

**PROPORTION AND CAUSES OF DELAYED INITIATION OF
OCCUPATIONAL THERAPY AMONG CHILDREN WITH
CEREBRAL PALSY RECEIVING CARE AT UBUNTU LIFE
FOUNDATION IN MAAI MAHIU, KENYA**

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REG No. H58/37429/2020

**A RESEARCH DISSERTATION SUBMITTED IN PARTIAL
FULFILLMENT FOR THE AWARD OF THE DEGREE OF MASTER
OF MEDICINE IN PAEDIATRICS AND CHILD HEALTH FROM THE
UNIVERSITY OF NAIROBI.**

2023

DECLARATION

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ACKNOWLEDGEMENTS

I sincerely thank my supervisors Prof Elizabeth Obimbo and Dr Beatrice for their invaluable support towards the completion of this study.

Special thanks to the Department of Paediatrics and Child Health at the University of Nairobi, and my colleagues.

I would also like to express my deepest appreciation to the patients, parents/caregivers, and staff at Ubuntu Life Foundation for offering continuous support during my study. Many thanks to my family and to God who has been with me throughout the study period.

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LIST OF ABBREVIATIONS

CNS	Central Nervous System
CP	Cerebral Palsy
EI	Early Intervention
GMFCS	Gross Motor Classification System
LMIC	Low-Middle Income Countries
MACS	Manual Ability Classification System
OT	Occupational Therapy
ULF	Ubuntu Life Foundation
UMIC	Upper-Middle Income Countries

ABSTRACT

Background

National cerebral palsy registrations suggest that cerebral palsy (CP) prevalence is around 1.8–2.3 cases per 1000 children worldwide. In Sub-Saharan Africa, the estimated prevalence of CP is 2.9 (2.4–3.6) per 1000 children. Paediatric occupational therapy (OT) focuses on strengthening the capacity to play and learn in children with CP which is critical for their growth and independence. Cognitive, physical, and social abilities, as well as posture and fine motor skills, can all be improved with optimal occupational therapy; however, this intervention should begin early and should be individualized to meet patients' goals. The findings of this study will guide interventions to strengthen occupational therapy services for children with cerebral palsy.

Study Objectives

To determine the proportion of children with cerebral palsy receiving care at Ubuntu Life Foundation who are initiated on occupational therapy more than 6 months after diagnosis. To describe causes of delay in initiation of occupational therapy among children with cerebral palsy receiving care at Ubuntu Life Foundation and to determine the adequacy of occupational therapy received by children with cerebral palsy at Ubuntu Life Foundation based on the number of sessions per week and the number of hours per session.

Methodology

A mixed-method study approach was applied, using in-depth interviews for the qualitative aspect and a retrospective cohort method. Only children whose parents/guardians provided consent after getting information about the study were enrolled and allocated study numbers. A master study register was created. Data were obtained using a medical abstraction form on participants' socio-demographic factors as well as clinical characteristics.

Data Analysis

Quantitative data was imported into R software version 4.1.2 for analysis. Continuous variables were summarized using means and standard deviations or medians and interquartile ranges. Categorical variables were summarized using frequencies and proportions. Qualitative data was analyzed using manual thematic analysis.

Results

Out of 85 children, 52 (61%) were males, 39 (46%) were aged below 4 years, and 32 (38%) were 4-7 years. Fifty-six (66%) had a GMFCS score of class IV-V and the median duration of attending OT services was 3.2 years (IQR 2.6, 4.0). The proportion of delay in the initiation of OT services was 41% (95% CI 31%, 52%). The majority of children had received inadequate OT services in terms of length of OT sessions at 61.2% and in the number of sessions at 56.5%. The causes of delay in the initiation of OT services were lack of knowledge of CP among parents, and lack of community sensitization on CP. Caregivers reported a lack of social and economic support, negative attitudes towards CP and denial that the child has CP. Other causes of delay included a lack of adequate OT facilities and late diagnosis.

Delay in seeking OT services remain high among children with cerebral palsy. Children with higher GMFCS scores are more likely to receive adequate OT services compared to those with lower scores. Causes of delay in seeking OT services include lack of social and economic support, late diagnosis, and lack of awareness among caregivers.

CHAPTER ONE: INTRODUCTION

Cerebral palsy (CP) is a diverse group of disorders marked by non-progressive motor dysfunction affecting muscle tone, posture, and/or movement. It arises as a result of anomalies in the growing fetal or infantile brain secondary to a range of non-progressive causes. Post-neonatal CP, which occurs after infancy, is caused by brain damage sustained after the neonatal period and before the age of five, as a consequence of meningitis, near-drowning, or brain trauma. Although the condition does not advance, the clinical manifestations of the disorder may change as the Central Nervous System (CNS) matures. As documented by Rosenbaum et al in 2006, several other symptoms frequently accompany CP, including cognitive impairment, diminished sensation or perception, communication, and behavioral difficulties, convulsive disorders, and musculoskeletal effects (1).

Few population-based research on CP has been conducted in low- and middle-income countries. The statistics in Africa are not properly recorded. There has been no published data from Kenya that depicts the extent of CP. According to national cerebral palsy registrations and population-based studies undertaken in Europe, Australia, and the United States, the prevalence of CP is around 1.8–2.3 occurrences per 1000 children globally (1). In a 2017 research conducted by Kakooza-Mwesige, Carin, et al in a rural eastern Uganda region, the estimated CP prevalence was 2.9 (2.4–3.6) per 1000 children. Spastic unilateral CP was the most prevalent subtype (46%), followed by bilateral CP (40%). This was the first research in Sub-Saharan Africa to offer population-based data on children with CP (2).

Cerebral palsy or a high risk of cerebral palsy can be successfully predicted before the age of 5–6 months. Early intervention is critical since infants who do not actively use their motor cortex risk having deteriorating cortical connections and particular functions. Additionally, there is growing evidence that the infant's motor behavior, through discovery and engagement with the environment, regulates and creates muscle, bone, and ligament growth and development, as well as drives continuous neuro-motor system development. Families may experience considerable psychological stress as a result of the delay in identification and management. When a family receives a clear diagnosis, they often feel a wide range of emotions. They are also stressed since there is a dearth of information regarding the problem and early assistance from health professionals. Chronic sickness commonly impacts parents' psychological functioning and influences the family, making it critical to decrease stress and utilize family-centered methods (3).

The primary goal of early intervention is to improve the development and well-being of children and their families by encouraging personal autonomy and engagement in the natural environment (3). Paediatric occupational therapy (OT) focuses on enhancing a child's capacity to play and learn, which is essential for growth and independence. OT can help children with CP with muscle and joint coordination difficulties that make daily chores challenging. Occupational therapy can help improve cognitive, physical, and social abilities, along with fine motor control and posture. To enhance the physical function of children with CP, OT intervention should begin early and focus on the execution of patients' goals. Children with CP benefit from early detection and treatment because it improves their standard of living and prevents developmental delays. It also reduces the burden on guardians/parents. The most successful practice is based on the client's objectives and whole-task engagement. Delay in the initiation of OT refers to the time elapsed between when a patient is diagnosed with CP and/or when a referral for OT is indicated and when OT is initiated, which is generally 2 months but can vary from 3 to 6 months in high-risk infants (4). Even though late OT initiation has been seen among children with CP visiting clinics in various institutions, primarily in rural settings, no research on variables related to late OT initiation has been reported in Kenya.

CHAPTER TWO: LITERATURE REVIEW

2.1 Overview of Cerebral Palsy

Cerebral palsy (CP) is a broad term for a variety of disorders defined by non-progressive motor dysfunction affecting muscle tone, posture, and/or movement. It arises as a result of anomalies in the growing fetal or infantile brain caused by a range of non-progressive causes. Post-newborn CP develops from brain damage after the neonatal period and before the age of five years due to meningitis, near drowning, or traumatic head traumas. Although the condition is not progressive, the clinical manifestation may vary as the CNS ages (5). As documented by Rosenbaum et al in 2006, several other symptoms frequently accompany CP, including intellectual incapacity, impaired perception and sensation, behavioral, and communication challenges, convulsive disorders, and musculoskeletal consequences (6)(1)(7).

In order of frequency, the most prevalent neurologic motor system abnormalities in children with CP are spasticity, dyskinesia, hypotonia, and ataxia. There are also mixed presentations. Spastic CP, also known as hypertonic CP, is characterized by high muscle tone, and exaggerated, jerky movements (spasticity). Thirty-five percent of all children with CP have spastic diplegia which is the most common type. It occurs between 20 and 34 gestational weeks secondary to an insult to the immature oligodendroglia and periventricular leukomalacia is the most frequent imaging finding. The majority of children will have normal cognitive function and a good probability of being ambulatory on their own. Spastic quadriplegia affects twenty percent of infants with CP and is associated with preterm delivery. Severe forms of periventricular leukomalacia and multicystic cortical encephalomalacia are seen on imaging. It is linked to significant physical limits, cognitive loss, visual impairment, and epilepsy. Several cases have a poor outcome for independent ambulation. Spastic hemiplegia affects 25% of children with CP, which is most frequent in term newborns and is usually caused by an in-utero or perinatal stroke. The majority of children in this category can walk independently, have normal cognitive abilities, and have a high degree of functional abilities (7). Spastic CP was the most prevalent kind in a cross-sectional study conducted from 2013 to 2014 by Bearden et al at a referral centre in Gaborone, Botswana, with 56 children (82%) and 6 children (9%) with combined spastic/dyskinetic CP. The remaining 12 children with non-spastic CP had 5 (7%) hypotonic, 2 (6%) dyskinetic CP, 2 (3%) ataxic CP, and 3 (3%) other unspecified kinds of CP (8).

Many categorization systems are used in children with CP to provide a systematic means of assessing each child's support and therapy requirements. In our setting, two essential systems are often employed. The Gross Motor Function Classification System (GMFCS), according to Palisano et al., is one of them, which is a validated instrument for children aged 2-18 years and is used for categorizing gross motor abilities and limits, specifically the capacity to walk. The second approach is the Manual Ability Classification System (MACS), which provides a legitimate single grade for a child's level of cohesive use of both hands when handling different items in their daily life between 4 -18 years of age. In this study, we will use GMFCS since it is a legitimate and dependable method that is relatively stable over time (9). It is divided into four age groups: under 2 years, 2 to 4 years, 4 to 6 years, and 6 to 12 years. It has an 80% content validity and good inter-rater reliability, which means that guardians/parents and health workers may use the same terminology and comprehend one another when using it to evaluate their child's motor functional categorization (10).

2.1.1 Gross Motor Function Classification System

The GMFCS is a recognized and dependable instrument that categorizes children with CP into one of five categories depending on each child's motor function, ranging from I (mildly affected) to V (significantly affected) (11). It is used to assess gross motor function in people with CP based on self-initiated physical abilities such as sitting, strolling, and wheeled locomotion.

The necessity for walkers, crutches, wheelchairs, or walking sticks is used to differentiate between levels. Robert Palisano et al. in 1997, created the first category of the GMFCS. As of 2007, there was a new category known as GMFCS - E&R which covers an age range for children ages 12 to 18 years (12). Below is a table showing what each level of GMFCS entails.

Table 1: Gross Motor Function Classification System of Severity of Impairment in Cerebral Palsy

Level	Description
GMFCS I (Minimal Impairment)	-Able to walk outdoors and indoors as well as climb stairs without the use of hands for support. -Participates in activities such as jumping and running -Has slowed down in terms of coordination, speed, and balance.
GMFCS II (Mild Impairment)	-Able to use a handrail to climb steps. -Has difficulty with slopes, uneven ground, or crowded places. -Only has a limited capacity to sprint and jump.
GMFCS III (Moderate Impairment)	- Walks on flat surfaces indoors and outdoors using assisted mobility equipment. -May be able to use a rail to ascend stairs. -For lengthy trips or rough surfaces, a wheelchair may be required.
GMFCS IV (Severe Impairment)	-Even with support aids, the walking ability is severely limited. -Majority of the time uses wheelchairs and may propel their motorized wheelchair. -Standing transfers, assisted or unassisted.
GMFCS V (Very Severe Impairment)	-Has physical constraints that impair movement under voluntary control. -Limited ability to hold head and neck posture against gravity. -Motor function is impaired in all areas. -Impossible to sit or stand on one's own, even with adapted equipment. -Is unable to walk independently but may be able to employ motorized mobility.

2.1.2 Manual Ability Classification System of Level of Impairment of Hand Function

The Manual Ability Categorization System (MACS) is a classification system used in children with cerebral palsy aged 4 to 18 years to describe how their hands interact with objects during daily activities, with a focus on utilizing both hands simultaneously. There are 5 levels of severity involved. Because MACS levels remain consistent throughout time, they can be used to predict the prognosis of patients, particularly those receiving therapy. It can also be utilized in children aged 2 to 4 years with CP. MACS, unlike GMFCS, does not have

an age range. There are 5 levels of severity involved. Because MACS levels remain consistent throughout time, they can be used to predict the prognosis of patients, particularly those receiving therapy. It can also be utilized in children with CP aged 2 to 4 years. MACS, unlike GMFCS, does not have an age range (13).

Table 2: Manual Ability Classification System of Level of Impairment of Hand Function

Level	Description
Level I	Handles things with ease and success
Level II	Handles most items with somewhat reduced quality or speed of achievement
Level III	Handles things with difficulty; needs assistance in preparing or modifying activities
Level IV	Handles a limited selection of easily managed things and always requires some assistance from others.
Level V	Has no capacity to grasp items and has a highly limited range of motion.

