DETERMINANTS OF CONGENITAL ANOMALIES AND THEIR EFFECT ON AFFECTED MOTHERS: A CASE OF KENYATTA NATIONAL HOSPITAL, NEWBORN UNIT

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DECLARATION

I, Ruth Wagathu, student at the University of Nairobi (UON), School of Nursing Sciences, hereby declare that this dissertation is my original work and has not been submitted anywhere else by any other person(s) for research purpose or award of any degree or otherwise.

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DEDICATION

I dedicate this work to my loving husband and friend, Alex Mwangi, and our beautiful daughter Eden. You make my life so beautiful.

To my parents; thank you for sowing the seed of education in me. I am eternally grateful.

To all mothers of babies with congenital anomalies, you are stronger that you think.

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OPERATIONAL DEFINITIONS

Affected mothers Mothers who have sired children with congenital anomalies

Consanguineous marriage A matrimony between individuals who are closely related.

Determinants Variables that have the potential of causing congenital anomalies

High Risk Pregnancy A condition where the mother or developing fetus or both are at increased risk of complicating during or after pregnancy and birth.

Mother A woman who has given birth.

Newborn This is an infant in the first 28 days after birth

Newborn Unit This is a unit specialized in taking care of ill and premature neonates

Preterm Born before 37 completed weeks of gestation

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LIST OF ABBREVIATIONS

ANC	Ante-Natal Care
ARVs	Ante-Retro Virals
CA	Congenital Anomaly
CDC	Centres for Disease Control
CHD	Congenital Heart Disease
CNS	Central Nervous System
CTEV	Congenital Talipes Equino-Varus
CVS	Cardiovascular System
DALY's	Disability Adjusted Life Years
GIT	Gastrointestinal Tract
HRP	High Risk Pregnancy
ICD	International Classification of Diseases
KDHS	Kenya Demographic Health Survey
KNH	Kenyatta National Hospital
MCA	Multiple Congenital Anomalies
MDG	Millennium Development Goal
MOH	Ministry of Health
MTRH	Moi Teaching and Referral Hospital
NBU	New Born Unit
NICU	Neonatal Intensive Care Unit
PDA	Patent Ductus Arteriosus
PMH	Pumwani Maternity Hospital
SDG	Sustainable Development Goals
SPSS	Statistical Package for Social Sciences
UON	University of Nairobi
WHO	World Health Organization

ABSTRACT

Background: Congenital anomalies are defects of structure, function or metabolism that are present at birth. It is estimated that 3-7% of children worldwide are born with congenital anomalies. With advanced medical and neonatal care, infant mortality related to sepsis, respiratory diseases and asphyxia has steadily declined. This makes congenital anomalies an important cause of neonatal mortality. Despite this information, limited studies have been done in Kenya to establish determinants of congenital anomalies and their effect on affected mothers

Study objective: The objective of this study was to describe the determinants of congenital anomalies and their effect on affected mothers.

Methodology: This was a hospital based descriptive, cross-sectional study design; which utilized both qualitative and quantitative approaches. 55 respondents were recruited for this study; 52 neonates (Fishers formula) and 3 Key Informants. Some of the 52 were recruited for In-depth interviews (data saturation method). A researcher-administered questionnaire and an interview guide were used to collect data. Data from structured questionnaires was entered, checked, cleaned and analyzed using SPSS version 20. Descriptive analysis using means, frequency and proportions was computed. Qualitative data was analyzed thematically using N-Vivo software.

Results: Analysis of the data showed that among the 315 neonates admitted in NBU, KNH, the prevalence of Congenital Anomalies (CAs) was 19.4%. The Musculoskeletal system was the most affected (38.5%). 88.4% of the mothers were below 35years of age and 61.5% were not working. The prevalence of CAs was more among neonates born vaginally. Four themes were narrated: Knowledge, Reaction, Support from social environment and support from heath care system.

Conclusion: KNH and MOH should mobilize more resources to combat this burden because of the high prevalence of birth defects recorded. The public should be educated on risk factors of CAs. Social and psychological support should be offered to affected mothers.

CHAPTER ONE: INTRODUCTION

1.0 INTRODUCTION

This chapter introduces the orientation of the study. The following will be discussed: definitions and classification of congenital anomalies, background of the problem, statement of the problem, purpose, justification and significance of the study, the overall objective of the study as well as specific objectives.

1.1 DEFINITIONS AND CLASSIFICATION OF CONGENITAL ANOMALIES

According to the Online Etymology Dictionary, Teratology is the study of abnormalities of physiological development. This word stems out of two Greek words: *teras,* meaning 'monster', and *logos*, meaning 'study of'.

The International Classification of Diseases (ICD) 10th edition and World Health Organization (WHO) define Congenital Anomaly (CA) as an anomaly that has an effect on a body part or interferes with the physiological function. It is also present at birth. The types of anomalies defined are:

Malformation: It is as a result of unusual development of the organ/tissue, which is abnormal from the onset.
Disruption: It is prompted by a destructive process that affects an organ/tissue which had initially developed normally.
Deformation: It is secondary to an abnormal physical force that destroys healthy organ/tissue.
Dysplasia: It is caused by an anomalous organization of the cells in an organ.

Congenital anomalies are also described in terms of association:
Isolated anomaly: This is an anomaly that has no relationship with any other conditions (e.g. isolated extra digits).
Sequence: These are multiple malformations that result from the pathologic sequence caused by a primary insult (e.g. Potter's sequence).
Association: These are selected defects that develop all together – in an association (e.g. VATER association).
Syndrome: These are complex of phenotypic traits (e.g. Down syndrome).

According to ICD 10-WHO, Congenital Anomalies are classified as follows:

i. Congenital malformations of the nervous system
ii. Congenital malformations of eye, ear, face and neck
iii. Congenital malformations of the circulatory system
iv. Congenital malformations of the respiratory system
v. Cleft lip and cleft palate
vi. Other congenital malformations of the digestive system
vii. Congenital malformations of genital organs
viii. Congenital malformations of the urinary system
ix. Congenital malformations and deformities of the musculoskeletal system
x. Other congenital malformations
xi. Chromosomal abnormalities, not elsewhere classified

1.2 BACKGROUND INFORMATION

WHO (2012) defines Congenital Anomalies as functional, metabolic and even structural deficiencies that may be isolated or multiple in nature; and are existing at birth. Some of the congenital malformations may be fatal, and may damage the physical and mental ability of an individual. These abnormalities are due to multiple etiological factors (Khan et al., 2012).

Congenital anomalies can be categorized into two; major and minor anomalies. Major congenital anomaly is defined as a structural abnormality present at birth which has a significant effect on function or social acceptability; examples: cleft lip, spina bifida. Minor congenital anomaly is defined as a structural abnormality present at birth, has minimal effect on clinical function but may have a cosmetic impact, e.g., pre-auricular pit (Gillani et al., 2011).

Birth defects are a major contributor to perinatal and infant morbidity and mortality. The impact is severe in countries of low socio-economic status (Jamison et al., 2006). It is estimated that 270,000 neonates die during the neonatal period annually from birth defects (Organización Mundial de la Salud, 2008). Actually, about 95% of infants who die from congenital anomalies are from these poor countries (King, 2008).

Previously, the causes of the infant mortality used to be traced mostly in the prevalence of infectious diseases. The introduction of the new antibiotics and advances made in the field of preventive medicine and immunology has arrested this trend, and it has been concluded that

infancy deaths were more due to malformations than infectious diseases (Singh and Gupta, 2009a).

Worldwide, there are variations in the incidence of congenital anomalies and related infant mortality between geographical regions. As a rough calculation, it has been recorded that 3-7% of infants are diagnosed with birth defects (Rosano et al., 2000). In the United States of America, the prevalence of birth defects is 2-5% of all babies born alive (Sekhobo, 2001). The outlined prevalence of CAs in Asia is 0.88% in India (Parmar et al., 2010) and 844.2 per 10,000 births in China (Zheng et al., 2007). Consanguineous marriages, a practice common in the middle east is associated with increased incidence of anomalies (Parmar et al., 2010). In Iran, 2.8% of the anomalies reported were from familial marriages as compared to 0.9% from non-familial marriages (Tayebi et al., 2010a).

Few reports on the prevalence of congenital anomalies in Africa exist. This may be due to various reasons which include: underreporting, deficiencies in diagnostic capabilities and poor follow-up for examinations in the postnatal period (Ndibazza et al., 2011a). Nigeria records a prevalence of 2.8% (Daly et al., 2010) while in South Africa its 1.1% (Delport et al., 1995)

In East Africa, Tanzania has recorded the highest prevalence rate of anomalies of 29% (Mashuda et al., 2014a). Uganda reported a prevalence of 7.6% (Ndibazza et al., 2011a) while in Kenya, reported prevalence of externally discernible malformations is 28.1 per 1000 total births (Muga et al., 2009). `.

Most of the causes of birth defects in humans are idiopathic. According to WHO (2012), approximately 50% of all birth defects cannot be linked to a specific cause. Maternal illnesses like diabetes mellitus and rubella, folic acid deficiency, consumption of medicinal and recreational drugs like thalidomide and tobacco respectively, certain environmental chemicals and high doses of radiation are factors that can cause birth defects (El Koumi et al., 2013a).

The pattern of birth defects varies from an area to another and also difference in time. In general, birth defects involving the musculoskeletal and central nervous systems have been reported to be the most common (El Koumi et al., 2013b).

A newborn baby is considered the beginning of hopes and dreams, and becoming parents is one of life's greatest joys. Siring a child with birth defect challenges those dreams (Singh and

Ghimire, 2017). Presence of rare and multiple congenital anomalies in an infant are recognized as a source of stress to parents, family and society at large. This is associated with greater parenting challenges. However, there isn't much data to illustrate how families of children with these conditions deal with stress (Okuyama et al., 2017).

1.3 PROBLEM STATEMENT

Neonatal mortality from sepsis, birth asphyxia and respiratory disease has steadily declined due to improvements in obstetric and neonatal care. This has led to birth defects being a significant cause of perinatal mortality and morbidity (Parmar et al., 2010). Congenital malformations are also known to cause long-term disabilities. This may cause a remarkable effect on a child's health and development, as well as on other stake holders (King, 2008).

Birth defects account for 9% of the surgical burden of disease; and this contributes to the disability experienced by 150 million children globally (World Health Organization and World Bank, 2011). These disabilities represent a burden placed on child development and family responsibilities, and they cause and result to poor socioeconomic status (Velayutham et al., 2016). In Kenya, a survey to demonstrate the Burden of Surgical Congenital Anomalies showed that the overall prevalence of congenital malformations was 6.3per 1000 children, amounting to 54–120 disability-adjusted life years (DALYs) per 1000 children (Wu et al., 2013)

Kenya as a country is still ranked as a low-income earner by the World Bank Group. As a matter of fact, it had comparable under-5 mortality rates in relation to the numbers quoted by the World Health Organization (WHO) for low-income countries.

According to Kenya Demographic Health Survey (KDHS) 2014, the Millennium Development Goals (MDGs) for maternal and child health were not achieved.

Globally, there is a lot of published information on prevalence, risk factors and effects of siring a child with congenital anomalies. Giving birth to a child with congenital anomalies is source of stress to the parents (Mazer et al., 2008a). Given this high levels of stress among parents with congenitally abnormal children, the problem of their psychological neglect makes them vulnerable to stress outcome as they may not have any coping mechanism in place, like it is in Kenya.

In Kenya, there is little empirical data on this subject. For instance, statistics from Kenyatta National Hospital indicate occurrence of congenital anomalies but little is documented on the risk factors and effect of congenital anomalies. The study therefore seeks to explore the determinants of congenital anomalies and their effect on affected mothers.

1.4 JUSTIFICATION

The Kenyatta National Hospital (KNH) located in Nairobi, Kenya, is the biggest referral hospital in East and Central Africa. Apart from its environs in Nairobi, KNH serves patients from all over the country and beyond; and therefore has a large catchment area. Neonates born with congenital anomalies are referred from far and wide to KNH for specialized care. Therefore, this makes it the ideal study area as its subjects are a true representation of the whole population.

According to KDHS (2014), the neonatal mortality rate in Kenya is 22 deaths/1000 live births. The report indicates that there has been a decline in early childhood mortalities. However, Neonatal mortality has exhibited the slowest rate of decline. According to a report by The Maternal and Child Health report, approximately 35% of under-5 mortalities occurred during the neonatal period; 33% of all neonatal mortalities are secondary to severe infections, followed by perinatal asphyxia, preterm deliveries and birth defects.

A study done at the Moi Teaching and Referral Hospital (MTRH), Kenya's second largest referral hospital showed that congenital malformations ranked fourth in causes of neonatal mortality (Yego et al., 2013).

In KNH, there isn't a recent study on this topic.

It is against this background that a quantitative and qualitative study would be done as a prerequisite to the initiation of prevention of congenital anomalies, and psychological coping mechanism for these parents.

1.5 SIGNIFICANCE OF THE STUDY

Results from this study will act as a baseline for the development of policy frameworks in prevention and combating the rising incidence of congenital anomalies by the Ministry of Health. It is important to conduct such a study as it will contribute to the national, regional and global knowledge bank on care to be given to pregnant and women of reproductive age.

The information derived from this study may assist health care workers in formulating protocols and guidelines on how to manage and minimize the risk factors of birth defects. They will also have better understanding on how to handle affected mothers. Strategies on coping mechanisms will be put up for psychological support to parents of these children.

The findings of the study will inform family members of parents of children with congenital abnormalities and the community on how to understand, assist and support these parents.

Future researchers who would be interested in conducting a research on the same or related topics will use the findings of the study to add to their knowledge.

1.6 RESEARCH OBJECTIVES

1.6.1 Broad Objective

To describe the determinants of congenital anomalies and their effect on affected mothers at New Born Unit (NBU), KNH.

1.6.2 Specific Objectives

1. To determine the prevalence and pattern of congenital anomalies among neonates admitted in NBU, KNH
2. To describe risk factors associated with congenital anomalies among neonates admitted in NBU, KNH
3. To establish the effect of a child with congenital anomalies admitted in NBU on their mothers, KNH

1.7 RESEARCH QUESTIONS

1. What is the prevalence and pattern of congenital anomalies among neonates admitted in NBU, KNH?
2. What are the risk factors associated with congenital anomalies among neonates admitted in NBU, KNH?
3. What is the effect of a child with congenital anomalies admitted in NBU, KNH on their mother?

CHAPTER TWO: LITERATURE REVIEW

2.0 INTRODUCTION

This chapter seeks to discuss the pattern and prevalence of congenital anomalies, associated risks and causative factors, and the impact of bearing a child with congenital anomalies on mothers.

Throughout history, congenital anomalies or birth defects are considered a mystery, and have been a topic of frequent discussions. Research has been conducted, from the ancient studies in early times to modern scientific researches.

2.1 PREVALENCE AND PATTERN OF CONGENITAL ANOMALIES

The pattern and prevalence of congenital anomalies may vary over time and also with geographical location (Mashuda et al., 2014b). This is demonstrated in the following paragraphs:

Worldwide, a systematic literature review was conducted to describe the prevalence of neural tube defects. Multiple databases prevalence were reviewed. These included peer-reviewed journals, birth defects surveillance registries and reports published over a period of 14 years. The reported neural tube defects prevalence for each region were as follows: African (11.7/10,000 births), Eastern Mediterranean (21.9/10,000 births), European (9.0/10,000 births), Americas (11.5/10,000 births), South-East Asian (15.8/10,000 births), and Western Pacific (6.9/10,000 births). This report indicated that the prevalence varied with the geographical location (Zaganjor et al., 2015).

In India, at Bangabandhu Sheikh Mujib Medical University (BSMMU) Hospital in Dhaka, an observational study was done to assess the occurrence of congenital anomalies among newborns. Out of 1630 births, 60 (3.68%) newborns had congenital malformations. The commonest type of anomaly was Neural tube defect (46.67%), followed by renal system (23.33%), GIT (6.68%) and musculoskeletal system (5%). Newborns with multiple birth defects were 7(11.67%) (Fatemaq et al., 2011).

An earlier study (2004) at the same center was done prospectively. Congenital malformations were studied, covering 11680 consecutive deliveries. An incidence of 2.3% was recorded, musculoskeletal system being the most commonly involved (Khanum et al., 2004).

These two reports at BSMMU show that the prevalence and pattern of congenital anomalies varies with time, even at the same geographical location.

In Urmia, northwest of Iran, 14,121 deliveries for both live and still births were studied. The total prevalence at birth of overt congenital anomalies was 1.87%. Defects rated with the highest prevalence were CNS defects (52.65%) then musculoskeletal defects (23.86%). The measures for live and still births were 1.17% and 40.7%, respectively (Abdi-Rad et al., 2008).

In Europe, though Multiple Congenital Anomalies (MCA) is rare, it was found that the total prevalence of MCA cases was 15.8 per 10,000 births (Calzolari et al., 2014). In Glasgow city, United Kingdom, the prevalence was 324 per 10,000 births. Cardiovascular system recorded the highest prevalence (50 per 10 000 births) (Dastgiri et al., 2002). In Sweden, the prevalence of major congenital malformation was 3.4%, with congenital heart defects being the most prevalent (Persson et al., 2017). In Russia, the total prevalence was 36.1/1000 newborns (Postoev et al., 2015).

Mexico, in North America, has observed a decline in infant mortality in the last 30 years. In contrast, deaths secondary to birth defects has been going up. The prevalence of birth defects is 73.9/10,000. The most common malformations were of the musculoskeletal system (Hernández et al., 2013). Over a 20 year study in Barbados, the prevalence of congenital malformations was 62 per 10,000 births. Cardiovascular system recorded the highest (20%) of all the anomalies (Singh et al., 2014)

Scientific studies have been done in Africa to investigate pattern and prevalence of congenital anomalies.

