PREVALENCE OF EMOTIONAL AND BEHAVIORAL PROBLEMS IN CHILDREN WITH EPILEPSY ATTENDING THE CHILD NEUROLOGY CLINIC AT KENYATTA NATIONAL HOSPITAL

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DECLARATION

This research dissertation is my original work and has not been presented for a degree in any other university.

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LIST OF ABBREVIATIONS

ADHD	Attention Deficit and Hyperactivity Disorder
AED	Antiepileptic drug
ASEBA	Achenbach System of Empirically Based Assessment
CBCL	Child Behavior Checklist
CI	Confidence Interval
EEG	Electroencephalogram
ILAE	International League Against Epilepsy
KNH	Kenyatta National Hospital
OR	Odds Ratio
SD	Standard Deviation
TLE	Temporal Lobe Epilepsy
WHO	World Health Organization

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ABSTRACT

Background: Epilepsy is a common neurological condition, with close to 80% of people living with epilepsy residing in developing countries. Approximately half of epilepsy in the population occurs during childhood. Epidemiologic studies internationally have shown a strong association between pediatric epilepsy and mental disorders. However, there is scarcity of research on this topic regionally and locally.

Aims: The purpose of this study was to determine the prevalence of emotional and behavioral problems in children with epilepsy on follow-up at the Kenyatta National Hospital neurology clinic and examine associated sociodemographic variables.

Methods: This was a cross-sectional descriptive study. Children with epilepsy aged between 6 to 12 years attending the Kenyatta National Hospital neurology clinic who met the study criteria were recruited, having obtained consent from their legal guardians. A sociodemographic questionnaire as well as the Child Behavior Checklist school age version (CBCL/6-18) was administered to the caregiver accompanying the child.

Data analysis: This was done using Stata (version 15). The overall prevalence of emotional and behavioral problems in childhood was determined by calculating the percentage of children with child behavior checklist score indicative of specific emotional and behavioral problems. Prevalence for specific morbidities was also calculated and reported separately for each condition. Multivariate analysis was used to determine sociodemographic factors which were significantly associated with emotional and behavioral problems. Results were presented in form of tables, charts, graphs and narratives.

Results: The overall prevalence of emotional and behavioural problems in children with epilepsy on follow-up at the KNH paediatric neurology clinic was 46.3%. Attention problems, aggressive behaviour, social problems and withdrawal/ depression were the four leading syndromes. For the internalizing and externalizing groupings of syndromes, the prevalence of internalizing syndromes was higher (10.2%) than the externalizing syndromes (6.8%). The prevalence of emotional and behavioural problems was significantly associated with age, diagnosis of mental disorder, types of antiepileptic drugs taken and reduced frequency of seizures.

Conclusion: There is a high prevalence of emotional and behavioral problems in children with epilepsy. Therefore, early screening for these problems, as well as integrated management consisting of pharmacotherapy, psychotherapy and psychoeducation would help to reduce their effect in these patients.

CHAPTER ONE

1. Introduction

Epilepsy is one of the most common neurological conditions, affecting approximately 50 million people worldwide. The World Health Organization (WHO) defines epilepsy as a neurological condition characterized by the occurrence of two or more unprovoked seizures (1). Seizures are symptoms caused by abnormal discharges in neurons in the central nervous system. Approximately 5% to 10% of children have a seizure episode during the first 2 decades of life. The lifetime prevalence rate of epilepsy is 1%. (2).

Pediatric epilepsy is of particular concern to psychiatrists due to the high frequency of associated mental problems, including psychiatric and neurodevelopmental disorders, and psychosocial problems. Children with epilepsy have also been found to be at an increased risk for unmet mental health needs (3).

The original community-based study on the association between pediatric epilepsy and mental disorders was by Rutter et al. The prevalence of behavioral and emotional disorders in the general childhood population was found to be 6.6%. In children with uncomplicated seizures the prevalence of these problems was 28.6%. Children known to have central nervous system (CNS) dysfunction of any etiology were seen to have a higher prevalence of the problems of 37.5%. The highest prevalence of behavioral and emotional problems was seen in children with both seizure disorders and CNS complications (4). More recently, another population-based study by Austin et al. found a higher prevalence of behavioral problems using the Child Behavior Checklist in children with new-onset epilepsy as compared to their nearest-in-age siblings (5).

The etiology of psychiatric disturbance in pediatric epilepsy has been attributed to various factors in including common underlying pathophysiologic mechanisms, the seizures themselves, antiepileptic medications, poor child and family adaptation and associated neurological dysfunction. A study by Austin et al. reported a high prevalence of behavioral symptoms before occurrence of first recognized seizure (6).

The WHO African report on epilepsy (2004) states that more than 80% of people living with epilepsy reside in low and middle income countries (7).However, there is scarcity of research regionally and locally, specifically on mental health problems in pediatric epilepsy. This reflects a knowledge gap that

needs be addressed in order to lay a framework for sound mental health policies and clinical management of patients.

CHAPTER TWO

2. Literature Review

2.1 Epilepsy

2.1.1 Definition

The WHO defines epilepsy as a chronic neurological disorder that is characterized by recurrent seizures. Seizures are symptoms caused by abnormal discharges in neurons in the central nervous system. Epilepsy is comprised of several syndromes whose main characteristic is the recurrent seizures (1).

The International League Against Epilepsy (ILAE) defines epileptic seizures as a transient occurrence of signs and/or symptoms caused by abnormal excessive or synchronous neuronal activity in the brain (8).

Symptoms of seizures vary depending on the region in the brain where the disturbance starts and how far it spreads. They are usually temporary and may include disturbances in movement, sensation, mood and\or other cognitive functions, and may or may not be accompanied by loss of consciousness (1).

2.1.2 Classification of epileptic seizures

The International Classification of Epileptic Seizures was originally done in 1981(9). The most recent recommendations for future classification have been made in 2010 (10). However, the 1981 classification is still in use. It classifies epileptic seizures based on clinical features and EEG findings as follows:

A. Focal onset

- Simple partial seizures
    1. With motor signs
    2. With somatosensory or special-sensory symptoms
    3. With autonomic symptoms or signs
    4. With psychic symptoms
- Complex partial seizures
    1. Simple partial seizures at onset, followed by impairment of consciousness
    2. With impairment of consciousness at onset
- Partial seizures evolving to secondarily generalized seizures
    1. Simple partial seizures evolving to generalized seizures
    2. Complex partial seizures evolving to generalized seizures

3. Simple partial seizures evolving to complex partial seizures evolving to generalized seizures

B. Generalized onset

- Tonic-clonic
- Myoclonic
- Absence
    1. Typical absence seizures
    2. Atypical absence seizures
- Atypical-with special features e.g. eyelid myoclonia
- Clonic
- Tonic
- Atonic

C. Not clear. Any form of seizure that does not fit in the above e.g. rhythmic eye movements, chewing, swimming movements.

As regards to etiology of the seizures, epilepsies are divided into idiopathic (without visible structural brain lesion), symptomatic (with visible structural lesion on neuroimaging examination) and cryptogenic (with presumable etiology, not diagnosed) (10).

2.1.3 Epidemiology

According to the WHO, approximately 50 million people worldwide suffer from epilepsy, making it one of the commonest neurological diseases. Approximately half of epilepsy in the population occurs during childhood. Close to 80% of people with epilepsy live in low and middle income countries, due to the higher rate of infections, road traffic accidents, birth related injuries and variations in accessibility and quality of medical care (1).

Approximately 5% to 10% of children have a seizure episode during the first 2 decades of life and 1% develops epilepsy (2).

A recent population-based study by Russ et al. on children in the United States found a lifetime prevalence rate of epilepsy of 1%. Epilepsy prevalence was higher in lower income families and in older male children (3).

2.1.4 Global burden of disease

The WHO reports that epilepsy accounts for 0.75% of the global burden of disease Epilepsy is actually considered to be a public health problem (1).

The challenges affecting children with epilepsy, their families and the society at large reach far beyond the seizures. They are multifaceted and include medical, educational and psychosocial challenges (11).

The medical effects are varied. Due to the unpredictable nature of the seizures, the mental health of the patients is often affected resulting in depression and anxiety. Cognitive effects sometimes also occur due to the injurious effects of the seizures on the brain. The patients may also sustain physical injuries such as burns and fractures as a result of the seizures. In addition, the medications (AEDs) for epilepsy are often associated with side effects which may impair patients' quality of life (12).

Various negative educational effects have also been described. Mitchell et al. reported a high rate of academic underachievement ranging from 16% (reading recognition) to 50% (general knowledge) (13). In a study by Fastenau et al. which assessed the prevalence of learning disorders in children with epilepsy, 48% exceeded the cutoff for learning disorder in at least one academic area (14).

Psychosocially, patients at times experience stigmatization and social exclusion due to the seizures, leading to lack of confidence and low self-esteem.

The majority of patients living with epilepsy do not receive any treatment at all. This increases the burden and results in a higher disability weight, which includes psychiatric comorbidity (15).

2.2 Association between pediatric epilepsy and psychiatric disturbance

2.2.1 Historical perspective

The association between epilepsy and psychiatric disturbance has been well known and documented in history since antiquity. Hippocrates at round 400 B.C. observed a dichotomy between epilepsy and melancholia, stating, "Melancholics ordinarily become epileptics, and epileptics, melancholics" (16).

In many societies worldwide, epilepsy was thought to be associated with supernatural phenomena such as demons, gods and witches, similar to mental illness. The Greeks referred to epilepsy as the sacred disease. They believed it was a curse caused by the offense of the godess Selene. In Rome epilepsy was referred to as morbidus lunaticus, as the timing of the seizures was thought to be related to the light of the full moon (17).

In the 19th and early 20th century, epileptics together with those with mental illness were detained in asylums. Those with less severe forms of the illnesses remained in the community. Major advances in the diagnosis and treatment of epilepsy and mental illness occurred during the 19th and 20th century, notably the invention of the EEG, introduction of advanced neuroimaging techniques, the discovery of

antiepileptic and psychiatric medications, and the delineation of common underlying pathophysiological mechanisms to both epilepsy and psychiatric disorders through scientific research (18).

In Africa, despite modernization, these beliefs still persist. Dale et al. in a study on treatment preference for neuropsychiatric disorders in Botswana found that indigenous care was mostly preferred for epilepsy, whilst psychosis took an intermediate position as compared to tuberculosis for which modern care was favored (19).

2.2.2 Epidemiology

It has been shown by several epidemiologic studies that children with epilepsy have are at an increased risk for emotional and behavioral comorbidities.

One of the original community-based studies on the association between psychopathology and pediatric epilepsy was by Rutter et al. It reported a prevalence of emotional and behavioral disorders of 6.6% in the general childhood population as compared to 28.6% in children with uncomplicated seizures. Children known to have central nervous system (CNS) dysfunction of any etiology were seen to have a higher prevalence of the problems of 37.5%. The highest prevalence of behavioral and emotional problems was seen in children with both seizure disorders and CNS complications (4). Hoare et al. compared children with epilepsy, diabetic children and children in the general population. The prevalence of psychiatric disturbance was highest in epileptic children (45% in new-onset epilepsy and 48% in chronic epilepsy), as compared to 17% of diabetic children and 10% of the controls (20).

More recently, various studies have further emphasized the enduring impact of pediatric epilepsy on mental health. A recent population-based study by Austin et al. found a higher prevalence of behavioral problems using the Child Behavior Checklist in children with new-onset epilepsy as compared to their nearest-in-age siblings (5). Dunn and Austin reported on behavioral problems in adolescents and found a high prevalence specifically in attention problems, depression and anxiety (21). A meta-analysis of 46 studies by Rodenburg et al. indicated a high prevalence of attention problems, thought problems, and social problems as compared to healthy controls (22). Other recent studies (Ott et al.; Caplan et al.) indicate high rates of psychiatric diagnoses in children diagnosed with epilepsy (23, 24). Reilly et al. in another population-based study reported a prevalence of behavioral disorders and/or intellectual disability of 80% (25).

2.2.3 Risk factors associated with psychiatric comorbidity in pediatric epilepsy

There have been several risk factors that have been cited to be commonly associated with psychopathology in pediatric epilepsy. These include neurobiological, psychosocial and pharmacological factors.

Major neurobiological factors include seizure variables i.e. type of seizure, duration, frequency, age of onset and lateralization of epileptic focus; genetic predisposition; gender and presence of structural lesion (26). Pathophysiological mechanisms involve structural and chemical changes in the limbic system circuitry, which is the locus of processing of emotions and behavior (27). A specific type of epilepsy that has been found to have an increased risk for psychiatric disorders is temporal lobe epilepsy (TLE). However, it is still controversial as to whether this is due to the higher prevalence of TLE as compared to other types of epilepsy. It has been postulated that the same pathophysiological mechanisms involved in production of psychiatric symptoms also occur in TLE (28).

Some of the psychosocial factors are anxiety and "learned helplessness" due to unpredictability of the seizures; low self-esteem; restriction in activities of daily living e.g. cooking; educational difficulties e.g. being banned from school; social stigmatization due to negative attitudes of society towards people with epilepsy; and financial constraints (29).

