

**THE LIVED EXPERIENCE OF MOTHERS WHOSE NEWBORNS ARE  
HOSPITALIZED WITH CONGENITAL ANOMALIES IN A TERTIARY HOSPITAL  
IN CENTRAL UGANDA**

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## Declaration

I **Olimporera Joseph** hereby declare that this research report is my personal work and has never been submitted to any institution for any academic award. Where other people's work has been included, credit has been given by way of citation.

Signature: .....

Date: *16<sup>th</sup> / 10 / 2024*.....

This dissertation on *'The lived experience of mothers whose newborns are hospitalized with congenital anomalies'* has been submitted for examination with the approval of the undersigned supervisor.

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## **Dedication**

I dedicate this research report to my beloved family, friends, and mentors whose unwavering support and love made this journey possible. Secondly, to the global nursing fraternity that relentlessly pursues knowledge, innovation and patient-centered care as a beacon of light in our communities.

## Table of Contents

Declaration.....	ii
Acknowledgements.....	iii
Dedication.....	iv
Table of Contents.....	v
List of Tables.....	vii
Acronyms Commonly Used in This Paper.....	viii
Abstract.....	ix
Chapter One: Introduction.....	11
Background.....	12
Statement of the Problem.....	14
Purpose of the Study.....	15
Research Question.....	15
Study Objectives.....	15
Significance of the Study.....	15
Theoretical Framework.....	16
Operationalization of the Theory.....	18
Operationalization of Terms in the Study.....	20
Summary.....	20
Chapter 2: Literature Review.....	22
The Birth of Newborns with Congenital Anomalies is becoming an Increasingly Common Phenomenon.....	22
The Hospitalization of Newborns with Congenital Anomalies has Significant Effects on their Mothers.....	30
Exploring the Mothers' Lived Experiences can highlight their Challenges and Support they need during their Newborns' Hospitalization.....	36
Chapter Three: Methodology.....	44
Study Design.....	44
Study Setting.....	44
Study Population and Sample Size.....	45
Inclusion and Exclusion Criteria.....	45
Sampling Method.....	45
Data Collection.....	46
Data Management.....	47
Data Analysis.....	47
Trustworthiness and Integrity.....	48
Confirmability.....	48
Dependability.....	49
Transferability.....	49
Ethical Considerations.....	50
Summary.....	51
Chapter Four: Presentation and Analysis of Study Findings.....	51

Demographic Characteristics of the Participants .....	52
Participants' Lived Experiences of Delivering and Hospitalizing their Newborns with Congenital Anomalies in a Tertiary Hospital .....	53
Mixed Feelings and Emotions .....	54
Summary .....	66
Chapter Five: Discussion, Recommendations and Conclusion .....	67
Discussion and Interpretation of Findings .....	67
Demographic Characteristics .....	68
Participants' Lived Experiences of Delivering and Hospitalizing their Newborns with Congenital Anomalies .....	69
Application of the Theoretical Framework.....	77
Recommendations .....	78
In collaboration with cultural and religious leaders, nurses and nurse leaders should organize community outreach programs aimed at reducing stigma, misconceptions, and blame directed toward mothers and families of children born with congenital anomalies. These initiatives should promote cultural sensitivity, raise awareness, and foster community support systems that encourage acceptance and inclusivity. ....	79
Limitations .....	79
Areas of Further Studies .....	80
Conclusion .....	81

**List of Tables**

<i>Table 1: Demographics Distribution of Study Participants</i> .....	52
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### **Acronyms Commonly Used in This Paper**

ANC- Antenatal Care

CA- Congenital Anomalies

CME- Continuous Medical Education

FCC- Family-Centered Care

GS- Gastroschisis

LMIC- Low- and Middle-Income Countries

MNRH- Mulago National Referral Hospital

MOH- Ministry of Health

NICU- Neonatal Intensive Care Unit

PCC- Patient-Centered Communication

PTSD- Post-Traumatic Stress Disorder

REC-Research Ethics Committee

SSA- Sub-Saharan Africa

WHO- World Health Organization

### Abstract

**Background/Purpose:** There is minimal literature in Uganda that describes mothers' experiences of caring for their hospitalized newborns with congenital anomalies. Mothers who give birth to newborns with congenital anomalies often experience untold stress, worry, and fear of losing their newborns to the anomalies. The purpose of this study was to explore the lived experience of Ugandan mothers' whose newborns are hospitalized as a result of the congenital anomalies.

**Theoretical/Conceptual Framework:** Descriptive phenomenology as postulated by Edmund Husserl, was used to explore and describe the universal character of the mothers' lived experience during their newborns' hospitalization, and the meaning they attributed to it. Descriptive phenomenology emphasizes the application of a researcher's objective mind to unravel the universal nature of a particular lived experience.

**Method:** This qualitative study purposively sampled participants until saturation plus one more was reached. Nine eligible mothers who had their newborns hospitalized with congenital anomalies were sampled. A semi structured interview guide was used to probe the mothers' experiences during their newborns' hospitalization. The interviews were audio recorded and later transcribed verbatim for analysis using the Colaizzi method of qualitative data analysis.

**Results:** The study reveals several significant factors that pertain to the lived experience of mothers whose newborns are hospitalized with congenital anomalies. Three major themes and fifteen subthemes emerged from the mothers' narratives of their experiences. The major themes were mixed feelings and emotions, healthcare concerns and responsibilities, and participants' support system and support needs. The sub-themes were feeling shocked, feeling worried, feeling scared, first time experiences, unknown cause of the anomalies, anticipation of blame, financial woes, pregnancy concerns, the load of care giving responsibilities, faith with hope during hospitalization, familial support, peer support, relationship with the nurses, and support needs.

**Conclusion:** The hospitalization of newborns with congenital anomalies requires nurses to not only take care of the sick babies, but also pay close attention and care to their mothers during hospitalization. Nurses were crucial in providing and influencing the care mothers received, to reduce their physical and emotional vulnerability during their newborns' hospitalization.

**Recommendations:** Nurses should actively involve mothers in the care of their newborns by teaching how to bathe, feed, and bond with the babies, while also clarifying medications and treatment plans, as well as sharing with them the necessary information about congenital anomalies. Evaluating the mothers' mental well-being and supporting them to cope with their newborns' hospitalization can boost their emotional resilience and care-giving confidence to perform their maternal roles towards their hospitalized newborns.

**Keywords:** Mothers' Lived Experience, Newborns, Congenital anomalies, Family Centered Care, Descriptive Phenomenology, Colaizzi Data Analysis Method

## Chapter One: Introduction

Becoming a mother is often celebrated as a transformative life event, with maternal identity closely tied to the expectation of delivering a healthy newborn. However, this expectation is disrupted when a baby is born with a congenital anomaly, an event that presents profound psychological, emotional, and social challenges. Research indicates that delivering a newborn with a congenital anomaly can cause maternal stress, anxiety and depression with lasting effects on maternal mental health and family dynamics (Abuidhail et al., 2017; Staver et al., 2020). Congenital anomalies are defined as structural or functional malformations that develop in a fetus while still in the womb, and are typically detected at birth (Yu et al., 2019). The anomalies not only threaten the infant's health but also challenge the mother's sense of self-worth, relationships, and her capacity to navigate motherhood under these unforeseen circumstances.

From a critical perspective, the transition into motherhood in the context of congenital anomalies is not merely a personal struggle, but also a healthcare system concern. Staver et al. (2020) highlights that the implications of congenital anomalies stretch beyond the adverse psychological effects on mothers' well-being, and put additional strain on healthcare system resources. This underscores the need for health systems to adopt holistic and family-centered care interventions that extend beyond the treatment of sick infants, to include the mothers' psychosocial and emotional adjustment as well.

Apparently, there is a significant gap in empirical literature documenting the lived experiences of Ugandan mothers whose newborns are hospitalized as a result of congenital anomalies (Mumpe-Mwanja et al., 2019). This gap reflects a broader neglect of maternal perspectives within neonatal care, despite overwhelming evidence that links maternal well-being

to improved infant's outcomes, recovery and bonding. The limited attention also raises concerns about whether healthcare systems adequately prepare and support mothers who are facing such unforeseen realities. Silvio et al. (2018) recommends incorporating mothers and their families into healthcare processes, a model that aligns with global best practices such as family-centered care and patient-centered communication. Without such integration, mothers risk being marginalized in decision-making regarding their infants' care, consequently compounding their distress and weakening their coping capacity.

As such, exploring the lived experiences of Ugandan mothers in this context is not only of academic importance, but also of practical significance for nursing and health policy formulation. Insights from such studies can inform the development of culturally sensitive interventions including counseling sessions, peer support groups, community awareness programs and antenatal education which prepare mothers for possible anomalies. In real-world nursing practice, these findings call for a deliberate shift toward empathetic communication, psychosocial support services, and resource mobilization strategies to mitigate the financial and emotional burdens these mothers face. Ultimately, this approach can strengthen maternal resilience, enhance mother-infant bonding, and contribute to improving the healthcare outcomes of newborns with congenital anomalies.

## **Background**

The diagnosis of congenital anomalies often occurs at birth, although advances in antenatal screening and technology allow for earlier detection in some cases (Yu et al., 2019). The anomalies may appear as isolated birth defects or as parts of complex syndromes that are linked to genetics or environmental exposures (Ekowchi et al., 2018; Yu et al., 2019). Regardless of the cause, a newborn with a congenital anomaly typically requires specialized medical and

surgical care, often necessitating prolonged periods of hospitalization. Such prolonged hospitalization not only places heavy demands on healthcare systems but also disrupts the mothers' social and emotional support networks, exacerbating their psychological distress (Fleck et al., 2017).

Critically, the burden of congenital anomalies disproportionately falls on women in low- and middle-income countries, where preventive measures such as folic acid supplementation, adequate nutrition (balanced diet), routine antenatal screening and fortified foods are not readily available (Ajao & Adeoye, 2019). Mothers in these contexts face an abnormal and often traumatizing birth experience that is characterized by fear, guilt, and feelings of helplessness (Staver et al., 2020). Unlike mothers of healthy infants, these women are confronted with profound stressors that disrupt early maternal role formation. This highlights a critical gap in maternal care, specifically, the need for targeted psychosocial interventions, including counseling, emotional support, and structured guidance to buffer the distress and strengthen mother-infant interactions (Holditch-Davis et al., 2014; Staver et al., 2020).

Epidemiologically, congenital anomalies remain a pressing global health concern. Although their incidence is estimated at 3–7% worldwide, prevalence rates vary across settings and reflect differences in health system capacities and surveillance mechanisms. In Uganda, for example, a cross-sectional study at Mulago Hospital reported a significant prevalence of 440 congenital anomalies per 10,000 live births (Mumpe-Mwanja et al., 2019). System-specific anomalies showed a wide variation with cardiovascular anomalies at (32.3%), musculoskeletal (18.8%), chromosomal (10.9%), central nervous system (9.6%), gastrointestinal (6.9%), genital (5.3%), and respiratory (4.2%). The least common anomalies were of the renal and urinary systems estimated at (2.8%), although their impact on morbidity remains profound (ElAwady et

al., 2021). These figures signal both the scale of the problem and the urgent need for systematic surveillance, prevention strategies, and maternal health education in Uganda.