A retrospective study done in South East of Nigeria reviewed all the records of all babies admitted in NBU of the University of Nigeria Teaching Hospital (UNTH) in a period of 4 years. 17 out of a total of 670 newborn babies were found to have congenital abnormalities of various types, giving a prevalence of 2.8%. Common abnormalities seen included cleft lip/cleft palate and neural tube defects (Daly et al., 2010).

In Zagazig University Hospital, Egypt, the overall incidence of CAs was 2.5%. The most commonly involved system was the musculoskeletal system (23%), followed by the CNS (20.3%). Multiple anomalies were noted in 28.6% of the cases (El Koumi et al., 2013a).

In Zambia, at Arthur Davison children's Hospital, data was collected from the hospital's records over a period of 1 year. Of the 161 cases of congenital anomalies recorded, the Central Nervous System (CNS) had the highest occurrence with 65 (40.4%) cases; urogenital system showed 39 (24.2%) cases; musculoskeletal system had 37 (22.9%) cases; GIT system 13 (8.1%) cases; CVS showed 2 (1.2%) cases. 5 (3.1%) cases were for multiple anomalies (Kunda et al., 2016).

Studies have been done in Eastern Africa on this topic.

At Bugando Medical Center in Mwanza, 445 children were registered for a study. The prevalence was cited as 29%, with the CNS as the most affected system at a prevalence of 29.8% (Mashuda et al., 2014a).

In Entebbe, Uganda; of the 2365 births recorded, 180 infants had a congenital anomaly. The commonly affected systems were the musculoskeletal (42.7 per 1000 births) and integumentary (16.1 per 1000 births). In overall, the prevalence of major anomalies was 20.3 per 1000 births. (Ndibazza et al., 2011b)

There isn't a lot of published research done in Kenya on congenital anomalies. The extent of congenital problems in Kenya is not clearly understood and documented.

A study done at Pumwani Maternity Hospital (PMH) in 2015 showed that out of 6633 newborns, 129 had congenital anomalies giving an overall incidence rate of 1.94%. Malformations affecting the musculoskeletal system were the commonest, at a rate of 0.95%. The central nervous system and the genital organs were equally affected with 0.12% of total admissions each (Nabea et al., 2015).

A prospective survey was conducted at the maternity unit of KNH, which is Kenya's leading referral hospital in Nairobi. The study was over a period of 12 months from 8th September 1983 to 7th September 1984. The prevalence of CAs was 2.8%. Musculoskeletal system had the highest incidence of the defects, accounting for 33.9 % (38) of all major defects, then the CNS at 28.6% (Muga et al., 2009).

2.2 RISK FACTORS OF CONGENITAL ANOMALIES

WHO report of 2016 indicated that approximately 50% of all known congenital anomalies cannot be linked to a specified cause. Nevertheless, there are some known genetic, environmental and other causes or risk factors.

Genes play an important role in occurrence of many congenital anomalies. This might be through inherited genes that code for an anomaly, or from genetic mutations.

Consanguinity (when parents are related by blood), greatly increases the prevalence of rare genetic congenital anomalies. It nearly doubles the risk for neonatal and childhood mortality, developmental defects, intellectual disability and other anomalies (Tayebi et al., 2010b).

Consanguineous marriages are a common social trend mainly in North Africa and most parts of Asia, where one in every three marriages is between cousins. The product of a consanguineous marriage has an greater risk for recessive anomalies because of the expression of autosomal recessive gene mutation gotten from a familiar ancestor (Hamamy, 2012).

Some ethnic communities, such as Caucasians (Egbe, 2015) Asians and Blacks (Knowles et al., 2017), have been found to have a comparatively high prevalence of rare genetic mutations such as Cystic Fibrosis and Haemophilia C.

Being a Low-income earner may be an indirect determinant of congenital anomalies, with a higher frequency among families and countries with constrained resources. It is estimated that approximately 95% of severe congenital anomalies occur in low- and middle-income countries. As an indirect determinant, this higher risk relates to a possible lack of access to sufficient, nutritious foods by pregnant women, an increased exposure to agents and factors such as infection and alcohol, or limited access to healthcare and screening (Mashuda et al., 2014a).

Maternal age is a known risk factor for abnormal intrauterine fetal development. Younger maternal age is associated with nervous and abdominal wall anomalies. Advanced maternal age increases the risk of chromosomal abnormalities, including Downs and Turners syndrome (Tennant et al., 2010).

Use of certain substances like alcohol and cigarette smoking, have been associated with occurrence of birth defects. If a pregnant woman is subjected to certain products like pesticides,

drugs and other pollutants; she is at risk of having an infant with birth defects. Radiation has also been linked with congenital anomalies. Occupational exposure or living near, or in, waste sites, smelters or mines may also be a risk factor. This is particularly true if the mother has exposure to other environmental risk factors and is nutritionally deficient (Stingone et al., 2014).

Maternal infections such as Cytomegalovirus and Rubella are a significant risk factor of congenital anomalies (Wright, 1966).

In the recent past, the effect of being exposed to Zika virus during the intrauterine life on the growing baby has been recorded. Commonly noted birth malformations associated with the infection include microcephaly and related brain problems in infants (Rather et al., 2017). The Center for Disease Control and Prevention (CDC) defines microcephaly as a congenital anomaly where a child is born with an abnormally small sized head caused by Zika virus.

Insufficient folate intake during the pre and peri-conception time increases the chances of having a baby with a neural tube and congenital heart anomalies (Feng et al., 2015). Excessive vitamin A intake may affect the normal development of an embryo (Brody, 1995).

A case control study was conducted in the United Kingdom to investigate the relationship between smoking and oro-facial clefts. 199 infants with oral cleft were investigated. The conclusion was that there was an association between a pregnant woman smoking in the first three months of pregnancy and occurrence of cleft lip, with or without cleft palate (Little et al., 2004).

Other studies in the UK indicate that birth defects are a significant cause of neonatal mortality and disability. It has been cited that this incidence is different among the ethnic groups. The study demonstrated that the risk of birth defects was more for Pakistanian women than for those originally from Britain. 18% of the babies were products of marriages between first-cousins. The study showed that consanguineous marriages were linked with increasing the risk of birth defects to almost twice. 31% of all malformations in newborns of Pakistanian mothers could be associated with consanguinity. Among the Britons, the risk was higher among mothers with the age above 34 years. Maternal education to degree level was cited as protective regardless of ethnicity (Sheridan et al., 2013).

In Jammu, the prevalence of anomalies was found to be greater in males with a sex ratio of 1.6:1.4. Other findings were; Congenital anomalies were more common in Muslims (1.77%) compared to Hindus (1.4)%, in caesarian born babies (1.96%) as compared to those delivered vaginally (1.48%) and in still born babies (4.46%) compared to those born alive (1.39%) (Singh and Gupta, 2009b).

In South India, pregnant women who were classified as high risk were studied to describe the risk factors. Maternal age of > 25 years, paternal age of > 30 years, consanguinity and being a primigravida were recognized as risk factors. Toxoplasmosis was identified as a key player in pregnant women with bad obstetrics history (BOH) in current pregnancy with previous normal pregnancies. A conclusion was made that there was higher prevalence of congenital anomalies among HRP women compared to general population (Sunitha et al., 2017).

At Sir T Hospital, the incidence of congenital anomalies was significantly higher (6.1%) in mothers aged >30 years as compared to younger age group. The higher incidence was also noted in Primiparous patients (47.2%) and decreasing with increasing birth order. The religious pattern and consanguinity had no much effect on the incidence. Prematurity in the newborns had four times more incidence of congenital defects as compared to term babies. Slightly higher incidence was more in female newborns, with a ratio of 1.6:1 (Parmar et al., 2010).

In Lebanon, there was a noteworthy relationship between drinking alcohol while pregnant and parental consanguinity with increased occurrence of birth defects. Stillbirths and perinatal death, mothers' consumption of drugs during pregnancy, neonate having a low birth weight and low Apgar score at 5 minutes were factors positively associated with congenital defects (Francine et al., 2014).

In another study, the prevalence was higher in still born, preterm, low-birth weight babies and those with positive familial history. It was also higher in babies born to mothers older than 35 years and parity of ≥ 4. Other factors associated with high incidences of congenital anomalies were consanguinity of marriage, drugs and hormone ingestion during pregnancy, pregnancy complications like pre-eclampsia, toxemia and gestational diabetes (Khanum et al., 2004). In Australia, the prevalence of CAs was found to be notably more in the babies of mothers with diabetes in pregnancy (Sharpe et al., 2005).

At Bugando Medical Centre, Mwanza, Tanzania, factors related to the mother linked with congenital malformations were: not consuming folic acid while pregnant, maternal age of above 35 years and three or less antenatal clinic visits. Those for the newborn included: female gender, singleton pregnancy, a weight of ≥ 2.5kg at birth, and a parity of 4 or more than 4 (Mashuda et al., 2014a).

In KNH, the number of malformed babies appeared to increase with increasing maternal age especially from 35 years and above. These accounted for 13.4% of all malformed babies (Muga et al., 2009).

2.3 EFFECT ON AFFECTED MOTHERS

With availability of ultrasound techniques, more anomalies can be diagnosed ante-natally. This means that parents are faced early on with the fact that the fetus has a congenital malformation and there is a possibility of serious consequences (Mazer and Gischler, 2009). In most developed countries, routine ultrasonography in the antenatal period has become so vital in diagnosing congenital malformations. Once a diagnosis of severe congenital anomalies has been made, the parents are tasked with the resolve of either to terminate the pregnancy or to continue with it. (Bijma et al.,2007). In his study, (Boyd et al., 1998) reported that more than 50% of all anomalous infants can be diagnosed in the antenatal period through routine practice.

Teratology, the 'study of monsters', dates back from the ancient civilizations, and it was believed at one time that presence of birth defects was a divine punishment for wickedness or breaking a taboo (Olasoji et al., 2007). In Rural Western, Kenya, mothers underwent stigmatization and blamed following miscarriage, or the birth of a child with a congenital anomaly. This is because it was believed that they didn't follow cultural norms (Dellicour et al., 2013). (Cosme et al., 2017) reported that there was underreporting of congenital anomalies.

From the ancient times, superstitions regarding birth defects have been reported, and they are still prevalent in present days. (Garcias and Schüler-Faccini, 2004a) did a study to outline mothers ideas by comparing six well documented causes of malformations with current explanations in the public; and to discover common fallacies regarding such defects. He reported a gap in knowledge and emphasized on the importance of educating the public.

During pregnancy, every mother hopes for a perfect newborn. Diagnosing congenital anomalies pre-natally or immediately after birth can be devastating to the parents of the infant. Thinking through the serious consequences on birth defects may induce a process of parental mourning. This process of silent mourning that most parents go through is not always evident to everyone around them. Actually, it is a personal process felt by the person who is directly affected by the birth of such a child (Mazer et al., 2008b).

The news of abnormal ultrasound findings are oftenly unforeseen, and are bound to shock the parents in waiting. There may be several emotional reactions: firstly they may have negative feelings associated with anxiety, grief, anger, loneliness, hopelessness and guilt. These feelings may be made worse by the loss of an imagined future, now that the pregnancy may end in mortality or a gravely disabled child. This may eventually require the whole family to adjust (Bijma et al., 2007).

Children born with congenital anomalies are bound to face many problems, including prolonged neonatal hospitalization and multiple surgical interventions. More often than not, there is uncertainty in the future quality of life. Parental insecurity is heightened in the case of multiple congenital anomalies (Sabzevari et al., 2016).

Parents vividly recall the circumstances of congenital anomalies disclosure and can describe their reactions in great detail. Regardless of the type of birth defect, the range of parental emotional reactions seems to follow a similar pattern of grief response because the diagnosis is conceptualized as the loss of a healthy infant. Initially, the parents may describe their emotional reactions as intense and overwhelming, and are often composed of conflicting feelings. Negative feelings frequently expressed are shock, sadness, anxiety, anger, guilt, despair and frustration, and less frequently, shame. Less often reported are positive emotions like relief, and these are likely to occur when a prognosis and treatment options have been found. Hope is also a rare positive emotional reaction, and it may be associated with parental belief that their child will manage well, despite having a congenital anomaly, or they expect that the diagnosis was a mistake (Fonseca et al., 2011).

Taking care of a congenitally malformed baby is a challenge that mothers experience. It is a shared experience with those around her and it is bound to affect all aspects of a family. If there is support in tackling this challenge, positive outcomes will be experienced; family cohesion and

awareness of inner strength (Tusano, 2015). Affected mothers need support; they need some alone time to unwind and build new energy. If they are support groups, they feel understood and comforted. This is the place that they can vent and not feel alone (Bruce et al., 2014). In Sweden, parents felt that it was therapeutic to share their experiences with other parents on similar situation (Bratt et al., 2015).

In Namibia, the reactions of some spouses, family members and community traumatized the affected mothers. This resulted in them experiencing bitter feelings, anger and even self-blame. Delays and failure by the health workers in disclosing information about the congenital anomaly made the situation worse (Sankombo, 2015).

Affected mothers need information to gain understanding of the condition and situation at hand. (Bratt et al., 2015) cites the importance of the sonographers being professional in how they deliver information regarding congenital anomalies. The health care workers must be well updated and knowledgeable in matters pertaining birth defects.

After siring a child with congenital anomalies, parents face unique challenges. Some of these challenges include finding resources and support, creating awareness and even communication with health care workers (Lemacks et al., 2013a).

2.4 CONCEPTUAL FRAMEWORK

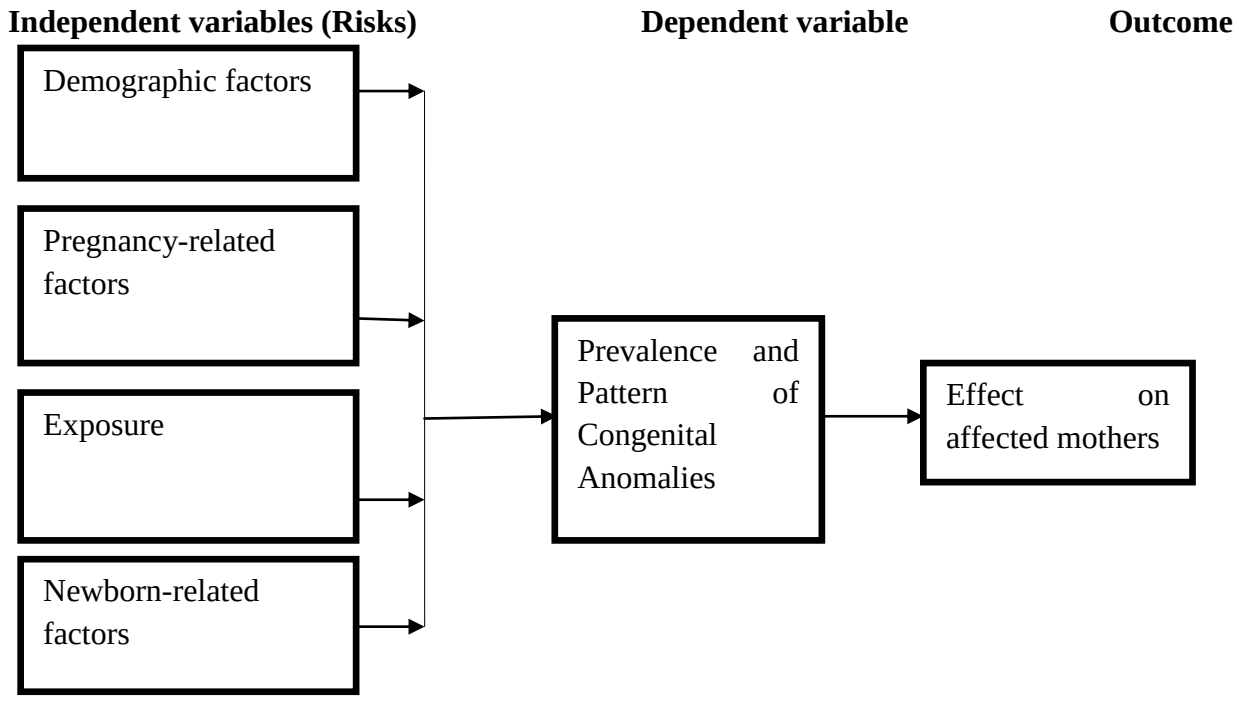

Figure 2.1 Conceptual Framework of the study

2.5 OPERATIONALIZATION OF VARIABLES

Based on the study objectives, the following variables have been identified:

2.5.1 Independent Variables

Demographic factors

Demographic factors are personal characteristics. In this study, these will include; maternal age, level of education, race, religion, occupation, income, consanguinity and familial history of congenital anomalies.

Pregnancy related factors

Parity, number of Antenatal Care visits, use of Folic acid, having a High Risk Pregnancy and pregnancy complications.

Exposure

This is exposure to alcohol, smoking, infections, use of medications during the pregnancy, pollutants and radiation.

Newborn related factors

These are gender, birth weight, birth order, gestation and mode of delivery.

2.5.2 Dependent Variables

Pattern and Prevalence of Congenital Anomalies

2.5.3 Outcome Variables

This is the effect on affected mothers. The indicators include: Shock, anxiety, grief, anger, loneliness and hopelessness, stigma, guilt, depression and despair.

CHAPTER THREE: MATERIALS AND METHODS

3.0 INTRODUCTION

This section seeks to gives details of methods, materials and procedures that were used in conducting the study. It describes the study design, study area, study population, target population, sample size, sampling technique, data collection and data analysis. The ethical issues considered are also highlighted.

3.1 STUDY DESIGN

This was a hospital based descriptive, cross-sectional study that employed quantitative and qualitative study designs.

Descriptive study is an observational study which describes the patterns of disease occurrence in relation to variables such as person, place and time. Using descriptive studies, a researcher discovers new meanings, determines what exists, determines the frequency in occurrence of a phenomenon and categorizes information. In this study, descriptive design was used to have an understanding of pattern and prevalence of congenital anomalies and their effect on affected mothers.

A cross-sectional design was used to collect all data at a set point in time, in the month of July 2018, allowing the researcher to assess the prevalence and other variables of interest (Admin, 2010).

