RISK FACTORS FOR NON-GENETIC MENTAL RETARDATION AMONG CHILDREN AGED 2 – 18 YEARS ATTENDING KENYATTA NATIONAL HOSPITAL

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OCTOBER, 2017

DECLARATION

I, Mathieu Nemerimana, declare that this dissertation is my own original work and it has not been presented in a University or an academic institution of higher learning for an academic award.

Sign……...

Date……

CERTIFICATE OF APPROVAL

We certify that this dissertation has been submitted with our approval as University supervisors.

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DEDICATION

To my beloved Parents, Brothers and Sister

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LIST OF ABBREVIATIONS

ADHD: Attention deficit, hyperactivity disorder

ANC: Antenatal Clinic

AOR: Adjusted odds ratio

APA: American Psychiatric Association

APGAR: Appearance, Pulse, Grimace, Activity, Respiration

ASD: Autism spectrum disorder

BSN: Bachelor of Science in Nursing

C.I: Confidence Interval

DSM–IV-TR: Diagnostic and Statistical Manual, 4th Edition, Text Revision

Ho: Null Hypothesis

ICD-10: International Classification of Diseases, 10th Edition

ID: Intellectual Disability

K.N.H: Kenyatta National Hospital

KES: Kenyan Shillings

KNH/UON-ERC: Kenyatta National Hospital-University of Nairobi Ethics & Research Committee

MR: Mental Retardation

NICU: Neonatal Intensive Care Unit

OR: Odds ratio

SPSS: Statistical Package for Social Sciences

WHO: World Health Organization

OPERATIONL DEFINITIONS

Children aged 2-18 years: Any child including adolescent who is between 2 and 18 years old. In this study, this range of age was taken based on the defining age criteria of mental retardation according to DSM-IV-TR which specifies that diagnosis of mental retardation is made above 2 years of life and during development period, before age 18 years old.

Co-morbid: condition that occur prior or together with mental retardation

Co-morbidity: co-existence of an identified disease or disorder with another clinical entity.

Environmental factors: all conditions, circumstances and influences within and/around the individual that can bring change or affect the development of the child's intellectual and adaptive functioning. In this study, environmental factors involve factors arising during perinatal and postnatal (including infant and childhood) periods.

Genetic factors: conditions related to mutations of genes or inherited conditions.

Intellectual Disability: similar term used to describe 'mental retardation'.

Mental Retardation: Developmental disability characterized by below-average general intellectual function and limitations in adaptive functioning (including academic performance, communication, social and interpersonal skills, self-care, self-direction, home living, leisure, work, use of community resources, health, and safety) occurring development period.

Non-genetic factors: no underlying genetic conditions or inherited conditions

Risk factor: Any attribute, characteristic or exposure of an individual that increase susceptibility of developing disease/disorder.

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ABSTRACT

Background: Children affected with Mental retardation (MR) face challenges in their entire life with adverse potential development and increased burden to their society. Mental retardation is associated with multi-causal risk factors including genetic and acquired. Many of the non-genetic causal risk factors of mental retardation can be prevented if they are identified early. There is paucity on information regarding potential risk factors associated with this condition in Kenya.

Study objective: To establish risk factors associated with non-genetic mental retardation among children presenting with this condition at Kenyatta National Hospital (K.N.H).

Methodology: A descriptive cross-sectional study including quantitative and qualitative methods was carried out at K.N.H. Using a convenient sampling method, 97 children aged from 2 to 18 years with non-genetic mental retardation were recruited in the study. Five Healthcare providers were also selected purposively for in-depth interviews. Quantitative data were analyzed individually for mean, standard deviation and frequencies distribution. Logistic regressions using odds and adjusted odds ratio with 95%CI and χ^2 test were done to test relationships between variables. Qualitative data were transcribed and analyzed manually in themes.

Results: Out of 97 children, 24% were having mild MR, 40% moderate, 23% severe-profound and 10% unspecified MR. The mean age of studied children was 5.6 years (SD±3.6 years). Male children were 62% while female were 38%. Child socio-demographic variables (including age, gender, family set up, number of children in family) and parental characteristics (age, level of education, occupation, and pregnancy history related factors) were not significantly associated with severe-profound MR. Three factors including 'labor complications' [AOR=9.45, 95%CI=1.23-113.29, P=0.036], 'admission to neonatal intensive care unit' [AOR=8.09, 95%CI=2.11-31.07, P=0.002] and 'cerebral palsy'[AOR=21.18, CI=4.18-107.40, P=0.000] were significantly associated with increased risk of severe/profound non-genetic mental retardation. Most prevalent co-morbid conditions identified among the children were convulsive disorders (82.5%), cerebral palsy (46.4%), pneumonia (28.9%), malnutrition (11.5%), ASD (10.3%), and ADHD (10.3%).

Conclusions: The present study findings suggest that perinatal complications as well as postnatal insults to be associated with increased risk of developing mental retardation, implying that this occurrence may be reduced with appropriate antenatal, perinatal and neonatal healthcare interventions.

CHAPTER 1 INTRODUCTION

1.1. Background information:

Mental retardation (MR), also referred as Intellectual Disability (ID), is a condition characterized by significant below average intellectual functioning and impairment in adaptive behaviors, manifested before age 18 years. The degrees of MR include mild, moderate, severe and profound mental retardation (American Psychiatric Association (APA), 2000; W.H.O, 1996). Mental retardation is a public concern due to the number of people affected by this condition with consideration of the increased demand of specialized medical, psychosocial and educational services required to improve their quality of life (Maulik & Harbour, 2010). According to recent reviews and meta-analysis, globally, about 1% of general population is affected by mental retardation (Goli, Moniri & Wilhelm, 2016, Maulik *et al*, 2011). Child/adolescent population has higher prevalence (18.30/1000) than the adult population (4.94/1000) (Maulik *et al*, 2011). Furthermore, 1% of children ages 3 to 10 years have intellectual disability (Pratt and Greydanus, 2007).

Mental retardation is associated with multi-causal risk factors including genetic and non-genetic or acquired causes. But in some cases, the etiology is unknown (Armatas, 2009). Genetic factors such as chromosomal abnormalities, inherited genetic traits and single gene disorders are the major causes accounting for 30% to 50% of all MR cases (Huang *et al*, 2016). Non-genetic causes comprise prenatal, perinatal, postnatal and environmental factors (Huang *et al*, 2016). Most prevalent reported non-genetic prenatal risk factors include maternal conditions such as asthma, diabetes, hypertension, renal conditions and epilepsy (Huang *et al*, 2016, Leonard *et al*, 2006). Other factors are tobacco or alcohol use, parental advanced age, low maternal education, multi-parity and maternal black race (Huang *et al*, 2016). Main perinatal factors are low birth weight, preterm birth, birth complications and

perinatal infections (Bilder *et al,* 2013, Huang *et al,* 2016). Postnatal infections, exposure to toxicants like lead or mercury, developmental disorders, central nervous system malignancies and chronic severe malnutrition (Armatas, 2009, Huang *et al,* 2016) have been reported as postnatal factors. These associated factors of mental retardation are in interactive complexity with environmental factors, socio-demographic and socio-economic characteristics of population (Leonard *et al,* 2003, Sharma *et al,* 2015). It is evidenced that many of the factors and causes of non-genetic mental retardation are preventable, if early detection is done and timely interventions are taken (Chapman, Scott, and Mason, 2002, Pratt & Greydanus, 2007).

Most of the studies regarding risk factors of mental retardation have been conducted in developed countries, with limited information from developing countries (Maulik & Harbour, 2010). In Kenya, information on incidence, prevalence and associated factors of mental retardation is scarce. Studies are needed to establish more information on the burden of this condition in Kenya. Furthermore, little is known on the proportion of children with mental retardation from different non-genetic causal factors. Given the paucity of epidemiological information on the causal risk factors associated with mental retardation in Kenya, the aim of this study was to explore potential risk factors for non-genetic mental retardation among children presenting with this condition at Kenyatta National Hospital (K.N.H).

1.2. Problem statement:

Children are future generation and form a potential intellectual and human capital for the future functioning, development and growth of any society. However, children affected with mental retardation face challenges in their entire life. This adversely affects not only their potential development but also development of their society with increased dependency, health care demands and burden in socioeconomic aspects as well (Maulik & Harbour, 2010). It is estimated that about 1% of children between ages 3 to 10 years are affected by mental

retardation worldwide (Pratt & Greydanus, 2007). Many of acquired causes and factors associated with development of mental retardation in children can be preventable if these causes and risk factors are identified at the right time and appropriate management and preventive measures are taken (Chapman, Scott, and Mason, 2002, Pratt & Greydanus, 2007).

Rates and risk factors of mental retardation vary from regions to regions, from developed countries to developing and under-developed countries. Recent systematic reviews and meta-analyses have highlighted limited literature on mental retardation from low- and middle income countries (Goli, Moniri & Wilhelm, 2016; Maulik *et al*. 2011). The prevalence rate of children with non-genetic mental retardation admitted in K.N.H is yet to be established. At the same time, little is known on the magnitude of potential non-genetic risk factors contributing to development of mental retardation among children affected with this condition in Kenya. Epidemiological studies are needed to identifying prevalent risk factors and causes of mental retardation. Information for these studies can help to design health programs and plan strategies for controlling these causes and risk factors, thus reducing number of children affected by mental retardation. This study aimed to explore potential risk factors associated with development of non-genetic mental retardation among children attending K.N.H.

1.3. Justification of the study:

Mental retardation is one of the common development disabilities affecting individuals commonly at early age. It is associated with genetic and non-genetic factors including environmental and parental factors. Children with this condition require specialized care which impacts the whole family system in terms of social welfare and economic capacity. It may be possible to prevent this burden if the causal risk factors associated with development of the disorder are identified.

This study intended to assess the potential risk factors associated with non-genital mental retardation among the children. Findings from this study may be used by health planners and policy makers to design policies and strategies for reducing occurrence of mental retardation thus further improving the quality of life of children.

1.4. Hypothesis:

Ho: There is no relationship between socio-demographic characteristics, maternal factors and environmental factors and the risk for developing of non-genetic mental retardation in children attending K.N.H.

1.5. Research questions:

1. What are the socio-demographic characteristics of children with non-genetic mental retardation attending K.N.H?
2. What are the parental factors potentially associated with development of non-genetic mental retardation among children presenting with this condition at K.N.H?
3. What are the environmental factors potentially associated with development of non-genetic mental retardation among children presenting with this condition at KNH?
4. What are the co-morbid conditions among children with non-genetic mental retardation attending K.N.H?

1.6. Objectives:

1.6.1. Broad objective:

The main objective of this study was to establish risk factors associated with non-genetic mental retardation among children presenting with this condition at Kenyatta National Hospital.

1.6.2. Specific Objectives:

1. To establish socio-demographic characteristics of children with non-genetic mental retardation attending K.N.H,
2. To determine the parental factors potentially associated with development of non-genetic mental retardation among children attending K.N.H,
3. To establish environmental factors potentially associated with development of non-genetic mental retardation among children presenting with this condition at KNH,
4. To identify co-morbid conditions to non-genetic mental retardation among children attending K.N.H.

CHAPTER 2: LITERATURE REVIEW

2.1. Introduction:

Mental retardation is one of the common developmental disabilities in children. This condition is characterized by arrested or incomplete development of the intellectual function with concurrent significant impairment adaptive skills, occurring during the development period or before age of 18 years (American Psychiatric Association (APA), 2000, W.H.O, 1996). Based on the degree of severity, International Classification of diseases, 10th Edition (ICD-10) classifies mental retardation as mild, moderate, severe and profound mental retardation, other mental retardation and unspecified mental retardation (WHO, 1996).

According to Diagnostic and Statistical Manual, 4th Edition, Text Revision (DSM-IV-TR), the diagnosis of MR is based on three criteria (APA, 2000). The first criterion is an intellectual functioning with significant below-average overall intelligence which is shown by an IQ (intellectual quotient) score below 70-75. A second criterion is impairment in adaptive behavior such as social, conceptual, or practical skills necessary for daily living. This includes substantial limitations in two adaptive functioning skills such as: functional academic skills, communication, social/interpersonal skills, self-care, self-direction, home living, leisure, work, use of community resources, health, and safety. A third criterion is an occurrence before age 18 years (APA, 2000). Based the IQ, MR is classified into three levels of severity including Mild with IQ score from 50-55 to 70-75; Moderate MR with IQ score from 35-40 to 50-55; Severe MR with IQ score from 20-25 to 35-40; Profound MR, from less than 20-25; and MR, severity unspecified, not readily testable but presumed low (IQ<70). Other labels used to describe mental retardation are mentally handicapped, mentally retarded, mental disability and intellectual disability (Maulik & Harbour, 2010).

Prevalence of mentally retarded children varies from country to country. A meta-analysis done by Maulik et al. (2011) and systematic review done by Dasteh, Farah and Ross (2016) report a global prevalence of mental retardation to be about 1%. Both studies mentioned a deficiency of studies from African developing countries. In India, the prevalence was reported to be about 2.15% (Sharma *et al*., 2015) and 1.7% (Raina *et al*., 2016, Sharma *et al.,* 2016) while the prevalence was shown to be 1.25% in Cuba (Cruz *et al.,* 2008). About 85% of the affected people have mild mental retardation while 10%, 4% and 2% of them are respectively affected by moderate, severe and profound mental retardation (Maulik *et al,* 2011). In Kenya, little is known on the spectrum of this condition and its associated risk factors.

The prevalence is subjected to be high in low-income and middle income countries where registries and screening methods are still limited (Maulik *et al,* 2011). Rates of people with mental retardation vary from the low-income to high-income countries. Low-income (prevalence: 16.41/1000) and middle income (prevalence: 15.94/1000) countries are estimated have highest rates comparing to high-income countries (prevalence: 9.21/1000) (Maulik *et al*, 2011). This variation is subjected to be related to limited availability resources to manage mental retardation, more births with inadequate antenatal screening procedures for hereditary illnesses, lack of adequate dietary iodine, intra-uterine growth retardation, high perinatal infections and injuries commonly due to poor maternal and child health care setups (Maulik *et al*, 2011).

Mental retardation is more prevalent in child/adolescent population comparing with the adult population (Maulik *et al,* 2011) and is one of the common developmental disabilities in children (Maulik & Harbour, 2010). Globally, it is estimated that about 1% of children aged between 3 to 10 years have mental retardation (Pratt & Greydanus, 2007). Information

regarding prevalence and risk factors of mental retardation in children in developing countries is still scanty; this is especially in African, Latin-America and South Asia countries (Maulik & Harbour, 2010), therefore, more studies are needed.

2.2. Child socio-demographic characteristics associated with mental retardation

Occurrence of mental retardation varies based on socioeconomic and demographic factors. Sharma *et al*. (2016), in their studies to find out the prevalence of mental retardation in the urban and rural populations of Himachal Pradesh in India, reported a high prevalence in families from the lower class and lower middle classes where 69% and 28.3% of children diagnosed with mental retardation were from the lower middle class and middle class families, respectively.

Older children between 6 to 10 years old are reported to be more commonly affected than younger children between 3 to 5 years of age (Pratt & Greydanus, 2007). In India, higher prevalence (3.3%) was found among children in the age group of 73-120 months as compared to the younger age groups (Sharma et al., 2016). Male children have been reported to be more affected than females (Maulik *et al.*, 2011, Maulik & Harbour, 2010, Sharma et al., 2016). Regarding distribution of degrees of mental retardation, a study in India among one hundred people with ID reported a distribution of the types of ID as 42%, 40%, 17% and 1% for mild, moderate, has severe, and profound ID, respectively (Naskar & Nath, 2016).

Lower socio-economic status plays significant role in development of mental retardation (Sharma *et al*, 2016). Socio-economic and demographic factors together with other environmental influences affect the child's brain development and cognitive functions which can thus lead to certain impairment in intellectual functioning and deficits in adaptive skills as well (Naskar & Nath, 2016). Lower socio-economic status is often associated with poor

diet, poor health practices and inadequate medical care, poor housing, environmental health hazards and generally poor living conditions which potentially lead to mental retardation.

2.3. Maternal and prenatal factors associated with development of mental retardation

Certain parental factors were found to be associated with increased risk of mental retardation. Early study by Drews *et al.* (1995) found parental advanced age and education, black race and high birth order to be associated with high prevalence of mental retardation. Moreover, systematic reviews showed that some maternal demographic factors such as advanced age, black race, low education and multiple pregnancies have significant association with mental retardation (Huang *et al*., 2016). Children from mothers who have lower level of education, those who did not complete high school, are four times more likely to be affected by mild mental retardation. However, in one Brazilian study, no difference was shown regarding maternal schooling among the groups (Karam *et al.,* 2016). These factors are together influenced by other socio-economical factors like poverty (Kliegman *et al*, 2016).

