FACTORS AFFECTING REGULAR ATTENDANCE TO REHABILITATION CARE AMONG CHILDREN WITH CEREBRAL PALSY AT MUHIMBILI NATIONAL HOSPITAL AND THE COMPREHENSIVE COMMUNITY BASED REHABILITATION CENTRE IN DAR ES SALAAM, TANZANIA

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Department of Paediatrics and Child Health

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By

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A Dissertation Submitted in (Partial) Fulfillment of the Requirements for the Degree of Master of Medicine (Paediatrics and Child Health) of

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CERTIFICATION

The undersigned certify that he has read and hereby recommends for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled: **''Factors affecting regular attendance to rehabilitation care among children with cerebral palsy in Muhimbili National Hospital and the Comprehensive Community Based Rehabilitation Centre(CCBRT) in 2018''**, in (partial) fulfilment of the requirement of degree of Masters of Medicine (Paediatric and Child Health) of Muhimbili University of health and Allied Sciences

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Dr. Edward Kija

(Supervisor)

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Date

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Prof. Karim Manji

(Co-Supervisor)

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Date

DECLARATION AND COPYRIGHT

I, Dr. Emmanuel Kaji Luchagula, declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award

Signature_____ **Date**_____

ACKNOWLEDGEMENT

I am so grateful to Almighty God the creator, life giver and protector

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DEDICATION

To my late father, Luchagula David through whom I acquired wisdom.

To my mother who carried me on her back and nurtured me selflessly.

To my lovely wife Rose Christopher who despite her illness was ever supportive and patient to miss my presence and care.

To my daughter Winfrida and her brothers, David and Denis for their endless prayer, may the Lord bless them as they grow up.

ABSTRACT

Background

Cerebral palsy is a common condition affecting nearly 3% of all live births globally. The mainstay of therapy is physical therapy and rehabilitation. This can reduce disability and improve the quality of life of the child with cerebral palsy. Access to regular rehabilitation services is not documented in Tanzania. This study aims to investigate the enablers and barriers of regular rehabilitation care at tertiary facilities Muhimbili national hospital and the Comprehensive community .based rehabilitation centre Tanzania (CCBRT).

Objectives

To determine factors affecting regular attendance to rehabilitation care among children with cerebral palsy at (MNH) and (CCBRT).

Methodology:

Study design

A cross section facility-based study which employed both quantitative and qualitative methods was conducted at Muhimbili National Hospital (MNH) and The Comprehensive Community Based Rehabilitation Centre Tanzania (CCBRT)

Participants

A total of 152 Children with cerebral palsy and their parents were consecutively enrolled in the rehabilitation clinic from October 2017 to April 2018. Quantitative data was collected using a structured questionnaire from the parents/caregivers. Data was analysed using statistical package for social science (SPSS) version 20. In qualitative study a total of 50 purposively selected participants were included out of which 32 participants were involved in focused group discussion (FGD) and 18 healthcare givers were selected for an In depth interviews. They participants included parents, health care providers (Paediatrician and nurses), hospital administrators, and rehabilitation professionals. An interview guide and digital tape were employed to collect qualitative data which was transcribed, and then

translated, from Swahili to English. Deductive content analysis method was used to analyse qualitative data.

Results

Out of 152 children recruited, 93 (61.2%) were from MNH and 59 (38.8%) were from CCBRT. Majority (69.1%) were aged between 12 to 60 months. Among parents/caretakers 140 (92.1%) were females and 12(7.9%) were males their age ranged between 18 to 57years with the mean age of 30.9years and SD±0.7458. Our study identified factors associated with regular attendance to rehabilitation care were marital status 103(91.2%), coverage by health insurance 58(85.5%), and being exempted from payment 69(85.2%). Other factors such as age, sex, education and employment were not associated with regular attendance. Qualitative findings showed that financial and social support from spouses, family members and at the community levels were facilitators of regular attendance, Barriers identified include stigma, misconception and witchcraft ideology.

Conclusion

Care of disabled children by two parents, financial capacity and psychosocial support from family and community members are associated with higher utilization of rehabilitation services, Barriers includes negative myths and misconceptions about the disease and stigma among community members.

Recommendations

Financial aids such as through insurance coverage, exemption from payments of some services may help the families to care for their infants. Intervention addressing stigma, myths and misconceptions about cerebral palsy are needed to ensure the society is aware of the disability and provide psychosocial supports are recommended.

TABLES OF CONTENTS

LIST OF TABLES

ABBREVIATIONS AND ACRONYMS

AAP	American Academic of Paediatric
CCBRT	Comprehensive Community Based Rehabilitation Tanzania
CP	Cerebral palsy
GMFCS	Gross Motor Function Classification System
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Healthy and Allied Science
MOHGEC	Ministry of Health Gender Elderly and Children
MOD	Ministry of Defence
MUAC	Mid Upper Arm circumference
OT	Occupational therapy
OFC	Occipito Frontal circumference
PT	Physiotherapy
SQCP	Severe Quadriplegic Cerebral Palsy
SPLT	Speech and Language Therapy
TPDFHQ	Tanzania People's Defence Forces Headquarter
UNICEF	United Nations for Children's Fund
WHO	World Health Organization
PVL	Periventricular Leucomalacia
IVH	Intraventricular Haemorrhage

DEFINITION OF TERMS

Attendance to rehabilitation care: is a term for an outpatient attending at a medical clinic, for consultancy care or as a follow-up (return) (1)

Adherence: The extent to which person's behaviour corresponds with agreed recommendations from a healthcare provider(1)

Comprehensive care: Means integrated or coordinated care(1)

Community based rehabilitation: Community participatory/involvement(1)

Cerebral palsy: Is defined as disorders of the development of movement and posture, causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain(2)

Occupational therapy: Is a treatment given to recover /maintain activities of a daily living/skills and improve quality of life (3)

Physiotherapy: Is a physical medicine and rehabilitation specialty that, by using kinesiology and positioning. May also involve occupational therapy.(1)

Quality of life (QOL): Is 'the individual's perception of their position in life in the context of their culture(3) and value systems in which they belong (1)

Rehabilitation: As "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment**.**(1)

1.0 INTRODUCTION

1.1 Background

Cerebral palsy (CP) was first described in 1862, in fact, described as a clinical syndrome of a wide variety of cerebral cortical or sub-cortical insults occurring during the first year of life. (2). The mainstay of therapy is rehabilitation therapy including physical therapy, occupational therapy, and speech and language therapy. The details of various associated features with cerebral palsy are described in subsequent section for understanding in-depth the various manifestations and care needed.

The worldwide incidence of CP is approximately 2 to 3.5 per live births. The incidence is strongly associated with gestational age, occurring in 1 of 20 surviving preterm infants (3). Prematurity is the commonest risk factor for developing CP in the western world (4). However ,in term of numbers most of affected children are full term. This can be explained by the fact that there are many more full-term than preterm infants (5). In Asia, the prevalence of CP reported to be 2-2.8% per 1000 live births (6,7) In Africa the prevalence estimated to be (2·4–3·6) per 1000 children which is unacceptable higher as compared to HICs which are usually (2·0–2·5) per 1000 children (8). While in Tanzania there is limited data on the magnitude of cerebral palsy but it is estimated to be relatively higher because of prevailing perinatal morbidity and mortality across the country (9).

1.2 Statement of the problem

CP is the most common cause of severe physical disability in childhood particularly in the low and middle-income countries including Tanzania, and its management is mainly rehabilitation intervention which is aimed at relieving the effects of impaired body structures and systems (70, 71).It is very true that even in the place where rehabilitation care has been established the number of children who receive such services is limited; transport, costs, distance and lack of expertise are mentioned to be the main obstacles to attend rehabilitation care (72, 74) .

Studies has shown that the defaulter rate among children with cerebral palsy attending rehabilitation in developing countries is at increase (75, 76,77). However, there is limited data in our settings. Therefore, knowledge on barriers to rehabilitation is important in order to plan for intervention.

1.3 Rationale of the study

This study was conducted to assess factors that affect attendance to rehabilitation care. It also provides data for improving quality of health care for rehabilitation services hence improve quality of life and prevent more disabilities among children with cerebral palsy in the region. Strengthening linkage between the healthcare provider and the caretaker/parent of children with cerebral palsy through improved health care services. and also provides data for ongoing studies for newer intervention therapies

1.4 Research Questions

1. What are factors affecting regular attendance to rehabilitation care among children with cerebral palsy attending MNH and CCBRT rehabilitation clinic
2. What are the types of rehabilitation services offered at MNH and CCBRT during rehabilitation clinic visit?
3. What is the role of social/cultural factors affecting attendance to rehabilitation care among children with cerebral palsy?