Triangulation technique was used where there was inquiry through quantitative approach and validation through qualitative approach. Phenomenological method under qualitative approach was employed. An in-depth experience of a mother to a newborn with congenital anomalies was recorded. Key informants were interviewed.

3.2 STUDY AREA

The study was carried out in KNH, the largest national referral teaching and research hospital in East and Central Africa. It is located in Upper Hill area of Nairobi, Kenya, approximately 2km from the Central Business District. It has a bed capacity of 1800 and has been in existence since 1901. One of the specialized units is New Born Unit, others being the Burns Unit, Renal Unit, Accident and Emergency Unit and Critical Care Unit.

The Newborn Unit is on the first floor of the hospital's tower block and it receives babies from the hospital's labor ward and theatres as well as from outside the hospital as referrals from private and provincial hospitals. It is subdivided into several sections namely; Neonatal intensive Care Unit (NICU), Kangaroo Mother Care and Nursery for the premature babies. There are 12 incubators, 40 cots and 6 NICU beds. 60 registered nurses work in the New Born Unit, some having specialized in Neonatal care. It was estimated that 10% of admissions to the NBU were neonates with congenital anomalies.

3.3 STUDY POPULATION

The study population was neonates with congenital anomalies admitted at the New Born Unit of the KNH, and their mothers. Data obtained from the NBU Inpatient Statistics, KNH, indicated that on average, 300 neonates are admitted per month.

3.3.1 Inclusion Criteria

Neonates with congenital anomalies admitted at NBU, KNH, and whose mothers gave consent to participate in the study were recruited into the study.

3.3.2 Exclusion Criteria

Neonates whose mothers declined to consent and abandoned Neonates were not included in the study.

3.4 SAMPLE SIZE CALCULATION

3.4.1 Quantitative

Using Fisher's formula of sample size calculation as described by Naing (Naing et al., 2014):

$$N = \frac{Z^2 pq}{d^2}$$

Where;

N = desired sample size (population > 10,000)

Z = normal deviation at the desired confidence interval (95%) = 1.96

P = proportion of the population with the desired characteristics (50% will be used. This is because there is no recent study in KNH on this or related topic)

Q = proportion of the population without the desired characteristics (50%)

d^2 = degree of precision (5%)

Substitution for the formula:

$$N = \frac{1.96^2[0.5][0.5]}{[0.05][0.05]} = 384.16$$

N=384.16

The formula will be adjusted using the Cochran formula (Stephanie, 2015), since the population is less than 10,000 using the formula:

$$nf = n/[1 + n/N]$$

Where;

nf = the adjusted sample size

n = total population 60 (Every month, it estimated that 300 neonates are admitted in NBU, KNH. 10% of these are estimated to have congenital anomalies. Data will be collected over a period of 2 months. Therefore, the total population will be [10% of 300 multiplied by 2] which is 60)

N = the sample size calculated

$$nf = 60/[1 + 60/384.16]$$

= 60 / [1+ 0.156]

= 60 / 1.156

= 51.9

A sample size of 52 participants was used.

3.4.2 Qualitative

There are no specific rules in determining an appropriate sample size in qualitative research. For a phenomenological study, 5-25 participants can be used (Creswell and Creswell, 2007). For this study, data was collected until saturation. This means sampling to the point at which no new information is obtained and redundancy is achieved. 15 participants were interviewed.

3 key informants were interviewed; Nurse in-charge of NBU, 1 Neonatal nurse and 1 Paediatric registrar.

3.5 SAMPLING PROCEDURE

3.5.1 Quantitative

Consecutive sampling method was used to collect quantitative data. This is a non-probability technique. In this study, sampling for proportionality was not the main concern, but reaching the target sample.

3.5.2 Qualitative

Purposive sampling was used in collecting qualitative data. The researcher chose respondents based on her own judgment on who she believed were a representative of the study population.

3.6 RECRUITMENT STRATEGY

3.6.1 Quantitative

Data collection was an ongoing process. Every neonate admitted in NBU who adhered to the inclusion criteria participated in the study until the target sample was attained.

3.6.2 Qualitative

Of the 52 neonates who participated in quantitative data collection, 15 were recruited for qualitative data collection. This was done after the questionnaire had been administered.

3.7 STUDY INSTRUMENTS

3.7.1. Questionnaire

A semi-structured questionnaire (SSQ) was used as the main tool of quantitative data collection. There was an option of using an English or Swahili questionnaire. The questionnaire was researcher-administered.

3.7.2 Interview guide and tape recorder

An open ended unstructured interview guide was used to collect qualitative data for participants as well as Key Informants Interviewees. A digital audio recorder was used to capture the

interviews. For those who could not speak English, the researcher and assistants used an interview guide translated in Swahili.

3.8 PRE-TESTING

This was done at Pumwani Maternity Hospital, the NBU unit. Approximately 10% of the sample size (6 participants) were used for pretesting after the participants gave consent (Hertzog, 2008). Pre-testing was done a month prior to commencement of data collection.

3.8.1 Quantitative

Validity

Validity of the research instrument was ensured through the use of a well-designed questionnaire. A pre-test study was done to check on the accuracy of the questionnaire so that the answers obtained from the study were true and accurate.

Reliability

Reliability was tested through Test-Retest reliability method (Stephanie, 2017). Reliability was also ensured through careful selection and training of research assistants, involving them in the pre-testing and overseeing them during the data collection process. Completed questionnaires were checked daily and errors corrected by the Principal Investigator.

3.8.2 Qualitative

The interview guide was subjected to Peer review and expert opinion was sought for accuracy and validity. Member check was also employed whereby the researcher allowed the respondents to read the transcription of their interviews to ensure that these had been accurately recorded (Birt et al., 2016).

3.9 DATA MANAGEMENT

3.9.1 Data collection procedure

Quantitative

Data collection was done by the researcher, being assisted by two trained research assistants. After convenience sampling, the study aim, objectives and expectations were explained to the participants. This was done in the classroom located within NBU: to observe privacy. Consenting process was voluntary with the recruited participants signing the consent forms. The

questionnaires were researcher-administered. Each questionnaire had a unique identifier to allow for validation. After filling the questionnaire, the researcher reviewed each of the participants' files for validation.

Qualitative

After filling the questionnaire, some of the participants were interviewed through purposive sampling. The researcher conducted an in-depth interview using the interview guide, and the conversation was recorded.

3.9.2 Data entry and cleaning

Filled questionnaires were collected and checked for completeness and consistency by the Principal investigator. Inconsistent information was eliminated and unclear responses clarified from the respondents. Double entry of the same data was done to ensure accuracy

3.9.3 Data analysis

Quantitative

Data was exported to Statistical Package for the Social Sciences (SPSS) computer software, version 20. Univariate analysis was performed in order to obtain descriptive statistics. Proportions like percentages and rates, Measures of central tendency like means modes and medians as well as measures of dispersion like standard deviations were determined during the analysis. Bivariate analysis was also performed in order to examine associations between the independent variables.

Results were presented in frequency tables, pie charts and bar graphs. Scientific conclusions were then drawn from the findings.

Qualitative

Audio responses recorded in the tape recorder were transcribed in verbatim. The researcher engaged the services of a translator to translate the transcripts from Swahili to English or English to Swahili. This depended with the language used to conduct the interview. The translated version was then translated back to the original language used to ensure data accuracy. N-vivo 10

computer assisted qualitative data analysis software was used. After, information was analyzed according to themes.

3.10 ETHICAL CONSIDERATION

Approval was sought from Kenyatta National Hospital Ethical Review Committee. Permission was sought from the Hospital administration, authority from the Ward in charge and consent from mothers. Consenting process was done by the researcher assisted by two trained research assistants. Objectives and procedures of the study were fully explained to mothers and a written informed consent was obtained prior to enrolling their newborns into the study. The information collected from the newborns and their mothers was kept confidential and within limits of research objectives. It was clearly explained to the mothers that the study primarily intends to provide valuable information that would be used to improve the care of newborns with congenital anomalies. The classroom located in NBU, KNH was used for consenting process and data collection. This was to ensure privacy.

In the occurrence of stigma and emotional distress, the services of the hospital counselor were sought.

In case a participant was not competent in English or Swahili, the services of a translator proficient in that particular language were sought.

3.11 PERSONNEL

Data was collected with the assistance of two research assistants; nurses working in NBU, KNH. They were trained for two days on the questionnaire and interview guide, data collection procedure, consenting process and on evaluation of the questionnaire for completeness. The Principal investigator worked with the assistants in data collection, data cleaning and data entry. The researcher analyzed the data with the assistance of a statistician.

3.12 MINIMIZING ERRORS AND BIAS

The questionnaire was pretested and reviewed to ensure consistency. Participants were purposively selected. All eligible subjects were allowed to participate irrespective of literacy levels.

3.13 DISSEMINATION PLAN

The findings of this study were presented to School of Nursing (UON). The information was also shared with KNH, Department of Clinical services and NBU to inform relevant planning and programming. A copy of the entire study was printed and kept in the university library for future reference. Findings will be published in peer reviewed journals. The researcher will also share findings of this study in scientific conferences.

CHAPTER FOUR: RESULTS

4.0 INTRODUCTION

This section seeks to give details of the findings of the study based on qualitative and quantitative data obtained from 52 mothers and 3 key informants.

4.1 PATTERN AND PREVALENCE OF CONGENITAL ANOMALIES

A total of 315 neonates were admitted in NBU during the one month study period. 61 neonates were noted to have congenital anomalies, thus giving a prevalence of 19.4%. Out of these, 32 had single congenital anomaly and the rest 20 had multiple anomalies. Thus, there were 82 anomalies among 52 newborn babies.

The commonest congenital anomaly was that of the Musculoskeletal system 38.5% (20/52), which was followed by the Central Nervous System 25% (13/52), Gastrointestinal 21.2% (11/52) and Cardiovascular System 19.2% (10/52) in that order (Table 4.1). The least common congenital anomalies were those of eye, ear, face and neck; and chromosomal abnormalities with each having one anomaly (1.9%)

Table 4.1: Distribution of Congenital Anomalies according to ICD 10 (n=52)

International Disease Classification (ICD-10)		N	%
ICD1	Congenital malformations of the nervous system	13	25.0
ICD2	Congenital malformations of eye, ear, face and neck	1	1.9
ICD3	Congenital malformations of the circulatory system	10	19.2
ICD4	Congenital malformations of the respiratory system	2	3.8
ICD5	Cleft lip and cleft palate	6	11.5
ICD6	Other congenital malformations of the digestive system	11	21.2
ICD7	Congenital malformations of genital organs	4	7.7
ICD8	Congenital malformations of the urinary system	2	3.8
ICD9	Congenital malformations and deformities of the musculoskeletal system	20	38.5
ICD10	Other congenital malformations	7	13.5
ICD11	Chromosomal abnormalities, not elsewhere classified	1	1.9

Among the infants with Musculoskeletal malformations, Congenital Talipes Equino-Varus (CTEV) was the most common; with a prevalence of 6 (30%). This was followed by Gastroschisis and Polydactyl, each with 3(15%) cases. Other Musculoskeletal anomalies are shown in Table 4.2.

Table 4.2: Musculoskeletal congenital anomalies 10 (n=52)

ICD 9 (Musculoskeletal system)	N	%
CTEV	6	30.0
Gastroschisis	3	15.0
Polydactyl	3	15.0
Nasal deformity	2	10.0
Omphalocele	2	10.0
Amniotic band syndrome	1	5.0
Bilateral absence of radio ulna bones	1	5.0
Macrocephaly	1	5.0
Prune Belly Syndrome	1	5.0

Hydrocephalus was the most common malformation affecting the CNS, accounting for 5 (38.5%) of all cases with CNS anomalies, followed by spina bifida which had a prevalence of 2 (15.3%). The commonest anomaly of the GIT was Atresia, accounting for 6 (54.5%) cases of all GIT malformations. For the CVS anomalies, only Congenital Heart Disease (CHD) and Patent Ductus Arteriosus (PDA) were found, each accounting for 5 (50%) cases each.

Out of the 52 cases and 82 anomalies, different types of GIT atresia and CTEV were the most common accounting for 7.3% of all the anomalies. The different types of GIT atresia are illustrated in Figure 4.1.

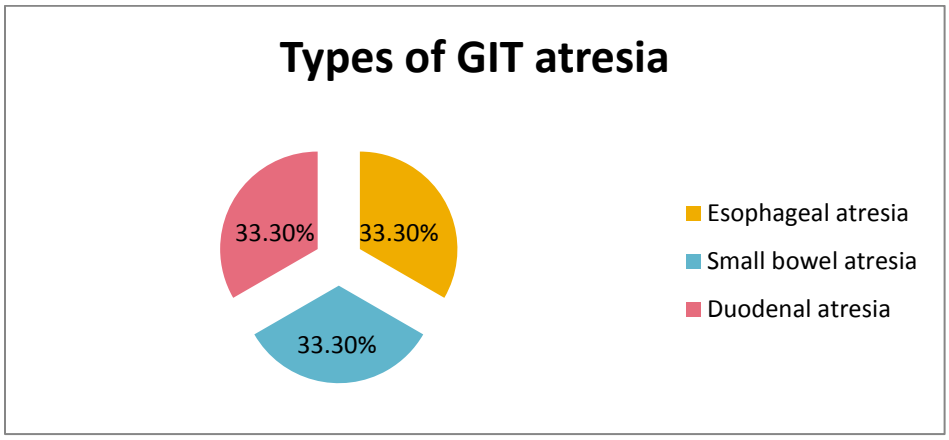

Figure 4.1: Types of GIT atresia (n=6)

4.2 RISK FACTORS OF CONGENITAL ANOMALIES

Maternal age showed that 46 (88.4%) of the mothers had an age of between 16 and 35 years of age. The other 6 (11.5%) were aged above 35 years. Mean maternal age was 26 years**.** The prevalence of congenitally anomalous babies born was 7 (13.5%) for mothers <20 years (teenage mothers). All participants were of African race. The correlation of various factors to the cause of various congenital malformations is shown in Table 4.3.

Table 4.3: The correlation of various factors to the cause of Congenital Malformations

		N	%
Age group	16 - 24 years	23	44.2
	25 - 35 years	23	44.2
	>35	6	11.5
Race	African	52	100.0
	Non-African	0	.0

In regards to parity; 24 (46.2%) were Primigravidas, 28 (53.8%) were multigravidas while none was a grand multigravida. Mothers' parity was not statistically significant in relation to occurrence of congenital anomalies. 49 (94.2%) of the respondents were Christians, while 3 (5.8%) were Muslims. None were found to be atheists or of mixed or other religious groups. Regarding education, those with primary education were 18 (34.6%), secondary education were 19 (36.5%) and 14 (26.9%) of the respondents had tertiary education. Only 1 (1.9%) participant didn't have any form of formal education.

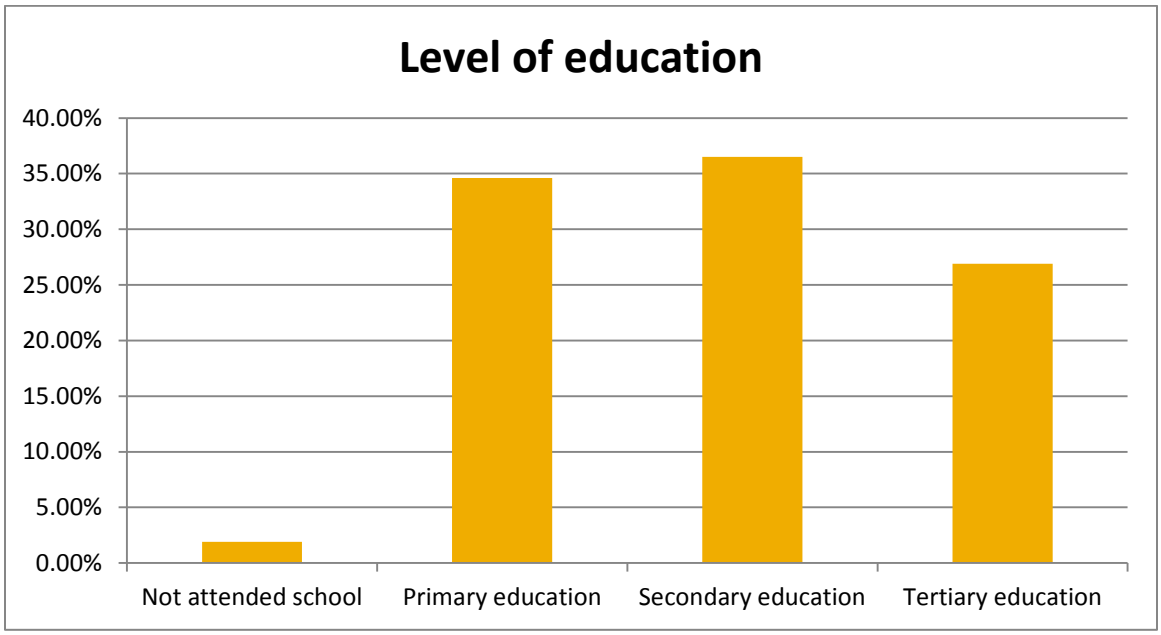

Figure 4.2: Distribution of respondents by Level of education

Majority of the mothers; 32 (61.5%), were not working; 11 (21.2%) were employed and 9 (17.3%) were self-employed.