Certain maternal conditions during pregnancy potentially affect genetically programmed brain development of the fetus thus resulting in MR after birth. Evidenced maternal medical conditions that increase risks for mental retardation in offspring include maternal diabetes, maternal hypertension, maternal epilepsy, maternal renal or urinary conditions during pregnancy, untreated maternal phenylketonuria and maternal asthma (Armatas, 2009, Huang *et al*., 2016, Langridge *et al*., 2013, Leonard *et al*, 2006, Stromme & Hagberg, 2007).

Significant association between complications of pregnancy to include threatened abortions before gestational age of 20 weeks, antepartum hemorrhages such as placenta praevia and abruption, maternal hypertension and urinary tract infections during pregnancy, and development of MR has been evidenced (Langridge *et al.,* 2013). Griffith, Mann & McDermott (2011) did a study to examine relationship between preeclampsia, low birth

weight (LBW) and ID. Their findings revealed that preeclampsia expose fetus to intrauterine growth restriction, LBW and prematurity which are associated with cognitive and other neurologic disability mostly including MR.

Nutritional deficiencies such as iodine deficiency during pregnancy restrict the growth of the brain of the fetus resulting neonatal hypothyroidism which is associated with mental retardation (Sharma et *al., 2016*). Environmental exposures such exposure to toxicants, neurotoxins or teratogenic products like anticonvulsants drugs to the pregnant women are associated with increased high risks for mental retardation in offspring (Leonard *et al*, 2006).

Use of alcohol and/or tobacco during pregnancy increases the susceptibility for developing MR in the child (Huang *at al.,* 2008). O'Leary *et al*. (2013) conducted a study in Australia to examine the relationship between alcohol use in pregnant women and intellectual disability in children. The findings hereof indicated that intellectual disability outcomes were observed in one-third (32%) of children who had been detected with fetal alcohol syndrome. Risk of intellectual disability was three times increased in children from mothers with alcohol-related diagnosis. This can be prevented by avoidance maternal alcohol use during pregnancy.

Congenital infections to include toxoplasmosis, herpes, rubella, syphilis, cytomegalovirus, infection with human immunodeficiency virus and any infections with prolonged fever in the first trimester of pregnancy are associated with MR (Goli, Moniri & Wilhelm, 2016). Another predisposing factor is Zika virus infection. According to recent WHO report (2016), the spread of the Zika virus has been increased across Brazil and other countries; however, no case has been in Kenya. Infection of Zika virus to pregnant mothers is associated with risk of microcephaly and other congenital malformations in children born from these mothers and consequently these children develop mental retardation due these malformations (WHO, 2016)**.**

The genetic causal factors are also conceptually prenatal. These causes involve early alterations of the embryonic genetic material development. They are the major causes of mental retardation accounting for 30% to 50% of all intellectual disability cases (Huang et al. 2016). Genetic causes include chromosomal abnormalities such as Down syndrome (trisomy 21 syndrome), trisomies 18 and 13, inherited genetic traits such as fragile X syndrome, and single gene disorders like Prader-Willi syndrome (Kliegman et al, 2016, Cruz *et al.,* 2008). Other genetic causal factor includes consanguinity (Cruz *et al.,* 2008).

2.4. Environmental factors associated with mental retardation

Heikura *et al.* (2005) noted that external environmental insults to central nervous system of the child are estimated to comprise one third of causes of MR. This is shown in one longitudinal study done in Brazil where environmental factors accounted 44.4% comparing to other causes of MR (Karam *et al.,* 2016). Environment insults can occur during prenatal, perinatal and postnatal period (Heikura *et al., 2005*). In this section, discussed environmental factors will focus on perinatal and postnatal factors including factors arising during developmental period.

Perinatal factors complications of pregnancy, maternal diseases during pregnancy such us heart diseases, kidney diseases and diabetes, placental dysfunctions, fetal distress, severe prematurity, small-for-gestational age, low birth weight, birth asphyxia, complicated delivery and birth injuries, neonatal sepsis, severe neonatal jaundice, neonatal hypoglycemia (Armatas, 2009, Blider *et al,* 2013, Kolevzon, Gross & Reichenberg, 2007). Additional risk factors include poly/oligohydramnios, premature rupture of membranes, primary/repeat cesarean sections, congenital infections, low Apgar scores, and assisted ventilation greater than 30 min (Blider *et al,* 2013). In the systemic review and meta-analysis conducted by Huang *et al.* (2016) on the prenatal, perinatal and neonatal risk factors for intellectual

disability concluded low birth weight, male sex, and preterm birth as the primary perinatal and neonatal risk factors. Some of the neonatal complications and problems like hypoglycemia, meningitis, anoxia, and other injuries may cause neonatal sequelae resulting in ID. These conditions were considered to be cause of ID in 13.2% of the cases (Karam *et al.,* 2016). Appropriate antenatal, perinatal and neonatal healthcare interventions can help to reduce the occurrence of these complications.

Postnatal factors involve postnatal problems including infections, trauma, exposure to toxicants and other environmental factors affecting mental development and ability during infancy and childhood period of the child. Common postnatal causes include developmental disorders, traumatic brain injury injuries, brain infections such as tuberculosis, encephalitis, and meningitis, central nervous system malignancies, chronic severe malnutrition and diseases like whooping cough, or measles can cause (Armatas, 2009). Endocrine disorders like congenital or acquired hypothyroidism are known to cause mental retardation (Maulik & Harbour, 2010).

Other environmental influences include postnatal exposure to toxins like lead or mercury. Lead and mercury which are found in the environment affect the child's growth and impair brain functioning and mental ability resulting to mental retardation. These products are found in polluted water and air, paints and polluted soils so children can easily contract them in the polluted environment (Goli, Moniri & Wilhelm, 2016).

2.4. Co-morbid conditions associated mental retardation

People with mental retardation are likely to develop different co-morbidities thus increasing the burden of the disease. These co-morbid conditions increase with the severity of mental retardation (Kliegman *et al*, 2016). A study done in Netherlands reported prevalence of 14 % of cardiac diseases among people with ID (Akker, Maaskant, & Meijden, 2006). Cerebral

palsy was reported in about 12.7% of patients with ID in the study done by Aggarwal *et al.* (2010). Certain conditions increase the severity of MR, examples of these conditions include sensory deficits, communication disorders, and poorly controlled seizure disorders. Other conditions co-occur with mental retardation; this is typically manifested in cerebral palsy or autism spectrum disorders where more than half of children with cerebral palsy or autism spectrum disorders also have intellectual disability as an associated deficit (Kliegman *et al*, 2016).

In one Indian study conducted at Maharajah's Institute Of Medical Sciences Psychiatry outpatient department on psychiatric and medical co-morbidities among different degrees of Mental Retardation by Makena, Ampalam and Reddi, (2014), revealed that 82.53% of the 63 patients with mental retardation in the study had co-morbid disorders; 41.26% of these patients had both psychiatric and medical illness; and on the other hand 22.22% had only medical co-morbidities while 19.06% had only psychiatric co-morbid conditions. The commonly identified medical co-morbid conditions were epilepsy at 45% prevalence, cerebral palsy at 15%, cleft lip and palate at 7.5%, asthma at 10% and recurrent fevers at 7.5%. The prevalent co-morbid psychiatric conditions included stereotyped movement disorder at rate of 36.85%, conduct disorder at 23.7%, attention-deficit/hyperactivity disorder (ADHD) at 18.42%, autism spectrum disorders at 10.52%, obsessive-compulsive disorder at 5.26%, depressive episode at 8%, manic episode at 5%, anxiety disorders a13%, eating disorders at 5.26%, post-traumatic stress disorder at 5.26%, and Separation Anxiety Disorders at 5.26% (Makena, Ampalam and Reddi, 2014).

In a study conducted in the Netherlands on prevalence of chronic diseases among adolescent patients with ID revealed the rates of prevalence for attention deficit/hyperactivity disorder (ADHD), pervasive developmental disorder-not otherwise specified (PDD-NOS), dyslexia,

chronic headache/migraine and autistic disorder 21.1%, 14.0%, 13.9%, 12.7%, and 10.9%, respectively (Oeseburg *et al*., 2010).

2.6. Theoretical framework

The theoretical framework used in this study was guided by Sister Callista Roy theory: Roy's Adaptation Model (Alligood, 2014). This nursing theory views human being as bio-psycho-social system and adaptive system. Person lives in constant interaction with the environment which is continuously changing. This person is an open living system that receives different stimuli from both external environment and internal environment, the self. In order to cope with this changing world, this person uses both innate and acquired biological, psychological and social mechanisms. The outcome of the person and environment interactions can result in effective adaptive response or in ineffective adaptive response. Effective adaptation is when there are the responses that promote individual's growth, survival, reproduction and self-mystery. Ineffective responses are regarded as deficit or result of inadequate coping with the changing environment (Alligood, 2014).

Based on the concepts of Roy's adaptation model, this study views the child as bio-psycho-social adaptive system with coping processes (cognator and regulator). Non-genetic mental retardation is associated with multi-causal risk factors acquired from the environment. These factors affect the cognitive, psychological, behavioral and physical developments of the child resulting to impairment in intellectual functioning and limitations in adaptive skills necessary for their daily living. With Roy's adaptation model, these causes can be grouped as focal, contextual and residual stimuli. The outcome of response to these factors/stimuli will depend on two coping processes: Regulator and cognator subsystems of adaptation. Through these coping processes the child interacts with internal and external environment, by which he/she can transform or he/she can be transformed by it.

2.6. Conceptual Framework

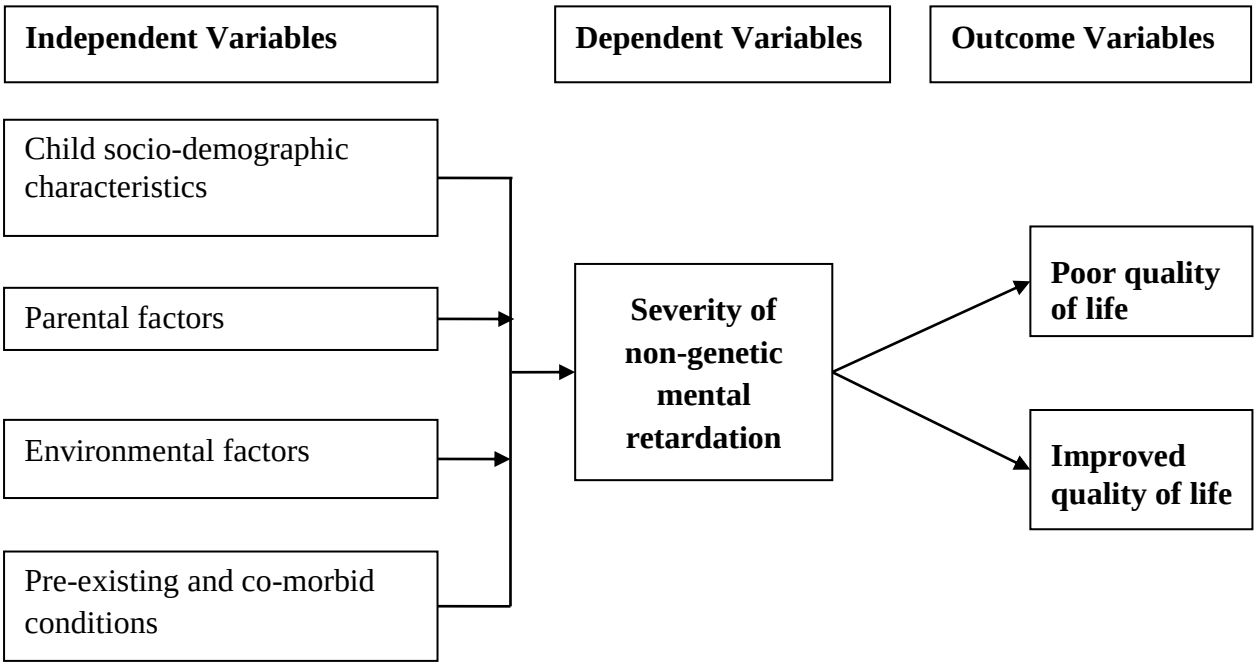

Figure 2.1 Conceptual framework

2.7. Operational Framework

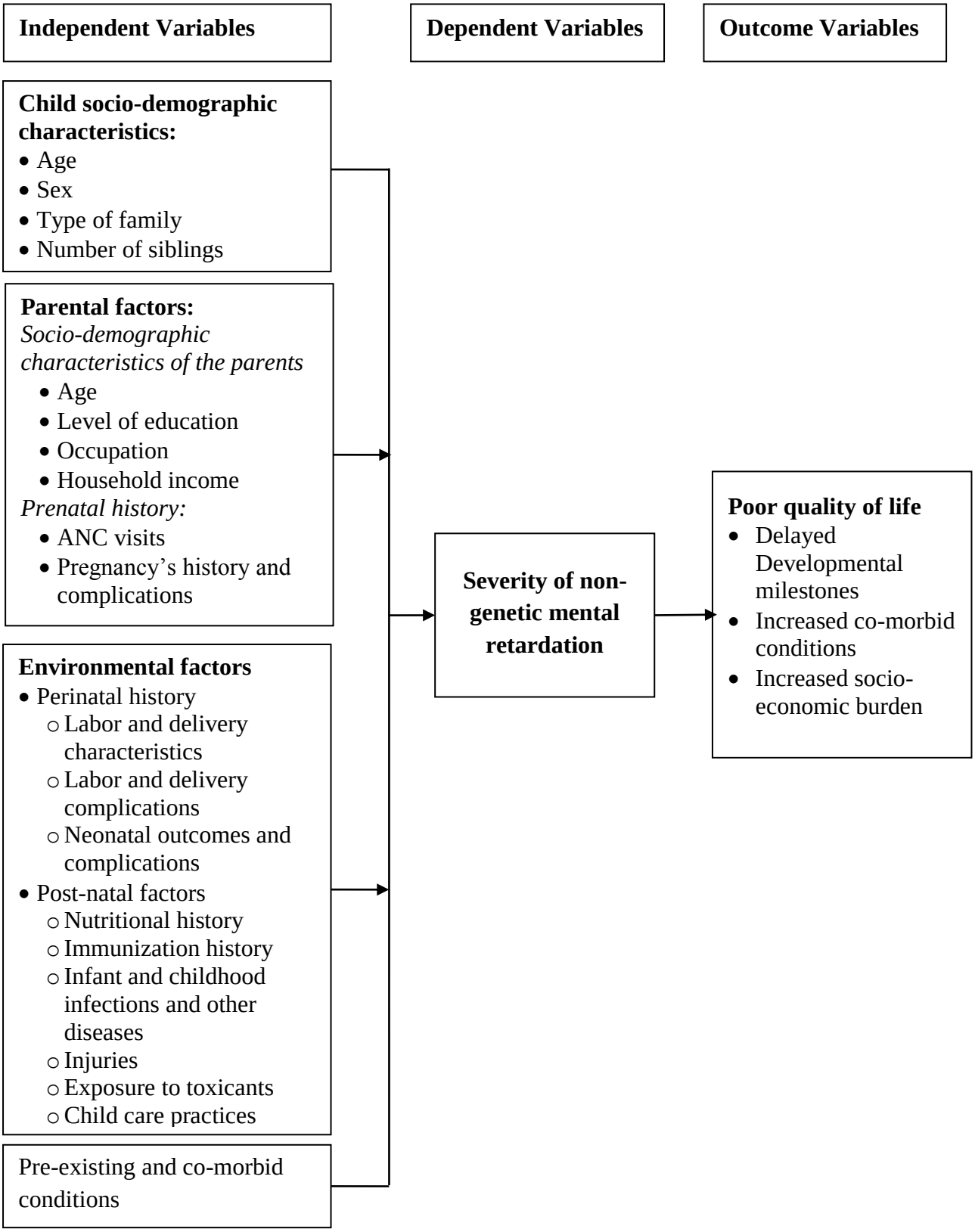

Figure 2.2 Operational framework

CHAPTER 3 METHODOLOGY

3.1. Study design

This is was a hospital-based, descriptive cross-sectional study whereby mixed methods were utilized to collect quantitative and qualitative data.

3.2. Study area

The study was conducted in pediatric in-patient and out-patients service at Kenyatta National Hospital (K.N.H). K.N.H is one of the biggest national referral hospitals in Kenya located in Nairobi, capital city of Kenya. This hospital is located in Upper-Hill area along hospital road, off-Ngong' road. It occupies about 5 hectares of land. Its total bed capacity is 1800 among these 256 are for children. K.N.H has 50 inpatient wards and different outpatient and specialized clinics.

This study was conducted in the pediatric medical wards, pediatric out-patient clinic and at mental health department in child psychiatric and youth clinics.

3.3. Study population

This study was targeting children aged between 2 and 18 years with a diagnosis of mental retardation (i.e. Intellectual Disability (ID) or Intellectual Disability Disorder (IDD)) and their parents who were attending K.N.H pediatric wards, pediatric out-patients clinics and mental health department. The age group of children was chosen based on the fact that DSM-IV-TR criteria specify that diagnosis of MR is made above 2 years of life and during development period, before age 18 years old.

Nurses, clinical psychologists and a pediatrician were recruited to participate in In-depth interviews.