1.5 Objectives

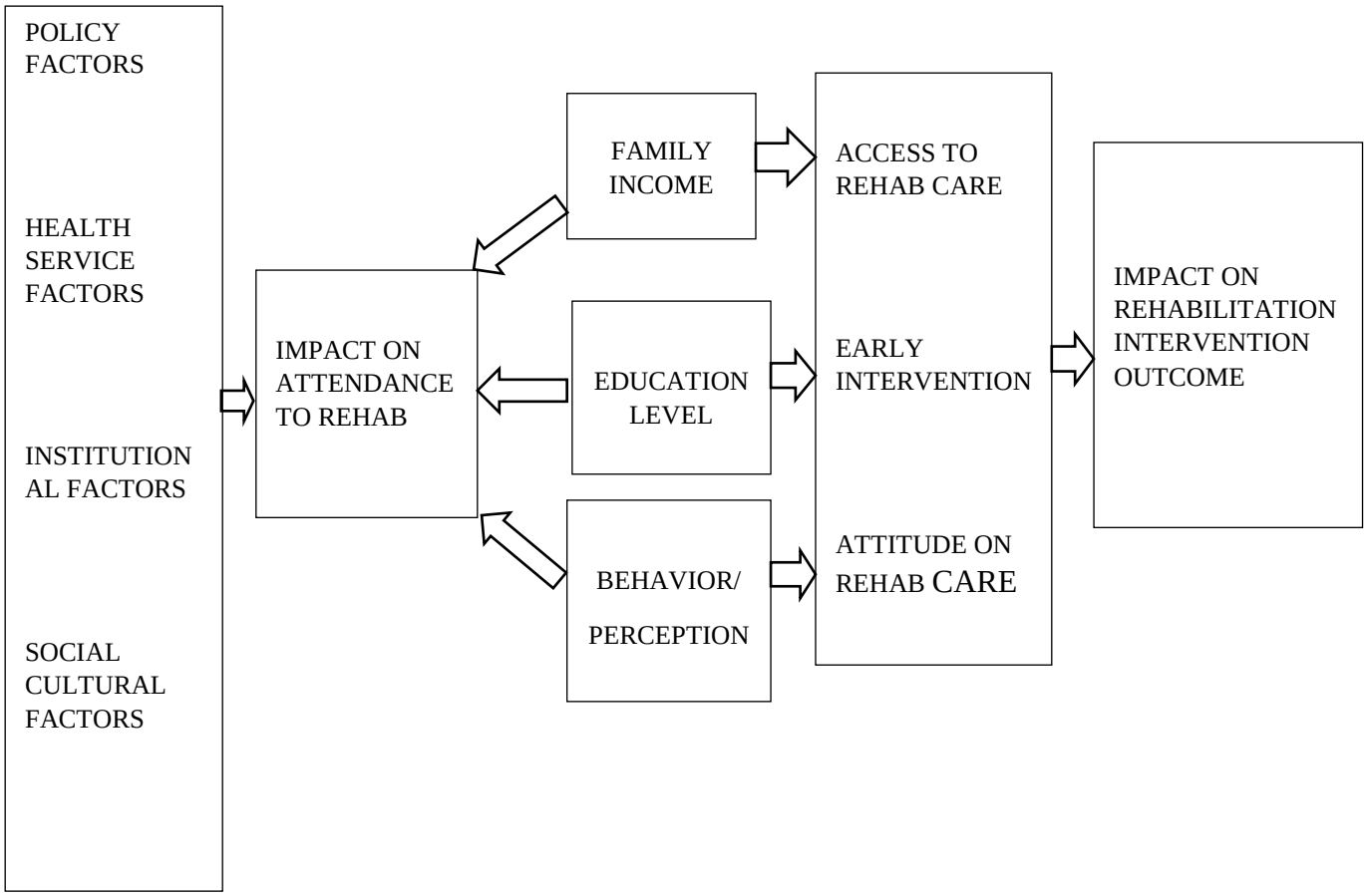
1.5.1 Broad Objective

To determine the factors affecting regular attendance to rehabilitation care among children with cerebral palsy at Muhimbili National Hospital and CCBRT Rehabilitation clinic.

1.5.2 Specific Objectives

1. To determine factors affecting attendance to rehabilitation care among children with cerebral palsy at Muhimbili National Hospital and CCBRT rehabilitation clinic
2. To determine the types and frequency of rehabilitation services offered to children with Cerebral Palsy at Muhimbili National Hospital and CCBRT, during rehabilitation clinic.
3. To explore the role of social/cultural factors on factors affecting attendance to rehabilitation care among parents/guardian of children with cerebral palsy.

1.6 Conceptual Framework



2.0 LITERATURE REVIEW

2.1Clinical manifestations and classification

Children with CP usually present with developmental delay and motor deficits (10). The distinction between a static (non-progressive) and progressive clinical course is very crucial. Loss of previously acquired milestones (regression) marks the onset of most metabolic and neurodegenerative disorders. However, some neurodegenerative disorders or metabolic disorders have a slow rate of progression and can be misdiagnosed as CP (11).

Therefore, clear developmental regression may not be evident especially in the early stages of the disease or at early age of onset. In addition, the neurological symptoms of CP may be delayed for several months because of the immaturity of the nervous system. (10,11).

CP can be classified according to the severity of motor deficits as mild, moderate, or severe. Several other classification systems exist based on the pathophysiology, aetiology and distribution of motor deficits (3).

2.2 Pathophysiologic classification

Insults resulting in neuronal loss can be cortical (pyramidal), resulting in spasticity, basal ganglia (extrapyramidal), resulting in abnormal movements such as choreoathetosis, cerebellar, resulting in hypotonic, or mixed. Spastic CP is the most common type, accounting for up to 75% of cases (12)

A smaller percentage of children with CP demonstrate extrapyramidal (dyskinesia) features, including combinations of athetosis, chorea and dystonia (13). The abnormal movements usually presentation in the second year of life and become most apparent during volitional motor activities with associated speech impairments. Most children with extrapyramidal CP have normal intelligence, but their abilities can be underestimated due to the severity of their motor and communication deficits (14).

Kernicterus (bilirubin encephalopathy) is a leading cause of extrapyramidal CP. The affected neonate appears weak, listless, and hypotonic, with poor feeding. Over a period of months, hypertonia, opisthotonus, choreoathetosis, and sensorineural hearing loss develops. Hypotonic cerebral palsy occurs rarely; however, most children progress to other CP subtypes. Mixed CP occurs when the child displays a combination of features, such as spasticity and choreoathetosis (15).

2.3 Etiologic Classification

Up to 50% of CP cases have no identifiable underlying aetiology (6). The aetiologies can be classified according the timing of the insult as prenatal (commonest), natal, or postnatal (8) another etiologic classification system depends on the actual cause such as congenital (developmental, malformations, syndromic) or acquired (traumatic, infectious, hypoxic, ischemic, TORCH infections, and others). Perinatal asphyxia is a cause in only 8% to 15% of all cases. Male child seems to be more affected (64.27%) than females (35.73%). (16)

Most of these children have clinical features of neonatal hypoxic ischemic encephalopathy (HIE) such as a disturbed level of consciousness, seizures, and end organ dysfunction. Although a normal cord pH excludes HIE, a pH of <7.0 is associated with encephalopathy in only 15% of infants (17)

Similarly, Apgar scores are predictive of mortality but not sensitive in predicting the neurological outcome. Chorioamnionitis and maternal infections have been shown to be risk factors for HIE and CP. Periventricular leukomalacia (PVL) is the strongest and most independent risk factor for the development of CP. Ultra sonographic abnormalities of persistent ventricular enlargement or persistent parenchymal echo densities carry a 50% risk for CP, and large bilateral periventricular cysts carry a risk of 85%. In another study, CP occurred in 56% of infants with Periventricular leucomalacia and Intraventricular haemorrhage (18)

2.4 Classification of Motor Dysfunction

Cerebral palsy can be classified according to the topographic distribution of motor involvement. Motor deficits include monoplegia, diplegia, hemiplegia, triplegia, quadriplegia, and double hemiplegia. Diplegia is present when the lower extremities are primarily affected, although the upper extremities are not completely spared. Spastic diplegia is the most common type of CP and is associated with prematurity in western world (2).

Further classification recommended by American Association of Paediatrics better described cerebral palsy according to their function ability. These classification systems are

The gross motor function classification system (GMFCS) which provide the severity of movement disability among children with CP (19). The manual ability classification system (MACS)classify how children aged 4 to 18 years with CP use both their hands together, when handling objects in daily activities across five levels (20). The communication function classification system (CFCS) classify the everyday communication performance of an individual with cerebral palsy into one of five levels. Mainly focuses on activity and participation levels as described in the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health ICF (21). The eating and drinking ability classification system EDACS is used to measure a child's eating and drinking ability. This includes safety (aspiration and choking) when eating and drinking, efficiency (food loss and speed of finishing meal) and the amount of assistance a person needs. (22). These measures are all standardized, reliable, and complementary to one another.

2.5 Co-morbidities associated with cerebral palsy

2.5.1 Intellectual disabilities

Not all children with CP are cognitively impaired, the cognition is normal in spastic diplegic cerebral palsy because the lesion is in the periventricular white matter, i.e. sparing the cortical grey matter. However, there is a relationship between the severity of CP and mental retardation (23) Children with spastic quadriplegic CP have greater risk of mental retardation than children with spastic hemiplegia. Other factors associated with increased cognitive impairment include epilepsy and cortical abnormalities on neuroimaging (24)

2.5.2 Epilepsy

Up to 36% of children with CP have epilepsy, with onset in the first year of life in 70%.(25) Focal seizures with or without secondary generalization are most common with frequently focal EEG abnormalities (26).Epilepsy can be an indicator of the severity of neurological injury (quadriplegic Cerebral palsy) or cortical insult (hemiplegic CP Children with spastic diplegic Cerebral Palsy are at a lower risk for epilepsy mainly because their pathology predominantly involves the periventricular white matter. (23,27)

2.5.3 Feeding, and Growth in Cerebral palsy

About 30% of children with severe. CP patients are undernourished, most of whom show reduced linear growth below the third percentile. The leading cause of poor growth appears to be poor nutrition due to pseudobulbar palsy. This is an upper motor neuron disorder resulting in poor coordination of sucking, chewing and swallowing. (28)

In addition, gastroesophageal (GE) reflux results in regurgitation, vomiting and possible aspiration. GE reflux can be a source of pain and food refusals in the difficult to feed child. Dystonic dyspepsia (Sandifer's syndrome) in children with severe GE reflux can be confused with tonic seizures. Early nasogastric (NG) or gastrostomy tube (GT) feedings can be solutions to these problems with improved growth and greater family satisfaction. Fundoplication may be indicated at the time of GT placement if medical treatment for GE reflux fails these children. (29)

2.5.4 Bladder Dysfunction

Children with CP are at increased risk for urinary incontinence, urgency, and infections Spastic Cerebral Palsy can be associated with spasticity of the detrusor muscles resulting in small frequent voids and a low capacity irritable bladder. Primary incontinence has been reported in up to 23% of these children and correlates with lower cognition and severe motor deficits. The communication skills and physical ability to go to the bathroom promptly and manage clothing influences the attainment of continence. Adapted toilet seats, handrails, and clothing modifications can increase toileting successes. (30)

2.5.5 Bowel Dysfunction

Constipation is a common complication in children with cerebral palsy and results from combined factors including poor feeding, reduced water intake and immobility. The long-term solution involves increased consumption of water, juices, semisolid food and vegetables. Initiating bowel evacuation is recommended and requires a combination of laxatives (upper intestinal tract) and enemas or suppositories (31). Afterward, a schedule of softening agents such as artificial powdered fibre or docusate sodium with dietary modifications can result in more regular and softer bowel movements. Sitting on the toilet daily after the main meal takes advantage of the gastro-colic reflex and may be further stimulated occasionally with glycerine suppositories (32).

2.5.6 Sleep Disturbances

Sleep disorders are common in children with CP particularly those with visual impairment, occurring in up to 50% of cases (33)

These children often have disturbed sleep patterns with fragmented sleep and frequent nocturnal awakenings, which is highly disruptive to parents. Medications that improve the sleep-wake cycle may also decrease spasticity and improve daytime behaviour (34).

