
 - There were few early diagnoses of CP, which delayed intervention.
- 2) The responsibilities of parents and caregivers in rehabilitation
 - The parents were not given the chance to practice exercises that they should continue with at home
 - The role of the medical personnel was not explained to the parents and caregivers.
- 3) Lack of multidisciplinary team approach.
 - The members involved in management of children with CP care were not working together to plan the treatment process

4.12.1 Initial assessment and diagnosis of children with Cerebral Palsy

a) Medical records

The initial assessment was not well documented in the medical records of children with cerebral palsy. According to the medical records, the types of CP were not recorded in most of the records except in two instances.

b) Interviews with parents / caregivers

The parents and caregivers reported that the staff giving treatment to the children with cerebral palsy was very committed. They also reported seeing that the children were being assessed initially.

c) Clarification / response from medical personnel (FGD)

A comprehensive initial assessment was challenging as children were often brought to therapy by caregivers who were not actual parents according to medical personnel. Often the caregivers were unable to give accurate information pertaining to the background and birthing history of the child. This made making an accurate diagnosis difficult for the medical personnel.

“Children with cerebral palsy are brought to us with caregivers who are not able to give a detailed medical history, making diagnosis and prescription very difficult. There are certain medications that cannot be taken together and so, paramedics need to know all prescriptions if any is being given to a child with cerebral palsy before administering certain drugs. It is therefore important that the real parent bring the child to the clinic, especially on the first visit. History of things like genetic disorders can be handled better with a real parent and not a care giver and questions geared towards maternal issues can be handled better by the real parent of a child. If possible both parents should be present during the first visit. Detailed information helps us to make quicker diagnosis and decisions when attending to children with cerebral palsy”

(MD006F)

During discussions with the medical personnel at KNH, it was revealed that children with CP who attended the clinic at KNH, had various types of CP, which were not classified according to location and severity of impairments. The child's primary care was with the doctor/pediatrician who first assessed the child's overall health for development and to formulate a comprehensive treatment plan to meet the individual child's unique medical or rehabilitation needs. According to the medical personnel, careful neurological examination was carried out at initial stages. This helped to reveal alterations of muscle tone, posture, coordination, reflexes, and strength. A series of examinations, separated by two weeks or one month, were conducted to help determine if the children were developing typically or had delays in developmental or other neurological findings.

Both the physiotherapists and occupational therapists mentioned lack of brain MRI scans for confirmation of cerebral palsy in children suspected to have the condition. There was also lack of precise measuring tools appropriate for use to evaluate the effectiveness of therapeutic interventions for muscle stiffness, especially in young children who were below six years old. The physiotherapists further explained that clinical assessment measurements of muscle stiffness and spasticity scales could provide some accurate information that could aid in helping children with CP at an early stage. Obtaining accurate assessment measurement of muscle stiffness or flexibility in a clinical setting would aid the physiotherapists to monitor the effect and how long an intervention should take while administering rehabilitation.

4.12.2. Responsibilities of parents and caregivers in rehabilitation

a) Medical records

The medical records indicated that the parents of children with cerebral palsy were given advice on how to take care of their children. They were shown how to do home exercises and were told when to bring their children to the rehabilitation clinics. The records contained information about referral to other departments or clinics.

b) Interviews with parents / caregivers.

During interviews with the parents/caregivers, they remarked that they had observed what the therapists were doing with their children but could not practice this while at the clinic. They were told to continue to do exercises demonstrated at home until the next appointment.

c) Clarification /response from medical personnel (FGD)

According to medical personnel, parents and caregivers of children with CP have several responsibilities; including assisting the children with physical tasks and making sure that the child gets adequate care. However, there are certain physical activities that they cannot be involved in doing unless they get thorough training from either the physiotherapists or occupational therapists. During interviews with the medical personnel, it was clear that the parents/caregivers were educated about the medications for their children, the side effects, suitable dosage, effectiveness and the purpose of the medication. They were trained on how to encourage normal postures, and movements in the legs, arms and head control. Training on how to perform simple exercises that they could practice at home on a daily basis for rehabilitation purposes was demonstrated. However, the training was not hands-on but by observation. Parents/caregivers were not trained in exercises that would enhance the children's ability to self-care e.g. toileting, dressing, wearing shoes and eating.

4.12.3. Lack of multidisciplinary team approach

a) Medical records

There was no indication in the records of involvement of the MDT personnel in planning of the rehabilitation. There were only referral notes in the files from the doctors to the rehabilitation clinics.

b) Interviews with parents / caregivers.

The parents/caregivers reported that their children were not seen by a group of therapists (MDT). They did not know the roles of the therapists except those to whom they were referred who were involved with exercise treatment for their children.

c) Clarification /response from medical personnel (FGD)

According to the medical personnel response during FGDs, the treatment process of children with cerebral palsy is a multidisciplinary approach that is highly dependent upon cooperation between a team of medical professionals. Children with CP present with many medical problems that can be treated or prevented if a multidisciplinary team approach are involved. Often the initial stage of treatment can involve a multidisciplinary team, which can consist of a doctor or pediatrician, preferably one with experience in neurological developmental disorders, a neurologist, a mental health practitioner, an orthopaedic surgeon, a speech therapist, a physical therapist, an occupational therapist and a social worker, among others. Each member of the team has important contributions to make in the care of the affected child. In the multidisciplinary approach, individual medical practitioners approach a situation from their own perspective and then share findings. Each discipline then develops its own intervention plan. The number of medical professionals involved could be less at the end of rehabilitation, which was attributed to a lack of enough staff of the different professions and each member of the MDT working on their own.

