

# In Hospital Experiences of Mothers of Children with Major External Birth Defects During Hospitalisation at a Tertiary Hospital in South Western Uganda

Kalubi Peters<sup>1</sup>, Ochora Moses<sup>2</sup>, Keneema Olive<sup>2</sup>, Nampijja Dorah<sup>2</sup>, Kyasimire Lydia<sup>2</sup>, Kyoyagala Stella<sup>2</sup>.

<sup>1</sup>- Department of Paediatrics and Child Health, Mbarara University of Science and Technology, Mbarara

<sup>2</sup>- Department of Paediatrics and Child Health, Mbarara Regional Referral Hospital, Mbarara

<sup>3</sup>- Department of Obstetrics and Gynaecology, Mbarara Regional Referral Hospital, Mbarara

Corresponding author

Kalubi Peters

**Abstract:-** Mothers are regarded as primary care givers and in many African countries, women are culturally held responsible for the child's health. The birth of a child with birth defect (s) may have significant impact on mothers psychological, physical and socioeconomic well-being. The in hospital experience of mothers of children with birth defects has not been adequately explored and therefore not fully attended to especially in low resource settings. At Mbarara Regional Referral Hospital (MRRH), the medical care team often is more directed towards medical treatment and surgery of the child born with a birth defect with little or no focused psychosocial support to their mothers.

## ➤ Objectives

The aim of this study was to explore and describe the experiences of mothers of children with major externally visible birth defects during their hospitalization at MRRH.

## ➤ Method

A phenomenological study with purposive sampling of 12 participants. The adjusted ecological model was used. Data was collected by self-report using unstructured face to face interviews until saturation was reached. Five themes emerged from the study which include: Negative emotional experience, acceptance of child's condition, supportive part of the medical team despite some medical system challenges (like stock outs of medications and sundries, fewer staffs in the night) financial challenges and spiritual, family plus health team support were cope strategies.

## ➤ Conclusion

Mothers of children with major external birth defects were negatively affected especially, emotionally and financially. These mothers, therefore require psychosocial,

financial and also spiritual support during their hospital stay at MRRH.

**Keywords:-** In Hospital, Experiences of Mothers, Major External Birth Defects, MRRH.

## I. INTRODUCTION

Birth defects (BDs) are also known as congenital abnormalities, congenital disorders or congenital malformations. World Health Organization (WHO) defines BDs as defects of function, metabolism and structure. They exist at, or before birth and they can be categorized into: major and minor and may be single or multiple. <sup>1</sup>The major are those that may cause serious functional disability, social rejection and stigma (like hydrocephalus), fetal loss or even deaths while the minors are those with minimal impact on clinical function but may have a cosmetic impact, e.g. pre-auricular pit.

Birth defects are associated with 17-fold higher mortality and morbidity in early childhood compared to those without defects <sup>2</sup>. The long-term disability caused by BDs may be of significant impact to the child's well-being and development, but also on their families, health care systems and societies. The birth of a child with birth defects causes extreme emotional stress to the entire family that is worsened by uncertainty about the causes, expected course of the disease, and survival of the child <sup>2</sup>.

Mothers are regarded as primary care givers and in many African countries, women are culturally held responsible for child's health <sup>3</sup> Mothers carry pregnancy for 9 months in anticipation of healthy normal child. However, a recently concluded study at MRRH showed that only 1.5% of BDs had been detected during the antenatal period despite the fact that

most mothers had attended antenatal care at least 4 times during their pregnancy<sup>4</sup>. Mothers of children with birth defects may experience feelings of fear, guilt, frustration uncertainty, anger, sadness and loss<sup>5</sup>. They have also been reported to develop grief that is almost similar to that of losing a child<sup>6</sup>. These mothers may develop psychological stress and disappointment when they realize that their children may not meet their expected mental, physical, and social milestones<sup>6</sup>.

Therefore, during this period mothers need adequate support from partners, families, health providers to reduce on the influence of the psychological impact to the mother and enhance acceptance of child with a birth defect<sup>6</sup>

At Mbarara Regional Referral Hospital, a recent study reported that one in 4 neonatal admissions had a birth defect<sup>4</sup>. Currently, we do not know the lived experiences of mothers of children with major external birth defects, yet this information would enable us to tailor the in hospital care towards their specific needs.