Melatonin is a recently developed natural compound with a phase setting effect on sleep. It is the hormone of darkness as the detection of darkness by visual receptors drives the hypothalamus to stimulate the pineal gland via sympathetic pathways to increase melatonin secretion. Visual impairment in children with CP diminishes the ability to perceive, interpret synchronises their sleep with the environment. This makes these children susceptible to circadian sleep-wake cycle disturbances. A 3-mg melatonin dose at bedtime will improve sleeping pattern and reduce nocturnal awakening (35)

2.5.7 Drooling

Drooling occurs in up to 30% of children with CP. It is not usually related to increased production of saliva unless an irritating lesion is present, such as dental caries or throat infection. Drooling is usually secondary to mouth opening and/or swallowing difficulties due

to pseudobulbar palsy. It is not socially acceptable and can lead to aspiration, skin irritation, and articulation difficulties. (36)

Management for this difficult problem includes. Anticholinergic medications, such as glycopyrrolate, decrease salivation by blocking parasympathetic innervation. Side effects include irritability, sedation, blurred vision, and constipation. But they are not effective. Surgical re-routing of salivary ducts is an option, but may lead to increased aspiration. Recent studies suggest that botulinum toxin injection into the parotid and submandibular glands may be an effective in reducing excessive drooling (37)

2.5.8 Hearing Loss

Kernicterus, post-meningitis, and congenital rubella, increase the risk for hearing loss. It can interfere with developmental progress and rehabilitation, thereby contributing further to developmental delays. Screening is recommended, including behavioural audiometry, auditory-evoked brainstem responses (ABR), should be performed before or shortly after discharge from the neonatal intensive care unit for every preterm. Hearing assessment is recommended routinely for any child with global developmental delay, particularly if language delay is present. (38)

2.5.9 Visual Abnormalities

Children with CP, particularly preterm infants, are at increased risk for visual impairment, including retinopathy of prematurity, myopia, strabismus, glaucoma, and amblyopia. (39)

If not diagnosed and managed early, visual deficits can interfere with developmental progress and rehabilitation. Strabismus can lead to permanent monocular vision loss (amblyopia) Visual impairments can be cortical due to damage to the visual cortex of the occipital lobes. Screening is recommended including acuity, eye movements, and fundoscopy. (40)

2.5.10 Orthopaedic Abnormalities

The developing bones grow in the direction of the forces placed upon them. Spasticity can lead to progressive joint contractures, shortened muscles, and hip or foot deformities. Other orthopaedic complications that need to be watched for include scoliosis and fractures due to

osteomalacia or osteoporosis. These manifestations are more common with severe motor disability and immobility, such as quadriplegia (41)

2.6 Diagnosis and management of Cerebral palsy

The diagnosis is mainly clinical with observation of delayed motor development , abnormal muscle tone and unusual postures being common initial clues to diagnosis however are dependent up the pattern of development of symptoms , clinical history of the mother and the infants (42) Serial developmental evaluations may be necessary in the young child for proper diagnosis and follow up. (43)

Perinatal complications such as prematurity, head injury, kernicterus, and meningitis are important risk factors for Cerebral Palsy. (44)

On the other hand, a family history of neurological disorders and early or unexplained deaths indicates an undiagnosed inherited neurodegenerative disorder. Note that there is no familial cerebral palsy therefore such a misdiagnosis should not be made (45)

A multidisciplinary evaluation is recommended and may necessitate input from physiotherapy, occupational therapy, ophthalmology, audiology, orthopaedics, radiology, neurology, genetics, developmental paediatrics, and social services (46)

2.6.1 Neuroimaging in cerebral palsy

About 63% to 73% of brain CT in CP cases may be normal. Brain MRI is more sensitive than CT, particularly in delineating the extent of white matter changes (47) If available should be used in preference. Biochemical tests such as Thyroid function test may also be relevant especially if there is no certainty that the pathology is non-progressive (48)

2.6.2 Rehabilitation

Among the rehabilitation options for children with cerebral palsy include physical, occupational, and speech therapies (49). Early institution of these interventions are essential for proper developmental progress. Drug treatments to control seizures can limit secondary brain insult hence improving patients' quality of life for spasticity (local, intrathecal,

systemic), orthopaedic and neurosurgical interventions may be required (50,51.) Most patients require combinations of these therapies, but physical therapy is always essential. (52)

2.6.3 Physical therapy

Focus on gross motor skills, including sitting, standing, walking, wheelchair mobility, transfers, and community mobility. Wheelchairs can allow the children to keep up with peers in social, educational, and recreational. (53)

2.6.4 Occupational therapy

Address the visual and fine motor skills that enable coordinated functions of activities of daily living such as dressing, toileting, eating, bathing, and writing.

This treatment plan should be team delivered and hospital- home-rehabilitation centre-based according to the needs of each child. (54)

The basic treatment goals include parent education, facilitation of normal motor development and function, prevention of secondary complications such as deformities and disabilities and improvement of functional acquisition, community integration, and family adjustment. (55)

Most care givers are mothers (80%) who require adjusting their life-styles for the care of the child, including quitting their current job (60%) and taking on income generation activities which allow close proximity of the child. (55, 56)

2.6.5 Orthotic interventions

Are aimed at the prevention and/or correction of deformities, provision of support, facilitation of skill development, and improvement of gait (41)

2.6.6 Parents counselling and Breaking the news

Once the diagnosis of CP is established, communicating such news to the parents is often both difficult and emotionally unwelcome. At the same time, it is important that the transfer of such information is done well as the manner in which neurological bad news is conveyed to parents can significantly influence their emotions, beliefs, and attitudes towards the child, the medical staff, and the future. (58)

2.7 The ongoing studies on newer intervention therapy for cerebral palsy

2.7.1 The role of genetic in cerebral palsy

In 2014, the American Congress of Obstetricians and Gynaecologists and the American Academy of Paediatrics, with many international consultants published a paper titled *Cerebral palsy and the role of genetic variants.* In this study findings revealed that neonates with genetic susceptibility to cerebral palsy when exposed to clinical risk factors triggered the development of CP.

Future clinical applications is targeted screening of parents for inherited causative genes, embryo preimplantation screening, or antenatal diagnostic DNA techniques in early pregnancy are possibilities in the near future (59)

2.7.2 Cerebral palsy and brain cooling

Severe hypoxic ischemic encephalopathy is a responsible risk factor for developing cerebral palsy in children worldwide.

Study by Jobes et al 2015 in Canada demonstrated that therapeutic hypothermia is an effective therapy in high resource environments, it has not been demonstrated to be effective in LMIC in a few trials due to several obstacles such as lack of trained personnel and infrastructure in our settings (60)

2.7.3 Transcranial magnetic stimulation (TMS) therapy in spastic cerebral palsy

Study by Gupta et al 2016 on repetitive transcranial magnetic stimulation which is a non-invasive technique of stimulating the brain employing magnetic pulses. Recent research has demonstrated the efficacy of rTMS in facilitating motor functions in spastic CP hence reduction in muscle tightness of both upper and lower limbs (61)

2.7.4 Magnesium sulphate in preterm babies and CP prevention

The study done in Canada by Lea et al 2017 demonstrated that Antenatal magnesium sulphate given prior to preterm birth for foetal neuro protection prevents CP and reduces the combined risk of foetal/infant death or CP(62)

2.8 Factors that affect attendance to rehabilitation care among children with Cerebral palsy

In a systematic review 2018 by Bright et al in low and middle income countries (LMIC) Pointed out some factors that affect attendance to rehabilitation care among people with disability including children with cerebral palsy these include unaffordability of services, lack of health insurance, distance to services and transportation (64) .Others includes discrimination from the society and health care provider, communication barriers, and lack of provider skill were also common (77).

In Tanzania, the laws and policies pertaining to disability particularly for children with cerebral palsy are well placed, (Disability Act of 2010 United Republic of Tanzania) (65). although in practice there are very few rehabilitation centers and the number of children. With cerebral pals receiving these services are not in proportion. Therefore, we have to address this problem and propose the best approach to overcome the barriers to rehabilitation care (65, 66)

2.9 Prognosis

Generally, children have an enhanced capacity for brain plasticity, resulting in a capacity to recover and improve from brain insults. It implies that normal and less damaged areas of the brain have the ability to develop and maturate with time to result in developmental progression and motor improvements (67).

A major concern of parents is whether the child will be able to walk independently. The ability to sit independently at 2 years of age is predictive of future ambulation. Most children with hemiplegic CP will be able to ambulate independently (68).

Regarding life expectancy and mortality rates in children with CP, the type and severity of disability and feeding skills are the prognostic indicators. Those who require nasal gastric feeding during the first year of life have a 5-times greater mortality rate than children with oral feeding. Overall, the probability of reaching the age of 20 years in a child with severe CP is 50%. Respiratory infections, aspiration, and epilepsy are leading causes of death (69).

The sooner and the more intense physical therapy and occupational as well as rehabilitative therapy, the better the outcome (70,71) .

3.0 MATERIALS AND METHODS

3.1 Study Design

This was a facility based cross-sectional study which employed both quantitative and qualitative methods.

3.2 Study Areas

Muhimbili National Hospital

Muhimbili National Hospital is a tertiary and teaching hospital located in Ilala municipal, Dar es Salaam. It provides general and specialized services, including paediatric care as well as rehabilitation care for children with disabilities like Cerebral Palsy. Rehabilitation care has been divided into three subunits which includes physiotherapy, occupational therapy and speech and language therapy. The rehab is run by specialised personnel in their respective fields. It is estimated that between 200-300 children with cerebral palsy are currently registered at Cerebral Palsy clinic monthly.

The Comprehensive Community Based Rehabilitation centre Tanzania (CCBRT)

This is a non-government faith-based hospital located in Kinondoni Municipality and is the largest provider of disability services in Tanzania, aiming to empower people with disabilities and their families, improve their quality of life, and ensures access to medical services and physical rehabilitation care. CCBRT serves up to 500 patients with disabilities on daily basis, out of these more than 10% are children with cerebral palsy. The rehabilitation unit (physiotherapy and occupation therapy) are run by at least four specialized personnel each day.

3.3 Study Populations

Children with CP and their parents attending at MNH and CCRBT rehabilitation clinic, health care providers and hospital administrators working at the respective facilities.

3.4 Study Duration

The study was conducted from October 2017 to April 2018.

