PREVALENCE OF AND FACTORS ASSOCIATED WITH EPILEPSY IN CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL; A DESCRIPTIVE CROSS-SECTIONAL STUDY

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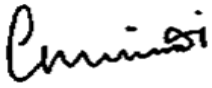
A RESEARCH DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT FOR THE AWARD OF MASTERS OF MEDICINE IN PAEDIATRICS AND CHILD HEALTH FACULTY OF HEALTH SCIENCES, UNIVERSITY OF NAIROBI.

2023

DECLARATION

This dissertation is my original work and has not been submitted for any academic award or published in any other university or any other institution of higher learning for the award of a degree.

Dr. Caroline Muindi

Signature:  **Date:** 18th January 2023

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ACKNOWLEDGEMENT

First and foremost I wish to thank the Almighty God for letting me through all the difficulties. I have experienced your guidance day by day.

I am deeply indebted to my mentor and supervisor Dr. Beatrice Mutai for her invaluable patience and feedback. Your immense knowledge on research aided the completion of this dissertation.

Many thanks to Dr. Lawrence Owino. The completion of this study would not have been possible without your expertise.

I am grateful to Dr. Maureen King'e for her constant encouragement when times got rough. I could not have undertaken this journey without your guidance. The extra effort you put in this document is much appreciated.

I wish to acknowledge the hard working and dedicated healthcare workers at the Kenyatta National Hospital, may the Almighty God bless you abundantly. To my research assistant Eugene Makori and statistician Mr. Kelvin Nyongesa, thank you for your hard work, integrity and dedication.

To all my classmates who have supported me in completing my dissertation, I couldn't have made it without you!

Lastly I would be remiss in not mentioning my family. Their belief in me has kept my spirit and motivation high during this process.

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ABBREVIATIONS

AEDS: Anti-Epileptic drugs

CI: Confidence Interval

CP: Cerebral Palsy

CT Scan: Computed tomography scan

EEG: Electroencephalogram

ERC: Ethics Review Committee

GMFCS (E & R): Gross Motor Function Classification System expanded and revised

GTCS : Generalized Tonic Clonic seizures

KNH: Kenyatta National Hospital

MRI: Magnetic resonance imaging

OT: Occupational Therapy

PI: Principal Investigator

PT: Physiotherapy

SD: Standard Deviation

SPSS: Statistical Package for Social Sciences

UON: University of Nairobi

WHO: World Health Organization

DEFINITION OF TERMS

Caregiver is someone that is engaged in giving child care and meeting his or her needs based on their abilities.

Cerebral Palsy: is a group of disorders that affect a person's ability to move and maintain balance and posture (1).

Epilepsy is a central nervous system (neurological) disorder in which brain activity becomes abnormal, causing seizures or periods of unusual behaviour, sensations and sometimes loss of awareness (2).

ABSTRACT

Background: Cerebral palsy (CP) is one of the most common neurologic disorders in children, often complicated with other disabilities. These include epilepsy, intellectual disability and feeding disorders. Epilepsy is the most commonly associated comorbidity and often confers a poor prognosis compared to those without epilepsy

Aim and objective: This study aimed to determine the prevalence of epilepsy and associated factors among children diagnosed with cerebral Palsy at the Kenyatta National Hospital.

Methodology: This hospital based cross sectional study that was conducted at Kenyatta National Hospital, enrolled 156 children aged 12 months to 12 years with diagnosis of cerebral Palsy receiving services at the physiotherapy clinic, occupational therapy clinic and paediatric wards. A structured questionnaire was used for data collection. The questionnaire included questions on demographic factors of mother and child, cerebral palsy diagnosis and Gross Motor Function Classification System (GMFCS) assessment.

Results: The prevalence of Epilepsy among Cerebral palsy children was 63% ,95% CI:55.4-71%. Among CP patients with epilepsy, 62.6% were female, 49.5% were resuscitated at birth, 76.8% were admitted to Newborn Unit, 54.5% had quadriplegia while 75.8% had spastic CP. The findings also revealed that 59.6% of the children had neurologic impairment severity grade IV – V. Multivariable analysis revealed that admission into New Born Unit and GMFCS score IV – V were independently associated with epilepsy in CP (AOR =12.31, 95%CI: 5.55 – 98.07, p =0.018), GMFCS classification (IV-V), AOR =3.64, 95%CI: 1.69 – 19.14, p<0.001)

Conclusion and recommendations: The prevalence of epilepsy in CP patients is high occurring in more than half of the patients. The predominant seizure type was generalized seizures. Other associated clinical manifestations included spasticity and severe neurological impairment (GMFCS IV and V). The associated risk factors for epilepsy in CP included birth asphyxia and admission in to NBU. There is need for routine screening for epilepsy among children with cerebral palsy with a history of birth asphyxia and severe neurological impairment.

1. CHAPTER ONE: INTRODUCTION

1.1.Background

Cerebral palsy is a leading cause of disability in childhood and is one of the three most common lifelong disabilities in children. It is defined as a group of non-progressive but often changing motor impairment syndromes secondary to lesions of the brain which occur during the early stages of development (3). In Europe the incidence of cerebral palsy averages two per 1,000 livebirths (4). CP occurs at a frequency of 1.5 to 3.0 per 1000 children in the United states (5). The physiological classification groups CP into four main categories which include ataxic, dyskinetic, spastic and mixed types on the basis of major motor abnormality while topographical classification divides them into monoplegia, diplegia, triplegia, quadriplegia, paraplegia, and hemiplegia, indicating involved extremities. (6).

Although posture and mobility involvement are the fundamental difficulty in children with cerebral palsy, these children frequently have various neurological abnormalities that further impede growth, schooling, ambulation, and eventual social integration. These deficits include epilepsy, learning disabilities, visual defects, hearing impairment, feeding disorders and speech defects (7). Epilepsy most commonly occurs in spastic CP and rarely in the ataxic and dyskinetic syndromes. In children with CP, epilepsy occurs in around 15-90 percent depending on setting, with higher prevalence in socio-economically deprived populations globally (8).

Epilepsy is a common childhood neurological disorder (2). According to the World Health Organization (WHO), approximately 10% of the global population who live a normal lifespan can expect at least one epileptic seizure in their lifetime. Around 50 million people globally suffer from epilepsy, including an estimated 2.5 million children. In most of these cases, approximately 85% occur in developing countries (9). However, there is a much higher proportion of epilepsy in children with CP. The prevalence of epilepsy in cerebral palsy is lower in advanced settings. In Italy, among children who had CP and epilepsy, 27% had spastic

quadriplegia, 42% had spastic hemiplegia, 12% had spastic diplegia and 15% did not have a well-defined type of CP. The frequency of epilepsy was higher in children with CP who showed major motor dysfunction (GMFCS IV–V types) (6). The prevalence has been higher in low- and middle-income countries. In Indonesia, the prevalence of epilepsy in spastic CP was 39% (10). Another study conducted in Egypt found that the prevalence of epilepsy in children with CP was 48.9% (11). Studies conducted in Sub-Saharan Africa have also shown high prevalence of epilepsy in children with CP (12). A study conducted in Nigeria revealed a prevalence of 46% (13). There are various factors that are associated with epilepsy in children with CP. The common associated factors include central nervous system infection, the occurrence of seizure in the first year of life, abnormality of EEG and spastic CP (13), (6).

2. CHAPTER TWO: LITERATURE REVIEW

2.1.Epidemiology of epilepsy in cerebral palsy

Cerebral palsy is the most common form of chronic physical disability in childhood; prevalence is variable and estimated at 1.5 to 3 per 1000 live births (4, 5). Epilepsy is one of the most common neuro-impairment in childhood (2). According to the World Health Organization (WHO), Around 50 million people globally suffer from epilepsy, including an estimated 2.5 million children (9).

Rahmat et al in Indonesia found that the risk factors for epilepsy in spastic CP were central nervous system infection, the occurrence of seizure in the first year of life, and abnormality of EEG (10). CP is classified into four main groups physiologically which include ataxic, dyskinetic, spastic and mixed types. The commonly occurring type of CP is spastic diplegia (14). Spastic CP results mainly due to injury to the under-developed oligodendroglia within 20 and 34 weeks of gestation. The risk of occurrence decreases with increasing gestational age with higher incidence in preterm compared to term infants. These abnormalities can be effectively determined on a Magnetic Resonance Imaging (MRI) which is essential in showing the extent of periventricular leukomalacia and multicystic cortical encephalomalacia (15). It has also been determined that some children with less severe spastic diplegia are more likely to have normal cognitive function and are capable of independent ambulation. Spastic hemiplegia affects approximately 25% of children having CP. In most cases, spastic diplegia occurs due to in utero or perinatal stroke (16).

Dyskinetic CP is also referred to as athetoid CP (17). This type of CP has negative effect on movement since it affects power in both the upper and lower limbs. Children with this type of CP have twisting, abrupt movements (18). This type of CP occurs from injury to the basal

ganglia. The underlying different forms of dyskinesia occurs due to slight variations in the type and extent of injury to different structures within the basal ganglia (19).

Ataxic CP is a form of CP that affects control and coordination of movement by an individual. Movements are characterized by clumsiness, imprecision or instability (18). The movements are not smooth and appear disorganized. The incoordination that occurs in this context becomes more apparent when an individual attempt to perform voluntary movements such as walking. Ataxic CP is mainly caused by abnormal brain development, bleeding in the brain or damage to the white matter of the brain (20).