CP is distinguished by variation in risk factors, an underlying particular cause, clinical symptoms and the degree of physical disabilities, related and tertiary disorders, treatment choices, and the condition's progression across the individual's lifespan. As a result, the epidemiology of this group of illnesses is anticipated to differ significantly across socioeconomic and geographic contexts. Most aberrant motor and neurological abnormalities in newborns and children disappear within 2 to 5 years of life; nonetheless, the incidence of CP has been reported to be greater during infancy (7). The aetiology of CP is frequently multifaceted and might include anything that has a deleterious influence on the developing prenatal or neonatal brain. Birth asphyxia, kernicterus, and newborn infections are the most commonly reported etiologies in Africa, with prematurity and low birth weight being less prevalent.(14)(15) Sixty-eight children with CP were engaged in a cross-sectional study done by Bearden et al at a referral facility in Gaborone, Botswana, from 2013 to 2014. The most prevalent causes of CP in the group were intrapartum hypoxia (18%), postnatal infections (15%), preterm (15%), localized ischemic strokes (10%), and prenatal infections (10%). Severe motor dysfunction was prevalent, with 41 percent falling into the most severe group (8).

Prematurity or low birth weight, on the other hand, is one of the primary risk factors identified in nearly all research in the United States and Europe (16). Several other variables

have been linked to or may enhance the incidence of CP. According to much epidemiological research, 50% of all infants with CP had no known risk factor at birth. Post-newborn CP is due to brain damage acquired after birth and before the age of five, as an outcome of trauma, near-drowning, or infections e.g., cerebral malaria, meningitis, or convulsive disorders. The table below summarizes the variables linked with an elevated risk of CP.

Table 3: Factors Associated with a Higher Risk of Cerebral Palsy

Congenital malformations of the brain
Genetic susceptibility
Hypoxic-ischemic encephalopathy
Strike in utero or perinatally
<i>In vitro</i> fertilization or the use of assisted reproductive technology.
Kernicterus
Preterm birth or low birth weight
Maternal disorders of clotting
Maternal-fetal infections
Multiple gestations
Neonatal seizures
Neonatal meningitis/sepsis
Post-neonatal meningitis
Post-neonatal traumatic brain insult
Obesity during pre-pregnancy

A multidisciplinary team is an ideal paradigm for medical treatment for children with CP throughout their lives. OT is important in the management of CP as it promotes fine motor performance. OT aids in the optimization of bodily function and the synchronization of small muscles, it focuses on enhancing the upper limbs' fine motor control to help the child conduct daily activities more effectively. Optimal OT should concentrate on the active practice of a child's goals as well as whole-task practice, considering the amount and focus based on the GMFCS level. Optimal OT depending on GMFCS level is either intensive (50-60 minutes per session or 4-5 sessions in a week) or non-intensive (no therapy required or 1-2 sessions in a

week) (17). With early intervention and with appropriate OT children with CP can regain some of the lost function as well as engage in some of the activities of daily living. Evidence suggests that OT is effective in increasing a child's function, involvement, and standard of living, particularly when provided at a young age and with vigor (4).

2.2 Epidemiology of Cerebral Palsy

There have been few population-based investigations of CP in countries with low and moderate incomes. The data is not well recorded in the African setup (15). There has been no published data from Kenya that reflects the magnitude of CP. In Africa, research on CP is mostly based on a biological perspective on disability and does not expressly employ the international classification of Functioning, disability, and health as a guiding framework. Body function and structure studies are often descriptive in nature, while activities and involvement, as well as environmental and personal variables, are changeable elements that may be tackled with therapy. Knowledge translation actions promoting ICF concepts in an African setting should thus be examined (18).

National cerebral palsy registrations and population-based studies conducted in Europe, Australia, and the United States suggest that the prevalence of CP is around 1.8–2.3 instances per 1000 children worldwide. The prevalence in Zimbabwe is estimated to be at 1.55 per 1000 in rural areas and 3.3 per 1000 in urban areas (19). In 2017 research conducted in a rural eastern Uganda region by Kakooza-Mwesige, Carin, et al, a total of 31,756 children were evaluated for CP and established in 86 (19%) of 442 who met the criteria in the preliminary screening stage. The predicted CP incidence was 29% which is 2.4–3.6 per 1000 children (1). The frequency was less in, older (8–17 years old) children than in younger (8 years old) children, implying a significant mortality rate among seriously afflicted children. Children aged 2–7 years (27%) had severe CP, Gross Motor Classification System (GMFCS) levels IV–V, compared to only 12 % aged 8–17 years. The most prevalent subtype (46%) was spastic unilateral CP, followed by bilateral CP (40%). Few children (2%) with CP were born prematurely, most likely due to limited preterm survival. Post-neonatal events were the most prevalent cause of CP in 25% of children, suggesting that cerebral malaria and convulsive disorders were common risk factors in this cohort. This was the first research in Sub-Saharan Africa to offer population-based data on children with CP (2).

From January 2015 and May 2019, 2664, children from Nepal, Ghana, Bangladesh, and Indonesia were recruited for research conducted by Israt, Mohammad, et al. Data from the

general population show that the number of severe instances of CP in LMICs is comparatively great, and they have limited access to rehabilitation programs. Preterm delivery, birth asphyxia, and neonatal encephalopathy all contributed to 86.6 % of infants acquiring CP prenatally and perinatally. The average age of CP diagnosis was 3 years. 79.2 % with CP had spastic CP, and 73.3 % were categorized in GMFCS levels III – V. Delay in diagnosis, considerable motor impairments, and a failure of therapy in the majority of children demand an immediate effort to identify preventative possibilities and encourage early detection and therapy for children with CP in the United States (20).

Donald, Kakooza-Mwesige, et al, identified 16 articles on the incidence and aetiology of CP in Africa in a systematic review of accessible literature (4 from Nigeria, 4 from South Africa, 2 from Ghana, Ethiopia, and Tanzania, and 1 each from Egypt and Kenya). Birth asphyxia, kernicterus, and newborn sepsis were the highest commonly reported etiologies in African demographics, with preterm or low birth weight being less common but still significant risk factors (16). Preterm birth is the major cause of child death in LMICs due to a lack of maternal and neonatal care. Table 2.4 summarizes significant prevalence and aetiology research.

Table 4: Overview of Major Publications Evaluating Prevalence and Etiology of Cerebral Palsy in Africa

Author, Year	Country	Study design	Incidence per 1000	Commonest etiology
El-Tallawy et al, 2005	Egypt	Prospective	2	Birth asphyxia (34.6%)
	North Africa	Community-based		Preterm birth (17.3%)
		Cross-sectional		Kernicterus (15.4%)
Ogunles et al, 2008	Nigeria	Retrospective	Not measured	Birth asphyxia (57.6%)
	West Africa	Case series		Kernicterus (36.9)
	LMIC	Hospital-based		CNS infections (21.7%)
Karumun and Mgone, 1990	Tanzania	Prospective	Not measured	Birth asphyxia (36%)
	Southern Africa	Hospital-based		Low birth weight (20%)
	Low income	Cross-sectional		CNS Infections (15%)

2.3 Adequacy of Occupational Therapy

OT is one of the rehabilitation therapies that are effective for children with CP. Various strategies are applied, including neurocognitive and sensory integration. The purpose of OT in children with CP is to work with the child to improve the abilities necessary for everyday life activities. Occupational therapists (OTs) concentrate their interventions on a variety of areas. Parents play a significant part in these children's recovery and are a key aspect in helping the therapeutic process. Parent-centred care is an essential strategy in the treatment of children with CP, and commitment has a significant impact on the capacity to achieve the best possible outcome (3)(21). OT should be started as soon as possible and should focus on helping patients to achieve their goals. Early detection of CP and intervention assist to prevent developmental delays, which improves the standard of living of children with CP and lessens the load on caregivers. The best practice concentrates on the patient's specified goals and task practice. The intervention is aimed at: -

- i. Clients choose their goals which should be measurable at the beginning and end, achievable, and well-defined.
- ii. Environment and social factors around clients can limit goal achievement.
- iii. Target the child's chosen goals for intervention.
- iv. Intervention should be inspiring and fun for the child.
- v. Practice goals should be within a child's environment or what they have.
- vi. Parent involvement is key.
- vii. Children, caregivers/parents should always be the major decision-makers.
- viii. Intervention needs to be of high intensity and dose, 15 to 20 hours to achieve functional goals.
- ix. Mobility intervention according to GMFCS and hand use according to MACS
- x. Self-care should be task-specific and goal-directed.

Adequacy is described as "enough in quantity, quality, or amount to deliver the intended therapeutic effect." According to various studies, intense therapy for children with CP is characterized as 50–60-minute sessions per session / 4 to 5 sessions per week, but non-intensive therapy ranged from 1 to 2 sessions weekly to no intervention at all (17). GMFCS or MACS strongly influence the amount and intensity of OT for each child. This is necessary to attain long-term goals that are appropriate for the child's requirements.

McManus et al did research in Denver from 2014 to 2016 comparing children without any special health care needs to children with mild to moderate severity of developmental delays who received higher intensive OT and newborns born below 1.5 kg to newborn babies larger than 2.5 kg who received more rigorous therapy. It was discovered that increased Early Intervention (EI) program intensity was related to functional benefits (4).

Between June 2009 and May 2015, Okenwa et al conducted 6-year retrospective research to determine the clinical presentation and physiotherapy care of CP patients at ESUT Teaching Hospital Enugu, Nigeria. During the study period, out of 483 children, 146 cases with CP (30.2 %) were identified. Most patients received 5 or fewer therapy sessions and were later lost to follow-up. Approximately 10% of patients received therapy regularly for three months. The children were referred by the hospital's pediatric neurology department and orthopaedic surgery clinic. There were also referrals from mission hospitals, private hospitals, and general hospitals in Enugu even though ESUT Teaching Hospital is the only public hospital in the city with a working pediatric physiotherapy section. Most of the patients, 118 (80.8 %) presented for therapy at the age of 2 years or less after referral.

The use of the given physiotherapy services did not appear to be particularly excellent. 86 patients (59.0%) received 5 or fewer PT treatments. 20 patients (13.6%) had 6–10 sessions, 12 patients (8.2%) had 11–15 sessions, 13 patients (9.0%) had 16–20 sessions, 4 patients (2.7%) had 21–25 sessions, and only 11 patients (7.5%) had 25 sessions or more. Using the gross motor function classification method, 28 (19.2%) of children who underwent physiotherapy for three months or longer were categorized as follows: class III, 14(9.5%), class IV, 8(5.5%), and class V, 6(4–1%). Those who received minimal sessions did not show any improvement at all (14). This may be attributed to the inability to pay the expense of therapy, since most patients, due to their socioeconomic status, may be unable to meet their financial obligations.

In a research conducted by Young Hong et al, in Korea between July 2011 and November 2015, 145 children were enrolled in the study and underwent voluntary intensive rehabilitation therapy every day for 8 weeks in the rehabilitation department at St. Vincent's Hospital. Participants were divided into three groups based on the aetiology of their developmental delay: cerebral palsy, genetic condition, or unknown aetiology. Intensive therapy consisted of 2 hours of therapist-led therapy (with a 30-minute break in between) and

60 minutes of self-help programs. The inclusion criteria were a child's age of less than seven years old, as well as a developmental delay needing both occupational and physical therapy.

As previously indicated, intervention programs were tailored to the patient's growth and condition. Gross motor function measurements were taken at the beginning and conclusion of the study using the Gross Motor Function Measure and Gross Motor Function Classification System (GMFCS). The study's findings revealed a substantial improvement in gross motor function following 8 weeks of treatment. Because there was no control group, it was difficult to infer that the intensive program had significant impacts on gross motor function beyond normal development or non-intensive therapy, even though significant score improvement was detected by the conclusion of the 8-week program (11).

2.4 Delay in Initiation of Occupational Therapy

Delay in the initiation of OT is the time from when a diagnosis of CP is made and/or referral for OT is indicated until OT is initiated, a period of an average of 2 months or from 3 to 6 months in high-risk infants. The baseline for early intervention (EI) timeliness is between 45 days from receiving the referral for EI to when the EI treatment plan is established, as required by the government of EI regulation (4). In a cohort study conducted by McManus et al among extremely low-income families between 2017 and 2018, only 43% of the 722 children who obtained an EI treatment plan did so within 45 days of their availability, and the majority received low-intensity early intervention programs. The monthly EI dose was 2.7 (2.3-3.6) hours. Children from families who earn more than the poverty threshold got more intensive OT and severe CP was related more to EI. When compared to infants, 2-year-olds received a treatment plan around 2 months earlier. An extra hour of EI every month was related to greater functional improvements (4). The results of the Groningen Vroege Intervention Project (VIP project), a research on treatment from 3 to 6 months corrected age in infants at high risk of cognitive problems, were associated with developmental effects instantly after the intervention, at 6 months corrected age, and one year afterward. The findings demonstrated that parental coaching and self-produced motor activities for the newborn were related to higher functional recovery at 18 months, particularly in terms of functional mobility (22). In affluent nations, children with CP have access to a diverse variety of early intervention services. For children at risk of cognitive deficits, such as those with prenatal, perinatal, or neonatal problems, OT is more beneficial when started early in infancy (23), this is because the most important period of brain growth and maturation ends at the age

of seven years, the sooner the intervention is initiated, the greater the functional benefit. However, other studies have found that OT can still have an impact even when begun after the key period has passed (22). Delayed therapy leads to the advancement of difficulties as well as a delay in the parental knowledge of the child's illness and how to manage it.