3.5 Sample Size estimate for the participants

The sample size is estimated from Kish and Leslie formula (80)

$$n = \frac{z^2 p(100-p)}{\varepsilon^2}$$

Where

Z= level of confidence (1.96 for 95% confidence level)

P= **proportional** of children with cerebral palsy and associated disability in Egypt was 10% by Osama et al 2017(73)

E = marginal error 5%

Therefore, $N = \frac{1.962^* 10 (100-10)}{5^2} = 138$

N= 138

Additionally, a 10% non-response rate gave a maximum sample size of 152.

3.6 Inclusion Criteria

- Parents /caretakers whose children with cerebral palsy attending rehabilitation clinic at MNH and CCBRT at least for 3months.
  Parents/guardian who consented for their children to be involved in the study.
- Health providers working in the respective rehabilitation clinic.

3.7 Exclusion criteria

- Parents/caretakers whose children with cerebral palsy are admitted.
- Children with cerebral palsy having other serious medical conditions which needed emergency treatment.

3.8 Recruitment of participants

Parents/care takers whose children were referred to rehabilitative department with a confirmed diagnosis of cerebral palsy by a Paediatric Neurologist through detailed birth history, physical examination, serial neurological evaluation and brain imaging. Their documents were checked upon arrival at the clinic. Participants who met the inclusion criteria were taken into the study consecutively until sample size was obtained. Prior to the study a written informed consent was given to participants. (Appendix v/vi page 65-68)

3.9 Variables

1. Dependent variable -cerebral palsy and attendance to rehabilitation care:

Regular attendance as per this study was regarded as number of attendance divided by number of session of the appointment attended per week multiplied by 100 those who scored > 50% were considered as regular attendance

$$\text{Regular attendance} = \frac{\text{no of attendance per week x 100}}{\text{No of sessions of app schedule attended per week}}$$

Minimum attendance was 2 days per week while max attendance was 5days a per week

Those who scored <50% were regarded as irregular attendance

2. Independent variables are age, gender of children and their parents, socio economic status, educational level of parents/caretaker, Work experience of healthcare provider, Insurance coverage, distance to health facilities and hospital administrators.

3.10 Data Collection and procedures

Pre-testing of the study instrument

Questionnaire Piloting – Two weeks prior to commencements of data collection a pilot study was done to test the practicability of the questionnaire and to modify if required, The results from the pilot were not included in the analysis.

1. Quantitative data collection

Training of researcher Assistants

A two consecutive days training was conducted by the principal investigator, the two researcher Assistants (intern doctors) were trained on proper recording of demographic data, history taking, physical examination, research ethics and proper documentation to be observed during data collection including confidentiality. A total of 152 Parents and their children with cerebral palsy were consecutively enrolled from the rehabilitation clinic from October 2017 to April 2018.

A structured questionnaire was administered to obtain quantitative data from the parents/caregivers after signing a written consent.

Quality control of data collection

After interview the questionnaire were collected from the research assistants and checked by Principal Investigator for the completeness and consistency, feedback of the shortcomings encountered were addressed for further improvement.

Data analysis

The principal investigator analysed quantitative data using Statistical package for social science (SPSS) version 20. Tabulations were used to examine for associations, coefficient correlations. Continuous variables were expressed as mean, median and interquartile range. Differences in proportions were tested using the chi-square test and Fishers exact test where applicable. Odds ratio (OR) and 95% confidence intervals (CI) was calculated to determine the associations between dependent variables and other variables. A p value equal to or less than 0.05 was considered significant.

2. Qualitative data

a. Focused Group Discussion (FGD)

A total of 32 parents (mothers, fathers and caretakers) who were involved in four focused group discussion(FGD) and were purposively sampled by the gate keeper to achieve diversity in terms of age, gender, education, employment and social economic status. Three days prior the scheduled date for an interview every participant was asked to confirm through mobile phone his or her readiness to participate.

The principal investigator arranged the venue, location and the convenient time for the interview. A round table sitting arrangement was followed during the FGDs. The rooms were well ventilated and had space adequate enough to accommodate all participants and researchers. Nurses were assigned the responsibility of taking care of the study participants' children for the duration of each FGD. Video recordings were done for both FGDs, and the consent for which was obtained before beginning the FGD.

The FGDs were facilitated by a team, comprising one moderator, one recorder, and one observer. Each FGD began with an introduction by the moderator of the entire team of researchers, followed by introduction from all the participants. A total of four sessions were conducted, one in every other day which lasted between 45 minutes to an hour each. An interview guide in page (65-68) were used to ask questions .All interviews were recorded on digital tape recorder.

b. An In-depth interview (IDI)

A total of 18 health care providers and hospital administrators were purposively selected for interviews. They included 5 groups of in-depth interviews. One on one interviews were conducted by the principal investigator after an informed consent was taken. The interviews were recorded by digital tape recorder.

The recorded voice was temporarily stored in the voice recorder and then transferred to a laptop computer. Voices were then transcribed into Microsoft word 2007version to create a word document. As soon as transcription was ended, recorded voices were deleted for

confidentiality. The word documents were stored in two folders named *Parents/caretakers **and health care providers***. In each folder, word documents were kept, all these document were in Swahili- language at the beginning but later were translated into English language.

Coding, categories generations and theming

The process of coding and formulation of categories was conducted manually. The principal investigators had predetermined categories prior to analysis (deductive content analysis,) The categories which were pre-determined on socio cultural factors affecting attendance to rehabilitation care among children with cerebral palsy were***;(*** *Parental/care givers factors, healthcare provider's factors and the health facility factors*) which gave rise to two major themes and four sub themes: The Themes included

THEME 1: Enablers of regular attendance to rehabilitation care

THEME 2: Barriers to regular rehabilitation care among children with cerebral palsy

Subthemes:

Subtheme i: Family social support

Subtheme ii: Positive perception to rehabilitation care

Subtheme iii: Community misconception on cerebral palsy

Subtheme iv: Facility related barriers

In total there were 18 units of analysis, 6 from each category. In each unit of analysis similar concepts related to pre-determined categories were grouped together, i.e. similar concept talking about socio economical support on health care. When all 18 units had been analysed in the manner of deductive content analysis, the two documents (Health care provider and parents/caretakers) were compared and combined to give compiled research findings.

3.11 Ethics Clearance

Ethical clearance was sought from MUHAS Research and publication Review Board (IRB) ref No (MU/PGS/SAEC/Vol .X dated 18 October 2017), Muhimbili National Hospital and The CCBRT administration respectively. Parents / caretakers included in this study were requested to sign a written informed consent form prior to recruitment. This was done after they had received information regarding the importance of this study and its benefits of participating in the study. All children received services as per protocol regardless of the willingness of their parents to participate in the study. Confidentiality of participant's information was ensured. Information obtained was stored in a password secured computer base and the hardcopies of the questionnaire were also secured in a locked cabinet.

4.0 RESULTS

Table 1 shows socio-demographic characteristics of the parents/caregivers and their children. A total of 152 children were recruited, among them ninety-three (61.2%) were from MNH and fifty-nine (38.8%) were from CCBRT.

Table 1:Distribution of socio-demographic characteristics of the parents/caregivers and their children.

Character	Frequency(n)=152	Per cent (%)
Age of children (months)		
< 12	44	28.9
12 – 60	105	69.1
>60	3	2.0
Sex of children		
Male	83	54.6
Female	69	45.4
Age of parents in (yrs)		
<25	39	25.7
26 – 30	53	34.9
31 – 35	23	15.1
>35	37	24.3
Sex of parents/caregiver		
Male	12	7.9
Female	140	92.1
Marital status of parents/caregiver		
Single	27	17.8
Married	113	74.3
Divorced	12	7.9

Table 2 shows distribution of regular attendance of more than 50% of session schedules appointed per week whereby 91.2% (103) of the married couple were found to have regular attendance as shown below

Table 2: Distribution of socio demographic characteristics among regular and non regular rehabilitation attendees

Character	Regular attendance n(%)		P- value
Age of parents (Years)	**Yes**	**No**	
< 25	35 (89.7)	4 (10.3)	
26 – 30	43 (81.1)	10 (18.9)	***0.69**
31 -35	19 (82.6)	4 (17.4)	
> 35	32 (86.5)	5 (13.5)	
Sex of child			
Male	11 (91.7)	1 (8.3)	
Female	118 (84.3)	22 (15.7)	***0.49**
Marital status of parent/caregiver			
Single	18 (66.7)	9 (33.3)	
Married	103 (91.2)	10 (8.8)	
Divorced	8 (66.7)	4 (33.3)	***<0.001**
Family size			
Single child	86 (83.5)	17 (16.5)	
2 children	25 (92.6)	2 (7.4)	
> 3 children	18 (81.8)	4 (18.2)	***0.457**
Employment status of parent/caregiver			
Employed	60 (89.6)	7 (10.4)	
Not employed	69 (81.2)	16 (18.8)	**0.153**
Education level of parent/caregiver			
Primary school	53 (82.8)	11 (17.2)	
Secondary school	55 (83.3)	11 (16.7)	
Higher education	21 (95.5)	1 (4.5)	***0.324**
Total Month income (Tsh.)			
>300,000	56 (76.7)	17 (23.3)	
300,000 -400,000	35 (94.6)	2 (5.4)	
410,000 - 600,000	21 (87.5)	3 (12.5)	
610,000-800,000	13 (92.9)	1 (7.1)	
> 810,000	4 (100)	-	***0.09**
Type of mobile devices child has			
Manual wheel chair	55 (83.3)	11 (16.7)	
Automated wheel chair	5 (100)	-	
None	59 (86.8)	9 (13.2)	***0.551**

NB: * denote fishers test was used

Factors influencing regular attendance

Table 3 shows factors influencing regular attendance; in this study those parents whose children had health insurance (HIF) 53(85.5%) and those with an exemption to treatment charges 69(85.2%) had a regular rehabilitation than out of pocket payment. Other factors did not affect regular attendance.

Table 3: Factors influencing regular attendance among rehabilitation attendees

Character	**Regular attendance**		**Total**	***p*- value**
	Yes	**No**		
Modality of payment	**n (%)**			
Health insurance fund	53 (85.5)	9 (14.5)	62 (40.7)	
Exempted	69 (85.2)	12 (14.8)	81 (53.3)	***0.038***
Self-payments	7 (77.8)	2 (22.2)	9 (6)	
Distance from facility (km)				
<10	14 (87.5)	2 (12.5)	16 (100)	
10 to 20	28 (84.8)	5 (15.2)	33 (100)	
20 to 30	59 (83.1)	12 (16.9)	71 (100)	
>30	28 (87.5)	4 (12.5)	32 (100)	***0.934***
Time spent at Rehab clinic				
<1	16 (72.2)	6 (27.3)	22 (14.4)	
1 to 2	96 (88.1)	13(11.9)	109 (71.7)	
>2	17 (81)	4 (19)	21 (13.8)	***0.161***
Type of transport used to rehab clinic				
Public	117 (83.6)	23 (16.4)	140 (92.1)	
Private car	12 (100)	0	12 (7.9)	***0.127***

Table 4 shows distribution of types and availability of rehabilitation care, in this study Physiotherapy was the most available services as compared to others rehab therapy as shown below.