The pharmacological factors that have been cited are adverse effects of antiepileptic drugs (AEDs), withdrawal of an AED with mood-stabilizing properties, polytherapy, starting a new AED, and dose adjustment (26). Loring and Meador reported on cognitive and behavioral side effects of AEDs in children and depression, irritability, hyperactivity, increased anxiety, psychosis and insomnia were found in children treated with phenobarbital, mysoline, levetiracetam, gabapentin, felbamate, zonisamide, topiramate and vigabatrin (30). Studies have also shown that children on AED polytherapy are more likely to experience side effects such as irritability, attention problems and poor frustration tolerance as compared to those on monotherapy (31). AED treatment is also associated with cognitive, linguistic and academic difficulties. It has not been established whether the association between AEDs and psychopathology is indirectly as a result of their effects on language and cognition (32).

2.2.4 Specific psychiatric disorders associated with pediatric epilepsy

There are specific psychiatric problems that have been found to be more prevalent in children with epilepsy as compared to the general childhood population.

Attention Deficit/ Hyperactivity Disorder (ADHD) symptoms have been reported in approximately one third of children with epilepsy. Symptoms of inattention are more common as compared to hyperactivity or impulsivity (33).

Mood disorders, specifically depression, have also been found to be common. Dunn et al. found symptoms of depression in approximately a quarter of adolescents with epilepsy (34).

Anxiety has also been noted to be more prevalent, especially in adolescents, though has not been assessed as extensively as mood problems. Caplan et al. examined affective disorders, anxiety disorders and suicidality in children with epilepsy and reported a prevalence of 33% of diagnoses of affective and anxiety disorders (35). Ettinger et al. assessed rates of symptoms of anxiety and depression in children with epilepsy and found that 16% met the criteria for significant anxiety while 26% had significantly increased depression scores (36).

Psychotic disorders are generally uncommon in children even with epilepsy, although an increased prevalence of illogical thinking has been found in children with complex partial seizures (37).

2.3 Regional studies (Africa)

The WHO African report on epilepsy states that epilepsy in Africa is mainly secondary, resulting from cerebral complications of endemic communicable diseases, head trauma and poor perinatal care for both mother and child. 80% of people with epilepsy reside in the developing world including Africa; hence these regions bear most of the global burden of health due to epilepsy. There is a pronounced treatment gap in the treatment of epilepsy in Africa, which is one of the factors contributing to further complications of the epilepsy, including psychiatric comorbidity (7).

Generally few studies have been done in Africa on mental health problems in pediatric epilepsy. In Nigeria, Laganju et al. screened children with epilepsy attending a pediatric neurology clinic for behavioral disorders using the Rutter A2 scale and found a prevalence of behavioral problems of 46.6%, with a higher prevalence in males (38). A community-based case-control study in Tanzania by Burton et al. assessed children aged 6 to 14 years using the Rutter scale. 66% of children with epilepsy were diagnosed with behavioral disorders as compared to 19% of their age-matched controls (39).

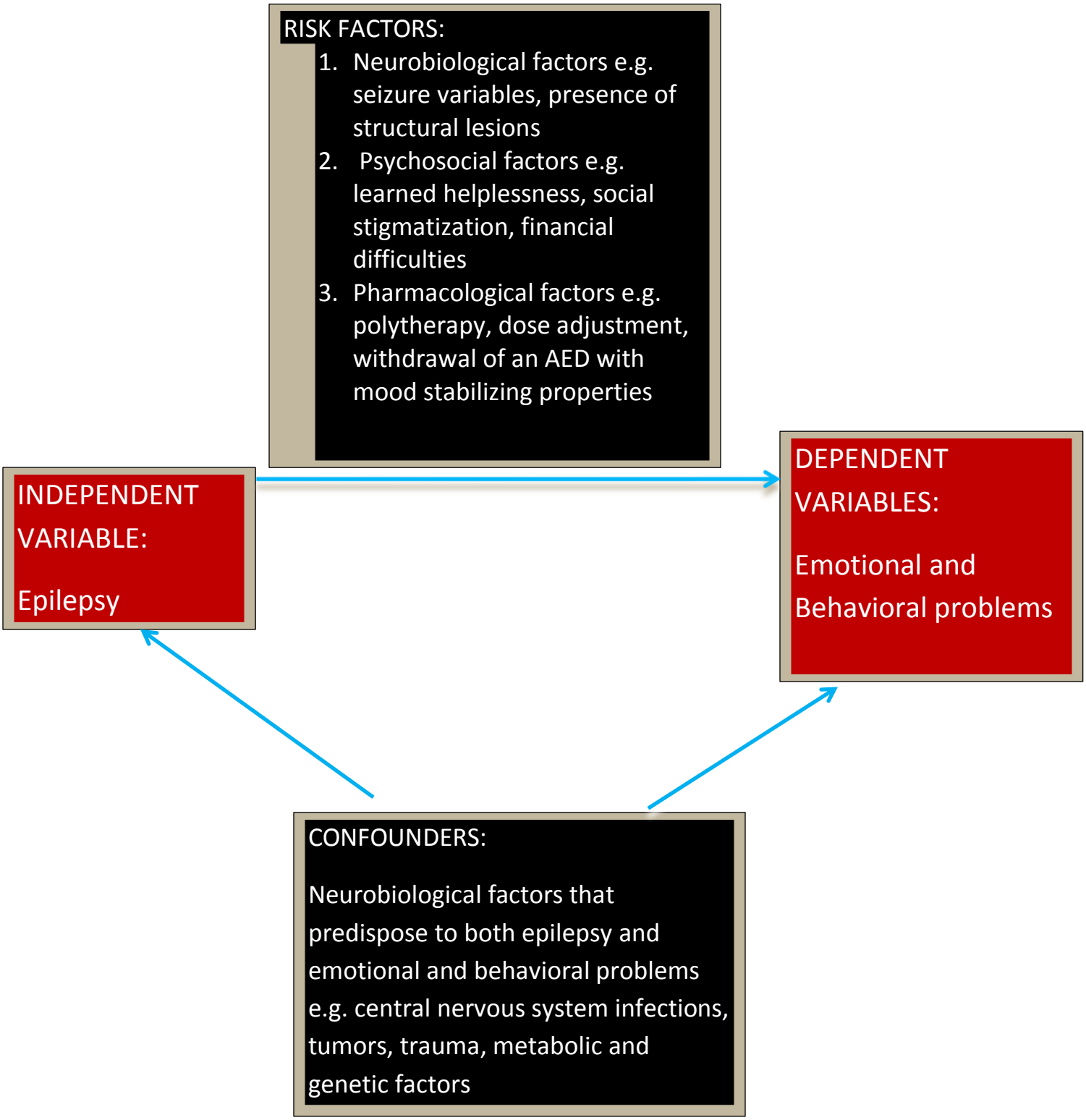
Spangenberg et al. reviewed the psychosocial issues surrounding children with epilepsy and their families and cited feelings of frustration, embarrassment and helplessness in the children resulting in anxiety, depression and concomitant social withdrawal. High levels of stress and burden in the parents also result in a higher prevalence of depression and anxiety (40).

2.4 Local studies (Kenya)

There is limited data available on studies done in Kenya on the subject. A study on behavioral problems in children with epilepsy in rural Kenya by Kariuki et al. using the Child Behavior Questionnaire For Parents (CBQFP) indicated a prevalence of 49% of behavioral disorders in children with epilepsy as compared to 26% of controls (41).

2.5 Conceptual framework

Figure 1: Conceptual framework



The above conceptual map depicts the factors which can lead to emotional and behavioral problems in children with epilepsy, as well as factors which can predispose to both epilepsy and emotional and behavioral disorders.

Starting on the right-hand side, epilepsy is the independent variable. It can lead to emotional and behavioral problems, as seen on the left-hand side, and these are the dependent variable.

This occurs due to a number of influencing factors seen at the top including neurobiological, psychosocial and pharmacological factors.

At the bottom, there are the confounding factors, i.e. factors which can lead to both epilepsy and emotional and behavioral problems. These are usually neurobiological, such as central nervous system infections, tumors, trauma, genetic and metabolic causes.

The study intended to find the prevalence and types of emotional and behavioral problems occurring in children, as well as various influencing factors such as sociodemographic factors and clinical factors e.g. the type of seizures, frequency, age of onset and number of medications.

2.6 Statement of the problem

Pediatric epilepsy is commonly associated with mental health problems. A high prevalence of emotional and behavioral problems in pediatric epilepsy has been demonstrated in various epidemiological studies internationally. Children with epilepsy have also been found to be at an increased risk for unmet mental health needs whereby they are treated for the seizures but the mental problems remain undiagnosed in some.

However, few studies have been done in Africa, and specifically in Kenya on the association between pediatric epilepsy and psychiatric problems.

2.7 Rationale of the study

Currently, there is paucity of research literature on studies done in Kenya on mental problems in pediatric epilepsy. Thus, there is a knowledge gap in this area that requires attention.

This study highlights the presence of comorbid emotional and behavioral problems in pediatric epilepsy, thus justifies the need for a holistic approach in the care of these patients. The study will also inform the making and implementation of policies in the management of pediatric epilepsy.

2.8 Study question

What is the prevalence of emotional and behavioral problems in children with epilepsy on follow-up at the KNH pediatric neurology clinic?

2.9 Study objectives

2.9.1 Broad objective

To determine the prevalence and types of emotional and behavioral problems occurring in children with epilepsy on follow-up at the Kenyatta National Hospital (KNH) pediatric neurology clinic and the associated sociodemographic characteristics.

2.9.2 Specific objectives

i. To determine the overall prevalence of emotional and behavioral problems in children with epilepsy on follow-up at the KNH pediatric neurology clinic.

ii. To determine the types of emotional and behavioral disorders occurring in children with epilepsy on follow-up at the KNH pediatric neurology clinic.

iii. To determine the association between sociodemographic characteristics and emotional and behavioral problems in children with epilepsy on follow-up at the KNH pediatric neurology clinic.

CHAPTER THREE

3. Study methodology

3.1 Study design

This was a cross-sectional descriptive study.

3.2 Study area

The study was conducted at Kenyatta National Hospital. This is Kenya's oldest and largest teaching and referral hospital, founded in 1901 by the British colonialists as the Native Civil Hospital, later renamed King George VI in 1952. It was renamed Kenyatta National Hospital following independence from the British. Kenyatta National Hospital (KNH) is located in Nairobi, the capital city of Kenya and occupies a total area of 45.7 hectares.

KNH has 50 wards, 22 outpatient clinics, 24 theatres (16 specialized) and Accident and Emergency Department. It has a total capacity of 1800 beds.

Within the KNH complex are the College of Health Sciences (University of Nairobi), the Kenya Medical Training College, Kenya Medical Research Institute and National Laboratory Service (42).

The hospital serves patients referred from all over the country; hence the study participants were a good representation of patients from the whole country.

3.3 Study population

The study population was children diagnosed with epilepsy on follow-up at the pediatric neurology clinic at Kenyatta National Hospital.

3.4 Inclusion criteria

Children diagnosed with epilepsy on follow up at KNH pediatric neurology clinic.

Age between 6 and 12 years in order to exclude those with febrile convulsions.

Accompanied by primary caregiver.

Primary caregiver willing to participate in the study.

3.5 Exclusion criteria

Children under the age of 6 years

Not accompanied by primary caregiver

Primary caregiver's or child's unwillingness to participate in the study

3.6 Sample size determination

The Cochran's formula for estimating sample size in prevalence studies was used with a finite population correction as suggested by Daniels (43).

$$n = \frac{NZ^2P(1-P)}{d^2\ N-1\ + Z^2P(1-P)}$$

n = sample size

N = population of epileptic children attending clinic at KNH per month is estimated at 200, yielding a population of 400 for the study period.

P = Prevalence of emotional and behavioral problems in children with epilepsy based on study by Rutter et al. (3)

1-P = 1 minus the prevalence of emotional and behavioral problems in children with epilepsy

Z = Z statistic representing 95% level of confidence (1.96)

d = desired level of precision set to 5% (0.05)

$$n = \frac{400 \times 1.96^2 0.286(1-0.286)}{0.05^2\ 400-1\ + 1.96^2 \times 0.286(1-0.286)}$$

n = 177

3.7 Sampling method

Children between the ages of 6 and 12 years on follow-up for epilepsy at the KNH pediatric neurology clinic who met the inclusion criteria were selected using the survey sampling method, specifically systematic sampling method, whereby every second patient who arrived for the clinic was selected. As

the waiting time was usually approximately one hour, the questionnaire was administered while waiting to be seen.

3.8 Data collection instruments

3.8.1 Researcher-designed sociodemographic questionnaire

This questionnaire captured data on various variables which included age, and sex. It also captured data on the primary caregiver including who is the primary caregiver, level of education of primary caregiver and total monthly income of the household.

Other information included variables related to the epilepsy including the type of seizures (information to be obtained from patient's records), frequency of seizures, age of onset of epilepsy and whether is on monotherapy, polytherapy or not on medication.

It also captured data related to associated psychiatric comorbidity including whether has been diagnosed with a psychiatric condition prior to the interview (information was obtained from patient's records).