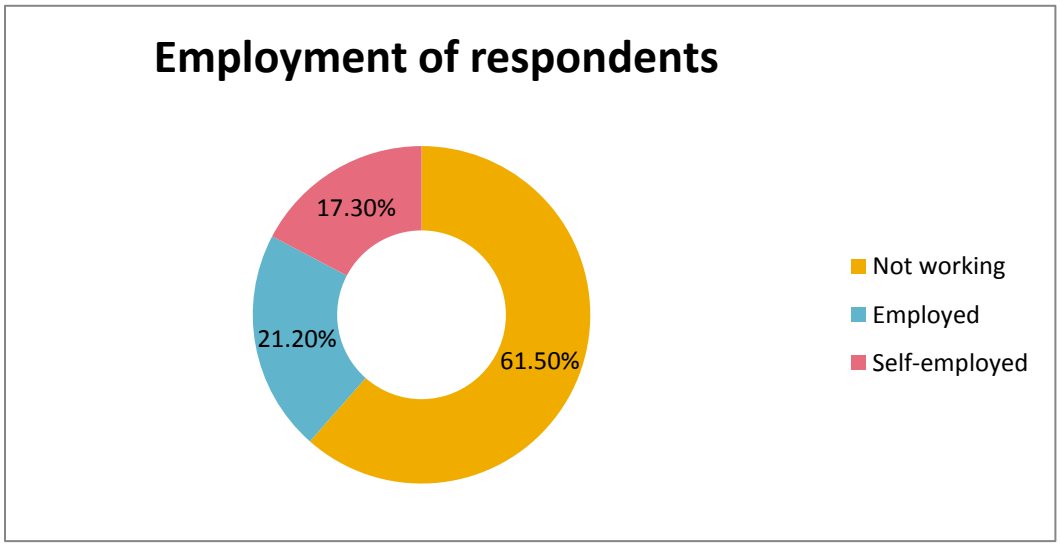

Figure 4.3: Distribution of respondents by Employment

Family history of congenital anomalies was forthcoming in 6 (11.5%) women. Majority of the respondents, 46 (88.5%), did not report of any family history of birth defects. The types of congenital anomalies that were present in those patients with a positive family history were as follows: cleft lip, congenital upper lip hemangiomas, cranial meningocele, Dandy walker

syndrome, Meningiomyelecele with Talipes and Tracheal esophageal fistula with esophageal atresia.

In the present study, there was only one case of consanguinity, where the father of the child was a cousin to the mother. This malformed baby was born to Muslim parents. Table 4.4 summarizes the Family history and Maternal factors associated with CAs at birth.

Table 4.4: Summary of the Family history and Maternal factors associated with CAs at birth.

		n	%
Is there history of Congenital anomalies in your family?	Yes	6	11.5
	No	46	88.5
Is the father of your child a relative?	Yes	1	1.9
	No	51	98.1
List all drugs taken while pregnant	Folic acid	37	77.1
	Vitamin A	0	.0
	Other	11	22.9
Did you suffer any medical condition during pregnancy?	Yes	14	26.9
	No	38	73.1

Out of 52 respondents, 37 (77.1%) took folic acid and iron supplements during pregnancy. No participant reported having taken Vitamin A supplements. Exposure to drugs was noted in 11 (22.9%) mothers who delivered congenitally malformed babies. The offender drugs included antibiotics like Amoxicillin and Cefuroxime, Paracetamol, Mebendazole, Albendazole, Clotrimazole pessaries, Anti-retroviral drugs (ARVs), Anti-diabetics, Byofater and Multivitamins. Some mothers were not able to specify the drugs they took during pregnancy. Majority of the mothers, 41 (78.8%), reported not taking any drugs or medications during pregnancy.

Fourteen (26.8%) respondents reported to have suffered a medical condition during pregnancy. Five (35.7%) had Hypertension and one (7.1%) had diabetes. Other medical conditions reported during pregnancy included Preterm Premature Rupture of Membranes (2), Urinary Tract Infection (2), Polyhydramnious (1), Oligohydramnious (1), Anemia (1), Antepartum hemorrhage

(1), Preterm labor (1) and respiratory tract infection (1). None of the participants reported to have suffered viral infection by Zika virus, Cytomegalovirus or Rubella virus.

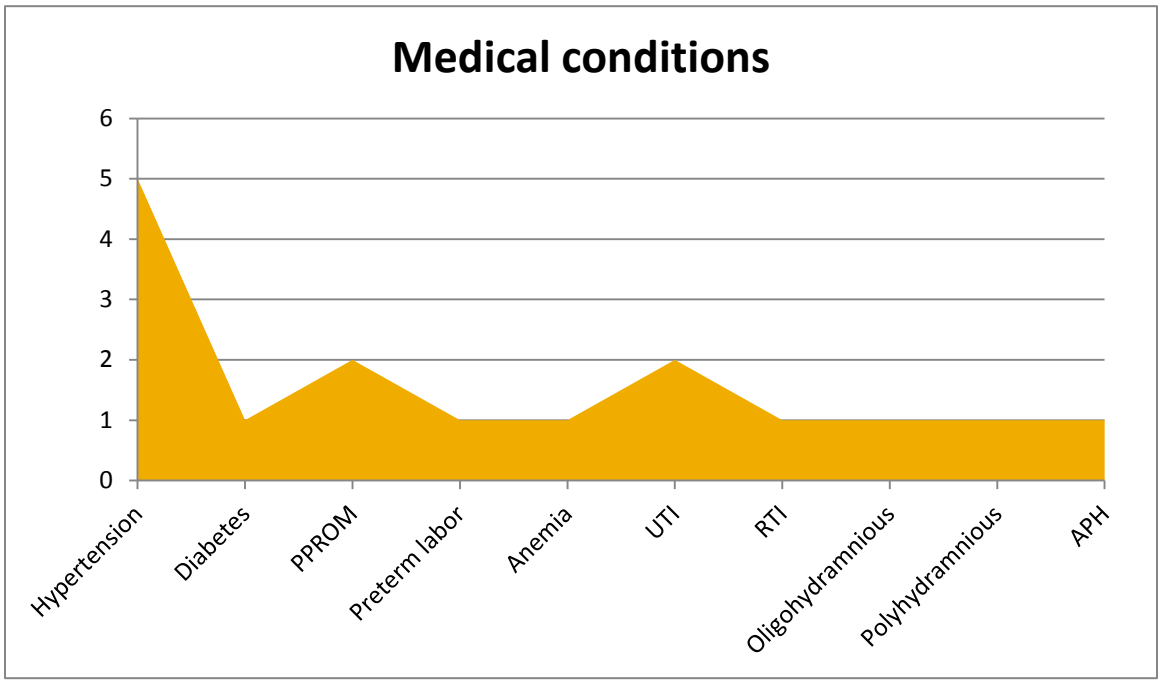

Figure 4.4: Medical conditions during pregnancy

Majority of the mothers, 48 (92.3%), did not report any drinking habits during pregnancy. Of the 52 participants, only 4 (7.7%) confirmed to have taken alcohol during pregnancy. None of the mothers who delivered a congenitally malformed baby was an active smoker during pregnancy.

Forty nine (98%) of the participants received antenatal care whereas 2 (2%) were deprived of it. For those who had attended ANC, 2 (3.8%) had attended once, 4 (7.7%) twice, 16 (30.8%) had attended thrice, 13 (25%) four times and 17 (32.7) more than four times.

Table 4.5: Summary of maternal factors associated with CAs at birth.

	Yes		No	
	N	%	N	%
Do you take alcohol	4	7.7	48	92.3
Do you smoke tobacco?	0	.0	52	100.0
Did you visit Ante-Natal Clinic?	49	98.0	1	2.0

Table 4.6: Summary of maternal factors and occurrence of CAs at birth

		n	%
Were you screened for congenital anomalies during pregnancy?	Yes	29	55.8
	No	23	44.2
Are there any industries close to where you live?	Yes	4	7.7
	No	48	92.3
Mode of delivery	Caesarian section	16	30.8
	Vaginal delivery	36	69.2

Antenatal Ultrasonography was done for 29 (55.8%) mothers as compared to 23 (44.2%) who did not. For those who did the ultrasound, 27 (93.1%) of the congenital anomalies were not detected. Only 2 (6.9%) participants knew prenatally that her child had a congenital malformation.

Most of the mothers, 48 (92.3%), didn't live anywhere close to industries; only 4 (7.7%) did. Frequency of congenital anomalies was observed more with vaginal route born babies as compared to cesarean section route (69.2% vs 30.8%). Out of the 52 neonates with congenital anomalies, 25 (48.1%) were males and 27 (51.9%) were females. Male to female ratio was 1:1.1.

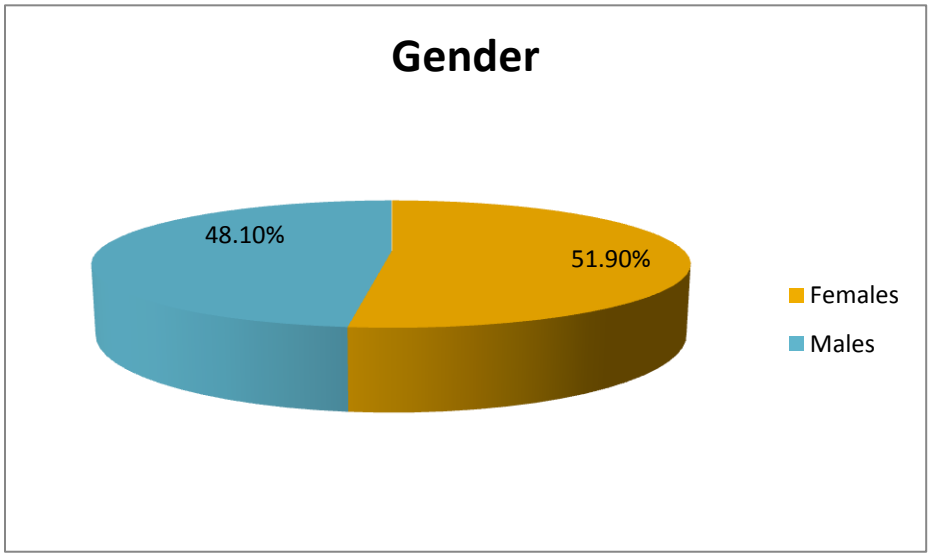

Figure 4.5: Distribution by Gender

Regarding weights of newborns; 26 (51%) had <2.5kg weight, 25 (49%) had between 2.5 to 4kg and none was more than 4kg weight.

Concerning birth order; 24 (46.2%) were 1st born, 13 (25%) were 2nd born, 13 (25%) were 3rd born, while 2 (3.8%) were 4th born.

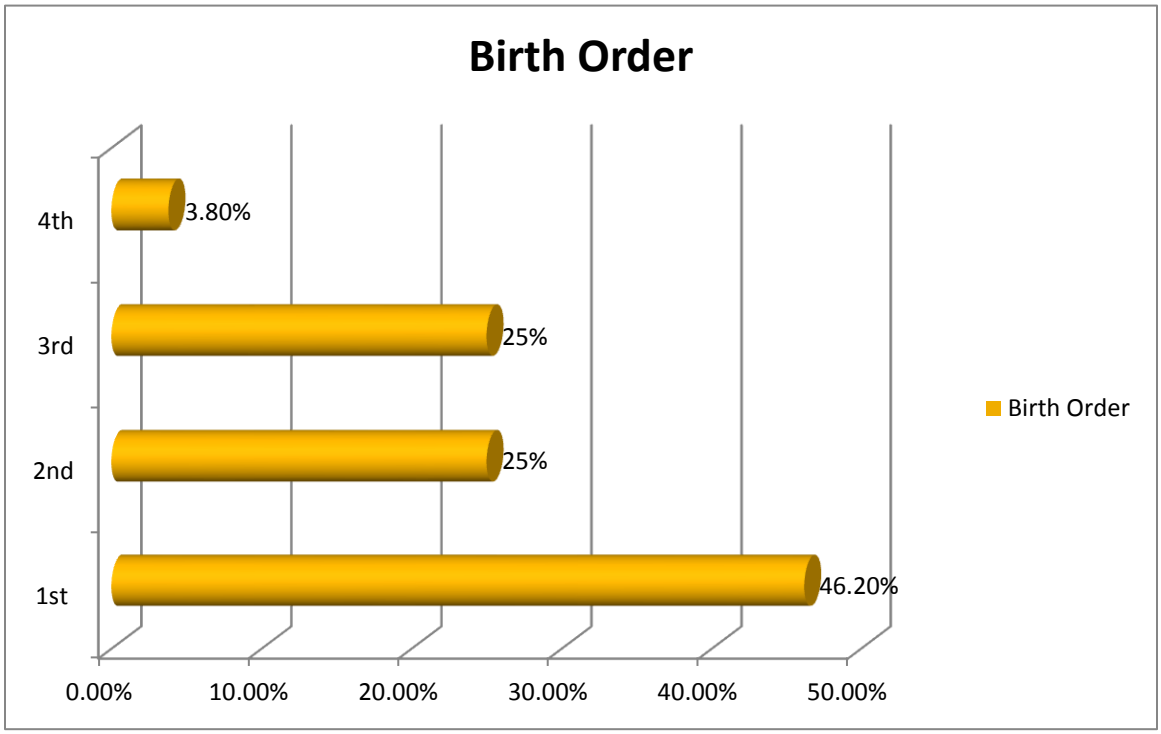

Figure 4.6: Distribution by Birth Order

Twenty four (46.2%) were preterm babies (before 37 completed weeks), 28 (53.8%) were term babies (37 completed weeks to 41 completed weeks) and none were post-dates babies (after 41 completed weeks). Mean weight of the babies was 2.563kg.

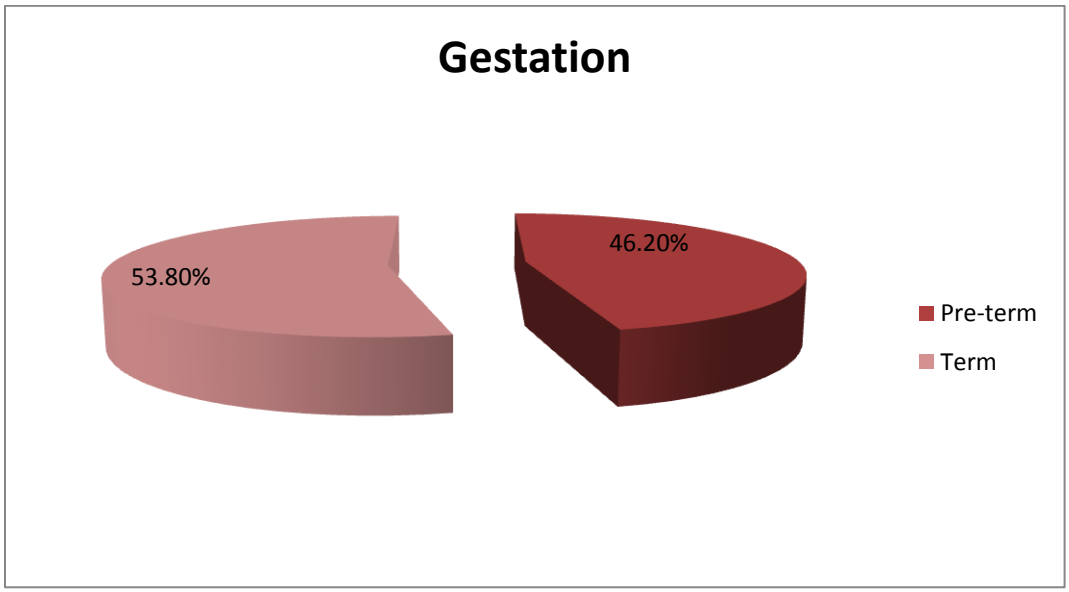

Figure 4.7: Distribution by Gestation

4.3 EFFECT ON AFFECTED MOTHERS

The findings of this study revealed various psychological, economic and social challenges that affected mothers experience after giving birth to an anomalous newborn. Data collected qualitatively was analyzed using the N-vivo software and findings narrated using themes. Four themes are highlighted: Knowledge, Reaction, Support from social environment and Support from heath care system.

4.3.1 Theme 1: Knowledge

Sub-theme 1: When they learn of their child's CA

Majority of the mothers got to learn of their child's congenital anomaly after delivery. In very few circumstances was the anomaly diagnosed antenatally through an ultrasound.

> *"They learn upon delivery, yes, because ideally, an ultrasound should be able to detect. But in our setting, typically it's after delivery…"* **(Key Informant 1)**

If it was an obvious anomaly, the mother learnt of it immediately at birth; if it was not, the mother learnt of it days after. Some had even gone home with the newborns, only to come back to the hospital when the noticed that something was wrong:

"I had already gone home with the child. I saw the way he was breathing; I decided not to sleep at home with him and went to the hospital." **(Respondent 12)**

Sub-theme 2: Previous encounter with CA

Most of the mothers reported to have never seen another case of congenital anomaly;

"The x-ray showed all those problems (congenital anomalies,) but now, I was not understanding at that time… because, I had never seen something like this." **(Respondent 6)**

"I have never seen this kind of sickness; I saw it here (at KNH)." **(Respondent 4)**

Sub-theme 3: Risk factors

Majority of the respondents didn't know what causes these birth defects;

"I cannot know where that thing is coming from; is it from the family or is it a disease. I can't tell." **(Respondent 14)**

"I don't know. Together with the father of my child, we have asked ourselves, we didn't have any problem. We just found ourselves with this problem." **(Respondent 11)**

Some of the risk factors that were cited were; use of medications, consuming chemicals, inadequate consumption of folic acid during pregnancy, not eating certain foods during pregnancy, gene mutation, use of family planning, doing a lot of work like digging and washing, and starting to attend the antenatal clinic late.

"I am just wondering because if its family planning; people say a lot of things about family planning…. there is a mentality that people have nowadays that if you use family planning…" **(Respondent 8)**

"I think it's those folic supplements and those ones for blood (iron). Maybe it's because I never took them the first 2 months." **(Respondent 6)**

Risk factors cited by Key informants include; exposure to radiology, nutrition, lack of folic acids, drugs like chemotherapy, congenital infections, genetic factors, lack of antenatal care and

incest marriages. All key informants reported that at times, the cause of a birth defect is unknown.

> *"Some are thought to be due to congenital infections like hydrocephalus. Some are genetic… Others it depends on, like spina bifida, the mum didn't take folic acid; so maternal malnutrition, antenatal care, such things. Most, we don't know, most are idiopathic, most you can't explain."* **(Key informant 2)**

Majority of the mothers didn't think that cultural habits can lead to congenital anomalies.