Epilepsy is a common comorbidity seen among children with CP. Incidence is higher in low- and middle-income countries. In Indonesia, Rahmat et al reported prevalence of epilepsy in spastic CP of 39%(92 among 236 children). This was a retrospective study carried out at the Neurologic outpatient clinic at the department of child health in Cipto Mangunkusumo. Data was obtained from medical records were all study participants were spastic CP patients registered at the facility between 2003 to 2008. (10). Another study conducted in Egypt by EL-Tallaway et al found that the prevalence of epilepsy in children with CP was 48.9%. This was a cross-sectional ,descriptive, population-based case control study. A sample size of 98 children with CP (with or without epilepsy were compared with 180 healthy children. 48(48.9%) among the 98 children who had CP had epilepsy while 50(51.02%) had no epilepsy. The children were enrolled from two regions in Egypt and only those who had lived in the 2 regions for 6 months at the time of the interview were eligible. The case control group was derived from same population with matched sex, age ,education level and social demographic state (11). Studies conducted in Sub-Saharan Africa have also shown high prevalence of epilepsy in children with CP (12).

A study conducted in Nigeria by Ejeliogu et al in 2020 revealed a prevalence of 46.3% and spastic CP accounted for more than half of the patients (13). It was a hospital based cross-sectional study which enrolled 162 Children with CP aged >12 years attending paediatric Neurology clinic. The factors most commonly associated with epilepsy in this study were history of central nervous system infection, the occurrence of seizure in the first year of life, abnormalities on EEG and spastic CP (6), (13).The prevalence of epilepsy was higher among children admitted with acute seizures than in those without seizures (21). In Kenya, Spastic CP is the most common type of CP and affects approximately 80% of children with CP. There is however, limited information on the prevalence of epilepsy in children with CP in Kenya which forms the basis of this study. Globally epilepsy is highly prevalent in patients with spastic hemiplegia and affects 42% of children with all types of CP. In addition, risk of epilepsy is higher in children who showed major motor dysfunction (GMFCS IV-V types) (6).

A retrospective study conducted by Singhi et al. in India investigating for presence of epilepsy among school children with cerebral palsy revealed that, out of the 452 children aged between 1 and 14 years, 160 (35.4%) had epilepsy. The highest incidence (66%) was seen in children with spastic hemiplegia, followed by those with spastic quadriplegia (42.6%) and spastic diplegia (15.8%) (22).

Furthermore, a retrospective study conducted in Kosovo by Hundozi-Hysenaj and Boshnja Dallku in university clinical centre of Kosovo in Pristinina, over a 5 year period investigating for epilepsy in children with CP revealed that CP was associated with epilepsy in 40% of participants 46% of whom had spastic quadriplegic CP; 27.0% had diplegic CP; and 23.8% had hemiplegic CP. Among children with spastic quadriplegia , there was no significant association between epilepsy and gender (45.2% of females had epilepsy compared to 46.9% of males) (23).

Rahman et al in a cross-sectional study conducted in Bangladesh in 2020 revealed that, out of 400 children studied, 150 had associated epilepsy, giving a prevalence rate of 37.5%. Further assessment revealed that, children who were most commonly affected by epilepsy were those with spastic quadriplegia (43.5%). Generalized tonic–clonic seizure (GTCS) disorder was the most common type of epilepsy seen in spastic quadriplegic CP followed by partial seizures which were more common in spastic hemiplegic CP (21).

2.2.Other comorbidities in cerebral palsy

Besides movement and motor dysfunction, many children with cerebral palsy have associated comorbidities such as seizures, hearing and vision impairment, feeding and swallowing difficulties and intellectual disability(24). All these associated neurological abnormalities further impede growth, schooling, ambulation, and eventual social integration.

Duke et al. in a population based cross-sectional study conducted in Nigeria revealed that, the common comorbidities that were detected among children with CP include speech impairment which occurred in 85 percent of children, feeding difficulties in 86 percent, swallowing difficulties in 77 percent, learning difficulties in 88 percent, abnormal behavior in 62 percent, visual acuity impairment in 54 percent, communication difficulties in 45%, epilepsy in 35 percent and malnutrition which occurred in 51 percent of the children (25).

2.3.Clinical presentation of epilepsy among children with Cerebral palsy

A retrospective study conducted by Singhi et al. in India found that among children with CP who had epilepsy, seizures began at an average age of 18.9 months, with 64 (60%) beginning before the age of one year. Seizures started earlier in childhood in children with myoclonic seizures and infantile spasms (P.01). The most prevalent type of seizure was generalized seizures, followed by partial seizures, infantile spasms, and other myoclonic seizures.

The study in Nigeria by Ejeliogu et al, found that, the mean age at the onset of seizure was 1.52±0.43 years. Among children with epilepsy, 69% had their first seizure before 1 year of age while 34% had a history of neonatal seizures. The commonest type of epileptic seizure seen was generalized tonic-clonic seizures in 44% of participants, followed by focal seizures in 40% myoclonic seizures in 6% and epileptic spasms in 4%.The findings further revealed that focal seizures were predominantly seen in spastic hemiplegic CP while generalized seizures predominated in other types of CP (13).

2.4.Factors associated with Epilepsy in children with CP

There are varied factors that are associated with epilepsy in children with cerebral palsy.

In a nationwide based cross-sectional study conducted in Taiwan, epilepsy in children with CP was found to be common in families with lower insurance premiums, rural residence and these children were more likely to have neuropsychiatric disease which included retardation, hearing impairment as well as hydrocephalus (26).

A prospective study conducted in United Arab Emirates revealed that the most prevalent type of CP associated with seizures was spastic tetraplegia, while the most common variety of CP was spastic diplegia. In comparison to infants without CP, children with CP began having seizures within the first year of life. Children with CP and epilepsy reported a higher incidence of new-born seizures, severe developmental delays, major abnormalities on brain imaging, and the requirement to take more than one antiepileptic medicine. The study revealed that, 78% of the children had generalized tonic clonic seizures, and 39% had focal epileptic discharges with or without secondary generalization on the electroencephalogram (EEG). In comparison to the control group of children with seizures and no CP, the overall control of seizures in children with CP was poor, necessitating a longer course of anticonvulsant drugs, polytherapy, and a higher frequency of refractory seizures and admissions for status epilepticus (27).

Another cross-sectional study in Nepal by Thapa revealed that epilepsy in CP was independent of socio-economic status of children's parents. The study looked at the use of medication and found that 29% of children were not taking their anti-epileptic drugs because of financial reasons and only 38% were seizure free (28). Gurkan et al. in a study conducted in Turkey, in 2018, found that risk of epilepsy in children with CP was associated with gestational age, delivery method, birth weight, duration of stay in neonatal intensive care unit as well as the need for ventilation (29).

In a retrospective study conducted by Karatoprak et al. in 2019, it was found that history of epilepsy in the family, history of neonatal seizure during the first 72 hours of life, severe degree of motor function, and quadriplegic type of CP were significantly associated with epilepsy in children with CP(30). A study conducted in Nigeria identified the risk factors associated with epilepsy in CP as presence of seizure in the first year of life, neonatal seizure and spastic CP (13). The study by Rahman et al revealed that there was positive correlation between low birth weight, and post-natal central nervous system infection with the occurrence of epilepsy in CP children. However, the results showed no significant relationship between prematurity, neonatal jaundice, neonatal sepsis, neonatal convulsion and the risk of developing epilepsy in CP (31).

Another study in Europe by Zelnik et al in 2010 revealed that within the first 12 months of life, about half of all epileptic children had experienced their first seizure. Seizures in infancy were a substantial predictor of epilepsy. Epilepsy was also predicted by the presence of at least one aberrant anatomical result (especially brain atrophy). Low Apgar scores at 5 minutes after birth and term births were also more common in epilepsy patients, although Apgar score was not significantly associated when investigators controlled for other risk variables. Mode of delivery, head circumference, adjusted birth weight, gender and ethnic group, consanguineous marriage, and prematurity were not identified as risk factors for epilepsy in these children (32)..

2.5.Study Justification

Cerebral palsy is heterogeneous disorder affecting tone, posture and movement due to injury to the immature developing brain. It is a common problem of major public health concern among children and has been associated with increased financial burden to caregivers (34).

In addition to movement and motor disorders, many children with cerebral palsy have associated comorbidities such as seizures, speech, hearing and vision impairment, feeding and swallowing difficulties and cognitive impairment. Epilepsy is the most commonly associated comorbidity reported among children with CP. Children with Cerebral Palsy and Epilepsy often have poor prognosis compared to those without epilepsy.

Early identification and appropriate management of epilepsy in this group of children is essential towards improving quality of life for the patient and family. At the Kenyatta National Hospital an average of 10 children with Cerebral Palsy are admitted monthly due to complications associated with comorbidities while an average of 30 and 20 children with CP are seen in the Occupational therapy and Physiotherapy department per month respectively. There is limited data on prevalence of epilepsy among children with CP at KNH as well as on associated factors. Identifying factors associated with epilepsy will provide useful data for early identification of children at risk hence aid in control of epilepsy and minimize impact on affected patients as well as improve the family's quality of life.

2.6.Research questions

i. What is the prevalence of and factors associated with Epilepsy in children with cerebral palsy at Kenyatta National Hospital?

ii. What is the clinical presentation of Epilepsy among children with Cerebral palsy at Kenyatta National Hospital?

2.7.Objectives

2.7.1. Primary objective

To determine the prevalence of epilepsy in children with cerebral palsy receiving services at Kenyatta National Hospital.

2.7.2. Secondary objectives

1. To describe clinical presentation of Epilepsy among children with Cerebral palsy at Kenyatta National Hospital.
2. To determine patient factors associated with epilepsy in children with cerebral palsy at Kenyatta National Hospital

3. CHAPTER THREE: METHODOLOGY

3.1.Research design

This was a hospital based cross sectional study.

3.2.Study setting

The study was conducted at Kenyatta National Hospital between August to November 2022, at the pediatric wards, and the physiotherapy and Occupational therapy clinics. Kenyatta National hospital is the largest referral hospital in Kenya with a bed capacity of 1,800 and approximately 6,000 staff. The hospital is located in Nairobi County in Kenya. The KNH Pediatrics wards admit an average of 10 cerebral palsy patients per month; while on average 20 children with CP are seen at the physiotherapy clinic per month and 30 are seen at the Occupational Therapy Clinic. A spot check at the pediatric Neurology clinic revealed that all the 12 patients with CP who were seen at the clinic on that particular day had seizure disorders, and the Neurology clinic was excluded in the study as including this clinic would create selection bias and not give a true representation of the actual prevalence of epilepsy among children with CP at KNH.