In an FGD with the medical personnel at KNH it was highlighted that(in agreement with the records at KNH) a medical doctor attended to most of the children with cerebral palsy. The medical doctors then referred them to the physiotherapists and the occupational therapist for further interventions. The therapists then referred the child to a social worker. The role of social workers is to integrate children with CP into special schools, vocational training institutes and into the community. It is very important that they establish the link with different institutions. The children with cerebral palsy cannot get access to institutions due to a lack of information and the limited number of social workers. The children thus lack the support of a social worker for admission to a special school, which was what the parents reported during interviews. The smaller numbers of children were reported to lack attendances by social

workers, which correlates with the finding that there were no home visits done by the same cadre of staff (Table 8).

During FGD with the occupational therapist it was revealed that there was a lack of multidisciplinary teamwork at KNH. The role of OT is to train the child in fine movement and functional activities. He had this to say:

“Multidisciplinary team approach is supposed to work together toward a common goal in rehabilitation process. Unfortunately this is not working. Every member of the team is working alone without involving the other. Example a Physiotherapist treats a child and does not refer him/her to the Occupational therapy. A child who might have benefitted from early intervention is sent very late when contractures have set in. There is no clinic day set for all the Multidisciplinary team to meet to discuss the progress of the child”.(OT 002F)

The social worker is the professional responsible for helping individuals, families, groups and communities to enhance the individual and collective wellbeing of a child with CP. Their work aims to help children with CP to develop their skills and their ability to use their resources and those of the community to overcome challenges in their environment. Society ridicules, teases and rejects children with CP, leading to depression and feelings of isolation (Marx et al., 2011; Parkes et al., 2011). The parents/caregivers often feel the stress and burden of having a CP child. The social and emotional wellbeing of parents/caregivers and children with cerebral palsy is just as important as their physical wellbeing and the intervention of a psychologist is important in dealing with these depressive symptoms (Kriger, 2006; Marx et al., 2011).

During FGD with a social worker at the hospital, it was revealed that there was a lack of funds allocated to them that could facilitate their involvement in working with the parents/caregivers of children with cerebral palsy.

“We are very few social workers and have no budget allocated to organize home visit to support children with cerebral palsy. I can do a lot but due to the mentioned limitation, I only provide advice whenever the parents/caregivers come to the rehabilitation clinics at KNH to get treatment and other services”. (SW004F)

The challenges involving the social worker prevented proper services to the children with cerebral palsy and advice to the parents/caregivers. A social worker has a very important role in follow-up and home visits. However, during FGD, it emerged that the parents/caregivers did not get the basic services. There was no therapist who did follow up visits at home except for the advice that they were given at the rehabilitation clinic. There was not any additional information except while attending clinic at the hospital. A parent had this to say:

“My child is three years and I have been wondering where I will take him to start his schooling. I think my child would need a special school that will accept him and attend to his educational and basic needs. The problem will be to take him and bring him back home and care of his personal hygiene like toileting while in school. My other worry is his future. He will be with us throughout his life and depend on us. I would like help from a social worker to advise us on the best plans we can make for our son for his future life. At the moment i do not know the schools that I can take our child. I do not see any hope for my child taking care of himself”.

(Participant 003)

During a Focus Group Discussion with the medical personnel, it emerged that there were many challenges experienced at their place of work that hindered their smooth operation as a multidisciplinary team at the hospital. During the FGDs, the medical personnel (MP) at Kenyatta National Hospital had highlighted issues of financial constraints, which to some extent clarified the lack of referral to the other members of the MDT. (FGD MP)

“Most parents who visited the clinics complained that the cost charged per visit is too high. They are asked to pay to every rehabilitation services they are referred to for services”. (MP 008F)

The main challenge facing the rehabilitation services was lack of adequate human resources and other resource allocation. Resource allocation is the distribution of resources, usually financial, among competing groups of people or programmes in a rehabilitation process. According to the medical personnel who participated in FGDs, there was less allocation of funds to medical rehabilitation services versus other medical needs. Some of the needs mentioned which could not be met included human resources such as other medical personnel specializing in different disciplines, and other professional members in order to work as a multidisciplinary team, including personnel such as wheelchair technicians or orthotists.

Summary of chapter 4 – Results: This chapter showed the results of the analysis of the study. The analysis was divided into rehabilitation process, quantitative, qualitative, focus group discussion results and incidence of CP. The quantitative analysis indicated in the records that there was lack of involvement of the entire medical personnel in planning of the rehabilitation.