Table 4: Types and availability of rehabilitation service at MNH and CCBRT

Chatacter	**Frequences n=152**
Type of rehab provided at Your facilities	
Physiotherapy	152 (100)
Occupational therapy	
Yes	49 (32.2)
No	103 (67.8)
How isthe rehab care been adminstered	
Proffesionaly	136 (90.1)
Guided	15 (9.9)
Duration of been on a rehab clinic (Yrs)	
<1	80 (53)
1 to 2	60 (39.7)
3 to 4	9 (6)
>4	2 (1.4)
The age your child started Rehab clinic (months)	
<12	92 (60.5)
12-24	34 (22.4)
25-36	19 (12.5)
>36	8 (5.3)

Table 5: Showing multivariate regression for factors affecting regular rehabilitation care

Variable	**Adjusted Odds Ratio(95%CI)**	***P value***
Marital status		
Single	1	
Married	5.65(1.70-18.92)	0.005
Divorced	0.75(0.13-4.34)	0.745
Time spent to Rehab clinic		
<1	1	
1 to 2	2.74(0.68-10.98)	0.682
>2	1.75(0.29-10.86)	0.285
Total Month income (Tsh.)		
>300,000	0.727	1.000
300,000 -400,000	4.099	1.000
410,000 - 600,000	1.066	1.000
610,000-800,000	1.836	1.000
> 810,000	1	
Employment		
Employed	1	
Not employed	1.35(0.40-4.56)	0.630
Transport		
Public transport	NS	0.999
Private transport	1	

Children, who had regular attendance at the facilities, had more than 5 times likely odds of having parents who are married than singles.

Qualitative Findings

Sociodemographic characteristics of participants for FGD and IDI who participated in interviews

A total of 50 participants among them 38 were females and 12 males. The participants were in three major categories (the parents/caretakers, Healthcare providers and the hospital administrators), their age ranged from 18-50yrs old. Of these 32 parents were involved in a total of 4 focused group discussion, the remaining 18 were Health care provider and hospital administrators who participated in 5 in-depth interview, as indicated below

Table 6: Sociodemographic characteristics of parents who were involved in FGD

Number of FGD	Number of participants	Education level		Marital status		Occupational	
		Informal Education	Formal education	Married	Unmarried	Employed	Unemployed
1	8	1	2	1	1	2	1
2	8	2	1	1	1	1	2
3	8	1	2	1	1	2	1
4	8	2	1	1	1	1	2
Total	**32**	**6**	**6**	**4**	**4**	**6**	**6**

Table 7: Sociodemographic profile of Health care provide (HCP) for In-depth Interview participants

Number of IDI	Professionals/ Position	Number of participants	Experience at work	Working station
1	Doctors	6	2-4 yrs.	MNH/CCBRT
2	Nurses	6	3-5 yrs.	"
3	I/c Rehab department	2	3yrs	"
4	i/c physiotherapy unit	2	2 yrs.	"
5	i/c occupational unit	2	1yr	"

THEMES

THEME 1: Enablers of regular attendance to rehabilitation care

Subtheme 1:1 Family social support

From this study, it was found that parents of children with cerebral palsy who had regular attendance to rehabilitation care, received financial and or psychosocial support from their spouse, family and community at large these were confirmed by some of respondent that:

"I get support from my parents, thus why I manage to bring my child to clinic every scheduled appointment" [P2, 31 yrs. Old woman,]

"My husband is very supportive he always picks us and drives to and fro the hospital when required" [P30 ,48Yrs old woman f4 leaver']

"I think it doesn't matter whether the parent is well off or educated but taking care of such a disabled child is stressful and very demanding, we need both spiritual and psychological support from our family member" [P24, 35yrs old petty business man]

Subtheme 1:2 Positive perceptions on rehabilitation care

The continuum of rehabilitation care results in better outcome among children with cerebral palsy, in this study positive perception towards intervention among parents and caretakers were of benefit to these disabled children, hence parents admitted that some of symptoms were improving thus giving them courage of adherence to appointment as confirmed by some of respondents.

"I think the rehabilitation is doing something good because before attending this clinic my child was unable to sit even to control the neck but now is able to sit and hold his neck [P30, 44yrs old petty business man.

"*My child has improved a lot, he was unable to do anything but now can roll over again and again to certain distance "[P1, 34yrs old woman a Lawyer]*

"*Initially my child had several attack of seizures but currently has stopped*" [P4, 23yrs old man f4 leaver]

"*At first the neck of my child was very loss could fall back but now is firm and he can sit" [P2,*31 yrs. old woman a teacher]

"*There is an improvement because he was unable to hold things or turn around but now he can*" [P3, 23yrs old housewife]

THEME 2: Barriers to regular rehabilitation care

Subtheme2:1 Community misconception on cerebral palsy

In this study major barriers to regular rehabilitation care among parents and care takers included witchcraft ideology and curse among community members which led to social isolation, divorce and stigma. For this matter parents of children with cerebral palsy feel ashamed to carry their disabled children publically especially when attending rehabilitation care. Below are the responses from some of participants

"Initially my relative was taking care of the child when I was at work but then she run away so I have to quit the job to take care of my sick child because no one to look after him at home and to bring to hospital" [P4, 27yrs old woman, a graduate*]*.

"In my society there are two groups those who give me courage and hope but other group discourages me" [P2,31yrs old, housewife].

"In my home place they say I have bewitched my own child but others say I have committed adultery" [P9,23 yrs old , a bussness woman].

"*In my community they believe that the source of problem is me because my child had delayed to sit they says I did something wrong like committing adultery in a Swahili word umembemenda mtoto****"*** *[P7 44yrs old woman, a lecturer]*

Subtheme 2:2 Facility related barriers

An in-depth interview was conducted in total of 18 health providers and hospital administrators on barriers to rehabilitation care, among parents and their children with cerebral palsy some of barriers pointed out includes unfriendly environment in terms of infrastructures, lack of rehabilitation professionals and consultation charges.

"Some of the shortcoming at our rehabilitative department is lack of privacy, especially during service children are being managed together, remember these children have different levels of severity in terms of disability so they need different modality of care" [HA40, 52yrs old woman HOD Rehab department]

"The challenges are firstly, there is no enough waiting space, second, there is no convenient place for mothers to sit and feed their children especially during rainy seasons" [HA16, 37yrs old man Physioth unit i/c]

"*There are few rehab professionals in the department especially for disabled children. Remember this is the only big public rehab center offering rehabilitation care in the city*"

[HCP1, 34 yrs. old man Physt]

"Here were are only two occupational therapists and the children are many, so the efficiency becomes less, for instance in a day we are attending children between 20-30 and it needs at least 25-30 minutes per patient depending on his /her disability" [HCP3, 26yrs old man dip Occup Thr]

Roughly its about 0-5 % of parents can afford to pay for service charges. Despite that introduction of health insurance has reduced the burden of cost up to 60% but a number of parents has failed to join health insurance because of lack of entrance fee. [HA, Nurse i/c Rehab department]

5.0 DISCUSSION

Cerebral palsy is the major cause of severe physical disability in childhood particularly in the low and middle-income countries including Tanzania, rehabilitation intervention (physical, occupational and speech therapy) have been proved to relieve the effects of impaired body structures and systems. Thus improving quality of life among children with cerebral palsy

However regular attendance to these rehabilitation services has a direct impact on prognostic outcome. This study looked at factors affecting regular attendance to rehabilitation care among parents and their children with cerebral palsy.

In this study it was found that married couples (91.2%) had regular attendance to rehabilitation care as compared to single parents or unmarried this could be explained possibly by the support they get from their spouses, this fact was also similar in triangulation with qualitative findings.

Majority of caretakers were female (92.1%) as compared to male parents/caretakers (7.9%). Similar findings in Kenya by Mbugua et al 2011 which showed that 89.5% of parents who brought their disabled children to rehabilitation care were married females (74). The similarities could be explained by interaction of socio cultural norms among African countries and that traditionally females are primary care takers for children as a social responsibility as an African culture.

This was also evident in triangulation with qualitative study which was confirmed by some of the participants after focused group discussion (FGD) they mentioned that most of men consider like taking care of children is the mothers responsibility *[P4 27yrs old woman, a graduate, P32 45yrs old housewife]*.

Furthermore, this study has also demonstrated that regular attendance to rehabilitation care among parents/caretakers with their children was influenced by health insurance coverage (85.5%) or exemption (85.2%) from treatment charges as compared to non-regular attendee (77.8%) who had to pay for their treatment bills out of their pockets, In this study however,

distance from the health facility, transport cost, and time spent at rehabilitation clinic were not associated factors.

However this was contrary to the study done in Kenya by Biwott et al 2014 in which the factors mentioned above were the case (77). The reason could be due to difference in sample size and the study design employed in that our study was facility based while the study done in Kenya was community based.

Similar findings in the study done in Canada 2013 which showed majority of children had health insurance coverage and received treatment care. This could be explained by differences in income and good health policy which promote health care services in the developed countries as compared to Low and Middle income countries (57)

It is evident that availability and accessibility of rehabilitation care influences utilization of the physical therapy among children with cerebral palsy. In this study the findings showed that physiotherapy was most available from both facilities, as compared to occupational and other physical therapies which were at decrease this could be explained by lack of professionals and rehabilitation equipment's. In other hand early age of attendance to rehabilitation care was noted though the default was at increase as the children grow older hence they become heavier to carry.

This was also similar in triangulation with qualitative study during IDI to some of the rehabilitation profession who pointed out that the number of profession at the facility and the children receiving this care were not in proportion. *[HCP3, 26yrs old man OT,* HCP*1, 34 yrs. old man Physiotherapist]*.

In the study done in Zambia by Singogo et al 2015 on challenges experienced by mothers when caring their disabled children revealed the higher degree of social isolation and discrimination hence poor attendance.(63)

This finding was in keeping with triangulation from qualitative part of this study as evidenced by response from participants who reported to have experienced the similar from our society which negatively affected their attendance to rehabilitation care*[P9,23yrs old business man,P7 44yrs old woman a lecturer]*.