3.3.Study Population

The study population constituted children aged 12 months to 12 years with diagnosis of Cerebral Palsy seen at the Kenyatta National Hospital physiotherapy clinic, occupational therapy clinic and paediatric wards.

3.4.Eligibility criteria

3.4.1. Inclusion criteria

- Children aged 12 months to 12 years with clinical diagnosis of CP documented in their medical files and met the criteria for diagnosis of Cerebral Palsy based on case definition provided in the CDC guidelines for Cerebral Palsy.

- Children whose guardians provided informed consent for participation

3.4.2. Exclusion criteria

- Children whose caregivers declined to consent.

3.5.Case definition

Cerebral palsy: was defined as a group of disorders that affect individual's ability to move (impaired movement associated with exaggerated reflexes), maintain balance (floppiness or spasticity of the limbs and trunk) and posture (unusual posture, involuntary movements, unsteady walking) as outlined in the CDC guidelines (1)

Epilepsy: was defined as having a history of two or more unprovoked seizures > 24 hrs apart at any time prior to the study period as defined in the International League Against Epilepsy (ILAE) guidelines, having documented clinician's diagnosis of Epilepsy in the child's medical records or EEG reporting epileptiform discharges (3).

3.6.Sample size determination

Sample size was determined using Fischer's formula.

$$n = \frac{Z\alpha^2\, p\,(1-p)}{d^2}$$

n= estimated minimum sample size

p= proportion of children with CP that we estimated to have Epilepsy = 0.35. A study conducted by Duke et al. (2021) revealed that the prevalence of epilepsy in children with cerebral palsy was 35% (25).

d= 5% margin of error

Zα = standard normal deviate for 95% confidence interval =1.96

Thus, substituting the formula,

$$n = \frac{1.96^2 * 0.35 * 0.65}{0.05^2}$$

0.873964/0.0025

n= 350

There are approximately 280 cerebral palsy patients seen at Kenyatta National Hospital occupational therapy and physiotherapy clinics and wards within a three-month period.

Thus, introducing a correction for finite population,

$$n = \frac{n_0}{1 + \frac{(n_0 - 1)}{N}}$$

Therefore

n = 350/(1+ 1.2464)

dd= 155.8

Thus, sample size of 156 was considered.

3.7.Sampling technique

Consecutive sampling technique was used to achieve the desired sample size.

3.8. Study Variables

Independent variables: The independent variables that were investigated in the study include the maternal characteristics: Marital status, education level, occupation and household income; and place of residence. The obstetric characteristics included: mode of delivery, and place of delivery. Neonatal characteristics included gender, age, gestational age at birth, birth weight, duration since diagnosis, type of CP and, age at first seizure.

Dependent variable: The primary study outcome was Prevalence of epilepsy among children with CP.

Secondary study outcomes of interest were: clinical presentation of Epilepsy including; age at first seizure occurrence, presentation of seizure (seizure type), type of CP, and the patient factors associated with epilepsy in children with cerebral palsy including; complications at

birth needing resuscitation, NBU admission, jaundice, CNS infection, type of cerebral palsy, severity of neurological impairment (GMFCS level) and findings on brain imaging.

3.8.Data collection tool

An interviewer administered structured questionnaire was used to collect information on relevant study variables as reported by the caregivers of children. The questionnaire was pre-tested prior to study conduct. Data on the following study variables on maternal and patient characteristics were obtained using the questionnaire as indicated on the study variables. Patient files were accessed to extract information relating to children's treatment history and diagnosis of epilepsy.

3.9.Research assistant

The principal investigator recruited a clinical officer with experience in research methods and data collection as a research assistant to help in the data collection process. The PI and research assistant underwent basic training on identification of CP and associated comorbidities, research procedures and research ethics and were trained on physiological and topographical classification of CP, grading of CP severity and clinical evaluation for epilepsy in children with CP using a curriculum developed by a Postgraduate student undertaking a Fellowship in Neurology at the University of Nairobi. The principal investigator oversaw the data collection to ensure quality control of data obtained by research assistant. In addition, the PI also reviewed all the filled questionnaires daily to ensure completeness.

3.10. Data collection procedure

The principal investigator together with the research assistant approached parent/caregivers at the pediatrics wards, physiotherapy and Occupational therapy clinics at KNH after identifying patients with diagnosis of CP from the medical files. The PI /research assistant explained about

the study to all those potential respondents with key emphasis on the purpose of the study, benefits of participating in the study, the risks involved, the level of privacy and confidentiality that would be accorded to them if they agreed to participate. Screening for CP was done for all potential participants were the investigators evaluated children for movement, posture and balance disorders based on the case definition for CP. Only patients who met the screening criteria for CP were recruited in the study. After obtaining informed consent from caregivers, a copy of the signed consent form was given to caregivers for their own reference. Patient characteristics of interest were extracted from children's medical files. For determination of presence of epilepsy, the following criteria was considered. History of two or more unprovoked seizures > 24 hrs apart at any time from 1 month of age to the time of the study. The diagnosis of epilepsy as documented in the children's medical records was also used to determine presence of Epilepsy. Available results from imaging such as EEG, brain CT and MRI scans were documented.

The PI and research assistant further contacted a physical and Neurological exam to ascertain the physiological and topographical classification of cerebral palsy. Participants were further assessed for severity of CP using the Gross motor function classification system revised and modified (GMFCS R & E) scale.

3.11. Quality assurance

During data collection process, all filled questionnaires were checked for completeness every day. Further follow-up was done on the participants record to obtain any missing data.

3.12. Data management

3.12.1. Data entry and cleaning;

Quantitative data entry was done using a structured questionnaire. The raw data was cleaned, coded and compiled in to a single excel and exported in to a single package for ease of analysis.

Epi data version 3.1 was used for data entry. Each of the responses were serialized to ensure that it is accurately entered and can be traced as well. Thereafter, the cleaned data was exported to the Statistical Package for Social Sciences (SPSS28) version 28 for analysis.

3.12.2. Data storage

Filled questionnaires were stored in a lockable cabinet only accessible to the Principal Investigator. Data was stored in a flash disk for back up and protected using a password in a computer. Only the researchers, statistician and study supervisors had access to the data. The PI had the rights to share the study dataset with any other interested party for the purpose of learning and knowledge management.

During data analysis, confidentiality was ensured by recruiting a qualified statistician who analysed the data based on the underlying objectives. The data was stored in a password protected computer where access was only with permission from the PI. The data was encrypted and stored on an online server for privacy and confidentiality. The data was not containing any participant identifiers hence the identity of the study respondents was not exposed during analysis stage.

The Data including the consent forms will be stored in a safe cupboard for a period of five years after which the hard copy papers will be shredded into pieces, and the soft copy data will be stored in the repository.

3.12.3. Data analysis

The SPSS version 28 program was used to analyse the data. All comparisons were made at a significance level of 0.05. Both descriptive and inferential analysis was used in the analysis.

Categorical data was examined and depicted in bar graphs and pie charts using frequencies and percentages. The mean (SD) or median (IQR) were used to describe continuous data. This was represented in frequency tables.

Fisher's exact tests or Pearson chi-squire were used to test for associations between categorical variables. Two sample Independent t-test was used to compare for differences between continuous independent variables

Odds ratio was obtained to determine the magnitude of the association between independent and dependent variables. Multivariable logistic regression was used to determine factors associated with epilepsy while controlling for potential confounders

3.13. Ethical Consideration

Approval to conduct this study was sought from KNH-UoN Ethics Committee and Kenyatta National Hospital for permission to collect data. Participation in the study was purely voluntary and thus only those caregivers who consented to have their children participate in the study were recruited. The researcher did not coerce anyone to participate in the study but focussed on willingness of the respondent to participate.

The purpose of the study was explained to the respondents which included, assessment of benefits and potential risks of participation in the study. Thus, the patients who met the inclusion criteria and parent/caregiver agree to participate in the study were required to consent. This study upheld strong emphasis on confidentiality and anonymity which is foundation of ethical research. The researcher also maintained anonymity and confidentiality by using none identifiers such as codes that cannot link a participant with the information provided during the study. The information obtained was solely for the purpose of this study and improving care and not to divulge personal information to the public. Recorded data was under custody of the principal researcher.

3.14. Dissemination of findings

The findings from the study will be presented to faculty and students at the Department of Paediatrics and Child health, University of Nairobi as well as Kenyatta National hospital

management. The findings will also be submitted for publication in a peer reviewed journal as a way of disseminating knowledge on local prevalence of epilepsy in CP to other healthcare practitioners.

4. CHAPTER FOUR: RESULTS

4.1.Introduction

The study investigated the prevalence of epilepsy and associated factors among children with Cerebral palsy at Kenyatta National Hospital. A total of 173 patients were screened, eleven caregivers declined to give consent and six patients did not meet criteria for CP diagnosis. Thus, 17 patients were excluded. A total of 156 participated in the study.

The remaining 156 participants were enrolled, questionnaires were completed and returned for analysis representing 100% response rate. Participants were drawn from 3 areas namely, Occupational therapy clinic 66% (n==103), Paediatric wards 19.9% (n=31) and physiotherapy department 14.1% (n=22).