The implications of congenital anomalies stretch far beyond perinatal morbidity and mortality. The survivors may live with permanent disabilities, requiring long-term care that stretches household resources and perpetuates maternal psychological distress (ElAwady et al., 2021). Maternal accounts from high-income settings such as Sweden further reveal a gap between the health services provided and the mothers' perceived support needs. Bruce et al. (2014) reported that while many mothers acknowledged receiving adequate healthcare services, they simultaneously expressed dissatisfaction with the limited opportunities for meaningful dialogue with health professionals. This disconnect underscores the importance of patient-centered communication in neonatal care where emotional, informational, and relational support are prioritized alongside the clinical management.

This study therefore sought to explore and describe the lived experiences of Ugandan mothers whose infants are hospitalized with congenital anomalies. Beyond documenting the emotional reactions, such an inquiry has practical implications for nursing and health system practice: identifying gaps in psychosocial support, guiding the integration of family-centered care, and shaping culturally sensitive interventions that improve maternal resilience, mother-infant bonding, and neonatal outcomes.

### **Statement of the Problem**

Birth of a newborn with a congenital anomaly and their subsequent admission is considered a traumatic event for the mother and her family as it presents them with significant challenges and stress during their initial hospitalization period. Global studies indicate that maternal distress, in particular, is a common phenomenon during this period, and its symptoms

range from feelings of denial, guilt, and sadness to anxiety, uncertainty, and depressive symptoms. One study conducted in Mulago Hospital in 2019 estimated the prevalence of congenital anomalies at 440 per 10,000 births for all the 754 newborn admissions registered in 4 months. However, the impact of these anomalies on Ugandan mothers and their newborns is not known. It is thus important to explore the lived experiences of mothers whose newborns are hospitalized with congenital anomalies to recognize their emotional responses, needs, concerns, and the support they require to cope with their experience.

### **Purpose of the Study**

This study seeks to explore the lived experience of Ugandan mothers whose newborns have been hospitalized with congenital anomalies, and to describe their experiences during their hospital stay.

### **Research Question**

What is the lived experience of mothers whose newborns are hospitalized with congenital anomalies in a national referral hospital in Central Uganda?

### **Study Objectives**

The objectives of this study are to explore, and describe the lived experiences of mothers during the hospitalization of their newborns with congenital anomalies.

### **Significance of the Study**

Findings from this study can increase nurse leaders' awareness of the adverse mental health states of mothers whose newborns are hospitalized with a congenital anomaly. This could consequently urge them to institute mental health therapeutic interventions that can support the mothers to cope with this difficult experience. The findings can also be used to evaluate the current support given to these mothers and also be used to plan training sessions of staff who

work with these mothers so that they are better prepared to provide holistic care to the newborns and their mothers.

The findings may help to enhance nurses' knowledge and perception of how mothers feel about their newborns' hospitalization, particularly in recognizing mothers' emotional responses, thoughts, and feelings during hospitalization. Additionally, findings may help nurses to empathetically perceive the concerns and needs of mothers and identify the kind of support they would like to receive during this experience. Finally, the study findings can be used to enlighten future mothers about congenital anomalies and how they can cope with the challenges they pose.

### **Theoretical Framework**

The theoretical framework used for this study is a qualitative descriptive phenomenology, as was postulated by Edmund Husserl. In this framework three frames of reference are emphasized for studying a lived-experience phenomenon in its pure and universal sense. The frames of reference include the live-world plane of interaction between the researcher and participants, transcendental subjectivity (which is the neutrality and openness to the reality of others), and the identification of eidetic essences or universal truths (Wojnar & Swanson, 2007).

The "live-world plane of interaction" between the researcher and participants involves extended one-to-one engagements and contact with the objects of research through which the meaning of lived experience may be unraveled. According to Wojnar & Swanson (2007), this concept also emphasizes that engagements must involve attentive listening, interaction, and participant observation so as to create representations of reality.

Transcendental subjectivity refers to the constant assessment of the impact of the researcher on the inquiry, with a focus on neutralizing all preconceived opinions, biases, and prior knowledge about the phenomenon under study (Wojnar & Swanson, 2007). This concept

emphasizes the process of remaining neutral and open-minded to the reality of participants' experiences, which is achieved by bracketing all personal values, preconceptions, prior knowledge, and personal biases about the phenomenon under study.

The identification of eidetic essences or universal truths refers to the analysis of participants' accounts to identify the common features that are considered representative of the true nature of a phenomenon under investigation (Lopez & Willis, 2004). For a description of the lived experience to be considered a science, commonalities in the experiences of participants must be identified so that a generalized description is possible. The universal essences or truths are then considered to represent the true structure of the lived experience (Lopez & Willis, 2004). Descriptive phenomenologists thus use four main steps to uncover the universal essential structure of a lived-experience phenomenon. These include (a) bracketing, (b) intuiting, (c) analyzing, and (d) describing (Polit & Beck, 2017).

Bracketing refers to holding in abeyance any preconceived beliefs, opinions, or biases about the phenomenon under study so as to confront the subject matter on its own terms and in a state of pure consciousness. This means that the researcher must actively strip his or her consciousness of all prior expert knowledge as well as personal biases about the phenomenon under study (Lopez & Willis, 2004). Intuiting refers to the process of being open to the meanings attributed to the phenomenon by those who have experienced it. As participants' accounts are being generated, the investigator's intuition is "fed" by more and more data through attentive listening, deep critical reflection about commonalities across participants' narratives, and a concerted effort to understand "what it must be like" (Wojnar & Swanson, 2007, p. 176).

Analyzing refers to the process of examining participants' accounts so as to identify common features that represent the essential structure of the lived experience. It involves reading

participant transcripts to extract significant statements that are then categorized into themes to form an exhaustive description of the structure of the lived experience (Shosha, 2012). The describing step marks the end of the descriptive phenomenology investigation and presents a theoretical model representing the essential structures of the phenomenon under study. According to Polit & Beck (2017), it is during this step that the phenomenon's structure is defined and described. If the true structure of the phenomenon is identified, then anyone who has experienced the phenomenon should be able to identify their own experience in the proposed description (Wojnar & Swanson, 2007).

### **Operationalization of the Theory**

The concept of the “live-world plane of interaction” between the researcher and participants was operationalized by holding one-on-one in-depth interviews with the mothers in the field regarding their newborns' hospitalization experience. In order to gather detailed experiences from mothers, questionnaires were developed to guide the in-depth interviews. The interview process was audio recorded using an Android smart phone while also observing the mother's body language and demeanor.

By staying neutral and open to the realities of the mothers' experiences, the concept of transcendental subjectivity was operationalized by identifying and suspending the researcher's personal ideas and biases whilst listening and reflecting on the mothers' experiences. A reflective journal was maintained to document new and surprising findings during data collection and analysis.

The concept of identifying eidetic essences (universal truths) was operationalized through searching for the common features appearing in mothers' narrated experiences. These features

were then aggregated and synthesized to form clusters of themes that give an exhaustive general description of the mothers' lived experience.

The concept of bracketing, involved using a reflexive journal that was used for documenting the researcher's personal values, areas of role conflict, biases, and any prior knowledge that could hinder studying the mothers' lived experiences in a neutral manner. An open-mind attitude for attentively listening to the mothers' accounts was intuitively adopted to critically reflect upon the commonalities across their narratives. This step also required the researcher to remain open to the meanings that mothers attribute to their lived experiences.

Analyzing involved repeated reviewing of mothers' transcripts, extracting significant statements, formulating meaning from the statements extracted, categorizing the formulated meanings into clusters of themes, and synthesizing the themes into an exhaustive description of the structure of the experience. The exhaustive description was then reduced by removing redundant, misrepresented, or overrated descriptions from the general structure so as to obtain a fundamental structure of the mothers' lived experiences.

Finally, the validation of the study findings was done through the "member checking" technique with the mothers. This was done by going back to the mothers and discussing the results with them to confirm whether the results truly reflected their feelings, meanings, and experiences. Upon portraying satisfaction with the research results as a true reflection of their experiences, a fundamental structure of the mothers' lived experience was developed. However, in instances where mothers portrayed dissatisfaction with the meaning of the research results, their transcripts were reviewed again with them to verify what they actually meant. This enabled the researcher to obtain a credible interpretation of what they actually meant. Finally, the

descriptive phase involved discovering and defining the experience in a theoretical framework that embodied the fundamental elements of the mothers' actual experiences.

### **Operationalization of Terms in the Study**

**Congenital Anomaly:** In this study, a congenital anomaly is referred to as a structural or functional malformation/birth defect that develops in a baby while still in the womb and is detected at birth, or within one-two week after birth.

**Newborn:** A newborn in this study refers to baby or neonate that has just been delivered with a congenital anomaly.

**Mother:** The study refers to a mother as a female who has delivered a baby with a congenital anomaly.

**Hospitalization Experience:** Refers to the encounters or experiences that a mother goes through during the period of her newborn's hospitalization with a congenital anomaly.

**Lived Experience:** The lived experience refers to the emotions, feelings and events that a mother encounters during the hospitalization period of her sick newborn, with a congenital anomaly

**Tertiary Hospital or Health Facility:** This study refers to a tertiary hospital as a health - care center or setting that provides specialized healthcare services.

### **Summary**

Chapter one introduces the experience of mothers delivering newborns with congenital anomalies. It also discusses the background of this experience or phenomenon, highlighting its prevalence. The chapter further discusses the statement of the problem, the purpose of the study, and the research question. Additionally, the chapter describes the study's objective, the significance of the study, and the theoretical framework used to underpin the study, including its

operationalization. Chapter two discusses the reviewed literature pertaining to the experience, while Chapter three identifies the methodology that will be used for this research study.

## **Chapter 2: Literature Review**

This chapter provides a comprehensive review of the existing literature related to mothers' experiences of having their newborns hospitalized with congenital anomalies. It explores the global and Ugandan perspectives on the burden of congenital anomalies, outlining their prevalence and the associated maternal risk factors that contribute to their occurrence. Furthermore, the chapter examines the emotional, psychological, and social experiences of mothers during the care and hospitalization of their newborns, while also highlighting the coping mechanisms they employ and the types of support they find most beneficial. The chapter concludes with a synthesis of the reviewed literature and identifies the existing knowledge gaps that the present study seeks to address.

### **The Birth of Newborns with Congenital Anomalies is becoming an Increasingly Common Phenomenon**

Congenital anomalies are defined as prenatal birth defects that are structural and functional in nature, occurring during the development process of a pregnancy (Ameen et al., 2018). The anomalies can be broadly categorized into two groups: single-system anomalies, which affect one organ or body part, and multiple-system anomalies, which involve multiple organs or systems (Ameen et al., 2018). The distinction is clinically relevant as the extent of systemic involvement often correlates with the complexity of management and prognosis. Furthermore, congenital anomalies are classified as either major, or minor, with the major anomalies defined as those which significantly impair physical functioning or reduce life expectancy if untreated. The minor anomalies are defined as benign and may be considered as normal population variants (Ameen et al., 2018). However, this classification can be context-

dependent, as even minor anomalies may carry social stigma or functional consequences in low-resource settings.