3.4. Inclusion criteria

All Parents of pediatric patients with non-genetic mental retardation and their children attending K.N.H during the period of study and who met the criteria below were eligible to participate in the study:

- Children aged between 2 and 18 years diagnosed with non-genetic mental retardation, whose parents consented to participate in the study.
- Consenting parents of children aged between 2 and 18 years diagnosed with non-genetic mental retardation
- Nurse or clinical psychologist working in mental health department or a pediatrician working pediatric medical ward and who consented participated in the study.

3.5. Exclusion criteria

The study excluded:

- Parents of pediatric clients with genetic disorders (e.g. trisomy 21 syndrome, Prader-Willi syndrome and fragile X syndrome) known to lead to mental retardation
- Children whose parents declined to consent to participate
- Children who were critically ill.

3.6. Sample size calculation

The sample size was determined using the Fisher's formula (1998)

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

Where:

n= the desired samples size (if the target population is greater than 10,000)

z = is the value for corresponding confidence level (i.e. 1.96 for a 95% confidence interval)

p= is the estimated value for the proportion of the target population that have the condition of interest (p= the most conservative estimate, there being no documented incidence of Mental Retardation in Kenya, 50% is used).

e= the level of statistical significance set which is 5% with a confidence interval of 95%

$$n = \frac{1.96^2 \times 0.5\,(1 - 0.5)}{0.05^2} = \frac{3.8416 \times 0.25}{0.0025} = \frac{0.9604}{0.0025} = 384.16$$

n=384

The sample size was estimated at 384 study participants. Since the study population is less than 10,000 the Fisher`s formula (1998) was used to calculate the finite study sample size as follows:

$$nf = \frac{n}{1+(n/N)}$$

Where

nf = the desired sample size (when the population is less than 10,000)

n = the desired sample size (when population is greater than 10,000)

N = the estimate of the population size in the study area (number of children with MR attending K.N.H is about 129)

$$nf = \frac{384}{1+ (384/129)} = 96.6 = 97 \text{ study participants}$$

So, the sample size for study was 97 study participants

3.7. Sampling procedure

K.N.H was purposefully selected because it is a major teaching and referral hospital in Kenya. Departments and clinics receiving children with mental retardation were purposefully selected. These departments include pediatric psychiatric and youth clinics from mental

health unit, pediatric medical wards and pediatric outpatient clinics. K.N.H mental health unit receive patients referred from in-patient wards and outpatient clinics and those referred from other Health facilities from all over the country. Some of the patients with mental retardation presenting with co-morbid medical conditions attend pediatric out-patient clinics and others may be admitted in the pediatric medical wards.

Children aged 2-18 years and their parents were conveniently selected as they arrived in the sampled sites until the sample size was attained.

Purposive sampling was used to select 2 nurses and 2 clinical psychologists from mental health unit and 1 pediatrician from the pediatric wards, respectively, to participate in in-depth interviews.

3.8. Study instruments

A semi-structured researcher administered questionnaire (Appendix 10) was used to collect data from parents and their children on socio-demographic characteristics and to conduct in-depth history taking about maternal, child and environmental factors which may be associated with development of mental retardation.

Desk Reviews of the patients' files were done to get more information about the health, family and social histories of the child.

Key informant interview guide (Appendix 11) was used to collect qualitative data for the healthcare personnel responsible to provide medical care to the participants.

3.9. Recruitment and Training of Research assistants

Two Nurses with Bachelor of Science in Nursing (BSN) were recruited and trained to be research assistants. They were also trained on purposes on the study, data collection process and the ethical principles in research.

3.10. Pre-testing of the study instrument

The developed study instrument was checked for clarity, comprehensiveness and content validity. It was pretested for reliability on 10% of the sample size at Mbagathi Hospital, two weeks prior to the data collection period, thereafter necessary adjustment or modifications were made. In case anyone of participants who have participated in the pretesting was referred to K.N.H, he/she was excluded in the study.

3.11. Recruitment and consenting procedure

The parent of any child diagnosed with mental retardation at K.N.H was approached and be invited to participate in the study. For children who were coming at the hospital as their first visit, the researcher waited the medical diagnosis process to take place. Thereafter, if the child and parent met the inclusion criteria, was recruited.

In case, the child was accompanied by guardian other than parents, the researcher talked with the guardian to tell parents to come with the child for next visit. The data about that child were collected at that visit he/she came with parent.

Participants who were meeting the inclusion criteria were approached and explained (Appendices 3 and 4) on the purpose of the study, study benefits and other relevant information regarding their participation in the study to make an informed consent. The

participants/parents who accepted to participate were asked to sign the parent permission/consent form (Appendices 5 and 6).

3.12. Data collection procedures

Data from parents and children were collected using a pre-coded, semi-structured questionnaire (Appendix 10). Additional information from the desk reviews of patients' files were also recorded on the related part of the questionnaire.

3.12.1. In-depth interview procedures

In-depth interviews were conducted with nurses, clinical psychologists and a pediatrician. The purpose of the interview was first explained to each the respondent. The respondent was then asked to consent to participate in study and for the use of voice recording by signing consent form (Appendix 9). The respondent was then assigned an identification number to ensure confidentiality.

Open ended questions were used (Appendix 11) to ensure the respondents expound on the topic. The researcher allowed them answering in their preferred way. Interactive process was employed and conversational interview was introduced within the process so as to probe for the meaning of some of the responses. The process was audio-recorded. At the end of interview, the audio-taped information was replayed to the respondent for confirmation. Written notes were also taken to link with the audio-recorded information.

3.13. Data management and analysis

Quantitative data gathered from parents and desk reviews were recorded on pre-coded questionnaires (Appendix 10). At the end of each day of data collection, each questionnaire was checked for completeness. Any missing values and inconsistencies were then corrected.

The data were entered in computerized database using Statistical Package for Social Sciences (SPSS) 23.0 version (IBM SPSS Statistics v23).

Statistical analysis was done using SPSS 23 version. The relationships between the independent and dependent variables were evaluated using bivariate and multivariate logistic regression models. Crude odds ratio in the bivariate analysis and adjusted odds ratio in multivariate analysis were used to determine the strength of association. Significance of statistical association were tested using confidence interval (CI) of 95% and p-value <0.05. Analyzed data are presented in graphs, charts and tables.

Qualitative data from in-depth interviews with health care personnel (nurses, clinical psychologists and a pediatrician) and field notes on the questionnaires were transcribed and coded. After transcription, the data was grouped into themes and analysis was done manually.

The filled questionnaires and audio-taped information were kept in lockable drawers whose access was only limited to the researcher. Data was stored in computer and external hard drives protected with personal passwords.

3.14. Ethical considerations

The ethical approval and permission to conduct the study was granted by the Kenyatta National Hospital–University of Nairobi Ethics and Research Committee (KNH/UON-ERC) (Approval number: P961/12/2016). The permission to collect data was provided by the K.N.H Administration. Parental permission/informed consents (Appendices 5 and 6) were obtained from the parents of children with mental retardation attending K.N.H. Clear explanations to participants about the study were given prior getting their consent to participate in the study.

For some children, due to the severity of mental retardation, their capacity may be severely affected hence they cannot be reasonably consulted. Because of that, the waiver of assent was requested from KNH/UON-ERC. In the event where the child presented with ability to talk and with mild mental retardation, parent permission/consent was obtained from his or her parent and an assent (appendices 7 and 8) was also gained from the child after providing him or her clear explanations.

To maintain confidentiality, questionnaires were anonymous and code numbers were used to ensure anonymity of study respondents. Participation was fully voluntary and participants could withdraw their participation at any point of the study. Information gathered would be shared to relevant parties for implementation.

3.15. Dissemination of the study results

The final findings and research report will be presented and submitted to the School of Nursing Sciences, University of Nairobi. Copies of the report will be submitted to the University Library. Findings will be also shared with the management of Kenyatta National Hospital. The work will be published in peer-reviewed journal.

3.16. Study limitations

This study was a hospital-based, descriptive cross-sectional study, it has included only study participants attending Kenyatta National Hospital, therefore findings may not reflect actual factors from general population in the community as well as country-wide population, and so might not be generalizable.

Because of the nature of study design, being a cross-sectional study, it limits its utility for causal inference.

The fact that parents of the children served as the key informants in correcting medical histories, family and social information raises probabilities of recall bias. There may have been underreporting or misreporting the information, to minimize that desk reviews of the necessary documents including Kenya maternal-child booklets and patient's files were done for confirmation and additional information.

CHAPTER 4 RESEARCH FINDINGS

4.0 Introduction

This chapter presents the findings of the study and analysis. The results are interpreted based on the objectives. A total of 97 children aged between 2 and 18 years diagnosed with mental retardation at Kenyatta National Hospital were studied, from March to June, 2017. In-depth interviews were conducted with healthcare providers (two nurses, two clinical psychologists, and a pediatrician) to get qualitative data supporting the collected information. The results are arranged as follows; descriptive information, then bivariate analyses and finally multivariate analyses of study variables.

4.1 Distribution of socio-demographic characteristics of the children

Table 4.1 Distribution socio-demographic characteristics among the children presents the socio-demographic characteristics of the children who participated in the study. The mean age of the children was 5.6 years (SD±3.6 years). The age category shows that 2 to 3 years were 32.0% (n=31), 4 to 5 years were 32.0% (n=31) and greater than 5 years were 36.1% (n=35). Majority of the children 60(61.9%) were males and about three quarter 72(74.2%) were living with both their parents. Number of children in the family was examined and the highest percentage 55(56.7%) had only one child. About 92 (94.8%) of children did not have any history of siblings with mental retardation. The highest percentage of the children 39(40.2%) had moderate mental retardation.

These findings are supported by the information reported by key informant interviewees. One Participant reported the following "…*Most of the times the one we receive are from 3 years because sometimes mothers are not aware whether their children have mental retardation until they reach three years, they start talking and when they start having other problems, they don't come early…."* Another one said *"...Mostly, the children we see here are young*

children up to around 15 years, because after that they go to the youth clinic, about gender I can say they are almost the same males and females".

From quantitative data (Table 4.1 Distribution socio-demographic characteristics among the children), we found high proportion of children having moderate MR, but in the in-depth discussions, mild MR was reported as the one being seen. One participant reported the following: "…*Mostly we have mild, we don't have these profound extreme cases; mostly it is mild mental retardation....."*

Table 4.1 Distribution socio-demographic characteristics among the children

Variable	N=97	%
Age in years		
2 to 3	31	32
4 to 5	31	32
6 and above	35	36
Mean(±SD) = 5.6(±3.6)		
Gender		
Male	60	62
Female	37	38
Family setup		
Both parents	72	74
Single mother	23	24
Orphan/adopted	1	1
Abandoned	1	1
Number of children in the family		
1 child	55	57
2 children	25	26
3 children	14	14
4 children	3	3
Siblings' history of mental retardation		
Yes	5	5
No	92	95
Degree of mental retardation		
Mild	23	24
Moderate	39	40
Severe/profound	22	23
Unspecified	13	13

4.1.1 Mean age of 1st, 2nd, 3rd and 4th born in the family

As indicated in Figure 4.1: Mean age of 1st, 2nd, 3rd and 4th born in the family, the mean age of 1st, 2nd, 3rd and 4th born in the family were 8 years, 7.4 years, 5.9 years and 5.7 years respectively.

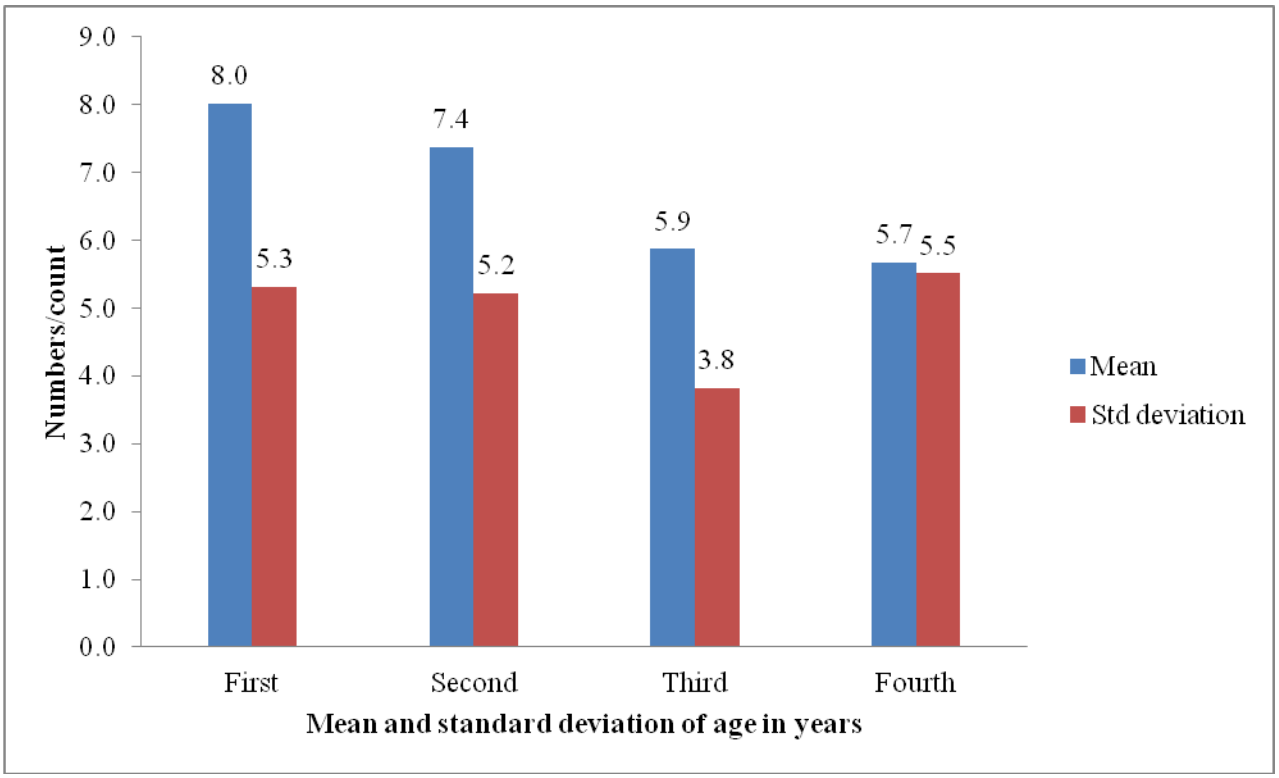

Figure 4.1: Mean age of 1st, 2nd, 3rd and 4th born in the family

4.2: Factors related to birth history

Most of the children 90(93%) were delivered at health facilities (Table 4.2). The main reason for not delivering at a health facility was that labor pain started at home without preparation 4(57%). Majority of the children 70(72%) were born after 37 weeks of gestational age. More than half of the children 51(53%) had complications during labor. Majority 74(76%)

delivered through spontaneous vaginal delivery whereas the remaining 23(24%) were delivered by cesarean section (Table 4.2).

Many children had history of complicated labor. In-depth interviews found the same. *"...Most of the parents when you ask them,..., most of the mothers complain that they had prolonged labor, others say that they have suffered malaria during the time of pregnancy"* Participant reporting.

Another participant said "…*in some cases, or in most cases when you take the histories you find that some of them and mothers had complicated birth, they had complications during birth and that could be as result of the cause of the mental retardation. Also we have other cases where there is some genetic predispositions which is running in the family. That is the common causes are found in the children coming in this department".*

Most of the children 78 (80%) had 2.5 Kg and above. The mean birth weight was 3.06 Kg and SD was 0.66. Almost half 48 (50%) of the children had less than 7 out of 10 Apgar score at birth. Similarly, about half 45 (46%) of the children were resuscitated at birth (Table 4.2).

Table 4.2: Factors related to birth history

Variable	N=97	%
Place of deliver for the baby		
Health facility	90	92.8
Home	7	7.2
Assistance received if it was not in the health facility (n=7)		
Self	2	28.6
Traditional birth assistant	5	71.4
Reasons for not delivered at the health facility (n=7)		
Cultural attribution prevent people to go to hospital	2	28.6
Labor pain started at home and was unprepared	4	57.1
Long distance to access hospital	1	14.3
Gestational age when the child born		
20 – 32 weeks	1	1.0
From 33 – 37 weeks	26	26.8
Over 37 weeks	70	72.2
Duration of labor in hours		
1 to 6	27	37.5
7 to 12	28	38.9
More than 12	17	23.6
Missing	25	
Labor complications		
Yes	51	52.6
No	46	47.4
Mode of delivery		
Spontaneous vaginal delivery	74	76.3
Cesarean section	23	23.7
Birth weight		
<2.5 kg	19	19.6
2.5 Kg and above	78	80.4
Mean (+SD) = 3.06(+0.66)		
Apgar score at birth		
<7/10	48	49.5
>7/10	49	50.5
Whether the baby was resuscitated at birth		
Yes	45	46.4
No	52	53.6

4.2.1 Type of labor complications (n=51)

Figure 4.2 demonstrates types of complications among those who had labor complications. The main complication was fetal distress (35.3%) followed by prolonged labor (33.3%).