4.1.1. Study flowchart

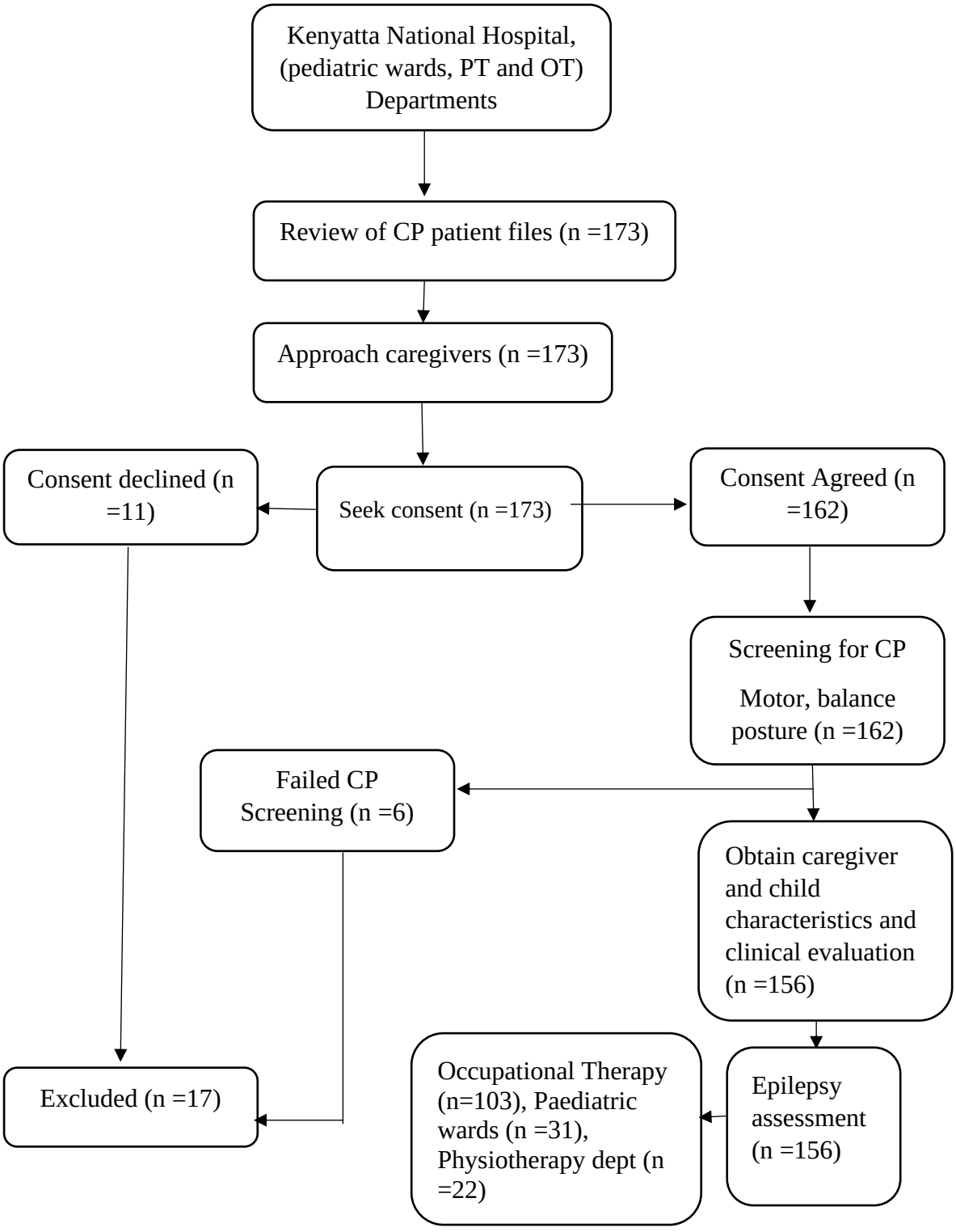


Figure 4.1: Study Flow chart

4.1.1. Socio demographic characteristics of children with cerebral palsy at Kenyatta National hospital

The median age of children was 3.6 (IQR: 1.8 – 5.7) years, and 38.5%(n =60) of the patients were aged between 3 to 5 years. Majority of the children 64.1%(n =100) were female, 94.9%(n =148) were born in hospital. Half of the respondents, 51.3%(n =80) of the children were born through spontaneous vaginal delivery, 39.1%(n =61) of the children were born prematurely, 58.3%(n =91) of the children had history of admission into new-born unit post-delivery as shown in Table 4.1.

Table 4.1:Socio-demoghraphic characteristics of children with cerebral palsy at Kenyatta National hospital

	Frequency (n)	Percent (%)
Age (Median, IQR)	3.6(IQR:1.8 – 5.7)	
<2 years	60	38.5
3 - 5 years	60	38.5
>5 years	36	23.1
Gender of child		
Male	56	35.9
Female	100	64.1
Place of birth		
Home	1	0.6
Hospital	148	94.9
Born before arrival	7	4.5
Mode of delivery		
Spontaneous vaginal delivery	80	51.3
Assisted vaginal delivery	15	9.6
Caesarean section	61	39.1
Prematurity	51	32.7
Low birthweight	27	17.3
Management performed		
Resuscitation	57	36.5
NBU admission	91	58.3
Assisted ventilation	22	14.1
Complications observed at birth		
Jaundice diagnosis	11	7.1
Central nervous system infections	7	4.5
Other neonatal infections	11	7.1
Seizures	17	10.9

4.1.2. Socio-demographic characteristics of the care givers

The findings revealed that 68.5%(n =107) of the caregivers were biological mothers to the children, and 78.8%(n =123 of the caregivers were from two parent household. Further analysis revealed that 42.3% (n =66) of the primary caregivers had secondary level education. The average monthly income analysis revealed that 66.9%(n =109) earned between Ksh10,000 and 50,000, 62.8%(n =98) of the caregivers were residing in urban setting as shown in Table 4.2.

Table 4.2:Socio-demographic characteristics of caregivers of children with CP at KNH

Demographic factors	Frequency (n)	Percent (%)
Caregiver relationship with child		
Biological mother	107	68.6
Biological father	29	18.6
Guardian	20	12.8
Family unit		
Single parent	33	21.2
Two parent household	123	78.8
Caregiver education level		
Primary level	52	33.3
Secondary level	66	42.3
Tertiary	38	24.4
Average monthly household income		
Less than Ksh.10,000	34	21.8
Ksh 10, 000 - 50,000	109	69.9
Ksh. 50,001 - 100,000	9	5.8
>Ksh 100,000	4	2.6
Place of residence		
Rural	58	37.2
Urban	98	62.8

4.1.3. Clinical presentation among children with cerebral palsy presenting at KNH

The findings revealed that 69.2%(n =108) of the children had their first seizure at age less than 12 months. The common presentations of seizures were generalized seizures 45.5%(n =71) and partial seizures 37.2%(n =58). The findings also showed that 55.8%(n =87) of the children had severity of neurologic impairment of between GMFCS IV – V while 44.2% (n=69) had severity

score grades 1-III. In investigating types of CP, quadriplegia was the common topographical type 53.8% (n =84) while spastic was common physiologic type 71.8%(n =112) as shown in Table 4.3.

Table 4.3:Clinical presentation of cerebral palsy among children presenting at KNH

Classification	Frequency	Percent
Time of first seizure after birth		
<12 months	108	69.2
≥12 months	33	21.2
Do not know	15	9.6
Presentation of the seizure		
Sudden falls	5	3.2
Generalized seizures	71	45.5
Partial seizures	58	37.2
Absence Seizures	15	9.6
Abnormal behaviour	7	4.5
GMFCS		
I - III	69	44.2
IV - V	87	55.8
Type of CP		
Topographical		
Hemiplegia	43	27.6
Diplegia	29	18.6
Quadriplegia	84	53.8
Physiologic		
Spastic	112	71.8
Mixed type	17	10.9
Dystonic	10	6.4
Ataxic	17	10.9

4.1.4. Diagnostic criteria and treatment history of study participants

The findings revealed that 58.9 % (=92) of the participants had done EEG and 26%(n =42) had abnormal findings while five had normal EEG reports while 44.1%(45) could not trace the EEG reports. Among the patients with abnormal EEG reports, 69%(n =29) had generalized seizures, 21.4%(n =9) had partial seizures and 9.5%(n =4) had myoclonic seizures. The findings also revealed that 20.5%(n =32) of the patients had Brain CT scan reports available. Among these patients, 71.9%(n =23) of them had cerebral volume loss with parenchymal cystic changes, 18.8%(n =6) white matter atrophy and hypodensities and 8.3%(n =3) had congenital

malformation including pachygyria and dandy walker. The brain MRI scan reports available were 15.1%(n =21). Among these available reports, 57.1%(n =12) had encephalomalacia, 23.8%(n =5) had unilateral or bilateral white matter lesions while 19.1%(n =4) had unilateral or bilateral gray matter injury. Majority of the patients 59%(n=92) were on treatment for epilepsy and 56.5% (n =52) of them were on polytherapy as shown in Table 4.4.

Table 4.4:Diagnostic criteria and treatment of cerebral palsy at Kenyatta national hospital

	Frequency	**Percent**
EEG done previously	47	30.1
Abnormal (n =42)		
Generalized seizures	29	69
Partial seizures	9	21.4
Myclonic seizures	4	9.5
Normal	5	11.9
Brain CT scan (n =32)	**32**	**20.5**
Cerebral volume loss with parenchymal cystic changes	23	71.9
White matter atrophy and hypodensities	6	18.8
Congenital malformation including pachygria and dandy walker	3	8.3
Brain MRI (n =21)	21	15.1
Encephalomalacia	12	57.1
Unilateral or bilateral white matter lesions	5	23.8
Unilateral or bilateral gray matter lesions	4	19.1
Child on treatment		
Yes	92	93.9
No	7	6.1
Type of treatment (n =92)		
Monotherapy	40	43.4
Polytherapy	52	56.5

4.2.Prevalence of epilepsy among children with Cerebral palsy at Kenyatta National hospital

The prevalence of epilepsy among children with cerebral palsy was 63%, 95%CI:55.4 – 71% as shown in Figure 4.2.