2.5 Causes of Delay in Initiation of Occupational Therapy

Early detection of CP and treatment assist to prevent developmental delays, which improves the standard of living of children with CP and lessens the load on parents/guardians. There has been no research published on the variables linked with the late initiation of OT in Kenya. Late OT initiation has been noticed among children with CP visiting clinics at various facilities, primarily in rural areas. In 2018, Kanyembo et al conducted research at the University Teaching Hospital (UTH) in Lusaka, Zambia where the population of the study comprised 10 women with children aged 0-5 years who were undergoing physiotherapy at UTH over the same period. Causes of late commencement of PT among children with CP were documented by parents/guardians and health care personnel, as summarized in Table 2.5 below. The primary elements were, poor socioeconomic level; late referral for PT; caregivers' lack of awareness about CP; and communities' attitude toward CP (24).

Table 5: Causes of Delay in Initiation of Intervention in Children with Cerebral Palsy

Themes identified	Subthemes identified
Socioeconomic support	-Social support -Financial support
Late referral	-Doctor's referral -Self-referral
Caregiver's knowledge of cerebral palsy	-Lack of education by clinicians -Lack of community sensitization about cerebral palsy -Caregiver's age
People's attitude towards cerebral palsy	-Negative attitude -Social stigma -Parent's denial
Caregiver's knowledge of therapy	-Lack of community understanding regarding physiotherapy -Caregiver education is lacking

Research on the factors of rehabilitation service utilization among children with CP in LMICs was conducted by Israt et al, 3441 children from Nepal, Bangladesh, Ghana, and Indonesia were enrolled. A prevalence of 66.2 % in Indonesia, 49.8% of children in Bangladesh, 45.8 % in Nepal, and 26.7 % in Ghana did not get rehabilitation. The most often mentioned barrier to seeking therapy was a lack of awareness. The age of a child, functional limitation, associated impairments, parental/guardian education level, and financial status all had an impact on treatment utilization in children with CP in LMICs. These data might be used by policymakers and service providers to remove barriers to rehabilitation and enhance equity in the use of treatment programs to improve cognitive outcomes in children with CP.

2.6 Study Justification

The prevalence of CP is high in our setting. Spasticity, cognitive impairment, behavioral disorders, speech, visual issues, and eating and gastrointestinal problems are associated complications. Children with CP rely heavily on caretakers for the majority of their everyday activities. OT is therefore vital for optimizing bodily functions as well as improving small muscle coordination, both of which are essential in performing everyday duties. To ensure improved motor function in children with CP, there is a need for early recognition of a high-risk group of neonates/infants, as well as early initiation of optimal OT.

However, there is limited data on the proportion of children with CP who get optimal OT, as well as causes of delayed initiation of OT among these children, in our setting. The study findings will provide insight into the facilitators and barriers to early initiation of OT among children with CP, as well as inform policy formulation to improve OT practice for these children. The goal of this research is to determine the degree of delay in the initiation of OT, as well as the related variables, among children with CP at the Ubuntu Life Foundation (ULF). ULF is an excellent location for my study since it provides critical services to children throughout the Maai Mahiu region.

2.7 Research Questions

1. What is the proportion of children with cerebral palsy receiving care at Ubuntu Life Foundation initiated occupational therapy more than 6 months after diagnosis; and what are the causes of delayed initiation?
2. How many sessions per week or how many hours per session of occupational therapy do children with cerebral palsy receive at Ubuntu Life Foundation?

2.8 Research Objectives

2.8.1 Primary Objectives

1. To determine the proportion of children with cerebral palsy receiving care at Ubuntu Life Foundation initiated occupational therapy more than 6 months after diagnosis.
2. To describe causes of delay in initiation of occupational therapy among children with cerebral palsy receiving care at Ubuntu Life Foundation.

2.8.2 Secondary Objective

3. To determine the adequacy of occupational therapy received by children with cerebral palsy at Ubuntu Life Foundation based on the number of sessions per week and number of hours per session.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Mixed-Method Study Approach

- a) A **retrospective cohort study** design was employed to determine the proportion of children with CP with delayed initiation of OT and adequacy of OT. Data for these children was gathered through a review of their medical records.
- b) **Qualitative aspect** in-depth interviews were done with parents/guardians of children with CP who attend OT at ULF, as well as health care staff, to investigate the causes of delayed initiation of OT using the grounded theory approach.

3.2 Study Site

The research was done at Ubuntu Life Foundation (ULF) situated on the Nairobi –Kampala highway, at Maai Mahiu, in Nakuru County, Kenya. The majority of the people living in this area are from the Kikuyu ethnic community and the main economic activity is subsistence farming and livestock keeping. The Ubuntu Life Foundation is a humanitarian organization that was established in 2019 to provide pediatric health care and foster social inclusion for children with exceptional educational and physical requirements in the Maai Mahiu area and its adjacent areas. Provided services include: -

- a) Physical, occupational, and rehabilitative therapy (in the school and at home).
- b) Individualized education programming including training on daily living skills as well as social and communication skills.
- c) Education for parents and families of children with special needs.
- d) Specialised care i.e., neurology clinics.
- e) Social inclusion and community awareness events.
- f) Advocacy and political action surrounding disability awareness. rights, services.
- g) The team includes doctors, pharmacists, nurses, clinical officers, occupational therapists, social workers, special needs educators, teachers, caretakers, and a cook.

ULF employs about 80 people in Maai Mahiu and its surrounding areas, the majority of whom are mothers of special-needs children who manufacture beaded decorations and shukas while generating additional money to support the organization. ULF also runs three social enterprises: Café Ubuntu, which offers tourists dining experiences in the Great Rift Valley on the route from Nairobi to the Maasai Mara; mineral water, Kenya's first social-impact water, sourced from a naturally healthy forest spring; and some products, such as shoes, are sold internationally. Jimmy Kimmel, Kerri Walsh Jennings, and other well-wishers have shown

their support for ULF. Over 70 children with diseases such as cerebral palsy, epilepsy, severe autism, and others benefit from specialized education and therapy at ULF. A neurologist, a medical officer, a pharmacist, a clinical officer, two occupational therapists, and nutritionists provide year-round medication and continuing medical treatment to around 270 pediatric neurological patients through the ULF health program.

3.3 Key Case Definitions and Outcomes of Interest

- **Cerebral Palsy (CP)** – Clinician diagnosis of CP (*clinical diagnosis based on the history of brain injury and features of non-progressive movement disorders and abnormal posture*).
- **Delay in initiation of OT** – was defined as the initiation of OT more than 6 months after diagnosis of CP.
- **Adequate OT based on frequency and duration of sessions:**
 - Adequate frequency – the child had attended four or more sessions per week.
 - Adequate duration - sessions lasted fifty or more minutes per session in the prior 3 months before the study period.

3.4 Study Population

3.4.1 Retrospective Cohort Arm

Children with CP aged 6 months to 10 years who are getting care at ULF, as well as their parents/caregivers, were included in the study.

Inclusion Criteria:

Children who satisfied the following requirements were considered for inclusion:

- Age – 6 months to 10 years.
- Documented clinical diagnosis of CP in their medical records.
- In care at Ubuntu and undergoing OT for the last 24 months before the study period.

Exclusion Criteria:

Children who met the inclusion criteria but had the following conditions were excluded: -

- Congenital anomalies
- Musculoskeletal deformities

3.4.2 In-depth Interviews

Parents/guardians of children with CP aged 6 months to 10 years who get treatment at ULF, as well as health personnel who care for the children, were included in the research population.

Inclusion Criteria:

- Healthcare workers who have provided care to children with cerebral palsy at ULF for a minimum of 6 months (Doctor, nutritionist, occupational therapist, social worker, and early childhood teacher).
- Parents/caregivers of children with a clinical diagnosis of CP between 6 months to 10 years, receiving care at Ubuntu and undergoing OT for the last 24 months before the study period.

Exclusion Criteria:

- Healthcare workers and parents/caregivers who declined to give consent.

3.5 Sample Size Calculation

The sample size was determined with the main goal of determining the proportion of children with CP who have delayed commencement of OT.

Fisher's formula where;

Z = Critical value at 95% confidence level = 1.96

P = Estimated to have delayed OT = 50% as per a study done on the conformity of OT uptake in Israt et al's research on predictors of rehabilitation service utilization among children with CP in the LMIC (20).

d = margin of error = 10%

$$N = \frac{1.96^2 \times 0.50(1-0.5)}{(0.1 \times 0.1)} = 96$$

3.6 Study Procedures

3.6.1 Retrospective Cohort Arm

Retrieval and Abstraction of Medical Records

The principal investigator identified 2 clinical officers working in ULF as research assistants and trained them on research ethics and study procedures. Children with CP under care in ULF during the last 2 years were identified from the central register in the Paediatric Clinic. Only children whose parents/caregivers provided consent after receiving an explanation about the study and those who met the inclusion criteria were assigned study numbers on each file by the research assistants and a corresponding medical abstraction form that captured factors of interest in the study. The records officer was approached to assist in the retrieval of physical files of identified children from the records office.

Informed consent was obtained from parents/caregivers. A master study register was also created, which included the patient's given study number, phone number, and physical address. This master study register was useful in locating children who had been labelled as "lost to follow-up" and in recruiting children's parents/caregivers who were actively caring for their children to engage in in-depth interviews. The information gathered from the medical abstraction form included:

- Sociodemographic characteristics: Age, gender, physical location (county, village).
- Clinical characteristics: Diagnosis of CP, date when the diagnosis of CP was made or date of referral for OT, duration of OT, number of OT visits per week and duration of OT per visit, topographical classification, and severity of CP.

3.6.2 In-Depth Interviews

The principal investigator and the research assistants obtained consent from the healthcare providers caring for the children with CP at ULF for a minimum of six months and parents/caregivers before setting a suitable time and place for conducting the interviews. An interview tool guide was used for the discussion. The interviews focused on answering the second research question on causes of delay in initiation of OT in children with CP receiving care at ULF. The principal investigator wrote down notes during discussions. The interviews lasted approximately 30 - 45 minutes. The participants were assured of confidentiality.

3.7 Sampling Procedure

Potential participants were identified from a master register that was set up during the retrospective cohort study. Participants that met the criteria, were contacted via telephone by the principal investigator and trained research assistant and invited to ULF to participate in the study.

Consecutive sampling was used to achieve the desired sample size. Participants were drawn from the patients receiving OT on the days of the week that the investigator was available to enroll participants.

3.8 Data Collection Tools

Medical records were used to obtain data on the primary objective of delay in the initiation of OT and the third objective on the adequacy of OT at ULF. An interview guide was used to conduct face-to-face in-depth interviews with the mothers and healthcare workers. The interviews addressed the second study objective on causes of delayed OT initiation in children with CP at ULF.

3.9 Data Management and Analysis

3.9.1 Quantitative Data

Questionnaire data was entered in excel and imported into R version 4.1.2 for analysis. Continuous variables were summarized using means and standard deviation (normally distributed), and medians and interquartile ranges for skewed variables. Categorical variables were summarized using frequencies and proportions. Results were presented in tables and charts.

3.9.2 Qualitative Data

Qualitative data was analyzed through manual thematic analysis. Themes and subthemes were generated after reading through the scripts. The themes and subthemes were presented in the results together with the narrative from the respondents using quotation marks.

3.10 Quality Assurance

The following measures were taken for quality assurance:

- a) Adherence to the participant criteria for inclusion and exclusion.
- b) To guarantee consistency in data collection, the research assistants were trained on the study procedures.
- c) In-depth interviews were performed in a language that the participants were comfortable with.

- d) The lead investigator-assessed data entry for errors and inconsistencies daily.

3.11 Study Results Dissemination Plan

The research results will be presented to the UoN Department of Paediatrics and Child Health in both soft and hard-copy versions as part of the MMed Course requirements. Hard copies of the findings will be delivered to the University of Nairobi repository for archiving, as well as to Ubuntu Life Foundation, as new information is obtained to enhance patient care. The findings will also be submitted for publication in a peer-reviewed scientific journal.

3.12 Control of Errors and Biases

Sampling bias was minimized through the use of consecutive sampling meaning all the participants who met the inclusion criteria were included. This ensured that the inclusion did not participants in terms of certain characteristics.

3.13 Measures Undertaken to Minimize the Risk of Covid-19 Transmission

The following infection prevention control measures were undertaken as per the Kenyan Ministry of Health and WHO guidelines and protocols.

The principal investigator and research assistants:

- Alcohol-based sanitisers and handwashing equipment were availed before and after contact with the participants.
- The research team and study participants wore surgical masks during all research sessions. N95 masks were used where participants were suspected to have respiratory illnesses.
- Minimal time was spent with participants, (not more than 60 minutes) to minimize risk of exposure.

3.14 Psychological Stress for Parents/Caregivers

Parents and caregivers were prone to undergo psychological stress during the interviews. Counseling and support were provided by the principal investigator and research assistants to those who need it.