The development of congenital anomalies in newborns has emerged as a growing global health concern, particularly due to their associated burden of morbidity and mortality. These anomalies develop during embryogenesis and can manifest in structural, functional, metabolic, or behavioral abnormalities (Ameen et al., 2018; Ajao & Adeoye, 2019). While the above definition varies slightly across the literature, a shared emphasis remains on the developmental origin and clinical significance of the congenital anomalies. Notably, congenital anomalies often necessitate surgical and medical interventions shortly after birth, underlining their critical impact on the neonatal clinical outcomes and the mothers' mental health.

The global burden of congenital anomalies is considerable, and estimated at about 7.9 million neonates born annually with some form of congenital anomaly (Ajao & Adeoye, 2019). Additionally, Ullrich et al. (2020) noted that approximately 2.5 million newborns die within the first month of life due to such conditions. However, the statistics should be interpreted with caution, as prevalence and mortality figures are significantly influenced by disparities in surveillance systems, diagnostic capabilities, and healthcare access, particularly in low- and middle-income countries.

The prevalence of congenital anomalies varies widely across geographical and socio-demographic contexts. For instance, reported rates range from 1.07% in Japan to 4.3% in Taiwan, 7% in Uganda, and a striking 11.1% in Nigeria (Ameen et al., 2018; Ajao & Adeoye, 2019). These variations likely reflect more than just biological or genetic factors; they are also shaped by differences in environmental exposures, maternal health, nutrition, healthcare infrastructure, and the reporting practices. Importantly, Ameen et al. (2018) emphasized the

complex interplay between genetic predisposition and environmental influences, including maternal age, socioeconomic status, and ethnicity in shaping the above rates.

In sub-Saharan Africa, including Uganda, the challenge is compounded by systemic health inequities that increase the mortality rates associated with the anomalies. Tiruneh et al. (2022) attributes the high mortality among infants with congenital anomalies to barriers such as poor access to antenatal care, inadequate diagnostic services, poor quality healthcare, and limited capacity for pediatric surgical interventions. These findings point to the critical gaps in healthcare systems which exacerbated the burden associated with the anomalies. Uganda presents a revealing case study where the neonatal mortality rate currently stands at 22 deaths per 1,000 live births, a figure greater than the WHO target of less than 12 deaths per 1,000 live births.

From a global health perspective, congenital anomalies are a major contributor to neonatal mortality, especially in resource-limited settings. Ajao and Adeoye (2019) emphasize that most deaths due to congenital anomalies occur in low- and middle-income countries, where early diagnosis and surgical care intervention are often unavailable or limited. Gedamu et al. (2021) estimated that approximately 303,000 newborns globally die within the first 28 days of life due to congenital anomalies; a figure that signals a persistent gap in preventive and curative healthcare for newborns with congenital anomalies.

According to Mumpe-Mwanja et al. (2019), congenital anomalies contribute 11.7% of the global neonatal deaths. Data from Hersi et al. (2022) revealed that in a period of just four months, 257 children presented with congenital musculoskeletal anomalies at two regional hospitals in Uganda, suggesting both a high burden and a potential underreporting of the less visible or fatal forms of congenital anomalies. Additionally, Mumpe-Mwanja et al. (2019) found a prevalence rate of 440 per 10,000 live births at Mulago National Referral Hospital, though this

figure may not be representative of the national average due to the hospital's urban and referral-based nature. Further evidence from a cross-sectional study by Ochieng et al. (2011) screened 754 neonates over a four-month period and found that 4.4% of them had external congenital anomalies, with two babies having two anomalies each. Although such studies are useful, they are often limited by small sample sizes, short observation periods, and a focus on visibly detectable anomalies, potentially underestimating the true prevalence.

Epidemiological data reveals significant differences in the prevalence and types of congenital anomalies between high-income and low-income regions. For instance, Caldeman et al. (2021) conducted a 20-year study in Sweden and identified gastrointestinal anomalies as the most prevalent (11.4%), followed by musculoskeletal (9.8%) and cardiovascular anomalies (7.9%). Gastroschisis emerged as the most common gastrointestinal condition (1.52 per 10,000 live births), while musculoskeletal anomalies like unstable hip (6.6%) and cardiac defects such as atrial septal defect (5.4%) were also prominent. These findings not only highlight the importance of having neonatal surgical capacity, but also underscore the role of early diagnostic screening in high-income settings.

In contrast, studies in Uganda reflect a different epidemiological landscape, likely shaped by disparities in healthcare infrastructure, diagnostic capacity, and environmental exposures. Ochieng et al. (2011) found that among 754 Ugandan newborns examined, 35 (4.4%) had external congenital anomalies, with limb and craniofacial defects making up 68% of the cases. Conditions such as cleft lip/palate (14.2%), central nervous system anomalies (8.4%), spina bifida (5.8%), and omphalocele (5.8%), were among the most common. The predominance of external and musculoskeletal anomalies in such studies may be due to the limitations of using

clinical observations and low quality imaging for diagnosis especially in low resource settings where advanced imaging or genetic testing is often unavailable.

Furthermore, regional variations in prevalence of anomalies within Uganda have also been documented. Cheung et al. (2019), reporting from Mulago National Referral Hospital in central Uganda, identified gastrointestinal anomalies including Hirschsprung disease, omphalocele, anorectal malformations, and intestinal atresias as the most frequent, accounting for 38.6% of cases. Meanwhile, Hersi et al. (2022), studying data from southwestern Uganda, reported musculoskeletal anomalies as the most common, led by Talipes equinovarus (34.6%), followed by spina bifida (30.4%) and polydactyly (5.8%). These contrasts may reflect regional differences in risk factors such as nutrition, folate supplementation, access to antenatal care, and possibly even environmental teratogens, though few studies have explored these connections in depth.

This geographic variability underscores a broader limitation in current research on congenital anomalies across many low- and middle-income countries. This is mainly attributed to a lack of harmonized, nationwide surveillance data on incidence and prevalence of the anomalies. Most findings available are based on localized hospital-based studies which can introduce selection bias and may under represent milder, internal, or prenatally diagnosed anomalies. Without standardized data collection and population-wide screening, the true burden and patterns of congenital anomalies may remain underestimated.

The burden of congenital anomalies in low- and middle-income countries (LMICs) like Uganda is exacerbated by severe limitations in accessing quality diagnostic imaging, surgical care and specialized neonatal support. Ullrich et al. (2020) estimated that up to 94% of newborn deaths from congenital anomalies in LMICs are attributable to factors such as the lack of

neonatal intensive care units (NICUs), pediatric surgeons, and anesthesiologists. Alarming, congenital anomalies many of which are surgically correctable have begun to account for a larger proportion of infant mortality than infectious diseases in some contexts. At Mulago National Referral Hospital, for example, 36% of the 1313 neonates admitted with congenital anomalies between 2012 and 2017 did not survive, with a median age of admission being just 3 days (Ullrich et al., 2020). Such mortality statistics raise critical concerns not only about clinical outcomes, but also about the responsiveness of healthcare systems.

In many LMICs, the true incidence, prevalence, and mortality burden of congenital anomalies remains poorly characterized due to limited surveillance, non-uniform diagnostic practices, and a limited access to tertiary care (Cheung et al., 2019; Commander et al., 2021; Ekwochi et al., 2018). Many neonates with congenital anomalies die before reaching tertiary centers thereby rendering them invisible in hospital-based data bases. This absence of reliable national registries contributes to a chronic underestimation of the problem and hinders targeted health interventions. Data reliability concerns like inaccurate reporting, incomplete health records, and limited diagnostic technologies also distort the understanding of the true prevalence of congenital anomalies. While this distortion is often noted in the literature (Ameen et al., 2018), the implications are more systemic and without accurate data, it is difficult to plan for resource allocation for targeted interventions of congenital anomalies' prevention and care.

The cause of congenital anomalies remains poorly understood, with more than 50% of cases globally having no definite cause (Taye et al., 2018). However, a combination of genetic, environmental, nutritional, and behavioral risk factors has been identified. According to Ajao and Adeoye (2019), genetic factors account for 10–30% of cases, environmental causes (such as infections) for 5–10%, multi-factorial causes for 20–35%, while unknown causes remain the

largest category at 30–45%. This epistemic uncertainty has a direct impact on both prevention and policy formulation, often leaving clinicians and public health officials without clear intervention pathways.

Despite the ambiguity in causality, a number of modifiable risk factors are repeatedly cited in the literature. These include extremes of maternal age, use of embryotoxic medications (such as antidepressants), having a low maternal body mass index, use of illicit substances like cocaine and marijuana, exposure to hormonal contraceptives in early pregnancy, and illnesses contracted during pregnancy (Taye et al., 2018; Wright et al., 2018). Socio-demographic variables such as low education levels, poverty, a high parity, and poor attendance to antenatal care were also identified as strong correlates of congenital anomaly occurrence and severity (Ekwochi et al., 2018; Tiruneh et al., 2022). A particularly at-risk demographic includes mothers who lower than 21 or over 35 years, who smoke, use herbal medications, or consume iron-deficient, unfortified diets (Ameen et al., 2018). Such findings point to an urgent need for pre-conception education, micro-nutrient supplementation, and behavioral health interventions, especially among the rural and marginalized populations.

Among the environmental causes, maternal infections during pregnancy are the most significant embryotoxic agents in LMICs (Ajao & Adeoye, 2019). Contributing factors also include poor prenatal care, failure to use folic acid supplements, a history of miscarriages, consanguineous marriages, and inherited genetic disorders (Ameen et al., 2018). These risk factors, while not individually causative, they interact within a complex ecosystem of socio-medical determinants consequently increasing the likelihood of anomaly development. What is particularly intriguing and often under-emphasized in policy discussions is that several of the congenital anomalies are preventable. The literature consistently identifies basic interventions

such as folic acid supplementation, vitamin use during pregnancy, infection control, vaccination, and abstention from alcohol, smoking, and irrational drug use as effective preventive measures (Ekwochi et al., 2018; Taye et al., 2018). These interventions are cost-effective, scalable, and could be integrated into existing antenatal care programs with minimal resource investment. However, the implementation remains inconsistent due to system-level gaps in healthcare service delivery.

Equally crucial is the role of clinicians in assisting mothers to organize and plan their deliveries in tertiary healthcare facilities that provide neonatal resuscitation, surgery, and intensive care services. Prenatal ultrasounds, when effectively used, can enable early detection of congenital anomalies and allow healthcare providers to plan for delivery in tertiary facilities with pediatric surgical and intensive care capabilities. This proactive strategy is one of the primary reasons for significantly better survival outcomes in well-resourced settings and should be prioritized in maternal care protocols in LMICs.

In summary, this body of literature points to a rising global burden of congenital anomalies, with LMICs like Uganda shouldering a disproportionate share due to the systemic challenges and weaknesses in diagnosis, treatment, and prevention. While many causes of the anomalies remain unknown, a range of modifiable risk factors and effective interventions have been identified and documented. The persistence of high mortality rates of newborns with congenital anomalies indicates a disconnection between knowledge and implementation; one that urgently needs to be addressed through stronger surveillance modalities, targeted policy interventions, and integrated clinical care.