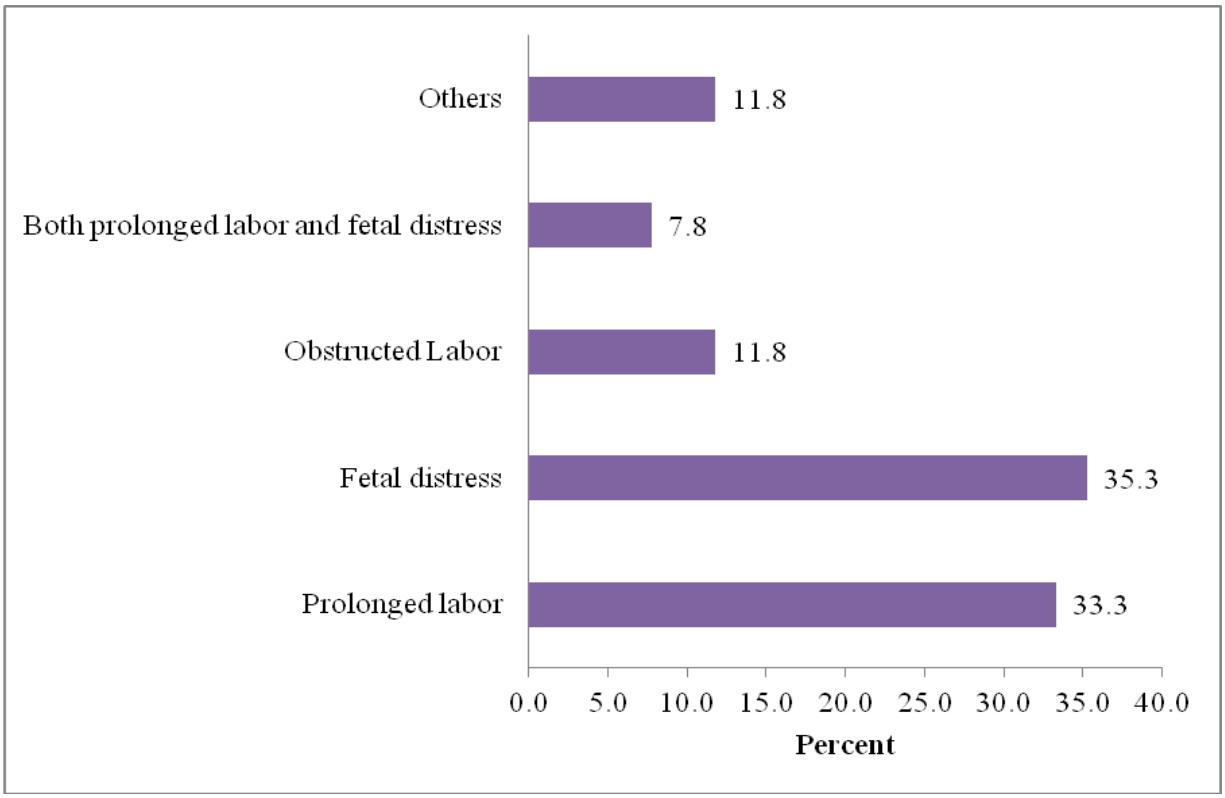

Figure 4.2: Type of labor complications (n=51)

4.3: Neonatal medical history

Table 4.3 shows factors related to neonatal medical history. Majority of the children 60(61.9%) had neonatal complications or difficulties and the main neonatal complication was birth asphyxia 42(70.0%). About half of children 48(49.5%) were admitted in neonatal intensive care (NICU). Considerable percentage had neonatal breathing difficulty 39(40.2%), neonatal seizures 27(27.8%) and neonatal infection 21(21.6%). Moreover, 18(18.6%) had neonatal feeding difficulties and 13 (13.4%) had neonatal jaundice.

Table 4.3: Neonatal medical history

Variable	N=97	%
Any neonatal difficulties/complications		
Yes	60	61.9
No	37	38.1
Types of the neonatal difficulties/complications at birth (n=60)		
Birth asphyxia	42	70.0
Birth trauma	4	6.7
Prematurity	8	13.3
Other Neonatal complications	6	10.0
Whether the baby was admitted in NICU		
Yes	48	49.5
No	49	50.5
Duration the child spent in hospital (n=46)		
One week	20	43.5
Two weeks	14	30.4
Three Weeks	4	8.7
One month and above	8	17.4
Neonatal breathing difficulty		
Yes	39	40.2
No	58	59.8
Neonatal seizures		
Yes	27	27.8
No	70	72.2
Neonatal infection		
Yes	21	21.6
No	76	78.4
Neonatal jaundice		
Yes	13	13.4
No	84	86.6
Neonatal feeding difficulties		
Yes	18	18.6
No	79	81.4
Time of initiation of breastfeeding for these with neonatal feeding difficulties (n=18)		
< 4 days	5	27.8
4 to 7 days	10	55.6
More than one week	3	16.7
Type of food the baby fed on before breastfeeding initiation (n=18)		
Expressed breast milk	13	72.2
Formula milk or IV fluids	5	27.8

4.4: Infant/childhood medical history

Most of the children 93(95.9%) were fully immunized. More than half 52(53.6%) suffered from illness during their infant or childhood period. Considerable number of the children 34(35.1%) had history of meningitis, 14(14.4%) with history of severe malnutrition, 12

(12.4%) with history of head injury and 8(8.2%) with history of encephalitis. About 3(3.1%) had suffered cerebral malaria. While almost all children 96(99%) had no history of poisoning or measles, none of them had history of near drowning (Table 4.4).

Table 4.4: Infant and childhood medical history

Variable	N=97	%
Immunization history		
Fully immunized	93	95.9
Not fully immunized	4	4.1
Reasons for not fully immunized (n=4)		
BCG lacked at health facility	1	25
Missed Measles Vaccine because he was sick/hospitalization	3	75
Suffer from any disease		
Yes	52	53.6
No	45	46.4
History of measles infection		
Yes	1	1.0
No	96	99.0
History of meningitis		
Yes	34	35.1
No	63	64.9
History of encephalitis		
Yes	8	8.2
No	89	91.8
History of cerebral malaria		
Yes	3	3.1
No	94	96.9
History of head injury		
Yes	12	12.4
No	85	87.6
Whether the child was treated for head injury (n=12)		
Yes	8	66.7
No	4	33.3
History of near drowning		
No	97	100.0
History of poisoning		
Yes (drug and treated)	1	1.0
No	96	99.0
History of severe malnutrition		
Yes	14	14.4
No	83	85.6
Age at which severe malnutrition occurred (n=14)		
Less than one year	11	78.6
More than one year	3	21.4

4.4.1: History of breastfeeding

Majority of the children 65(67.0%) breastfed 1 to 24 months and only 6(6.2%) breastfed less than 6 months and 1(1.0%) never breasted (Figure 4.3)

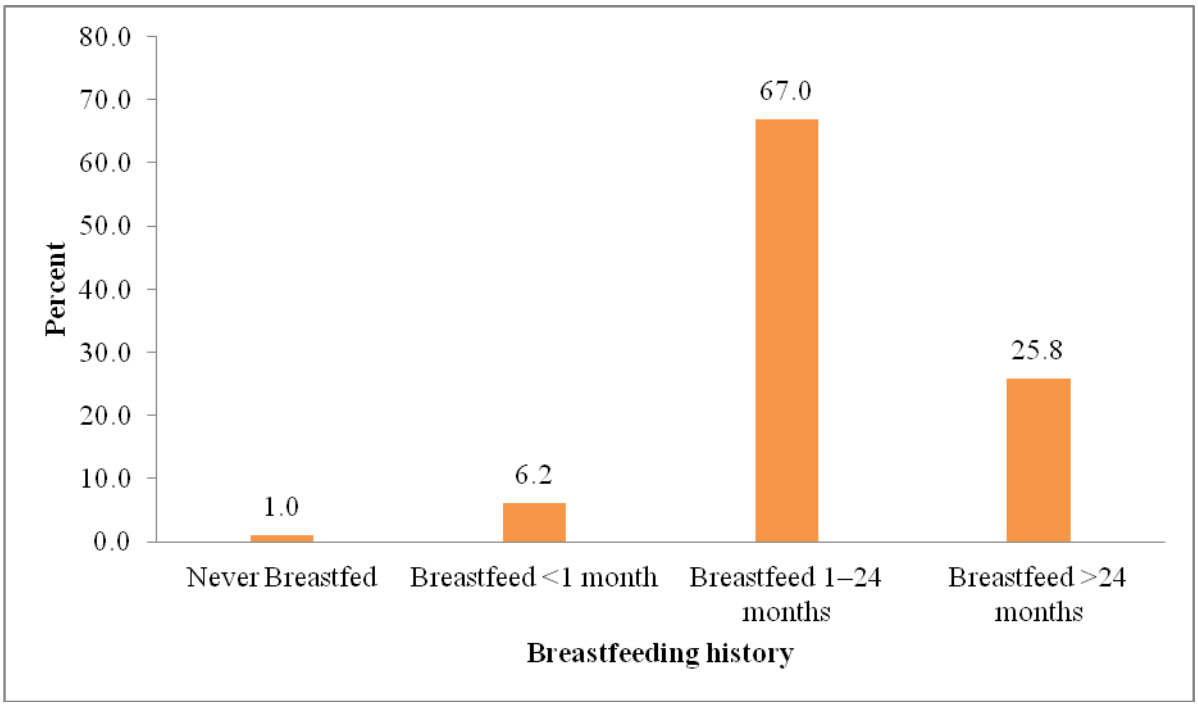

Figure 4.3: History of breastfeeding

4.5: Pre-existing and co-morbid conditions

As indicated in Table 4.5, all the children participated in the study had no history of thyroid disorder or depression. However, most 80(82.5%) of the children had convulsive disorder. About half of the children 45(46.4%) had cerebral palsy. A quarter 28(28.9%) had pneumonia. Considerable percentage of the children 11(11.3%) had also malnutrition. Ten (10.3%) of them had autism spectrum disorder and 10(10.3%) attention deficit hyperactivity disorder. Only 6(6.2%) had rickets, 4(4.1%) had asthma and 3(3.1%) had cardiovascular disease.

Table 4.5: Pre-existing and co-morbid conditions

Variable	N=97	%
Cerebral palsy		
Yes	45	46.4
No	52	53.6
Convulsive disorders		
Yes	80	82.5
No	17	17.5
Thyroid disorder		
No	97	100
Cardiovascular disease		
Yes	3	3.1
No	94	96.9
Asthma		
Yes	4	4.1
No	93	95.9
Pneumonia		
Yes	28	28.9
No	69	71.1
Malnutrition		
Yes	11	11.3
No	86	88.7
Rickets		
Yes	6	6.2
No	91	93.8
Autism Spectrum Disorder (ASD)		
Yes	10	10.3
No	87	89.7
Attention Deficit/Hyperactivity Disorder (ADHD)		
Yes	10	10.3
No	87	89.7
Depression		
No	97	100

4.6: Selected socio-demographic and economic characteristics of the mothers

The distribution of selected socio-demographic and socio-economic characteristics among mothers is shown in Table 4.6. Majority of the mothers 80(82.5%) were within the age group of 21-35 years and the same age category at the time of child's birth was 84(86.6%). Majority of the mothers 56(57.7%) had attained secondary school education. The highest percentage (47.4%) mothers were casual workers. Only 30(31%) were regularly employed. However

about 21(21.6%) were unemployed. Majority 52 (53.6%) reported having between 21,000 and 50.000 Kenyan Shillings (KES) as monthly family income.

Majority of children's mothers were in Middle Ages, about half of them were not having regular employment and almost all of them (cumulative rate of 96%) reported a monthly family income less than 50,000 KES, informing their family socioeconomic status. This finding corroborates with the information got from in-depth discussions with healthcare providers.

"In most cases these children are brought by the mothers, in very rare cases you find the fathers coming it's like when a child develop mental disorders the burden is left to the mothers or the grandparents for that child, …, that the trends I am seeing". "Mothers mostly are Middle Ages that is from around twenties to forties, that the range of mothers who bring the children here. And other is about grandmothers who are over fifties. (Participant reporting)

Another participant said *"About social demographic issues most of them they come from poor background, these are the ones we see mostly… We have more people from low socio-economic group*."

"in terms of socioeconomic status, so most of the children who have the mental retardation come from the poor families, or mild economic status so the incidence is higher as from the low to high economic status" (another Participant reporting)

Table 4.6: Selected socio-demographic and economic characteristics of mothers

Variable	N=97	%
Age of the mother		
21 – 35 years	80	82.5
≥ 36 years	17	17.5
Age of the mother at the time of child 's birth		
Below 20 years	6	6.2
21 – 35 years	84	86.6
≥ 36 years	7	7.2
Highest level of education of the mother		
Primary level	31	32
Secondary level	56	57.7
College/university Level	10	10.3
Occupation of the mother		
Regular employment	30	30.9
Casual employment	46	47.4
Unemployed	21	21.6
Average monthly income in the family in Kenyan Shillings		
More than 50,000	4	4.1
21,000 to 50.000	52	53.6
11,000 to 20,000	38	39.2
Less than 10,000	3	3.1

4.7: Pregnancy history related factors

Large percentage of the mothers 94(96.9%) attended antenatal care during pregnancy and majority 74(78.7%) of them had attended ANC 3 to 4 times. More than a quarter 28(28.9%) of the mothers took drugs during pregnancy. Majority of the mothers 87(89.7%) and 84(85.6%) were not smoking and never took alcohol during the pregnancy, respectively. Most of the participants 77(79.4%) indicate that they were living in an environment where people smoke (Table 4.7).

Table 4.7: Pregnancy history related factors

Variable	N=97	%
Attending ANC during pregnancy of the child		
Yes	94	96.9
No	3	3.1
Frequency of ANC attendance (n=94)		
1-2times	20	21.3
3-4times	74	78.7
Took any drugs during pregnancy		
Yes	28	28.9
No	69	71.1
Gestational trimester at when drugs were taken (n=28)		
First trimester	9	32.1
Second trimester	10	35.7
Third trimester	9	32.1
Smoking during pregnancy		
Yes	10	10.3
No	87	89.7
Living in environment where people smoke		
Yes	77	79.4
No	20	20.6
Using alcohol during this pregnancy		
Yes	14	14.4
No	83	85.6

*ANC= Antenatal Clinic

4.7.1: Medical conditions during pregnancy (n=22)

Among those mothers who had suffered any medical conditions during pregnancy, urinary tract infection was the main medical condition (45.5%) followed by preeclampsia/hypertension (31.8%) as shown in Figure 4.4.

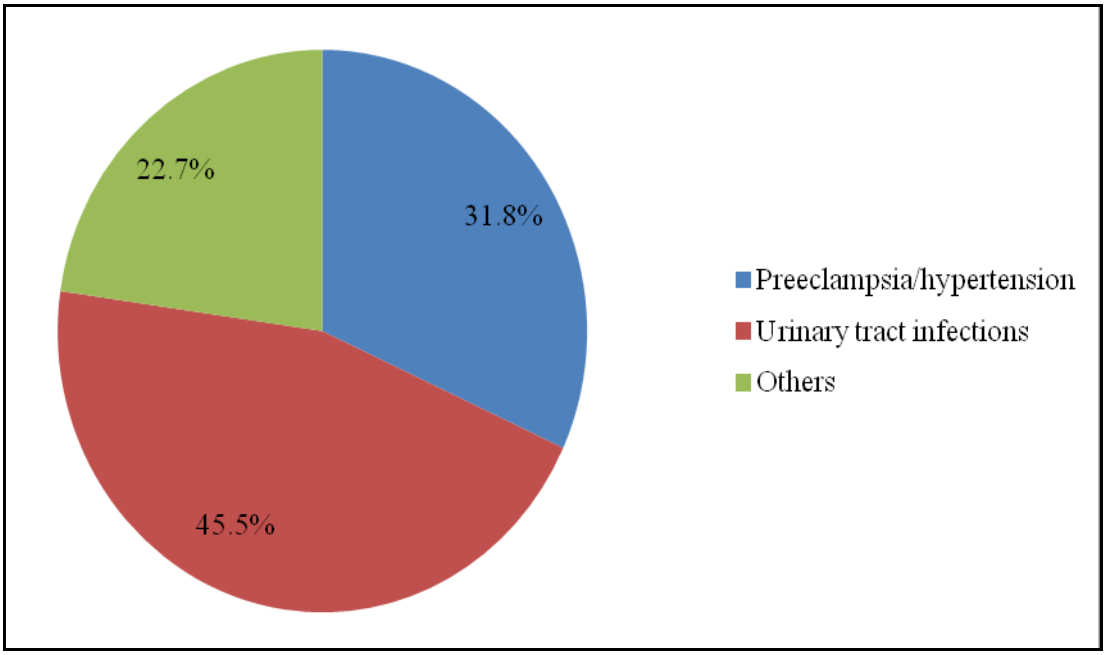

Figure 4.4: Medical conditions suffered during pregnancy

4.8: Socio-demographic characteristics of the fathers

Table 4.8 summarizes the socio-demographic characteristics of the fathers. Majority of the fathers 54(58.7%) were within the age group of 21-35 years. Most of the fathers 54(58.7%) attended secondary school followed by college/university level 28(30.4%). The highest percentages (52.2%) of the fathers were regularly employed and about 42(45.7%) were casual workers. More than a quarter of the fathers 27(29.3%) were smokers.