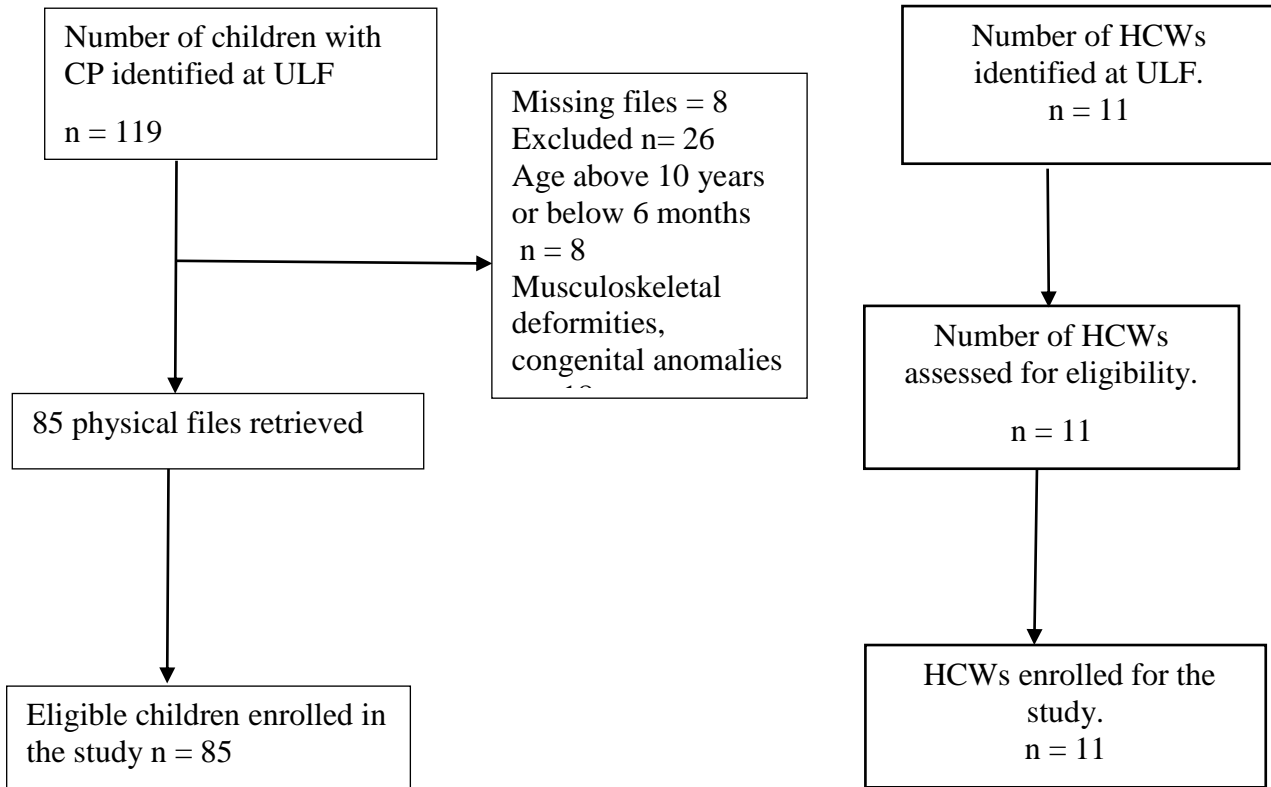
3.15 Ethical Considerations

- a) Ethical permission was obtained from the University of Nairobi /Kenyatta National Hospital research and ethics committee, as well as the Ubuntu Life Foundation ethics committee.

- b) Permission from ULF to conduct the study and access medical records of the patients with CP undergoing OT.
- c) The parents/caregivers of the children and the occupational therapists caring for the children were asked to sign a written informed consent form once the objective of the study has been explained to them. Consent was also obtained from the health workers who participated in the study.
- d) Consenting participants were notified that they can drop out of the research at any time without penalty.
- e) Hard copies were maintained by excluding identifiable data from data collection and instead allocating a unique study number for each participant to ensure confidentiality. Hard copies were kept in a lockable locker with no access to non-study personnel. Data in soft copy was stored in a password-protected computer to which only the principal investigator has access.
- f) Belmont Principles were used to ensure justice for participants and respect for their autonomy. All children with CP undergoing OT were given an equal chance to participate in the study.
- g) The evaluation process did not harm the participants in any way.
- h) The study was free of plagiarism and research misconduct, and the results were accurately presented.
- i) The study findings will be presented to the UON Department of Paediatrics and Child Health as part of the requirements of the MMed Program in both hard and soft copies. Hard copies of the results will be sent to the University of Nairobi repository for storage and to the Head of the Paediatrics Department in KNH with a view to the dissemination of the new knowledge that has been generated to improve patient care. The findings shall also be submitted for publication in peer-reviewed scientific journals. The study's findings were also disclosed to the participants and healthcare providers and will help facilitate the early initiation of occupational therapy among children with cerebral palsy.

CHAPTER FOUR: STUDY RESULTS

4.1 Screening and Enrolment



Child-parent flow chart

HCW flow chart

A total 119 children receiving services at ULF were screened for eligibility. Of the children screened, all 119 children had CP. The children with CP who did not meet inclusion criteria were 26 in number; and reasons for exclusion were as follows: age younger than 6 months or older than 10 years, and presence of other comorbidities such as musculoskeletal deformities and congenital anomalies in addition to CP. In total 34 children with CP were excluded from the study.

4.2 Descriptive Characteristics of the Children

Majority, 61% (52 out of 85) of the children were male while the rest were females. Children below the age of 4 years constituted majority of the participants at 46% (39 out of 85) followed by those aged 4-7 years, at 38% (32 out of 85). The median age of the children was 4.0 years (IQR 2.0, 5.0). The age distribution of children was negatively skewed. The majority of the children were aged less than 8 years. The youngest participant was 8 months old and the oldest was 10 years old (table 6 & Figure 1).

On the gross motor function classification score (GMFCS), the majority, 66% (56 out of 85) of the children were in the severe category (levels 4-5). Of the remainder, 34% (29 out of 85) were in the mild category. On topographical classification, 67% (57 out of 85) of the children were quadriplegic followed by those with hemiplegia at 15.3% (13 out of 85). The children with paraplegia were 11.8% (10 out of 85) and 5.9% (5 out of 85) were diplegic.

The median duration of attending occupational therapy services for the children was 3.2 years with an interquartile range of 2.6 to 4.0 years.

Table 6: Descriptive Characteristics of the Children (n = 85)

Variable	Detail	Frequency or median	Percent or IQR
Sex	Male	52	61
	Female	33	39
Age in years	<4	39	46
	4-7	32	38
	>7	13	16
	Median	4.0	2.0, 5.0
GMFCS	Level 1-3	29	34
	Level 4-5	56	66
Topographical classification	Diplegia	5	5.9
	Hemiplegia	13	15.3
	Paraplegia	10	11.8
	Quadriplegia	57	67.0
Duration of OT in years	Median	3.2	2.6, 4.0

4.3 Health Care Workers

The characteristics of the health care workers who participated in this study are presented in table 12 below.

Table 7: Characteristics of the Healthcare Workers (n = 11)

Variable	Detail	Frequency/Median	Percent or IQR
Sex	Male	2	18
	Female	9	82
Age in years	<30	4	36.4
	31-40	4	36.4
	>40	3	27.2
Cadre	Early childhood teacher	1	9
	Nurse	2	18
	Medical officer	1	9
	Occupational therapist	2	18
	Laboratory technician	1	9
	Nutritionist	1	9
	Social workers	3	27
Duration of work at ULF in years	Median	0.7	0.45, 1.5

Out of the 11 health workers 3 (27%) were social workers, 2 (18%) were nurses, 2 (18%) were occupational therapists. There was also one (9%) early childhood teacher, 1 (9%) medical officer, 1 (9%) laboratory technician and 1 (9%) nutritionist. The median duration of work in Ubuntu Child Life Foundation among the health workers was 8 months with an interquartile range of 5 to 18 months. The majority 82% (9 out of 11) of the health workers were female and the rest were males (table 7).

4.4 Clinical Features of the Children

The severity of CP according to gross motor function classification score

On the gross motor function classification score (GMFCS), 28% of the children had a severity score at level 5. These are children with impaired voluntary movements, limited ability to hold their head and neck up against gravity, inability to sit or stand on their own, and impaired motor function in all domains. The majority, 39% of the children were at severity score level four. These are children whose walking ability is severely limited even with walking aids and mostly use wheelchairs but may be able to propel themselves if motorized.

Thirteen percent of the children had a severity score level of 3. These are children who are able to walk on flat surfaces indoors and outdoors using assistive mobility devices but require a wheelchair for long distances. GMFCS levels 2 and 1 had 8% and 11% children

respectively. Children in GMFCS level 2, can use a handrail to climb stairs, but have difficulty walking up slopes or uneven surfaces and have a limited ability to sprint or jump while those in GMFCS level 1 can walk indoors and outdoors with the use of hands for support, and can participate in jumping and running although they are slow in terms of coordination, speed, and balance (figure 1).

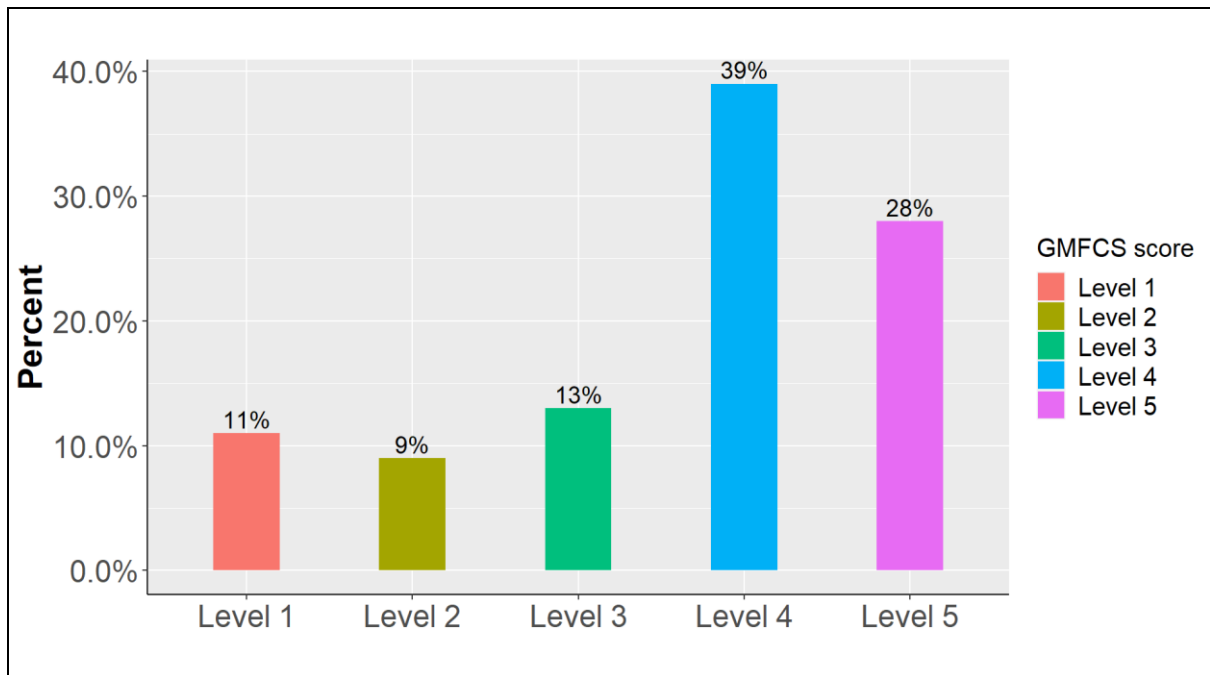


Figure 1: Gross Motor Function Classification Score of the Children with Cerebral Palsy

This score reflects the severity of motor impairment, level 1 denotes minimal impairment, level 5 denotes extreme impairment. Bars show proportion of the study population at each severity level.

4.5 Topographical Classification of Children with Cerebral Palsy

On topographical classification, majority 67% of the children were quadriplegic followed by those with hemiplegia at 15%. The children with paraplegia were 12% and 6% were diplegic (figure 2).

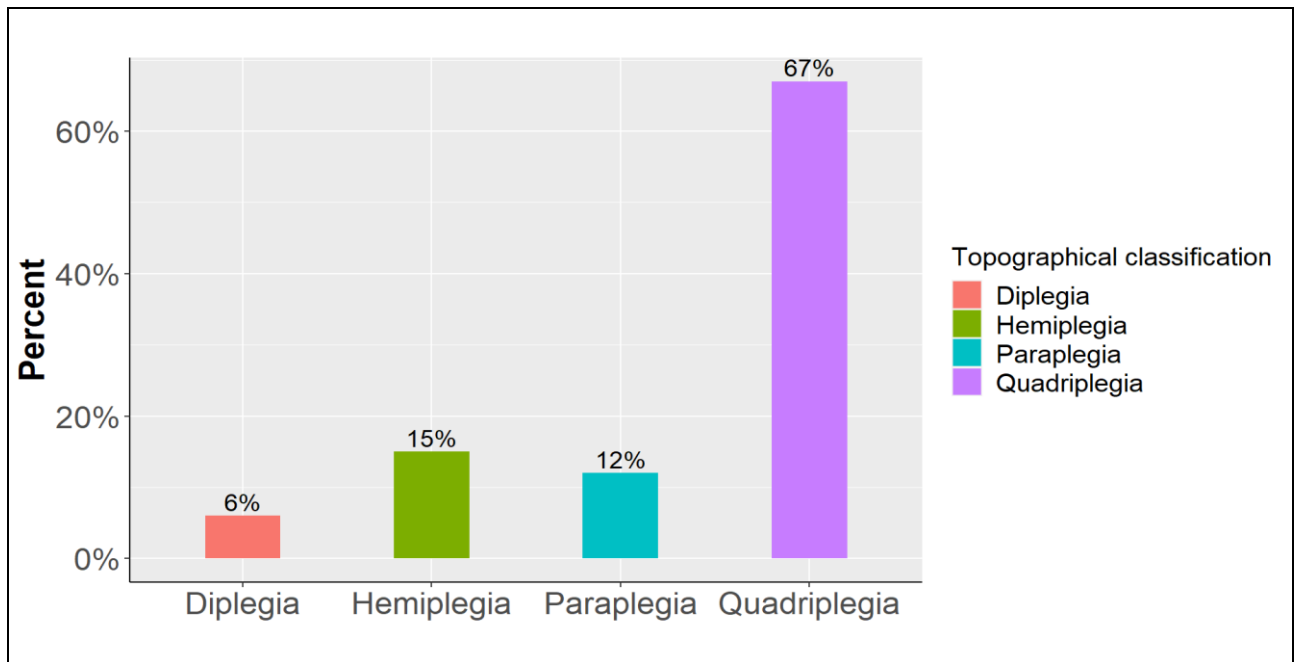


Figure 2: Topographical Classification of the Children with Cerebral Palsy

This describes the region of the body affected. Bars show the proportion of the study population at each classification.