3.8.2 Child Behavior Checklist (CBCL)

The Child Behavior Checklist is a commonly used instrument in identifying emotional and behavioral problems in children. It was developed by Thomas M. Achenbach and is a component of the Achenbach System of Empirically Based Assessment (ASEBA) (44).

The CBCL consists of a standardized form usually filled by a parent or caretaker who knows the child well. There are various versions of the checklist for different ages. The preschool version (CBCL/1½ -5) is used for children aged between 18 months and 5 years while the school-age version (CBCL/6-18) is for children aged 6 to 18 years.

There are alternative forms of the CBCL that can be filled by teachers or caretakers if the child attends daycare, the Caregiver-Teacher Report Forms (C-TRF), and by the children themselves for those aged between 11 and 18 years, the Youth Self Report (YSR) forms. These can be used for comparison with the CBCL forms filled by parents, for clarity, consistency and also to acquire additional information about the child.

The checklist consists of statements about the child's behavior e.g. "doesn't get along with other children". Responses to the statement are marked on a Likert Scale i.e. 0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true.

Similar statements are grouped together into a number of syndromes. Each syndrome consists of symptoms that were found to occur concomitantly when multivariate statistical analysis was done of CBCLs administered to a large number of children who had been referred clinically. Summing of the grouped symptoms is done to produce a total score for a particular syndrome. For each syndrome, there is a table used to determine whether the severity of the symptoms can be categorized as normal, borderline or clinical. These categorizations were determined after comparison of scores obtained by a clinically referred sample with scores of a large sample of their normal peers. Some syndromes are further summed up to provide scores for internalizing and externalizing problem scales.

The validity and reliability of this instrument has been demonstrated by a wide body of research, both in clinical and non-clinical populations. These include a study done by Dunn et al which used the CBCL to assess 42 children with new onset epilepsy and found the prevalence of emotional and behavioral problems to be similar to that found by Rutter et al (4,5). Dorrenbaum e al used the CBCL to assess 38 randomly selected children with epilepsy and found it to be a good screening tool for maladjustment (45).

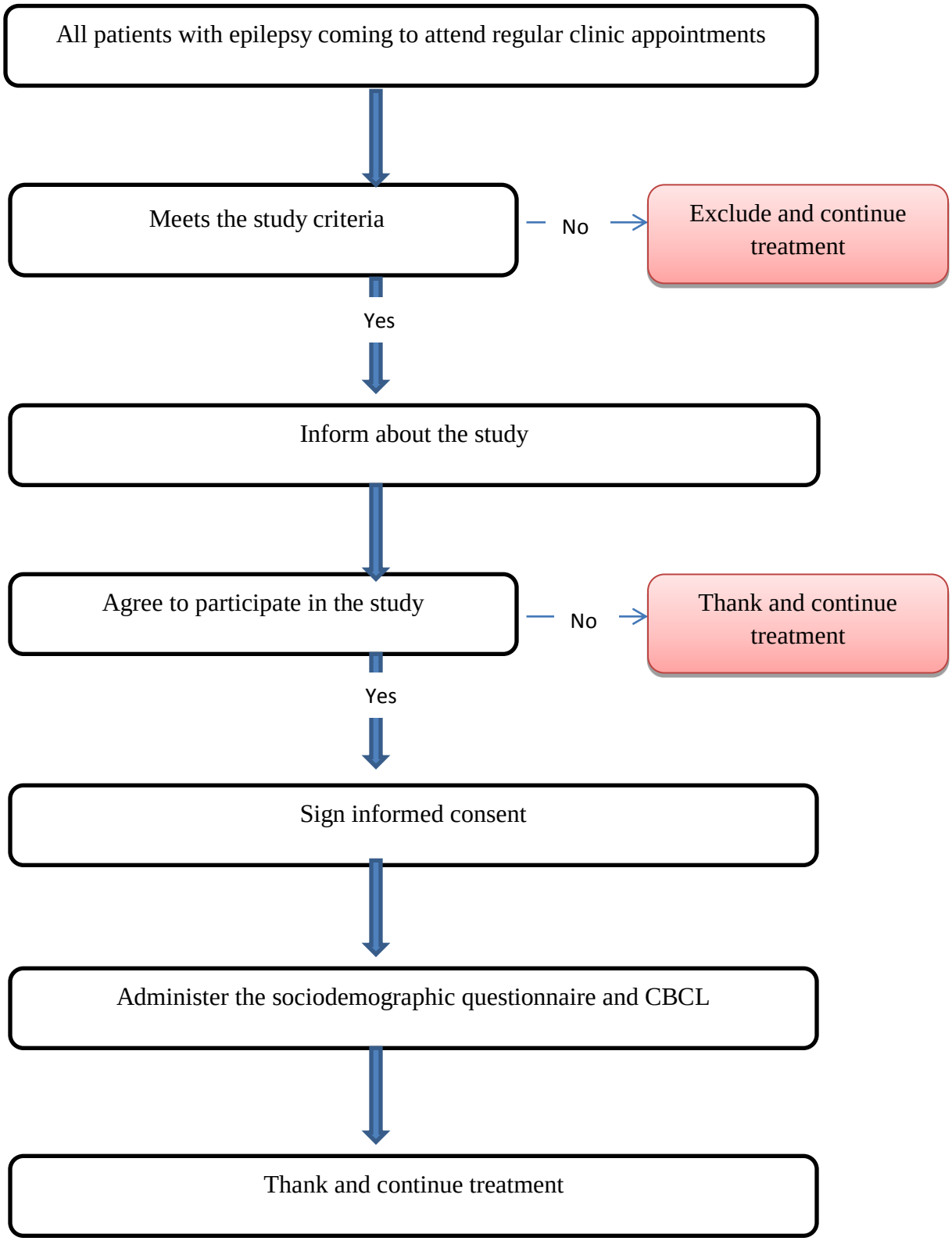
3.9 Recruitment and data collection procedure

Study participants were recruited from children between the ages of 6 and 12 years who have been diagnosed with epilepsy by clinical features and EEG findings, on follow-up at the KNH pediatric neurology clinic attending their regular clinic appointments.

The nurses assisting in the pediatric neurology clinic were informed about the study. They directed the primary caregivers of the children who met the inclusion criteria from the waiting area to a room where the researcher or research assistant explained the purpose of the study and any associated ethical concerns.

The caregivers willing to participate in the study signed the consent form after which the sociodemographic questionnaire and CBCL were administered to them. If a caregiver was not able to fill in the questionnaires independently, the items were read out aloud by the person administering it and the replies filled in. For those caregivers who neither understood English nor Kiswahili, assistance of a person conversant in their local language was enlisted, to translate the questions.

Figure 2: Recruitment and data collection procedure flowchart



3.10 Quality assurance procedures

The research proposal was reviewed by the University Of Nairobi Department Of Psychiatry and the Kenyatta National Hospital – University of Nairobi Ethics and Research Committee, which ensured that the proposal passed the quality threshold.

Emphasis was put by the researcher to ensure that study participants fully understood what the study was about, potential risks and benefits and the questions being asked.

The researcher received training on research methods and administration of the screening tools that were used in this study at the University of Nairobi and worked under supervisors from the University of Nairobi, Department of Psychiatry, to ensure high quality of data collection.

Information collected was stored in locked cabinets only accessible to the researcher (hard copies) while soft copies were stored in a password-protected Microsoft database to ensure proper organization of the data and confidentiality.

Data entry and cleaning was done using double-entry and double-checking procedures in order to minimize error.

Results of the research were presented formally to the University of Nairobi Department of Psychiatry and the Kenyatta National Hospital – University of Nairobi Ethics and Research committee for peer review, hence further ensuring high quality research.

3.11 Ethical considerations

Approval to carry out the study was obtained from the Kenyatta National Hospital – University of Nairobi Ethics and Research Committee. Written authorization to carry out the study was also obtained from the relevant authorities at Kenyatta National Hospital.

Study participants received adequate information about the study and the potential risk and benefits to ensure that they gave informed consent as per the consent explanation

Those who declined to participate or withdraw from the study did not suffer any consequences.

The information obtained from the participants was confidential and was only used for the purposes of this study. Serial numbers were used instead of names to ensure confidentiality.

The researcher strived to report data honestly and did not fabricate, falsify or misrepresent data. Plagiarism was also avoided to ensure integrity of the research.

3.12 Benefits to study participants

Study participants benefited from the diagnostic services and those found to have emotional or behavioral problems were referred to the mental health department at KNH, where they were managed accordingly.

The results from this study will assist clinicians in understanding the relationship between psychiatric disorders and pediatric epilepsy hence the need for an integrated multidisciplinary approach to these patients.

3.13 Risks to study participants

The time required to conduct the interview was an inconvenience to some study participants who were children hence got easily bored and impatient while their parents or caretakers were filling the questionnaire.

Some parents also felt uncomfortable revealing details about their children's behavior. This was overcome by assuring them of confidentiality and informing them of the purpose of the study.

3.14 Data management

Quality control measures were implemented prior to data collection to reduce errors in data. This included training of research assistants on study procedures, interviewing and data recording on the study tools. Additional measures included developing standard operating procedures (SOPs) and data collection manual to guide data collection. The principal investigator also supervised all data collection. Upon receiving the completed questionnaire form the principal investigator examined all questionnaires for completeness. All incomplete questionnaires were completed by referring back to patient record and in cases where data was missing from records a code was be assigned for missing values. Data was entered into databases designed in MS Office Access (2007). The databases were customized using the study questionnaire structure with data stored in numeric coded format, and text for open ended questions. Range and consistency checks were built into the database as a quality assurance measure aimed at reducing data entry errors. Data was transferred from Access databases to Stata for data cleaning and analysis. Data cleaning involved inspecting each variable in the database to check for invalid entries, and inconsistencies using Stata procedure for summarizing variables. In cases where data entry errors were noted cleaning involved validating entries by referring back to the study questionnaire using the unique study identifier contained in each questionnaire. Any inconsistency between the

questionnaire and data contained in the database was resolved by checking patient records and re-entering the data contained in the records.

3.15 Data analysis

Data was analyzed using Stata (version 15). Analysis was conducted in three stages, namely: univariable analysis, bivariable analysis and multivariable analysis. For the univariable analysis, each individual variable in the dataset was analyzed using descriptive statistics. During this stage, continuous variables like age were analyzed by calculating mean and standard deviation for normally distributed variables and median and ranges for skewed variables. Categorical variables were analyzed using frequencies, and relative frequencies or percentages calculated using the relevant denominator values. Presentation of results was done using frequency distributions and graphs. The main objective related to determining overall prevalence of emotional and behavioral problems in childhood was addressed by calculating the percentage of children with child behavior checklist score indicative of specific emotional and behavioral problems and the total number of study patients as denominator. Prevalence for specific morbidities was also calculated and reported separately for each condition. Analysis of the factors associated with emotional and behavioral problems in epilepsy involved calculating the percentages of patients with each of the sociodemographic factors. Next, bivariate analysis was conducted by cross tabulating each factor with the dependent variable (emotional and behavioral problems). For continuous factors for example age, mean age in patients with and without emotional and behavioral problems was compared using Student's t-test. Comparison of percentages across levels of categorical independent variables was done using Chi square test. Statistical significance was based on an alpha cut-off level of 0.05. The final stage of analysis was a multivariable analysis conducted using logistic regression for binary outcomes represented by the percentage of patients with psychiatric illness for each dependent variable. The independent variables in the logistic regression included all variables showing significant association with the dependent variable in the bivariate analysis. Odds ratios and 95% confidence intervals were reported from the multivariate analysis.

CHAPTER FOUR

4. Results

The study recruited a total of 177 children with epilepsy on follow-up at the KNH paediatric neurology clinic. The characteristics of these children, prevalence of emotional and behavioural problems and associated risk factors are presented in this chapter.

4.1 Sociodemographic characteristics of children with epilepsy

The mean age of the participants was 8.9 (SD 2) years. Table 1 shows that the modal age group was 10-12 years with 41.8% (n=74) of children aged 10 years and above. There were 117 males (66.1%) giving a male to female ratio of 2: 1. Both parents were the primary caregiver for 67.2% of children; mothers were the primary caregivers for 22.6% of children and 5.6% had other caregivers. Of the caregivers, 47.4% had primary level education and 5.1% did not attend formal schooling. Most households (52.6%) reported a monthly income between Ksh 10,000 and 50,000, 42.2% had a monthly income of less than Ksh, 10,000 and only 5.2% reported a monthly income of more than Ksh. 50,000.

Table 1: Sociodemographic characteristics of children with epilepsy in KNH

	Frequency (n)	**Percent (%)**
Age		
6-7 years	54	30.5
8-9 years	49	27.7
10-12 years	74	41.8
Sex		
Male	117	66.1
Female	60	33.9
Primary caregiver		
Mother	40	22.6
Father	8	4.5
Both parents	119	67.2
Other	10	5.6
Level of formal education of primary caregiver		
None	9	5.1
Primary	83	47.4
Secondary	56	32
Tertiary	27	15.4
Household monthly income		
< Ksh 10000	73	42.2
Ksh 10000-50000	91	52.6
More than Ksh 50000	9	5.2

4.2 Clinical characteristics of children with epilepsy

The mean age for onset of seizures was 4.7 years, while the median was 3 years (IQR 1 – 6 years). Almost one –half (48%) of the children had the first seizure at less than 2 years of age. 32% of children developed epilepsy beyond 5 years of age and in 20.6% onset occurred during the first year of life (Table 2). At least one-half (50.3%) of children attending epilepsy follow up clinic had not had a seizure during the last one year and 30.5% had irregular seizures.