In further interviews to explore socio cultural factors which affecting regular attendance to rehabilitation care among children with cerebral palsy it was revealed that psychosocial support at family and community level have a direct influence on regular attendance to rehabilitation care *[P2 31 yrs. Old housewife, P4 27yrs old woman, a graduate]*.

Studies done by Polita 2014 and O' Neal Margaret et al ,2009 demonstrated that mother's appraisal and social support reduces not only parenting stress but also facilitates attendance to rehabilitation care and improves quality of life for both disabled children and their parents(78,79).

This finding was equally similar with triangulation in qualitative data of this study obtained from participants who openly explained their inner feelings during focused group discussion (FGD) *[P2, 31 yrs. Old woman, P30, 48Yrs old woman f4 leaver' P24, 35yrs old petty business man]*

On further interviews among parents to explore socio cultural factors about their perception on rehabilitation care, majority they perceived that rehabilitation care has done something good to their babies and that they have observed some improvement to their disabled children in terms of symptoms such as reduction in frequency of seizures , improving in mobility and head and neck control .Some of participants said*"[P1 34yrs old woman a Lawyer, P4 23yrs old woman f4* leaver, P2 31 yrs. *old woman a teacher and P3 23yrs old woman*] Therefore this is the area of appraisal to parents and care takers because of its potential impact on attendance to physical therapy as well as intervention outcome, hence improving quality of life among children with cerebral palsy in Tanzania.

5.1 Strength and limitations

This study employed mixed method hence increasing the reliability of the findings

However, it is a facility based study therefore the findings could not be generalized to the entire population thus community based study is recommended

6.0 CONCLUSION AND RECOMMENDATION

6.1 Conclusion

- Care of disabled children by two parents, financial ability and availability of services at the facility level were are associated with higher utilization of rehabilitation services
- Lack of other rehabilitation services such occupational therapy has directly effect on frequency of attendance to rehabilitative care.
- Negative myths and misconceptions about the disease and stigma among community members were pervasive and were identified as barriers to rehabilitation care seeking.

6.2 Recommendations

- Financial aids such as through insurance coverage, exemption from payments of some services may help the families to care for their infants.
- Improving and facilitation of other rehabilitative services such as Occupational and speech therapy is recommended.
- Campaigns addressing stigma, myths and misconceptions about cerebral palsy are needed to ensure the society is aware of the disability and provide psychosocial support.
- Improving on a number trained personnel could improve patients care

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APPENDICES

Appendix I: Case record form

Demographic data for children with cerebral palsy

1. Code number: ……
2. Hospital Registration number: …….
3. Age: ……
5 Sex: …...
8. Body weight: Kgs

Birth history

Mode of delivery…….

APGAR SCORE……(ask if child cried immediately)

Gestation age (in weeks)……

Birth weight in Kg……..

Resuscitation done

YES/NO

If yes what was is it…… for How long……..(hrs)

H/o jaundice during neonatal /infancy period…….YES/NO

Appendix II: Questionnaires- Quantitative Study

1. **Demographic characteristics of parents/ caregivers**

a. Age …..code …….

b. gender, male [ ] Female [ ]

c. **Marital status**;

Single [ ] Married [ ] Divorced [ ]

d. Family size [ ] one child [ ] 2 children [ ] 3 children[ ]> 4 children[ ]

e. Employment

Yes [ ] No [ ]

If yes what is the type of employment [ ], Government [ ] private sector [ ] self [ ]Others

f. Education level

Primary education [ ] secondary [ ] higher degree [ ]

g. Ownership of properties

Own house [ ] land[ ] car [ ] motorcycle [ ]non [ ]

h Type of house you have

Mud [ ] bricks and cement [ ] cemented [ ]

h. Wall

Rough, [ ] plastered [ ] plastered with cement

i. Roofing.

Grass[ ]iron roofed[ ] Asbestors[ ]

j. Inventory

Redio[ ] Tv [ ] sofa set [ ] others [ ] non [ ]I

k. **what type of mobility device does your child** use [ ] manual wheelchair [ ] automated wheelchair[ ] non

l. what type of fuel does your family use for cooking

[_] firewood [_] charcol [_] Kerosene [_] electricity [_] gas

m. Source of water

Dip wells [ ] Tape water[ ]

n. Total monthly income in TZS

<300,000/=[ ]300,000-400,000/ [ ] 410,000-600,000[ ] 610-800,000[ ] >810,000

o. Total monthly expenditure

100,00-200,000/[ ] 210,000-400,000/[ ] 410,000,-600000/[ ] , 610.000-800.000/[ ]

2. Factors that affect rehabilitation care among cerebral palsy children

a. How far are you from this health facility

< 1km [ ] 1-5km [ ]6-10km[ ] 11-20km[ ] 30-40km[ ]>50km[ ]

b. How many hrs. do you spend on the way to rehab clinic

< 1hr [ ]1-2hrs[ ] 3-4 [ ]>4hrs

c. What type of transport do you always use when coming to rehab clinic

Public [ ] private car[ ] hired tricycle[ ]motorcycle[ ]foot[ ] other[ ]

d. How many times is your child required to attend for rehab clinic in a week/

once [ ] twice[ ] thrice[**]**four times**[ ]**five times**[ ]**

e. Are you attending regularly at the rehab clinic as scheduled ?

Yes [ ] No [ ]

f. Who pays your bill for treatment of your child

NHIF [ ] NGO's [ ] Government [ ] self [ ] exempted [ ]

g. If you are paying by yourself who supports you financially…

How much do you pay for every visit 10,000- 30,000[ ] 31,000-50,000[ ] 51,000 - 60,000 [ ]

3. **Types of rehabilitation services offered at CCBRT and Muhimbili National Hospital during visit**

   a. What types of rehab care your child had been receiving from this health facility

      Physiotherapy [ ] occupational therapy [ ] Speech and language therapy [ ] both[ ]

   b. Among the mentioned rehab care above which is most frequently offered

      Physiotherapy [ ] occupational [ ] speech and language therapy [

   c. How is the rehab care being administered [ ] professionalised [ ] guided [ ]

   d. For how long your child has been on rehab care

      < 1yr [ ] 1yr - 2yrs [ ] 3yrs - 4yrs [ ] >5yrs

   e. At what age did your child started attending the rehab clinic

      <1yr [ ] 1yr [ ] 2yrs [ ] 3yrs [ ] 4yrs+

   f. For how long you have to wait on queue before you get the service

      <1hr [ ] 1hr [ ] 2hrs [ ] 3hrs

Appendix III: Qualitative Question guide (English Version)

Parents FGD – To explore the role of socio-cultural factors that affect attendance to rehabilitation care among cerebral palsy children

Introduction, consent and rapport building:

Step 1: Introduce yourself
Step 2: Determine eligibility
Step 3: Obtain oral consent (separate document)
Step 4: Complete demographic questionnaire
S**tep 5:** Ask permission to turn on tape recorder
Step 6: Turn on recorder, then…
Step 7: Conduct the discussion
Step 8: At the end of the discussion, thank the respondent for his/her participation and write up FGD review.

Interviewer: My name is Dr. Emmanuel Luchagula. Thank you again for your willingness to be a part of this interview. I am looking forward to hearing your thoughts on the questions I will ask you.

Before we begin I'd like to confirm that voluntarily consented to participate on this in depth interview.

A: Basic Participant Information	
Time of the beginning of interview:	Name of the health facility
Date of interview:	Age
Region of origin	Sex
District	Highest level of education
I Occupation	Marital status
Main source of income	Interviewers Name
	Time for finishing interview
	Participant code

B: PARENTS /GUARDIAN'S GENERAL UNDERSTANDING ABOUT CEREBRAL PALSY

1 Please explain to me, what do you understand the term cerebral palsy

Probe:

- Meaning,
- causes,
- signs and symptoms

2 Please explain to me the initiation and process of seeking health care

Probe

- when did they seek care for the first time(Timing)
- where did they seek care(hospital, traditional healers)
- level of facilities

3. What were the motives for you to seek care?

Probe

- close relatives,
- health professionals
- severity of illness

C. CARE OF THE CHILD WITH CEREBRAL PALSY

4. How do you care your child with cerebral palsy?

Probe

- home
- facility

5. How about care of other children with cerebral palsy in the community

Probe

- Alternative medicine
- rehabilitation care

6. What has been improved from child's condition (treatment outcome?)

Probe

- Posture/movement
- Speech/ language
- Weight gaining

D. FAMILY/SOCIAL SUPPORT FOR CHILDREN CEREBRAL PALSY ON SEEKING CARE

7. Explain to me the support you get from you family for your sick child

Probe;

- Societal barriers- beliefs, altitudes
- Ignorance

8. In your own opinion, what are the facilitators for seeking and getting care for the child with cerebral palsy?

Probe

- Financial, transport
- Social support
- Health facilities aspect

Appendix IV: Interview Guide for Health Care Provider (IDI)

In-depth Interview Topic Guide – **To explore the role of socio-cultural factors on adherence to rehabilitation care among cerebral palsy children**

Introduction, consent and rapport building:

Step 1: Introduce yourself
Step 2: Determine eligibility
Step 3: Obtain oral consent (separate document)
Step 4: Complete demographic questionnaire
S**tep 5:** Ask permission to turn on tape recorder
Step 6: Turn on recorder, then…
Step 7: Conduct the interview
Step 8: At the end of the discussion, thank the respondent for his/her participation and write up IDI Review.

Interviewer: My name is Dr. Emmanuel Luchagula. Thank you again for your willingness to be a part of this interview. I am looking forward to hearing your thoughts on the questions I will ask you. I am going to ask you questions that will help us understand more about this cerebral.

Before we begin I'd like to confirm that you have given your voluntary consent to participate in this in-depth interview.

A: Basic Participant Information	
Time of the beginning of interview:	:Time of finishing interview
Date of interview:	Name of the health facility
Duration in current position:	Sex
Interviewer name:	Marital status
Participant Code:	Highest level of education

B: ATTENDANCE TO HEALTH CARE AMONG CHILDREN WITH CEREBRAL PALSY

1. Please can you explain to me how parents and their children with Cerebral Palsy children adhere to appointment schedule?