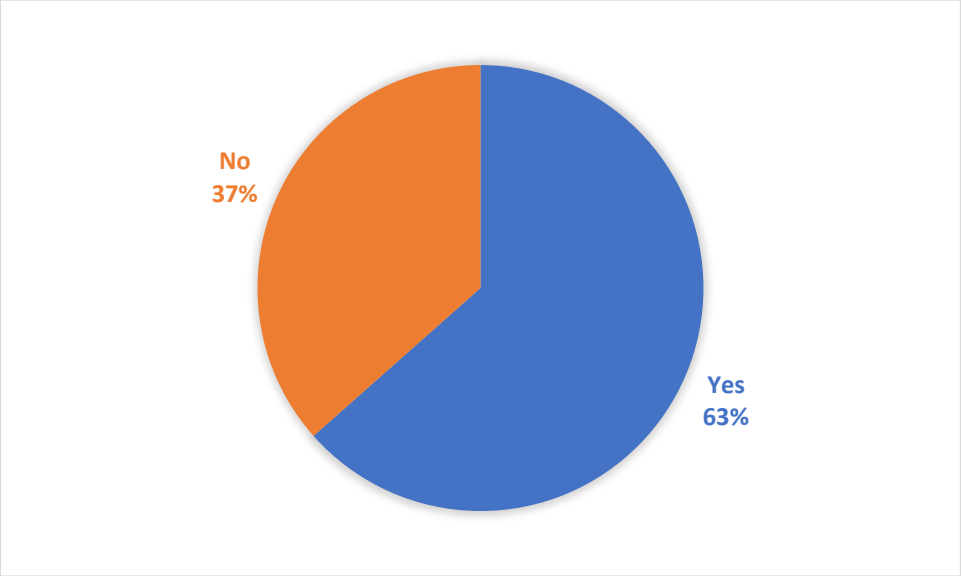


Figure 4.2: Prevalence of epilepsy among children with Cerebral Palsy

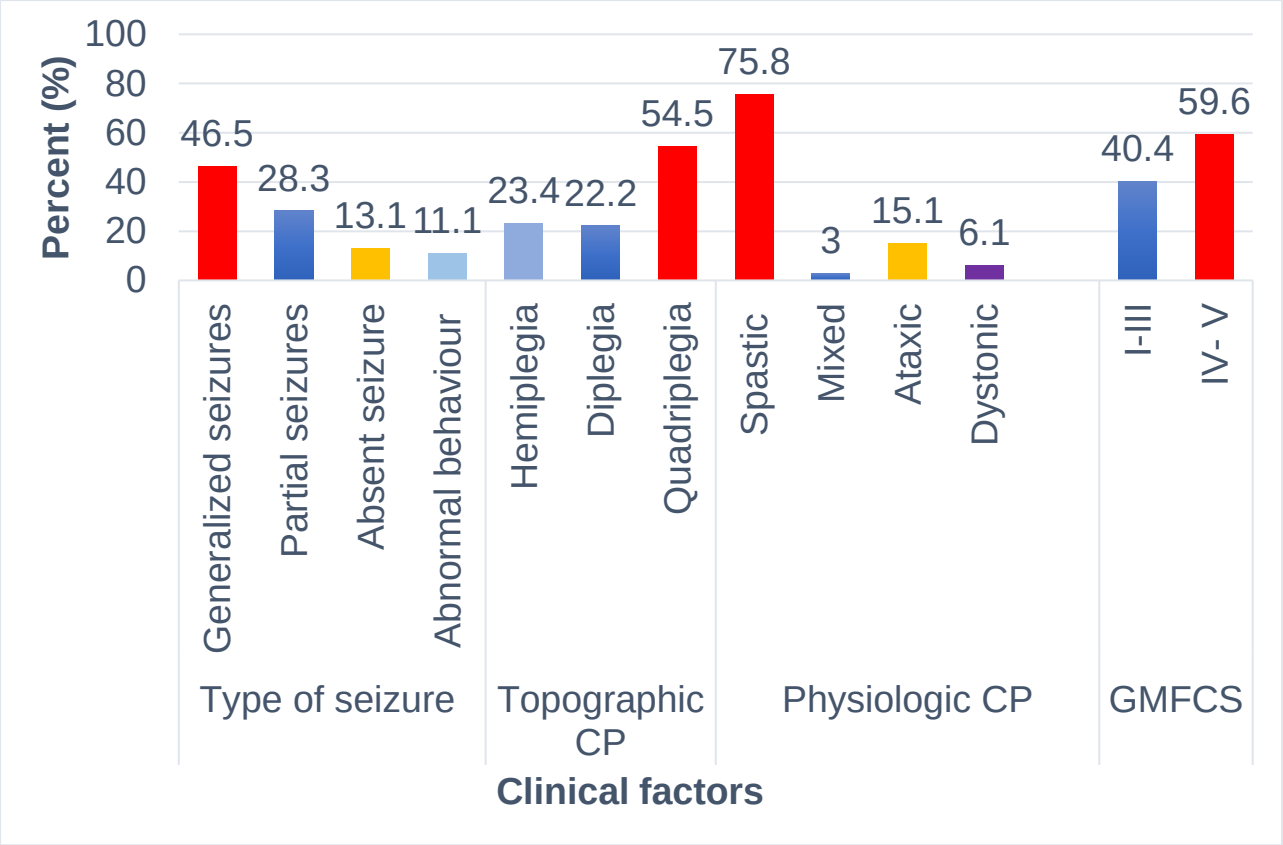
4.3. Clinical presentation of Epilepsy among CP patients at Kenyatta National Hospital

The findings established that among CP patients with epilepsy, 59.6%(n =59) of them were born through spontaneous vaginal delivery, 26.3% (n =26) were born premature. Post-delivery 76.8%(n =76) of them were admitted into new-born unit, and 49.5%%(n =49) of them were resuscitated. Spastic CP was the commonly occurring type of CP 75(75.8%). With regards to complications that were reported at birth, 14.1%(n =14) had seizures as shown in Table 4.5.

Table 4.5: Clinical presentation of CP patients with epilepsy presenting at Kenyatta National hospital.

Factors	Frequency (%)
Gender	
Male	37(37.4)
Female	62(62.6)
Mode of delivery	
Spontaneous vaginal delivery	59(59.6)
Assisted vaginal delivery	4(4.0)
Caesarean section	36(36.4)
Prematurity	26(26.3)
Low birthweight	17(17.2)
Resuscitation at birth	49(49.5)
New-born unit admission	76(76.8)
Jaundice	7(7.1)
Central nervous system infections	3(3.0)
Seizure	14(14.1)
Type of CP	
Topographic	
Hemiplegia	23(23.4)
Diplegia	22(22.2)
Quadriplegia	54(54.5)
Physiologic	
Spastic	75(75.8)
Mixed	3(3.0)
Ataxic	15(15.1)
Dystonic	6(6.1)
GMFCS	
I-III	40(40.4)
IV- V	59(59.6)
Type of seizure	
Generalized seizures	46(46.5)
Partial seizures	28(28.3)
Absence Seizures	13(13.1)
Abnormal behaviour	11(11.1)

Fig 4.3 Clinical presentation of CP patients with Epilepsy



4.4.Factors associated with epilepsy among patients with CP at Kenyatta National hospital

4.4.1. Patient characteristics associated with epilepsy among patients with cerebral palsy

On univariate analysis findings revealed that prematurity, resuscitation at birth and NBU admission were significantly associated with epilepsy in CP. Cerebral palsy patients who were born prematurely were 2.4 times more likely to develop epilepsy, COR = 2.42, 95%CI:1.11 – 5.27, p =0.026). Those who were resuscitated at birth were six times more likely to have epilepsy compared to those who were not resuscitation, COR =6.0, 95%CI:2.58 – 13.97, p<0.001). Children who were admitted into new born unit were nine times more likely to have epilepsy compared to those who were not admitted into NBU, COR =9.25, 95%CI: 4.36 – 19.62, p<0.001) as shown in Table 4.6.

Table 4.6: Factors associated with epilepsy among the study participants on univariate analysis

	Epilepsy		COR(95%CI)	P-value
	Yes	No		
Age				
<2 years	46(46.5)	14(24.6)	0.46(0.16 - 1.36)	0.159
3 - 5 years	29(29.3)	31(54.4)	1.83(0.77 - 4.38)	0.173
>5 years	24(24.2)	12(21.1)	Ref	
Gender				
Male	37(37.4)	19(33.3)	Ref	
Female	62(62.6)	38(66.7)	1.50(0.70 - 3.20)	0.296
Mode of delivery				
Spontaneous vaginal delivery	59(59.6)	21(36.8)	Ref	
Assisted vaginal delivery	4(4.0)	11(19.3)	0.60(0.28 - 1.29)	0.187
Caesarean section	36(36.4)	25(43.9)	3.88(0.93 - 16.27)	0.064
Prematurity				
Yes	26(26.3)	25(43.9)	2.42(1.11 - 5.27)	**0.026**
No	73(73.7)	32(56.1)	Ref	

Birthweight				
< 2500gm	17(17.2)	10(17.5)	0.90(0.34 - 2.38)	0.825
≥ 2500 gm	82(82.8)	47(82.5)	Ref	
Resuscitation at birth				
Yes	49(49.5)	8(14.0)	6.0(2.58 - 13.97)	**<0.001**
No	50(50.5)	49(86.0)	Ref	
NBU admission				
Yes	76(76.8)	15(26.3)	9.25(4.36 - 19.62)	**<0.001**
No	23(23.2)	42(73.7)	Ref	
Assisted ventilation post-delivery				
Yes	15(15.2)	7(12.3)	1.15(0.43 - 0.43 - 3.13)	0.779
No	84(84.8)	50(87.7)	Ref	
Jaundice				
Yes	7(7.1)	4(7.0)	0.90(0.24 - 3.38)	0.565
No	92(92.9)	53(93.0)	Ref	
Central nervous system infections				
Yes	3(3.0)	4(7.0)	0.43(0.93 - 2.03)	0.425
No	96(97.0)	53(93.0)		
Other neonatal infections				
Yes	10(10.1)	1(1.8)	6.04(0.74 - 49.29)	0.093
No	89(89.9)	56(98.2)	Ref	
Seizures				
Yes	14(14.1)	3(5.3)	2.69(0.72 - 10.06)	0.142
No	85(85.9)	54(94.7)	Ref	

4.4.2. Disease related factors associated with epilepsy in cerebral palsy patients at Kenyatta National hospital

The findings established that children who had more severe neurologic impairment (grades IV-V) were 5.7 times more likely to have epilepsy compared to those who had severity score grade I – III classification, COR =5.74, 95%CI: 2.45 – 37.49, p<0.001) as shown in Table 4.7.