The findings of the MDT indicated that the role of medical personnel was not explained to the parents or caregivers. There was no time when all the members involved in the management of children with CP came together as a multidisciplinary team to plan the treatment process. The responsibilities of parents and caregivers in rehabilitation showed that the parents were not involved in the treatment plan or practice but only watched what the therapists did at the rehabilitation clinics. They were not involved in setting appointment dates.

During Focus Group Discussion, the participants said that each member of the MDT was working separately without consultations. The medical personnel were not able to make an accurate diagnosis due to the lack of a clear history from the caregivers, who were not the real

parents of children with cerebral palsy. During the Focus Group Discussions, it was clarified that the medical personnel did not allow the parents/caregivers to practice what was demonstrated or encourage them to ask questions. The MDT clarified that it was difficult to identify the specific type of cerebral palsy when the children are very young.

The techniques commonly used during rehabilitation included; massage, positioning and stretching exercises.

CHAPTER FIVE: DISCUSSION OF THE RESULTS

5.1 Introduction

In this chapter the qualitative and quantitative results were integrated and discussed in relation to the relevant literature in order to answer the objectives of this study. The study objectives were namely: 1) To determine the incidence of CP amongst children aged 0 to 6 years in physiotherapy and occupational therapy departments in 2015; 2) To explore and describe the current rehabilitation process that was being followed for children with CP from the age of 0 to 6 years and; 3) exploring parental involvement in rehabilitation process at Kenyatta National Hospital, Kenya.

5.2 Objective 1.

To determine the incidence rate of CP amongst children aged 0 to 6 years at KNH, Kenya, for the years 2009-2015.

5.2.1. Incidence rate of cerebral palsy

In PT and OT rehabilitation clinics at Kenyatta Hospital, the incidence of CP in children under six years was 30 per 1000 live births in 2015. This incidence was much higher compared to the findings of a similar study in the United States of America (USA), where one in 34 000 children is born with CP (Report & Baio, 2012). In a study conducted in Europe by the Centre for Disease Control (CDC) (2009), it was found that the average incidence of CP in 2004 was reported as 3.3 per 1000 live births. Similarly, a study conducted by Rice (2009) in the USA found that the incidence of CP was 1.5 to 4 per every 1000 live births. Studies conducted by Pakula et al., (2009) showed that in Europe and Australia the incidence of CP ranged from 35.0 to 79.50 per 1000 live births for children born at 37 or more weeks of gestation. From the data of studies done during a similar period in Sweden by Pakula et al. (2009), the incidence was 1.4 per 1000 live births of children born at 37 weeks. A possible explanation for the higher incidence of CP at Kenyatta National Hospital can be that people living in this area have no

access to maternal-child healthcare, which can lead to a higher incidence of CP at birth. The high incidence of CP at Kenyatta Hospital highlights the need to raise awareness on the possible prevention of CP. It also highlights the need for adequate rehabilitation services in order to meet the demand for rehabilitation.

A study in the USA by (Winter, Autry & Yeargin-Allsopp 2002) showed that there was a decrease in the incidence rate due to the use of educational data to create national awareness on CP and autism. A study by Donald, Samia, Kakooza-Mwesige, & Bearden (2014), showed that the incidence of CP in Africa decreased, which was attributed to an increased awareness of available health services for children with cerebral palsy. According to this study, there were more children with CP enrolled at the beginning of 2009. The decrease could have been due to awareness of services in Kenya when mothers gave birth at Kenyatta National Hospital. These services were free before the year 2012 for children with CP conditions attending the maternal-child health care clinic (MCH) and those diagnosed with other conditions. The incidence showed a decline in 2012 that was attributed to the devolved health system, where 47 counties were formed with each county level managing its own affairs, including the health sector, in the republic of Kenya. The incidence rate of CP children accessing services at KNH steadily declined until 2015. This could be attributed to the introduction of a service charge to the parents who were asked to pay for treatment of their children at every visit. The decreased incidence of CP could have meant that parents were less likely to bring their children for rehabilitation services but did not necessarily indicate a decline in the actual incidence of CP. The introduction of fees for rehabilitation services could be another factor that might have contributed to the drastic decrease in the number of children brought to the KNH rehabilitation clinic for therapy.

The incidence rate of children with CP by gender showed that there were more male children than female children diagnosed with cerebral palsy. This finding corresponds with the literature

by Report & Baio (2012), which indicates that globally there is a higher reported incidence of CP amongst males. Similarly, according to Autism and Developmental Disabilities Monitoring (2006), in areas of Alabama in the United States of America, Georgia in Europe, and Missouri and Wisconsin in America, cerebral palsy was more common among boys than girls. The reasons for the higher incidences of CP in males were not investigated in this study and require further research.

Studies conducted by Damiano (2006), showed that early intervention helps children with CP to perform activities of daily living, which improve their self-confidence. According to this study, early identification of children with CP enables the children to start treatment early, which gives a better outcome for these children. The medical personnel at KNH confirmed during FGDs that children who were brought for early treatment had an improved prognosis.

In this study, there was no documentation in the file that indicated the different types of CP diagnosed. The research revealed that the numbers of children with different types of CP were also inadequately documented. According to (Rosenbaum et al., 2007), the lack of a clear diagnosis may result in the provision of an inappropriate rehabilitation treatment plan with inaccurate goal setting.