> *"It's nothing to do with culture."* **(Respondent 8)**

4.3.2 Theme 2: Reaction

The initial feelings and reaction after news about congenital anomaly diagnosis was delivered are vividly recalled by the mothers. Most mothers had similar negative reaction; they were shocked, they felt bad, had a lot of stress, experienced depression, felt frustrated and even lost hope. Some wondered how it's possible for their other children to be normal while the index one was born with an abnormality. This initial reaction was made worse by the fact that most were not expecting to sire such a child. This is illustrated in the following excerpts:

> *"I was shocked, I asked myself, how is it that I have given birth to this one and has a wound and my other children are ok? Yes, I was not expecting this."* **(Respondent 4)**

> *"I lost hope. I totally lost hope on the child because he is just there. I have never seen a newborn with a lot of stress like him…now I started asking myself, what kind of an abnormal child have I given birth to? ..as a mother, you ask yourself many questions."* **(Respondent 8)**

> *"I was shocked because I was not even able to control myself… I cried a lot"* **(Respondent 11)**

> *"The reaction is not good of course. They tend to become too emotional…they freak a lot.. they get depressed, immediately you see their reaction.. you see a mother is sulking all the time, she is not happy, she is tearing all the time.. the reaction is not always the best."* **(Key informant 3)**

One mother thought of running away and abandoning the baby. The mothers may give up along the course of treatment. This reaction was also reported by the key informants:

> *"You know I was saying, I leave the baby, I ran away because the baby has these problems."* **(Respondent 12)**

> *"Some of them will even tend to run away, abscond, by absconding the baby. They will leave the baby to the hospital."* **(Key informant 3)**

> *"Some despair because most anomalies, like there is a lot of imaging, a lot of others specialists, surgeons involved. And so, they tend to stay long in the unit"* **(Key informant 2)**

Trusting in God and praying was cited by several mothers as something they did to cope with the situation:

> *"And I told myself, my child is not going to pass on. So now from there, there is nothing much I could do, just to pray."* **(Respondent 13)**

After some time, some of the mothers came to accept the situation. Still, there were those who were feeling bad days after the diagnosis was made.

> *"Now I am just encouraging myself. I have accepted (the situation)."* **(Respondent 2)**

> *"After some time, they accept."* **(Key informant 1)**

> *"Am still not feeling ok…I don't even know it will end.* **(Respondent 14)**

4.3.3 Theme 3: Support from the social environment

Subtheme 1: Support from partner

Some mothers described their family relationships as normal, and that they were receiving support from their spouses and family members:

> *"..actually his love to the child has improved. Every time he is there at 1pm, he stays, then goes to sleep at the field and comes back at 4pm. He is so concerned, his support has increased."* **(Respondent 6)**

"..he is supportive…he was even here today…He cried…He said as long as he is treated well, and I should also go home with the baby." **(Respondent 10)**

Still, there were those ones that reported that the father of their child neglected them once they learn of the childs' congenital anomaly. This was also cited by the key informants.

"The father came only once, he saw the child is not reducing (the child's head). He came again at the end of January…he said (the father) he (the child) is not reducing (the head). From that day, I have not seen him. He even ran away from home so I sent my sister to go pick the children and take them home." **(Respondent 1)**

"It's only few of them that will support the mother...The rest will even run away. In fact, they are the causers of the depression of the mother. Because mothers, they don't get support from their husbands. But you see only a few…They are not supporting the mother. Even if you call them, they will tell, ***"You, that is not my baby. Who are you talking about? I don't even know who she is"****."* **(Key informant 3)**

Subtheme 2: Support from family members

Majority of the mothers cited that they were receiving a lot of help from their family members.

"…they are supportive, even my mother in law comes on a daily basis. My mother also comes but not every day because she comes from far." **(Respondent 6)**

"They always want to come and visit the child but they cannot be allowed inside the nursery. They visit many times..." **(Respondent 15)**

A few mothers reported not receiving any support from their family members, and even being ridiculed:

"One aunt called another aunt of mine and told her ***"Have you heard (name withheld) has given birth to a child with two heads"****. This aunt of mine now told my mother. I am waiting for him (my child) to get well I show them (that he doesn't have two heads)."* **(Respondent 5)**

4.3.4 Theme 4: Support from the Health Care System

Sub-theme 1: Treatment

Majority of the mothers cited that all they wanted was their child to be helped and treated; the diagnostic interventions to be done, appropriate surgery to be done and course of management to be determined and initiated.

> *"I am just asking for the child to be helped, the operation to be done. If the child can be helped, they be helped; the child not to be neglected…just for the child to be looked after like the rest."* **(Respondent 15)**

> *"I would want them to help my child. They do that ultrasound and scan, they determine what is wrong so that we can know the treatment. So that when I go home with the child, he fine, because if I carry him home, if he is sick, I will come back here."* **(Respondent 3)**

Sub-theme 2: Financial assistance

Financial assistance to clear the bill is something that was cited by some of the mothers;

> *"I would just want them to help me with that bill…. I heard that the bill for theater is paid in cash…they treat my child so that he recovers. But now the problem is the bill. Because there is no job that I was doing that can give me that kind of money."* **(Respondent 7)**

Sub-theme 3: Information

Some mothers wanted information; on how their child is being treated and advice to them and other mothers on how to prevent these congenital anomalies;

> *"Now when they are treating they baby, they tell me...any problem with the baby they tell me."* **(Respondent 10)**

> *"Once they what cause this (congenital anomalies), they caution people to stop using that thing. If it is certain food, we are told to stop eating it. If it is a certain drug, we are told we stop using it."* **(Respondent 3)**

Even so, some mothers cited to have been misinformed by the healthcare workers;

> *"It's better these nurses tell somebody the main reason why you take folic…during my first pregnancy, then I was misled by the nurse…because the nurse told me you are coming very early. You should have come by at least five months, when you feel the baby has started kicking."* **(Respondent 13)**

Sub-theme 3: Assurance

Assurance and giving hope was cited by some of the participants;

> *"The kind of assistance that I would really want is that one of treatment. They assure me that they will struggle with that child until he gets well….because if I am sure that child will be attended to in all possible ways, and I get hope that she will survive; that's the only thing that will make my heart to be at peace."* **(Respondent 13)**

> *"Theirs is to be reassured and counseled….you just reassure them and counsel them. You call a counselor…"* **(Key informant 3)**

Sub-theme 4: From the Key informants

The kind of assistance that ought to be given by the health care system as cited by the key informants includes; health education on risk factors, prevention and management of congenital anomalies, psychological support, improved antenatal care, pre-conception care and better collaboration among the different disciplines in managing these neonates.

> *"One, we need to improve our antenatal resources….two, we need to tell them of the preventable causes like folic acid. Then once they are born, I think we need better collaboration; because it's a multidisciplinary approach. There is a radiologist, there is a surgeon, we are here; everyone is involved. So you find that coordination between the specialists sometimes takes really long....psychological care is very important."* **(Key informant 2)**

CHAPTER FIVE: DISCUSSION

5.0 INTRODUCTION

This chapter presents the discussion of study findings. The discussion is organized according to the study objectives.

5.1 PATTERN AND PREVALENCE OF CONGENITAL ANOMALIES

The pattern and prevalence of birth defects varies with varying time, and also with location. This is a reflection of a complex interaction of known and unknown factors that include genes, environmental factors that include race, culture and ethnic variables. Improvement in combating neonatal infections and prematurity, congenital defects remain an important cause of neonatal mortality (Sarkar et al., 2013a).

Minority of the neonates admitted while the study was being conducted were diagnosed birth defects. This prevalence is high compared to reports in developed countries. At BSMMU Hospital in India, the prevalence was 3.68% (Fatemaq et al., 2011), in Iran it was 1.87% (Abdi-Rad et al., 2008). In Europe: 3.24% in Glasgow city (Dastgiri et al., 2002) and 3.4% in Sweden (Persson et al., 2017).

In Africa, the prevalence of birth defects was lower in most countries. In Nigeria, it was 2.8% (Daly et al., 2010) and 2.5% in Egypt (El Koumi et al., 2013a). Uganda recorded a prevalence of 2% (Ndibazza et al., 2011b) while in Tanzania, it was 29% (Mashuda et al., 2014a). Previously, Kenya also recorded a lower prevalence: PMH had a prevalence of 1.94% (Nabea et al., 2015) and 2.8% in KNH (Muga et al., 2009).

The high prevalence in this study may be explained by the study area; KNH is the largest teaching and referral hospital in East and Central Africa. Most neonates with congenital anomalies from Nairobi and beyond are referred to KNH, as this is the only public hospital with the capacity to conduct specific investigations and some surgical interventions. In addition, the classification used in the present study, (ICD10), may have resulted in a high prevalence, as it does not show the difference between minor and major defects.

Defects of the musculoskeletal system were the commonest in the present study, followed by CNS. Similar studies done in Kenya showed a similar trend; (Nabea et al., 2015) and (Muga et al., 2009). Musculoskeletal system anomalies were also were also leading in studies conducted in

Uganda (Ndibazza et al., 2011b), Egypt (El Koumi et al., 2013a) and in Mexico (Hernández et al., 2013). Some studies, however, recorded a higher incidence in CNS anomalies; Mwanza, Tanzania (Mashuda et al., 2014a), Zambia (Kunda et al., 2016), and cleft lip/cleft palate in Nigeria (Daly et al., 2010).

Of the musculoskeletal system anomalies, Talipes was the commonest, followed by polydactyl and gastroschisis. This is comparable to a previous study in PMH, where Talipes (53.97%) and polydactyl (17.46%) were also leading (Nabea et al., 2015).

Multiple congenital anomalies were observed in 38.5% of the participants. This occurrence was lower in Europe where it was 0.2% (Calzolari et al., 2014).

The difference in pattern and prevalence of congenital malformations indicates that they vary over time and also with geographical location. This is in line with what (Mashuda et al., 2014b) had concluded in his study.

5.2 RISK FACTORS OF CONGENITAL ANOMALIES

The relationship between the age of the mother and neonates born with birth defects revealed that a majority of anomalous babies were born of mothers' below 35 years. This is in agreement with (Tennant et al., 2010), who reported that younger maternal age is associated with nervous and abdominal wall anomalies. In contrast, a study in India showed that the occurrence of congenital anomalies was significantly higher in mothers aged > 30 years as compared to a younger age group (Parmar et al., 2010). Khanum et al., 2004 also notes that being above 35 years of age is a risk factor of congenital anomalies; something that was also reported in Tanzania (Mashuda et al., 2014b) and a study previously done in KNH (Muga et al., 2009). On the other hand, a study in Egypt reported that maternal age was not significantly associated with development of congenital anomalies (El Koumi et al., 2013a).

All the mothers interviewed were of African race. Blacks are reported to have a higher prevalence of rare genetic malformations (Knowles et al., 2017). KNH being in Kenya; which is mainly populated by blacks, and a public hospital, other races were not expected to be observed. This might explain why all participants were black.

Regarding parity; majority were multigravidas. Mothers' parity was not statistically significant in relation to occurrence of congenital anomalies. In South India, being a primigravida was

identified as a risk factor (Sunitha et al., 2017) while in Eastern India, the findings indicated significantly higher incidence of birth defects among the multiparous (Sarkar et al., 2013b). In another study, the birth defects were seen more frequently among mothers with a parity of four and above (Singh and Gupta, 2009b).

Most of the respondents were Christians, followed by Muslims. This is fairly the normal trend in Kenya according to the East African Living Encyclopedia which stated that Christians contribute 70% of the population while Muslims are approximately 6% ("East Africa Living Encyclopedia," 2014). In India, religious pattern had no much effect on prevalence of congenital anomaly (Parmar et al., 2010). In Jammu, the anomalies were more common among the Muslims compared to Hindus (Singh and Gupta, 2009b).

In Denmark, women whose attendance to school was <10 years had an almost three-fold higher chance of delivering an anomalous child, as compared with mothers who had received >4 years of tertiary education (Olesen et al., 2009). This is comparable with the present study since those with tertiary education were 26.9%. In UK, it was noted that a mothers education to degree level was protective regardless of ethnicity (Sheridan et al., 2013).

In the present study, a vast majority of the mothers were not working. Low social economic status has been found to be an indirect determinant of birth defects. Constrained resources may lead to inaccessibility of sufficient and nutritious as well as limited access to healthcare and screening (Mashuda et al., 2014a). A steep increase in the association of low maternal social economic status and congenital heart disease as the primary outcome have been noted (Yu et al., 2014).

A positive history in the family of congenital anomalies has been linked with a greater risk of siring other children with birth defects (El Koumi et al., 2013a). (Dupépé et al., 2017) concluded that genetics are associated with the pathogenesis of neural tube defects even in the modern era of folic acid use. In the present study, only few of the respondents had a family history of birth defects. It is possible that there was under-reporting of family history of birth defects due to shame and stigma. As (Dellicour et al., 2013) noted in his study, children with birth defects were neglected either because of deficient knowledge on where to seek help, or because these infants brought shame to the family, and so were hidden from the society.

Only one malformed baby was a product of consanguineous marriage. Consanguineous marriages are not a common practice in Kenya, its mainly in North Africa, Middle, East and West of Asia. Studies done in these regions have reported a correlation between consanguinity and occurrence of congenital anomalies (Tayebi et al., 2010b) (Mosayebi and Movahedian, 2007) and (Hamamy, 2012).

Neural tube defects are the recorded to be the most preventable congenital anomalies. Particularly, the adequate intake of Folic acid (daily dose of 0.4mg) reduces the prevalence and re-occurrence of neural tube defects (Taruscio et al., 2011). It is also known to reduce other defects like cardiovascular and renal system anomalies, cleft lips and limb reduction defects (Salerno et al., 2008). Majority of the mothers took folic acid and iron supplements during pregnancy. In as much as a majority of the respondents took folic acid, most of them reported to have started the intake in the second trimester. For normal brain and spinal cord development, it is crucial that the mother takes folic acid during the preconception period (Hall and Solehdin, 1998). This low uptake of folic acid during the first trimester could explain the higher prevalence of neural tube defects noted.

Few of the participants reported to have used medications during pregnancy. Some of the drugs listed include antibiotics like Amoxicillin and Cefuroxime, Paracetamol, Mebendazole, Albendazole, Clotrimazole pessaries, ARVs, Anti-diabetics, Byofater and Multivitamins. Some mothers were not able to specify the drugs they took during pregnancy. 78.8% of mothers reported not taking any medications during pregnancy which is comparable to those in Dhaka (75.3%) (Bari, 2014). Several medications consumed in the present study overlap with those ones in Dhaka where in Dhaka: 2.6% reported of taking antibiotics and 2.2% took some kind of medication but could not specify which ones. In Lebanon, mothers consumption of drugs was associated with higher risk of birth defects (Francine et al., 2014).

Several mothers reported to have suffered medical conditions. Hypertension was the most common. Others included diabetes, Anemia, UTI among others. In India, the occurrence of congenital anomalies was higher among the HRP women as compared to the general population (Sunitha et al., 2017). Chronic hypertension in pregnancy exposes the neonates to a significant risk of being born with renal, cleft lip/cleft palate and limb birth defects (Bellizzi et al., 2016). Diabetes in pregnancy has been found to have toxic effects on the developing embryo, and the risk of birth defects is significantly increased (Chen, 2005). Sharpe (Sharpe et al., 2005) also

found that occurrence of birth defects was significantly higher among neonates born of mothers with maternal diabetes.

The findings indicated that alcohol consumption and maternal smoking (active smoking) were not associated with birth defects. None of the mothers was an active smoker, and only very few reported to have consumed alcohol during pregnancy. Maternal smoking in the first three months of pregnancy has been found to have a positive correlation with cleft lip and cleft palate (Little et al., 2004). In contrast to other studies, there was a null association between alcohol intake during pregnancy and the risk of congenital anomalies when a meta-analysis was done (Wen et al., 2016). Alcohol consumption and active cigarette smoking are not common practices among Kenya women, especially during pregnancy due to cultural norms.

A significant majority of the participants had received antenatal care with only slightly less than a half attending clinic less than 4 times. The National Guidelines for Quality Obstetrics and Perinatal Care recommend at least 4 antenatal visits. In his study, Granado reported that no, 3 or less antenatal visits is associated with occurrence of birth defects (Costa et al., 2006). In BSMMU research findings (Fatemaq et al., 2011) 92% had sought antenatal care irregularly while 8% had had regular visits. Similar findings were recorded in Dhaka where 42% of the mothers had not received any antenatal care, 42% had irregular visits while those who had regular visits were 15% (Bari, 2014). Receiving antenatal care is an integral part of prenatal care. It is during those visits that mothers are taught on importance of adequate nutrition, avoiding teratogens and even infectious diseases in pregnancy. Iron and folate supplements are also distributed during these visits (Penchaszadeh, 2002).

Less than a third of the participants did an ultrasound during pregnancy. Even so, only 2 of these knew prenatally that their child had a birth defect. The diagnosis of a congenital malformation prenatally helps the mother and health care workers make informed decisions during pregnancy and appropriate management perinatally, like place of delivery and mode of delivery. This is assumed to have an improved outcome (Todros et al., 2001).

Majority of the participants reported to not live near industries. Stingone concluded that there was some positive correlation between certain pollutants and birth defects. (Stingone et al.2014). Most of the participants in this study were referrals from outside Nairobi, and most industries are located in industrial area.

More than two thirds of the anomalous neonates were born via the vaginal route as compared to less than a third who were born through caesarian delivery. This is in contrast in Jammu where most babies were born via caesarian section compared to vaginal delivery (Singh and Gupta, 2009b).The choice of delivery route must be based on fetal maturity, the presenting part and even the nature of the anomaly in question (McCurdy and Seeds, 1993). Since most of the anomalies in the present study were not diagnosed prenatally, presence of congenital anomaly did not dictate the route of birth; other factors did.

There were more malformed female than male neonates; however, the sex of the neonate was not significant. BSMMU had contrary outcome where males were more than the females (Fatemaq et al., 2011). A previous study in KNH also reported more anomalous male than female infants, although the difference was not statistically relevant (Muga et al., 2009).