#### ➤ *Objective*

The aim of this study was to describe the experiences of mothers of children with major external birth defects

## II. MATERIALS AND METHODS

#### ➤ *Study Design*

An exploratory descriptive phenomenological study design was used. Phenomenology as a form of qualitative research focuses on an individual's lived experience of a particular event or series of events<sup>7</sup>. This approach seeks to explore the experiences from the perspective of the mothers who take care of children with congenital anomalies in south-western Uganda. The mothers explained on how having children with congenital anomalies and living with them have impacted their lives.

The theoretical model for this study was the ecological model of health. This theory emphasizes the environmental and policy contexts of behavior while incorporating the influence of social and psychological influences. The ecological model of health suggests that behavior is influenced at multiple levels. This includes individual mother's behavior due to guilt, self-blame, frustration, and disappointment. Other influences are also at interpersonal levels with family, spouses, and close friends, or organizational, community, and public policies towards children with congenital anomalies in terms of care, support, and legislation.

#### ➤ *Study Setting*

The study was conducted at MRRH from both the neonatal and paediatric surgical units. MRRH is public and Regional Referral hospital with more specialized diagnostic and surgical services, receiving most patients with birth

defects in South Western Uganda. About 10 new children with major externally visible birth defects are received at the hospital weekly. Children with major external birth defects are initially stabilized from the Neonatal Intensive Care Unit (NICU) by the paediatric team in close collaboration with the paediatric surgical team.

Both teams also provide post-operative care from the Paediatric Surgical Unit until discharge and also post discharge.

#### ➤ *Study Population and Sampling*

Purposeful sampling was used to recruit 12 mothers. These were above 18 years of age, were also able to communicate during hospitalization at MRRH and their newborns had major external BDs like gastroschisis, omphalocele, hydrocephalus, cystic hygroma.

#### ➤ *Data Collection*

The study was conducted between December and January, 2023. Infants with major external birth defects were identified during their admission to MRRH. The research team enrolled their mothers at the time of hospital discharge. The mother was informed about the study and informed consent was then sought. Saturation was reached after 12 maternal in depth interviews which formulated our sample size. Data was gathered through unstructured and voice recorded individual interviews. It was primarily collected in Runyankole / Rukiga, which is the major local language in our setting. The interviewer also spoke additional languages: Kinyarwanda, Swahili and Luganda which enabled ease of communication during the interviews since the four are commonest languages in the study area. The interviews were conducted in a confidential manner and a conducive quiet place that favored mothers to freely provide information.

Mothers were asked one central question: 'What is your experience of having a child with a congenital abnormality?' Probing and clarity-seeking questions then followed, interviews lasted about 30–40 minutes until data saturation was reached. Data obtained from in-depth interviews was transcribed from Runyankore to English by a skilled transcriber and translator.

#### ➤ *Data Analysis*

The thematic content analysis method was used to organize and analyze the data using nVIVO software. Thorough reading through the transcripts was done to ensure that the information was comprehensible with the feelings expressed. Some data were triangulated through discussion with 2 hospital staff to verify the information related to the hospital. Verbatim transcriptions from audio recordings to paper were analyzed after saturation was reached. Subcategories and categories were identified and categories later merged to form themes.

➤ *Trust Worthiness.*

The researcher ensured confidentiality. Mothers were also handled with care and utmost respect.

➤ *Ethical Considerations*

The study was approved by Mbarara University of Science and Technology, MUST Ethics Review Board (MUST -2023-855). Site Clearance was provided by the Paediatrics Department, MUST. Informed consent was provided by mothers before inclusion. The interviews of mothers were conducted in a confidential manner and in a private, and quiet

place. We used initials of names of mothers, instead of their full names to preserve their identity. All information collected from the mothers was kept confidential and strictly amongst the research team.

**III. RESULTS**

The age range of mothers was 19 – 40 years. Fifty (50%) were catholic. Majority (67%) had attained primary education and fewer with secondary. All mothers were in informal employment with majority as peasant farmers.