5.3 Objective 2

To explore and describe the current process of direct patient care followed for children with CP from the age of 0 to 6 years at Kenyatta National Hospital, Kenya.

5.3.1 Multidisciplinary team

According to studies by Nolan et al. (2000); Caliset al. (2008); and Jan, (2006), effective rehabilitation is achieved when it is done by a multidisciplinary team. The discrepancies that emerged in the current study in KNH during discussions by the medical personnel, was lack of multidisciplinary team approach in the management of children with cerebral palsy. In this study, medical doctors, physiotherapists and occupational therapists were identified as the

personnel who were most frequently involved with the rehabilitation of children with CP. The research indicated that there was a lack of a true multidisciplinary involvement. The composition of the MDT at KNH was limited to doctors, physiotherapists, occupational therapists, social workers and a speech therapist. The missing members of the MDT would include a pediatrician and a neurologist.

The study indicated that social worker participation was minimal in the rehabilitation process of children with cerebral palsy. The involvement of a social worker as a member of MDT was to take care of psychological issues or trauma, which may be experienced by children with CP and their parents or caregivers. The involvement of the entire MDT team, and more active participation of the social workers, would potentially assist in facilitating children with CP to be integrated into special schools, vocational rehabilitation centers and the promotion of their acceptance and welfare with the community. The literature by Grecco et al. (2013) states that the functional outcomes of a child with CP are achieved with the collaboration of PTs, OTs and other medical personnel in the rehabilitation team who perform different therapeutic resources/approaches of treatment. According to the findings of this research, it was confirmed during FGD that the medical team works in isolation, with little consultation with the other professionals at KNH. Parents/caregivers were not involved.

5.3.2 Rehabilitation techniques

A study by Thomas et al. (2014) shows that different rehabilitation techniques used by physical therapists help to decrease limitations of functions and strive to increase the overall function of the physical performance in children with CP. The common physical treatment techniques that were used by PT and OT at KNH in Kenya were massage, stretching exercises and positioning of the children with cerebral palsy.

According to studies conducted by de Graaf-Peters et al. (2007) the physiotherapist's main objective of treatment for a CP child includes promoting and developing their motor skills,

such as using postural stabilizing exercises. This treatment technique was not documented on the patient's files, although the physiotherapists and occupational therapists clarified during FGD that it was followed and done. Range of movement (ROM) exercises are done to prevent contractures and to maintain the ROM of the joints and soft tissue. A variety of studies advocates for the inclusion of a strengthening programme for children with CP (Thorogood and Lorenzo, 2013; Krigger, 2006; Misbach, 2004). Strengthening exercises were not included in the study at KNH as part of the treatment regime. To the contrary, active stretching exercises were used as a way of improving the state of the muscles to improve power and function.

Respiratory complications commonly occur in children with CP. Chest physiotherapy, consisting of breathing and coughing exercises, percussions, vibrations, postural drainage and suctioning, are performed to clear the lungs if there are secretions and to improve general lung function and prevent any further respiratory complications (Hall et al. 1991; Ntoumenopoulos et al. 2002). However, only a few children with CP received chest physiotherapy from the rehabilitation clinic at Kenyatta National Hospital. This could mean that chest physiotherapy as a treatment programme for CP children was not performed, or caregivers were not aware that physiotherapists could provide chest physiotherapy.

5.4. Objective 3

5.4.1 Parental involvement in the process of care

Studies conducted by Kavlak et al. (2014) showed that the ideal role of physiotherapists and occupational therapists should be to provide rehabilitation treatment and to consult with the parents/caregivers of the children with CP cerebral palsy. The findings in this study indicated that, in interviews with the parents and caregivers, the parents were only partially involved during treatment by watching what the therapist was doing during the rehabilitation process of children with CP at Kenyatta National Hospital. According to a study conducted by Misbach (2004), the physical therapists and occupational therapists are encouraged to train and develop

the skills of the parents/CGs so that continuation of therapy and rehabilitation outcomes is achieved at home. However, this was not adequately done at the rehabilitation clinics at Kenyatta National Hospital.

Studies conducted by (Thorogood and Lorenzo, 2013; Krigger, 2006; Sakzewski et al. 2013; Misbach, 2004), showed that occupational therapists provided assistive devices that enabled improvement of functional activities of children with CP during early intervention. The occupational therapy was an integral part of treatment of children with cerebral palsy and many children with cerebral palsy were referred for occupational therapy at Kenyatta National Hospital. The occupational therapists attend to 81% of the CP children referred by the doctor to a rehabilitation clinic. This study affirms the importance of OT in the achievement of a maximum functional level of CP children in early rehabilitation process. If the parents and caregivers are not adequately trained to continue with basic rehabilitation techniques at home, the patient might have worse functional outcomes.

5.4.2 Socio-demographic details of the parents and Caregivers

The majority of the parents/caregivers, who were interviewed in this study, were female participants, i.e. 90% (n=19). According to studies conducted in Uganda by Hartley, Ojwang, Baguwemu, Dolamulira, Chavuta (2005) in households where there are children with disabilities, the extended family systems are breaking down and the members of the family are left with the burden of taking care of a disabled family member. The responsibility for the child generally falls on one of the female caregivers.