4.6 Children Follow-Up Characteristics: Adherence, Schedule, Retention

The proportion of children who attended the recommended number of sessions/duration and how the OT schedules are at ULF and the retention of the children attending OT services is presented in table 7 below.

Table 8: Children Follow-Up Characteristics: Adherence, Schedule, Retention (n = 85)

Variable	Detail	Frequency	Percent
Adherence to OT services	Yes	84	98.8%
Pattern of visits	Weekly	79	93%
	Monthly	6	7%
Status on follow-up	Active	83	98%
	Lost	1	1%
	Transferred	1	1%

**Adherence to OT services means the child was able to attend the recommended sessions in terms of length and number per week*

There was 98.8% (84 out of 85) adherence to occupational therapy services. The majority 97.6% (83 out of 85) of the children attended OT services weekly and the rest attended

monthly. In terms of follow-up, 97.6% (83 out of 85) were actively attending OT services at ULF, 1.2% (1 out of 85) had been lost to follow-up and one child had been transferred out (table 8).

4.7 Timing of Occupational Therapy Initiation

The children with extreme delay in the initiation of occupational therapy (> 9 months after diagnosis of CP), were 30% (26 out of 85). Those who had delayed in starting OT services (6-9 months after diagnosis of CP) were 11% (9 out of 85) and another 22% (19 out of 85) had there OT initiated between 3 and 6 months. The majority, 37% (26 out of 85) of the children attended OT services early within 3-month from the time of diagnosis of CP. Table 9 and Figure 3.

Table 9: Time to Initiation of Occupational Therapy (n = 85)

Variable	Time to start OT	Frequency	Percent (%)
Initiation of OT	0-3 months	31	37
	>3 to 6 months	19	22
	>6 to 9 months	9	11
	More than 9 months	26	30

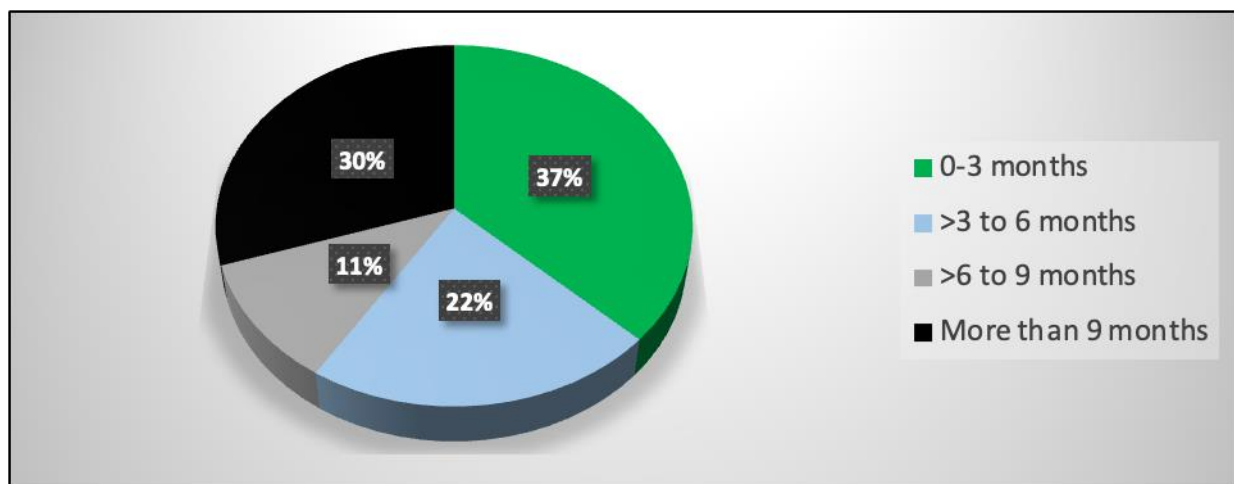


Figure 3: Time to Initiation of Occupational Therapy after Diagnosis.

4.8 Proportion of Children with Cerebral Palsy who delayed in Initiation of Occupational Therapy

The proportion of delayed initiation of occupational therapy from the time of diagnosis (more than 6 months after diagnosis) was 41% (95% CI 31%, 52%) Figure 4.

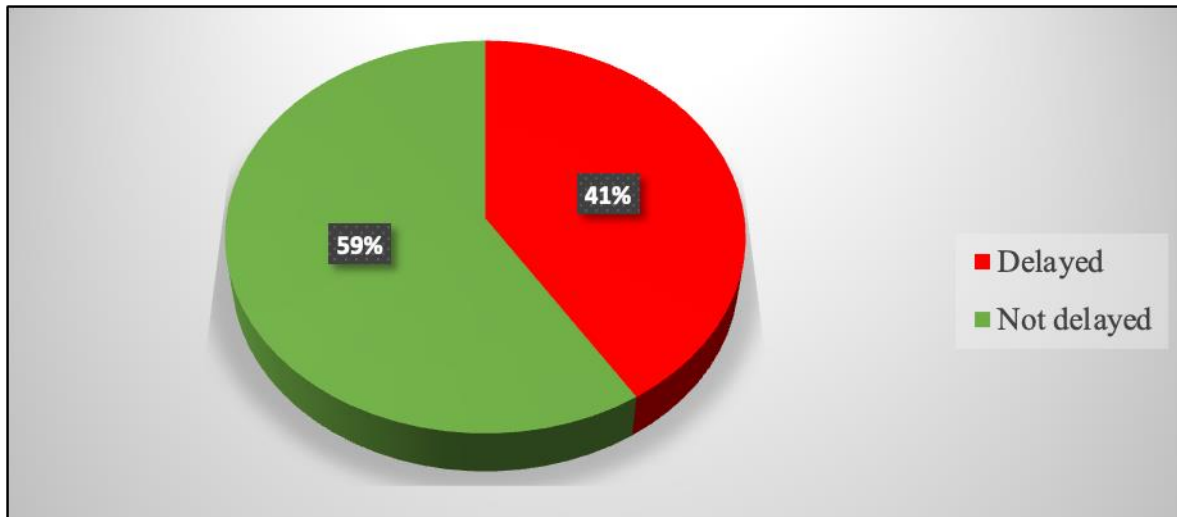


Figure 4: Proportion of Delayed Initiation of Occupational Therapy

4.9 Adequacy of Occupational Therapy Based on Number of Sessions and Hours per Session

This section describes the adequacy of occupational therapy sessions in terms of length in minutes and number of sessions attended in a week.

Table 10: Adequacy of Occupational Therapy Session

Variable	Detail	Frequency/Mean n = 85	Percent (%) / SD
Duration of OT sessions	Adequate ≥ 50 minutes	33	38.8
	Inadequate < 50 minutes	52	61.2
Average length of sessions in minutes	Mean	47.8	6.9
Number of sessions/weeks	Adequate ≥ 4	37	43.5
	Inadequate < 4	48	56.5
Average number of sessions/week	Mean	4.0	1.4
Adequacy of OT based on the levels of GMFCS scores			
	Level of GMFCS score	Adequate Frequency (%)	Inadequate Frequency (%)
GMFCS score	Levels I-III	0 (0)	29 (100%)
	Levels IV-V	9 (16%)	47 (84%)

In terms of the duration of OT sessions, the majority, 61.2% (52 out of 85) of the children with cerebral palsy did not receive adequate OT services. The proportion of children who

received adequate OT services in terms of duration was 38.8% (33 out of 85). The mean duration per session was 47.8 minutes with a standard deviation of 6.9 minutes.

The adequacy of OT sessions was also determined in terms of number of sessions per week. The mean number of sessions per week was 4.0 with a standard deviation of 1.4 sessions. The majority, 56.5% (48 out of 85) of the children attended less than five sessions in a week, and their attendance was considered inadequate.

In terms of overall adequacy, based on the number of sessions per week and the duration of each session, none of the children in GMFCS levels I-III received adequate OT services while only 16% (9 out of 56) of the children in levels IV-V received adequate OT services (table 10).

4.10 Causes of Delayed Initiation of Occupational Therapy among Children with Cerebral

Palsy Receiving Care at Ubuntu Life Foundation – Caregivers’ Perspective

Parents narrated the various causes that resulted in delays among children in seeking early intervention for OT services. The causes were described under the following themes: Socioeconomic support, cerebral palsy awareness, occupational therapy facilities, stigma, ill health, and late diagnosis.

Table 11: Parent Perspective on Causes of Delay in Initiation of Occupational Therapy Services

Themes	Subthemes
Parent's knowledge of cerebral palsy	-Lack of education by clinicians -Lack of community sensitization about cerebral palsy
Socio-economic support	-Lack of social support -Lack of financial support
Attitude towards cerebral palsy	-Parents denial -Social stigma
Occupational therapy services	-Lack of OT services in the locality -Lack of knowledge of OT
Late diagnosis	-Parents unable to detect delayed milestones -Health workers not diagnosing the children early
Ill health among the children	-Frequent admissions -Frequent illness

Parents' Knowledge of Cerebral Palsy

Most caregivers reported that they were not aware of what cerebral palsy was. Even after the diagnosis of the children, they still did not understand. As a result of this, it was difficult to make a connection between cerebral palsy and occupational therapy services. Under parents' knowledge about cerebral palsy, two subthemes were identified: lack of knowledge of cerebral palsy and lack of knowledge of occupational therapy.

Lack of Education by Clinicians

Caregivers reported that due to a lack of knowledge of cerebral palsy, there was a delay in seeking OT services as some thought that the children will grow up normally.

“At the age of 5 months, I took my child to the hospital following concerns of her not developing normally but the doctor dismissed my concerns and instead prescribed medication that would help with weight loss since they thought that was the cause of the developmental delay”. [ULF 48]

Lack of Community Sensitization about Cerebral Palsy

Under lack of knowledge on occupational therapy, caregivers reported that they did not know that there was help for children with CP. By the time they knew that OT could help, they had already delayed.

“Lack of awareness on developmental delays associated with cerebral palsy”. [ULF 49]

“I did not know of any service that helps children with developmental delays”. [ULF 54]

“I had no idea that there was help for children who had development delay”. [ULF 53]

Socio-Economic Support

Socio-economic support was reported by the parents as one of the causes of delayed initiation of occupational therapy services for children with cerebral palsy. It was described under the subthemes: social support and financial support.

Lack of Social Support

Under social support, the parents reported that they were not being supported by their families. Caregivers who were single mothers reported that they were not helped to raise the necessary finances by the family to take the child for OT.

"I am a single mother and I have no one to look up to in the family for support and therefore I have to provide for the other children. Due to this, I could not afford to take the child for OT" [ULF 68]

"Lack of family support to start on therapy". [ULF 56]

Apart from the general family support, some of the mothers got rejected by their spouses after revealing that the child had CP. This delayed decision-making on seeking early OT services for the child.

"Lack of family support; my husband did not want to be associated with anything concerning my child (since he also felt there was a problem)" [ULF 72]

"Cultural views also played a huge role as my child was unacceptable in our community" [ULF 77].

Lack of Financial Support

Most of the caregivers reported that financial support was one of the major causes of delay in seeking OT services for their children after diagnosis with cerebral palsy. Most of them reported this as financial constraint. The lack of funds means they could not afford to pay for the OT services and even transport costs to OT facilities.

"Financial constraints; I am unable to raise both school fees and therapy fee charges". [ULF 62]

"Lack of money for therapy services which look more expensive". [ULF 64]

"Expensive therapy services in private facilities that offer therapy services". [ULF 67]

"My family has challenges in raising money for therapy services". [ULF 69]

"I had financial constraints and could not raise money for therapy and transport costs". [ULF 61]

Attitude towards Cerebral Palsy

Parents also mentioned that the attitude towards cerebral palsy hampered efforts to seek OT care for their children. Two main subthemes were identified and this theme: Social stigma and denial by the parents.

Social Stigma

Parents reported that having a child with cerebral palsy will expose them to ridicule from society. Some were therefore not willing to bring their children out of the house. This means they could also not take them for OT services. Under stigma, denial came out clearly as a major reason for the delay.

“I was in fear of exposing my child to the world that would judge me harshly as I come from a very strict community ‘the Maasai community,’.” [ULF 47]

Denial by Parents

Some parents reported that they did not readily accept that their children had a neurodevelopmental disorder. As a result of this denial, they did not see the need to seek early OT care.

“I was personally in denial that my child had a problem, and this delayed OT services.” [ULF 56]

“Denial that my child needed help”. [ULF 78]

Occupational Therapy Services

Caregivers reported that lack of OT facilities was a major reason why they delayed in seeking OT care for their children. The subthemes identified under occupational therapy services were lack of OT services and parents' lack of knowledge on occupational therapy.

Lack of Occupational Therapy Services

Parents reported that OT services were not accessible in their locality and that they had to look for services elsewhere. In cases where parents were unable to travel far for OT care, their children were delayed in accessing OT services.

“Where I come from in Longonot, there is no service as occupational therapy is being offered in hospitals”. [ULF 50]

“Therapy services were not accessible”. [ULF 31]

“Lack of availability of services in my locality since I live in an interior base far from the town centre” [ULF 78]

Parents' Lack of Knowledge of Occupational Therapy Services

Most parents reported that they had no information on occupational therapy. They, therefore, stayed home with their children hoping that they would grow normally.