Table 4.7:Disease related factors associated with epilepsy among the study participants

	Epilepsy			
	Yes n(%)	**No n(%)**	**COR(95%CI)**	**P-value**
Type of CP				
Topographical				
Hemiplegia	23(23.2)	20(35.1)	3.88(0.73 - 20.79)	0.113
Diplegia	22(22.2)	7(12.3)	3.60(0.45 - 28.56)	0.225
Quadriplegia	54(54.6)	30(52.6)	8.0(0.77 - 44.31)	0.064

Physiologic				
Spastic	75(75.8)	37(64.9)	1.47(0.67 – 3.23)	0.411
Mixed	3(3.0)	14(24.6)	3.75(0.69 - 20.38)	0.126
Dystonic	6(6.1)	4(7.0)	2.77(0.53 - 14.36)	0.225
Ataxic	15(15.1)	2(3.5)	1.43(0.41 – 3.12)	0.131
GMFCS				
I - III	40(40.4)	47(82.5)	Ref	
IV - V	59(59.6)	10(17.5)	5.74(2.45 - 13.43)	<0.001

4.4.3. Multivariable analysis of factors associated with epilepsy among children with cerebral palsy

Multivariable analysis was conducted including variables with p≤0.05 under bivariable analysis as shown in Table 9. The findings revealed that admission into New Born Unit was associated with 12 times higher likelihood of epilepsy, (AOR =12.31, 95%CI: 5.55 – 98.07, p =0.018). Those who had GMFCS classification as IV-V were 3.6 times more likely to have epilepsy compared to those who were classified between 1-111, AOR =3.64, 95%CI: 1.69 – 19.14, p<0.001) as shown in Table 4.8.

Table 4.8:Multivariable analysis of factors associated with epilepsy among children with cerebral palsy

Factors	**AOR(95%CI)**	**P-value**
Prematurity		
Yes	2.32(0.37 - 14.63)	0.372
No	Ref	
Resuscitation		
Yes	0.67(0.33 - 3.21)	0.321
No		
New-born unit admission		
Yes	12.31(5.55 - 98.07)	0.018
No		
GMFCS		
I – III	Ref	
IV – V	3.64(1.69 - 19.14)	<0.001

5. CHAPTER FIVE: DISCUSSION

Epilepsy is a common childhood neurologic disorder and one of the most common comorbidities in cerebral palsy patients. The study sought to investigate the prevalence of epilepsy and associated factors among children with cerebral palsy at Kenyatta National Hospital. The present study established that the prevalence of epilepsy was high at 63%. This is comparable to a previous study conducted by Tsige et al. (2021) in Ethiopia which revealed that the prevalence of epilepsy in CP patients was 60.9% (35). The slightly higher prevalence of epilepsy among CP patients in our study could be due to lack of routine screening for epilepsy among CP patients hence most of these epileptic cases could have been missed in the study by Tsige. However, our study findings show higher prevalence of epilepsy in CP patients compared to majority of studies. A study conducted in Indonesia by Rahmat et al. revealed that the prevalence of epilepsy in CP was 39% (10), in another study conducted in Egypt revealed that almost half of patients , 48.9% had epilepsy 11). Another study in Nigeria established that 46.3% of children with CP had epilepsy. However, across all the studies conducted in SSA, the prevalence of epilepsy is high among CP patients with increased risk of complications if not well management (35) (13) (21). It is essential to ensure regular screening of epilepsy among CP patients to help ensure early identification and appropriate management for better quality of life.

The current study also established that 75.8% of the patients with epilepsy had spastic CP. These findings are comparable to Samia et al. (21) in study conducted in Kenya which found that 80% of children with CP had spastic. Further, present study established that among CP patients with epilepsy, 54.5% had quadriplegia while 23.2% had hemiplegia. These findings compare to those from a study conducted in Kosovo by Hundozi-Hysenaj and Boshnja Dallku who found that among participants with epilepsy, 46% had spastic quadriplegic CP; 27.0% had diplegic CP; and 23.8% had hemiplegic CP (23). Similarly, Singhi et al. in a study conducted

in India established that epilepsy was common among patients with spastic quadriplegia CP followed by spastic diplegia (15.8%) (22).

The present findings showed that almost half of the patients with epilepsy presented with generalized seizures (46.5%). Other forms of presentation observed among epileptic children included partial seizures (28%), day dreaming (13%) and abnormal behaviour (7.1%). These findings are in line with those from a study conducted in Bangladesh which established that generalized tonic–clonic seizure (GTCS) disorder was the most common type of epilepsy seen in spastic quadriplegic CP followed by partial seizures which were more common in spastic hemiplegic CP (21). Similarly, in a study conducted in Nigeria by Ejeliogu et al. established that, the commonest type of epileptic seizure seen was generalized tonic-clonic seizures in 44% of participants, followed by focal seizures in 40% myoclonic seizures in 6% and epileptic spasms in 4%.

The findings from present study established that majority, 77% of the CP patients with epilepsy had been admitted into the new born unit after delivery. This was mainly due to development of neonatal seizures or convulsions. Neonatal seizures or neonatal convulsions are epileptic fits occurring from birth to the end of the neonatal period. Other conditions that led to admission included need for resuscitation, low birthweight, prematurity, infection and jaundice. These findings are consistent with Tsige et al. who found that prematurity and low birthweight are risk factors for epilepsy in CP patients(35). Furthermore, the results established that majority, 59.6% of CP patients with epilepsy had GMFCS score of between IV to V. These findings align with those from a study conducted in Catania, Italy by Pavone et al. who found that the risk of epilepsy is higher in children who showed major motor dysfunction (6). The findings established that 69.6% of the patients had their first seizure at the of age of less than 12 months. The common presentation of seizures was generalized seizure 46.8% These results compare to those from a study in Nigeria by Ejeliogu et al, found that,

among children with epilepsy, 69% had their first seizure before 1 year of age while 34% had a history of neonatal seizures (13). Most of the patients 93.9% of the patients in the current study were on treatment with 56.5% being on polytherapy. A study in UAE by Gururaj also revealed that Over half of the children in the study had generalized tonic clonic seizures, majority of CP patients with epilepsy were on polytherapy resulting from higher comorbidities (27).

The findings from present study established that new-born unit admission was associated with 12 times higher likelihood of having epilepsy among CP patients. NBU admission is associated with development of complications after delivery such as need for resuscitation, prematurity and low birthweight. These findings are consistent with those by Gurkan et al. in a study conducted in Turkey, in 2018, who found that risk of epilepsy in children with CP was associated with stay in neonatal intensive care unit as well as the need for ventilation (29). Cases of cerebral palsy, especially those with the identified risk factors should be closely monitored for epilepsy in order to ensure a timely diagnosis and proper treatment. Previous studies have reported Family history, structural abnormalities (primarily brain atrophy and gray matter involvement), neonatal seizure, low Apgar scores, and mental retardation as significant risk factors for the development of epilepsy in patients with CP (36). Similarly, Karatoprak et al. found that history of epilepsy in the family, history of neonatal seizure during the first 72 hours of life, severe degree of motor function, and quadriplegic type of CP were significantly associated with epilepsy in children with CP(30).

In the present study, there was no significant association between prematurity, neonatal jaundice, neonatal sepsis, neonatal convulsion and the risk of developing epilepsy. These findings are consistent with those from a study conducted in Nigeria which revealed that there was no association between prematurity, neonatal jaundice, neonatal sepsis, neonatal convulsion and the risk of developing epilepsy in CP (31). A study conducted in Nigeria

identified the risk factors associated with epilepsy in CP as presence of seizure in the first year of life, neonatal seizure and spastic CP (13). The study by Rahman et al revealed that there was positive correlation between low birth weight, and post-natal central nervous system infection with the occurrence of epilepsy in CP children. However, the results showed no significant relationship between prematurity, neonatal jaundice, neonatal sepsis, neonatal convulsion and the risk of developing epilepsy in CP (31). Therefore, even though neonatal jaundice, sepsis, prematurity and low birthweight are contributing factors to NBU admission, they were not found to be independently associated with increased likelihood of epilepsy.

The current study showed that those children with major motor dysfunction (GMFCS stages IV or V) were four times more likely to have epilepsy. Level IV and V include higher level of dysfunction with very limited movement ability among children even with the use of assistive technology. These findings are consistent with those by Pavone et al. in Catania, Italy who revealed that the risk of epilepsy in CP patients was higher in those who had either group IV and group V GMCSF severity score (6). Another retrospective study conducted by Karatoprak et al.2019 found that, severe degree of motor function, was significantly associated with epilepsy in children with CP (30).

The present study revealed that most of the CP patients with epilepsy were on polytherapy treatment. These findings compare to those from a study in United Arab Emirates by Gururaj et al which found that most of the CP patients with epilepsy were on polytherapy resulting from higher comorbidities (27).

5.1.Study strengths

1. This study provides a detailed understanding on the prevalence of epilepsy in CP patients and underlying clinical characteristics and factors associated with epilepsy in CP patients at our setting.

2. We conducted objective interview and assessment of all study participants to determine presence or absence of epilepsy.