“Male members (fathers) act as gatekeepers, directing the main decisions regarding the child and the related incomes” according to research by Hartley et al. (2005). In Kenya, as in most African countries, females are entrusted with the care of the children and are in charge of the household and taking care of the children, while a man is the head of the household and is responsible for decision-making and providing income for the family, according to a study by

Hartley et al. (2005). Children with cerebral palsy from this context are not able to come regularly for clinical appointments/ services if the mother has other children or is employed.

5.5 Summary of Chapter Five

This chapter contained the discussion of the results. It was found that:

The incidence of children with Cerebral Palsy under the age of six years since 2009 – 2015 was 30 children per 1000 live births. The incidence rate of children with Cerebral Palsy was higher at Kenyatta National Hospital than the global average. Cerebral Palsy was also more common amongst male children than in female children.

The process of rehabilitation at Kenyatta National Hospital in Kenya did not involve all the crucial multidisciplinary team required to work with children with Cerebral Palsy. This could have been attributed to insufficient number of staff at the KNH hospital in ratio to the patients they receive at the hospital. Secondly, the MDT was not working as a team, which decreased the effectiveness of treatment. The techniques used in the treatment were limited to three main methods, which were massage, stretching exercises and positioning. Parents and caregivers were not adequately trained to perform a home exercise programme. Lack of participation of parents/caregivers during treatment provided a major challenge for continuity with the home programme. The lack of involvement of the social worker in the management of children with CP resulted in challenges with integration into schools and the community.

Parental involvement was not fully realised as a section of parents were satisfied with the extent in which they were involved while the majority of the parents felt they needed to be more involved.

CHAPTER SIX: CONCLUSION

6.1 Introduction

In this chapter, the most important findings of the study were summarized and recommendations made based on the findings. The relevant limitations that applied in this study are discussed, and the final conclusions based on the research questions and aims of the study presented.

6.2 Summary of the main findings of this study

6.2.1 Incidence of CP

The incidence rate of cerebral palsy in children under six years in this study was 30 per 1000 live births (3%) in 2015 at Kenyatta National Hospital. Globally the incidence rate of cerebral palsy ranges between 1.5 to 4% according to CDC (2015).

6.2.2 Rehabilitation Techniques

The most common techniques used at KNH were massage and stretching and positioning, while other techniques such as hydrotherapy were rarely used.

6.2.3 Multidisciplinary team

According to the study findings, the multidisciplinary team approach in PT and OT departments at Kenyatta National Hospital is not working together as a team during the assessment and planning of the rehabilitation process of children with cerebral palsy. There are no consultations between the MDT, except when making referrals. The social worker's responsibility is limited to advice to the parents/caregivers at the clinic but there is no follow-up with the community. The speech and language therapist receives very few children with cerebral palsy as referrals.

6.2.4 Parental involvement in home education

The findings of this study are that parents/caregivers are not involved in the practical demonstration of treatment methods during visits at the clinic. According to the study, parents only observe what the therapists are doing during their visits to the rehabilitation clinic. As a result they are not able to provide effective continuity of treatment at home. Lack of basic rehabilitation equipment to use at home also hampered the execution of an effective home program.

6.3 Recommendations for clinical practice and future research

This study proposes that the following could be implemented to improve the rehabilitation process:

- i. Further research could be done in order to determine why the incidence rate of CP in children under six years is high in Kenyatta National Hospital.
- ii. The reasons for the higher incidences of CP in males were not investigated in this study and require further research.
- iii. There should be a MDT working together in the rehabilitation departments/clinic in order to plan for short, medium and long-term treatment goals for the children with cerebral palsy on initial assessment.
- iv. Other methods of treatment for children with CP, like the use of hydrotherapy, weight jackets, use of Botulinum A-toxoid or hippo therapy, could be incorporated into the management plan.

6.4 Limitations of the Study

- i. Parents/caregivers may not have been willing to talk openly about their children or about the therapist, which could potentially have biased the findings.
- ii. Rehabilitation staff may not have been willing to talk about shortcoming or weakness in the rehabilitation process, due to fears of compromising their position. Again, inaccurate information might have biased this study's findings.
- iii. The "at risk" population that was used in the calculation of the incidence rate in this study was based only on the number of live births in maternity ward at Kenyatta Hospital. The number of live births at KNH was considered the most accurate as the other regions of the country do not have census data on the number of children less than six years that could be used to calculate the incidence rate. It also does not include the number of children that were born at home but within the catchment area of the hospital. The use of this data to determine the "at risk" population could potentially overinflate the incidence rate in this study. Hence, it should be interpreted with caution.

6.5 Conclusion of the Study

There was a relatively high incidence rate of children with cerebral palsy under the age of six years in 2015 at Kenyatta National Hospital, but this statistic should be interpreted with caution. The lack of functioning MDT team approach to rehabilitation and the high cost of rehabilitation services potentially compromise the quality of rehabilitation that children under six years with CP receive at KNH rehabilitation clinics. The full spectrum of treatment techniques available to children with CP was not utilized in this study. Involving parents and caregivers with a more hands-on approach during the practical demonstrations and treatment sessions could be a start to improving the functional outcomes of children under six years of age with CP at KNH rehabilitation departments.