## **The Hospitalization of Newborns with Congenital Anomalies has Significant Effects on their Mothers**

This section examines the impact of newborn hospitalization on mothers' mental and physical wellbeing. It explores the mothers' emotional responses, feelings, and concerns arising from the hospitalization of their newborns, highlighting the depth of distress and adjustment required during this period. Guided by Edmund Husserl's descriptive phenomenological approach, the section presents an authentic and unbiased account of the mothers' lived realities by focusing on how they consciously perceived and made meaning of their experiences, rather than interpreting them solely through psychological or medical lenses. The reviewed literature consistently indicates that mothers encounter complex, emotionally intense, and unexpected challenges upon learning that their newborns are affected by congenital anomalies necessitating hospitalization.

The anticipation of childbirth is typically framed by optimism, preparation, and positive maternal expectations. As Kidane et al. (2020) observed, pregnancy often initiates a journey of emotional investment in the idea of having a healthy newborn, with the mother actively preparing for the responsibilities and joys of parenthood. However, the abrupt confrontation with a congenital anomaly at birth disrupts this psychological trajectory, replacing joy with fear, anxiety, and emotional turmoil. Staver et al. (2020) underscored the mental health consequences of such events, linking them directly to increased rates of maternal depression, distress, and postnatal anxiety; outcomes that are often under-acknowledged in neonatal care settings. The mothers face an abnormal and often frightening birth experience that is characterized by fear, worry, guilt, and feelings of being out of control when they deliver a newborn with a congenital anomaly (Staver et al., 2020).

While the emotional reaction of mothers may be seen as understandable from a psychological perspective, this response is compounded by social and cultural implications, particularly in African societies where congenital anomalies are often interpreted through lenses of blame, shame, superstition, and cultural beliefs (Kidane et al., 2020). Rather than receiving empathy and support, mothers are sometimes stigmatized by family and community members and viewed as having somehow caused the anomaly, whether through perceived spiritual fault, past behavior, or even moral failure. This cultural attribution of shame and fault further isolates the mother, intensifies her grief, and can obstruct her access to both formal healthcare and social support.

The psychosocial burden of caring for a newborn with a congenital anomaly is also tied to feelings of helplessness and disenfranchised grief, as noted by Seyedrasooli et al. (2020). The parents not only deal with the immediate medical realities of hospitalization but also with the loss of an imagined future that had centered on raising a healthy child. This kind of grief, though deeply felt by the mothers, is often invisible and unsupported by standard hospital protocols, particularly in low-and middle-income countries. Fontoura et al. (2018) rightly framed this period as one of cumulative stress marked by physical exhaustion, emotional pain, and financial depletion. The situation becomes particularly acute when the congenital anomaly is incompatible with life, compounding sorrow with the logistical and psychological trauma of neonatal death.

Interestingly, parallels can be drawn between the hospitalization of newborns with congenital anomalies, and those born with terminal illnesses such as cancer. Lavee and Mey-Dan (2003) present compelling evidence that such experiences disrupt family systems, not only emotionally but structurally. While some couples reported strengthened bonds through mutual care giving, others experienced decrease in their marriage intimacy, with the sexual relationship

being the most commonly cited area of strain. Notably, the decline in intimacy was not always accompanied by breakdowns in other aspects of the relationship, such as communication or parenting roles. This suggests that emotional resilience may be compartmentalized, allowing families to maintain outward function even while navigating internal strain.

The relative absence of detailed studies on the effects of newborn illnesses on marital dynamics is a glaring research gap. The current literature as highlighted by Lavee and Mey-Dan (2003) leans heavily toward maternal narratives and rarely interrogates paternal or relational perspectives beyond surface-level observations. This oversight hinders our understanding of how families adapt or fracture under the stress of neonatal hospitalization and points to a need for couple-based research frameworks in pediatric care contexts. It is thus important for social workers and healthcare professionals to not only focus on the well-being of the sick infant but also apply a holistic and family-oriented healthcare approach that caters to the proper functioning of the parents' marital relationship.

Rozensztrauch et al. (2020) further emphasized that a family's ability to manage the diagnosis and prognosis of a congenital anomaly is dependent on multiple variables: the emotional stability of the caregivers, the cohesion of the family unit, and the availability, affordability and quality of specialized healthcare support. The physical separation of mother and newborn during hospitalization often exacerbates the sense of loss and emotional disequilibrium, especially when the healthcare system lacks adequate psychosocial support structures. Without targeted interventions, mothers may struggle to balance care giving duties with household and familial roles, thereby straining their mental health and disrupting established family dynamics.

According to Rozensztrauch et al. (2020), the parents of a hospitalized newborn may not only feel overwhelmed by the hospitalization experience but also worry about the future of the

entire family. It was also documented that the newborn's illness or birth anomaly is a severe emotional shock for the family and can impair social connections and interactions amongst the family members as well as outside the family. In a study that examined fathers' experiences during the hospitalization of their newborns, Jerntorp et al. (2021) found that mothers frequently concentrated more on the newborn's needs while inadvertently forgetting to care for themselves and the rest of their family members. The fathers, on the other hand, perceived their personal needs as secondary to those of their partners and newborns, despite feeling alienated and not totally in charge of the newborn care. This highlights a structural neglect of the paternal roles in neonatal care planning, as well as a need to expand the available psychosocial services to both parents rather than just focusing exclusively on the mother-child dyad.

The hospitalization of a newborn with a congenital anomaly constitutes a profound disruption to the anticipated trajectory of motherhood. Jerntorp et al. (2021) noted that the parents of a hospitalized newborn with a congenital anomaly often face emotional and psychological strain that interferes with their adjustment to parenthood. The abrupt transition from a hope for a healthy delivery, to the reality of neonatal illness reshapes not only maternal expectations, but also the entire framework of early parenthood. Mothers frequently report a perceived loss of control, and in many cases view interactions with medical personnel during post-discharge homecare as opportunities to restore control over their family life.

There is substantial evidence that mothers experience greater psychological pain and vulnerability than fathers during the postnatal period when a baby is born with a congenital anomaly. Seyedrasooli et al. (2020) documented that this heightened maternal anxiety is exacerbated by insufficient knowledge about the newborn's condition and the mother's poor communication with healthcare providers. These stressors not only hinder maternal coping

mechanisms but also compromise the quality of care provided by the mother. When anxiety and emotional overload lead to avoidance or emotional withdrawal, the early mother to infant bond may be weakened, further compounding the developmental and psychological risks for the child. As such, it is a difficult and challenging moment when a mother learns that her newborn has a congenital anomaly that makes them look and function differently from healthy newborns.

The physical health of the mother is also implicated in this prolonged period of psychological strain. Eyal et al. (2016) found that the mothers of newborns with congenital anomalies often face significantly higher risks of developing chronic physical and mental health conditions, as compared to the mothers of healthy infants. These risks include reduced physical functioning, increased activity restrictions, and sustained poor mental health. Conspicuously, long-term cohort studies from Denmark revealed that maternal mortality was slightly increased over a ten-year period following the birth of a newborn with a major congenital anomaly; an unsettling indication of the life-altering toll exerted by care giving experiences under extreme stress (Eyal et al., 2016).

Moreover, Jerntorp et al. (2020) emphasized the traumatic dimensions of neonatal hospitalization, pointing to a high prevalence of post-traumatic stress disorder (PTSD) symptoms in both mothers and fathers. The repeated exposure to uncertainty, invasive medical interventions on the newborn, and the fear of neonatal death transforms the pediatric surgical care environment into a site of chronic emotional trauma. Unfortunately, in most LMIC contexts such as Uganda, trauma-informed care remains absent or inconsistently applied; leaving families to navigate profound psychological trauma without adequate support.

Additionally, beyond the psychological burden, economic hardship emerges as a parallel and equally distressing reality. Commander et al. (2021) provided a sobering account of how

congenital anomalies are perceived within the Ugandan context. In a qualitative study involving 198 respondents, including both relatives of affected infants and community members, it was unanimously agreed that surgical intervention would drive the families into poverty. Alarming, nearly half of the respondents (43%) believed that a father would abandon a child with an anomaly, and over a quarter (26%) explicitly supported letting such a child die (Commander et al., 2021). These statistics underscore a serious intersection of poverty, fatalism, and gendered caregiving roles, where women often bear the double burden of caregiving and social blame, while men may disengage or abdicate responsibility.

Further complicating maternal well-being is the sense of parental role distortion, a theme echoed across several studies (Govindaswamy et al., 2020). For many mothers, the transition into parenthood is not merely delayed but profoundly reconfigured. The emotional distress stems not only from the anomaly itself, but also from the associated loss of imagined normalcy, compounded by the child's altered physical appearance, dependence on medical care interventions, and the accompanying financial devastation. These multiple layers of distress (psychological, social, physical, and economic) render the maternal care giving role one of profound endurance and adaptation.

Critically, these findings expose significant gaps in health systems preparedness. While congenital anomalies demand clinical intervention, they also necessitate a parallel infrastructure of psychosocial and financial support services and resources that are often fragmented or unavailable in low-resource settings like Uganda. The lack of integrated family-centered care, particularly in low-and middle-income countries, risks perpetuating the cycles of psychological trauma, maternal ill-health, and neonatal neglect or abandonment. Moreover, healthcare professionals are sometimes ill-equipped to respond to the emotional needs of the mothers or to

navigate the cultural stigmas surrounding congenital anomalies, a situation that further erodes trust between families and the healthcare systems.

### **Exploring the Mothers' Lived Experiences can highlight their Challenges and Support they need during their Newborns' Hospitalization**

This section explores the needs of mothers during the hospitalization of their newborns with congenital anomalies. It also examines the nature of assistance that mothers receive while caring for their hospitalized infants, and highlights the forms of support that have been identified in the literature as particularly beneficial in helping mothers cope with the challenges of this period.

Although there is a growing body of literature documenting the emotional turmoil experienced by parents of newborns in Neonatal Intensive Care Units (NICUs), there remains a significant research gap regarding the specific stressors faced by mothers whose infants require surgery due to congenital anomalies (Fontoura et al., 2018; Govindaswamy et al., 2020). In a Brazilian study, Fontoura et al. (2018) underscored the unique and distressing nature of the moment when a mother learns that her newborn has a congenital anomaly that makes them look different from healthy newborns. Mothers described this period as one marked by grief, pain, confusion, and the overwhelming financial, physical, and social demands of navigating a fragmented and resource-intensive healthcare experience. Notably, however, there is little to no published research in Uganda exploring these experiences in comparable surgical contexts. This leaves a crucial gap in understanding how the social, cultural, and structural healthcare factors shape maternal stress during hospitalization of newborns with congenital anomalies.

In contrast, studies from high-resource settings such as Australia provide more detailed accounts of maternal psychological stressors. Govindaswamy et al. (2020) found that one of the

most pronounced stressors was the alteration of the maternal role, including feelings of helplessness, inability to protect their child, and distress from observing painful procedures being conducted on the newborns. Mothers in these settings had access to supportive neonatal infrastructure and family-centered care policies, yet still reported high levels of emotional turmoil. This calls into question the magnitude of distress in under-resourced settings, where both surgical infrastructure and psychosocial support are limited. Indeed, Mumpe-Mwanja et al. (2019) acknowledge a critical lack of literature from Uganda capturing maternal stressors in the context of congenital anomalies, and suggesting an urgent need to investigate and document these experiences locally.