The relationship between low birth weight and an greater risk of birth defects is clearly documented (Francine et al., 2014) (Khan et al., 2012). The findings of this present study are in accordance with that.

The prevalence of birth defects was decreasing with increasing birth order. At Sir T Hospital, similar findings were filed (Parmar et al., 2010). On the contrary, (Khanum et al., 2004), as well as in Mwanza, Tanzania (Mashuda et al., 2014b); the occurrence of birth defects was higher in babies who had a birth order of ≥ 4.

The prevalence of malformations was slightly higher in term babies as compared to preterm babies. Many studies have reported different findings: in Eastern India (Sarkar et al., 2013b) and Egypt (Koumi et al., 2013), the incidence of birth defects was significantly higher in preterm babies compared to term babies. At Sir T Hospital, newborns who were premature had 4 times more incidence of birth defects in comparison with term babies (Parmar et al., 2010).

5.3 EFFECT ON AFFECTED MOTHERS

The circumstances under which the news about the congenital anomaly was delivered is clearly recalled by the mothers. With a majority of the mothers learning of the diagnosis after birth, it is a clear indication that there is low use of antenatal ultrasonography. From the ancient days, a prenatal ultrasound is considered the most effective tool in diagnosing congenital malformations (Boyd et al., 1998). (Bijma et al., 2007) had a contrary report to the present study: He cited that in the last few decades, the use of antenatal ultrasonography for the detection of fetal defects has

been on the rise. This had resulted in shifting in the time a malformation is diagnosed; from the neonatal period, to the prenatal period. When gross anomalies are detected prenatally, especially those that are not compatible with life, terminating the pregnancy is a viable alternative.

Most mothers had not seen a birth defect before. A study in Western Kenya reported that children with congenital malformation were believed to bring shame to the family and were therefore hidden from the society (Dellicour et al., 2013). This behaviour could create a notion that congenital anomalies are rare, but in essence, they are common.

Most mothers didn't know what causes these anomalies. Some had the wrong information. This is similar to what was found in Brazil: there were erroneous ideas on the causes of birth defects, and this was regardless of the socioeconomic status (Garcias and Schüler-Faccini, 2004b). This conventional knowledge on risk factors cannot be ignored because it interferes with how a woman takes care of her health. The prevalence of siring an anomalous baby caused by exposure of the mother to specific risk factors can be reduced if the mother is aware of such factors. Such awareness is likely to lead to preventive behaviour.

The arrival of a baby is an important occurence in the life cycle of a family as there are many expectations. Therefore, giving birth to a newborn who appears different or one who presents with life threatening conditions is bound to trigger some reactions (Tusano, 2015). Some of the emotions reported are; shock, feeling bad, depression, hopelessness and grief. In his study, (Bijma et al., 2007) reported the same emotions. (Mazer et al., 2008a) said that the parents of such a neonate undergo silent mourning that may not be evident to those around them. Having carried a child for nine months, a mother hopes for a normal child who will be a productive citizen. When this doesn't happen, the parents are hopeless, wondering how they will face the reality of living with an anomalous child (Tusano, 2015).

Most of the mothers cited receiving support from spouses and family members. (Tusano, 2015) confirmed that mothers that have an anomalous child have a tendency of functioning effectively with family support. According to (Bruce et al., 2014), mothers desired to receive competent care and support from health care workers as well as relatives and friends. Swedish mothers cited that being in support groups with couples with similar experiences was a source of immense support (Bratt et al., 2015). For mothers who have been indirectly rejected by their spouses and family members, they are the sole bearers of the burden.

Healthcare workers can play a vital role in helping families cope with the challenges of siring a baby with birth defects. Some mothers wanted information regarding risk factors and management of congenital anomalies disseminated to them. (Lemacks et al., 2013a) and (Gitsels-van der Wal et al., 2015) cited the importance of mothers being well informed. Majority of the mothers primarily desired that their children be treated. WHO reports that most structural anomalies can be corrected through surgery ("WHO," 2015). Some mothers cited financial support as something they would want from the healthcare system. Numerous studies have cited financial burden as a source of stress to the parents of anomalous infants (Tusano, 2015), (Lemacks et al., 2013b)and (Anderson et al., 2007). Importance of counseling has also been reported by many researchers (Marokakis et al., 2016) and (Gitsels-van der Wal et al., 2015).

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

5.0 INTRODUCTION

This chapter seeks to draw conclusions and make recommendations based on the findings.

5.1 CONCLUSION

The prevalence of Congenital Anomalies (CAs) at NBU, KNH is 19.4%. This is a high prevalence compared to the global prevalence of 3-7%. This disease burden poses a challenge in attainment of Sustainable Development Goal (SDG) 3.

CAs were more likely to be associated with younger maternal age, being of low socio-economic class, vaginal delivery and the neonate being a first born. There was deficient knowledge by the mothers regarding congenital anomalies as well as the risk factors.

Giving birth to an anomalous child brings feelings of consternation and apprehension. Mothers need counseling and support groups. The cost of treating these children is something of concern. Support groups for the affected mothers don't exist. There is little to no counseling to the mother after the diagnosis on a congenital anomaly is made. A long hospital stay for these anomalous neonates is experienced due to slow interventions and lack of prompt management.

5.2 RECOMMENDATIONS

5.2.1 Ministry of Health

Ministry of Health should be intentional in mobilizing and allocating more resources in preventing, screening and prompt management of these congenital anomalies.

Through the 'Department of Preventive and Promotive health', the Ministry of Health should educate the public about birth defects. Preventable causes of congenital anomalies need to be taught; preconception care, use of folic acid, cessation of smoking and consumption of alcohol and consanguinity. Health education can be done through mass media like television, social media like Facebook and Twitter; and fliers.

The 'National guidelines for quality obstetric and perinatal care' recommends at least 4 antenatal visits. The MOH should, through the antenatal clinics should encourage pregnant women to have

regular antenatal visits. Ultrasounds for prenatal diagnosis of CA should be recommended for prevention, early intervention and even termination of the pregnancy where necessary.

Peri-conception screening and counseling, as recommended by WHO, should be adopted by the Ministry of Health. This includes screening for extremes of age, substance use. Genetic counseling centres can also be set up in every region. This is useful in identifying those at risk for certain anomalies or at risk of passing certain disorders to their offspring.

5.2.2 KNH

The hospital should mobilize and channel more resources to tackle congenital anomalies. Ensure better collaboration between the different specialties for prompt diagnosis and management of birth defects. This can be done through effective communication.

For the health care workers involved in prevention and management of birth defects; the hospital should increase and strengthen their knowledge.

Support groups for the affected mothers need to be formed, and the mothers encouraged to join them. There should be a permanent counselor in NBU to offer psychological support to affected mothers.

5.2.3 Further research

A larger study should be done in Kenya, for a longer period of time, to determine the prevalence and pattern of birth defects and describe further the risk factors.

A study should be conducted to describe the relationship between genetic makeup and occurrence of congenital anomalies.

REFERENCES

Abdi-Rad, I., Khoshkalam, M., Farrokh-Islamlou, H.-R., 2008. The prevalence at birth of overt congenital anomalies in Urmia, Northwestern Iran. Arch. Iran. Med. 11, 148–151.

Admin, 2010. Cross-sectional Studies [WWW Document]. Health Knowl. URL https://www.healthknowledge.org.uk/public-health-textbook/research-methods/1a-epidemiology/cs-as-is/cross-sectional-studies (accessed 2.16.18).

Anderson, D., Dumont, S., Jacobs, P., Azzaria, L., 2007. The Personal Costs of Caring for a Child with a Disability: A Review of the Literature. Public Health Rep. 122, 3–16.

Bari, C.F.M., 2014. Spectrum of congenital anomalies among children attending the pediatric departments of dhaka medical college hospital. IOSR J. Dent. Med. Sci. 13, 20–46.

Bellizzi, S., Ali, M.M., Abalos, E., Betran, A.P., Kapila, J., Pileggi-Castro, C., Vogel, J.P., Merialdi, M., 2016. Are hypertensive disorders in pregnancy associated with congenital malformations in offspring? Evidence from the WHO Multicountry cross sectional survey on maternal and newborn health. BMC Pregnancy Childbirth 16. https://doi.org/10.1186/s12884-016-0987-8

Bijma, H.H., Heide, A. van der, Wildschut, H.I.J., 2007. Decision-making after ultrasound diagnosis of fetal abnormality. Eur. Clin. Obstet. Gynaecol. 3, 89–95. https://doi.org/10.1007/s11296-007-0070-0

Birt, L., Scott, S., Cavers, D., Campbell, C., Walter, F., 2016. Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? Qual. Health Res. 26, 1802–1811. https://doi.org/10.1177/1049732316654870

Boyd, P.A., Chamberlain, P., Hicks, N.R., 1998. 6-year experience of prenatal diagnosis in an unselected population in Oxford, UK. Lancet Lond. Engl. 352, 1577–1581.

Bratt, E.-L., Järvholm, S., Ekman-Joelsson, B.-M., Mattson, L.-Å., Mellander, M., 2015. Parent's experiences of counselling and their need for support following a prenatal diagnosis of congenital heart disease - a qualitative study in a Swedish context. BMC Pregnancy Childbirth 15, 171. https://doi.org/10.1186/s12884-015-0610-4

Brody, J.E., 1995. Study Links Excess Vitamin A and Birth Defects. N. Y. Times.

Bruce, E., Lilja, C., Sundin, K., 2014. Mothers' lived experiences of support when living with young children with congenital heart defects. J. Spec. Pediatr. Nurs. 19, 54–67. https://doi.org/10.1111/jspn.12049

Calzolari, E., Barisic, I., Loane, M., Morris, J., Wellesley, D., Dolk, H., Addor, M.-C., Arriola, L., Bianchi, F., Neville, A.J., Budd, J.L.S., Klungsoyr, K., Khoshnood, B., McDonnell, B., Nelen, V., Queisser-Luft, A., Rankin, J., Rissmann, A., Rounding, C., Tucker, D., Verellen-Dumoulin, C., Walle, H. de, Garne, E., 2014. Epidemiology of multiple congenital anomalies in Europe: A EUROCAT population-based registry study. Birt. Defects Res. A. Clin. Mol. Teratol. 100, 270–276. https://doi.org/10.1002/bdra.23240

Chen, C.-P., 2005. Congenital Malformations Associated with Maternal Diabetes. Taiwan. J. Obstet. Gynecol. 44, 1–7. https://doi.org/10.1016/S1028-4559(09)60099-1

Cosme, H.W., Lima, L.S., Barbosa, L.G., 2017. PREVALENCE OF CONGENITAL ANOMALIES AND THEIR ASSOCIATED FACTORS IN NEWBORNS IN THE CITY OF SÃO PAULO FROM 2010 TO 2014. Rev. Paul. Pediatr. 35, 33–38. https://doi.org/10.1590/1984-0462/;2017;35;1;00002

Costa, C.M. da S., Gama, S.G.N. da, Leal, M. do C., 2006. Congenital malformations in Rio de Janeiro, Brazil: prevalence and associated factors. Cad. Saúde Pública 22, 2423–2431. https://doi.org/10.1590/S0102-311X2006001100016

Creswell, J.W., Creswell, J.W., 2007. Qualitative inquiry & research design: choosing among five approaches, 2nd ed. ed. Sage Publications, Thousand Oaks.

Daly, M.J., Gaidamakova, E.K., Matrosova, V.Y., Kiang, J.G., Fukumoto, R., Lee, D., Wehr, N.B., Viteri, G.A., Berlett, B.S., Levine, R.L., 2010. This is an open-access article distributed under the terms of the Cre...

Dastgiri, S., Stone, D.H., Le-Ha, C., Gilmour, W.H., 2002. Prevalence and secular trend of congenital anomalies in Glasgow, UK. Arch. Dis. Child. 86, 257–263. https://doi.org/10.1136/adc.86.4.257

Dellicour, S., Desai, M., Mason, L., Odidi, B., Aol, G., Phillips-Howard, P.A., Laserson, K.F., ter Kuile, F.O., 2013. Exploring Risk Perception and Attitudes to Miscarriage and Congenital Anomaly in Rural Western Kenya. PLoS ONE 8. https://doi.org/10.1371/journal.pone.0080551

Delport, S.D., Christianson, A.L., Berg, H.J.S. van den, Wolmarans, L., Gericke, G.S., 1995. Congenital anomalies in black South African liveborn neonates at an urban academic hospital. S. Afr. Med. J. 85, 11–15.

Dupépé, E.B., Patel, D.M., Rocque, B.G., Hopson, B., Arynchyna, A.A., Bishop, E.R., Blount, J.P., 2017. Surveillance Survey of Family History in Children with Neural Tube Defects. J. Neurosurg. Pediatr. 19, 690–695. https://doi.org/10.3171/2016.12.PEDS1668

East Africa Living Encyclopedia [WWW Document], 2014. URL https://www.africa.upenn.edu/NEH/kreligion.htm (accessed 9.4.18).

Egbe, A.C., 2015. Birth Defects in the Newborn Population: Race and Ethnicity. Pediatr. Neonatol. 56, 183–188. https://doi.org/10.1016/j.pedneo.2014.10.002

El Koumi, M.A., Al Banna, E.A., Lebda, I., 2013a. Pattern of congenital anomalies in newborn: a hospital-based study. Pediatr. Rep. 5. https://doi.org/10.4081/pr.2013.e5

El Koumi, M.A., Al Banna, E.A., Lebda, I., 2013b. Pattern of congenital anomalies in newborn: a hospital-based study. Pediatr. Rep. 5. https://doi.org/10.4081/pr.2013.e5

Fatemaq, K., Begum, F., Akter, N., Zaman, S.M.M., 2011. Major Congenital Malformations Among The Newborns in BSMMU Hospital. Bangladesh Med. J. 40, 7–12.

Feng, Y., Wang, S., Chen, R., Tong, X., Wu, Z., Mo, X., 2015. Maternal Folic Acid Supplementation and the Risk of Congenital Heart Defects in Offspring: A Meta-Analysis of Epidemiological Observational Studies. Sci. Rep. 5. https://doi.org/10.1038/srep08506

Fonseca, A., Nazaré, B., Canavarro, M.C., 2011. Patterns of parental emotional reactions after a pre-or postnatal diagnosis of a congenital anomaly. J. Reprod. Infant Psychol. 29, 320–333.

Francine, R., Salameh, P., Hamadé, A., 2014. Congenital Anomalies: Prevalence and Risk Factors. J. Public Health 2, 58–63.

Garcias, G. de L., Schüler-Faccini, L., 2004a. The beliefs of mothers in southern Brazil regarding risk-factors associated with congenital abnormalities. Genet. Mol. Biol. 27, 147–153. https://doi.org/10.1590/S1415-47572004000200003

Garcias, G. de L., Schüler-Faccini, L., 2004b. The beliefs of mothers in southern Brazil regarding risk-factors associated with congenital abnormalities. Genet. Mol. Biol. 27, 147–153. https://doi.org/10.1590/S1415-47572004000200003

Gillani, S., Kazmi, N.H.S., Najeeb, S., Hussain, S., Raza, A., 2011. Frequencies of congenital anomalies among newborns admitted in nursery of ayub teaching hospital abbottabad, pakistan. J Ayub Med Coll Abbottabad 23.

Gitsels-van der Wal, J.T., Martin, L., Manniën, J., Verhoeven, P., Hutton, E.K., Reinders, H.S., 2015. Antenatal counselling for congenital anomaly tests: Pregnant Muslim Moroccan women′s preferences. Midwifery 31, e50–e57. https://doi.org/10.1016/j.midw.2015.01.002

Hall, J., Solehdin, F., 1998. Folic acid for the prevention of congenital anomalies. Eur. J. Pediatr. 157, 445–450.

Hamamy, H., 2012. Consanguineous marriages. J. Community Genet. 3, 185–192. https://doi.org/10.1007/s12687-011-0072-y

Hernández, E.N., Serrano, S.C., Pablo, A.E.R., 2013. Prevalence of congenital malformations recorded on the birth certificate and fetal death certificate, Mexico, 2009 to 2010. Bol Med Hosp Infant Mex 70, 7.

Hertzog, M.A., 2008. Considerations in determining sample size for pilot studies. Res. Nurs. Health 31, 180–191. https://doi.org/10.1002/nur.20247

Jamison, D.T., Breman, J.G., Measham, A.R., Alleyne, G., Claeson, M., Evans, D.B., Jha, P., Mills, A., Musgrove, P. (Eds.), 2006. Disease Control Priorities in Developing Countries, 2nd ed. World Bank, Washington (DC).

Khan, A.A., Khattak, T.A., Shah, S.H.A., Roshan, E., Haq, A., 2012. Pattern of congenital anomalies in the newborn. J Rawal Med Coll 16, 171–173.

Khanum, S., Noor, K., Kawser, C.A., 2004. Studies on congenital abnormalities and related risk factors. Mymensingh Med. J. MMJ 13, 177–180.

KIng, I., 2008. Controlling Birth Defects: Reducing the Hidden Toll of Dying and Disabled Children in Low-Income Countries.

Knowles, R.L., Ridout, D., Crowe, S., Bull, C., Wray, J., Tregay, J., Franklin, R.C., Barron, D.J., Cunningham, D., Parslow, R.C., Brown, K.L., 2017. Ethnic and socioeconomic variation in incidence of congenital heart defects. Arch. Dis. Child. 102, 496–502. https://doi.org/10.1136/archdischild-2016-311143

Koumi, M.A.E., Banna, E.A.A., Lebda, I., 2013. Pattern of congenital anomalies in newborn: a hospital-based study. Pediatr. Rep. 5, 5.

Kunda, I., Siziya, S., Mwanakasale, V., 2016. A Review of Congenital Anomalies Presenting at Arthur Davison Children's Hospital. Int. J. Sci. 29, 7.