**Table 1. Sociodemographic Characteristics of participants and birth defect in their child**

Study Number	Initial of study participants	Age (years)	Religion	Educational level	Occupation	Birth Defect Type in child
BD1	KA	19	Catholic	Secondary	House wife	Meningocele
BD2	KM	40	Protestant	Primary	Peasant farmer	Meningomyelocele
BD3	JN	44	Muslim	Primary	Peasant farmer	Cystic hygroma
BD4	OM	21	Catholic	Secondary	Tailor	Hydrocephalus
BD5	SN	37	Muslim	Primary	Peasant farmer	Hydrocephalus
BD6	WL	28	Protestant	Primary	Peasant farmer	Omphalocele
BD7	NE	43	Catholic	Secondary	Business	Gastroschisis
BD8	KP	33	Catholic	Primary	Peasant farmer	Omphalocele
BD9	KS	22	Muslim	Secondary	Peasant farmer	Hydranencephaly
BD10	TM	20	Protestant	Primary	Peasant farmer	Encephalocele
BD11	EG	39	Catholic	Primary	Business	Gastroschisis
BD12	SR	25	Catholic	Primary		Hydranencephaly

➤ *Theme 1. Having an emotional experience*

Participants expressed negative emotional experiences; fear and surprise as their initial experiences and many felt hurt after seeing that their child had been born with birth defects. Other feelings included: sadness, disappointment, confusion, pain, loss, worry

Although, most mothers had ultrasonography during their antenatal visits, only one was informed of having a malformed fetus. Most were also informed about having a normal baby during antenatal care which further worsened their experience. Some of the mothers were hurt emotionally by how their spouses reacted to the birth of a child with a birth defect. The paternal family side provided negative reactions after they had a baby with birth defects.

Some mothers expressed disappointment as this had been their only live child who had also been a result of seeking long time medical care to conceive. Mothers felt disappointed especially by how they would be able raise children with major external birth defects. Only one mother new about birth defects because a child with similar condition existed in the family but most mothers lacked any knowledge or information about birth defects.

*“Imagine, we did 2 scans during pregnancy and I was told that my fetus was normal. Do you mean that scans are unable to detect fetus with big birth defects like this! or the health workers feared to tell me?” OM a 21-year-old with child with hydrocephalus*

Most mothers expressed great fear, scared and shocked by the physical external abnormalities of their babies. Many were also worried about the likely hood of survival of their babies with birth defects.

*“After delivery, I was terrified after seeing all the intestines of my baby hanging out. I never imagined I would ever carry him. I thought he was going to die soon after birth from hospital”.*

*NE 43-year-old child with gastroschisis*

Some mothers reported they felt guilt about their child’s condition mainly due to the variable beliefs and misconceptions about different birth defects in the local community. Many times mothers and the communities strongly believe that birth defects were caused by witch craft, evil spirits, extra marital affair during pregnancy, mother to have done something wrong in the community during pregnancy. Some thought it was punishment from God for committing sin or not wanting the pregnancy. Most mothers

actually felt the birth defects were due to their faults. Many mothers were not emotionally prepared and were caught with surprise and shock because during antenatal period most were informed of carrying normal babies.

*“When I delivered my child with birth defects, Annet my best friend told me that this was because my husband had engaged in a sexual affair with another woman during the pregnancy”. TM 20 years old with encephalocele KP 33 omphalocele*

*“I aborted several times before because I was not ready to care for a child. May be God punished me for having committed the several abortions” SN 37 hydrocephalus*

➤ **Theme 2: Having acceptance of child’s condition**

Many mothers got to accept their child’s condition with patience, sincerity as they stayed in hospital despite the initial states of denial, fear and surprise. This was mainly due to the health workers who provided words of comfort, hope for possible recovery especially post-surgery, and also having seen many children with similar birth defects recovering post-surgery during their hospital stay.