“I did not know of any service that helps children with developmental delays”. [ULF 54]

“I had no idea that there was help for children who had development delay”. [ULF 53]

Late Diagnosis

Parents reported that they did not seek early therapy because the diagnosis was made late. Under late diagnosis, two subthemes were identified; parents unable to detect delayed milestones and health workers not diagnosing cerebral palsy early.

Parents Unable to Detect Delayed Milestones

Some parents said that they were unable to detect that their children were not growing normally. As a result, they did not take their children to the hospital early enough so that the problem could be identified.

“I had no knowledge of developmental milestones”. [ULF 57]

Health Workers not Diagnosing Cerebral Palsy Early

Parents also attributed their late seeking of occupational therapy services to delay in diagnosis by the health workers. A parent reported that no one told her that her child had cerebral palsy, and another said it took long to know the diagnosis.

“It took long to know the diagnosis”. [ULF 38]

“The medical professionals did not mention cerebral palsy but instead advised on proper breastfeeding”. [ULF 52]

“The nurse/medical person attending to me during the first and second clinic did not mention that my child had a problem instead they asked me to wait he would develop normally”. [ULF 53] Table 4

Ill Health among the Children

Some parents reported that their children were often sick and that delayed them from seeking OT services. They would mostly attend to the sickness and not seek OT services. Two subthemes were identified under ill health: frequent admissions and frequent illness.

Frequent Admissions

A parent reported that due to frequent admissions, she could not get time to take her child to the occupational therapy clinic.

“He was often ill limiting access to occupational therapy due to frequent admissions”. [ULF 51]

Frequent Illness

Some parents attributed delays in seeking OT services to frequent illness. One parent said that the child had frequent stridor and she was therefore unable to take the child for OT services.

“My child had chronic stridor, and this prevented me from seeking OT services”. [ULF 37]

4.11 Facilitators to Early Initiation of Occupational Therapy –Caregivers’ Perspective

Caregivers were also asked what could be done to facilitate early initiation of occupational therapy services. Table 12 below shows the recommendations of the caregivers on solutions towards reducing delays in seeking OT services.

Table 12: Facilitators to Early Initiation of Occupational Therapy – Caregivers’ Perspective

Themes	Subthemes
Government support	-Introduce OT services in lower-level health facilities -Employ more therapists -Reduce the cost of OT
Education	-Community Sensitization on cerebral palsy -Clinicians educate parents after diagnosis
Diagnosis and referral	-Early diagnosis -Prompt referral
Medical advice	-Follow the doctor's advice -Adhere to schedules

Government Support

Most caregivers reported that government support was very critical in reducing delays for parents who are seeking OT services. The subthemes identified under government support were; the introduction of OT services in lower-level health facilities, lowering the cost of OT services and employment of more occupational therapists.

Introduction of OT Services in Lower-Level Health Facilities

Some respondents said that the services should be made locally available. This will increase accessibility according to them.

“The services should be made locally available and affordable”. [ULF 47]

“Government to establish OT facilities in all parts of the country”. [ULF 64]

Employ More Therapists

A parent also said that the queues were long because of fewer OT professionals. They, therefore, proposed that the government employs more OT staff to save time when patients are taken to the clinic.

“The government needs to employ more occupational therapy staff to reduce the waiting time when children are taken to the clinic. Waiting discourages return”. [ULF 49]

Reduce the Cost of OT

The cost of OT services was one of the major causes identified in delaying seeking OT services. Some of the parents, therefore, said that to reduce delays in seeking OT services, the government needed to make services affordable.

“Government support; the services should be made affordable for all”. [ULF 34]

“Government support in special children care would greatly help parents as they are quite dependent”. [ULF 68]

“Government support in taking care of children with CP would greatly help parents as they are dependent limiting parents to live effectively”. [ULF 58]

Education of Parents and the Community

Parents reported that educating parents and the community will greatly help parents to seek early OT services for their children. They said that knowing the future implications of not seeking OT services would motivate them to take their children for occupational therapy.

Two subthemes were identified under this theme: sensitization of the community on cerebral palsy and clinicians educating parents on cerebral palsy.

Community Sensitization on Cerebral Palsy

Some parents reported that if the whole community was informed about cerebral palsy and occupational therapy, it would be easier for affected families to get help from other community members. It would also reduce the stigmatization of children with cerebral palsy, and this will prevent parents from hiding their children when they are diagnosed with CP.

“The community at large needs to have insight on disabilities, especially cerebral palsy”.

[ULF 77]

Clinicians Educate Parents after Diagnosis

Education of parents about neurodevelopmental disorders e.g., cerebral palsy and its long-term implications was key as reported by some parents. Parents said that knowing the presentation of these disorders will help them know when to seek help.

“Medical practitioners to educate parents about all conditions which could affect the child’s developmental milestones during and even before pregnancy to help parents to seek medical aid early when such a problem arises”. [ULF 65] Table 5.

Diagnosis and Referral

Diagnosis and referral were identified by some parents as one way of preventing delay in seeking occupational therapy services. Early diagnosis and prompt referral for OT services were identified as key to early OT services.

Early Diagnosis

Some parents reported that had their children have been diagnosed early enough, they wouldn't have delayed in seeking occupational therapy services.

“Medical practitioners should be equipped to diagnose CP before a child's age advances”.

[ULF 77]

Prompt Referral

Referral was also cited by some parents as a reason for the delay in seeking OT services. A parent said that medical practitioners did not refer her child immediately after diagnosis.

“Medical practitioners should refer immediately after diagnosis”. [ULF 57]

“Healthcare workers should inform the parent of the need for therapy immediately after diagnosis”. [ULF 25]

4.12 Causes of Delay in Initiation of Occupational Therapy among Children with Cerebral Palsy Receiving Care at Ubuntu Life Foundation – Health Care Workers’ Perspective

The causes of delay to initiation of occupational therapy services according to health workers are presented in table 13 below in terms of themes and subthemes.

Table 13: Healthcare Workers' Perspective on Causes for Delay in Initiation of Occupational Therapy Services

Theme	Subthemes
Attitude towards cerebral palsy	-Denial by parents and family -Social stigma
Information about cerebral palsy	-Lack of education by clinicians -Lack of community education for CP
Socio-economic support	-Social support -Economic support
Occupational therapy services	-Not enough OT facilities -Lack of knowledge of need for OT
Diagnosis	-Clinicians not diagnosing the condition early -Parents not aware of the cause of developmental delays

Attitude towards Cerebral Palsy

On health care workers' perspective on causes for delay in initiation of OT services, most of the healthcare workers said the delays were a result of attitudes towards cerebral palsy. The attitude was either on the parents or the community's side. Two subthemes were identified under this theme: Denial by parents and family and social stigma (table 13).

Denial by Parents and Family

Some healthcare workers reported that parents do not readily accept their children after diagnosis with cerebral palsy. This denial delays their willingness to take their children for OT services even after being referred.

“Some families fail to accept the child with CP and therefore keep them in the house” [HCW 4].

“Denial (parents fail to accept that their children have developmental concerns)” [HCW 5].

Social stigma

Social stigma was identified by some healthcare workers as an impediment to seeking early OT services. The way the community looks at disability leads parents of children with cerebral palsy into hiding their children in the house.

“Cultural myths and misconceptions have played a huge role in the delay of starting OT. Parents hide their children because of the way the society looks at them”. [HCW 5]

Information about Cerebral Palsy

Lack of information on CP and its interventions e.g., occupational therapy was also listed among the challenges to early initiation of OT by the health workers. Parents and the community in general did not know about CP. Parents did not know about occupational therapy and even those who know about it do not know that it is an important intervention. The subthemes identified under this theme were lack of education by clinicians and lack of community sensitization.

Lack of Education by Clinicians

Some healthcare workers reported that clinicians failed to educate parents on cerebral palsy. Therefore, parents did not know what step to take next to help their children and some thought that the children would develop normally.

“Lack of information on the condition, poor information dissemination from practitioners and therefore parents did not know what to do” [HWC 6].

“Health care workers failing to inform parents of kids with CP about the importance of OT”. [HCW 9]

Lack of Community Sensitization

Healthcare workers reported that the community was not informed and therefore there was no sharing of information. Had the community been sensitized, most people would be having information on CP and hence would not delay seeking OT services.

“The community is not informed and that makes it difficult to share information on cerebral palsy and its treatment”. [HCW 3]

Socio-economic Support

Socio-economic support also came out as a major theme in challenges towards early initiation of OT in children with CP. They said that most families who have children with CP have challenges with economic and social support.

Social Support

Some healthcare workers reported that some mothers after giving birth to children with cerebral palsy are deserted by their husbands. This impedes seeking OT services as there is no support.

“Women are abandoned by their husbands after giving birth to children with CP. Since most of them tend to be poor, going for OT services becomes impossible”. [HCW 1]

Economic Support

The costs of providing occupational therapy services are high and therefore these families cannot afford them. The occupational therapy facilities are found far away and this makes it difficult to access services due to transport costs.

“Financial constraints - cannot afford transport and cost of OT” [HCW 2].

“Lack of money for therapy services every week” [HCW 1].

“Lack of resources to pay for the OT services” [HCW 9].

Late Diagnosis

Late diagnosis was also reported by most of the health workers. This is one of the reasons attributed to the delay in the initiation of OT services even by the parents. The subthemes identified under this theme were; Clinicians not being able to diagnose cerebral palsy early and Parents not being aware of the cause of developmental delays (table 7)

Clinicians not being able to Diagnose Cerebral Palsy Early

Some healthcare workers reported that diagnoses were not being made early enough to enable parents to seek early OT services.

“Some of the children get diagnosed late by clinicians hence OT is not initiated early” [HCW 11].

Parents not Aware of the cause of Developmental Delays

Some healthcare workers said that parents do not know the cause of developmental delays in their children. This is because no one informs them of the causes and therefore fails to seek early OT services.

“Lack of information (parents are not aware of their children’s problems as no one explains the cause of the delayed development)”

4.13 Facilitators to Early Initiation of Occupational Therapy – Health Care Workers’ Perspective

A set of themes were identified as factors contributing to the effective initiation of OT services and they are presented in Table 14 below.

Table 14: Facilitators to Early Initiation of Occupational Therapy - Health Care Workers’ Perspective

Theme	Subtheme
Education on cerebral palsy	-Education of parents by clinicians on CP and OT -Sensitize the community on CP
Occupational therapy services	-Create more OT centres -Educate parents on OT
Reduction of negative attitude towards CP	-Counsel parents of children with CP -Reduce social stigma through sensitization
Affordability of services	-Government support -Use of National Hospital Insurance Fund

Education on Cerebral Palsy

Lack of knowledge of CP and OT by parents and the community was reported as one of the causes of late initiation of OT services. For early initiation of OT services, two subthemes were identified: education of parents by clinicians and community sensitization on CP.

Educate Parents on Cerebral Palsy by Clinicians

On factors that contribute to the effective initiation of early occupational therapy services, most health workers said there was a need to educate parents on cerebral palsy and the recommended interventions. This they said will foster understanding and motivate parents to seek early OT services.

“Education of young mothers on signs and symptoms of CP and its interventions” [HCW 10].

Sensitize the Community on CP

Some healthcare workers reported that there was a need for community sensitization to improve the understanding of CP.

“Outreach campaigns to educate the public on CP and OT to improve their understanding” [HCW 9].

Occupational Therapy Services

An increase of occupational therapy centers was also reported by most health workers as a good facilitator towards early initiation of OT. They said this will allow more people to access OT services.

Create more OT Facilities

Introducing OT facilities in lower-level government facilities would increase accessibility, and lower costs and therefore most people will access the services early enough (table 7).

“Setting up more OT clinics in every health facility” [HCW 1].

“Avail OT services in every regional hospital” [HCW 5].

Educate Parents on Occupational Therapy

Healthcare workers reported that there was a need to educate parents on occupational therapy after diagnosis. This way the parents will know the importance of occupational therapy and therefore will seek early services.

“Education forums to educate young and old on the importance of early intervention”. [HCW 5]

Reduction of Negative Attitudes towards CP

Some healthcare workers reported that reducing negative attitudes was necessary for parents whose children have been diagnosed with CP. According to the healthcare workers, this will enable the parents to accept the child's condition and seek OT services early. The subthemes identified here were; Counsel parents of children with CP and reducing social stigma through sensitization.

Counsel Parents of Children with CP

For parents to accept their children's condition, psychological counselling was necessary. Acceptance according to health care workers will increase the parents' motivation to seek OT services.

“Counselling/psychological support to overcome the challenge of denial to enable parents to seek help in OT”. [HCW 7]

Reduce Social Stigma through Sensitization

According to the health care workers, parents keep their children indoors due to the social stigma attached to disabilities. Reducing social stigma was therefore key to seeking OT services.

“Community awareness to reduce negative attitude from people so that parents can bring their children out” [HCW 6]

Affordability of Services

Some healthcare workers reported that making the services affordable by reducing the cost of OT services will encourage the parents of children with cerebral palsy to seek OT services early. Reduction of costs would be made possible under two subthemes; government support and use of National Health Insurance Fund to cater for OT services.

Government Support

Some healthcare workers said that the government can reduce the cost of OT services by creating more OT facilities and helping parents of children with cerebral palsy.

“Government intervention in equipping or hiring more OT practitioners”. [HCW 9]

Use of National Health Insurance Fund to Cater for OT Services.

A health worker reported that charges for OT services should be paid by NHIF. This she said will greatly reduce the cost as parents will only pay the monthly fee for NHIF.