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APPENDICES

APPENDIX A: LETTER OF ETHICAL CLEARANCE FROM UNIVERSITY OF THE WESTERN CAPE



OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 2988/2948
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E: research-ethics@uwc.ac.za
www.uwc.ac.za

01 November 2016

Mr D Ngota
Physiotherapy
Faculty of CHS

Ethics Reference Number: HS/16/2/14

Project Title: The process of rehabilitation for 0 - 6 year old children with cerebral palsy at Kenyatta National Hospital, Kenya.

Approval Period: 31 October 2016 – 31 October 2017

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

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

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

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

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

PROVISIONAL REC NUMBER - 130416-049

APPENDIX B: STUDY REGISTRATION CERTIFICATE FROM KENYATTA

NATIONAL HOSPITAL

KNH/R&P/FORM/01



KENYATTA NATIONAL HOSPITAL
P.O. Box 20723-00202 Nairobi

Tel.: 2726300/2726450/2726565
Research & Programs: Ext. 44705
Fax: 2725272
Email: knhresearch@gmail.com

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
DANIEL ODHIAMBO NGOTA
2. Email address: dangota2001@yahoo.com Tel No. 7254 717 574 601
3. Contact person (if different from PI) MAOMI K. WANJIRU
4. Email address: nkwanjiru@yahoo.com Tel No. 7254 721 422 899
5. Study Title
"THE PROCESS OF REHABILITATION FOR 0-6 YEAR OLD CHILDREN WITH CEREBRAL PALSY IN KENYATTA NATIONAL HOSPITAL, KENYA"
6. Department where the study will be conducted PHYSIOTHERAPY AND OCCUPATIONAL THERAPY
(Please attach copy of Abstract)
7. Endorsed by Research Coordinator of the Department where the study will be conducted.
Name: Peter Haman Signature: [Signature] Date: 21/07/16
8. Endorsed by Head of Department where study will be conducted.
Name: Dickson Oluani Signature: [Signature] Date: 21/07/2016
9. KNH UoN Ethics Research Committee approved study number _____
(Please attach copy of ERC approval)
10. I DANIEL ODHIAMBO NGOTA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.
Signature: [Signature] Date: 21/07/2016
11. Study Registration number (Dept/Number/Year) Physiotherapy 15/1/2017
(To be completed by Research and Programs Department)
12. Research and Program Stamp _____

All studies conducted at Kenya National Hospital must be registered with the Department of Research and Programs and investigators must commit to share results with the hospital.



Version 2: August, 2011

**APPENDIX C: LETTER OF ETHICAL CLEARANCE UNIVERSITY OF NAIROBI
AND KENYATTA NATIONAL HOSPITAL**



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
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Tel: (254-020) 2726300 Ext 44355



KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: <http://www.erc.uonbi.ac.ke>
Facebook: <https://www.facebook.com/uonknh.erc>
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC



KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
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Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/42

8th February 2017

Daniel Odhiambo Ngota
Student Number: 3515681
Department of Physiotherapy
University of the Western Cape

Dear Daniel

REVISED RESEARCH PROPOSAL: "THE PROCESS OF REHABILITATION FOR 0-6 YEAR OLD CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL (P529/07/2016)"

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above revised proposal. The approval period is from 8th February 2017 – 7th February 2018.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
- c) Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- f) Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
- g) Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Protect to discover


**APPENDIX D: CERTIFICATE OF PERMISSION TO CONDUCT RESEARCH IN
KENYA FROM NACOSTI**

THIS IS TO CERTIFY THAT **MR. DANIEL ODHIAMBO NGOTA** of **UNIVERSITY OF WESTERN CAPE, BELLEVILLE, SOUTH AFRICA, 0-40103** **Kisumu, Kenya, has been permitted to conduct research in Nairobi County** on the topic: **THE PROCESS OF REHABILITATION FOR 0-6 YEAR OLD CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL, KENYA** for the period ending: **10th February, 2018**

Permit No. : NACOSTI/P/17/23228/15591
Date Of Issue : 13th February, 2017
Fee Received : Ksh 1000

[Handwritten Signature]
Applicant's Signature

[Handwritten Signature]
Director General
National Commission for Science, Technology & Innovation



APPENDIX E: INFORMATION SHEET



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

Project Title: The process of rehabilitation for 0-6 year old children with cerebral palsy in Kenyatta National Hospital, Kenya.

What is this study about?

This is a research project being conducted by Daniel Odhiambo Ngota pursuing a Master degree in physiotherapy (MSc. Physiotherapy) at the University of the Western Cape. We are inviting you to participate in this research project because you are taking care of a child with a disability. We would like to know more about the different types of treatment that you have received at the center.

What will I be asked to do if I agree to participate?

We will ask you some questions about what types of exercises the therapists did with your child. If this is ok with you, we will record your voice in order for us to remember what you said, and altogether this should not take more than 45 minutes to an hour of your time.

