

**EFFECT OF GIVING BIRTH TO A CHILD WITH CONGENITAL  
ANOMALIES ON MOTHERS IN NEWBORN UNIT, KENYATTA  
NATIONAL HOSPITAL**

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**Abstract**

*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. There is limited empirical data in Kenya to describe the effect of giving birth to a child with congenital anomalies on the mother. The objective of the study was to establish the effect of giving birth to a child with congenital anomalies on mothers, NBU, KNH.*

*A one month cross sectional study was conducted, and a qualitative design was used. 15 mothers who had their newborns with congenital anomalies in NBU were interviewed, as well as 3 key informants.*

*Results showed that most mothers learn of their children's congenital anomalies after birth. Most mothers are shocked, and they feel bad after this knowledge.*

*In conclusion, these mothers undergo a lot of negative emotions. There is therefore need for social support.*

**Key words**

Congenital anomalies

Affected mothers

Newborn Unit

Kenyatta National Hospital

**1.1 Background information**

Congenital anomalies are defined as functional, metabolic or 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, Khattak, Shah, Roshan, & Haq, 2012).

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 & 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).

**1.2 Problem statement**

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).

Giving birth to a child with congenital anomalies is source of stress to the parents (Petra Mazer et al., 2008). 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.

Hypothetically speaking, the amount of stress anticipated among mothers of babies with birth defects and the impaired coping mechanisms makes them vulnerable to depression and eventually lifestyle diseases. It is with this knowledge that a qualitative study was done to narrate the mothers' experiences.

### **1.3 Purpose of the study**

The purpose of the study was to describe the effect of giving birth to a child with congenital anomalies on the mothers.

### **2.0 Literature Review**

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 (Petronella Mazer & Gischler, 2009). 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, Heide, & Wildschut, 2007).

From the ancient times, superstitions regarding birth defects have been reported, and they are still prevalent in present days. (Garcias & Schüler-Faccini, 2004) 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. 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).

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. 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, Nazaré, & Canavarro, 2011).

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, Lilja, & Sundin, 2014). In Sweden, parents felt that it was therapeutic to share their experiences with other parents on similar situation (Bratt, Järholm, Ekman-Joelsson, Mattson, & Mellander, 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, Fowles, Mateus, & Thomas, 2013a).

### **3.0 Methodology**

This was a hospital based descriptive, cross-sectional study that employed qualitative study design. The study was carried out in NBU, KNH, the largest national referral teaching and research hospital in East and Central Africa. 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 mothers and 3 key informants were interviewed; Nurse in-charge of NBU, 1 Neonatal nurse and 1 Paediatric registrar.

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

Piloting was done at Pumwani Maternity Hospital, the NBU unit. Approximately 10% of the sample size (2 participants) was used for pretesting after the participants gave consent. 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.

The researcher conducted an in-depth interview using the interview guide, and the conversation was recorded. 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.

Data was presented in narration format whereby themes and subthemes were elicited from the recorded data. Poignant quotes were selected to support the themes.

## 4.0 Results

The findings of this study revealed various psychological, economic and social challenges that affected mothers experience after giving birth to an anomalous newborn. Four themes are highlighted: Knowledge, Reaction, Support from social environment and Support from health care system.

### 4.1 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)*

#### 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)*

#### 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)*

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)*

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 mother didn't think that cultural habits can lead to congenital anomalies.

*“It's nothing to do with culture.”(Respondent 8)*

#### **4.2 Theme 2: Reaction**

The initial feelings and reaction after news about congenital anomaly diagnosis was delivered are vividly recalled by the mothers. Most mothers experienced similar negative emotions; 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 give birth to 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)*

*“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)*

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)*

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

### **4.3 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)*

Still, there were those ones that reported that the father of their child neglected them once they learn of the child's congenital anomaly.

*“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)*

#### **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)*

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)*

#### **4.4 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)*

##### **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)*

##### **Sub-theme 3: Assurance**

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

*“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)

## **5.0 Discussion**

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 & Schüler-Faccini, 2004). 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 occurrence 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. (Petra Mazer et al., 2008) 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, Fowles, Mateus, & Thomas, 2013b) 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., 2013a) and (Anderson, Dumont, Jacobs, & Azzaria, 2007). Importance of counseling has also been reported by many researchers (Marokakis, Kasparian, & Kennedy, 2016) and (Gitsels-van der Wal et al., 2015).

## **6.0 Conclusion**

Giving birth to an anomalous child brings feelings of consternation and apprehension. There is deficient knowledge on what causes congenital anomalies. Mostly, the diagnosis of a congenital anomaly is made after birth. Support groups for the affected mothers don't exist. A long hospital stay for these anomalous neonates is experienced due to slow interventions and lack of prompt management.

## **7.0 Recommendation**

Mobilize and allocate more resources in preventing, screening and prompt management of congenital anomalies.

The Ministry of Health should educate the public about congenital malformations. Health education can be done through mass media like television, social media like Facebook and Twitter; and fliers.

Ultrasounds for prenatal diagnosis of CA should be recommended for early intervention and even termination of the pregnancy where necessary.

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.

Ensure better collaboration between the different specialties involved for prompt diagnosis and management of birth defects. This can be done through effective communication.

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