“Therapy charges should be affordable to all by using NHIF”. [HCW 7]

CHAPTER FIVE: DISCUSSION

This study looked at the proportion and causes of delayed initiation of occupational therapy among children with cerebral palsy and the adequacy of the occupational therapy services received by children. Delay in initiation of OT was defined as the initiation of OT beyond six months after diagnosis of cerebral palsy in a child. Adequacy of OT sessions was defined as attending 4 or more sessions in a week with each session lasting 50 or more minutes.

The Proportion of Children with Cerebral Palsy with Delay in Initiation of Occupational Therapy

The proportion of delay in the initiation of occupational therapy services in this study was 41% (95% 31%, 52%). A study by Grilli et al. on “*Waiting Times for Paediatric Rehabilitation*” found that more than 50% of the patients waited for more than 11 months to attend occupational therapy services (26).

Waiting times to access rehabilitative services remains a major problem in settings where rehabilitation is necessary to reduce impairments among children with disabilities. Evidence has demonstrated that rehabilitative services should best be initiated in childhood as the neuroplasticity of the developing brain provides optimal periods in which the interventions are most effective for maximum functioning (25).

Causes of Delay in Initiation of Occupational Therapy

The causes of delay in the initiation of occupational therapy were presented in terms of themes and subthemes. The causes of delays in seeking occupational therapy services identified in this study through in-depth interviews include; parents denying that their children have cerebral palsy and need early developmental interventions, social stigma which forced parents to keep their children indoors, clinicians not educating parents of children with cerebral palsy, the community was also not informed, lack of social and economic support, few occupational therapy facilities and sometimes situated far away, lack of knowledge on the need for OT services on the parents' side. Late diagnosis by clinicians and the parents not being aware of the causes of delays in milestones was also reported as a cause for delays.

Parental knowledge of cerebral palsy among parents of children with cerebral palsy is key to initiating early occupational therapy services. The role of the clinicians is to educate parents immediately after diagnosis on the need for OT services and sensitize the community on the

same. A sensitized community will share knowledge and assist each other in solving health issues in the community. This study revealed that parents lacked knowledge of CP and that health workers did not inform them that OT was necessary. Previous studies have shown that parents who lacked knowledge of cerebral palsy and physiotherapy delayed in seeking physiotherapy services for their children (27).

Our study revealed that lack of socio-economic support was one of the reasons parents delayed seeking OT services for their children. Parents reported that there was no social support from partners and family to encourage them to take their children for occupational therapy services. Some of the mothers who took part in this study said that they had been shunned by their families after giving birth to a child with a developmental issue. On economic support, parents reported that the OT services were expensive and located far away. Parents even lacked transport money to access the facilities. Some of the parents did not have jobs and their families did not support them economically to access these services.

The study conducted by Kanyembo et al. on barriers to early physiotherapy services among children with CP reported similar findings to ours. Kanyembo et al. reported that in their study, family and community did not encourage mothers to take their children for rehabilitation but rather spent a lot of time blaming the mothers for giving birth to children with CP and this agrees with our findings. On financial support, Kanyembo et al. reported that most caregivers lacked transport money to take their children to the hospital for physiotherapy. Similar to our findings, some mothers of children with CP did not have jobs and hence could not depend on themselves entirely according to the cited study (24)(28).

Our study revealed that social stigma from the community hampered parents from taking their children for OT services as reported by parents and healthcare workers. Some parents also reported that they did not accept that their children had cerebral palsy and did not see the need for occupational therapy. Previous studies have reported shows that caregivers sometimes prefer home or alternative treatment for children with cerebral palsy. The effect of this is that they will never know the right rehabilitative services that the children need. The reasons attributed for choosing home or alternative treatment were; social stigma, caregiver burden and cost of treatment (29).

Our study found that lack of access to OT services either from inadequate facilities or lack of knowledge of the need and availability of OT was also a major factor as reported by the

parents. Access to occupational therapy services remains a challenge in low-resource settings such as ours. In low-resource settings, there are fewer facilities and the few that are there are also unreachable, and therefore cannot cater for the unmet needs. In addition, parents of children with CP are mostly unaware of the existence of OT services, their availability and how useful they are (30).

Our study revealed that despite children being reviewed by health workers when they were still young, none mentioned that they were likely to have cerebral palsy and the required interventions. Parents reported that they had raised concerns about their children's developmental milestones, but the healthcare workers told them that the children will grow normally. From these findings, late diagnosis was the main cause of delay in seeking OT services. Late or wrong diagnosis raises mistrust and despair among the mothers of children with CP. Even when mothers raised concerns, the clinicians sent them away with the hope of normal development. Similar reasons for the delay in seeking OT services have been noted in previous studies (24).

Adequacy of Occupational Therapy Sessions among Children with Cerebral Palsy

Occupational therapy is premised on a child's needs and is indicated any time after diagnosis with Cerebral Palsy. A transfer to an occupational therapist is made when a child proves that being helped with everyday duties is required. The approach to management is individualized. A complete evaluation of a child's motor skills, mental abilities, developmental state, and environmental, physical and psychological requirements will govern therapy targets (31).

This study found that more children in GMFCS levels IV and V received adequate OT services compared to those in levels I-III. A similar study on the adequacy of occupational therapy by Palisano et al. found that children in GMFCS score IV-V had more mean minutes of occupational therapy compared to those in GMFCS I-III (17).

Another study by McCoy et al. found that therapy services increased with functional deficiency. In this study, children in GMFCS I received two to thirty sessions of therapy and those in GMFCS V received between thirty-one to fifty-two sessions per year. This is in support of our study where more children in GMFCS IV-V received more adequate therapy sessions than those in GMFCS I-III (32).

Contrary to the findings of our study, a qualitative study conducted in Iran among occupation therapists found that when a child's clinical condition is more severe, parents are often less motivated to adhere to the prescribed treatment. This is probably due to the slimmer chances of improvement. The investigators established that motivational discussions and manageable goal-setting with the occupational therapist improve adherence in these scenarios (33). The disparity between these two studies could be as a result of cultural differences as the two studies were conducted in two distinct settings.

5.1 Study Strengths and Limitations

This is the first study in Kenya to give insight into the proportion and causes of delayed initiation of OT in a rural community. The use of a qualitative approach from both healthcare workers and parents/caregivers of children with CP gave added insights into the causes of delayed initiation of OT.

Data was collected retrospectively and hence the previous data may not have been for purposes of research but routine use and may not be complete. This is a single-center study and cannot be generalized to other centers. Our sample size for the cross-sectional study was small; however, we achieved thematic saturation.

5.2 Conclusions

1. The delay between diagnosis of cerebral palsy and initiation of occupational therapy was commonly observed in two-fifths of this population.
2. Common causes of delay in initiation of OT in this setting included socioeconomic support, cerebral palsy awareness, lack of occupational therapy facilities, ill health, and late diagnosis.
3. Half of the children with cerebral palsy did not receive adequate frequency of OT sessions, and for 60% of children, the sessions were of inadequate length.

5.3 Recommendations

1. There is a need to increase awareness through sensitization on CP and early initiation of OT among parents and caregivers.
2. Overcoming barriers such as decentralizing OT services away from referral hospitals to the children in the community, early diagnosis, and referral, financial constraints, and employing more occupational therapists to enable the children to get adequate OT.
3. There is need for ULF to advocate for more funding from responsible donors and well-wishers to provide financial allocation to the rehabilitation sector.

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APPENDICES

Appendix I: Study Timeline

The following is the proposed time frame of the study process from January 2022 to December 2022 using a Gantt chart.

Activity	2022				2023				
	Mar- April	May- June	July- Sept	Sept- Dec	Jan- Mar	Mar- April	May-Aug		
Proposal development									
ERC approval									
Initial data collection									
Study modification									
Data collection									
Data analysis									
Results presentation									
Dissertation write-up									
Submission of dissertation									

Appendix II: Study Budget

Category	Remarks	Units	Unit Cost (Kshs)	Total (Kshs)
Proposal development	Printing drafts	1000 pages	5	5,000
	Proposal copies	8 copies	500	4,000
Data Collection	Stationary packs	10	100	1,000
	Training Research Assistant	1 day	1,000	1,000
	Research Assistant	8 weeks	18,000	18,000
Data Analysis	Statistician	1		35,000
Thesis Write up	Computer services			5,000
	Printing drafts	1000 pages	5	5,000
	Printing Thesis	10 copies	500	5,000
Contingency Funds				10,000
TOTAL				89,000

Appendix III (a): Consent Form for Parents/Caregivers
Study Title: “Proportion and Causes of Delayed Initiation of Occupational Therapy Among Children with Cerebral Palsy Receiving Care at Ubuntu Life Foundation in Maai Mahiu, Kenya.”

Principal Investigator:

Dr. Mercy Muthoki Mutiso

Tel: 0723531520

Email: mutisomercy@students.uonbi.ac.ke

Supervisors: Prof. E. M. Obimbo and Dr. Beatrice Mutai

(Department of Paediatrics and Child Health, University of Nairobi)

Tel: 0721257746

Introduction

I am a post-graduate student at the University of Nairobi pursuing a Master of Medicine in Paediatrics and Child Health. I am doing a study to find out the causes of delayed initiation of occupational therapy at Ubuntu Life Foundation.

It is critical to begin occupational therapy for children with cerebral palsy as soon as possible to enhance the activities of daily life. It is fundamental to comprehend the potential barriers associated with delayed initiation of occupational therapy because the study's findings will shed light on these facilitators and barriers to early initiation of occupational therapy among children with cerebral palsy and will guide policymaking to improve occupational therapy practice for these children.

You are requested to participate in in-depth interviews as part of the study. This is voluntary. You are allowed to take some time and think about this, and even consult friends and family if you so wish. In case you don't understand or need clarifications with regards to this consent frame please feel free to seek help from the principal investigator or any of the research assistants.

Scope of the Study

The in-depth interviews aim to allow you to share your views and experiences on the causes of delayed initiation of occupation therapy, what made it easier or harder for you, and how best we can improve the process. Your input will be highly regarded and will help in enhancing the early initiation of occupational intervention in children with cerebral palsy.

The location of the discussion will be communicated to you. Discussions will take 30-45 minutes and participants will be asked questions about the causes of delayed initiation of occupational therapy. We shall record and take notes of your responses during discussions to allow for further analysis.

Ethical considerations

i) Ethical clearance from KNH-University of Nairobi Ethical Review Committee will be sought before commencing the study. Permission from Ubuntu Life Foundation will be sought to allow data collection and authority from KNH Research and programs will also be sought.

ii) Informed consent – The principal investigator will take time to explain the study to you. Participation will be voluntary and declining to participate in the study will have no penalties nor will it have any impact on the health care services you are eligible for at this hospital.

Informed consent will be obtained from you. Participants will be allowed time to read and understand the study and the consent form. Time will be allowed for questions. If you accept to be part of the study, consent will be indicated by either a signature or a fingerprint.

iv) Confidentiality - Hard copies will be maintained by excluding identifiable data from data collection and instead allocating a unique study number for each participant. Hard copies will be kept in a lockable locker with no access to non-study personnel. Data in soft copy will be stored in a password-protected computer to which only the principal investigator will have access.

v) Risks to participants – There will be no dangers to your health since we will not give you any medicine or perform any procedures on you, only questions will be asked. None of your rights will be infringed during this research.

Protocols will be put in place to mitigate risks of getting COVID-19 infection – hand washing stations, hand sanitizing, wearing of masks, social distancing, and minimal time of interaction. Other risks such as psychological stress to parents/caregivers will be addressed by offering counseling services.

vi) Benefits to participants – There will be no personal benefit. The study's findings will be disclosed to you and your healthcare providers and will help facilitate the early initiation of occupational therapy.

vii) Tool guide – Pre-set questions will be used for in-depth interviews for data collection after obtaining informed consent from the participant.

Consent to Participate in the Study

I have reviewed or had the content on this consent form read to me. I got the opportunity to speak with the principal investigator about this study. He or she has addressed my queries in a language that I understand. I've been informed of the risks and advantages. I acknowledge that I will be provided a copy of this consent form after signing it. I understand that my involvement in the study is voluntary and that I could withdraw at any moment. I understand that every effort will be made to keep the information concerning me confidential. I realize that by signing this, I have not surrendered any of my constitutional rights as a participant in this research project.

I freely consent to take part in this research study: Yes: No:

Name of participant: Date:

Thumb stamp/Signature:

Statement of Researcher

I, the undersigned, have thoroughly described the relevant material of this research to the above-mentioned subject and feel that the participant has comprehended and knowingly provided his/her permission.

Name of researcher..... Date.....

Signature of researcher.....

If you have any concerns about your rights as a research participant, please feel free to contact any of the following:

Principal Investigator:

Dr. Mercy Muthoki Mutiso

Phone number: 0723531520

Email: mutisomercy@students.uonbi.ac.ke

The Chairperson:

KNH-UON ERC Committee

Tel: 2726300/2716450 Ext: 44102

Email: uonknh-erc@uonbi.ac.ke

Appendix III (b): Consent Form for Parents/Caregivers (Swahili version)

Fomu ya idhini kwa wazazi wa washiriki.

Kifunguo

Mimi ni Dkt. Mercy Muthoki Mutiso, mwanafunzi ninayesomea Shahada ya Afya na Magojwa ya Watoto katika Chuo Kikuu cha Nairobi. Nafanya utafiti kuhusu mambo ambayo yanayohusiana na kuchelewa kwa kuanza tiba ya occupational therapy kwa watoto ambao wakona cerebral palsy wanaohudumiwa katika Ubuntu Life Foundation.