General tonic clonic seizures were reported in 76.8% of children, absence seizures in 10.2%, simple partial seizures in 6.2%, complex partial in 4.4% and atonic seizures in 2.8% of children.

One hundred and two children (57.6%) were on a single type of AED. 38.4% (n=68) were on more than one drug and 7% (n=4) were not on any medication. 16% reported being diagnosed with mental illness prior to the interview (Table 2).

Table 2: Clinical characteristics of children with epilepsy in KNH

	Frequency (n)	**Percent (%)**
Age at first seizure		
< 1 year	36	20.6
1-2 years	48	27.4
3-4 years	35	20
5 years and above	56	32
Frequency of seizures		
Once or more daily	10	5.6
Once or more monthly but not daily	13	7.3
Less than once monthly	11	6.2
Occur with irregular frequency	54	30.5
None in the last one year	89	50.3
Type of seizure		
GTC	136	76.8
Absence	18	10.2
Simple Partial	11	6.2
Complex partial	7	4
Atonic	5	2.8
Types of epilepsy drugs taken		
One	102	57.6
More than one	68	38.4
None	7	4
Child ever diagnosed with mental illness		
Yes	28	16
No	147	84

4.3 Emotional and behavioral problems in epilepsy

The raw score for the eight CBCL syndrome profiles are presented in tables 3.

Table 3: Mean (SD) and median CBCL syndrome scores in children with epilepsy

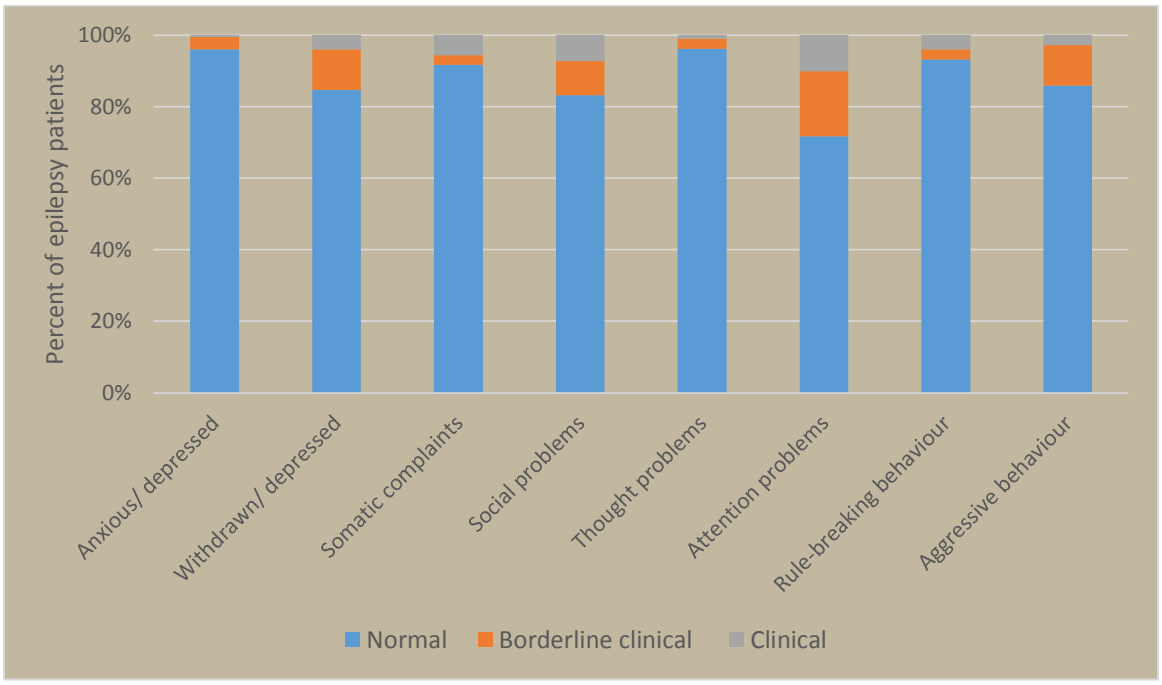
	Mean	**SD**	**Median**
Internalizing			
Anxious/ depressed	2.0	2.4	2
Withdrawn/ depressed	1.6	2.1	1
Somatic complaints	1.6	2.2	1
Social problems	3.6	3.3	3
Thought problems	1.2	1.8	0
Attention problems	6.1	4.9	5
Externalizing			
Rule-breaking behaviour	1.8	2.6	1
Aggressive behaviour	5.9	5.6	5

4.4 Types of emotional and behavioral problems occurring in children with epilepsy

The prevalence of the eight CBCL clinical syndrome profiles are presented in figure 3. Attention problems (18.1% borderline clinical and 10.2% clinical), aggressive behaviour (11.3% and 2.8%), social problems (9.6% and 7.3%) and withdrawal/ depression (11.3% and 4%) were the four leading syndromes.

For the internalizing and externalizing groupings of syndromes, the prevalence of internalizing syndromes was higher (10.2%) as compared to the externalizing group of syndromes (6.8%).

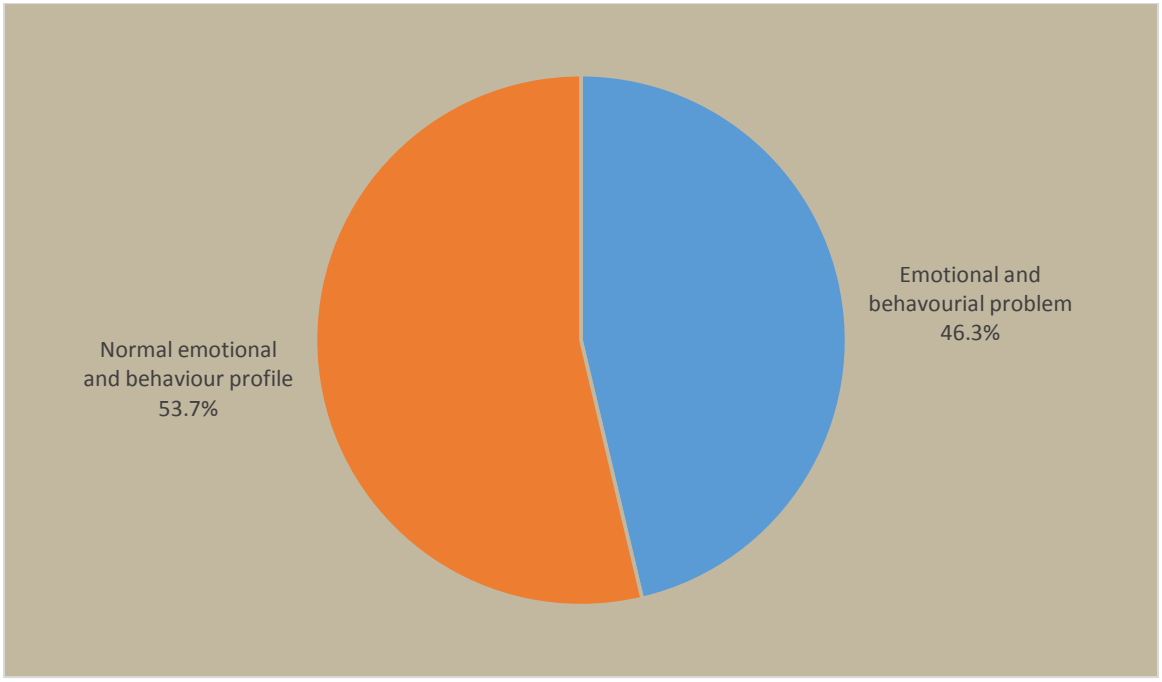
Figure 3: Prevalence of CBCL clinical syndromes in children with epilepsy



4.5 Overall prevalence of emotional and behavioral problems in children with epilepsy

There were 82 children diagnosed with at least one of the eight clinical CBCL syndromes. The overall prevalence of emotional and behavioural problems in children with epilepsy on follow-up at the KNH paediatric neurology clinic was 46.3% (95% CI 38.8 to 54). These results are presented in figure 4 below..

Figure 4: Prevalence of emotional and behavioural problems in epileptic children



4.6 Sociodemographic characteristics and emotional and behavioral problems

Logistical regression revealed a significant association between age and emotional and behavioural problems in children with epilepsy. The children aged 10 years and above were 2.7 times more likely to have emotional and behavioural problems (OR 2.7; 95% CI 1.3 to 5.64; p = 0.008). The prevalence of emotional and behavioural problems was not associated with child's sex (p = 0.483), reported primary care giver (p > 0.05), caregiver's level of education or household monthly income. These results are presented in table 4 below.

Table 4: Sociodemographic characteristics and emotional and behavioural problems

	Emotional and behavioural problem			
	Yes	**No**	**OR (95% CI)**	**P**
Age				
6-7 years	17(31.5)	37(68.5)		
8-9 years	24(49.0)	25(51.0)	2.09(0.94-4.66)	0.072
10-12 years	41(55.4)	33(44.6)	2.70(1.30-5.64)	0.008
Sex				
Male	52(44.4)	65(55.6)		
Female	30(50.0)	30(50.0)	1.25(0.67-2.33)	0.483
Primary caregiver				
Mother	17(42.5)	23(57.5)		
Father	4(50.0)	4(50.0)	1.35(0.30-6.19)	0.697
Both parents	56(47.1)	63(52.9)	1.20(0.58-2.48)	0.617
Other	5(50.0)	5(50.0)	1.35(0.34-5.43)	0.67
Level of education of primary caregiver				
None	7(77.8)	2(22.2)		
Primary	42(50.6)	41(49.4)	0.29(0.06-1.49)	0.139
Secondary	22(39.3)	34(60.7)	0.18(0.04-0.97)	0.046
Tertiary	11(40.7)	16(59.3)	0.20(0.03-1.13)	0.068
Household income				
< Ksh 10000	38(52.1)	35(47.9)		
Ksh 10000-50000	37(40.7)	54(59.3)	0.63(0.34-1.17)	0.146
More than Ksh 50000	6(66.7)	3(33.3)	1.84(0.43-7.93)	0.412

4.7 Clinical characteristics and emotional and behavioral problems

The prevalence of emotional and behavioural problems was significantly associated with diagnosis of mental disorder (p = 0.004), types of antiepileptic drugs taken (p = 0.013), and reduced frequency of seizures (p = 0.018). The odds of emotional and behavioural problems reduced by 72% in patients who had not been diagnosed with a mental illness compared to who had been diagnosed with a mental illness (OR = 0.28; 95% CI 0.11-0.67). Children who were taking more than one antiepileptic drug were twice as likely to have had emotional and behavioural problems (OR = 2.21; 95% CI 1.18 - 4.14). The odds of

emotional and behavioural problems were 92% lower in children with seizures occurring infrequently (OR = 0.08; 95% CI 0.01 – 0.06) or those reporting no seizure in the last one year (OR = 0.08; 95% CI 0.01 – 0.06) compared to children having one or more seizure daily (table 5).

Table 5: Clinical characteristics of epilepsy and emotional and behavioural problems

	Emotional and behavioural disorder			
	Yes	**No**	**OR (95% CI)**	**P**
Age at first seizure				
< 1 year	19(52.8)	17(47.2)		
1-2 years	25(52.1)	23(47.9)	0.97(0.41-2.31)	0.95
3-4 years	13(37.1)	22(62.9)	0.53(0.20-1.36)	0.188
5 years and above	25(44.6)	31(55.4)	0.72(0.31-1.67)	0.446
Frequency of seizures				
Once or more daily	9(90.0)	1(10.0)		
Once or more monthly but not daily	8(61.5)	5(38.5)	0.18(0.02-1.86)	0.15
Less than once monthly	6(54.5)	5(45.5)	0.13(0.01-1.44)	0.097
Occur with irregular frequency	22(40.7)	32(59.3)	0.08(0.01-0.65)	0.018
None in the last one year	37(41.6)	52(58.4)	0.08(0.01-0.65)	0.018
Type of seizure				
GTC	68(50.0)	68(50.0)		
Partial	5(45.5)	6(54.5)	0.83(0.24-2.86)	0.772
Complex partial	4(57.1)	3(42.9)	1.33(0.29-6.18)	0.713
Atonic	2(40.0)	3(60.0)	0.67(0.11-4.12)	0.662
Other	3(16.7)	15(83.3)	0.20(0.06-0.72)	0.014
Types of epileptic drugs taken				
One	40(39.2)	62(60.8)		
More than one	40(58.8)	28(41.2)	2.21(1.18-4.14)	0.013
None	2(28.6)	5(71.4)	0.62(0.11-3.35)	0.579
Ever diagnosed with mental illness				
Yes	20(71.4)	8(28.6)		
No	60(40.8)	87(59.2)	0.28(0.11-0.67)	0.004

CHAPTER FIVE

5. Discussion

5.1 Sociodemographic characteristics of children with epilepsy

There were 177 males (66.1%) giving a male to female ratio of 2: 1. In previously reported studies, the prevalence of epilepsy by gender is variable. In Uganda and Nigeria, a higher prevalence has been reported in females as compared to males while in the U.S., Ethiopia, Tunisia, Kenya and Zambia, a higher prevalence has been reported in males (46, 52).