Research from low-resource countries such as Iraq further emphasizes that emotional responses ranging from denial and grief, to guilt and shame and these can manifest even when the anomalies are detected antenatally (Ameen et al., 2018). These findings underscore the mothers' psychological uncertainties of the diagnosis itself, irrespective of the quality of the healthcare that can be provided. This further suggests that the detection of the anomaly antenatally is in itself insufficient in helping mothers, if it is not combined with appropriate psychosocial care and informational support. In Uganda, qualitative reports on spina bifida care suggest that mothers are often unprepared for the complex care requirements of infants with congenital anomalies, highlighting challenges in screening for anomalies antenatally, counseling, and planning for their delivery in tertiary healthcare centers. This lack of preparedness significantly compounds maternal distress and undermines effective postpartum care (Asasira, 2018; Ameen et al. 2018).

The disparities between high-income countries and under-resourced countries in terms of antenatally diagnosing congenital anomalies are profoundly significant. For instance, abdominal

anomalies such as gastroschisis are routinely diagnosed antenatally in countries like Sweden, enabling timely delivery planning and emotional preparation (Kidane et al., 2020). In contrast, Rwandese mothers reported shock and dismay upon delivery of newborns with congenital anomalies, despite attending antenatal care and being falsely reassured of fetal normality. This phenomenon highlights critical systemic failures in diagnostic accuracy and communication, and potentially creates a crisis of trust and credibility in maternal health services in low resource settings.

Fontoura et al. (2018) further observed that the emotional instability caused by maternal-infant separation, failure to bond effectively, invasive treatments, and the lack of adequate connection with the family members exacerbates the maternal anxiety arising from the newborn's hospitalization. The authors emphasized the need for health professionals to provide not just technical care, but also compassionate and emotionally attuned support, particularly when the diagnoses are made postpartum. The timing of diagnosis whether antenatally or postnatally significantly influences the maternal reactions, with the postnatal surprises often leading to deeper psychological shock and stigma.

In addition, educational interventions have been shown to mitigate some of these stressors. Ajao and Adeoye (2019) note that increasing maternal awareness of congenital anomalies, their causes, and treatment pathways significantly reduced emotional distress. Improvements in early surgical intervention and health system responsiveness were also associated with reduced maternal anxiety. However, these positive outcomes hinge on an informed and easily accessible and affordable healthcare system, yet these conditions are not universally available in Uganda and other similar LMIC contexts.

The combination of stigma, misinformation, and medical inadequacy further complicates maternal adaptation. Kidane et al. (2020) and Commander et al. (2021) point out that public education campaigns targeting mothers who deliver newborns with congenital anomalies have shown hope for reducing stigma and promoting early healthcare-seeking behaviors. In settings where social blame is often directed at mothers being accused of moral or spiritual failure, such interventions are not just medical but deeply socio-political in impact. In addition to systemic and educational interventions, psychological support mechanisms have also demonstrated effectiveness in aiding maternal adaptation. In Iran, Seyedrasooli et al. (2020) found that encouraging mothers to reflect on their emotional responses and engage in bonding behaviors (e.g., holding or gently touching their newborns) improved maternal coping. Anxiety-reducing techniques such as relaxation exercises, deep breathing, and taking daily warm baths and emotional expression also improved their coping and adaptation, yet these techniques require trained personnel who are often scarce in low-resource settings like Uganda.

Beyond clinical management, the emotional and psychosocial needs of mothers caring for newborns with congenital anomalies are a critical component of holistic healthcare. It is widely acknowledged that such mothers face significant physical and emotional strain during hospitalization, which can negatively affect maternal-infant bonding and psychological well-being (Silvio et al., 2018). To address these challenges, interventions such as Family-Centered Care (FCC) and Patient-Centered Communication (PCC) have emerged as essential strategies in neonatal care.

According to Jerntorp et al. (2020), FCC promotes the active involvement of mothers and families in care giving decisions and routines, fostering a sense of autonomy, competence, and emotional connection. Practices such as kangaroo mother care, individualized developmental

care plans, and structured parent education programs were shown to empower mothers by enhancing their care giving capacity and emotional resilience. PCC, on the other hand, emphasizes respectful and empathetic communication, tailoring care to each mother's unique psychosocial context. When implemented effectively, PCC helps mothers to feel seen, heard, and valued as essential partners in their newborn's care, consequently reducing feelings of stress and helplessness (Jerntorp et al., 2020).

However, the implementation of these care models remains inconsistent, particularly in resource-limited settings like Uganda, where healthcare personnel shortages and infrastructure limitations hinder the delivery of comprehensive psychosocial support. There is a clear gap in literature assessing how FCC and PCC principles are applied or neglected in Ugandan neonatal surgical settings. This raises important questions about how best to adapt these models within the local setting constraints to ensure they are and practically feasible and culturally relevant.

Peer support has also emerged as a crucial coping mechanism for mothers of hospitalized newborns. Kidane et al. (2020) found that in Rwanda, support from other mothers who had faced similar challenges, particularly with conditions such as gastroschisis, was highly valued. These informal support networks helped women process their experiences and offered emotional solidarity. Remarkably, many mothers expressed willingness to support others going through similar struggles, suggesting that peer-led counseling or mentorship programs could be a sustainable community-driven strategy. In Uganda, however, such peer support structures remain undocumented and or underexplored in neonatal surgical care settings; despite the likely value they could offer in settings where formal psychosocial services are limited.

Additionally, Seyedrasooli et al. (2020) highlighted the importance of sharing information and educational tools to help mothers better understand and care for their newborns

with physically visible anomalies. It is suggested that providing mothers with visual guides, photographs, and step-by-step care instructions can reduce anxiety and improve the mothers' care giving confidence. These interventions help to reframe the child's condition in less threatening terms and support the maternal-infant bonding. In Uganda, similar tools tailored to local literacy levels and cultural contexts could significantly improve maternal adaptation to the unexpected diagnoses.

The type and source of social support available to mothers also plays a key role in shaping their adjustment to the newborn's hospitalization. Asasira (2018) observed that Ugandan mothers of children with spina bifida rely heavily on interpersonal support from partners, extended family, and the health system. Material and emotional support from spouses, relatives, friends, community members, and healthcare professionals were additionally reported as pivotal in helping mothers cope with their children's hospitalization. The support ranged from basic needs such as food, money, and transport, to more emotional and informational forms, such as advice or counseling. However, the adequacy and availability of this support is often inconsistent, particularly when compared to the comprehensive care available in high-income countries. In these better-resourced settings, timely diagnosis, coordinated care plans, and structured follow-up services contribute to improved maternal and neonatal outcomes, underscoring the systemic inequities that Ugandan mothers face during their newborns' hospitalization.

It has also been widely reported that religion and spirituality have become important coping mechanisms for mothers during their newborns' hospitalization. In the Rwandan context, Kidane et al. (2020) found that many mothers leaned on their faith as a source of strength, particularly in the face of medical uncertainty and poor prognosis of the anomalies. Spirituality

helped mothers maintain emotional stability and find meaning during hospitalization. These findings highlight the importance of religious and culturally sensitive holistic care models that respect and incorporate religious beliefs as part of the emotional and psychological support strategies. Mothers who receive such multifaceted support demonstrate higher levels of acceptance and reduced emotional distress. However, Kidane et al. (2020) noted the absence of research into the experiences of bereaved mothers those whose newborns did not survive hospitalization; indicating a critical research gap in understanding how to support grief and recovery in such tragic outcomes.

Finally, research from high-income countries like Sweden reveals the long-term psychological toll of neonatal hospitalization on the mothers' mental health. Jerntorp et al. (2020) reported a high incidence of post-traumatic stress disorder (PTSD) among mothers and fathers of hospitalized infants with congenital anomalies. While these findings underscore the emotional burden even in the most advanced healthcare systems, there is virtually no comparable research in Uganda examining the prevalence or impact of such stress disorders in mothers with hospitalized newborns due to congenital anomalies. Given the potentially enduring mental health consequences of such experiences, there is need for a systematic psychological screening, counseling and follow-up of mental health services for the parents involved.

### **Summary**

The literature in Chapter two reveals that mothers face several emotionally charged, complex, and unanticipated realities, upon discovering that their babies are sick and require hospitalization as a result of the congenital anomalies. The use of Edmund's descriptive phenomenology framework enabled the uncovering how mothers subjectively experienced and interpreted the hospitalization of their newborns, including the associated emotional burden,

distorted maternal identity, and the social implications. However, it has been noted that mothers can adapt to and cope with this challenging experience when they are supported and actively involved by health professionals in the care processes of their hospitalized newborns.

The literature clearly indicates that formal support systems like FCC and PCC, as well as the informal support systems like peer, familial, and religious support, all play a crucial role in maternal adaptation and adjustment during the hospitalization of their newborns. While these interventions have been shown to reduce stress, anxiety, and even PTSD in high- and middle-income settings, their implementation and effectiveness in Uganda remain under-researched and poorly documented, especially in neonatal surgical care settings. Chapter three describes the methodological procedures that were applied in this study.

### **Chapter Three: Methodology**

This chapter presents the methodology employed in this study, describing the research design, study setting, and characteristics of the sampled population. It further outlines the procedures used for data collection, the approaches applied for data analysis, and the strategies implemented for data management throughout the study.

#### **Study Design**

This research uses a qualitative study approach that applies the phenomenology research design to explore the lived experience of mothers whose newborns are hospitalized with congenital anomalies. Phenomenology is a study-design approach that explores and identifies the essential structures of people's everyday life experiences (Polit & Beck, 2017). The aim of a phenomenology investigation is to understand the universal character of a lived experience and the meaning that participants attribute to it. This approach is the most appropriate because the use of descriptive phenomenology as postulated by its author Edmund Husserl, emphasizes the application of the investigator's objective mind to guide the discovery of the universal character and nature of a lived experience and its fundamental structure.

#### **Study Setting**

The study was conducted in one of Uganda's national referral hospitals, a tertiary health facility. This site was purposefully chosen for the study because it is where mothers are referred for specialized care when they deliver newborns with congenital anomalies. The hospital has a bed capacity of about 60 patient beds in the pediatric surgical unit, where mothers and their newborns are admitted for surgical management. Additionally, the hospital has outpatient clinics for the management of children with such birth anomalies and the scheduling of the same for surgical correction.

### **Study Population and Sample Size**

This study was carried out amongst mothers who were caring for their hospitalized newborns with congenital anomalies irrespective of how long they had been hospitalized. The study participants were mothers recruited from the inpatient ward of pediatric surgery where they are admitted with their sick newborns. The process of enrolling mothers was done until no new information arose from the mothers' narratives during the follow-up questions. The enrollment process ultimately determined the actual sample size which was nine mothers. After achieving saturation at eight mothers, one more mother was interviewed to confirm the study findings bringing the total sample size to nine.

### **Inclusion and Exclusion Criteria**

The inclusion criterion for this study was any Ugandan mother caring for their hospitalized newborn with congenital anomalies, and such a mother being able to communicate in English, Luganda, Runyankore, or Rukiga. The exclusion criteria was any Ugandan mother caring for her hospitalized newborn who was critically ill and thus unable to participate in the study, and any mother who declined to consent for participation.