5.2.Study limitation

1. Missing medical records especially imaging reports and recall bias as some caregivers could not remember all the child's clinical history.
2. This was a facility-based study conducted in a tertiary hospital thus findings may not be generalizable

6. CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1.Conclusions

1. The prevalence of epilepsy in CP patients is high occurring in more than half of the patients.
2. Commonly occurring clinical characteristics among CP patients with epilepsy included admission into newborn unit, resuscitation at birth, generalized seizures, spastic CP and severe neurological impairment.
3. Factors associated with epilepsy in CP were severe neurologic impairment GMFCS IV-V and spastic quadriplegia.

6.2.Recommendations

There is need for routine screening for epilepsy among children with cerebral palsy with a history of birth asphyxia and severe neurologic impairment.

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APPENDICES

Appendix I: Informed Consent

PART I: Information Sheet

Introduction/Purpose of the study

I am Dr. Caroline Muindi, a registrar at the University of Nairobi, Department of Paediatrics and Child Health. I am conducting a study to investigate the prevalence of epilepsy and associated factors in children diagnosed with Cerebral Palsy

Participant selection

I intend to recruit your child to be part of this study considering that your child meets the inclusion criteria that I am looking at enrolling him/her as a participant. This study does not alter the intervention given to your child and thus participation is a simple process.

Voluntary Participation/Participants rights and roles

Your participation in the study is voluntary and you are free to withdraw from the study even after recruitment without any consequences

Procedure

Once you agree to participate in my study, I will ask you some questions using a pre-developed questionnaire. The information sought include demographic, clinical related information based on the objectives of this study.

Protection of the study participant

The study participants are patients with cerebral palsy which is vulnerable population. Thus, during the data collection, the researcher will ensure that a caregiver is available to help the patient in case there is needs assistance. The caregivers will be contacted to help in helping managing the mood changes among the study respondents.

Confidentiality

Neither your child's name or your name or contact details will appear on the questionnaire. Instead, the questionnaires will have serial numbers. The form containing your information will be kept in a locked cabinet and I will be the only person with access to the cabinet. The information that will be obtained from the research will be used strictly for research purposes.

All the information obtained during the research will be kept confidential to everyone who will participate in it.

Benefits and Reimbursements

The researcher is a medical doctor and thus will monitor the progress of your child effectively. She will be available to help you with any questions that you might be having regarding the condition of your child. There will however be no monetary compensation and we will not be responsible for your mobile phone charges. The findings obtained will be important for the management of the children and will be used by health care providers and policymakers.

Risks

There are no major risks involved in participation in the study. The procedures that will be undertaken are common standard procedures which do not increase the risk of adverse outcomes to your child.

In case of any questions concerning the study, feel free to contact the following persons during official working hours

Principal investigator:

Dr. Caroline Muindi

Post graduate student in the department of Paediatrics and Child Health university of Nairobi
Tel no: 0725 241 251. Email:carolinemuindi@student.uonbi.ac.ke

Supervisors

Dr. Beatrice Mutai

Lecturer, Department of Pediatrics and Child Health, University of Nairobi & Consultant Pediatrician, Mbagathi County Hospital

Dr. Lawrence Owino

Lecturer, Department of Paediatrics and Child Health, University of Nairobi

Dr. Maureen King'e

Lecturer, Department of Paediatrics and Child Health, University of Nairobi

Tel No. +254 0202726300, +2540202725102. Email:dept.paediatrics@uonbi.ac.ke

You may also contact Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee Telephone No. 2726300 Ext. 44102. Email: uonknh_erc@uonbi.ac.ke.

PART II: Certificate of Consent

I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to have my child and I participate in this research.

Name of Parent/Legal Guardian:_____

Signature/thumbprint of Parent/ Legal Guardian: _____Date:__Day/month/year

Statement by person taking consent:

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the purpose of the study.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered to the best of my ability. I confirm that the individual has not been coerced in to giving consent, and the consent has been given freely and voluntarily.

Name of person taking the consent:_____

Signature of person taking the consent:_____

Date:__

Dr. Caroline

Signature_____Date___

Kiambatisho II: Idhini ya Taarifa

SEHEMU YA I: Karatasi ya Habari

Utangulizi/Madhumuni ya utafiti

Jina langu ni Dkt. Caroline Muindi, msajili katika Chuo Kikuu cha Nairobi, Idara ya Afya ya Watoto na Watoto. Ninafanya utafiti kuchunguza kuenea kwa kifafa na sababu zinazohusiana na watoto waliopatikana na Cerebral Palsy

Uteuzi wa washiriki

Ninakusudia kumwajiri mtoto wako kuwa sehemu ya utafiti huu kwa kuzingatia kuwa mtoto wako anakidhi vigezo vya ujumuishaji ambavyo ninaangalia kumwandikisha kama mshiriki. Utafiti huu haubadilishi uingiliaji kati uliopewa mtoto wako na hivyo ushiriki ni mchakato rahisi.

Ushiriki wa Hiari / Haki na majukumu ya Washiriki

Ushiriki wako katika utafiti ni wa hiari na uko huru kujiondoa kwenye utafiti hata baada ya kuajiriwa bila madhara yoyote

Utaratibu

Mara baada ya kukubali kushiriki katika utafiti wangu, nitakuuliza maswali kadhaa kwa kutumia dodoso lililoandaliwa kabla. Habari zilizotafutwa ni pamoja na idadi ya watu, habari zinazohusiana na kliniki kulingana na malengo ya utafiti huu.

Ulinzi wa mshiriki wa utafiti

Washiriki wa utafiti ni wagonjwa wenye utindio wa ubongo ambao ni hatari kwa watu walio katika mazingira magumu. Hivyo, wakati wa ukusanyaji wa takwimu, mtafiti atahakikisha kuwa mhudumu anapatikana ili kumsaidia mgonjwa kuingia ndani kunahitaji msaada. Walezi watawasiliana ili kusaidia katika kusaidia kusimamia mabadiliko ya hisia kati ya wahojiwa wa utafiti.

Usiri

Wala jina la mtoto wako au jina lako au maelezo ya mawasiliano yataonekana kwenye dodoso. Badala yake, dodoso zitakuwa na nambari za mfululizo. Fomu yenye taarifa zako itatunzwa kwenye baraza la mawaziri lililofungwa na nitakuwa mtu pekee mwenye uwezo wa kuingia kwenye baraza la mawaziri. Taarifa ambazo zitapatikana kutokana na utafiti zitatumika kwa

madhumuni ya utafiti. Taarifa zote zilizopatikana wakati wa utafiti zitawekwa siri kwa kila mtu atakayeshiriki katika utafiti huo.

Faida na Marejesho

Mtafiti ni daktari wa tiba na hivyo atafuatilia maendeleo ya mtoto wako kwa ufanisi. Atapatikana kukusaidia kwa maswali yoyote ambayo unaweza kuwa nayo kuhusu hali ya mtoto wako. Hata hivyo hakutakuwa na fidia ya fedha na hatutawajibika kwa malipo yako ya simu ya mkononi. Matokeo yatakayopatikana yatakuwa muhimu kwa usimamizi wa watoto na yatatumiwa na watoa huduma za afya na watunga sera.

Hatari

Hakuna hatari kubwa zinazohusika katika ushiriki katika utafiti. Taratibu zitakazofanyika ni taratibu za kawaida za kawaida ambazo haziongezi hatari ya matokeo mabaya kwa mtoto wako.

Mawasiliano

Iwapo kutakuwa na swali lolote: Ikiwa una maswali yoyote kuhusu utafiti, jisikie huru kuwasiliana nami Dkt. Caroline Muindi kwenye Simu yangu ya Mkononi no: 0725 241 251. Unaweza pia kumfikia msimamizi wangu yeyote, Dkt. Beatrice Mutai Mhadhiri, Idara ya Afya ya Watoto na Watoto, Daktari Bingwa wa Watoto wa Chuo Kikuu cha Nairobi, Hospitali ya Kaunti ya Mbagathi Simu ya mkononi no:0708 552 909 Dkt. Lawrence Owino Mhadhiri, Idara ya Afya ya Watoto na Watoto, Chuo Kikuu cha Nairobi Simu ya Mkononi No:0711 130 227 Dkt. Maureen Kinge Mhadhiri, Idara ya Afya ya Watoto na Watoto, Chuo Kikuu cha Nairobi Simu ya mkononi no:0723 261 795 Unaweza pia kuwasiliana na Katibu / Mwenyekiti, Hospitali ya Kitaifa ya Kenyatta-Chuo Kikuu cha Maadili na Kamati ya Utafiti ya Nairobi Simu Na. 2726300 Ext. 44102. Barua pepe: uonknh_erc@uonbi.ac.ke.

SEHEMU YA II: Cheti cha Ridhaa

Nimesoma taarifa, au imesomwa kwangu. Nimepata fursa ya kuuliza maswali juu yake na maswali yoyote ambayo nimeuliza yamejibiwa kwa kuridhika kwangu. Ninakubali kwa hiari kuwa na mtoto wangu na ninashiriki katika utafiti huu.

Jina la Mzazi/Mlezi wa Sheria: .....

Saini / kidole gumba cha Mzazi / Mlezi wa Kisheria:.....

Tarehe: Siku / mwezi / mwaka Kauli ya mtu kuchukua ridhaa:

Nimesoma kwa usahihi karatasi ya habari kwa mshiriki anayeweza, na kwa kadri ya uwezo wangu nilihakikisha kuwa mshiriki anaelewa madhumuni ya utafiti. Nathibitisha kuwa mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti, na maswali yote niliyoulizwa na mshiriki yamejibiwa kwa kadri ya uwezo wangu. Nathibitisha kuwa mtu huyo hajalazimishwa kutoa ridhaa, na ridhaa imetolewa kwa uhuru na hiari.

Jina la mtu anayechukua ridhaa:.....