Of the caregivers, 47.4% had primary level education, and 5.1% did not attend formal schooling. This is due to the social setting where the study was done, which was a government hospital hence most of the patients were of a low socioeconomic status.

Most (52.6%) households reported a monthly income between Ksh 10,000 and 50,000, 42.2% had a monthly income of less than Ksh, 10,000 and only 5.2% reported a monthly income of more than Ksh. 50,000. This is reflective of the average monthly income of households in Kenya where majority earn a monthly income of between Ksh. 10,000 and Ksh. 20,000 (49). The reason for this could be the fact that this study was done at Kenyatta National Hospital where majority of the patients seeking treatment at the hospital are of low socioeconomic status.

5.2 Clinical characteristics of children with epilepsy

The mean age for onset of seizures was 4.7 years, while the median was 3 years. This is similar to a study done in Finland where the mean age of onset was 4.3 years (50). Almost one–half (48%) of the children had the first seizure at less than 2 years of age, which reflects the pattern of incidence of epilepsy, usually occurring in both extremes of life. Similar findings have been reported in rural Kenya, where in 69% of the active cases and 75% of the inactive cases, the onset of seizures was reported to be within the first two years of life. In Uganda, 50.2% had presented during infancy (63).

At least one-half (50.3%) of children attending epilepsy follow up clinic had not had a seizure during the last one year, which is the definition of inactive epilepsy. This contrasts with a study done by Mung'ala et al. in rural Kenya where the prevalence of inactive epilepsy was found to be 68.2% (53). The reason for this could be due to the fact that the study was done in a community setting as opposed to this study which was done in a hospital setting where more severe forms of disease are likely to be found.

The most common type of seizures were generalized tonic clonic seizures were reported in 76.8% of children. Mung'ala et al. in a study in rural Kenya also reported a high prevalence of generalized tonic clonic seizures and/or secondarily generalized seizures in overall two thirds of children (53). Similar findings have been reported in Pakistan and Uganda where the prevalence was 77% and 53% respectively (46, 63). In contrast, in the U.S., a study found that approximately 60% of incidence cases experienced partial seizures (2). A study done in Nigeria reported complex partial seizures to be the most prevalent at 76.6% (51) . The second most prevalent type of seizures were absence seizures in 10.2% of children. This prevalence is similar to that reported in the U.S. (10%) (2). The reason for these differences may be due to difficulties in diagnosis in low and middle income social settings, whereby many of the patients are not able to afford EEG and other imaging studies such as MRI and CT scans, hence diagnosis may be based on history and examination findings only.

5.3 Overall prevalence of emotional and behavioral problems in epilepsy

The overall prevalence of emotional and behavioural problems in children with epilepsy on follow-up at the KNH paediatric neurology clinic was 46.3% (95% CI 38.8 to 54). These findings are similar to those studies which have been done in other low and middle income countries as shown in table 6.

Table 6: Prevalence of emotional and behavioral problems reported in low and middle income countries

Author	**Country**	**Tools**	**Findings**
Kariuki et al. (2011)(41)	Kenya	Child Behavior Questionnaire for Parents (CBQFP)	49% vs 26% of controls were reported to have behavioral problems
Lagunju et al. (2008)(38)	Nigeria	Rutter A2 scale	Behavioral problems were found in 39 (46.6%) of 84 subjects
Ibinga et al. (2015) (54)	Gabon	Quality Of Life Scale(QOLS)	42.2% were suspected to have behavioural disorders
Sriudokamjorn et al. (2008) (55)	Thailand	Thai Youth Checklist (TYC)	prevalence of behavioral problems in epileptic children was 57 percent
Mishra et al. (2017) (56)	India	Child Behavior Checklist (CBCL)	Found a 54% prevalence of behavioral problems

The findings are in contrast with studies done in higher income countries, as seen in table 7.

Table 7: Prevalence of emotional and behavioral problems reported in higher income countries

Author	Country	Tools	Findings
Freilinger et al. (2006) (57)	U.S.	Child Behavior Checklist (CBCL)	22% had emotional or behavioural problems
Keene et al. (2008)(58)	Canada	Child Behavior Checklist (CBCL)	39.3% had significant behavior problems
Davies et al. (2003)(59)	U.K.	Development and Well-Being Assessment in combination with specialist clinician rating	The rate of behavioural disorders was 37%

The higher prevalence in low and middle income countries is likely to be due to the high level of untreated epilepsy, resulting in more comorbidity. Another reason could be due to the differences in study tools used.

The high prevalence reported suggests that screening for emotional and behavioral problems should be conducted during evaluation of childhood seizures.

5.4 Types of emotional and behavioral problems occurring in children with epilepsy

Attention problems (18.1% borderline clinical and 10.2% clinical), aggressive behaviour (11.3% and 2.8%), social problems (9.6% and 7.3%) and withdrawal/ depression (11.3% and 4%) were the four leading syndromes. These findings are similar to a meta-analysis by Rodenburg et al. (2005) in which attention problems, thought problems and social problems were found to be relatively specific to epilepsy (60). Freilinger et al. (2008) demonstrated high behavioural ratings on the atypicality, withdrawal, and attention Problems scales (57). A study by Kariuki et al. (2012) had similar findings whereby a high prevalence of problems with attention span and social relationships was reported (41). Dunn and Austin (1999) reported on behavioral problems in adolescents and found a high prevalence specifically in attention problems, depression and anxiety (21). The results also correlate with studies on Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM IV) disorders associated with

pediatric epilepsy, whereby higher rates of ADHD, depressive disorders and anxiety disorders have been reported (61). Children with epilepsy are often overwhelmed by feelings of embarrassment, frustration and helplessness due to the frightening and unpredictable nature of the seizures, and display resultant fearfulness, dependence and demanding behavior, which may explain the high prevalence of the above reported problems. Another cause may be a shared pathophysiological mechanism causing both the seizure and the behavioral problems. The behavioral symptoms may also occur as sequelae of the seizures themselves.

5.5 Sociodemographic characteristics and emotional and behavioral problems

There was a significant association between age and emotional and behavioural problems in children with epilepsy (table 4). The children aged 10 years and above were 2.7 times more likely to have emotional and behavioural problems (OR 2.7; 95% CI 1.3 to 5.64; p = 0.008). This finding is similar to other studies where younger children are reported to be less likely to have received treatment compared to older children (62). In contrast, other studies reported an association between earlier age of onset and problems on the social scale (57). Dunn et al. (1999) reported age to be an unreliable predictor of behavioural issues in pediatric epilepsy (21).

The prevalence of emotional and behavioural problems was not associated with child's sex (p = 0.483), or the reported primary care giver (p > 0.05), caregiver's level of education or household monthly income.

5.6 Clinical characteristics and emotional and behavioral problems

The prevalence of emotional and behavioural problems was significantly associated with diagnosis of mental disorder (p = 0.004), types of antiepileptic drugs taken (p = 0.013), and reduced frequency of seizures (p = 0.018).

Children who were taking more than one AED were twice as likely to have had emotional and behavioural problems (OR = 2.21; 95% CI 1.18 - 4.14). Several studies have shown a significant association between polytherapy and behavioural problems (21). Freilinger et al.(2006) found polytherapy to be associated with higher scores in attention, social and aggressive behaviour scales (57). The specific types of AEDs that the patients were on was not within the scope of this study, though phenobarbital and benzodiazepines have been associated with hyperactivity (21), and are known to be the most commonly prescribed AEDs in resource-poor settings due to their being cheaper (51).

The odds of emotional and behavioral problems were 92% lower in those reporting no seizure in the last one year (OR = 0.08; 95% CI 0.01 – 0.06) compared to children having one or more seizure daily. Similar findings have been reported in several other studies where increased frequency of seizures has been associated with emotional and behavioural problems (21, 57). These findings suggest that better seizure control also results in a reduction in emotional and behavioral comorbidity. Another reason may be due to the differences in severity of the central nervous dysfunction causing both the seizure and the behavioral morbidity, whereby more severe dysfunction will result in higher frequency of seizures as well as behavioral morbidity, and vice versa.

CHAPTER SIX

6. Conclusion, recommendations and limitations

6.1 Conclusion

The results provide an important estimate of the burden of behavioral problems in children with epilepsy in Kenya, although the study was done in a specialized clinic where more complicated forms of epilepsy are referred hence the children may be more prone to behavioral problems. Generalization of this sample should therefore be done with this limitation in mind. There is a high prevalence (46.3%). of emotional and behavioral problems among children on treatment for epilepsy at Kenyatta National hospital. Therefore, early screening for these problems as well as education of the parents and other caregivers as well as the children about their concerns would help to reduce their effect and help in management of these patients.

The most prevalent problems were attention problems, aggressive behaviour, social problems and withdrawal/ depression. Awareness of these conditions by the clinicians managing these patients would inform the choice of AED prescribed to avoid those which may contribute to behavioural difficulties, as well as form a basis for integrated management comprising of both pharmacotherapy and psychotherapy.

6.2 Recommendations

Screening of children with epilepsy for emotional and behavioral problems by clinicians would ensure early detection and hence reduce their effect. Sensitization of the clinicians who treat childrben with epilepsy which will inform the choice of AEDs used in their management, to avoid those medicatons linked to behavioral problems.

Psychoeducation of families and children with epilepsy to help address their fears and concerns about the disease may help to reduce emotional problems, due to increased knowledge of the condition, which would reduce feelings of helplessness due to the frightening and unpredictable nature of seizures.

Individual and group psychotherapy may be of help in children with epilepsy. It has been reported to improve self-esteem and reduce emotional and behavioral problems.

Further studies including prospective studies, to establish causal relationships the risk factors found to be associated with emotional and behavioral problems, as well as studies in the general population. This would provide results which would allow for generalization.

6.3 Limitations

The study design was cross-sectional, hence a causal relationship could not be established between the risk factors found to be associated with behavioral problems, as it was not possible to tell which occurred before the other.

The respondents may have suffered recall bias, while others may have exaggerated the extent of the problems. A multireporter approach may reduce such effects.

The study population was in a referral hospital setting, specifically in a child neurology clinic, where patients with more severe forms of disease are likely to be seen. This restricts generalizability of the findings to the general population of children with epilepsy.

There was a prolonged doctor's strike, which delayed data collection, and may possibly have had an effect on the results, due to the patients being off medication for a considerable length of time, resulting in more comorbidity.

CHAPTER SEVEN

7. References

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APPENDICES

Appendix I: Consent Information Document (English Version)

Title: Prevalence of emotional and behavioral problems in children with epilepsy attending the pediatric neurology clinic at Kenyatta National Hospital

Investigator:

Dr. Serah Wangari Karanja

Supervisors:

Prof. Caleb Othieno

Dr. Rachael Kang'ethe

Introduction

My name is Dr. Serah Karanja, a postgraduate student at the University of Nairobi. I wish to conduct a study on the prevalence of emotional and behavioral problems in children with epilepsy attending the pediatric neurology clinic at Kenyatta National Hospital.

I would like to invite you to participate in the study.

Description of the study and study objectives

This research is a cross-sectional descriptive study among children with epilepsy on follow up at the Kenyatta National Hospital neurology clinic.

The objective of this research is to determine the prevalence of emotional and behavioral problems in children with epilepsy attending the pediatric neurology clinic at Kenyatta National Hospital. It will have approximately 188 respondents and will take about 2 months to collect research data.

Requirements

For one to participate in the study your child needs to:

1. Be aged between 6 and 18 years
2. Have been diagnosed with epilepsy

Procedure

If you agree to participate in the study you will

1. Be asked to sign a consent form expressing your voluntary participation
2. Be asked questions that relate to you and your child's socio-demographic information, and your child's behavior. This will be in form of a questionnaire that will take about 20 minutes to complete

Benefits:

There are no direct benefits for participating in this study.

However, results from this study can help patients and clinicians to better understand the association between epilepsy in children and mental disorders.

This will help in improving the management of children with epilepsy.

If your child is found to be suffering a mental disorder, he or she will be referred to the child psychiatric clinic at this hospital for treatment

Risks:

It is possible that you might feel uncomfortable as you reveal information about your child's behavior, which is a potentially sensitive topic.

I would like to assure you that any information that you share will be strictly confidential and will be used for the purposes of this study only.

Voluntary Participation:

Your participation in this research is entirely voluntary and if you decide to participate, you are free to withdraw at any time. You may also choose not to answer specific questions. Your choice not to participate or choice to withdraw will not affect any treatment needs that your child may have at Kenyatta National Hospital now and in the future.

Confidentiality:

Your child's identity will be kept confidential. In addition, your child's name or any other personal identifier will not be used in any reports or publications arising from this study. Instead, your child will be assigned a number to protect their identity.

The questionnaires that you will complete will be stored safely, with nobody having access to them apart from the investigator and the supervisors. The data collected from this study will be entered in computers and kept away from public access.

Compensation:

You will not be paid to participate in this study.