Would my participation in this study be kept confidential?

We will do everything in our power to keep your name and identity confidential. The interview will be conducted in private selected room away from other parents and the rehabilitation staff team. We will use numbers to identify your information when we write up the findings of the study in order to protect your identity. We will store the recorded tapes in a safe, locked cupboard, and only the researcher will have access to it.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfill our legal responsibility to report to the designated authorities.

What are the risks of this research?

There may be some risks from participating in this research study. You may feel a bit emotional during the interview, however anyone that is traumatized by participation in the study will be referred to a professional counselor. Any participant is free to leave in case s/he wants not to continue with the discussion.

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about some gaps in the rehabilitation process and provide some information to improve the rehabilitation of children with cerebral palsy. This information might be helpful to the Kenyatta National hospital, Ministry of Health, and other stakeholders in planning and budget to support to rehabilitation services in Kenya. We hope that, in the future, other people might benefit from this study through improved understanding of rehabilitation process of children with cerebral palsy.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify. Your decision will not affect services your child is receiving in Kenyatta National Hospital.

What if I have questions?

Daniel Odhiambo Ngota, Master's student at the University of the Western Cape is conducting this research. If you have any questions about the research study itself, please contact;

Ngota Daniel Odhiambo,
P.O Box 4165 – 40103,
Kisumu, Kenya.

+254 717574601. e-mail address 3515681@myuwc.ac.za or dongota2001@yahoo.com or his supervisor Dr Liezel Wegner at liezelwegner@gmail.com. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department:

Dr. NondweMlenzana
University of the Western Cape
Private bag X17
Bellville 7535
nmlenzana@uwc.ac.za

Dean of the Faculty of Community and Health Sciences:

Prof José Frantz
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

APPENDIX F: CONSENT FORM



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

3515681@myuwc.ac.za

Title of Research Project: The process of rehabilitation for 0-6 year old children with cerebral palsy in Kenyatta National Hospital, Kenya.

The study has been described to me in language that I understand. My questions about the study have been answered.

I agree to be [videotaped/audiotaped/photographed] during my participation in this study. I agree that information in the medical records of my child to be used in this study. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name.....

Participant's signature.....

Date.....

APPENDIX G: FOCUS GROUP CONFIDENTIALITY BINDING FORM



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

Title of Research Project: The process of rehabilitation for 0-6 year old children with cerebral palsy in Kenyatta National Hospital, Kenya

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality. I hereby agree to the following:

I agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

APPENDIX H: INTERVIEW GUIDE FOR PARENTS/CAREGIVERS



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

My name is Daniel Odhiambo Ngota. I am a student of University of the Western Cape pursuing a Masters Degree in Physiotherapy. I am currently working on my research proposal where i would like to determine and explore the process of rehabilitation for 0-6 years old children with Cerebral palsy in Kenyatta National Hospital, Kenya. You have been identified as one of the respondents in this study and therefore, kindly requested to read through the information sheet, provide informed written consent then respond to the following questions. The information provided will only be used for the purpose of this study and confidentiality and anonymity is highly assured. Responding to this interview guide is voluntary on your part. You will be asked some questions and research assistant will record your answers. The questions in this interview guide will take about 40 - 45 minutes of your time to answer. Thank you for agreeing to participate.

Section A: Background Information

- Number of participant.....
- Location/Address.....
- Gender of parent/caregiver.....
- Gender of the child.....
- Age of the child.....
- Number of treatment sessions (if attended before).....

Section B: Main Questions

- Explain what the therapists do to your child during rehabilitation time to your child?

.....
.....
.....

- How happy are you with the services that your child receives? (Prompt: what makes you happy; treatment, commitment, advices)

.....
.....
.....

- Does the therapist explain to you what they are doing when they are treating your child?

.....
.....
.....

- Please tell me of the exercises you have observed physiotherapists / occupational therapists do with your children with C. P.?

.....
.....
.....

- Did the therapists send you or your child to another person to give information on treatment or rehabilitation process?(prompts: a doctor, nurse, your involvement or communication)

.....
.....
.....

- Share with me any achievement you have seen in your child who is undergoing the rehabilitation process?

.....
.....
.....

- Tell me if there are challenges you feel prevent your child from getting good rehabilitation?

.....
.....
.....

- What are the challenges you face when doing exercises to your to child at home?

.....
.....
.....

- Do you have any other information you want to share about questions above or on any other issue to close our discussion?

.....
.....
.....

I sincerely thank you for taking your time to answer the questions.

APPENDIX I: FOCUS GROUP DISCUSSION FOR MEDICAL PERSONNEL

My name is Daniel Odhiambo Ngota. I am a student of University of the Western Cape pursuing a Masters Degree in Physiotherapy. I am currently working on my research proposal where I would like to determine and explore the process of rehabilitation for 0-6 years old children with Cerebral palsy in Kenyatta National Hospital. You have been identified as one of the respondents in this study and therefore, kindly requested to respond to the following questions. The information provided will only be used for the purpose of this study and confidentiality and anonymity is highly assured. Participating in this Focus Group Discussion is voluntary on your part. The questions will take about 40 - 45 minutes of your time to answer. Thank you for agreeing to participate.