Kuanzia tiba ya occupational therapy ni muhimu kusaidia watoto ambao wakona cerebral palsy kuweza kufanya shughuli za kila siku kwa urahisi. Ni muhimu kuelewa vizuizi ambavyo vinasababisha kuchelewa kwa kuanza occupational therapy kwa watoto ambao wakona cerebral palsy ili tuweze kuwasaidia.

Hii fomu ya kupata idhini kushiriki katika utafiti. Taarifa nitakayokupa ni ya kukukaribisha kwa utafiti huu. Tafadhali kuwa na huru wa kuuliza maswali kwa maneno ambayo huelewi, nitachukua muda kukueleza mpaka uelewe.

Sababu ya Utafiti

Kushiriki kwa hii utafiti itakuwezesha kutuarifu mambo yanayohusiana na kuchelewa kwa kuanza tiba ya occupational therapy kwa watoto ambao wakona cerebral palsy na jinsi tunavyoweza kurahisisha huo mchakato.

Maandalizi ya Utafiti

Ukumbi wa majadiliano utatangazwa. Majadiliano yatachukua dakika 30-45. Maswali kuhusu mambo yanayohusiana na kuchelewa kwa kuanza tiba ya occupational therapy kwa watoto ambao wakona cerebral palsy yataulizwa. Tutarekodi majadiliano haya ilikutuwezesha kufanya utafiti zaidi. Ni chaguo lako kushiriki au la. Utapokea huduma zote za kawaida katika Ubuntu Life foundation ata usipochagua kushiriki kwa hii utafiti.

Masuala ya Kimaadili

i) Ruhusa ya utafiti itachukuliwa kutoka chuo kikuu cha Nairobi na kutoka Ubuntu Life Foundation kabla ya kuanza utafiti.

ii) Ni hiari yako kushiriki kwa hii utafiti. Hakutakuwa na adhabu yoyote ukipungua kushiriki katika utafiti. Utachukua ridhaa kwa kuweka Sahihi ama alama za vidole.

iii) Usiri - Habari yote kukuhusu tutakayokusanya itakuwa ya siri.

v) Utafiti huu hautamdhuru mtoto wako kwa njia yeyote.

vi)Majibu ya utafiti huu utaelezwa kwako na madaktari wanaoona watoto.

Nimesoma/nimesomewa habari hii na nimeruhusiwa kuuliza maswali yoyote kuhusu huu utafiti. Nimeidhini kwa hiari kushiriki kwa huu utafiti.

Jina la mshiriki: Tarehe:

Sahihi la mshiriki:

Nimesomea mwakilishi fomu hii, nilihakikisha kwamba mimi kama mshiriki nimeelewa kwa kadri ya uwezo wangu. Nilithibitisha kwamba mimi kama mshiriki alipewa nafasi ya kuuliza maswali na kuyajibu vyema kwa kadri ya uwezo wangu. Ninathibitisha kuwa mshiriki hakulazimishwa kutoa kibali.

Mtu wa kuchukua kibali/Jina la mtafiti: Tarehe:

Mtu wa kuchukua kibali/ Sahihi ya mtafiti:

Mtafiti Mkuu:

Dkt. Mercy Muthoki Mutiso

Nambari ya simu: 0723531520

Barua pepe: mutisomercy@students.uonbi.ac.ke

Kamati ya maadili ya hospitali kuu ya Kenyatta:

Nambari ya simu: 2726300/2716450 Ext: 44102

Barua pepe: uonknh-erc@uonbi.ac.ke

Appendix IV: Consent Form for Health Care Workers

Study Title: “Proportion and Causes of Delayed Initiation of Occupational Therapy Among Children with Cerebral Palsy Receiving Care at Ubuntu Life Foundation in Maai Mahiu, Kenya.”

Principal Investigator:

Dr. Mercy Muthoki Mutiso

Tel: 0723531520

Email: mutisomercy@students.uonbi.ac.ke

Supervisors: Prof. E. M. Obimbo and Dr. Beatrice Mutai

(Department of Paediatrics and Child Health, University of Nairobi)

[Tel:072125774](tel:072125774)

Introduction

I am a post-graduate student at the University of Nairobi pursuing a Master of Medicine in Paediatrics and Child Health. I am doing a study to find out the causes of delayed initiation of occupational therapy at Ubuntu Life Foundation.

It is critical to begin occupational therapy as soon as possible to enhance the activities of daily life for children with cerebral palsy. It is fundamental to comprehend the potential barriers associated with delayed initiation of occupational therapy because the study's findings will shed light on these facilitators and barriers to early initiation of occupational therapy among children with cerebral palsy and will guide policymaking to improve occupational therapy practice for these children.

You are requested to participate in in-depth interviews as part of the study. This is voluntary. You are allowed to take some time and think about this, and even consult friends and family if you so wish. In case you don't understand or need clarification with regards to this consent frame please feel free to seek help from the principal investigator or any of the research assistants.

Scope of the Study

The in-depth interviews aim to allow you to share your views and experiences on the causes of delayed initiation of occupation therapy, what made it easier or harder for the children with cerebral palsy and their parents/guardians, and how best we can improve the process. Your input will be highly regarded and will help in enhancing the early initiation of occupational therapy in children with cerebral palsy.

The location of the discussion will be communicated to you. Discussions will take 30-45 minutes and participants will be asked questions about the causes of delayed initiation of occupational therapy. We shall record and take notes of your responses during discussions to allow for further analysis.

Ethical considerations

i) Ethical clearance from the KNH-University of Nairobi Ethical Review Committee will be sought before commencing the study. Permission from Ubuntu Life Foundation will be sought to allow data collection and authority from KNH Research and programs will also be sought.

ii) Informed consent – The principal investigator will take time to explain the study to you. Participation will be voluntary and declining to participate in the study will have no penalties nor will it have any impact on the health care services you are eligible for at this hospital.

Informed consent will be obtained from you. Participants will be allowed time to read and understand the study and the consent form. Time will be allowed for questions. If you accept to be part of the study, consent will be indicated by either a signature or a fingerprint.

iv) Confidentiality - Hard copies will be maintained by excluding identifiable data from data collection and instead allocating a unique study number for each participant. Hard copies will be kept in a lockable locker with no access to non-study personnel. Data in soft copy will be stored in a password-protected computer to which only the principal investigator will have access.

v) Risks to participants – There will be no dangers to your health since we will not give you any medicine or perform any procedures on you, only questions will be asked. None of your rights will be infringed during this research.

Protocols will be put in place to mitigate risks of getting COVID-19 infection – hand washing stations, hand sanitizing, wearing of masks, social distancing, and minimal time of interaction. Other risks such as psychological stress to parents/caregivers will be addressed by offering counseling services.

v) Benefits to participants – There will be no personal benefit. The study's findings will be disclosed to you and your healthcare providers and will help facilitate the early initiation of occupational therapy.

vi) Tool guide – Pre-set questions will be used for in-depth interviews for data collection after obtaining informed consent from the participant.

Consent to Participate in the Study

I have reviewed or had the content on this consent form read to me. I got the opportunity to speak with the principal investigator about this study. He or she has addressed my queries in a language that I understand. I've been informed of the risks and advantages. I acknowledge that I will be provided a copy of this consent form after signing it. I understand that my involvement in the study is voluntary and that I could withdraw at any moment. I understand that every effort will be made to keep the information concerning me confidential. I realize that by signing this, I have not surrendered any of my constitutional rights as a participant in this research project.

I freely consent to take part in this research study: Yes: No:

Name of participant: Date:

Thumb stamp/Signature:

Statement of Researcher

I, the undersigned, have thoroughly described the relevant material of this research to the above-mentioned subject and feel that the participant has comprehended and knowingly provided his/her permission.

Name of researcher..... Date.....

Signature of researcher.....

If you have any concerns about your rights as a research participant, please feel free to contact any of the following:

Principal Investigator:

Dr. Mercy Muthoki Mutiso

Phone number: 0723531520

Email: mutisomercy@students.uonbi.ac.ke

The Chairperson:

KNH-UON ERC Committee

Tel: 2726300/2716450 Ext: 44102

Email: uonknh-erc@uonbi.ac.ke

Appendix V: Medical Records Abstraction Form

Study Title: “Proportion and Causes of Delayed Initiation of Occupational Therapy Among Children with Cerebral Palsy Receiving Care at Ubuntu Life Foundation in Maai Mahiu, Kenya.”

Study ID No: **Date** /...../.....

1. D.O.B: **Age (years)**.....

2. Gender: Male..... Female.....

3. Physical Location:

County.....

Sub County.....

Village.....

4. Date when a diagnosis of CP was made or date of referral for OT

5. Date at first enrolment to Ubuntu Life Foundation

6. Duration of OT

7. Severity of CP according to GMFCS

8. Topographical classification

9. Pattern of visits for OT and duration of OT per visit:

a) Adhered to the scheduled appointments? Yes..... No.....

b) Weekly..... (specify).....

c) Monthly..... (specify).....

d) Years..... (specify).....

5. Status follow-up:

In active care.....

Transferred.....

Lost to follow up.....

Appendix VI: In-Depth Interview Guide for Health Care Workers

Study Title: “Proportion and Causes of Delayed Initiation of Occupational Therapy Among Children with Cerebral Palsy Receiving Care at Ubuntu Life Foundation in Maai Mahiu, Kenya.”

Study Number: _____ Study Site: _____ Moderator: _____
Interviewee category: _____ Notes taker: _____ Date: _____
Start time: _____
End time: _____

Guide questions for in-depth interviews with healthcare workers caring for children with cerebral palsy

Introduction: I will introduce myself and the aim of the study before beginning the interview. Thank the participant for agreeing to be interviewed and assure them of confidentiality.

1. What is your current job title?
2. How long have you been caring for children with cerebral palsy at Ubuntu Life Foundation?
3. What are some of the unique challenges for these families with children with cerebral palsy that you believe cause delays in the initiation of occupational therapy?
4. What factors contribute to the effective initiation of early occupational therapy?
5. What are some of the factors that will contribute to the improvement of occupational therapy services?

Closing session: Request any final remarks or more information. Thank them for taking part in the study.

Appendix VII (a): In-Depth Interview Guide for Parents/Guardians

Study Title: “Proportion and Causes of Delayed Initiation of Occupational Therapy Among Children with Cerebral Palsy Receiving Care at Ubuntu Life Foundation in Maai Mahiu, Kenya.”

Study Number: _____ Interviewee category: _____ Notes taker: _____

Study Site: _____

Moderator: _____

Date _____

Start time: _____

End time: _____

Guide questions for in-depth interviews for parents/guardians of children with cerebral palsy.

Introduction: I will introduce myself and the aim of the study before beginning the interview. Thank the participant for agreeing to be interviewed and assure them of confidentiality.

1. When was your child diagnosed with cerebral palsy or referred for occupational therapy?
2. How many years has your child been attending occupational therapy?
3. What do you think are some unique challenges that led to delay in the initiation of occupational therapy for your child?
4. What can be done to achieve successful initiation of early occupational therapy?

Closing session: Ask for any final comments or additional information. Thank them for participating in the study.

Appendix VII (b): In-Depth Interview Guide for Parents/Guardians (Swahili Version)
Mwongozo wa mahojiano ya kina

Nambari: _____ Kategoria: _____

Tovuti ya utafiti: _____

Msimamizi: _____

Tarehe: _____ Kuanza: _____ Kumaliza: _____

Maswali ya mwongozo

Utangulizi: Nitajitambulisha kabla ya kuanza mahojiano na nieleze washiriki lengo la utafiti. Nitawashukuru washiriki na niwahakikishe kuwa habari yote kuhusu tutakayokusanya itakuwa ya siri.

1. Je ni lini moto wako alithibitishwa kuwa na ugonjwa wa kupooza kwa ubongo ama kuithinishwa kuanza matibabu?
2. Je mtoto wako amekuwa akihudhuria tiba ya kwa miaka mingapi?
3. Je unahisi ni changamoto zipi zakipekee zilichangia kutopeleka mtoto mapema kwenye kituo cha tiba?
4. Je kufaulu kuanzisha tiba mapema inawezekana kwa kufanya nini?

Kufunga kikao: Uliza washiriki kama wakona maoni ama maswali yoyote. Waambie asante alafu ufunge mkutano.

Appendix VIII: Approval Letter



UNIVERSITY OF NAIROBI
FACULTY OF HEALTH SCIENCES
P O BOX 10676 Code 00202
Telegrams: varsity
Tel: (254-020) 2726300 Ext 44355



KENYATTA NATIONAL HOSPITAL
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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

Ref: KNH-ERC/A/290

26th July, 2022

Dr. Mercy Muthoki Mutiso
Reg. No H58/37429/2020
Dept. of Paediatrics and Child Health
Faculty of Health Sciences
University of Nairobi



Dear Dr. Mutiso,

RESEARCH PROPOSAL: PREVALENCE AND FACTORS ASSOCIATED WITH DELAYED INITIATION OF OCCUPATIONAL THERAPY AMONG CHILDREN WITH CEREBRAL PALSY RECEIVING CARE AT UBUNTU LIFE FOUNDATION IN MAAI MAHIU, KENYA (P175/03/2022)

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P175/03/2022**. The approval period is 26th July 2022 – 25th July 2023.

This approval is subject to compliance with the following requirements;

- i. Only approved documents including (informed consents, study instruments, MTA) will be used.
- ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
- iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
- iv. Any changes, anticipated or otherwise that may increase the risks or affected 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.
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. 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.
- vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

Protect to discover

Appendix IX: Certificate of Plagiarism

PROPORTION AND CAUSES OF DELAYED INITIATION OF OCCUPATIONAL
THERAPY AMONG CHILDREN WITH CEREBRAL PALSY RECEIVING CARE AT
UBUNTU LIFE FOUNDATION IN MAAI MAHIU, KENYA
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