### **Sampling Method**

This study applied purposive sampling method as a strategy for recruiting the participants. Purposive sampling is a strategy in which a researcher chooses eligible participants who can best contribute to the purpose of the study (Polit & Beck, 2017). The eligible mothers chosen for the study were those admitted on the ward to care for their hospitalized newborns that had congenital anomalies. Purposive sampling was suitable for this study to deliberately select such mothers who had the experience of caring for their hospitalized newborns with congenital anomalies.

The mothers were identified in the pediatric surgery ward where they are admitted with their newborns awaiting surgical correction and management of the anomalies. The mothers were contacted on a one-on-one basis and requested to consent and participate in the study by answering questions that pertained to their lived experience of caring for their hospitalized newborns. A mother who agreed to this request was then guided to a conference room where the purpose of the study was explained to her in detail, and an informed consent was obtained. (Appendix A). While the mother was away participating in the study, a relative to the mother was left behind to attend and care for the admitted baby.

### **Data Collection**

A mother who consented to participate in the study was then taken to a private, quiet room in the hospital for an interview. Two mothers were interviewed on each day of the study, and a token of thanks (10,000 Uganda shillings) was given to each participating mother in appreciation of their cooperation during the interview. An interview guide was developed and guided by the research objective, theoretical framework, and the literature review done. The interview guide contained question probes that allowed mothers to express themselves in detail regarding their experiences of caring for their hospitalized newborns (Appendix B). The study used in-depth interview questions that were semi-structured to collect narrative information from the mothers participating in the study.

The interview tool was composed of three sections. Section one contained the demographic characteristics of the mothers; section two contained a description of the mother's experiences during the care and hospitalization of their newborn; and section three contained a discussion of the mother's needs, concerns, and the support she would like to have. Additionally, the researcher used an Android smart phone to make audio recordings of mothers' narratives of

their experiences. A paper and pen was also be used to write down what required more clarification from the mothers.

### **Data Management**

The process of collecting data was started after obtaining an informed consent from the mothers. The android phone recorder was set and a diary book and pen were used to record the researcher's reflections on the mothers' responses, and their non-verbal communication cues. The diary used in writing, consent forms, and the recorder containing the mothers' audio files were all kept securely under lock and key to avoid any unauthorized access to them. The phone recordings of the mothers 'narratives were also secured using a phone password and computer password that are only known to the researcher to ensure privacy. The diary notes, consent forms, and audio files were finally locked in a cabin drawer that is only accessed by the researcher.

### **Data Analysis**

The researcher transcribed all the audio data collected into a Word document for analysis. The mothers' responses that were recorded in other local dialects, like Luganda, and Runyankore, were directly transcribed in English by the researcher. A second person who was a neutral peer was contacted to cross-check the researcher's translations to confirm their accuracy. Data analysis was done using the Colaizzi method of analyzing qualitative data. The analysis involved reading and re-reading mothers' transcripts, extracting significant statements, formulating meaning from the significant statements, and categorizing the formulated meanings into clusters of themes. The data analysis also involved doing a thematic analysis to synthesize the themes and form an exhaustive general description of the mothers' lived experiences. The general description was then reduced by removing redundant themes and statements to form a

fundamental structure that describes the mothers' lived experiences. The data was coded and analyzed manually, with each particular interview as a unit of analysis. After analyzing the study results, a validation of the study findings was done using the "member checking" technique to confirm whether they truly reflected the meanings, feelings, and experiences of the mothers.

### **Trustworthiness and Integrity**

Authors of phenomenology studies strive to obtain integrity and trustworthiness by demonstrating confirmability, credibility, dependability, and transferability during the research process. Below are the quality control measures that were applied to achieve the trustworthiness and integrity of this study and its findings.

#### ***Confirmability***

Confirmability refers to the quality of data being neutral and objective (Polit & Beck, 2017). Confirmability in this study was enhanced by conducting a member-checking process that involved taking the researcher's interpretation of the study findings back to the mothers to confirm if the researcher's interpretation actually represented their feelings and experiences. Confirmability was also enhanced by contacting another peer of the researcher who cross-checked the researcher's transcribed interpretations to ensure their accuracy.

#### ***Credibility***

Polit & Beck (2017) define credibility as the degree of trustworthiness and confidence in the study results. Credibility for this study was enhanced by having research experts in phenomenology who cross-checked the appropriateness of the methodology and how it was applied to achieve the data findings. Credibility was also enhanced by the fact that the researcher has the experience of working with mothers whose newborns have been hospitalized with congenital anomalies.

### ***Dependability***

Dependability refers to the ability of data to remain consistent across time and under various circumstances (Polit & Beck, 2017). Dependability of the study was enhanced by doing data and method triangulation. During these processes, different data collection methods were applied like audio recording, physical observation, and the use of questionnaire interview probes. The researcher also actively listened and observed the mothers' nonverbal communication to collect more comprehensive data about the mothers' feelings and emotions. The researcher also deliberately chose to use purposive sampling so as to enable the selection of only relevant participants who had the required experience in caring for their hospitalized newborns with congenital anomalies.

### ***Transferability***

Transferability refers to the degree to which conclusions drawn from data can be applied to different contexts or populations (Polit & Beck, 2017). Transferability of the study results was enhanced by documenting the comprehensive descriptions of the mothers' demographic characteristics, their interview narrations, and described in detail the research site, sampling design, and data collection methods; i.e., interviews, recording, and physical observation of the mothers' body language. Ultimately, it is the responsibility of the reader to use the comprehensive descriptions given in this study to decide whether the study findings can be applied to the reader's setting. The researcher provides adequate details in this study to help the reader make the determination of whether the findings can apply to the reader's setting.

## **Ethical Considerations**

Administrative clearance was obtained from Mulago National Referral Hospital (M.N.R.H.) where the study was done. A written permission/approval was also obtained from Uganda Christian University's Research Ethics Committee in order to proceed with the study. The study began by obtaining a written informed consent (Appendix A) from each of the participants to secure their cooperation and participation in the study. To ensure the confidentiality and privacy of the participants' information, the mothers were informed that they would be audio recorded and interviewed from a secure private room using an android phone recorder. The mothers consented to participating in the study and the android phone and diary used were kept under lock and key to prevent unauthorized access to them.

One of the potential risks of the study was its ability to cause psychological pain to the mothers as they narrated their experiences. This risk was mitigated by assuring mothers that the researcher would continue to listen in carefully while also observing their non-verbal communication. Additionally, a social worker/counselor would be contacted to intervene and calm down the mothers' in case of an emotional breakdown during the interviews.

During publication of the study findings, the researcher intends to keep the mothers names anonymous by using pseudonyms to ensure their privacy and confidentiality. The participants were also informed that even when they decide to participate, they can still withdraw from the study at any time if they feel seriously concerned and uncomfortable continuing with it. The researcher has no conflict of interest in this study or its outcomes, and it is therefore not of any personal advantage.

## **Summary**

This chapter discusses the methods and procedures that were applied during the study of the mothers' lived experiences. The chapter specifies the type of research design, the study setting, the characteristics of the study population, and the sample size. It further elaborates on the inclusion and exclusion criteria for choosing the study participants, as well as the quality control measures and ethical considerations.

## **Chapter Four: Presentation and Analysis of Study Findings**

This chapter presents the findings that were obtained after interviewing the mothers about their lived experience with the aim of exploring and describing their newborns' hospitalization with congenital anomalies. The findings arose from a thematic analysis of the mothers' interviews and narratives that were used to explore their lived experiences. Saturation was reached at 8 mothers and one more mother was interviewed to validate the findings making a total of nine mothers. In order to address the objectives of this study, the meaning mothers' attached to their lived experience was explored by interviewing them, revising important statements from their narratives, and further probing into their perceptions, feelings, and emotions to clarify the meaning and interpretation they attached to their experiences.

To ensure the trustworthiness of the data findings, bracketing of the researcher's preconceptions, prior knowledge, and personal biases was done prior to conducting the interviews. The data analysis was done through reading and re-reading mothers' transcripts to get familiar with the data, extracting significant statements from the transcripts, and identifying the common features that were recurring in the mothers' narratives. The discovery of the universal truths about the nature of the mothers' lived experiences was aided by the identification of the common features in their experiences which was done through color coding, and these were later

analyzed to form themes and sub themes that represent the general structure of their lived experience. The findings below describe the themes and sub themes that were obtained from the interviews. They are presented in two sections, that is; demographic characteristics of the participants, and participants' lived experiences of delivering and hospitalizing their newborns with congenital anomalies. These sections represent the major categories of the interview probes that were used during data collection.

### **Demographic Characteristics of the Participants**

The participants hailed from different parts of Uganda and represented different religious denominations. Their real names were hidden for anonymity purposes, and were given pseudo-names for this research. The majority of the participants reported being married and with children, while one of them was unmarried. The mothers' education backgrounds were of primary or secondary level education, with six out of nine mothers reporting to have no formal gainful employment. All mothers were of youthful age ranging between 19 to 33 years of age.

Table 1

#### *Demographic Characteristics Distribution of Study Participants*

<b>Participant</b>	<b>Age</b>	<b>Employment Status</b>	<b>Marital Status</b>	<b>Education Level</b>	<b>Number of Children</b>
01	22	Employed	Married	Primary Education	1
02	31	Unemployed	Single	Secondary Education	2
03	25	Employed	Married	Secondary Education	2
04	28	Unemployed	Single	Primary Education	3
05	30	Employed	Married	Secondary Education	3
06	26	Unemployed	Single	Secondary Education	4
07	24	Employed	Married	Secondary	2

				Education	
08	29	Unemployed	Single	Primary Education	4

### **Participants' Lived Experiences of Delivering and Hospitalizing their Newborns with Congenital Anomalies in a Tertiary Hospital**

This section describes the experiences of mothers whose newborns were delivered and hospitalized as a result of congenital anomalies. It highlights the participants' experiences during pregnancy, delivery and hospitalization of their newborns. Their initial thoughts, feelings, reactions, and experiences that surrounded the entire lived experience are described in the themes and sub themes that appeared common in the mothers' interview transcripts. In order to aid the learning, interpretation, and discovery of the meaning mother's attributed to their lived experience, excerpts of the mother's actual experiences are used to personify their perceptions and reactions. Quotations have been used to highlight the key issues in the mothers' experiences and to support each theme and sub theme.

The application of Edmund Husserl's theoretical framework in this study provides a robust theoretical foundation for exploring the mothers' lived experiences. Husserl's emphasis on universal essences aligns well with the goal of the study in identifying the common themes that cut across the diverse mothers' narratives, irrespective of their variations in socio-economic and cultural backgrounds. This allows the researcher to construct a rich, nuanced understanding of the shared experiences of mothers navigating the difficult journey of hospitalization due to congenital anomalies. Below are the common themes that emerged and these included; mixed feelings and emotions, healthcare concerns and responsibilities, support system and support

needs. Under these themes, several other sub themes are discussed to further highlight the mothers' shared experiences during their newborns delivery and hospitalization.