Additional Information:

If you have questions about the study that are not answered in the consent information, please ask them. In addition, if you have questions in the future you may contact the following:

1. Investigator:

    a. Dr. Serah Wangari Karanja
    P.O Box 75 – 10100,
    Nyeri
    Tel: (254) 720991527

2. Supervisors:

    a. Prof. Caleb Othieno
    P.O BOX 19676-00202 NAIROBI
    cjothieno@gmail.com

    b. Dr. Rachael Kang'ethe
    P.O BOX 19676-00202 NAIROBI
    drkangethe@gmail.com

3. Kenyatta National Hospital/U.O.N/ Ethics & Research committee

    a. Kenyatta National Hospital
       P.O Box 20723-00202 Nairobi

       Tel: (254) 020 726300, Ext 44102, 44355

       Fax: 725272 Telegrams: medsup, Nairobi

       Email: uonknh_erc@uonbi.ac.ke

    b. University of Nairobi, College of Health Sciences
       P.O. Box 19676 – 00202 Nairobi

       Tel: (254) 020 2726300 Ext: 44355, Telegrams: varsity.

Appendix II: Informed Consent Form (English Version)

I .....(name of participant) have read/heard and understood the explanations given to me about this study entitled **"Prevalence of emotional and behavioral problems in children with epilepsy on follow-up at the Kenyatta National Hospital pediatric neurology clinic"**.

I have had the opportunity to ask questions that have been clarified to my satisfaction by .....(name of person taking consent/researcher) in the language I understand.

I understand that my participation in this study is entirely voluntary and I can withdraw my participation at any time I want to without giving an explanation for doing so. I understand that if I withdraw my participation, it will not affect my livelihood or management in any way.

I understand that all the information I give, including private information will be kept confidential. I accept to give information that will help in this study and also that whatever information is received will be reported and published confidentially.

I agree to participate in this study.

Name of participant:.....

Signature of participant:..... Date:.....

Signature of witness:..... Date:.....

Name of person taking consent:.....
Signature:..... Date:.....

You will receive a copy of the signed consent form to take away with you.

If you have questions about or would like further clarification about this study, please contact:

1. Investigator:

    a. Dr. Serah Wangari Karanja
    P.O Box 75 – 10100,
    Nyeri
    Tel: (254) 720991527

2. Supervisors:

    a. Prof. Caleb Othieno
    P.O BOX 19676-00202 NAIROBI
    cjothieno@gmail.com

    b. Dr. Rachael Kang'ethe
    P.O BOX 19676-00202 NAIROBI
    drkangethe@gmail.com

3. Kenyatta National Hospital/U.O.N/ Ethics & Research committee

    a. Kenyatta National Hospital
    P.O Box 20723-00202 Nairobi

    Tel: (254) 020 726300, Ext 44102, 44355

    Fax: 725272 Telegrams: medsup, Nairobi

    Email: uonknh_erc@uonbi.ac.ke

    b. University of Nairobi, College of Health Sciences
    P.O. Box 19676 – 00202 Nairobi

    Tel: (254) 020 2726300 Ext: 44355, Telegrams: varsity.

Appendix III: Consent Information Document (Swahili Version)

HATI YA RIDHAA

Andiko:

Idadi ya shida za hisia na tabia miongoni mwa watoto wanaotibiwa ugonjwa wa kifafa katika kliniki ya neurology ya watoto ya hospitali kuu ya Kenyatta.

Mpelelezi:

Dr. Serah Karanja

Wasimamizi:

Prof. Caleb Othieno

Dr. Rachael Kang'ethe

Utangulizi

Mimi Dr. Serah Karanja ni mwanafunzi wa uzamili katika chuo kikuu cha Nairobi.

Ningependa kufanya utafiti huu kuhusu idadi ya shida za hisia na tabia miongoni mwa watoto wanaotibiwa ugonjwa wa kifafa katika kliniki ya neurology ya watoto ya hospitali kuu ya Kenyatta.

Ningependa kukukaribisha katika utafiti huu.

Maelezo kuhusu utafiti na lengo la utafiti

Huu ni utafiti wa maelezo miongoni mwa watoto wanaopokea matibabu ya ugonjwa wa kifafa ambao wanafuatiliwa katika kliniki ya neurology ya watoto katika hospitali kuu ya Kenyatta. Wagonjwa watakaohusishwa wako na umri katikati ya miaka sita na miaka kumi na minane na wazai wao wako tayari kushiriki katika utafiti

Huu utafiti unalenga kupata kiwango cha shida za hisia na tabia miongoni mwa watoto walio na ugonjwa wa kifafa.

Washiriki wapatao mia moja, sabini na saba (177) watahusishwa katika muda wa yapata miezi miwili katika ukusanyaji wa takwimu.

Mahitaji ya kushiriki

Ili kushiriki katika utafiti huu mtoto wako anahitajika;

1. Kuwa na umri katikati ya miaka sita na miaka kumi na minane
2. Kuwa anatibiwa ugonjwa wa kifafa

Utaratibu

Ukikubali kushiriki katika utafiti huu;

1. Utaulizwa kutia sahihi fomu ya kuridhia kushiriki kwa hiari yako.
2. Utaulizwa maswali kuhusu jamii yako na maisha yako na ya mtoto wako ya kila siku, na maswali kuhusu tabia za mtoto wako. Hii itakuwa katika dodoso litalochukua muda wa dakika ishirini (20).

Faida

Hakuna faida ya moja kwa moja kwa kushiriki katika utafiti huu.

Hata hivyo, matokeo ya utafiti huu yatasaidia wagonjwa, walezi na madaktari kuelewa vyema ushirikiano baina ya magonjwa ya akili na ugonjwa wa kifafa katika watoto. Hii itasaidia kuboresha matibabu ya wagonjwa na pia katika utekelezaji wa mikakati ya matibabu ya ugonjwa wa kifafa katika watoto.

Mtoto wako akipatikana na ugonjwa wa akili, atatumwa kutibiwa katika kliniki ya magwonjwa ya akili ya watoto katika hii hospitali.

Hatari Ya Usumbufu

Kuna uwezekano unaweza kuhisi wasiwasi ukipeana habari kuhusu tabia za mtoto wako.

Nugependa kukuarifu ya kwamba maelezo yoyote utakayopeana itawekwa kwa faragha na itatumika kwa huu utafiti pekee.

Kushiriki Kwa Hiari

Kushiriki kwako katika utafiti huu ni kwa hiari yako na ukiamua kushiriki una uhuru wa kuondoka kwa wakati wowote. Unaweza pia kuamua kutojibu baadhi ya maswali.

Uamuzi wako kutoshiriki ama kuondoka kutoka kwa utafiti hautaadhiri matibabu ya mtoto wako katika hospitali kuu ya Kenyatta kwa sasa au katika siku za usoni.

Faragha

Utambulisho wa mtoto wako utawekwa kwa faragha. Jina la mtoto wako wala namna yoyote ya kumtambulisha hazitatumika kwa ripoti yoyote ya utafiti huu. Badala yake atapewa nambari ya kulinda utambulisho.

Dodoso (Fomu ya maswali ya utafiti) utakayojaza itahifadhiwa kwa usalama, hakuna mtu ataweza kuifikia isipokuwa mimi au wasimamizi wangu. Takwimu zitakazokusanywa katika utafiti huu zitahifadhiwa kwa komputa an kuzuiliwa kwa watu wengine. Komputa zitakazohifadhi takwimu zitalindwa na nywila au namba za kisiri ili kulinda takwimu kutokana na matumizi yasioidhinishwa, kupotea ama marekebisho.

Fidia

Hakuna fidia yoyote kwa kushiriki katika utafiti huu.

Maelezo Zaidi

Iwapo unahitaji ufafanuzi zaidi au una maswali yoyote kuhusu utafiti huu unaweza kuwasiliana na:

1. Mpelelezi:

    a. Dr. Serah Wangari Karanja
    P.O Box 75 – 10100,
    Nyeri
    Tel: (254) 720991527

2. Wasimamizi wa upelelezi:

    a. Prof. Caleb Othieno
    P.O BOX 19676-00202 NAIROBI
    cjothieno@gmail.com

    b. Dr. Rachael Kang'ethe
    P.O BOX 19676-00202 NAIROBI
    drkangethe@gmail.com

1. Kamati ya maadili ya utafiti ya pamoja ya chuo kikuu cha Nairobi na Hospitali kuu ya Kenyatta

    a. Kenyatta National Hospital
    P.O Box 20723-00202 Nairobi

    Tel: (254) 020 726300, Ext 44102, 44355

    Fax: 725272 Telegrams: medsup, Nairobi

    Email: uonknh_erc@uonbi.ac.ke

    b. University of Nairobi, College of Health Sciences
    P.O. Box 19676 – 00202 Nairobi

    Tel: (254) 020 2726300 Ext: 44355, Telegrams: varsity.

Appendix IV: Informed Consent Form (Swahili Version)

FOMU YA RIDHAA

Mimi,..... (jina la mshiriki) nimesoma/nimeskiza na kuelewa yaliyotolewa kuhusu utafiti huu " **Idadi Ya shida za hisia na tabia miongoni mwa watoto wanaotibiwa ugonjwa wa kifafa katika kliniki ya neurology ya watoto ya hospitali kuu ya Kenyatta.**

Nilikuwa na nafasi ya kuuliza ..... (jina la anyechukua ridhaa); maswali katika lugha ninayoelewa na sasa ni wazi na nimeridhika.

Naelewa kwamba kushiriki kwangu katika utafiti huu ni kwa hiari yangu kabisa na naweza kujiondoa wakati wowote natakapo bila ya kutoa maelezo kwa kufanya hivyo. Mimi naelewa kwamba kuondoa ushiriki wangu, hukutaadhiri huduma yangu kwa njia yoyote.

Naelewa kwamba taarifa zote nitakazotoa, pamoja na taarifa binafsi itakuwa siri.

Mimi ninakubali kushiriki katika utafiti huu.

Jina la mshiriki: .....

Sahihi ya mshiriki:.....Tarehe:.....

Sahihi ya shahidi: .....Tarehe:.....

Jina la anayechukua ridhaa:.....

Sahihi: ..... Tarehe: .....

Utapokea nakala ya fomu hii.

Iwapo unahitaji ufafanuzi zaidi au una maswali yoyote kuhusu utafiti huu unaweza kuwasiliana na;

3. Mpelelezi:

    a. Dr. Serah Wangari Karanja
    P.O Box 75 – 10100,
    Nyeri
    Tel: (254) 720991527

4. Wasimamizi wa upelelezi:

    c. Prof. Caleb Othieno
    P.O BOX 19676-00202 NAIROBI
    cjothieno@gmail.com

    d. Dr. Rachael Kang'ethe
    P.O BOX 19676-00202 NAIROBI
    drkangethe@gmail.com

2. Kamati ya maadili ya utafiti ya pamoja ya chuo kikuu cha Nairobi na Hospitali kuu ya Kenyatta

    a. Kenyatta National Hospital

    P.O Box 20723-00202 Nairobi

    Tel: (254) 020 726300, Ext 44102, 44355

    Fax: 725272 Telegrams: medsup, Nairobi

    Email: uonknh_erc@uonbi.ac.ke

    b. University of Nairobi, College of Health Sciences

    P.O. Box 19676 – 00202 Nairobi

    Tel: (254) 020 2726300 Ext: 44355, Telegrams: varsity.

Appendix V : Assent form (English Version)

Title: Prevalence of emotional and behavioral problems in children with epilepsy attending the pediatric neurology clinic at Kenyatta National Hospital

Investigator:

Dr. Serah Wangari Karanja

Supervisors:

Prof. Caleb Othieno

Dr. Rachael Kang'ethe

Why are you here?

The doctors want to tell you about a study about children with epilepsy. They want to see if you would like to be in this study. This form tells you about the study. If there is anything you do not understand, please ask your parent, your guardian or the study staff.

Why are they doing this study?

They want to learn more about the problems that children with epilepsy go through, their behavior and the feelings that they have.

What will happen to you?

The doctor will ask your parent or guardian to fill in a form with a number of questions about your illness, as well as your feelings and behavior. This will take around ten minutes.

Will the study have any bad effects?

You may have to wait for a short time while your parent or guardian is replying to the questions.

Will you get better if you are in the study?

This study won't make you feel better or get well. But the doctors might find out something that will help other children like you later.

What if you have any questions?

You can ask questions any time, now or later. You can talk to the doctors, your family or guardian.

Who will know what I did in the study?

Any information you give to the study staff will be kept secret. Your name will not be on any study paper and no one but the study staff and nurse will know that it was you who was in the study.

Do you have to be in the study?

You do not have to be in the study. No one will be mad at you if you don't want to do this.

If you don't want to be in this study, just say so. We will also ask your parents or guardians if they would like you to be in the study. Even if your parents or guardians want you to be in the study you can still say no. The doctors will still take care of your epilepsy.

Even if you say yes now you can change your mind later. It's up to you.

Do you have any questions?

What questions do you have?

Assent

I want to take part in this study. I know I can change my mind at any time.

_____ Verbal assent given Yes ☐

Print name of child

Written assent if the child chooses to sign the assent.