Remind participants you want to hear about positive experiences, negative experiences, and ideas for improvements.

Topic: Multidisciplinary approach to rehabilitation

- How does the physiotherapist work with the children with CP?

Sample prompts

- Rehabilitation Plan
 - Participation
 - Level of collaboration with caregivers
 - Discipline conflicts
 - Nature of communication
- Who are the other health workers working in collaboration with you? If no why not?

Sample prompts

- Teamwork
- Nature of the professionals

- Knowledge of professionals
- Briefly describe the role of a physiotherapist/occupational therapist/ rehabilitation doctor in the rehabilitation?

Sample prompts

- Evaluation of the need for rehabilitation
- Rehabilitation goals
- Actions and steps according to the goals
- Social services
- Evaluation and follow up

Topic: Techniques used

4. Do you follow any concept when treating children with CP?

Sample prompts

- Goal setup
- Therapies

5. Describe the techniques used?

Topic: Education

- What is the role of the guardians/relatives in the rehabilitation process?
- **Sample prompts**
 - Presence of parents/caregivers during rehabilitation
 - Communication of health professionals with caregivers
 - Sample tests for caregivers
 - State of collaboration
 - Support to understand child needs
 - Information and skills to help caregivers assists their child.
- What can each of the guardians/relatives do to sustain rehabilitation at home?

Please share with me positive or negative experiences of rehabilitation process you have undergone

WRAP UP- QUESTIONS

Before we finish, are there any other issues or areas we haven't discussed you want to rise?

Thank you for your time and giving me honest answers to the answers. I promise to share the results of my findings at a later date.

APPENDIX J: FOCUS GROUP DISCUSSION QUESTIONS FOR PARENTS

My name is Daniel Odhiambo Ngota. I am a student of University of the Western Cape pursuing a Masters Degree in Physiotherapy. I am currently working on my research proposal where I would like to determine and explore the process of rehabilitation for 0-6 years old children with Cerebral palsy in Kenyatta National Hospital. You have been identified as one of the respondents in this study and therefore, kindly requested to respond to the following questions. The information provided will only be used for the purpose of this study and confidentiality and anonymity is highly assured. Participating in this Focus Group Discussion is voluntary on your part. The questions will take about 40 - 45 minutes of your time to answer. Thank you for agreeing to participate.

Remind participants you want to hear about positive experiences, negative experiences, and ideas for improvements.

- How have you been involved in the rehabilitation process of your child during the rehabilitation sessions?
- Think back over the periods that you have been taking your child for rehabilitation, tell me about the positive experiences that you have had.
- Share with me about the disappointments you have had during the rehabilitation sessions
- What can each of us do to make rehabilitation of children with cerebral palsy effective and meaningful?
- Following the discussion that we have had, what would you give as our way forward?

APPENDIX K: DATA EXTRACTION SHEET FOR INCIDENCE RATE

DATA EXTRACTION SHEET – 1: INCIDENCE RATE

2009-2015

Case nr	Year	Type of CP	Age	Gender	Ethnicity	Therapy Yes (√) / No (x)

APPENDIX L: DATA EXTRACTION SHEET INFORMATION FROM PATIENTS

FILE

INFORMATION FROM PATIENTS FILE

1. Demographics of a child

- Identity Code
- Age.
- Sex.
- Type of CP

2. Assessment - Delayed milestones.

Activities	Yes(√) / No(x)
Head control	
Neck control	
Reach objects hands	
Rolling	
Sitting	
Crawling	
Standing	
Walking	

3. Techniques used for rehabilitation summarized into categories

Physical therapy	Tick (√) or (x)
Passive stretching	
Active movements	
Positioning	
Balance & coordination exercises.	
Chest physiotherapy	
Massage	
Sitting on a corner chair	
Hippo therapy	
Hydrotherapy	

Assistive Devices issued	Tick (√) or (x)
C P chair	
Wheelchair	
Walking frame	
Crutches	
Orthosis for walking (AFO)	
Splints support/correction	

Medical Interventions	Tick (√) or (x)
Surgery	
Medication or drugs	
Botulinum-A injection	
Electrical stimulation	

Education and Home advice to caregiver	Tick (√) or (x)
Programme given	
Equipment available at home	
Follow up Home visit	

Multidisciplinary team involvement	Tick (√) or (x)
Doctor	
Physiotherapist	
Occupational therapist	
Social worker	
Speech therapist	
Prosthetist	
Wheelchair technician	

APPENDIX M: LETTER FROM THE EDITOR

ISOBEL BLAKE

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2 November 2017

TO WHOM IT MAY CONCERN

This is to state that I, Isobel Blake, edited independently and professionally a Master's degree thesis entitled "The process of rehabilitation for 0-6 year old children with cerebral palsy at Kenyatta National Hospital, Kenya." My brief role was to check the article for grammar, syntax, spelling and overall correct English of a high standard for submission to the university. At no time did I make any changes to the context or format of the article, which is still true to its original state.

ISOBEL BLAKE

BA (UNISA) English, Psychology