### ***Mixed Feelings and Emotions***

Under this theme of mixed feelings and emotions, it was noted that the majority of mothers interviewed experienced a diverse range of feelings and emotions at the realization that their newborns are sick and needed hospitalization. There are several sub themes that emerged out of this major theme and these included feeling shocked, feeling worried, feeling scared, anticipation of blame, and hope with faith, amidst hospitalization. Some of the mothers acknowledged feelings of being shocked and scared on seeing the physical appearance of their newborns, while others reported breaking down in tears and worrying about their newborn's health and survival chances. Whereas several mothers voiced their concerns of being emotionally challenged by their delivery and the need to hospitalize their newborns, some of the mothers expressed a sense of comfort, relief, hope and faith as their newborns showed signs of improvement in their health, and as the family members offered them more support and encouragement.

**Feeling Shocked.** The experience of delivering a newborn with a congenital anomaly caused the majority of the mothers to feel surprised and shocked on seeing the health condition of their newborns. The mothers indicated being shocked by the appearance of the newborn and the unforeseen need for hospitalization. One of the mothers who expressed her feelings of shock was quoted saying "*At first, I was shocked at the appearance of the baby. Then I thought that it might be satanic and evil forces that caused it...I have never seen this in my life.*" (Brendah, 29 year old) Another mother who felt shocked at the delivery of her newborn was heard to say, "I

*got shocked and scared and began wondering what the problem was... because I did everything they told me to do. The nurses there told me that she will be fine.”*(Sharon, 19 year old)

**Feelings of Worry.** The lived experience of delivering and hospitalizing a sick newborn with a congenital anomaly caused some of the mothers to feel worried about their baby’s need for medical intervention and their survival chances. Some of the mothers acknowledged being worried about their newborns’ survival chances, the nature of their babies’ sickness, and others reported worrying about the medical and surgical interventions that will be needed for their newborns’ ill health. One of the mothers was quoted saying *“We reached a time and the baby was very sick, he was put on oxygen. Me and my mother felt so scared and worried thinking that the child may not survive. I even came crying all the way from Kabarole in the ambulance.”* (Martha, 20 year old). Another mother who reported her worry regarding the needed medical interventions was heard saying, *“I did not expect this. I thought I will be going home after delivering. But I got worried on realizing that the baby will also require an operation”*. (Doreen, 27 year old)

**Feeling Scared.** The feelings of being scared and fearful permeated several of the mothers’ experiences during the hospitalization of their newborns with congenital anomalies. Some of the mothers perceived their sick and hospitalized newborns as being at high risk of death which made them feel scared to the extent of breaking down emotionally in tears. One of the mothers was quoted as saying, *“When I saw the baby’s condition, I got so scared and cried...and even coming here, I came crying...thinking that the child may die.”* (Namukasa,32 year old). Another mother was heard saying, *“After I noticed the baby’s condition, I got shocked and scared and began wondering what the problem was... because I did everything they told me to do. The nurses there told me that she will be fine”*. (Sharon, 19 year old)

**Anticipation of Blame.** Another sub theme that kept recurring in some of the mothers' transcripts was their concern and anticipation that they would be blamed for delivering such sick newborns with congenital anomalies. One of the mothers who anticipated being blamed by her in-laws was quoted saying *"They were understanding. They did not blame me because the baby was born sick. I think they understood that sickness can happen to everyone....including the newly born babies"*. (Jackie, 29 year old) Another mother who anticipated being blamed by the husband was heard saying *"...we were all confused and worried about the baby's situation. My husband was a bit stronger than me. He appeared okay, and he did not blame me for anything"* (Jalia, 32 year old) The other mother who shared a similar sentiment of anticipating to be blamed, judged or cursed was heard saying, *"When person sits alone in that situation, a lot comes into their heads....you feel like you are cursed, you feel like you are abandoned, you feel like...a lot...everything is on you"*.(Sharon, 19 year old)

**Hope with Faith, Amidst Hospitalization.** Despite the various responsibilities, challenges, and concerns mothers reported experiencing during their newborns' hospitalization, a few mothers expressed a sense of relief, hope, and faith, on seeing the health of their newborns improve. One of the mothers was quoted as saying *"I have no much challenges....now what can I say? At this time, I don't actually see any problem with the baby now. He even appears to be doing well, because I can now give him milk and he takes it well. He really wants to breast feed. I have no complaints."* (Martha, 20 year old)

### ***Health Concerns and Responsibilities***

In this theme of health concerns and responsibilities, the mothers' accounts described particular healthcare concerns, challenges, and responsibilities that surrounded their newborn's delivery, illness and hospital stay. These are further discussed and explored in the sub themes

below that emerged out of the main theme. The sub themes include: first time experiences, causality, pregnancy concerns, financial woes, and the load of care giving responsibilities. Specific quotes from the mothers' narratives are also used to highlight the mothers' particular experiences.

**First Time Experiences.** The majority of mothers reported experiencing their newborns sickness and hospitalization as being unheard of, rare, and unique; describing the experience as unprecedented and the first of its kind in their lives. This sentiment was also shared by the majority of mothers' spouses, siblings, parents, and in-laws. One of the mothers was quoted as saying, *“My siblings were scared and shocked when they heard about it because no one has ever seen or experienced it in our family. This is the first time for me to see this sickness. I don't know what happened.”* (Justine, 25 year old) Another mother recounted saying *“My husband also got so confused just like me. He just saw it the way it was. It was also his first time to see a baby born like this...with the intestines outside”.* (Brendah, 27 year old)

**Unknown Cause of the Anomalies.** Another recurring concern that emerged from some of the mothers' accounts was their apprehension and uncertainty about what could have caused them to give birth to newborns with congenital anomalies. Several mothers were concerned about the causes of such congenital anomalies in their newborns. One of the concerned mothers was heard to say *“At first, I was shocked at the appearance of the baby. Then I thought that it might be satanic and evil forces that caused it...I have never seen this in my life. Me I would like to ask, ...what brings about such sickness. Like, ... what causes them?”* (Brendah, 27 year old) Another mother was quoted saying *“I saw it later and the nurse told me that we should immediately bring the child here....then I started asking myself what could have happened....because I used to do the scan stuff, and they never told me anything. After I noticed*

*the baby's condition, I got shocked and scared and began wondering what the problem was... because I did everything they told me to do.*"(Sharon, 19 year old)

**Pregnancy Concerns.** Out of the nine mothers interviewed, five of them reported having got infections and sickness during pregnancy. The others indicated that they did not experience any form of illness during the pregnancy period. The nature of the reported illnesses includes malaria, fevers, infections, and lower back pains. One of the mothers who got sick during the pregnancy was quoted saying *"I have not been well at all this entire pregnancy. I have been falling sick often, and going to hospitals for treatment. I have been getting on and off fevers throughout the pregnancy."* (Martha, 20 year old). Another mother who got sick during pregnancy was quoted saying *"I got sick with malaria at 3 months of the pregnancy...I was also over vomiting and had no appetite for eating. I however got treatment for malaria and became fine."* (Sharon, 19 year old)

Another recurring feature that was noted in the mothers' narratives was the unexpected health condition of their newborns on delivery, despite having done ultrasound scans during pregnancy that were interpreted as normal by the health workers. Although this was noted from the majority of mothers interviewed, there was one mother who indicated that the ultrasound detected the umbilical cord around the baby's neck at 37 weeks of pregnancy. There were also some mothers who reported never doing any ultrasound scans during their pregnancy. One of the mothers who undertook the ultrasound scan was quoted saying *"Yes I did the three scans during antenatal. But they did not tell me anything like that. The scans were normal but when I delivered the midwives there told me that it is just a big umbilicus" and that will go back and reduce in size.*" (Irene, 31 year old) Another mother who undertook an ultrasound scan was quoted saying *"After delivery I was excited and happy. I did not see anything at the beginning. I*

*saw it later and the nurse told me that we should immediately bring the child here....then I started asking myself what could have happened....because I used to do the scan stuff, and they never told me anything.” (Sharon, 19 years old)*

**Financial Woes.** The majority of the mothers identified financial constraints as one of the significant challenges they encountered during their newborns’ hospitalization. They described financial constraints as the lack of money to buy particular items they needed to use during the hospitalization experience. Such items included medicines like amino acids, theater items that the hospital could not avail, money for doing ultra sound scans and buying other items like baby’s sanitary pads, soap, sugar, and food. One of the respondents was quoted as saying, “...*I have no money to cater for us. My mind ran to the finances that I was going to need to have him treated. They have sent us to do a scan but the money I am expecting has not yet come. I was also told that the baby will need to be operated and that we shall need to buy some theatre items they will use. I was worried about the finances...mainly.*” (Irene, 31 year old)

**Load of Care Giving Responsibilities.** The newborns hospitalized as a result of congenital anomalies have special needs, care, and attention they require from their mothers. While some mothers reported seeing their newborns’ health improving and having no much challenges in their care giving roles, the majority of the mothers reported that the nature of their care giving responsibility was quite demanding and resource-intensive. One of the mothers who felt strained by her care giving responsibilities was quoted saying “*The baby needs constant monitoring to not remove the cannula. The doctors and nurses struggled to put it and also the tube in the nose. It is sometimes hard to get a good night sleep because I need to make sure they are not removed.*”(Sharon, 19 year old). Another mother was quoted as saying “*The only challenge I see is that sometimes I have to go and buy some medicines and other things from*

*outside and I end up leaving my baby alone. I am alone here and the baby can remove those tubes in the nose and on the belly. So sometimes I tell another colleague to help me and keep watching on the baby when I go outside.”(Justine, 25 year old)*

While several mothers acknowledged not having any major problems with caring for their newborns, some mothers shared a different sentiment of not being able to adequately take care of their newborns in doing care giving activities like breastfeeding and cleaning up the newborns. This was reportedly owed to the medical advice restrictions and the presence of medical equipment wires and tubes that are connected on the newborns. One of the mothers was quoted saying *“Hospital environment?!, I think can take care of the baby well here. The hospital has no effect on me.”* (Olivia, 30 year old). The other mother was quoted saying *“I feel bad that am not able to take care for the baby properly due to the sickness. I cannot breastfeed him because they refused me. There are also machine wires and tubes connected to him which sometimes makes it hard to turn and clean up the baby.”* (Jalia, 32 year old)

### ***Participants’ Support Systems***

Under this participants’ support theme, it was discovered that mothers received different forms of support and encouragement that enabled them to cope with their newborns’ hospitalization experience. Several kinds of support, coping measures, and support needs were highlighted by the mothers and these are presented below as sub themes, namely; familial support, peer support and encouragement, relationship with health care workers, and spiritual support. While the majority of the mothers acknowledged receiving different kinds of support from their significant others, some mothers still highlighted their desire to have more of their support needs met; and these are also described below.

**Familial Support.** The majority of the mothers reported having one or two dedicated significant others or relatives as their support persons during their newborn's hospitalization. However, one of the mothers reported having been denied to allow her caretaker be with her in the hospital. The support persons, who were also referred to as caretakers, were mainly relatives who reacted with sympathy to encourage and comfort the mother during their newborn's hospitalization. It was also identified that some of them extended physical support in form of money and food to enable the mothers cope with the experience.