*“God gives His wish for every one, I also accept what He has decided to give me. He has the reason and no one else.” KA 19 meningocele*

*“While on paediatric surgery ward at MRRH I saw 2 other children that had their defects repaired and were discharged. I then began to accept that this was not only a problem my child and it was fixable by doctors” EG 39 gastroschisis.*

➤ **Theme 3. Mothers found some members of the medical team very supportive but also expressed some negative experiences with the medical care of their newborns**

Generally, mothers were grateful to the hospital medical team. They were received and also handled with love and care. The initial treatments were received in time and generally the medical team checked on them frequently especially during the day. They were grateful that the medical team always taught them and also supported them in caring for their babies: keeping them clean, tube feeding and also keeping oxygen nasal prongs in situ

*“I was scared too with my baby having a very abnormally big head but, the doctors told me it was a common problem and that my child would be seen by surgical specialists who work on such children” SN 37 hydrocephalus*

*“The medical team at MRRH is well coming and they treat you with love. At the hospital we visited first, our baby was not even touched by the doctor. They just told us to leave quickly and go to MRRH.” SR 25anencephaly*

However, mothers also expressed some negative experiences with the health care system while at MRRH. Some medications were not available and they had to be bought out of pocket, during the night the nursing team was too thin to support the many sick babies as compared to day time. Mothers had no beds to rest with their babies yet they were still weak post-delivery, the neonatal room was small with many babies and it felt too warm and often mothers preferred to keep out of ward.

*“One night the nurses gave me a prescription in the night at about 10:00 am to purchase some medicines from a private pharmacy. That night I had no money at all and also my care takers had also left for home. The baby had to wait till morning to receive that night’s treatment.” KN 19 meningocele*

*“During the day nurses are many but often in the night we had only one nurse who could not serve all the babies. The ward often was full with about 30 sick babies.” JN 44 cystic hygroma*

*“The room is too small with no adult beds for weak mothers to sleep. I often felt too hot and preferred to rest outside the ward”.*

Despite the few system challenges, mothers were generally grateful to the health workers at MRRH for their care, love and passion.

➤ **Theme 4. Financial challenges occurred during care for children with birth defects in hospital.**

Mothers expressed major financial challenges during hospitalization of their children with birth defects as most were house wives and peasant farmers. Many mothers were from low income households yet they had to spend especially on daily feeds, purchasing medications and other sundries during hospitalization. They also had to provide for other family members especially children who stayed home. Family financial dynamics were greatly affected during hospitalization. Mothers had to fully abandon their work so as to provide care to their babies. Some families also sold off their domestic animals especially cows and goats. Some even had to sale off some land during hospitalization or even borrowed sums of money from money lenders, friends and savings schemes.

*“Before surgery I was told I had to do a number of investigations by the surgical team. It was during the week end and I had to source most of them out of the hospital because I wanted my baby to be operated soon. Unfortunately, we had no single coin and had to sell our 2 goats back home” SN 37 hydrocephalus*

*“I used to earn per my day of work and spent all the little savings in preparation for delivery. Honestly me and my husband had no single coin on admission to the neonatal unit yet I needed to feed daily.” KA 19 meningocoele*

➤ *Theme 5: Religious faith, Support especially from their husbands, family members and medical team were important coping mechanisms.*

*“My pastor comes every evening to provide prayer for us while in hospital. This has made me feel relief and feel that God was in control of my child’s condition.” KS 22 hydranencephaly*

*“The doctors and nurses always kept us encouraged that our children would have an operation and would survive longer.” JN 44 cystic hygroma.*

*“I would not make it this long stay in hospital with such a baby. My husband has been there for me right from birth. At times he stays in hospital to care for our baby yet he has also to provide for other children at home.”*

*“Some nurses and medical students became my friends and helped me a lot especially when I had no money for food and my husband away. They would also clean my baby.” EG 39 gastroschisis*

#### IV. DISCUSSION

Mothers of children with major external birth defects admitted at MRRH experienced many challenges and emotions during their hospital stay. Their negative experiences started right from the time of birth, seeing their malformed new born babies up to the time of their time of discharge from hospital. Many mothers were referred from lower health units after delivery of their babies with major external birth defects and travelled long distances to reach MRRH. However, fewer mothers had delivered from MRRH and were transferred straight away to the neonatal unit.

Five themes to describe the experiences of the mothers of children with major external birth defects were derived as follows: Significant emotional feelings, acceptance of child’s condition, Supportive part of medical team despite some medical system challenges like absence of certain medications and sundries, fewer staffs in the night. Major financial challenges also occurred during their hospital stay. Devine intervention, help from the medical team members and other mothers in hospital were important cope mechanisms.