Table 4.8: Socio-demographic characteristics of the fathers

Variable	N=97	%
Age of the father		
21 – 35 years	54	58.7
≥ 36 years	38	41.3
Missing	5	
Age of the father at the time of birth of the child		
21 – 35 years	68	73.9
≥ 36 years	24	26.1
Missing		
Highest level of education of the father		
No formal education	2	2.2
Primary level	8	8.7
Secondary level	54	58.7
College/university Level	28	30.4
Missing	5	
Occupation of the father		
Regular employment	48	52.2
Casual employment	42	45.7
Unemployed	2	2.2
Missing	5	
Whether the father smokes		
Yes	27	29.3
No	65	70.7
Missing	5	

4.9: Relationship between socio-demographic characteristics of children and severity of mental retardation

Bivariate analysis of the association between selected socio-demographic characteristics of children and severity of mental retardation is summarized in Table 4.9. There was more proportion of severe/profound mental retardation among children staying only with mothers (38.9%) compared to those children staying with both parents (23.4%). However, this was not statistically significant [OR=2.08; 95%CI=0.69-6.31; P=0.196]. Moreover, there was no significant association between the other socio-demographic characteristics of children and severity of mental retardation (Table 4.9).

Table 4.9: Relationship between socio-demographic characteristics of children and severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	N	%	n	%		Lower	Upper	P value
Age in years								
2 to 3	8	42.1%	11	57.9%	2.10	0.64	6.87	0.219
4 to 5	5	16.7%	25	83.3%	0.58	0.17	1.96	0.379
6 and above	9	25.7%	26	74.3%	1.00			
Gender								
Male	12	23.5%	39	76.5%	0.71	0.26	1.90	0.490
Female	10	30.3%	23	69.7%	1.00			
Family setup								
Both parents	15	23.4%	49	76.6%	1.00			
Single mother	7	38.9%	11	61.1%	2.08	0.69	6.31	0.196
Number of children in the family								
1 child	9	19.1%	38	80.9%	1.00			
2 children	6	28.6%	15	71.4%	1.69	0.51	5.57	0.389
3 -4 children	7	43.8%	9	56.3%	3.28	0.96	11.19	0.057
Siblings' history of mental retardation								
Yes	1	25.0%	3	75.0%	0.94	0.09	9.50	0.956
No	21	26.3%	59	73.8%	1.00			

OR= Odds Ratio, CI= Confidence Interval, χ2= Chi-square

4.10: Relationship between birth history of the children and severity of mental retardation

Table 4.10 shows the relationship between birth history of the children and severity of mental retardation.

Children with labor complications during birth had significantly more proportion of severe/profound mental retardation (39.1%) [OR=5.46; 95%CI=1.66-18.02; P=0.003] compared to those children without labor complications (10.5%).

There was significantly higher proportion of severe/profound mental retardation among children delivered by cesarean section (50.0%) [OR=4.64; 95%CI=1.61-13.38; P=0.005] than

those children delivered by spontaneous vaginal delivery (17.7%) and this was statistically significant.

Apgar score at birth was also significantly associated with severity of mental retardation among children. Children with Apgar score lower than 7 out of ten significantly suffered severe/profound mental retardation (38.6%) [OR=4.41; 95%CI=1.44-13.46; P=0.007] more than children who scored above 7 out of ten (12.5%).

Likewise, children who were resuscitated at birth had significantly higher proportion of severe/profound mental retardation (40.0%) [OR=4.22; 95%CI=1.45-12.29; P=0.006] than those children never resuscitated at birth (13.6%).

Table 4.10: Association between birth history of the children and severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	N	%	n	%		Lower	Upper	P value
Place of deliver for the baby								
Health facility	22	28.6%	55	71.4%	1.00			
Home	0	0.0%	7	100.0%	UD	UD	UD	0.100
Gestational age when the child born								
from 33 – 37 weeks	7	31.8%	15	68.2%	1.43	0.49	4.17	0.510
Over 37 weeks	15	24.6%	46	75.4%	1.00			
Labor complications								
Yes	18	39.1%	28	60.9%	5.46	1.66	18.02	**0.003**
No	4	10.5%	34	89.5%	1.00			
Mode of delivery								
Spontaneous vaginal delivery	11	17.7%	51	82.3%	1.00			
Cesarean section	11	50.0%	11	50.0%	4.64	1.61	13.38	**0.005**
Birth weight								
<2.5 kg	5	27.8%	13	72.2%	1.11	0.34	3.57	0.863
2.5 Kg and above	17	25.8%	49	74.2%	1.00			
Apgar score at birth								
<7/10	17	38.6%	27	61.4%	4.41	1.44	13.46	**0.007**
>7/10	5	12.5%	35	87.5%	1.00			
Whether the baby was resuscitated at birth								
Yes	16	40.0%	24	60.0%	4.22	1.45	12.29	**0.006**
No	6	13.6%	38	86.4%	1.00			

OR= Odds Ratio, CI= Confidence Interval, $\chi 2$= Chi-square; UD= Undefined

4.11: Association between neonatal medical history of the children and severity of mental retardation

Table 4.11 shows the relationship between history of neonatal medical related factors and severity of mental retardation. There was significantly increased proportion of severe/profound mental retardation among children who had any neonatal difficulties (36.5%) [OR=5.57; 95%CI=1.49-20.75; P=0.006] than those children without (9.4%).

Children who were admitted to NICU during neonatal period had significantly more proportion of severe/profound mental retardation (41.9%) [OR=6.66; 95%CI=2.01-22.03;

P=0.001] compared those children never admitted in NICU during neonatal period (9.8%). Similarly, children with neonatal breathing difficulties had significantly higher proposition of severe/profound mental retardation (37.8%) [OR=2.97; 95%CI=1.08-8.15; P=0.031] than to those children without neonatal breathing difficulties (17.0%).

There was also significant association between neonatal feeding difficulties and severe/profound mental retardation where children with neonatal feeding difficulties had significantly more severe/profound mental retardation (50.0%) [OR=3.86; 95%CI=1.23-12.09; P=0.016] compared to those children without (20.6%).

No statistical significant relationship was found in the factors such as neonatal seizures, neonatal infection and neonatal jaundice.

Table 4.11: Association between neonatal medical history of the children and severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	N	%	n	%		Lower	Upper	P value
Any neonatal difficulties								
Yes	19	36.5%	33	63.5%	5.57	1.49	20.75	**0.006**
No	3	9.4%	29	90.6%	1.00			
Whether the baby was admitted in NICU								
Yes	18	41.9%	25	58.1%	6.66	2.01	22.03	**0.001**
No	4	9.8%	37	90.2%	1.00			
Neonatal breathing difficulty								
Yes	14	37.8%	23	62.2%	2.97	1.08	8.15	**0.031**
No	8	17.0%	39	83.0%	1.00			
Neonatal seizures								
Yes	6	30.0%	14	70.0%	1.29	0.42	3.91	0.657
No	16	25.0%	48	75.0%	1.00			
Neonatal infection								
Yes	4	20.0%	16	80.0%	0.64	0.19	2.17	0.471
No	18	28.1%	46	71.9%	1.00			
Neonatal jaundice								
Yes	3	27.3%	8	72.7%	1.07	0.26	4.44	0.930
No	19	26.0%	54	74.0%	1.00			
Neonatal feeding difficulties								
Yes	8	50.0%	8	50.0%	3.86	1.23	12.09	**0.016**
No	14	20.6%	54	79.4%	1.00			

OR= Odds Ratio, CI= Confidence Interval, χ2= Chi-square

4.12: Association of infant and childhood medical history with severity of mental retardation

Analysis of the relationship between infant and childhood medical and severity of mental retardation among the children is summarized in Table 4.12. There was no statistically significant association observed between the variables.

Table 4.12: Association of infant and childhood medical history with severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	N	%	n	%		Lower	Upper	P value
Immunization history								
Fully immunized	20	25.0%	60	75.0%	1.00			
Not fully immunized	2	50.0%	2	50.0%	3.00	0.40	22.71	0.287
Suffer from any disease								
Yes	10	22.7%	34	77.3%	0.69	0.26	1.82	0.449
No	12	30.0%	28	70.0%				
History of meningitis								
Yes	6	20.0%	24	80.0%	0.59	0.20	1.73	0.336
No	16	29.6%	38	70.4%				
History of encephalitis								
Yes	0	0.0%	6	100.0%	UD	UD	UD	0.130
No	22	28.2%	56	71.8%	1.00			
History of cerebral malaria								
Yes	2	66.7%	1	33.3%	6.10	0.53	70.90	0.104
No	20	24.7%	61	75.3%	1.00			
History of head injury								
Yes	2	18.2%	9	81.8%	0.59	0.12	2.96	0.571
No	20	27.4%	53	72.6%	1.00			
History of severe malnutrition								
Yes	3	23.1%	10	76.9%	0.82	0.20	3.31	0.781
No	19	26.8%	52	73.2%	1.00			
Breastfeeding history								
Breastfeed <1 month	1	33.3%	2	66.7%	1.14	0.09	14.78	0.919
Breastfeed 1–24 months	13	22.8%	44	77.2%	0.68	0.23	1.99	0.477
Breastfeed >24 months	7	30.4%	16	69.6%	1.00			

OR= Odds Ratio, CI= Confidence Interval, χ2= Chi-square

4.13: Relationship between pre-existing/co-morbid and severity of mental retardation

Table 4.13 shows the bivariate analysis of relationship between pre-existing/co-morbid and severity of mental retardation. Children with cerebral palsy were significantly more likely to suffer severe/profound mental retardation (47.6%) [OR=18.18; 95%CI=3.88-85.14; P=0.000] compared to those children without cerebral palsy (4.8%). There was no statistically significant association observed in other variables.

Table 4.13: Relationship between pre-existing/co-morbid and severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	n	%	n	%		Lower	Upper	P value
Cerebral palsy								
Yes	20	47.6%	22	52.4%	18.18	3.88	85.14	**0.000**
No	2	4.8%	40	95.2%	1.00			
Convulsive disorders								
Yes	19	27.5%	50	72.5%	1.52	0.39	5.99	0.547
No	3	20.0%	12	80.0%	1.00			
Cardiovascular disease								
Yes	1	50.0%	1	50.0%	2.91	0.17	48.53	0.438
No	21	25.6%	61	74.4%	1.00			
Asthma								
Yes	1	50.0%	1	50.0%	2.91	0.17	48.53	0.438
No	21	25.6%	61	74.4%	1.00			
Pneumonia								
Yes	6	26.1%	17	73.9%	0.99	0.33	2.96	0.989
No	16	26.2%	45	73.8%	1.00			
Malnutrition								
Yes	3	33.3%	6	66.7%	1.47	0.34	6.48	0.606
No	19	25.3%	56	74.7%				
Rickets								
Yes	1	25.0%	3	75.0%	0.94	0.09	9.50	0.956
No	21	26.3%	59	73.8%	1.00			
Autism Spectrum Disorder (ASD)								
Yes	1	10.0%	9	90.0%	0.28	0.03	2.35	0.215
No	21	28.4%	53	71.6%	1.00			
Attention Deficit/Hyperactivity Disorder (ADHD)								
Yes	2	22.2%	7	77.8%	0.79	0.15	4.10	0.774
No	20	26.7%	55	73.3%				

OR= Odds Ratio, CI= Confidence Interval, χ2= Chi-square

4.14: Association between socio-demographic and economic characteristics of mothers and severity of mental retardation

Table 4.14 shows the relationship between socio-demographic and economic characteristics of mothers and severity of mental retardation. Even though mothers aged above 35 years had increased proportion of children with severe/profound mental retardation (46.7%) compared to those aged between 21 to 35 years (21.7%), this was not statistically significant [OR=3.15; 95% CI=0.98-10.09; P=0.053]. Similarly, there was no significant association between

severity of mental retardation among children and the other demographic characteristics of the mothers.

Table 4.14: Association between socio-demographic and economic characteristics of mothers and severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	n	%	n	%		Lower	Upper	P value
Age of the mother								
21 – 35 years	15	21.7%	54	78.3%	1.00			
≥ 36 years	7	46.7%	8	53.3%	3.15	0.98	10.09	0.053
Age of the mother at the time of birth of the child								
Below 20 years	2	33.3%	4	66.7%	1.25	0.12	13.24	0.853
21 – 35 years	18	25.4%	53	74.6%	0.85	0.15	4.76	0.852
> 36 years	2	28.6%	5	71.4%				
Highest level of education of the mother								
Primary level	8	30.8%	18	69.2%	0.74	0.14	3.88	0.722
Secondary level	11	22.0%	39	78.0%	0.47	0.10	2.28	0.349
College/university Level	3	37.5%	5	62.5%	1.00			
Occupation of the mother								
Regular employment	8	30.8%	18	69.2%	1.00			
Casual employment	6	14.6%	35	85.4%	0.39	0.12	1.28	0.120
Unemployed	8	47.1%	9	52.9%	2.00	0.56	7.09	0.283
Average monthly income in the family (in KES)								
< 21,000	8	23.5%	26	76.5%	0.79	0.29	2.16	0.647
21,000 and more	14	28.0%	36	72.0%	1.00			

OR= Odds Ratio, CI= Confidence Interval, χ2= Chi-square

4.15: Relationship between pregnancy-related factors and severity of mental retardation

Bivariate analysis of pregnancy related factors and severity of mental retardation among children is presented in Table 4.15. Children whose mothers used to take drugs during pregnancy had significantly increased severe/profound mental retardation (47.8%) [OR=4.17; 95%CI: 1.46-11.87; P=0.006] compared to those whose mothers indicated otherwise (18.0%). Mothers who indicated living in an environment where people smoke had significantly less

children with severe/profound mental retardation (18.2%) [OR=0.18; 95%CI: 0.06-0.55; P=0.001] than those who reported otherwise (55.6%).

Table 4.15: Relationship between pregnancy-related factors and severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	n	%	n	%		Lower	Upper	P value
Attending ANC during pregnancy of the child								
Yes	22	27.2%	59	72.8%	1.00			
No	0	0.0%	3	100.0%	UD	UD	UD	0.293
Frequency of attending ANC								
1-2times	3	16.7%	15	83.3%	0.46	0.12	1.79	0.256
3-4times	19	30.2%	44	69.8%	1.00			
Took any drugs during pregnancy								
Yes	11	47.8%	12	52.2%	4.17	1.46	11.87	**0.006**
No	11	18.0%	50	82.0%	1.00			
Smoking during pregnancy								
Yes	1	10.0%	9	90.0%	0.28	0.03	2.35	0.215
No	21	28.4%	53	71.6%	1.00			
Living in environment where people smoke								
Yes	12	18.2%	54	81.8%	0.18	0.06	0.55	**0.001**
No	10	55.6%	8	44.4%	1.00			
Using alcohol during this pregnancy								
Yes	5	35.7%	9	64.3%	1.73	0.51	5.88	0.375
No	17	24.3%	53	75.7%	1.00			

OR= Odds Ratio, CI= Confidence Interval, χ2= Chi-square, UD= Undefined

4.16 Association between socio-demographic characteristics of the fathers and severity of mental retardation

Table 4.16 shows the bivariate analysis of relationship between socio-demographic characteristics of the fathers and severity of mental retardation. There was no significant association observed between the paternal socio-demographic characteristics and severity of mental retardation among the children.

Table 4.16 Association between socio-demographic characteristics of the fathers and severity of mental retardation

Variables	Severe/profound		Mild/moderate		OR	95%CI		χ^2 test
	n	%	n	%		Lower	Upper	P value
Age of the father								
21 – 35 years	8	17.4%	38	82.6%	0.44	0.15	1.26	0.120
> 36 years	11	32.4%	23	67.6%	1.00			
Age of the father at the time of birth of the child								
21 – 35 years	12	20.7%	46	79.3%	0.56	0.19	1.68	0.296
> 36 years	7	31.8%	15	68.2%	1.00			
Highest level of education of the father								
Primary level	2	28.6%	5	71.4%	0.90	0.14	5.66	0.911
Secondary level	9	20.0%	36	80.0%	0.56	0.19	1.70	0.309
College/university Level	8	30.8%	18	69.2%	1.00			
Occupation of the father								
Regular employment	13	30.2%	30	69.8%	2.60	0.82	8.20	0.096
Casual employment	5	14.3%	30	85.7%	1.00			
Unemployed								
Whether the father smokes								
Yes	3	12.0%	22	88.0%	0.33	0.09	1.27	0.096
No	16	29.1%	39	70.9%	1.00			

OR= Odds Ratio, CI= Confidence Interval, χ2= Chi-square

4.17 Factors associated with severity of mental retardation among children

Binary logistic regression analysis was applied to identify the variables independently associated with severity of mental retardation among children aged 2 to 18 years. Eleven (11) factors were considered in the analysis including: labor complications, mode of delivery, APGAR score at birth, whether the baby was resuscitated at birth, any neonatal difficulties, whether the baby was admitted in NICU, neonatal breathing difficulty, neonatal feeding difficulties, cerebral palsy, using drugs during pregnancy and living in environment where people smoke. Upon fitting these factors using binary logistic regression and by specifying *'backward LR'* method with removal at P<0.05, three (3) factors remained in the final analysis (Table 4.17).