   Probe

   - Frequency, of attendance
   - Which age group
   - severity

2. What do you think are the reasons that influence parents to attend to health care as scheduled?

   Probe

   - Expertise
   - Cost free service
   - Facilities

3. In your own opinion can you explain how matrimonial relationship among parents influenced adherence to health care

   Probe

   - support from spouses
   - Male participation in health care
   - Gender discrimination

C: HEALTH FACILITY ENVIRONMENT TO CHILDREN WITH CEREBRAL PALSY

4. In your own opinion what do you think are the institutional barriers among Cerebral Palsy children to attend health care

   Probe,

   - Infrastructure,
   - Process,
   - Finance barriers

5. What are influences attendance to rehabilitation care of children to attend health care .

   Probe .

   - Friendly health care
   - Short duration on queue

6. In your own opinion can you tell to what extent the parents with Cerebral palsy children are be to pay for treatment Charges of their sick children.

   Probe

   - Ability to pay.
   - Financial barrier

Appendix V: Parent/Guadian In-depth Interview Guide (Swahili Version)

MWONGOZO WA DODOSO LA MAHOJIANO KWA WAZAZI/WALEZI WENYE WATOTO WALIO NA MTINDIO WA UBONGO

Utangulizi, ukubali na kujenga mahusiano:

Hatua 1: jitambulishe **Hatua 2:** Baini sifa za mshiriki **Hatua 3:** Pata ridhaa ya mdomo (nyaraka inayojitegemea) **Hatua 4:** Jaza kikamilifu taarifa binafsi za mshiki kwenye dodoso **Hatua 5:** Omba kwa mshiki kibali cha kuwasha kinasa sauti **Hatua 6:** washa kinasa sauti **Hatua 7:** Anza mahojiano
Hatua 8: Mwisho wa mahojiano, mshukuru mshiriki kwa kushiriki na kisha andika taarifa ya mahojiano

Mtafiti: Naitwa Dr. Emmanuel Luchagula. Nakushukuru tena kwa utayari wako wa kushiriki katika mahojiano haya,natarajia kusikia mawazo yako kuhusiana na maswali nitakayo kuuliza.

Kabla hatujaanza napenda kuthibitisha utayari wako wa kuridhia kushiriki katika mahojiano haya

A: Taarifa muhimu za mshiriki	
Muda wa kuanza mahojiano:	Jina la kituo cha afya
Tarehe ya mahojiano:	Umri
Mkoa ulipozaliwa	Jinsia
Wilaya	Kiwango cha juu cha elimu
Kazi	Ndoa
Njia kuu za kuingiza kipato	Jina la mtafiti
	Muda wa kumaliza mahojiano
	Namba ya mshiriki

B.UELEWA WA WAZAZI /WALEZI KUHUSU UGONJWA WA MTINDIO WA UBONGO

1 Tafadhali nielezee una fahamu nini kuhusu ugojwa wa mtindio wa ubongo

(Dadisi uelewa wa wazazi kuhusu

- Ugonjwa wa mtindio wa ubongo
- Unasababishwa na nini
- Dalili zake ni zipi

2. Tafadhali naomba nielezee utaratibu wa mchakato wa matibabu ya mtindio wa

Ubongo kwa mara ya kwanza ulikuwaje? (Dadisi kuhusu

- Muda wa kugundulika kwa tatizo ,
- Liligulika wapi, ,
- Alipata huduma za matibabu wapi

3. Ni kitu gani kilikupa msukumo wa kutafuta huduma zatiba kwa mwanao? Dadisi kuhusu

- Ushauri toka wa ndugu au,
- Watumishi wa afya au ,
- Hali ya makali ya ugonjwa

C. HUDUMA ZA MATIBABU KWA WATOTO WENYE MTINDIO WA UBONGO

4. Ni matibabu ya namna gani mwanao anapata? Dadisi kuhusu

- Aina ya huduma shufaa
- Huduma shufaa za nyumbani ,
- Huduma shufaa vituo vya afya

5. Vipi kuhusu watoto wengine wenye mtindio wa ubongo kwenye jamii yako hupatiwa matibabu ya namna gani ? Dadisi kuhusu

- Tiba mbadala,
- Tiba shufaa,
- Maombezi

6. Ni kwa kiasi gani mwanao amepata nafuu baada ya tiba shufaa?Dadisi kuhusu mtoto

- Kuweza kusimama/ kutembea,
- Kuongea, na
- Kuongezeka uzito

D. MSAADA WA KIFAMILIA/ KIJAMII KWA WATOTO WENYE MTINDIO UBONGO KUPATA MATIBABU

7. Tafadhali nieleze unapata msaada gani toka kwa wanafamilia juu ya matibabu ya mtoto wako? Dadisi kuhusu

- Msaada wa wazazi na ndugu wengine ,
- Msaada wa kifedha ,
- Msaada toka kwa jamii inayokuzunguka

8 Tafadhali nieleze mahudhurio ya kumpeleka mtoto wako kwenye vituo vya huduma za afya yakoje? Dadisi kuhusu

- Kuzingatia miadi ya watoa huduma,
- Vizuizi gani,
- Sababu gani

9 .Tafadhali nielezee ni kwa kiasi gani wanaume katika jamii yako wanashiriki kufuatilia matibabu ya watoto wenye mtindio wa ubongo? Dadisi kuhusu

- wanaume kuambatana na wenzi hospitali kufuatilia tiba za watoto wao,
- wanaume kuwasidie kinama kuwatunza watoto wenye mtindio wawapo nyumbani

10. Katika jamii yako mtoto mwenye mtindio wa ubongo ana chukuliwaje? Dadisi kuhusu

- Mtazamo wa jamii
- Uelewa
- imani

E: TAMADUNI, DESTURI NA TABIA YA JAMII KATIKA KUTAFUTA HUDUMA ZA TIBA SHUFAA.

11 .Ni kwa namna gani tamaduni na desturi za jamii yako zinachochea kutafuta huduma za kiafya kwa mtoto mwenye mtindio wa ubongo? Dadisi kuhusu

- Utaratibu wa kuanza mchakato wa kutafuta huduma za afya
- Tamaduni, na desturi zinazosaidia kutafuta huduma za afya

11. Ni kwa namna gani tamaduni na desturi za jamii yako zinakuzuia kutafuta huduma za afya kwa mtoto wako. Dadisi kuhusu

- Vizuizi vya kijamii(mtazamo, imani,
- Uelewa

13 Kwa maoni yako una fikiri ni mambo gani yanachochea kutafuta na kwenda kwenye matibabu ya mtoto mwenye mtindio wa ubongo? Dadisi kuhusu

- Kuwezeshwa kifedha
- Usafiri
- Upatikanaji wa huduma shufaa

HEALTH PROVIDER IN DEPTH INTERVIEW GUIDE- SWAHILI VERSION

DODOSO KWA WATOA HUDUMA ZA AFYA KUHUSU HUDUMA SHUFAA KWA WATOTO WENYE MTINDIO WA UBONGO

Utangulizi, ridhaa na kujenga mahusiano:

Hatua 1: jitambulishe

Hatua 2: Baini sifa za mshiriki

Hatua 3: Pata ridhaa ya mdomo (nyaraka inayojitegemea)

Hatua 4: Paza taarifa binafsi za mshiki kwenye dodoso

Hatua 5: Omba kwa mshiki kibali cha kuwasha kinasa sauti

Hatua 6: washa kinasa sauti

Hatua 7: Anza mahojiano

Hatua 8: Mwisho wa mahojiano, mshukuru mshiriki kwa kushiriki na kisha andika taarifa ya mahojiano

Mtafiti: Naitwa Dr. Emmanuel Luchagula. Nakushukuru tena kwa utayari wako wa kushiriki katika mahojiano haya,natarajia kusikia mawazo yako kuhusiana na maswali nitakayo kuuliza.kuhusu ugonjwa wa mtindio wa ubongo

Kabla hatujaanza napenda kuthibitisha utayari wako wa kuridhia kushiriki katika mahojiano

A: Taarifa muhimu za mshiriki	
Muda wa kuanza mahojiano:	Jina la kituo cha afya
Tarehe ya mahojiano:	Umri
Mkoa ulipozaliwa	Jinsia
Wilaya	Kiwango cha juu cha elimu
Kazi	Ndoa
Njia kuu za kuingiza kipato	Jina la mtafiti
	Muda wa kumaliza mahojiano
	Namba ya mshiriki

A: UZINGATIAJI WA HUDUMA ZA TIBA SHUFAA MIONGONI WA WATOTO WENYE MTINDIO WA UBONGO .

1. Tafadhali nieleze ni kwa kiasi gani wazazi wenye watoto wa mtindio wa ubongo wanatilia manani ratiba yao ya matibabu kama walivyopangiwa,Dadisi kuhusu ,

    - Idadi ya mahudhurio
    - Kundi la umri gani linahudhuria zaidi
    - Hali ya makali ya ugonjwa wanaokuja nayo

2. Uanadhani ni sababu gani inayo wasukuma wazazi kuhudhuria matibabu ya watoto wao kama walivyopangiwa. .Dadisi kuhusu

    - Watalaam mahili
    - Huduma bila malipo
    - Upatikanaji wa huduma

3. Kwa maoni yako unadhani ni kwa namna gani mahusiano ya wanandoa yanaweza kuleta msukumo miongoni mwa wazazi katika kuzingatia huduma za tiba shufaa kwa watoto wenye mtindio wa ubongo .Dadisi kuhusu

    - Msaada toka kwa mwenza
    - Ushiriki wa wanaume kuleta watoto kwenye matibabu
    - Unyanyasji wa kijinsia

B; MAZINGIRA YA VITUO VYA KUTOLEA HUDUMA SHUFAA KWA WATOTO WENYE MTINDIO WA UBONGO .

10. Kwa maoni yako unadhani ni mambo gani yaliyopo kwenye vituo vya kutolea huduma yamekuwa vizuzi kwa watoto wenye mtindio wa ubongo Dadisi

    - miundombinu
    - mchakato mrefu
    - vikwazo vya kifedha

11. Ni kitu gani kinachochea mahudhurio ya tiba shufaa kwa watoto wenye mtindio wa ubongo Dadisi kuhusu

    - Huduma rafiki
    - Mda wa kukaa foleni

12. Kwa maoni yako unadhani ni kwa kiasi gani wazazi wenye watoto wa mtindio wa ubong wanao uwezo wa kugharamia matibabu ya watoto wao?Dadisi kuhusu

    - Uwezo wa kulipa.
    - Vikwazo vya kipato

Appendix VI: Consent Forms (English Version)

ID NO……..