Lemacks, J., Fowles, K., Mateus, A., Thomas, K., 2013a. Insights from Parents about Caring for a Child with Birth Defects. Int. J. Environ. Res. Public. Health 10, 3465–3482. https://doi.org/10.3390/ijerph10083465

Lemacks, J., Fowles, K., Mateus, A., Thomas, K., 2013b. Insights from Parents about Caring for a Child with Birth Defects. Int. J. Environ. Res. Public. Health 10, 3465–3482. https://doi.org/10.3390/ijerph10083465

Little, J., Cardy, A., Arslan, M.T., Gilmour, M., Mossey, P.A., 2004. Smoking and Orofacial Clefts: A United Kingdom–Based Case-Control Study. Cleft Palate. Craniofac. J. 41, 381–386. https://doi.org/10.1597/02-142.1

Marokakis, S., Kasparian, N.A., Kennedy, S.E., 2016. Prenatal counselling for congenital anomalies: a systematic review. Prenat. Diagn. 36, 662–671. https://doi.org/10.1002/pd.4836

Mashuda, F., Zuechner, A., Chalya, P.L., Kidenya, B.R., Manyama, M., 2014a. Pattern and factors associated with congenital anomalies among young infants admitted at Bugando medical centre, Mwanza, Tanzania. BMC Res. Notes 7, 195. https://doi.org/10.1186/1756-0500-7-195

Mashuda, F., Zuechner, A., Chalya, P.L., Kidenya, B.R., Manyama, M., 2014b. Pattern and factors associated with congenital anomalies among young infants admitted at Bugando medical centre, Mwanza, Tanzania. BMC Res. Notes 7, 195. https://doi.org/10.1186/1756-0500-7-195

Mazer, P., Gischler, S.J., 2009. Children with anatomical congenital anomalies; a portait follow-up over five years. The Author] ; Erasmus University [Host, S.l.]; Rotterdam.

Mazer, P., Gischler, S.J., Koot, H.M., Tibboel, D., van Dijk, M., Duivenvoorden, H.J., 2008a. Impact of a child with congenital anomalies on parents (ICCAP) questionnaire; a psychometric analysis. Health Qual. Life Outcomes 6, 102. https://doi.org/10.1186/1477-7525-6-102

Mazer, P., Gischler, S.J., Koot, H.M., Tibboel, D., van Dijk, M., Duivenvoorden, H.J., 2008b. Impact of a child with congenital anomalies on parents (ICCAP) questionnaire; a psychometric analysis. Health Qual. Life Outcomes 6, 102. https://doi.org/10.1186/1477-7525-6-102

McCurdy, C.M., Seeds, J.W., 1993. Route of delivery of infants with congenital anomalies. Clin. Perinatol. 20, 81–106.

Moore, K.L., Persaud, T.V.N., 1998. Human Birth Defects in: The Developing Human: Clinically Orientated Embryology , 1998. WB Saunders Co. 167–200.

Mosayebi, Z., Movahedian, A.H., 2007. Pattern of congenital malformations in consanguineous versus nonconsanguineous marriages in Kashan, Islamic Republic of Iran. East. Mediterr. Health J. 13, 868–875.

Muga, R., Mumah, S.C.J., Juma, P.A., 2009. Congenital malformations among newborns in Kenya. Afr. J. Food Agric. Nutr. Dev. 9. https://doi.org/10.4314/ajfand.v9i3.43008

Nabea, G.M., Kamau, T.M., Kaburu, E.W., 2015. The Incidence of Congenital Anomalies among Newborns at Pumwani Hospital, Nairobi, Kenya.

Naing, L., Winn, T., Rusli, B.N., 2014. Practical Issues in Calculating the Sample Size for Prevalence Studies 6.

Ndibazza, J., Lule, S., Nampijja, M., Mpairwe, H., Oduru, G., Kiggundu, M., Akello, M., Muhangi, L., Elliott, A.M., 2011a. A description of congenital anomalies among infants in Entebbe, Uganda. Birt. Defects Res. A. Clin. Mol. Teratol. 91, 857–861. https://doi.org/10.1002/bdra.20838

Ndibazza, J., Lule, S., Nampijja, M., Mpairwe, H., Oduru, G., Kiggundu, M., Akello, M., Muhangi, L., Elliott, A.M., 2011b. A description of congenital anomalies among infants in Entebbe, Uganda. Birt. Defects Res. A. Clin. Mol. Teratol. 91, 857–861. https://doi.org/10.1002/bdra.20838

Okuyama, J., Funakoshi, S., Amae, S., Kamiyama, T., Ueno, T., Hayashi, Y., 2017. Coping Patterns in a Mother of a Child with Multiple Congenital Anomalies: A Case Study. J. Intensive Crit. Care 3. https://doi.org/10.21767/2471-8505.100075

Olasoji, H.O., Ugboko, V.I., Arotiba, G.T., 2007. Cultural and religious components in Nigerian parents' perceptions of the aetiology of cleft lip and palate: implications for treatment and rehabilitation. Br. J. Oral Maxillofac. Surg. 45, 302–305. https://doi.org/10.1016/j.bjoms.2006.09.005

Olesen, C., Thrane, N., Rønholt, A.-M., Olsen, J., Henriksen, T.B., 2009. Association between social position and congenital anomalies: A population-based study among 19,874 Danish women. Scand. J. Public Health 37, 246–251. https://doi.org/10.1177/1403494808100938

Organización Mundial de la Salud, 2008. World health statistics 2008. World Health Organization, Geneva, Switzerland.

Parmar, A., Rathod, S.P., Patel, S.V., Patel, S.M., 2010. A study of congenital anomalies in newborn.

Penchaszadeh, V.B., 2002. Preventing congenital anomalies in developing countries. Community Genet. 5, 61–69. https://doi.org/10.1159/000064632

Persson, M., Cnattingius, S., Villamor, E., Söderling, J., Pasternak, B., Stephansson, O., Neovius, M., 2017. Risk of major congenital malformations in relation to maternal overweight and obesity severity: cohort study of 1.2 million singletons. BMJ 357, j2563. https://doi.org/10.1136/bmj.j2563

Postoev, V.A., Nieboer, E., Grjibovski, A.M., Odland, J.Ø., 2015. Prevalence of birth defects in an Arctic Russian setting from 1973 to 2011: a register-based study. Reprod. Health 12. https://doi.org/10.1186/1742-4755-12-3

Rather, I.A., Lone, J.B., Bajpai, V.K., Park, Y.-H., 2017. Zika Virus Infection during Pregnancy and Congenital Abnormalities. Front. Microbiol. 8. https://doi.org/10.3389/fmicb.2017.00581

Rosano, A., Botto, L.D., Botting, B., Mastroiacovo, P., 2000. Infant mortality and congenital anomalies from 1950 to 1994: an international perspective. J. Epidemiol. Community Health 54, 660–666. https://doi.org/10.1136/jech.54.9.660

Sabzevari, S., Nematollahi, M., Mirzaei, T., Ravari, A., 2016. The Burden of Care: Mothers' Experiences of Children with Congenital Heart Disease. Int. J. Community Based Nurs. Midwifery 4, 374–385.

Salerno, P., Bianchi, F., Pierini, A., Baldi, F., Carbone, P., Mantovani, A., Taruscio, D., 2008. [Folic acid and congenital malformation: scientific evidence and public health strategies]. Ann. Ig. Med. Prev. E Comunita 20, 519–530.

Sankombo, M.T., 2015. Experiences of parents with congenital abnormalities at Oshakati Intermediate hospital, Oshana region (Thesis). University of Namibia.

Sarkar, S., Patra, C., Dasgupta, M.K., Nayek, K., Karmakar, P.R., 2013a. Prevalence of Congenital Anomalies in Neonates and Associated Risk Factors in a Tertiary Care Hospital in Eastern India. J. Clin. Neonatol. 2, 131–134. https://doi.org/10.4103/2249-4847.119998

Sarkar, S., Patra, C., Dasgupta, M.K., Nayek, K., Karmakar, P.R., 2013b. Prevalence of Congenital Anomalies in Neonates and Associated Risk Factors in a Tertiary Care Hospital in Eastern India. J. Clin. Neonatol. 2, 131–134. https://doi.org/10.4103/2249-4847.119998

Sekhobo, J.P., 2001. An Evaluation of Congenital Malformations Surveillance in New York State: An Application of Centers for Disease Control and Prevention (CDC) Guidelines for Evaluating Surveillance Systems. Public Health Rep. 116, 296–305. https://doi.org/10.1093/phr/116.4.296

Sharpe, P.B., Chan, A., Haan, E.A., Hiller, J.E., 2005. Maternal diabetes and congenital anomalies in South Australia 1986-2000: a population-based cohort study. Birt. Defects Res. A. Clin. Mol. Teratol. 73, 605–611. https://doi.org/10.1002/bdra.20172

Sheridan, E., Wright, J., Small, N., Corry, P.C., Oddie, S., Whibley, C., Petherick, E.S., Malik, T., Pawson, N., McKinney, P.A., Parslow, R.C., 2013. Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. The Lancet 382, 1350–1359. https://doi.org/10.1016/S0140-6736(13)61132-0

Singh, A., Gupta, R.K., 2009a. Pattern of Congenital Anomalies in Newborn : A Hospital Based Prospective Study. Httpwwwjkscienceorgarchive11111-SA-Pattern20of20congenitalpdf.

Singh, A., Gupta, R.K., 2009b. Pattern of Congenital Anomalies in Newborn: A Hospital Based Prospective Study.

Singh, B., Ghimire, P., 2017. Stress and Coping among the Parents of Children with Congenital Heart Disease: A Hospital Based Study. J. Health Educ. Res. Dev. 05. https://doi.org/10.4172/2380-5439.1000212

Singh, K., Krishnamurthy, K., Greaves, C., Kandamaran, L., Nielsen, A.L., Kumar, A., 2014. Major Congenital Malformations in Barbados: The Prevalence, the Pattern, and the Resulting Morbidity and Mortality [WWW Document]. Int. Sch. Res. Not. https://doi.org/10.1155/2014/651783

Stephanie, 2017. Test-Retest Reliability / Repeatability [WWW Document]. Stat. To. URL http://www.statisticshowto.com/test-retest-reliability/ (accessed 5.8.18).

Stephanie, 2015. Sample Size in Statistics (How to Find it): Excel, Cochran's Formula, General Tips [WWW Document]. Stat. To. URL http://www.statisticshowto.com/probability-and-statistics/find-sample-size/ (accessed 5.2.18).

Stingone, J.A., Luben, T.J., Daniels, J.L., Fuentes, M., Richardson, D.B., Aylsworth, A.S., Herring, A.H., Anderka, M., Botto, L., Correa, A., Gilboa, S.M., Langlois, P.H., Mosley, B., Shaw, G.M., Siffel, C., Olshan, A.F., National Birth Defects Prevention Study, 2014. Maternal exposure to criteria air pollutants and congenital heart defects in offspring: results from the national birth defects prevention study. Environ. Health Perspect. 122, 863–872. https://doi.org/10.1289/ehp.1307289

Stoe_el, J., Townsend, J., 1991. Design SecondEdition.

Sunitha, T., Rebekah Prasoona, K., Muni Kumari, T., Srinadh, B., Laxmi Naga Deepika, M., Aruna, R., Jyothy, A., 2017. Risk factors for congenital anomalies in high risk pregnant women: A large study from South India. Egypt. J. Med. Hum. Genet. 18, 79–85. https://doi.org/10.1016/j.ejmhg.2016.04.001

Taruscio, D., Carbone, P., Granata, O., Baldi, F., Mantovani, A., 2011. Folic acid and primary prevention of birth defects. BioFactors Oxf. Engl. 37, 280–284. https://doi.org/10.1002/biof.175

Tayebi, N., Yazdani, K., Naghshin, N., 2010a. The Prevalence of Congenital Malformations and its Correlation with Consanguineous Marriages. Oman Med. J. 25, 37–40. https://doi.org/10.5001/omj.2010.9

Tayebi, N., Yazdani, K., Naghshin, N., 2010b. The Prevalence of Congenital Malformations and its Correlation with Consanguineous Marriages. Oman Med. J. 25, 37–40. https://doi.org/10.5001/omj.2010.9

Tennant, P.W.G., Raza, F., Bythell, M., Rankin, J., 2010. Maternal age and the risk of structural congenital anomalies. Arch. Dis. Child. - Fetal Neonatal Ed. 95, Fa4–Fa4. https://doi.org/10.1136/adc.2010.192310.1.2

Todros, T., Capuzzo, E., Gaglioti, P., 2001. Prenatal diagnosis of congenital anomalies. Images Paediatr. Cardiol. 3, 3–18.

Tusano, S.M., 2015. THE UNIVERSITY OF NAMIBIA 171.

Velayutham, Banurekha, Velayutham, Boopathi, Joshua, V., Mehendale, S., 2016. Prevalence of Disability in Children and Adolescents in India, 2011. Indian J. Youth Adolesc. Health ISSN 2349-2880 3, 34–41.

Wen, Z., Yu, D., Zhang, W., Fan, C., Hu, L., Feng, Y., Yang, L., Wu, Z., Chen, R., Yin, K., Mo, X., 2016. Association between alcohol consumption during pregnancy and risks of congenital heart defects in offspring: meta-analysis of epidemiological observational studies. Ital. J. Pediatr. 42. https://doi.org/10.1186/s13052-016-0222-2

WHO [WWW Document], 2015. . World Health Organ. URL http://www.who.int/news-room/fact-sheets/detail/congenital-anomalies (accessed 9.10.18).

World Health Organization, World Bank (Eds.), 2011. World report on disability. World Health Organization, Geneva, Switzerland.

Wright, H.T., 1966. Congenital Anomalies and Viral Infections in Infants—The Etiologic Role of Maternal Viral Infections. Calif. Med. 105, 345–351.

Wu, V.K., Poenaru, D., Poley, M.J., 2013. Burden of Surgical Congenital Anomalies in Kenya: A Population-Based Study. J. Trop. Pediatr. 59, 195–202. https://doi.org/10.1093/tropej/fmt001

Yego, F., Stewart Williams, J., Byles, J., Nyongesa, P., Aruasa, W., D'Este, C., 2013. A retrospective analysis of maternal and neonatal mortality at a teaching and referral hospital in Kenya. Reprod. Health 10, 13. https://doi.org/10.1186/1742-4755-10-13

Yu, D., Feng, Y., Yang, L., Da, M., Fan, C., Wang, S., Mo, X., 2014. Maternal socioeconomic status and the risk of congenital heart defects in offspring: a meta-analysis of 33 studies. PloS One 9, e111056. https://doi.org/10.1371/journal.pone.0111056

Zaganjor, I., Sekkarie, A., L. Tsang, B., Williams, J., Razzaghi, H., Mulinare, J., E. Sniezek, J., Cannon, M., Rosenthal, J., 2015. Describing the Global Burden of Neural Tube Defects: A Systematic Literature Review.

Zheng, X., Song, X., Chen, G., Chen, J., Ji, Y., Wu, J., Liu, J., Zhang, L., Fan, X., 2007. [Epidemiology of birth defects in high-prevalence areas of China]. Zhonghua Liu Xing Bing Xue Za Zhi Zhonghua Liuxingbingxue Zazhi 28, 5–9.

APPENDICES

APPENDIX 1: GHANTT CHART

ACTIVITY	Nov. 2017	Dec. 2017	Jan. 2018	Feb. 2018	Marc. 2018	Apr. 2018	May. 2018	Jun. 2018	Jul. 2018	Aug. 2018	Sept. 2018
Proposal Writing											
Presentation for correction and approval											
Submission of proposal to ethical committee & approval											
Pre-testing											
Analysis and evaluation of pre-test											
Field data collection											
Data cleaning											
Data analysis and report writing											
Defense of project report											
Dissemination; submission and publication											

APPENDIX 2: BUDGET

ITEM	NO. OF UNITS	COST PER UNIT (KSHS)	TOTAL COST (KSHS.)
A. STATIONERY			
Foolscaps	½ ream	400	200
Pens	20	10	200
Pencils	10	10	100
Rubbers	4	15	60
Rulers	4	25	100
Folders	4	75	300
Flash disc	1	500	500
Sub Total			**1460**
B. **SERVICES**			
Proposal printing	50 pages	5	250
Proposal Photocopying	50 pages*10	2	1000
Proposal binding	3 copies	80	240
Report printing	90 pages	5	450
Report photocopying	90 pages*10	2	1800
Report binding	5 copies	100	500
Questionnaire printing	3 pages	5	15
Questionnaire copies	3 pages*52	2	312
Consent form	3 page	5	15
Consent form copies	3 pages*52	2	312
Ethics Committee Fee	1	2000	2000
Research assistants	2	10,000	20,000
Statistician fee	1	35,000	35,000
Publishing cost	2	30,000	60,000
Sub Total			**121,894**
Contingencies (10% of total cost)			**12,335**
TOTAL			**135,689**

APPENDIX 3: INFORMED CONSENT

STUDY TITLE:
Determinants of congenital anomalies and their effect on affected mothers: A case of Kenyatta National Hospital, New Born Unit.

Dear Respondent,

I am Ruth Wagathu, a post graduate student in the University of Nairobi, School of Nursing. I am carrying out a study on *Determinants of congenital anomalies and their effect on affected mothers: A case of Kenyatta National Hospital, New Born Unit.*

The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign this form.

You should understand the general principles which apply to all participants in a medical research: i) Your decision to participate is entirely voluntary; ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal; and iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

This study has approval by The Kenyatta National Hospital-University of Nairobi Ethics and Research Committee protocol No.: _____

What is this study about?

I will interview mothers whose neonates have congenital anomalies. The purpose of the interview is to find out the risk factors of congenital anomalies and their effect on affected mothers. You will be asked questions about this. This conversation may be recorded using a tape recorder. There will be 52 participants in this study. We are asking for your consent to participate in this study.

What will happen if you decide to be in this research study?

If you agree to participate in this study, you will be interviewed by a trained interviewer in a private area where you feel comfortable answering questions. The interview will last approximately 30 minutes.

Are there any risks, harms or discomforts associated with this study?