Severe/profound mental retardation was about 10 times more among children with labor complications during birth [AOR=9.45; 95%CI=1.23-113.29; P=0.036] compared to those children without labor complications.

Children who were admitted to nursery during neonatal period had 8 times more likely to have severe/profound mental retardation [AOR=8.09; 95%CI=2.11-31.07; P=0.002] compared those children never admitted in nursery during neonate.

Children with cerebral palsy were 21 fold more likely to have severe/profound mental retardation [AOR=21.18; 95%CI=4.18-107.40; P=0.000] compared to those children without cerebral palsy.

Table 4.17: Factors associated with severity of mental retardation among children

Variable	COR	95% CI		p value	AOR	95% CI		p value*
		Lower	Upper			Lower	Upper	
Labor complications								
Yes	5.46	1.66	18.02	0.003	9.45	1.23	113.29	**0.036**
No	1.00				1.00			
Mode of delivery								
Spontaneous vaginal delivery	1.00				1.00			
Cesarean section	4.64	1.61	13.38	0.005	3.48	0.59	20.56	0.169
APGAR score at birth								
<7/10	4.41	1.44	13.46	0.007	9.15	0.47	179.54	0.145
>7/10	1.00				1.00			
Whether the baby was resuscitated at birth								
Yes	4.22	1.45	12.29	0.006	0.08	0.00	3.37	0.186
No	1.00				1.00			
Any neonatal difficulties/complications at birth								
Yes	5.57	1.49	20.75	0.006	2.13	0.10	46.61	0.631
No	1.00				1.00			
Whether the baby was admitted in NICU								
Yes	6.66	2.01	22.03	0.001	8.09	2.11	31.07	**0.002**
No	1.00				1.00			
Neonatal breathing difficulty								
Yes	2.97	1.08	8.15	0.031	0.26	0.02	2.92	0.272
No	1.00				1.00			
Neonatal feeding difficulties								
Yes	3.86	1.23	12.09	0.016	0.52	0.09	3.23	0.486
No	1.00				1.00			
Cerebral palsy								
Yes	18.18	3.88	85.14	0.000	21.18	4.18	107.40	**0.000**
No	1.00				1.00			
Took any drugs during pregnancy								
Yes	4.17	1.46	11.87	0.006	3.92	0.70	21.97	0.120
No	1.00				1.00			
Living in environment where people smoke								
Yes	0.18	0.06	0.55	0.001	0.09	0.11	1.31	0.092
No	1.00				1.00			

COR= Crude Odds Ratio, CI= Confidence Interval, AOR =Adjusted Odds Ratio

CHAPTER 5 DISCUSSIONS, CONCLUSIONS, RECOMMENDATIONS

This chapter includes discussions of the study findings, conclusions and recommendations.

5.1. DISCUSSION

This study was a hospital-based, cross-sectional study conducted at Kenyatta National Hospital on consecutively selected 97 pediatric patients diagnosed with mental retardation (MR); i.e. Intellectual Disability (ID) and who were aged between 2 to 18 years. The main objective was to explore risk factors for non-genetic mental retardation. Quantitative findings were computed and descriptive analysis was done. Transcribed qualitative data was analyzed manually in themes. The range of characteristics and factors has been examined using odds ratio and adjusted odds ratio for its likelihood of relationships with mental retardation severity.

5.1.1. Child socio-demographic characteristics

The study findings indicate that mean age of study population was ±5.6 years with a standard deviation of 3.6 years. Given that this was hospital-based study, this finding may be attributed to the fact that this is the development period. Most parents tend to seek medical and psychological assessment for their children after observing they are not meeting expected developmental milestones or have deficits in adaptive skills and/or in intellectual development. As expected, male children were more affected than female children, 62% versus 38% respectively; this finding is in consistence with the results from other studies which reported male predominance (Goli, Moniri & Wilhelm, 2016, Maulik *et al.*, 2011, Sharma *et al.,* 2016). There was only one child in the family in more than half (57%) of participants. Most (74%) of the children were having both of their parents while 34% were living in family of single mothers. However, it was observed that children staying with single

mothers had high proportion of severe/profound mental retardation (38.9%) compared to those staying with both parents (23.4%). A possible explanation for this could be that single-mothers face many challenges such fulfilling the child's every day needs in addition to their own socioeconomic needs. Hence, when these needs are not fulfilled, there are effects on the child's growth and development which may lead to poor health outcomes including development of mental retardation in the child.

Current findings show that high proportion (40%) of children was suffering moderate mental retardation. This result agrees with a similar study conducted in India (Naskar & Nath, 2016) where 40% of children had moderate MR. This high proportion of moderate MR could be attributed to referrals. Children with moderate intellectual disability tend to have remarkable limitations in meeting expected standards of personal independence and social responsibility in different aspects of daily life, especially when they start school. Therefore, when child starts to show slow academic achievements, he/she is referred for psychological evaluation. Contrary, many children with severe/profound MR tend to be stigmatized and hidden as they do not achieve much in life therefore they are not referred.

Logistic regressions analysis did not reveal any significant association of child socio-demographic variables (including age, gender, family set up, number of children in family) and severity of MR. This result is similar to the findings of a study done in India (Naskar & Nath , 2016) which examined correlation of socio-demographic variables of patients with ID and types of ID.

5.1.2. Parental factors and mental retardation

5.1.2.1. Demographic characteristic

In this study, most mothers (86.6%) and fathers (73.9%) were aged between 21 to 35 years at the time of delivery of their children. There was no statistically significant relationship between parental age and severity of MR. A study done in by Drews *et al.* (1995) and a systemic review and meta-analysis done by Huang *et al.* (2016) reported a positive association between advanced parental age and MR though these studies were combining both genetic and non-genetic cases. The present study included only children with MR considered non-genetic, with exclusion of those who were having genetic disorders known to lead to MR. This fact may explain the predominance of parents of middle ages in this study. Nevertheless, maternal age still contributes to MR. In the present study; mothers aged 35 and above years were having increased proportion of severe-profound MR (46.7%) compared to those aged 21 – 35 years (21.7%).

More than half of the parents, 58.7% of fathers and 57.7% of mothers had at least completed secondary education. This was as expected taking into account that more than 50% of Kenyans attend secondary education according to UNESCO report (UNESCO, 2009). No relationship was revealed between parental level of education and severity of MR. However, previous studies (Durkin, Hasan & Hasan, 1998, Huang *et al.* 2016) reported positive association of lack maternal education with MR. One of the findings reported by Bilder *et al.* (2013) from their study carried out in Utah, America indicated a significant association between MR with exclusion of genetic cases and maternal education while that was not significant on paternal education.

5.1.2.2. Parental socioeconomic status

Findings demonstrate that only about 31% of mothers and half of the fathers (52.2%) had regular employment, the rest were either unemployed (21.6%) or had casual jobs (47.4%). Most (95.9%) of the families were having gross family income of less than Kenyan shillings 50,000. Participants in the in-depth interviews reported that most of the children with MR come from poor social background, from families with low and middle socioeconomic status. These findings agree with the evidence from numerous studies **(**Karam *et al*., 2016, Maulik *et al*., 2011, Sharma *et al*., 2016). Lower socio-economic status has negative effects on child's development as it is often associated with poor diet, poor health practices and inadequate medical care, poor housing, and environmental health hazards thus generally poor living conditions. All these factors potentially hamper the normal growth and development of the child consequently leading to development of MR. Even though socioeconomic status of the parents as reported did not show any statistically significant relationship with the severity of MR, elevated proportion (47.1%) of children with severe-profound MR were found in mothers who were unemployed compared to those with regular and casual employment. Comparable findings were reported in Indian study in which no significant association of ID severity and socioeconomic status was found (Naskar & Nath, 2016), while similar pattern is found in findings of the cohort study done by Karam *et al*. (2016), where no association were found between socioeconomic status and groups with ID. On the other hand, these findings are different from the findings of a study done in Australia by Leonald *et al.* (2005) which found positive relationship of socioeconomic disadvantage and increased risk of intellectual disability. Probably this difference may be due to the fact that the latter studies used different methods and large population comparing to the present study.

5.1.2.3 Pregnancy related factors

Regarding pregnancy related factors, almost all mothers of children studied (97%) reported to have attended antenatal clinic (ANC) during pregnancy with the child, with majority (78.7%) attending at least three to four times. This result obviously reflects the improvements of prenatal care services delivery in Kenya and this may be attributed to initiation of free maternity services. No relationship was seen between the ANC attendance and severity of MR. This means that those who attended less and those who attended as required suffered the same predicament. This points out to the need of evaluation of health education given to the mothers on prevention of disease/conditions during ANC.

Tobacco smoking and use of alcohol during pregnancy was found to be a major risk factor for developing MR in the offspring (Huang *et al.*, 2016, Goli, Moniri & Wilhelm, 2016). In this study, alcohol use and tobacco smoking during pregnancy were not found to be associated with the severity of MR. Contrary, O'leary *et al.* (2013), in their population based study to examine the association of maternal alcohol use disorder and intellectual disability, found that children of mothers with an alcohol-related diagnosis recorded during pregnancy had three times increased risk of intellectual disability than others. Unexpectedly, inverse association with severity of MR was found in mothers who reported living in the environment where people smoke.

About 28.9% of mothers reported to have taken drugs. In the bivariate logistic regression analysis, the use of drugs during pregnancy was significantly increasing the likelihood of severe/profound MR (OR=4.17, CI=1.46-11.87, P=0.006) compared to the mothers who reported otherwise. Nonetheless, this factor was not found to be statistically significant in the multivariate logistic regressions analysis (AOR=3.92, CI=0.70-21.97, P=0.120). Use of

teratogenic drugs during early pregnancy could affect brain development (Kliegman *et al.*, 2016) hence increasing the risk of developing intellectual disability of the child.

5.1.3. Environmental factors and mental retardation

5.1.3.1. Perinatal and neonatal history

Almost all children (92.8%) were delivered at health facilities with majority (72.2%) being delivered at gestational age over 37 weeks. No significant association was found between severity of MR and both place of delivery and gestational age. Most (76.3%) of children were born via spontaneous vaginal delivery. Bivariate analysis demonstrated significant association of delivery through cesarean section and MR severity (OR=4.64, CI=1.61-13.38, P=0.005) though this lost its significance in multivariate analysis. This quietly corroborate with results reported by Langridge *et al*., (2013) in which there was an increased risk of intellectual disability (ID) in children born via cesarean section compared to those delivered through a spontaneous vaginal birth and the study by Blider *et al*., (2013) which found significant association of primary/repeat cesarean sections and ID. The present study did not establish which the indications of cesarean sections were. It is however difficult to conclude from this study whether merely cesarean section as mode of delivery is a risk factor for MR. it is therefore necessary to further examine the relationship between the various indications of cesarean section with the incidence of MR.

More than half (52.6%) had obstetrical history of complicated labor. The Children who had history of having complications of labor during their childbirth were having elevated likelihood of severe/profound MR (OR=5.46, CI=1.66-18.2, P=0.003), they had about 10 times risk of severe/profound MR (AOR=9.45, 95%CI=1.23-113.29, P=0.036) compared with others without history of labor complications. This compares with the findings from

other studies (Durkin, Hasan & Hasan, 1998, Maulik *et al.* 2011, Langridge *et al*., 2013) that report positive and significant association of labor and delivery complications and degrees of ID. Labor and delivery complications lead to complications such fetal distress, and birth asphyxia as well as intracranial hemorrhage leading poor neonatal outcomes which later affect child brain development due to damages resulting from hypoxia related to these complications.

Low Apgar scores is risk factor for ID (Blider et al, 2013). In this study, nearly half (49.5%) of the children had history of lower Apgar scores (<7/10). About 46.4% of all children were resuscitated at birth and majority (61.9%) had history of neonatal complications/difficulties with birth asphyxia as main complication. Bivariate analyses, children with histories of lower Apgar score, neonatal complications and resuscitation at birth were with increased risks of having severe-profound MR comparing to their counterparts without these histories (OR=4.41, 95%CI=1.44-13.46, P=0.007, OR=5.57; 95%CI=1.49-20.75; P=0.006 and OR=4.22, CI=1.45-12.29, P=0.006, respectively); though this association lost its significance after multivariate regressions analysis. Comparing to other studies, histories of perinatal difficulties and neonatal resuscitation required at birth were distinctly associated with increased in ID (Durkin, Hasan & Hasan, 1998, Langridge *et al*., 2013). Low Apgar scores indicate poor birth outcomes with need of neonatal resuscitation; thus increased probability of neonatal sequelae which expose the child to develop MR during development period. This supported by evidence from cohort study conducted in Brazil where 13.2% of ID cases were attributed to neonatal sequelae (Karam *et al.,* 2016).

About 40.25% of the children had history of neonatal breathing difficulty, these children had with increased risks of having severe-profound MR (OR=2.97; 95%CI=1.08-8.15; P=0.031) compared to those without such history. About 18.6% had history of neonatal feeding

difficulties and they were having four odds of having severe-profound (OR=3.86; 95%CI=1.23-12.09; P=0.016) compared to their counterparts. However, these associations were not significant in multivariate logistic regressions. Despite that, neonatal breathing difficulties as well as feeding difficulties still contributes to development of MR as they can lead to other complications (including admission to ICU) reported in present study to be associated with MR. Karam *et al.,* (2016) noted that some of the neonatal complications and problems like hypoglycemia, meningitis, anoxia, and other injuries may cause neonatal sequelae resulting in MR.

Almost half (49.5%) of children were admitted to NICU and these children were having 8 times risk to have severe-profound mental retardation (AOR=8.09, CI=2.11-31.07, P=0.002) compared to their counterparts not admitted in NICU. This could be attributed to the fact that labor complications lead to birth difficulties and neonatal complications which increase the probability to be admitted in neonatal intensive care unit or nursery. Being born with birth complications suggests increased risk of debilitating conditions which predict likelihood to be affected with MD.

The present study did not find any significant association between severity of MR and medical histories of neonatal seizures, neonatal infection, and neonatal jaundice. However these conditions could have played role particularly in affecting perinatal outcomes. Contrary, Durkin, Hasan and Hasan (1998) in their study carried out Pakistan reported independent significant association of histories neonatal infections with MR and Maulik *et al.* (2011) indicated neonatal infections among the common postnatal causes.

5.1.3.2. Postnatal history

The history of meningitis, severe malnutrition, head-related injuries and encephalitis were reported in about 35.1%, 14.4%, 12.4% and 8.2%, respectively. Although, there was no significant relationship found between the severity of MR and these childhood medical conditions in the present study, these percentages found are considerable and these medical may have played a role in the development of MR. Further studies are needed to examine the causal risk factors particularly medical conditions and development of MR. Contrary to present findings, a study conducted in Pakistan reported significant independent association of postnatal brain infections, malnourishment, and traumatic brain injuries and mental retardation (Durkin, Hasan & Hasan, 1998). In addition Armatas (2009) indicated traumatic brain injury as one of the main acquired causes of MR.

5.1.4. Co-morbid conditions and mental retardation

Children were reviewed for presence of any co-existing medical and mental-psychiatric co-morbid conditions. Although, there was no association observed between convulsive disorders and severity of MR. Convulsive disorders were the most prevalent co-morbid conditions, occurring in 82.5% of children. This proportion is too high and it may be attributed to increased number of referrals, given that the study setting was a referral hospital. it may also be assumed to be relating to that fact that majority of the studied children were also found to have history of labor related complication that are also known to lead to convulsive disorder as sequelae.

Cerebral palsy was observed in 46.4% of patients. This rate was high compared to a study conducted in India by Aggarwal *et al.* (2010) whereby 12.7% of studied patients were having co-morbid cerebral palsy. Furthermore, findings of the present study indicate an elevated

likelihood to suffer severe/profound MR in children with cerebral palsy than those without. Children with cerebral palsy were twenty-one fold more likely to have severe-profound MR compared to others without it (AOR=21.18, CI=4.18-107.40, P=0.000). This result is supported by early findings which also observed an increased risk of MR in children with cerebral palsy (Camp *et al.*, 1998).