PERMISSION FOR A CHILD TO TAKE PART IN RESEARCH

Study title: **FACTORS AFFECTING REGULAR ATTENDANCE TO REHABILITATION CARE AMONG CHILDREN WITH CEREBRAL PALSY AT MUHIMBILI NATIONAL HOSPITAL, AND CCBRT DAR ES SALAAM, TANZANIA**

Introduction:

Your child is being asked to take part in this study because I Dr. Emmanuel Luchagula plan to assess factors that either limit or facilitate attendance to rehabilitation clinic for your child and see the service offered if appropriate to his/her need at Muhimbili national hospital and CCBRT hospital.

Your decision whether or not to allow your child to take part will have no effect on the quality of your child's medical care. Please ask questions if there is anything about this study you do not understand.

What is the purpose of this study?

The purpose of this study is to assess factors that affect regular attendance to rehabilitation care among children cerebral palsy rehabilitation clinic at Muhimbili national hospital and CCBRT hospital

Will you benefit from taking part in this study?

Your child will be a volunteer and might not benefit from being in this research study. However, this study may help to improve rehabilitation care for children in the future.

What does this study involve?

Your child's evaluation as part of this study will be done at clinic. It will involve thorough physical assessment, which include detailed neurological examination weight weighing, height and MUAC measuring in children under five and OFC.

What are the options if you do not want to take part in this study?

Your child's participation in this study is completely voluntary. Your child will continue to receive regular care at the clinic regardless of whether he/she participates in the study.

What are the risks involved with taking part in this study?

There is no any risk in taking part in this study

Leaving the study: You may choose to stop taking part in this study at any time for any reason. If you decide to stop taking part, it will have no effect on your child's medical care

New Information: New information related to this study and specifically new information about your child will be made known to you when it becomes available.

How will your privacy be protected?

The information you provide will be kept strictly confidential. The study information will be stored in protected computer files and in paper records stored in locked filing cabinets. Only study staff will have access to the information. The information will be maintained indefinitely.

Who may use or see your health information?

By signing this form, you allow the research team to use your child's health information and give it to others involved in the research. The research team includes the study director plus others working on this study at either MUHAS or CCBRT hospital.

Your permission to use your child's health information for this study will not end until the study is completed. You may ask for your child's study data at any time.

It is possible for a court or government official to order the release of study data including information about your child.

What if you decide not to give permission to use and share your personal health information?

If you do not allow use of your child's health information for this study, you may not take part in this study.

If you choose to stop taking part in this study, you may cancel permission for the use of your child's health information. You should let the researcher know if you want to cancel your permission. The study team will assist you in putting your wishes in writing. Information collected for the study before your permission is cancelled will continue to be used in the research.

Whom should you call about this study?

If you have questions about this study or need to report a study related injury, you can call: Dr. Emmanuel Luchagula (0784387279) during normal working hours. If you have questions about your rights as a participant, you may contact, Dr Joyce Masalu the Director of Publications and Research, Muhimbili University of Health and Allied Sciences, Research and Publication Committee, P. O. Box 65001, Dar es Salaam, Telephone number 2150302-6

What about the costs of this study?

There will be no costs for you if you agree to have your child participate in the study. All study costs will be supported by the research team

Will you be paid to take part in this study?

There will be no payment for you or your child for participation in the study.

If you agree that your child take part in this study and you sign this consent form, you are not giving up any of your legal rights.

CONSENT

I have read the above information about CEREBRAL PALSY and have been given time to ask questions. I agree to take part in this study and I have been given a copy of this signed consent form.

SIGNATURE

_____

Researcher or Designee Signature and Date Printed Name

_____

Legally Authorized Representative (Parent/legal guardian) and Date Printed Name

Appendix VII: Consent Forms (Swahili Version)

RIDHAA YA KUSHIRIKI KWENYE UTAFITI HUU

Namba ya Utambulisho……

Study title: MAMBO YANAYO ATHIRI MAHUDHURIO YA TIBA SHUFAA KWA WATOTO WENYE MTINDIO WA UBONGO KATIKA HOSPITALI YA TAIFA MUHIMBILI NA CCBRT DAR ES SALAAM, TANZANIA

Utangulizi:

Mtoto wako anaombwa kushiriki katika utafiti huu kwa sababu Mimi Dkt .Emmanuel Luchagula ninafanya utafiti wa kubaini vizuizi vinavyopelekea kuathiri mahudhurio ya tiba shufaa kwa watoto wenye mtindio wa ubongo katika Hospitali ya Taifa Muhimbili. Na CCBRT

Uamuzi wako wa kumruhusu au kutomruhusu mototo wako kushiriki hautakua na athari zozote kwenye ubora wa huduma ya mtoto wako. Tafadhali uliza swali kama kuna kitu usichokielewa kuhusu utafiti huu.

Je dhumuni la utafiti huu ni lipi?

Dhumuni la utafiti huu ni kuchunguza na kubaini vizuizi vinavyapelekea kutokufikia huduma ya mazoezi tiba, . Utafiti huu utatusaidia kuboresha huduma ya mazoezi tiba kwa watoto wenye mtindio wa ubongo kwa siku za usoni

Je utafaidika kwa mwanao kushiriki kwenye utafiti huu?

Mtoto wako atapimwa kwa ridhaaa yako na inawezekana kuwa binafsi asifaidike kwa kuwepo kwenye utafiti huu. Lakini tafiti hizi zitawasaidia watoto wengine siku za mbeleni.

Je Utafiti huu unahusisha nini?

Uchunguzi wa mtoto wako kama sehemu ya utafiti huu utafanyika klinik, atachungulizwa vizuri pamoja na kupima uzito,urefu wake,unene wa mkono wakati na ukubwa wa mzunguko wa kichwa pia atachunguzwa mfumo wa neva.

Je itakuwaje kama hutataka kushiriki kwenye utafiti huu?

Kushiriki kwa mtoto wako kwenye utafiti huu ni hiari kabisa. Mtoto wako ataendelea kupata huduma bila kujali kama ameshiriki kwenye utafiti ama la.

Je kuna athari gani za kushiriki katika utafiti huu?

Hakuna athari yeyote

Kuondoka kwenye utafiti:

unaweza kuamua kusitisha kuendelea kushiriki kwenye utafiti huu muda wowote na kwa sababu yoyote. Kama utaamua kuacha kushiriki hautaathiri huduma za afya kwa mtoto wako.

Maelezo mapya

Maelezo mapya kuhusiana na utafiti huu na hasa maelezo mapya kuhusu mtoto wako utajulishwa mara tu yatakapokuwa yamepatikana.

Utunzaji wa siri?

Habari mtakazotoa wewe na mtoto wako pamoja na majibu ya vipimo yatatunzwa kwa usiri mkubwa. Habari zihusuzo utafiti zitatunzwa kwenye kompyuta zenye ulinzi na rekodi, zilizopo kwenye makaratasi zitatunzwa kwenye makabati yanayofungwa. Ni wafanyakazi wanaohusika na utafiti tu ndio watakaoweza kuona taarifa, na taarifa hizi zitatunzwa siku zote.

Ninani anaweza kutumia au kuona taarifa zako za afya?

Kwa kuweka sahihi kwenye fomu hii umeruhusu watafiti kutumia taarifa za afya za mtoto wako na kuwapatia wengine wanaohusika na utafiti huu. Watafiti ni pamoja na mwendesha utafiti pamoja na wengine wanaohusika na utafiti huu ambao ama wapo chuo kikuu cha muhimbili au kituo cha CCBRT.

Ruhusa ya kutumia taarifa za afya za mtoto wako itaisha wakati utafiti utakapokamilika. Unaweza kuomba taarifa za mtoto wako wakati wowote.

Inawezekana mahakama au afisa wa serikali akaamuru kuonyeshwa kwa taarifa za utafiti ikiwa ni pamoja na taarifa za mtoto wako

Je itatokea nini kama utaamua kutotoa ruhusa ya kutumia na kushirikisha wengine taarifa zako za afya ?

Kama hautaruhusu taarifa ya afya ya mtoto wako zitumike, hautaweza kushiriki kwenye utafiti huu.

Kama utachagua kuacha kushiriki katika utafiti huu, unaweza kufuta ruhusa ya matumizi ya taarifa za afya za mtoto wako. Watafiti watakusaidia kuweka matakwa yako kwenye maandishi. Taarifa zitakazokuwa zimekusanywa kabla ya kufuta ruhusa zitaendelea kutumika kwenye utafiti.

Je utampigia nani kuhusu utafiti huu?

Kama una maswali kuhusu utafiti au ukiwa na haja ya kuripoti athari zitokanazo na utafiti, unaweza kumpigia daktari wako au mwendesha utafiti huu: **Dr. Emmanuel Luchagula (0784387279) muda wa masaa ya kazi.** Kama una swali kuhusu haki zako kama mshiriki unaweza kuwasiliana na **Mkurugenzi wa Kamati ya Kitengo cha Utafiti, Chuo Kikuu Cha Sayansi na Tiba Cha Muhimbili, S.L.P 65001, Dar es Salaam, Namba ya Simu 2150302-6**

Je kuna gharama juu ya tafiti huu?

Hakuna gharama kama utakubali mtoto wako ashiriki kwenye utafiti huu. Watafiti na Chuo kikuu cha Muhimbili watasaidia gharama zote za utafiti .

Je utalipwa kwa kushiriki kwenye utafiti:

Hapatakuwa na malipo kwako au mtoto wako kwa kushiriki kwenye utafiti

Kama utakubali mtoto wako ashiriki kwenye utafiti huu na ukasaini fomu hii ya ridhaa, haujiondolei haki yoyote ya kisheria.

Appendix VIII: Consent Forms (Swahili Version)

FOMU YA KUKUBALI KUSHIRIKI KWENYE UTAFITI HUU

Namba ya Utambulisho……

Study title: MAMBO YANAYO ATHIRI MAHUDHURIO HUDUMA YA TIBA SHUFAA KWA WATOTO WENYE MTINDIO WA UBONGO KATIKA HOSPITALI YA TAIFA MUHIMBILI NA CCBRT DAR ES SALAAM, TANZANIA

UKUBALI

Nimesoma maelezo hapo juu kuhusu utafitiwa vizuizi vinavyopelekea kuathiri mahudhurio ya tiba shufaa kwa watoto wenye mtindio wa ubongo nimepewa muda wa kuuliza maswali. Nakubali kushiriki katika utafiti huu na nimepewa fomu ya ridhaa hii iliyowekwa sahihi

Sahihi

_____

Sahihi ya mtafiti au kaimu na tarehe Jina kamili

_____

Sahihi ya mwakilishi wa kisheria (mzazi/mlezi) na tarehe Jina kamili