The current study shows the critical need to support mothers of children with major birth defects at MRRH beyond medical. The findings show that mothers were emotionally hurt having babies with abnormalities and also had intense fear about their survival.

During pregnancy, mothers anticipate delivery of a normal baby and await<sup>9</sup> this with positive expectations. Mothers having no prior knowledge about presence of major external birth defects during antenatal checks rendered them unprepared to receive their occurrence after delivery. Major external birth defects like gastroschisis, omphalocele, hydrocephalus may be detected by antenatal ultrasound. Most mothers were shocked and also non-anticipative of the major surgical procedures that were going to be done on their newborn babies. Some other studies have also reported similar negative emotions when mothers had no prior knowledge about presence of major birth defects and the abnormal image of their newborns<sup>9,10,13</sup>.

Many mothers were referred from lower health units to MMRH for surgical management after delivery of their babies with major birth defects. Many mothers travelled to MRRH by private means and the whole referral travel process occurred with variable challenges and delays. Challenges of transport after referral remain a challenge in low resource settings<sup>9</sup>. Most mothers of children with birth defects were likely to have lower education levels and survived on relatively lower household income which were Similar findings in Rwanda and Zimbabwe<sup>9,10</sup>.

In the current study many mothers also experienced disbelief self-blame and guilt having babies with birth defects. In another study in Iran, Abbasi reported high levels of stress, anxiety, negative emotions and fear of child’s future among mothers of children with birth defects<sup>8</sup>. Most mothers experienced disbelief, denial and difficulty to accept their children born with major externally visible birth defects. However, this was a similar finding reported from Rwanda and Zimbabwe where family members fail to accept children with birth defects<sup>9,10</sup>. The current study found lack of psychological support for mothers of children at diagnosis of birth defects which would enhance their cope up. This was similar to findings reported from Rwanda and Gert Sibande district, respectively<sup>9,11</sup>. However, a Korean study reported that parents who receive information and resources at the time of diagnosis tend to have positive emotions to the condition<sup>12</sup>. Some of the mothers in our study also reported having been blamed by their family members and others for the baby’s condition. The existence of a birth defect was met with a lot of social, personal and cultural beliefs<sup>13</sup>. There is still need for sensitization of society to reduce on the stigma associated with birth defects.

Despite the initial states of denial, fear and surprise, many mothers got to accept their child’s condition with patience, sincerity as they stayed in hospital. This was mainly due to the health workers who provided words of comfort, hope for possible recovery especially post-surgery, and also having seen many children with similar birth defects recovering post-surgery during their hospital stay. This has been a similar report by other studies.<sup>9,11,16</sup>

Many respondents also reported to have faced financial challenges while at MRRH. Some took loans from financial saving groups or sold off their animals especially goats and cows or even land to meet their financial obligations during their stay at MRRH. Some other studies have also reported parents facing financial challenges during hospitalization of their children<sup>9, 17, 18</sup>. Financial challenges during hospitalization remain a challenge especially in low resource countries.

Also similar to reports by other studies<sup>8,9</sup>, mothers were appreciative of the support from the medical team although fewer staffing existed in the Neonatal Intensive Care Unit (NICU). Inadequate human resource in medical settings remains a major challenge especially in low resource countries.

## V. LIMITATIONS

This study was of contextual nature and results may not be generalizable.

It was beyond scope of this study to describe the challenges mothers met after discharge from hospital.

## RECOMMENDATIONS

Comprehensive care is critical during admission of mothers with major external birth defects to cater for their physical, psychosocial and emotional and spiritual support other than solely focusing on medical needs.

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### ➤ Abbreviations

MUST: Mbarara University of Science and Technology  
MRRH: Mbarara Regional Referral Hospital  
DRGT: Directorate of Research and Graduate Training  
BDs: Birth Defects  
NICU: Neonatal Intensive Care Unit

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### ➤ Authors Contributions

KP was the principal investigator. The team developed and wrote the proposal. KP, OM and ND contributed to the methods data analysis. KP wrote the initial draft of the manuscript. All authors proof read the final manuscript.

### ➤ Conflict of Interest:

The authors declare no conflict of interest.

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