In the current findings the proportion of children with co-morbid attention deficit/hyperactivity disorder (ADHD) is 10.3%. This rate agrees with the review by Shea (2006) that reports a prevalence of ADHD in children with MR to range from 9% to 15%. On the other hand, the present rate (10.3%) found is low compared to the result of a study conducted in Netherlands (Oeseburg et al., 2010) whereby 21.1% of participants were having a co-morbid ADHD. About 20% to 30% of children with MR are estimated to have a co-concurrent ASD (Shea, 2006). In the current study, the co-morbidity of ASD was found in about 10.3% of children. This is quite similar to the findings reported by Oeseburg et al. (2010) whereby 10.9% of participants were found with autistic disorder as co-existing chronic disease to ID. This co-occurrence of those conditions can be explained by the fact that children with ADHD and those with ASD often tend to develop ID thus are referred to hospital due either reason of those conditions.

Other co-morbid conditions observed include pneumonia (28.9%), malnutrition (11.5%), rickets (6.2%), asthma (4.1%), and cardiovascular diseases (3.1%). These proportions can presumably be attributed to the fact most of children studied were recruited at the hospital when they were referred or coming for seeking care of co-morbid conditions or primarily for psychological assessment. Proportion of cardiovascular diseases found in the present study was low compared to that of a study done in Netherlands which reported prevalence of 14 % of cardiac diseases among people with ID (Akker, Maaskant, & Meijden, 2006); though their

study was including individuals of all ages. Raina *et al.* (2016) reported a weakly association with malnutrition and development of MR. Although, there was no statistical significant relationship found between severity of MR and those co-morbid conditions in the present, the development of medical conditions in the child affected by MR can probably worsen the severity of MR in the affected child.

5.2. CONCLUSIONS

The study indicates the characteristics of children with mental retardation attended KNH over period of four months. Child socio-demographic information, parental and environmental factors were determined.

1. The mean age of studied children was 5.6 years (SD±3.6 years) and male children were more affected than female children. Moderate mental retardation was the most prevalent degree of mental retardation among these children.
2. Parental characteristics were not found to be significantly associated with the severity of mental retardation.
3. Environmental factors were mainly related to perinatal and postnatal insults. Children with history of labor complications during their childbirth and those admitted to neonatal intensive care unit during their neonatal period were at higher increased risk of having severe/profound mental retardation.
4. Most prevalent co-morbid conditions were convulsive disorders, cerebral palsy, pneumonia, malnutrition, ADHD, and ASD. Children with cerebral palsy were at a more risk of having severe/profound mental retardation than those without it. No association was found in other co-morbid conditions.

5.3. RECOMMENDATIONS

1. It was shown that children who were having history of labor complications during their childbirth were 10 times more likely to develop severe/profound mental retardation. This indicates the need to strengthen the existing and to redesign new programs with appropriate antenatal, perinatal and neonatal healthcare interventions. This can help to reduce the occurrence of perinatal insults including labor complications thus improving child survival and preventing development of mental retardation.
2. Prevalence of mental retardation in Kenya was not found throughout the literature, there is need for establishing registries for people with mental retardation can assist for appropriate epidemiological surveillance of mental retardation.
3. Based to the present findings of this study, it is important in future to carry out a large longitudinal cohort study to examine perinatal outcomes and its association with intellectual disability while also investigating other causal risk factors.
4. It is also important to study whether there is any relationship between the various indications of cesarean section and the incidence of MR.
5. Large population based study done at community level are also needed to be carried out.

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APPENDICES

APPENDIX 1: STUDY TIME FRAME

Duration of study: Ten months (October 2016 - August 2017)

Time frame:

Activity \ Month	October – December 2016	January 2017	February 2017	March – June 2017	July 2017	August 2017	August 2017
Research proposal writing and submission to supervisor							
Submission to E.R.C							
E.R.C recommendations acted upon							
Training research assistants							
Pre-testing of data collection tools							
Data collection, entry and cleaning							
Data analysis							
Writing report							
Discussion and presentation							

APPENDIX 2: STUDY BUDGET

Component	**Item**	**Unit cost**	**Quantity**	**Total cost**
Supplies and equipments	Pens	20	10	200
	Foolscaps	500	2 reams	1,000
	Printing papers	500	6 reams	3,000
	Flash-disk	1,500	2	3,000
	Modem	3,000	1	3,000
	Printer	7,000	1	7,000
	Ink - Printer	3,000	3	9,000
	Airtime	1,000	10 months	10,000
	Binding	500	4	6000
KNH-UON ERC	Ethical Review – application fees	2000	1	2000
Data collection	Research assistants (2)	1,000	75 days	75,000
Data Analysis process	SPSS installation	1,000	1	1,000
	Biostatistician	30,000	1	30,000
Final report	Binding	1500	8	4,000
	Transport	1000	-	1000
Total				**155,200**
Contingency	**15% of total cost**			**23,280**
Grand total				**178,480**

APPENDIX 3. PARENT PERMISSION/CONSENT INFORMATION SHEET

Investigator: Mathieu Nemerimana

School of Nursing Sciences, University of Nairobi

Mobile Phone no.: **0790484423**

Email: **matnemer@gmail.com**

Hello!

My name is Mathieu Nemerimana. I am a postgraduate student at School of Nursing of the University of Nairobi, pursuing a Master of Science in Nursing (Pediatric). I am carrying out a study on the "**Risk factors for mental retardation among children/adolescents (2-18 years) attending Kenyatta National Hospital**".

You and your child were selected as possible participants in this study because the child was diagnosed with intellectual disability. I would like to invite you to participate in this study. The following information will assist you to make your decision, please take time to read it carefully. Do not hesitate to ask questions or any clarifications for anything you read and find it not clear to you.

What is the purpose of the study?

The main purpose of this study is to identify risk factors that could lead to development of mental retardation among children. It aims at establishing socio-demographic characteristics and determining parental and environmental factors which potentially contribute to development of mental retardation among children/adolescents 2-18 years affected by this condition.

I am conducting this study in partial fulfillment of the requirements for the award of degree of Master of Science in Nursing (Pediatrics) of the University of Nairobi.

Why have you been invited?

You have been invited because you meet the inclusion criteria in the study. All parents of clients who are between 2 and 18 years old attending Kenyatta National Hospital and who their children have been diagnosed with mental retardation are eligible to participate in the study.

What participation means?

Participation in this study is voluntary. If you agree to participate, I will ask you to sign the consent form to show that you agreed to participate. You are free to withdraw from the study at any time. Withdrawing from the study will not, at any point, affect the standard of care that your child will receive in this hospital.

The study involves interviews by which you will be asked questions by the researcher or research assistant and respond to them. The information you provide will be recorded on the questionnaire. The interview will take between 15 and 30 minutes.

The information which you will provide will be strictly kept confidential and will be used only for the purposes of the study. Your names will not be indicated anywhere in the questionnaire.

The patient's medical files will be reviewed to get more information about the child.

What are possible benefits of taking part in the study?

There is no direct or immediate benefit to the participant. However the study will provide baseline information on the risk factors associated development of mental retardation in children. This may be used in developing and putting in place strategies aiming to reduce these causes and factors thus preventing mental retardation.

What will happen on the study findings?

The study findings will be shared with management of Kenyatta National Hospital and will be published in peer reviewed journal.

Will information about my participation be kept confidential?

Any information which is obtained in relation with this study and that can identify you and your child will remain confidential.

Who can I contact in case I have any questions about this study?

If you have any questions, or concerns about this study, you can talk to the researcher (Mathieu Nemerimana, Tel.: 0790484423) or one of following persons:

Contact details:

Supervisors: Dr. Margaret Chege

Tel. **0725555114** Email: **margaret.chege@gmail.com**

Mrs. Eunice Ajode Odhiambo

Tel. **0722358164**

KNH/UON ERC: Tel. **+254-020-2726300** extension **44355**

Email: **uonknh_erc@uonbi.ac.ke**

APPENDIX 4. PARENT PERMISSION/CONSENT INFORMATION SHEET: SWAHILI VERSION

Mtafiti: Mathieu Nemerimana

Shule ya Wauguzi

Chuo Kikuu cha Nairobi

Rununu: **0790484423**

Barua pepe: **matnemer@gmail.com**

Utangulizi: Hujambo! Jina langu naitwa Mathieu Nemerimana, mwanafunzi katika Chuo Kikuu cha Nairobi. Ninafanya utafiti kuhusu vipengele husika kwa ugonjwa wa kutokomaa kwa akili katika watoto kutoka umri wa miaka miwili (2) hadi umri wa miaka kumi na nane (18) ambao wanaonekana katika Hospitali Hii kuu Ya Kenyatta.

Umekaribishwa kushiriki katika utafiti huu. Walakini, maelezo yafuatayo yatakusaidia kumakinika unapotoa idhini yako kushiriki katika utafiti.

Lengo la utafiti

Lengo la utafiti huu ni kutambua vipengee katika mama na mazingara vinavyoweza kuchangia kuibuka kwa maradhi yanayoweza kuzuiwa kukomaa kwa akili katika mototo wa umri wa miaka miwili (2) hadi maika kumi na nane (18) .

Utafiti unalenga kutambua hivyo vipengee kutoka nyumbani vile mama na mtoto wanavyoishi hadi maradhi yanavyo anza ndiposa kuweka mikakati ya kupunguza uwezekano wa watoto kuugua maradhi hayo.

Umehesabiwa kuwa mshirika ufaaye kwa sababu wewe ndiye mzazi wa mtoto anayeugua maradhi hayo.

Kuhusika kushiriki.

Kushiriki ni kwa hiari yako.

Utaulizwa maswali ulipo kuhusu unapo ishi na maswali mengine.. Kujibu maswali kutachukua muda wa dakika 15 hadi 30.

Habari utakazopeana zitalindwa zisiweze kupatikana na watu wasiohusika kwa utafiti na habari yako haitaweza kutambulishwa nawe.

Unao uhuru wa:

1. Kushiriki au kutoshiriki.

2. Kujibu maswali uko sawa kwayo.

3. Kusitisha kushiriki wakati wowote na habari yako italindwa na kuharibiwa.

Faida za utafiti

Majibu utakayopeana yatasaidia kutambua yaliyochangia kuugua kwa mtoto ndiposa tuweze kuzuia.

Matokeo ya utafiti yataweza kutumika kuelekeza maamuzi kuhusu kutambulikana kwa mapema kwa uwezekano wa ugonjwa kutokelezea na kuzuia hayo maradhi kwa mapema katika mlengo wa juu serikalini.

Kutoa habari kujihusu na mtoto ndio madhara yanayotarajiwa.

Kwa habari na maelezo zaidi, una uhuru wa kuulizia,

Mwalimu wangu: Daktari Margaret Chege

Shule ya wauguzi, Chuo Kikuu Cha Nairobi.

Barua Pepe : margaret.chege@gmail.com

Rununu: 0725555114

Au

Bi. Eunice Ajode Odhiambo

Shule ya wauguzi

Chuo Kikuu Cha Nairobi.

Rununu. **0722358164**

Au

KNH/UON ERC: simu. **+254-020-2726300** ext **44355**

Barua pepe: **uonknh_erc@uonbi.ac.ke**

APPENDIX 5. PARENT PERMISSION/INFORMED CONSENT FORM: ENGLISH VERSION

I (Serial number)……do agree to participate in the study on "risk factors for mental retardation among children/adolescents (2-18 years) attending Kenyatta National Hospital", which purpose, benefits and risks has been explained to me.

I have been explained and understand that taking part of this study is voluntary and that I can withdraw at any point I find appropriate to do so

I understand that there is no financial benefits are provided.

I have been informed that my participation in this study is confidential, my information and information regarding my child will be confidentially maintained and my no material will identify me personally or my identity and identity of my child will appear to any report.

I consent that the research staff collect information from me and information about the health of my child.

I therefore consent to participate in the study,

_____ _____

Signature/Thumb Print of Parent Date

In presence of Researcher/Research Assistant:

_____ _____ _____

Name Signature Date

APPENDIX 6. PARENT PERMISSION/INFORMED CONSENT FORM: SWAHILI VERSION

Mimi (numbari ya siri) ……..…… natoa idhini yangu kwa hiari kushiriki katika utafiti ambao nimeelezewa lengo, faida na madhara yake. Nimejulishwa kwamba kushiriki kwangu ni kwa hiari na hakuna faida zozote za kifedha nitapokea.

Nimejulishwa pia kwamba ujumbe nitakaotoa utawekwa kisiri na hautaweza kutambulishwa nami. Nafahamu naweza kusitisha kushiriki kama itafaa kwa wakati wowote.

Hivyo basi natoa idhini yangu na ya mtoto wangu kushiriki katika utafiti utakaosaidia kutambua vipengele husika katika kusababisha maradhi ya kutokomaa kwa akili kwa watoto, kwa hiari yangu**.**

Sahihi ya mshirika…….

Tarehe……....

Jina la mtafiti……Sahihi…….

Tarehe……..

APPENDIX 7. ASSENT FORM FOR CHILDREN ABOVE 12 YEARS OF AGE: ENGLISH VERSION

Hello! My name is Mathieu NEMERIMANA, a post-graduate student at the school of nursing sciences, in the University of Nairobi.

1. I want to learn more about the risk factors leading to mental retardation among children aged 2 – 18 years attending Kenyatta National Hospital in Kenya.

2. You are being invited to join the study because you are one of the children with intellectual disability and within the age of 2 - 18 years. At least 97 children will be participating in this research study with you.

3. If you decide that you want to be part of this study, I will ask questions regarding your health to your parent/guardian to get more information about your health history, and I will review your medical files.

4. There will be indirect benefit for anyone who takes part in this study. Information from this study shall help to planning measures to prevent and reduce number of children affected by mental retardation.

5. The information which will be collected about you will be kept confidential.

6. When I am finished with this study I will write a report about what was learned. This report will not include your name or that you were in the study.

7. Your parents know about the study too. Your participation is voluntary; you can decide not to be part of this study. If you refuse, you will still have medical care which you have come for today.

8. If you decide you want to be in this study, please sign your name.

I, _____, hereby accept to be in this research study.

Child's signature/Thumb stamp _____ Date _____

Person obtaining Assent _____ Signature _____ Date _____

APPENDIX 8. ASSENT FORM FOR CHILDREN: SWAHILI VERSION

Hujambo! Jina langu naitwa Mathieu NEMERIMANA, mwanafunzi baada ya kuhitimu katika shule ya sayansi ya uuguzi, katika Chuo Kikuu cha Nairobi.

1. Nataka kujifunza zaidi kuhusu mambo ya hatari na kusababisha ulemavu wa akili miongoni mwa watoto wenye umri wa miaka miwili (2) hadi umri wa miaka kumi na nane (18) ambao wanaonekana katika Hospitali Hii kuu ya Kenyatta.

2. Wewe ni kuwa walioalikwa kujiunga utafiti kwa sababu wewe ni mmoja wa watoto wenye ulemavu wa akili na ndani ya umri wa miaka miwili (2) hadi umri wa miaka kumi na nane (18). Kwa uchache watoto tisini na saba (97) itakuwa kushiriki katika utafiti huu na wewe.

3. Kama kuamua kwamba unataka kuwa sehemu ya utafiti huu, nami kuuliza maswali kuhusu afya yako kwa mzazi / mlezi wako ili kupata taarifa zaidi kuhusu historia yako ya afya, nami kupitia mafaili yako ya matibabu.

4. Kutakuwa na moja kwa moja faida kwa mtu yeyote ambaye anashiriki katika utafiti huu. Taarifa kutoka utafiti huu atakuwa kusaidia mipango hatua za kuzuia na kupunguza idadi ya watoto walioathirika na matatizo ya kiakili.

5. maelezo ambayo itakuwa zilizokusanywa kuhusu wewe itakuwa siri.

6. Wakati mimi kumaliza na utafiti huu nitaandika ripoti kuhusu kile kujifunza. Ripoti hii si pamoja na jina lako au kwamba walikuwa katika utafiti.

7. Wazazi wako kujua kuhusu utafiti pia. ushiriki wako ni wa hiari; unaweza kuamua si kuwa sehemu ya utafiti huu. Ukikataa, bado utakuwa na huduma ya matibabu ambayo umekuja kwa leo.

8. Kama kuamua unataka kuwa katika utafiti huu, tafadhali ishara jina yako.

Mimi, _____, hili kukubali kuwa katika utafiti huu.

Mtoto sahihi / Thumb stempu _____ Tarehe _____

Mtu kupata kutiwa saini na _____Sahihi _____ Tarehe ____

APPENDIX 9. KEY INORMANT INTERVIEW CONSENT FORM FOR HEALTH PROFESSIONNAL

Hello! My name is Mathieu Nemerimana. I am a postgraduate student pursuing Master of Science in Nursing (Pediatrics) at the School of Nursing Sciences, of the University of Nairobi.

I am carrying out a study on "risk factors for non-genetic mental retardation among children attending Kenyatta National Hospital". I am inviting you to participate in this study.

The main purpose of this study is to investigate non-genetic risk factors associated with development of mental retardation among children attending KNH. The findings from this study are expected to provide baseline information on the non-genetic risk factors associated with occurrence of mental retardation in Kenya and this may help in designing strategies and policies to prevent this condition and reduce number of children being affected with mental retardation.