Saini ya mtu kuchukua idhini:.....

Tarehe: .....Tarehe ya Saini

Appendix III: Study Questionnaire

DATE

PARTICIPANT ID

STUDY SITE

Section A: Parent/Caregiver demographic characteristics

1. Are you the primary caregiver?

Yes [ ] No [ ]

2. What is your relationship to the child

Biological mother [ ] Biological father [ ] Grandparent [ ]

Auntie or uncle [ ] Sibling [ ] Nanny/househelp [ ] Other [ ]

3. Describe the family unit to which this child belongs

Single parent [ ] Two parent household [ ]

Primary caregiver is a guardian other than biological parent [ ] children's home [ ]

4. What is the primary care givers level of education level of education?

None [ ] Primary level [ ] Secondary level [ ] tertiary [ ]

5. Household income

<10 k kes [ ] 10-50 k kes [ ] 50-100 k kes [ ] > 100 kes [ ]

6. What is your place of residence?

Rural [ ] Urban [ ]

Section B: Demographic characteristics of the child

1. What is the gender of the child

Male [ ] Female [ ]

Date of Birth.

……./……./……

Day/ Month / Year

Section C: Birth History of the child

1. Place of birth

Home [ ] Hospital [ ] Other specify [ ]

2. Mode of delivery

Sponteneous Vaginal delivery [ ] Assisted Vaginal Delivery [ ] Caesarean Section [ ]

3. Gestational age at delivery (weeks) ……
4. Birth weight… < 2500gm [ ] >2500gm [ ]
5. Did your child require management for any of the conditions listed below?

Resuscitation [ ] Newborn Unit Admission [ ] Assisted ventilation [ ]

Jaundice [ ] Central Nervous System infections [ ] Other Neonatal infections [ ]

Seizures [ ]

Section D: Cerebral palsy diagnosis and classification

1. Age at Cerebral palsy diagnosis (in months) _____
2. Has anyone ever told you that your child had a seizure or convulsion or have you ever observed any seizure or convulsion at any circumstance

   Yes [ ] No [ ]

3. If yes, has he/she ever had more than two unprovoked seizures > 24 hours apart at any given time

   Yes [ ] No [ ]

4. Has anyone ever told you that your child has a seizure disorder

   Yes [ ] No [ ]

5. When did the first seizure occur after birth…… < 12 Months [ ] > 12 Months [ ] Do not know [ ]
6. Describe the presentation of the seizures
   Memory gaps [ ] Sudden falls [ ] generalised seizures [ ]
   specific parts of body twitching [ ] Day dreaming/staring into space [ ]
   Abnormal behavior [ ]

   Others (Specify)……

7. Is your child on any treatment for Seizures

Yes [ ] No [ ]

8. If yes what type of treatment

Monotherapy [ ] Polytherapy [ ]

Others (specify)……

4 EXAMINATION

FEATURES FOUND DURING CHILDS CLINICAL EVALUATION

1. Increased tone …...yes [ ] No [ ]

If yes list limbs involved

Right upper limb [ ] Left upper limb [ ]

Right lower limb [ ] Left lower limb [ ]

2. Increased reflexes
   Yes [ ] No [ ]
   Yes…. list limbs involved
   Right upper limb [ ] Left upper limb [ ]
   Right lower limb [ ] Left lower limb [ ]

3.Ataxia

Any of the following features

Walking with feet spread far apart

Yes [ ] No [ ]

Trouble bringing hands together

Yes [ ] No [ ]

Trouble grasping objects

Yes [ ] No [ ]

Trouble with repetitious movements

Yes [ ] No [ ]

4.Dyskinesia

Any of the following features

Regular slow movements and sustained posture

Yes [ ] No [ ]

Difficulty in maintaining posture and coordination

Yes [ ] No [ ]

Jerky and abrupt movements

Yes [ ] No [

5.The GMFCS classification of severity of motor impairment?

a. Level I: walks without limitations [ ]

b. Level II: walks with limitations in some settings [ ]

c. Level III: walks using a hand-held mobility device or uses wheelchair for greater distances [ ]

d.Level IV: uses a wheelchair in most settings [ ]

e. Level V: uses a wheelchair in all settings and may require additional support for the head or torso. [ ]

1. EEG done previously?

   Yes [ ] No [ ] yes but unavailable [ ]

   If yes, specify EEG abnormalities…….

2. Head CT scan done previously?

   Yes [ ] No [ ] yes but unavailable [ ]

3. If yes, specify CT scan abnormalities…..…….

4. MRI done previously?

   Yes [ ] No [ ] yes but unavailable [ ]

5. If yes, specify MRI abnormalities…..…….

Appendix IV: GMFCS

CanChild Centre for Childhood Disability Research
Institute for Applied Health Sciences, McMaster University,
1400 Main Street West, Room 408, Hamilton, ON, Canada L8S 1C7
Tel: 905-525-9140 ext. 27850 Fax: 905-522-6095
E-mail: canchild@mcmaster.ca Website: www.canchild.ca

GMFCS – E & R
Gross Motor Function Classification System
Expanded and Revised

(Reference: Dev Med Child Neurol 1997;39:214-223)

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that **environmental** and **personal** factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the **child's or youth's present abilities and limitations in gross motor function**. Emphasis is on usual **performance** in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child's/youth's current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.

OPERATIONAL DEFINITIONS

Body support walker – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

Hand-held mobility device – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

Physical assistance – Another person manually assists the child/youth to move.

Powered mobility – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

Self-propels manual wheelchair – The child/youth actively uses arms and hands or feet to propel the wheels and move.

Transported – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

Walks – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

Wheeled mobility – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

GENERAL HEADINGS FOR EACH LEVEL

LEVEL I	-	Walks without Limitations
LEVEL II	-	Walks with Limitations
LEVEL III	-	Walks Using a Hand-Held Mobility Device
LEVEL IV	-	Self-Mobility with Limitations; May Use Powered Mobility
LEVEL V	-	Transported in a Manual Wheelchair

DISTINCTIONS BETWEEN LEVELS

Distinctions Between Levels I and II - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.

Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)

BEFORE 2ND BIRTHDAY

LEVEL I: Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

LEVEL III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

LEVEL IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

LEVEL V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

BETWEEN 2ND AND 4TH BIRTHDAY

LEVEL I: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III: Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 4TH AND 6TH BIRTHDAY

LEVEL I: Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

LEVEL II: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

LEVEL III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

LEVEL IV: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 6TH AND 12TH BIRTHDAY

Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

BETWEEN 12TH AND 18TH BIRTHDAY

Level I: Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a hand-held mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when traveling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Appendix V: Authority to collect data

KENYATTA NATIONAL HOSPITAL
P.O. BOX 20723, 00202 Nairobi

Tel.: 2726300/2726450/2726550
Fax: 2725272
Email: knhadmin@knh.or.ke

Ref: KNH/PAEDS-HOD/48 Vol.II

Date:23rd September 2022

Dr. Caroline Muindi
Reg. No H58/34408/2019
Department of Paediatrics and Child Health
Faculty of Health Sciences
University of Nairobi

Dear Dr.Caroline Muindi,

RE: AUTHORITY TO COLLECT DATA IN PAEDIATRICS DEPARTMENT

Following approval of your Research proposal by the KNH/UON-Ethics & Research Committee and subsequent filing of the Study Registration Certificate, this is to inform you that authority has been granted to collect data in ***Paediatrics Department*** *on* your study titled **"Prevalence of and factors associated with epilepsy in children with cerebral palsy at Kenyatta National Hospital"** Kindly liaise with the Senior Assistant Chief Nurse (SACN) Paediatric General Wards.

You will also be required to submit a report of your study findings to the office of the HOD, Paediatrics - KNH after completion of your study.

Dr. Juliana Muiva-Gitobu
Head of Department, Paediatrics

Cc. SACN, Paediatric General Wards.

Appendix VI: KNH-UoN Approval

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

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

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/310

23rd August, 2022

KENYATTA NATIONAL HOSPITAL APPROVED 23 AUG 2022 KNH/UoN ERC P.O. Box 20723 - 00202 NAIROBI

Dr. Caroline Muindi
Reg. No. H58/34408/2019
Dept. of Paediatrics & Child Health
Faculty of Health Sciences
University of Nairobi

Dear Dr. Muindi,

RESEARCH PROPOSAL: PREVALENCE OF AND FACTORS ASSOCIATED WITH EPILEPSY IN CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL (P387/05/2022)

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P387/05/2022.** The approval period is 23rd August 2022 – 22nd August 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.

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) https://research-portal.nacosti.go.ke and also obtain other clearances needed.

Yours sincerely,

DR. BEATRICE K.M. AMUGUNE
SECRETARY, KNH-UoN ERC

c.c. The Dean, Faculty of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Chair, Dept. of Paediatrics & Child Health, UoN
Supervisors: Dr. Beatrice Mutai, Dept. of Paediatrics & Child Health, UoN
Dr. Lawrence Owino, Dept. of Paediatrics & Child Health, UoN
Dr. Maureen Kinge, Dept. of Paediatrics & Child Health, UoN

Appendix VI: Similarity Report

PREVALENCE OF AND FACTORS ASSOCIATED WITH EPILEPSY IN CHILDREN WITH CEREBRAL PALSY AT KENYATTA NATIONAL HOSPITAL.

ORIGINALITY REPORT

14%	10%	12%	1%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	www.ajns.paans.org Internet Source	3%
2	"26th IEC PROCEEDINGS 26th International Epilepsy Congress Paris, France, August 28th-September 1st 2005", Epilepsia, 2005 Publication	2%
3	paediatricaindonesiana.org Internet Source	2%
4	www.ncbi.nlm.nih.gov Internet Source	2%
5	repository-tnmgrmu.ac.in Internet Source	1%
6	Ritesh Thapa. "Epilepsy in children with cerebral palsy as observed in Nepal", European Journal of Paediatric Neurology, 2017 Publication	1%