_____ _____ _____

Signature of Child Age Date

Appendix VI : Assent form (Swahili Version)

Andiko:

Idadi ya shida za hisia na tabia miongoni mwa watoto wanaotibiwa ugonjwa wa kifafa katika kliniki ya neurology ya watoto ya hospitali kuu ya Kenyatta.

Mpelelezi:

Dr. Serah Karanja

Wasimamizi:

Prof. Caleb Othieno

Dr. Rachael Kang'ethe

Uko hapa kwa nini?

Madaktari wangetaka kukuambia kuhusu andiko wanalofanya kuhusu watoto walio na ugonjwa wa kifafa. Wangetaka kujua kama ungependa kuhusika katika hili andiko. Hii fomu itakuelezea kuhusu hili andiko. Kama kuna kitu ambacho huelewi, tafadhali uliza wazazi wako, walezi wako ama daktari.

Wanafanya hili andiko kwa nini?

Wangetaka kuelewa zaidi shida ambazo watoto walio na ugonjwa wa kifafa hupitia, tabia na jinsia zao.

Nini kitafanyika kwako?

Daktari atauliza mzazi ama mlezi wako ajaze fomu iliyo na maswali kuhusu ugonjwa wako, na pia tabia na jinsia zako. Hii itatumia muda wa dakika kumi.

Andiko litakuwa na athari yoyote kwako?

Itabidi ungoje kidogo wakati mzazi ama mlezi wako atakuwa akijibu maswali.

Utapona ukihusika katika hili andiko?

Hili andiko halitafanya upone. Lakini kuna uwezekano wa madaktari kutambua jambo litakalosaidia watoto wengine kama wewe baadaye.

Uko na maswali yoyote?

Unaweza kuuliza maswali wakati wowote, saa hii ama baadaye. Unaweza kuongea na madaktari, wazazi ama walezi wako..

Nani atajua nililofanya katika andiko?

Maelezo yote utakayopea madaktari itawekwa siri. Jina lako halitakuwa katika karatasi la andiko na hakuna atakayejua kuwa ulihusika katika hili andiko ila madaktari.

Ni lazima uwe katika hili andiko?

Si lazima uwe katika hili andiko. Hakuna atakayekukasirikia kama hutaki kufanya hivi.

Kama hutaki kuwa katika hili andiko, sema tu. Pia tutauliza wazazi ama walezi wako kama wangetaka uwe katika hili andiko. Hata kama wazazi ama walezi wako wangetaka uhusike katika hili andiko umeruhusiwa kukataa. Madaktari bado wataendelea kutibu ugonjwa wako..

Hata ukikubali saa hii umeruhusiwa kukataa baadaye. Uamuzi ni wako.

Uko na maswali yoyote?

Uko na maswali gani?

Kibali

Ningetaka kuhusika katika hili andiko. Najua ninaweza kubadilisha nia wakati wowote.

_____ Kibali kimepeanwa kwa mdomo ndio ☐

Jina la mtoto

Kibali cha kuandikwa, mtoto akiamua kupiga sahihi kibali.

_____ _____ _____

Sahihi ya mtoto Miaka Tarehe

Appendix VII : Researcher-designed Sociodemographic/clinical Questionnaire (English Version)

Prevalence of emotional and behavioral problems in children with epilepsy attending the pediatric neurology clinic at Kenyatta National Hospital

Study no_____ Date_____

Instructions

Please fill in the questions below with the appropriate answer. For those that require marking, mark the appropriate answer with a tick (√).
Fill in all the questions apart from question 9.
You may ask for assistance or clarification.

Sociodemographic information

1. Age of your child _____

2. Sex of your child male ☐ female ☐

3. Primary caregiver: mother☐ father ☐ both parents ☐ other (specify) _____

4. Level of education of primary care giver: none☐ primary☐ secondary☐ tertiary ☐

5. Household monthly income: less than Ksh. 10, 000 ☐
Between Ksh. 10,000-50,000 ☐
More than Ksh. 50,000 ☐

Clinical information

6. At what age did your child have their first seizure (years)? _____

7. How often does your child get seizures? once or more daily ☐

once or more monthly but not daily ☐

less than once monthly ☐

occur with irregular frequency ☐

has not had a seizure in the last one year ☐

8. How many types of drugs is your child taking for the epilepsy? one ☐ more than one ☐ none ☐

9*. Type of seizures (do not fill in this question) _____

10*. Has your child ever been diagnosed with a mental illness?

yes (specify) _____ No ☐

NB: *Information on no. 9 and 10 to be confirmed from patient's records

Appendix VI : Researcher-designed Sociodemographic/clinical Questionnaire (Swahili Version)

Idadi ya shida za hisia na tabia miongoni mwa watoto wanaotibiwa ugonjwa wa kifafa katika kliniki ya neurology ya watoto ya hospitali kuu ya Kenyatta.

Nambari ya utafiti_____ Tarehe_____

Maagizo

Tafadhali jaza maswali yaliyo chini na jibu linalofaa. Kwa maswali yanayohitaji kujibiwa na alama, tia alama hakikishi (√) kwa jibu linalofaa.
Jibu maswali yote ila swali la tisa (9).
Unaweza kuomba usaidizi.

Maelezo kukuhusu

1. Umri wa mtoto wako _____

2. Jinsia ya mtoto wako kiume ☐ kike ☐

3. Mhudumu wa kwanza: mama ☐ baba ☐ wazazi wote wawili ☐
   mwingine (elezea) _____

4. Kiwango cha elimu cha mhudumu wa kwanza:
   sina ☐
   shule ya msingi ☐
   shule ya upili ☐
   chuo kikuu ☐

5. Mapato ya nyumbani kwa kila mwezi: <Ksh. 10, 000 ☐ Ksh. 10,000-50,000 ☐ >Ksh. 50,000 ☐

Maelezo kuhusu ugonjwa

6. Mtoto wako alishikwa na mshtuko wa kwanza akiwa na umri gani? (miaka) ___

7. Mtoto wako hupata mishtuko mara ngapi? Moja ama zaidi kila siku ☐

Moja ama zaidi kila mwezi lakini sio kila wiki ☐

Kidogo kuliko moja kila mwezi ☐

Hutokea kwa kipindi ambacho hubadilika ☐

Hajapata mshtuko wowote kwa mwaka mmoja ulyopita ☐

8. Mtoto wako anatumia aina ngapi za dawa za kifafa? Moja ☐

Nyingi kuliko moja ☐

Hatumii yoyote ☐

9. * Aina ya mishtuko (usijibu hili swali) _____

10.* Mtoto wako amewahi kutuambuliwa kuwa na ugonjwa wa akili?

ndio (elezea) _____ La ☐

NB:* Maelezo kuhusu swali la tisa (9) na la kumi (10) kuthibitishwa kutoka rekodi za mgonjwa.

Appendix VII: CBCL/6-18 (English Version)

Please print

CHILD BEHAVIOR CHECKLIST FOR AGES 6-18

For office use only
ID #

CHILD'S FULL NAME First Middle Last

CHILD'S GENDER ☐ Boy ☐ Girl

CHILD'S AGE

CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo. ____ Day ____ Year ____

CHILD'S BIRTHDATE Mo. ____ Day ____ Year ____

GRADE IN SCHOOL _____

NOT ATTENDING SCHOOL ☐

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to print additional comments beside each item and in the space provided on page 2. ***Be sure to answer all items.***

PARENTS' USUAL TYPE OF WORK, even if not working now.
(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)

PARENT 1 (or FATHER)
TYPE OF WORK _____

PARENT 2 (or MOTHER)
TYPE OF WORK _____

THIS FORM FILLED OUT BY: (print your full name)

_____

Your gender: ☐ Male ☐ Female

Your relation to the child:
☐ Biological Parent ☐ Step Parent ☐ Grandparent
☐ Adoptive Parent ☐ Foster Parent ☐ Other (specify)

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Less Than Average	More Than Average		Don't Know	Below Average	Above Average		Don't Know
a. _____	☐	☐	☐	☐	☐	☐	☐	☐
b. _____	☐	☐	☐	☐	☐	☐	☐	☐
c. _____	☐	☐	☐	☐	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: video games, dolls, reading, piano, crafts, cars, computers, singing, etc. (Do ***not*** include listening to radio, TV, or other media.)

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do each one?			
	Less Than Average	More Than Average		Don't Know	Below Average	Above Average		Don't Know
a. _____	☐	☐	☐	☐	☐	☐	☐	☐
b. _____	☐	☐	☐	☐	☐	☐	☐	☐
c. _____	☐	☐	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

	Compared to others of the same age, how active is he/she in each?			
	Less Active	Average	More Active	Don't Know
a. _____	☐	☐	☐	☐
b. _____	☐	☐	☐	☐
c. _____	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: doing dishes, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

	Compared to others of the same age, how well does he/she carry them out?			
	Below Average	Above Average		Don't Know
a. _____	☐	☐	☐	☐
b. _____	☐	☐	☐	☐
c. _____	☐	☐	☐	☐

Be sure you answered all items. Then see other side.

Please print. Be sure to answer all items.

V. 1.About how many close friends does your child have? (Do *not* include brothers & sisters)

❒None ❒ 1 ❒2 or 3 ❒4 or more

2.About how many times a week does your child do things with any friends outside of regular school hours? (Do *not* include brothers & sisters) ❒Less than 1 ❒1 or 2 ❒3 or more

VI. Compared to others of his/her age, how well does your child:

	Worse	Average	Better	
a. Get along with his/her brothers & sisters?	❒	❒	❒	❒ Has no brothers or sisters
b. Get along with other kids?	❒	❒	❒	
c. Behave with his/her parents?	❒	❒	❒	
d. Play and work alone?	❒	❒	❒	

VII. 1. Performance in academic subjects. ❒ **Does not attend school because _____**

_____

Check a box for each subject that child takes		Failing	Below Average	Average	Above Average
Other academic subjects–for example: computer courses, foreign language, business. Do ***not*** include gym, shop, driver's ed., or other nonacademic subjects.	a. Reading, English, or Language Arts	☐	☐	☐	☐
	b. History or Social Studies	☐	☐	☐	☐
	c. Arithmetic or Math	☐	☐	☐	☐
	d. Science	☐	☐	☐	☐
	e. _____	☐	☐	☐	☐
	f. _____	☐	☐	☐	☐
	g. _____	☐	☐	☐	☐

2. Does your child receive special education or remedial services or attend a special class or special school?

❒No ❒Yes—kind of services, class, or school:

3. Has your child repeated any grades? ❒No ❒Yes—grades and reasons:

4. Has your child had any academic or other problems in school? ❒No ❒Yes—please describe:

When did these problems start?

Have these problems ended? ❒No ❒Yes–when?

Does your child have any illness or disability (either physical or mental)? ❒No ❒Yes—please describe:

What concerns you most about your child?

Please describe the best things about your child.

Please print. Be sure to answer all items.

Below is a list of items that describe children and youths. For each item that describes your child ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of your child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of your child. If the item is ***not true*** of your child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1.Acts too young for his/her age
0 1 2 2. Drinks alcohol without parents' approval (describe): _____
_____
0 1 2 3. Argues a lot
0 1 2 4. Fails to finish things he/she starts
0 1 2 5.There is very little he/she enjoys
0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): _____
_____
0 1 2 10.Can't sit still, restless, or hyperactive
0 1 2 11.Clings to adults or too dependent
0 1 2 12.Complains of loneliness
0 1 2 13.Confused or seems to be in a fog
0 1 2 14.Cries a lot
0 1 2 15.Cruel to animals
0 1 2 16.Cruelty, bullying, or meanness to others
0 1 2 17.Daydreams or gets lost in his/her thoughts
0 1 2 18.Deliberately harms self or attempts suicide
0 1 2 19.Demands a lot of attention
0 1 2 20.Destroys his/her own things
0 1 2 21.Destroys things belonging to his/her family or Others
0 1 2 22.Disobedient at home
0 1 2 23.Disobedient at school
0 1 2 24.Doesn't eat well
0 1 2 25.Doesn't get along with other kids
0 1 2 26.Doesn't seem to feel guilty after misbehaving
0 1 2 27.Easily jealous
0 1 2 28.Breaks rules at home, school, or elsewhere
0 1 2 29.Fears certain animals, situations, or places, other than school (describe): _____
_____
0 1 2 30.Fears going to school
0 1 2 31.Fears he/she might think or do something bad

0 1 2 32.Feels he/she has to be perfect
0 1 2 33.Feels or complains that no one loves him/her

0 1 2 34.Feels others are out to get him/her
0 1 2 35.Feels worthless or inferior

0 1 2 36.Gets hurt a lot, accident-prone
0 1 2 37.Gets in many fights

0 1 2 38.Gets teased a lot
0 1 2 39.Hangs around with others who get in trouble

0 1 2 40.Hears sound or voices that aren't there
(describe): _____
_____

0 1 2 41.Impulsive or acts without thinking

0 1 2 42.Would rather be alone than with others
0 1 2 43.Lying or cheating

0 1 2 44.Bites fingernails
0 1 2 45.Nervous, highstrung, or tense

0 1 2 46.Nervous movements or twitching (describe):
_____
_____

0 1 2 47.Nightmares

0 1 2 48.Not liked by other kids
0 1 2 49.Constipated, doesn't move bowels

0 1 2 50.Too fearful or anxious
0 1 2 51.Feels dizzy or lightheaded

0 1 2 52.Feels too guilty
0 1 2 53.Overeating

0 1 2 54.Overtired without good reason
0 1 2 55.Overweight

56.Physical problems ***without known medical cause:***
0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses)
(describe): _____
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): _____
_____