If you decide to participate, I will have an interview session with you which will take about 15-20 minutes. You will be asked questions about your experience concerning the causes and factors of mental retardation.

The interview session will be audio-recorded. At the end of this session, the audio-recorded information will be replayed to you for confirmation. Thereafter the information will be transcribed by researcher for analysis.

The information you will be provided will not be linked to you. Your name will not appear in any way during the interview process. Whatever you say during this discussion will be kept confidential.

If you accept to be part of this study, please sign your name.

I, _____, want to be in this research study.

(Signature) _____ (Date) _____

APPENDIX 10. STUDY QUESTIONNAIRE

Title of Study: **"Risk factors for non-genetic mental retardation among children aged 2-18 years attending Kenyatta National Hospital"**

Serial Number: …….. Date: …….

Instructions: Thank you for accepting to respond to my questions and for your time. This session will take around 15 and 30 minutes. You will be interviewed as well as your answers being recorded as they are on the questionnaire. Thank you

Interviewee: Mother [ ] Father [ ]

A: Child socio-demographic information;

1. Age of the child _____

2. Gender:
    1. Male [ ]
    2. Female [ ]

3. Degree of mental retardation:
    1. Mild [ ]
    2. Moderate [ ]
    3. Severe [ ]
    4. Profound [ ]

4. Family setup:
    1. Both parents [ ]
    2. Single Mother [ ]
    3. Orphan/adopted [ ]
    4. Abandoned [ ]

5. What is the number of children in the family? _____
    1st born – Age ……..
    2nd born – Age ……
    3rd born – Age ……
    4th born – Age ……

6. Does anyone in of the siblings have a history of mental retardation?

1. yes [ ]
2. No [ ]

6.1. If yes, who? Which degree? _____

B. Birth History

7. Where did you deliver this baby?

1. At Health facility [ ]
2. At home [ ]
3. On way to the hospital [ ]

7.1. If it was not in the health facility, who assisted in the birth?

1. Self [ ]
2. Traditional birth assistant [ ]
3. Others, explain: _____

7.2. If not at the health facility, what were the reasons? Please explain:

_____

8. At what gestational age was this child born?

1. 20 – 32 weeks [ ]
2. 23 – 37 weeks [ ]
3. Over 37 weeks [ ]

9. How long did labor take? (Duration of labor, in hours) _____

10. Was the labor with complications?

1. Yes [ ]
2. No [ ]

10.1. If yes, which type of complication? Explain: _____

11. What was the mode of delivery?

1. Spontaneous vaginal delivery [ ]
2. Assisted Vaginal delivery [ ]
3. Cesarean section [ ] Indication _____

12. What was the birth weight of this child? _____kg

13. What was the APGAR score at birth? _____

1. ≤7/10 [ ]
2. >7/10 [ ]
3. If not known explain the status of the baby at birth
    1. Cried immediately [ ]
    2. Did not cry [ ]

14. Was the baby resuscitated at birth?

1. Yes [ ]
2. No [ ]

14.1. If yes, for how long? _____

15. Were there any neonatal difficulties/complications at birth?

1. Yes [ ]
2. No [ ]

15.1. If Yes, Specify:

1. Birth asphyxia [ ]
2. Birth trauma [ ]
3. Prematurity [ ]
4. Low birth weight [ ]
5. Congenital malformations [ ] Specify: _____
6. Other Neonatal complications (specify)_____

    _____

    _____

16. Was the baby admitted in nursery?

1. Yes [ ]
2. No [ ]

16.1. If yes, how long did he/she spend in hospital? _____

17. After birth, did the child suffer from any of the following conditions?

1. Neonatal breathing difficulty [ ]
2. Neonatal seizures [ ]
3. Neonatal infection [ ]
4. Neonatal jaundice [ ]
5. Neonatal feeding difficulties [ ]
6. Other (specify): _____

18.1. If there was neonatal feeding difficulties, after how long did baby feed? Please explain:

_____

19.2. What was the baby fed on? _____

C: Infant and childhood medical history

20. Immunization history

1. Fully immunized [ ]
2. Not fully immunized [ ]
3. Never immunized [ ]

21.1. If not/not fully immunized, why? Explain: _____

22. Did the child suffer from any of the following Infections?

Disease/condition	YES	No
Measles infection		
Meningitis		
Encephalitis		
Cerebral Malaria		
Others (specify): …….. …… …….		

23. History of head injury?

1. Yes [ ]
2. No [ ]

24.1. If yes, how did this happen? Explain: _____

24.2. Where was the child treated and how? Please explain _____

25. History of near drowning?

1. Yes [ ]
2. No [ ]

25.1. If yes, how did this happen? Explain: _____

25.2. Where was the child treated and how? Please explain _____

26. History of poisoning?

1. Yes [ ]
2. No [ ]

26.1. If yes, which type of poisoning? _____

26.2. How did this happen? Explain: _____

26.3. Where was the child treated and how? Please explain _____

27. History of severe malnutrition?

1. Yes [ ]
2. No [ ]

27.1. If yes: at what age _____

28. Breastfeeding history:

1. Never Breastfed [ ]
2. Breastfeed <1 month [ ]
3. Breastfeed 1–24 months [ ]
4. Breastfeed >24 months [ ]

28.1. If never breastfeed why? Please explain: _____

D: Preexisting and co-morbid conditions

29. Did the child suffer from the following conditions before she/he suffer mental retardation?

Condition	**Yes**	**No**
1. Cerebral Palsy		
2. Convulsive disorders		
3. Thyroid disorder		
4. Endocrine disorders, specify: ……		
5. Cardiovascular disease		
6. Asthma		
7. Pneumonia		
8. Malnutrition		
9. Other(s) Specify: ……..		

30. Did the child suffer from the following mental/psychiatric conditions?

Condition	**Yes**	**No**
1. Autism Spectrum Disorder (ASD)		
2. Attention Deficit/Hyperactivity Disorder (ADHD)		
3. Depression		
8. Other(s) Specify: ……..		

E: Parental socio-demographic data and characteristics

E.1. Maternal information

31. Age of the mother _____

1. Below 20 years [ ]
2. 21 – 35 years [ ]
3. ≥ 36 years [ ]

32. Age of the mother (at the time of birth of the child)

1. Below 20 years [ ]
2. 21 – 35 years [ ]
3. ≥ 36 years [ ]

33. Highest level of education of the mother

1. No formal education [ ]
2. Primary level [ ]
3. Secondary level [ ]
4. College/university Level [ ]

34. Occupation of the mother

1. Regular employment [ ]
2. Casual employment [ ]
3. Unemployed [ ]

35. What is the average monthly income in the family (in Kenyan Shillings)?

1. Less than 10,000 [ ]
2. 11,000 to 20,000 [ ]
3. 21,000 to 50.000 [ ]
4. More than 50,000 [ ]

E.2: Pregnancy history

36. Did you attend ANC during pregnancy of this child?

1. Yes [ ]
2. No [ ]

37.1. If yes, how many times did you visit the Antenatal Clinic (ANC)?

1. 1-2 times [ ]
2. 3- 4 times [ ]

37.2. If no, why did you not attend the ANC? _____

38. Did you have any of following medical conditions during pregnancy?

1. Preeclampsia [ ]
2. Diabetes Mellitus [ ]
3. Hypertension [ ]
4. Urinary tract infections [ ]
5. Prolonged fever [ ]
6. Other(s) specify [ ]: _____

38.1. If yes, were you treated? Please explain _____

39. Did you take any drugs during pregnancy?

1. Yes [ ]
2. No [ ]

40. If yes, which medications did you take during pregnancy?

_____

_____

_____

41. At what age of pregnancy the medications were given? _____

42. History of exposure during pregnancy:

To what extent were exposed to the following?

Exposure	**Never**	**rarely**	**sometimes**	**often**	**always**
1. Active smoking during pregnancy					
2. Living in environment where people smoke					
3. Using alcohol during this pregnancy					

E.3. Paternal information

43. Age of the father _____

1. Below 20 years [ ]
2. 21 – 35 years [ ]
3. ≥ 36 years [ ]

44. Age of the father (at the time of birth of the child)

1. Below 20 years [ ]
2. 21 – 35 years [ ]
3. ≥ 36 years [ ]

45. Highest level of education of the father

1. No formal education [ ]
2. Primary level [ ]
3. Secondary level [ ]
4. College/university Level [ ]

46. Occupation of the father

1. Regular employment [ ]
2. Casual employment [ ]
3. Unemployed [ ]

47. Does the father smoke?

1. Yes [ ]
2. No [ ]

Thank you for your participation

Data Collected by: _____

APPENDIX 11. KEY INFORMANT INTERVIEW TOOL

Title of Study: "Risk factors for non-genetic mental retardation among children aged 2-18 years attending Kenyatta National Hospital"

Thank you for accepting to participate in this study. We are going to discuss questions regarding the factors associated with development Mental retardation (referred as Intellectual Disability (ID) among children. This session will take about 15 to 30 minutes. Thank you.

1. What are the common demographic characteristics associated with non-genetic mental retardation among children attending K.N.H

   ---

2. You have been caring some of the children who present with mental retardation in this unit, what have you noted in the interaction of these child as the environmental factors do you see contributing to development of non-genetic mental retardation among children you receive at K.N.H?

   ---

3. What have you seen as the parental factors associated with non-genetic mental retardation among children received here at K.N.H?

Thank you for your time.

APPENDIX 12: APPROVAL LETTER FROM KNH/UON-ERC

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

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

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

KENYATTA NATIONAL HOSPITAL APPROVED 06 FEB 2017 KNH/UoN-ERC P.O. Box 20723-00202 Nairobi

Ref: KNH-ERC/A/41

6th February 2017

Mathieu Nemerimana
Reg. H56/82636/2015
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Mathieu

REVISED RESEARCH PROPOSAL: "RISK FACTORS FOR NON-GENETIC MENTAL RETARDATION AMONG CHILDREN AGED 2-18 YEARS ATTENDING KENYATTA NATIONAL HOSPITAL (P961/12/2016)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above revised proposal. The approval period is from 6th February 2017 – 5th February 2018. Approval is also granted for waiver of informed consent/assent.

This approval is subject to compliance with the following requirements:

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

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

Protect to discover

APPENDIX 13: PERMISSION LETTER TO COLLECT DATA IN PEDIATRIC DEPARTMENT

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

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

Ref: KNH/PAEDS-AD/48 Vol.I

Date: 17th February 2017

Mathieu Nemerimana
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Mathieu

RE: PERMISSION TO COLLECT DATA IN PAEDIATRICS DEPARTMENT

Following approval by the KNH/UON-Ethics & Research Committee for your Research Proposal, this is to inform you that authority has been granted to collect data in **Paediatrics Department,** on your study titled ***"Risk factors for non-genetic mental retardation among children aged 2-18 years attending Kenyatta National Hospital".***

Kindly liaise with the Senior Assistant Chief Nurse Paediatrics for facilitation and forward to this office a report of your findings.

DR. IRENE INWANI
HEAD OF DEPARTMENT, PAEDIATRICS

Cc. Senior Assistant Chief Nurse, Paediatrics

APPENDIX 14: PERMISSION TO COLLECT DATA IN MENTAL HEALTH DEPARTMENT

KNH/R&P/FORM/01

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

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

Study Registration Certificate

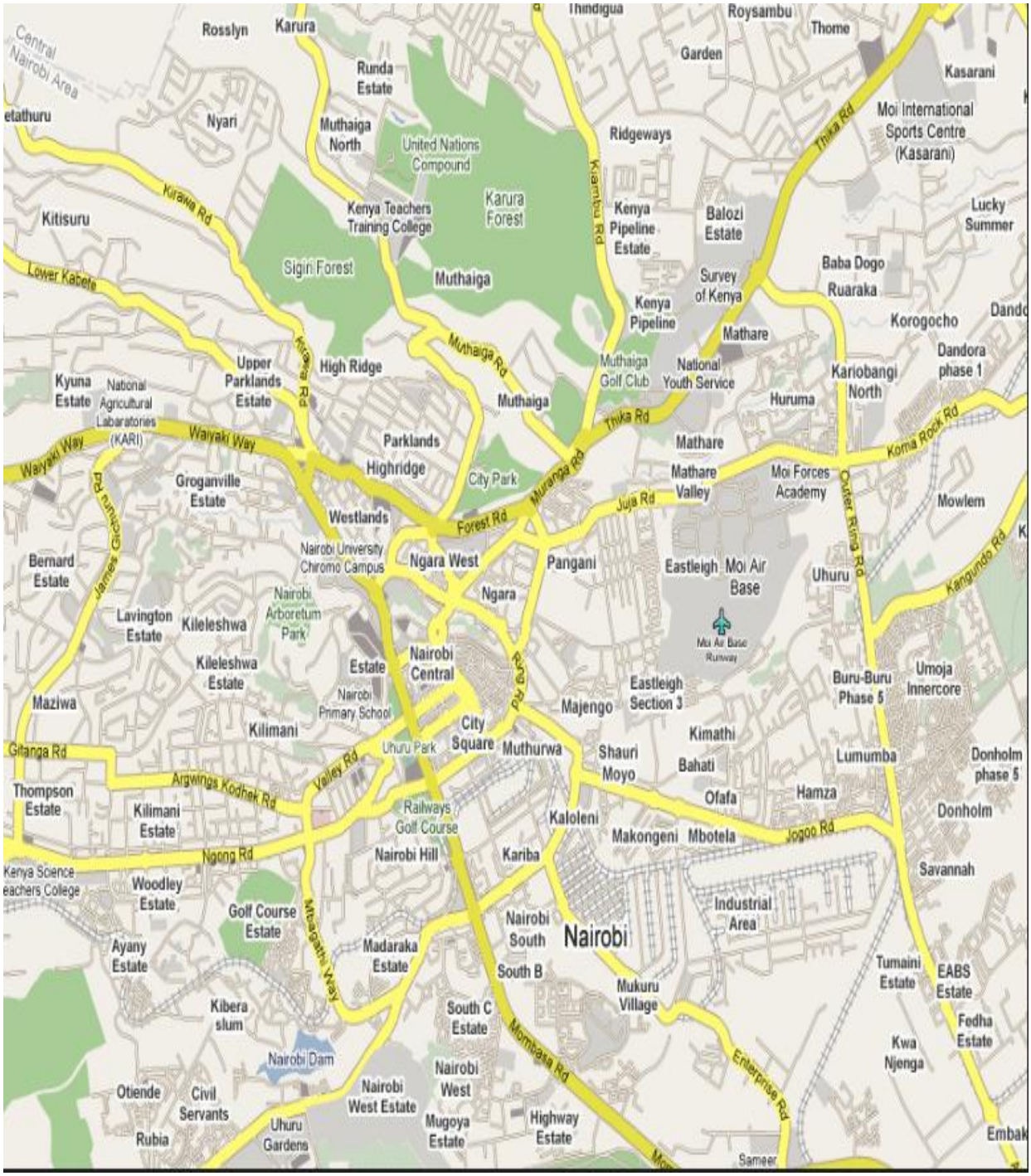
1. Name of the Principal Investigator/Researcher
   NZUZIRIMANA MATHIEU
2. Email address: Matnzmer@gmail.com Tel No. 0790484423
3. Contact person (if different from PI).....
4. Email address: ..... Tel No. .....
5. Study Title
   RISK FACTORS FOR NON-GENETIC MENTAL RETARDATION AMONG CHILDREN AGED 2-18 YEARS ATTENDING KENYATTA NATIONAL HOSPITAL.
6. Department where the study will be conducted Pediatrics and mental Health
   (Please attach copy of Abstract)
7. Endorsed by Research Coordinator of the Department where the study will be conducted.
   Name: ..... Signature ..... Date .....
8. Endorsed by Head of Department where study will be conducted.
   Name: Dr P.A. Kegamba Signature ..... Date 12.4.2017
9. KNH UoN Ethics Research Committee approved study number _____
   (Please attach copy of ERC approval)
10. I NZUZIRIMANA MATHIEU commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.
    Signature..... Date 16/02/2017
11. Study Registration number (Dept/Number/Year) MENTAL HEALTH/ 6 /2017
    (To be completed by Research and Programs Department)
12. Research and Program Stamp _____

KENYATTA NATIONAL HOSPITAL H.O.D. RESEARCH & PROGRAMS 19 APR 2017 P.O. Box 20723 NAIROBI

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

Version 2: August, 2014

APPENDIX 15: MAP OF NARIOBI COUNTY



Source: http://ictville.com/wp-content/uploads/2012/09/googlemaps-nairobi.gif

APPENDIX 16: MAP OF KENYATTA NATIONAL HOSPITAL

https://www.google.com/maps/place/Kenyatta+National+Hospital

Turnitin Originality Report

RISK FACTORS FOR NON-GENETIC MENTAL RETARDATION AMONG CHILDREN AGED 2 – 18 YEARS ATTENDING KENYATTA NATIONAL HOSPITAL by Mathieu Nemerimana

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