Although any medical research has the potential to introduce psychological, social, emotional and physical risks, efforts will be made to minimize the risks. One potential risk of being in the study is the loss of privacy. However, we will safeguard your privacy by keeping everything you tell us as confidential as possible and also by interviewing you in a private room. We will use a code number to identify you in a password-protected computer database and will keep all of our paper records in a locked file cabinet.

If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any questions asked during the interview.

All study staff and interviewers are professionals with special training in these interviews. In case of an injury, illness or complications related to this study, contact the study staff right away using the number provided at the end of this document. There will be counselor on standby in case of emotional distress.

Are there any benefits being in this study?

Participants in this study will benefit through free counseling on management of congenital anomalies. The findings of this research will provide more scientific information in prevention of congenital anomalies as well as build on the existing body of knowledge on human health and science.

Will being in this study cost you anything?

This study will cost you about thirty minutes of your time.

Will you get refund for any money spent as part of this study?

This study will not cost you money.

What if you have questions in future?

If you have further questions or concerns about participating in this study, please call or send a text message to the study staff at the number provided at the bottom of this page.
For more information about your rights as a research participant you may contact the Principal Investigator on Email: *wagathu08@gmail.com,* and Telephone: **0723 533 600** or the Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee Telephone No.: **020 2725272** Ext: **44102** Email: *uonknh_erc@uonbi.ac.ke.*

PARTICIPANT'S STATEMENT

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with the researcher. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation

in this study is voluntary and that I may choose to withdraw anytime. I freely agree to participate in this research study. I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study: **YES** ☐ **NO** ☐

Participant signature / Thumb Print _____

Date _____

RESEARCHER'S STATEMENT

I, the undersigned, have fully explained the relevant details of this research study to the participant. The participant has understood and has freely given her consent.

Researcher's Name: _____ **Signature** _____

Date: _____

WITNESS'S STATEMENT

I, the undersigned have witnessed the consenting process. The researcher has fully explained the relevant details of this research study to the participant. The participant has understood and has freely given her consent.

Witness's Name: _____ **Signature** _____

Date: _____

APPENDIX 4: UTOAJI IDHINI

KICHWA CHA UTAFITI:
Vigezo vya maumbile ya kuzaliwa yanayoweza kusababisha ulemavu, na adhari zake kwa walioadhirika: Hospitali kuu ya Kenyatta, kitengo cha watoto wachanga.

Mhojiwa,

Jina langu ni Ruth Wagathu, mwanafunzi wa uzamili, chuo kikuu cha Nairobi, shule ya uuguzi. Nafanya utafiti kuhusu ***Vigezo vya maumbile ya kuzaliwa yanayoweza kusababisha ulemavu, na adhari zake kwa walioadhirika: Hospitali kuu ya Kenyatta, kitengo cha watoto wachanga.***

Umuhimu wa mazungumzo haya ni kukufahamisha zaidi ili ufanye uamuzi wa busara kushiriki au kutoshiriki katika utafiti huu. Kuwa huru kuuliza maswali yoyote kuhusu kitakachofanyika utakapokubali kushiriki, madhara yanayoweza kutokea, manufaa ya utafiti huu, haki zako kama mshiriki na maswali yoyote kuhusu lolote ambalo hulieleweki. Tutakapo jibu maswali yako yote, basi utaamua kushiriki au la. Utakapokubali, nitakuuliza tafadhali utie sahihi na jina lako kwa ukurasa hapa chini.

Unafaa uelewe kwa ujumla nguzo muhimu ambazo zinalinda washiriki katiaka ufatiti wa sayansi ya afya: i) Kushiriki kwako ni kwa hiari; ii) Unaweza kujiondoa wakati wowote bila kushurutishwa kutoa maelezo ya kufanya hivyo; na iii) Kutoshiriki kwako katika utafiti huu hakutaathiri huduma unazopaswa kuzipata kwa hosipitali hii. Tutakupa nakala yako ili ujiwekee kwa manufaa yako binafsi.

Utafiti huu umeidhiniswha na kitengo cha maadili na utafiti cha hospitali kuu ya Kenyatta na chuo kikuu cha Nairobi nambari: _____

Utafiti huu unahusu nini?

Nitakao wahoji ni akina mama walio na watoto walio na maumbile ya kuzaliwa yanayoweza kusababisha ulemavu. Mahojiano haya yana madhumuni ya kuchunguza vigezo vya maumbile haya, na adhari yake kwa walioadhirika. Washiriki wataulizwa maswali kuhusu mambo hatari yanayoweza sababisha maumbile haya, na jinsi wameadhirika. Mahojiano haya yaweza pia nakiliwa kutumia kinasa sauti. Kutakuwa na washiriki 52 ambao wamechaguliwa kwa njia ya kisayansi. Ninaomba idhini yako uwe mshiriki wa utafiti huu.

Nini kitakachofanyika ukikubali kushiriki?

Yafuatayo yatafanyika: Utahojiwa na mtafiti aliyehitimu kwa sehemu ya tulivu na ya kisiri ambapo utakuwa huru kwa muda wa dakika thelathini hivi.

Utafiti huu una madhara yoyote?

Ijapokuwa utafiti wa kiafya una madhara yake kama ya kisaikolojia, tutajitahidi kabisa kupunguza madhara yoyote kwako. Kwa mfano, dhara moja ni uwezekano wa kupoteza usiri wako. Hata hivyo, mambo yote utatueleza tutayaweka kwa siri. Tutakupa nambari ya siri kwa compyuta ambayo imelindwa. Stakabadhi zote zitawekwa kwenye kabati itakayofungwa kwa kufuli.

Kama kutakuwa na maswali ambayo hungetaka kuyajibu, utaruhusiwa kutoyajibu. Uko na haki ya kutojibu swali lolote katika mahojiano. Watafiti wetu wote wamehitimu kufanya mahojiano haya. Kama kutakuwa na kuumia, ugonjwa au shida zingine zozote kwa ajili ya utafiti huu, tafadhali wasiliana nasi kupitia nambari iliyo chini ya kurasa hizi. Ikiwa kutakuwa na adhari yeyote ya kisaikologia, tunaye mshauri atakaye zungumza nawe.

Ufatiti huu una manufaa yoyote?

Utafaidika kwa kupata wosia mwafaka kuhusu kudhibiti maumbile haya ya kuzaliwa. Pia, utafiti huu utatuwezesha kuelewa magonjwa haya zaidi and jinsi ya kukabiliano nayo. Pia, tutaongeza ufahamu zaidi kwa sayansi ya afya na binadamu.

Kuna gharama ya kushiriki?

Utafiti huu utahitaji dakika thelathini za muda wako.

Utarejeshewa pesa zako?

Utafiti huu hautakugharimu pesa.

Na kama utakuwa na maswali baadaye?

Kama una maswali zaidi au lolote ambalo hulielewi kuhusu utafiti huu, tafadhali usisite kuwasiliana nasi kupitia nambari ambazo zimeandikwa hapa chini.
Kwa maelezo zaidi kuhusu haki za mshiriki katika utafiti, wasiliana na Mtafiti Mkuu Tovuti: *wagathu08@gmail.com* Simu: **0723 533 600** au Mwenyekiti kitengo cha maadili na utafiti cha hospitali kuu ya Kenyatta Tovuti: *uonknh_erc@uonbi.ac.ke*, simu: 020 2725272

TAARIFA YA MSHIRIKI

Nimesoma au nimesomewa nakala hii. Nimepata kuzungumza kuhusu utafiti huu na mtafiti mwenyewe. Maswali yangu yamejibiwa kwa lugha ninayoielewa vizuri. Madhara na manufaa yameelezwa wazi. Ninaelewa kushiriki kwangu ni kwa hiari na kwamba ninao uhuru wa kutoshiriki wakati wowote. Ninakubali bila kushurutishwa kushiriki katika utafiti huu. Ninaelewa kwamba bidii itatiwa kuhakikisha habari zangu zimewekwa siri. Kwa kutia sahihi kwa daftari hili, sijapeana haki zangu za kisheria ambazo ninazo kama mshiriki katika utafiti huu.

Nimekubali kushiriki katika utafiti huu: NDIO☐ LA ☐

Sahihi / Kidole _____

Tarehe _____

TAARIFA YA MTAFITI

Mimi, ninayetia sahihi hapo chini, nimeeleza maswala muhimu ya utafiti huu kwa mshiriki na ninaamini ya kwamba ameyaelewa vilivyo na kwamba ameamua bila kushurutishwa kukubali kushiriki.

Jina la Mtafiti: _____ **Sahihi** _____

Tarehe: _____

TAARIFA YA SHAHIDI

Mimi, ninaye tia sahii hapo chini, nimeshuhudia mazungumzo kati ya mtafiti na mhojiwa. Mhojiwa ameelezewa maswala muhimu ya utafiti huu, naamini ameyaelewa vilivyo kwamba ameamua kushurutishwa kukubali kushiriki.

Jina la shahidi: _____ **Sahihi** _____

Tarehe: _____

APPENDIX 5: ETHICAL APPROVAL

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

KENYATTA NATIONAL HOSPITAL APPROVED 22 JUN 2018 KNH/UoN-ERC P.O. Box 20723-00202 NRB.

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

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

Ref: KNH-ERC/A/246

June 22, 2018

Ruth Wagathu Kalae
Reg. No. H56/88051/2016
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Ruth,

RESEARCH PROPOSAL – DETERMINANTS OF CONGENITAL ANOMALIES AND THEIR EFFECT ON AFFECTED MOTHERS; A CASE OF KENYATTA NATIONAL HOSPITAL, NEWBORN UNIT (P136/03/2018)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is from 22nd June 2018 – 21st June 2019.

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) 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.

Protect to discover

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

Yours sincerely,

PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Deputy Director, CS, KNH
The Chairperson, KNH-UON ERC
The Assistant Director, Health Information, KNH
The Director, School of Nursing Sciences, UoN
Supervisors: Dr. Abednego Ongeso, Dr. Jennifer Oyieke

APPENDIX 6: AUTHORITY TO COLLECT DATA AT KNH

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

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

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

Date: 27th June, 2018

Ruth Wagathu Kalae
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Ruth

RE: AUTHORITY 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, Newborn Unit*** on your study titled ***"Determinants of congenital anomalies and their effect on affected mothers: A case of Kenyatta National Hospital, Newborn Unit ".***

Kindly liaise with the Senior Assistant Chief Nurse, Paediatrics for facilitation.

You will also be required to submit a report of your study findings to the Department of Paediatrics after completion of your study.

DR. IRENE INWANI
HEAD OF DEPARTMENT, PAEDIATRICS

Cc. Senior Assistant Chief Nurse, Paediatrics
Assistant Chief Nurse Incharge, NBU

APPENDIX 7: QUESTIONNAIRE

TOPIC: DETERMINANTS OF CONGENITAL ANOMALIES AND THEIR EFFECT ON AFFECTED MOTHERS: A CASE OF KENYATTA NATIONAL HOSPITAL, NEWBORN UNIT

Questionnaire number: …… Date: ……..

SECTION A: PATTERN AND PREVALENCE

1. Type of Congenital Anomaly diagnosed

   …….....

   .....

2. System(s) involved ……

   ……

SECTION B: RISK FACTORS

3. Mothers age in years (from the file) ……
4. Race (to be observed)
   a. African ☐
   b. Non-African (specify) ……
5. Mothers parity (from the file) ……..
6. Religion ☐
   a. Christian
   b. Islam ☐
   c. Other (specify) ……..
7. Level of education
   a. Not attended school ☐
   b. Primary education ☐
   c. Secondary education ☐
   d. Tertiary education ☐
8. Occupation
   a. Employed ☐
   b. Self-employed ☐ (specify)……..
   c. Not working ☐

9. Is there history of Congenital anomalies in your family?
    a. Yes ☐
    b. No ☐

    If Yes, who? …….

10. Is the father of your child a relative?
    a. Yes ☐ (specify) ……..
    b. No ☐
11. List all drugs taken while pregnant
    a. Folic acid ☐
    b. Vitamin A ☐
    c. Others

    …….....……

    ……
12. Did you suffer any medical condition during pregnancy?
    a. Yes ☐
    b. No ☐

    If Yes, state,
    a. Zika virus ☐
    b. Rubella virus ☐
    c. Cytomegalovirus ☐
    d. Diabetes ☐
    e. hypertension ☐
    f. Other (specify) …….
13. Do you take alcohol
    a. Yes ☐
    b. No ☐
14. Do you smoke tobacco?
    a. Yes ☐
    b. No ☐
15. Did you visit Ante-Natal Clinic?
    a. Yes
    b. No

If Yes, how many visits?

a. Once ☐
b. Twice ☐
c. Thrice ☐
d. Four times ☐
e. More than four times ☐

16. Were you screened for congenital anomalies during pregnancy?

a. Yes ☐
b. No ☐

If yes, which screening method was used? ……..

17. Are there any industries close to where you live?

a. Yes ☐
b. No ☐

If Yes, which one(s)? ……..

18. Mode of delivery

a. Caesarian section ☐
b. Vaginal delivery ☐

19. Sex of the baby

a. Male ☐
b. Female ☐
c. Other …….

20. Birth weight (grams) ……

21. Birth order ……..

22. Gestational age (weeks) ……

APPENDIX 8: DODOSO

KICHWA CHA UTAFITI: VIGEZO VYA MAUMBILE YA KUZALIWA YANAYOWEZA KUSABABISHA ULEMAVU, NA ADHARI ZAKE KWA WALIOADHIRIKA: HOSPITALI KUU YA KENYATTA, KITENGO CHA WATOTO WACHANGA.

Nambari ya dodoso: …… Tarehe: ……..

SEHEMU YA KWANZA: MUUNDO NA KIWANGO CHA MAUMBILE HAYA

1. Aina ya maumbile ya kuzaliwa yanayoweza sababisha ulemavu

   …….....**.....**

   .....

2. Mifumo inayohusika

   ……

   ……

SEHEMU YA PILI: MAMBO HATARI

3. Umri wa mama (kutoka faili ya mgonjwa) ……
4. Rangi (tazama)
   a. Mwafrika ☐
   b. Asiye mwafrika (eleza) ……
5. Mama amejifungua mara ngapi (kutoka faili ya mgonjwa)

   ……..
6. Dini
   a. Mkristo ☐
   b. Mislamu ☐
   c. Dini nyingine (eleza) ……..
7. Kiwango cha masomo
   a. Sijasoma ☐
   b. Shule ya msingi ☐
   c. Shule ya upili ☐
   d. Elimu ya juu ☐
8. Kazi
   a. Nimeajiriwa ☐

b. Nimejiajiri ☐

(eleza)……..

c. Sifanyi kazi ☐

9. Kuna historia ya maumbile ya kuzaliwa yanayoweza sababisha ulemavu katika familia yenu?

a. Ndio ☐

b. La ☐

Kama ndio, nani? …….

10. Je, baba mzazi wa moto huyu ni jamaa?

a. Yes ☐ (eleza) ……..

b. No ☐

11. Zitaje dawa zote umekunywa ukiwa mja mzito

a. Foliki ☐

b. Vitamini A ☐

c. Zingine…….....……

……

……

12. Umekuwa na shida yeyote ya kiafya ukiwa mja mzito?

a. Ndio ☐

b. La ☐

Kama ndio, taja,

a. Virusi vya Zika ☐

b. Virusi vya Rubella ☐

c. Cytomegalovirus ☐

d. Ugonjwa wa sukari ☐

e. Shinikizo la damu ☐

f. Mengine (eleza) …….

13. Unakunywa pombe?

a. Ndio ☐

b. La ☐

14. Unavuta sigara?

a. Ndio ☐

b. La ☐

15. Ulihudhuria kliniki ya wamama wajawazito?

a. Ndio

b. La

Kama ndio, mara ngapi?

a. Moja ☐

b. Mbili ☐

c. Tatu ☐

d. Nne ☐

e. Zaidi ya mara nne ☐

16. Ulichunguzwa kuhusu matatizo ya maumbile haya ukiwa mja mzito?

a. Ndio ☐

b. La ☐

Kama ndio, vipi? ……..

17. Kuna viwanda karibu na mahali unaishi?

a. Ndio ☐

b. La ☐

Kama ndio, viwanda vipi?? ……..

18. Ulijifungua vipi

a. Upasuaji ☐

b. Njia ya kawaida ☐

19. Jinsia ya mtoto

a. Kiume ☐

b. Kike ☐

c. Nyingine …….

20. Uzito wa kuzaliwa (gramu) ……

21. Mtoto wa ngapi …….

22. Umri wa uja uzito (wiki) ……

APPENDIX 9: INTERVIEW GUIDE (FOR AFFECTED MOTHERS)

1. When did you learn about your child's congenital anomaly?
2. How did you feel when you first saw/learnt that your child had congenital anomalies?
3. Are you aware of any factor that might have contributed to your child's congenital anomaly?
4. Since the birth of your child, how do you view your partner's and family's attitude towards you?
5. What kind of assistance would you want from the healthcare providers?

APPENDIX 10: MWONGOZO WA MAHOJIANO (WALIOADHIRIKA)

1. Ulijua lini mtoto wako ako na maumbile ya kuzaliwa yanayoweza sababisha ulemavu?
2. Ulihisi vipi ulipogudundua mtoto wako ako na maumbile ya kuzaliwa yanayoweza sababisha ulemavu?
3. Je, unafahamu nini ilisababisha maumbile haya?
4. Tangu kujifungua mtoto huyu, je, mtazamo wa mpenzio na familia yako kwako umebadilika?
5. Ungetaka usaidizi wa aina gani kutoka kwa wahudumu wa afya?

APPENDIX 11: INTERVIEW GUIDE (FOR KEY INFORMANTS)

1. When do mothers first learn about their child's congenital anomaly?
2. How do they react when they first see/learn that their child has congenital anomalies?
3. Does the partners and family's attitude change towards the affected mothers since the birth of these children?
4. Are you aware of any factors that might have contributed to these congenital anomalies?
5. What kind of assistance do you think the affected mothers need from healthcare workers?