Please print. Be sure to answer all items.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 57.Physically attacks people
0 1 2 58.Picks nose, skin, or other parts of body (describe): _____
_____

0 1 2 59.Plays with own sex parts in public
0 1 2 60.Plays with own sex parts too much

0 1 2 61.Poor school work
0 1 2 62.Poorly coordinated or clumsy

0 1 2 63.Prefers being with older kids
0 1 2 64.Prefers being with younger kids

0 1 2 65.Refuses to talk
0 1 2 66.Repeats certain acts over and over; compulsions (describe): _____
_____

0 1 2 67.Runs away from home
0 1 2 68.Screams a lot

0 1 2 69.Secretive, keeps things to self
0 1 2 70.Sees things that aren't there (describe): ___
_____
_____

0 1 2 71.Self-conscious or easily embarrassed
0 1 2 72.Sets fires

0 1 2 73.Sexual problems (describe): _____
_____
_____

0 1 2 74.Showing off or clowning

0 1 2 75.Too shy or timid
0 1 2 76.Sleeps less than most kids

0 1 2 77.Sleeps more than most kids during day and/or night (describe): _____
_____

0 1 2 78.Inattentive or easily distracted

0 1 2 79.Speech problem (describe): _____
_____

0 1 2 80.Stares blankly

0 1 2 81.Steals at home
0 1 2 82.Steals outside the home

0 1 2 83.Stores up too many things he/she doesn't need (describe): _____
_____
_____

0 1 2 84.Strange behavior (describe): _____
_____

0 1 2 85.Strange ideas (describe): _____
_____

0 1 2 86.Stubborn, sullen, or irritable
0 1 2 87. Sudden changes in mood or feelings

0 1 2 88.Sulks a lot
0 1 2 89.Suspicious

0 1 2 90. Swearing or obscene language
0 1 2 91. Talks about killing self

0 1 2 92.Talks or walks in sleep (describe): _____
_____

0 1 2 93.Talks too much

0 1 2 94.Teases a lot
0 1 2 95. Temper tantrums or hot temper

0 1 2 96. Thinks about sex too much
0 1 2 97.Threatens people

0 1 2 98.Thumb-sucking
0 1 2 99. Smokes, chews, or sniffs tobacco

0 1 2 100.Trouble sleeping (describe): _____
_____

0 1 2 101.Truancy, skips school

0 1 2 102.Underactive, slow moving, or lacks energy
0 1 2 103.Unhappy, sad, or depressed

0 1 2 104.Unusually loud
0 1 2 105.Uses drugs for nonmedical purposes (***don't*** include alcohol or tobacco) (describe): ____
_____
_____

0 1 2 106.Vandalism
0 1 2 107.Wets self during the day

0 1 2 108.Wets the bed
0 1 2 109.Whining

0 1 2 110.Wishes to be of opposite sex
0 1 2 111.Withdrawn, doesn't get involved with others

0 1 2 112. Worries

113. Please write in any problems your child has that were not listed above:

0 1 2 _____
0 1 2 _____
0 1 2 _____

Appendix VIII: CBCL/6-18 (Swahili Version)

CHILD BEHAVIOR CHECKLIST 6-18 – GUARDIAN CHILD ID BL ET 3M POST

Hapo chini ni orodha ya mambo yanayo muelezea mtoto au kijana.kwa kila swali muelezee mtoto wako kwa sasa au miezi 6 iliyopita Zungushia duara na 2 ikiwa hilo ni kweli kabisa au mara nyingi ni kweli juu ya mtoto wako,zungushia namba 1 kama ni wakati mwingine ni kweli. Na kama jibu sio kweli zungushia kwenye 0.Tafadhali jibu maswali yote kadri uwezavyo hata ikiwa mengine hayaonekani kwa mtoto wako.

0 = Sio kweli (kama unavyojua) 1 = wakati mwingine kweli 2 = Kweli kabisa au mara nyingi kweli

0 1 2 1. Anajifanya mtoto mdogo kwa umri wake

0 1 2 2. Anakunywa pombe bila ruhusa ya mzazi

(Elezea): _____

0 1 2 3. Anabishana sana

0 1 2 4. Anashindwa kumalizia vitu alivyoanza

0 1 2 5. Ni kiasi kidogo tu anafurahia

0 1 2 6. (tumbo linamuuma anaka karibu na choo)

0 1 2 7. Anajiona ni muhimu

0 1 2 8. Hawezi kuwa makini au kuzingatia kwa muda Mrefu

0 1 2 9. Hawezi jiepusha na mawazo
(Elezea):_____

0 1 2 10. Hatulii au amechangamka kupita kiasi.

0 1 2 11. Yuko karibu zaidi na watu wazima

0 1 2 12. Analalamika kuwa Mpweke

0 1 2 13. Amechanganyikiwa au anaonekana Kuchanganyikiwa

0 1 2 14. Analia sana

0 1 2 15. Ni mkali kwa wanyama

0 1 2 16. Mkatili,mnyanyasaji au sio mwema kwa wengine.

0 1 2 17. Anafikiria kuhusu vitu vingine (mawazo yanayopotosha)

0 1 2 18. Anakusudia kujiumiza au anajaribu kujiua

0 1 2 19. Anahitaji uangalizi mkubwa

0 1 2 20. Anaharibu vitu nyake

0 1 2 21. Anaharibu vitu vya familia au watu wengine.

0 1 2 22. Hana heshima nyumbani

0 1 2 23. Hana heshima shuleni

0 1 2 24. Hawezi kula vizuri

0 1 2 25. Haambatani na watoto wengine

0 1 2 26. Haonekani kujutia baada ya kukosea

0 1 2 27. Anaona wivu kwa urahisi.

0 1 2 28. Anavunja sheria za nyumbani,shuleni na sehemu nyingine.

0 1 2 29. Anaogopa baadhi ya wanyama,hali au sehemu nyingine zaidi ya shule.(Elezea):_____

0 1 2 30. Anahofu kwenda shule

0 1 2 31. Anahofu anaweza kufikiri au kufanya jambo baya.

0 1 2 32. Anajisikia kuwa lazima awemwema au makamilifu mwema

0 1 2 33. Anajisikia au analalamika kuwa hakuna anayempenda

0 1 2 34. Anafikiri watu wapo nje kumuwinda

0 1 2 35. Alijisikia si kitu au hana thamani

0 1 2 36. Mara kwa mara anajiumiza bila kutarajia

0 1 2 37. Anajipata katika vita vingi

0 1 2 38. Anataniwa sana

0 1 2 39. Anajihusisha na wengine wanaopatikana Matatani

0 1 2 40. Anasikia sauti au kelele ambazo hazipo (Elezea):_____

0 1 2 41. Anafanya mambo bila kufikiria

0 1 2 42. Anaona sawa kukaa peke yake kuliko kukaa na Wengin
e

0 1 2 43. Anadanganya au anaongea uongo

0 1 2 44. Anauma kucha

0 1 2 45. Ana wasiwasi au mfadhaiko

0 1 2 46. Anashtuka kwa urahisi

(Elezea):_____

0 1 2 47. Ndoto za kutisha

0 1 2 48. Hapendwi na watoto wengine

0 1 2 49. Anapata choo kigumu au utumbo haufanyi kazi vizuri.

0 1 2 50. Ana hofu sana au wasi wasi

0 1 2 51. Anajisikia kizunguzungu au kichwa Chepesi

0 1 2 52. Anajisikia kujutia sana.

0 1 2 53. Anakula kupita kiasi

0 1 2 54. Anachoka sana bila sababu za msingi

0 1 2 55. Anauzito mkubwa.

56. Matatizo ya kiafya bila kujua sababu za kimatibabu:

0 1 2 a. Vichomi au maumizu (sio ya tumbo au kichwa)

0 1 2 b. Kichwa kuuma

0 1 2 c. Kichefuchefu,kujisikia kuumwa

0 1 2 d. Matatizo ya macho (sio kama yanahusiana na miwani) (elezea)_____

0 1 2 e. Vipele au matatizo mengine ya Ngozi.

0 1 2 f Kuumwa tumbo

0 1 2 g. Kutapia

0 1 2 h. Nyingine (elezea):_____

0 1 2 57. Anawashambulia watu

0 1 2 58. Tar pua, ngozi au sehemu nyingine ya mwili (Elezea):_____

0 1 2 59. Anachezea sehemu zake za siri hadharani

0 1 2 60. Anachezea sana sehemu zake za siri

0 1 2 61. Hafanyi vizuri kazi za shule

0 1 2 62. Hajipangi vizuri

0 1 2 63. Anapendelea kuwa na watoto wakubwa

0 1 2 64. Anapendelea kuwa na watoto wadogo.

0 1 2 65. Anakataa kuongea

0 1 2 66. Hurudia vitendo fulani mara kwa mara (Elezea):_____

0 1 2 67. Anatoroka nyumbani

0 1 2 68. Anapiga mayowe sana.

0 1 2 69. Ni msiri anatunza vitu mwenyewe

0 1 2 70. Anaona vitu ambavyo watu wanafikiri havipo elezea_____

0 1 2 71. Hajiamini anasumbuliwa kwa urahisi

0 1 2 72. Anawasha moto

0 1 2 73. Matatizo ya kingono

(Elezea):_____

0 1 2 74. Anafanya vitu vya kuchekesha watu

0 1 2 75. Anaibu sana / ana haya au uoga

0 1 2 76. Analala kidogo kuliko watoto wengine

University of Vermont
1 S. Prospect St., Burlington, VT 05401
www.ASEBA.org

0 1 2 77. Analala zaidi kuliko watoto wengine wakati wamchana au usiku. (Elezea):_____

0 1 2 78. Hazingatii au anachanganyikiwa kwa urahisi

0 1 2 79. Matatizo ya matamshi au kuongea (Elezea):_____

0 1 2 80. Anazubaa

0 1 2 81. Anaiba nyumbani.

0 1 2 82. Kuiba mahali popote isipokuwa nyumbani

0 1 2 83. Anakusanya vitu vingi ambavyo haviitaji

(Elezea):_____

0 1 2 84. Anatabia ya ajabu.
(Elezea):_____

0 1 2 85. Anamawazo ya ajabu

(Elezea):_____

0 1 2 86. Ni msumbufu au ana hasira

0 1 2 87. Anabadilika ghafla kitabia au kihisia

0 1 2 88. Ananuna sana

0 1 2 89. Hamwamini mtu

0 1 2 90. Anaapa au ana lugha ya matusi

0 1 2 91. Anazungumza kuhusu kujiuwa

0 1 2 92. Anaongea au anatembea akiwa na usingizini

(Elezea):_____

0 1 2 93. Anaongea sana

0 1 2 94. Ana utani mwingi

0 1 2 95. Ana hasira kali

0 1 2 96. Anafikiria kuhusu ngono kupita kiasi

0 1 2 97. Anatishia watu

0 1 2 98. Ananyonya kidole Gumba.

0 1 2 99. Anavuta anatafuna au anavuta tumbaku

0 1 2 100. Anatatizo la kulala

0 1 2 101. Anatoroka shuleni

0 1 2 102. Hana nguvu ,sio mchangamfu, au ni goigoi

0 1 2 103. Hana raha, ana huzuni, au kusononeka

0 1 2 104. Ana sauti ya juu isiyo ya kawaida

0 1 2 105. Anatumia vidonge bila sababu za kimatibabu (usihusishe vileo au tumbaku)

(Elezea):_____

0 1 2 106. Mharibifu

0 1 2 107. Anajikojolea wakati wa mchana

0 1 2 108. Anakojoa kitandani

0 1 2 109. Analalamika sana

0 1 2 110. Anatamani kuwa na jinsia nyingine

0 1 2 111. Anajitenga hajihusishi na wengine

0 1 2 112. Ana wasiwasi

0 1 2 113. Tafadhali andika tatizo lolote ambalo mtoto wako analo na halijaorodheshwa juu.

Appendix IX: Study timeline and budget

Table 8: Study timeline

Activity	Duration	Dates
Drafting the proposal	1 year 4 months	January 2015 - April 2016
Seeking approval at ethics committee	2 months	June 2016 - August 2016
Data collection	2 months	September 2016 - May 2017
Data analysis and report writing	2 months	June 2017 - September 2017

Table 9: Budget

Category	Remarks	Units	Cost (Ksh)	Total (Ksh)
Proposal development	Printing Photocopying Internet charges	3 x 66 3 x 66 -	10/page 5/ page -	1,980 990 10,000
Data collection	Questionnares Stationary (Assorted) Transport Buying of research materials from ASEBA website	177x12 - 1 day/ week for 3 months (12 days)	5/ page - 500/day	10,620 5,000 6,000 28,700
Data analysis and report writing	Biostatician Printing report	1 3	20,000	30,000 3,000
Contingencies	10% of total	-	10%	9,629
Grand total	-	-	-	105,919

The researcher met all the costs in the budget.