**Spouses.** The majority of mothers' regarded their spouses as being supportive and concerned about their newborns sickness and hospitalization experience, although one mother reported feeling bad when her spouse refused the suggestion of bringing their newborn to urban hospitals citing financial challenges and safety concerns in non-native communities. The mother was quoted saying *"I felt bad because he never wanted us to come this side to the hospital when we have no money. But I said I must go...whether there is money or not."* (Kansiime,20 year old).The other mother who was quoted acknowledging her spouse as quite supportive and concerned was heard saying, *"He is caring as usual and supporting. I think that is good because he feels concerned too about the baby's sickness."* (Olivia, 30 year old)

**Siblings.** Some of the mothers reported receiving encouragement, support and comfort from their siblings who were able to call them on phone and to visit them in the hospital. One of the mothers was quoted saying *"They felt pity for me and keep encouraging me when we talk on phone. They also sent me some money for food and to comfort me. They really felt sorry for me and encouraged us to come to the hospital."* (Martha, 20 year old). One mother was however quoted saying that she has one sibling who is not aware of her newborn's hospitalization due to communication gaps. *"I have only one sibling who is also abroad outside Uganda. He is not*

*aware that we are in hospital and I have not communicated with him for a long time now. I lost his contact and changed mine several times. We are not in touch.”* (Namakula Jackie, 29 years old)

**In-laws.** The majority of the mothers perceived their in-laws to be concerned, understanding, and comforting regarding the mothers’ experience. One of the mothers was quoted saying *“My in-laws have comforted me. One of them is here, the brother to my husband. He escorted us to come here and has been helping us so much. We can send him to the shops and pharmacies outside and buys the things we need.”* (Olivia, 30 year old) However, it was also noted that some of the in-laws were against the idea of bringing the sick newborn to hospital. One of the mothers whose in-laws felt bad regarding her decision to bring the sick newborn to hospital was quoted saying *“My in-laws felt bad and even never wanted us to take the child to theatre. They said it that is a spiritual problem and advised that we go to the pastors for prayers.”* (Doreen, 27 year old)

**Parents.** With the exception of one participant who was an orphan and did not have parents, the rest of the participants reported finding solace and encouragement from their parents who stood with them in unity and solidarity during their newborns sickness and hospitalization. The participants viewed their parents as having been pillars of hope in strengthening them to cope with the difficult experience. One of the mothers was quoted as saying *“She was so much worried and concerned about the baby’s survival chances thinking that we may lose the baby...but she told me to be strong and prayerful. That God will decide the fate of the child.”* (Brendah, 27 year old) Another participant was quoted saying *“I felt strengthened and encouraged me. They told me to be strong, prayed for the baby and gave me advice to come here to this hospital.”* (Martha, 20 year old)

**Encouragement and Comfort.** While the majority of mothers indicated being emotionally challenged by their newborns delivery and hospitalization experience, some of them also acknowledged feeling comforted and encouraged by their concerned family members. The family members reportedly counseled and supported them during hospitalization period. One of the mothers was quoted saying *“They also comforted me. They came here and brought me some items to use...like soap and sugar. I felt okay and comforted. I think that was good.”* (Sharon, 19 year old).

**Spiritual Support.** In the midst of the various concerns and responsibilities that mothers experienced during the hospitalization of their newborns, some of the mothers acknowledged the application of prayers to manage and cope with the challenges they encountered. One of the mothers was quoted saying *“I just keep praying that my child gets better and we get discharged. Sometimes that is the only thing you can do”* (Justine, 25 year old). Another mother who regarded prayer as a coping means was quoted saying *“Me I just pray to God to heal my baby and we get discharged. Otherwise it is hard here when you are broke.”* (Jalia, 32 year old)

**Peer Support and Encouragement.** While several mothers acknowledged receiving support and encouragement mainly from their relatives, other mothers reported managing and coping with their challenging experience through peer support. One of the mothers who had no relative as a caretaker was quoted saying *“Like now that I do not have a caretaker here, I have to rely on my fellow mothers for help like in case I want to buy something from outside. I have to send another mother who maybe going there.”* (Justine, 25 year old) Another mother was quoted saying *“It has been hard to cope here. But I keep encouraging myself and with those other mothers.... we usually talk together and discuss the problems we have and how to handle the babies”* (Martha, 20 year old) Another mother recounted the different scenarios of how they have

been able to cope with their challenging experiences through peer support. She was heard to say, *“we just keep encouraging each others as mothers to do the right things here...because we all have problems and our babies are sick. We do not want to become problems to one another.”* (Jackie, 29 years old)

Another mother who was heard acknowledging the impact of peer support was quoted saying *“Many things are needed here and they are all for buying. Things like amino acids, we have to combine money as five mothers and buy one bottle”*. (Justine, 25 year old)

**Relationship with the Nurses** While several of the mothers reported receiving adequate health care services from nurses they perceived as caring and supportive, one of the mothers recounted experiencing very harsh and unkind remarks from a nurse who she quoted as often talking rudely to the mothers. The mother was quoted saying *“I was not happy with what she said. She often talks rudely to mothers in ways that are very hurting. We would love to be treated and handled with kindness and politeness. That thing made me feel really bad.”* (Jackie, 29 years old) However, one of the mothers who expressed her gratitude regarding the health workers was quoted saying, *“I have no much challenges...because the staffs are really caring and concerned. Whenever I call any of them to come and see the baby, they come fast. I think they are trying to do their best.”* (Justine, 25 year old). Another mother who seemed grateful for the healthcare services offered was heard to say *“I have not encountered so many challenges here, because when I came we had come for treatment and the health workers have been attending to me and the baby...only that locating the veins is a problem when putting on a cannula.”* (Jalia, 32 year old)

**Support Needs.** While it was identified that some mothers were grateful for the support they received from family members and health workers, it was also discovered that some of the

mothers still had other support needs they desired to have fulfilled. These included food, finances, medicines, a clean environment with abundant supply of water, and theatre items to use in the operations of their newborns. One respondent who was grateful for the health workers support was quoted saying *“The health workers are very caring and supportive. Ever since I came here, different health workers come and work on the baby and go. They are concerned. They taught me how to breastfeed and clean up the baby”* (Martha, 20 year old). One of the respondents who acknowledged the need for financial support was quoted as saying *“A mother would like to be supported with finances because some medicines here are for buying. Like amino acids. I was also told to buy some theatre items...they gave me a list of things for buying. Financial support is what I can say we need.”* (Justine, 25 year old)

Another recurring desire for material support was the mothers' request for the hospital to provide essential medicines and supplies to them. One of the mothers was quoted saying *“We would love to be supported with the medicines. The medicines are the important thing. I wish they could provide us the medicines so that we do have to buy from outside pharmacies...like the amino acids...and also the theater items to use. If they could help and give us these things here in the hospital, it would help us a lot.”* (Jalia, 32 year old).

While some of the mothers recounted their interactions with the health workers as being supportive in teaching them on how to breast and clean up their newborns, one mother expressed her emotional support need to have more guidance and counseling done on how to handle their fragile babies. The mother was quoted saying, *“We need to be guided and counseled on how to handle the babies since they are very fragile. We usually fear to hurt them or cause any problems to them.....and maybe comforting us can be of help”* (Sharon, 19 year old)

Another recurring feature from some of the mothers' experiences was their perception that the hospital environment did not adversely affect their ability to care for their babies. One of the mothers was quoted saying *"I have no problem with the hospital because I have to be here and get treatment for my sick child. I have no problem in caring for my baby."* (Irene, 31 year old) However, two of the participants voiced their concerns regarding the hygiene of hospital facilities by particularly highlighting the dirtiness of bathrooms, unreliable water supply, and dirty hand washing sinks. One of the concerned mothers who requested for their daily cleaning was quoted saying, *"One of the challenges I noticed is that here water is on and off. Sometimes those places of convenience and washrooms can be very dirty. The place can stay dirty like that for some days especially over the weekends"* (Olivia, 30 year old) Another mother was quoted saying *"I feel bad that am not able to take care for the baby properly due to the sickness. I cannot breast feed him because they refused me. There are also machine wires and tubes connected to him which sometimes make it hard to turn and clean up the baby."* (Jalia, 32 year old)

## **Summary**

The purpose of Chapter 4 was to present the study findings after their analysis from the mothers' transcripts. Quotations from the mothers' interviews were extracted and used as excerpts to clarify the themes and subthemes that emerged. The themes are presented here in two sections, demographic characteristics, and participants' lived experiences of delivering and hospitalizing their newborns. The trustworthiness of the data findings was ensured through bracketing of the researcher's preconceived opinions, prior knowledge, and personal biases, prior to collecting data. The results were cross-checked by one other peer to the researcher who confirmed the accuracy of the data transcriptions. Lastly, the credibility of the study results was

evaluated and approved by research experts in phenomenology. Chapter five will discuss the study findings, limitations, recommendations, and conclusion.

### **Chapter Five: Discussion, Recommendations and Conclusion**

This chapter presents the discussion of the study findings in relation to other studies that have been done in the area of mothers' lived experiences during their newborn's hospitalization. The chapter also describes the limitations of the study, recommendations, conclusions, and areas that need further study.

#### **Discussion and Interpretation of Findings**

The anticipation of the giving birth to a healthy newborn is what usually an expecting mother awaits. From the purchase of the baby's clothes, to informing others about the news of the pregnancy, and getting ready for parenting, mothers generally have positive expectations. However, when these expectations are met with an unexpected reality, it is reasonable for the mothers to experience a diverse range of emotions just as it was observed in this research.

Furthermore, through intentionality, another key concept in Edmund Husserl's descriptive phenomenology work, this study recognizes that mothers are not merely passive recipients of their experience but actively ascribe meaning to their newborns' conditions, societal reactions, and the support they receive. Descriptive phenomenology permits the construction of these unique meanings to emerge from the mothers' emotions and perceptions of their consciously lived experiences, and without imposing any external judgments. For example, the literature and discussion below shows that mothers in Uganda and Rwanda, mothers often reinterpret their experiences through spiritual or religious lenses, or based on their healthcare interactions and the support they have received (Asasira, 2018; Kidane et al., 2020).

## **Demographic Characteristics**

All the participants in this study had an infant born with a congenital anomaly and majority were mothers of low maternal age ranging from 19 to 27 years old. This characteristic portrays a tendency of lower maternal age women giving birth to newborns with congenital anomalies, a pattern that corresponds with the findings of (Ameen et al., 2018; Taye et al., 2018) who similarly identified low maternal age as a significant risk factors predisposing mothers to deliver newborns with congenital anomalies. Additionally, Ameen et al., (2018) also documented that the odds of delivering a baby with a congenital anomaly are high in females who are greater than 35 years of age.

The participants in this study were generally of lower educational backgrounds with the majority unemployed and having no formal source of income. This characteristic can influence the delivery of sick newborns with congenital anomalies as it can hinder mothers' access to good healthcare, folic acid supplementation, nutrition of a balanced diet, and fortified foods, especially in LMIC's where healthcare systems are inadequately funded. The poor socio-economic background was similarly documented by Ajao and Adeoye (2019) as a significant factor that is strongly associated with the delivery of congenital anomalies in mothers from low-and middle-income countries.

Eight out of the nine participants in this study were married and acknowledged obtaining adequate support from their family members and significant others. However, the one mother who was unmarried also reported getting adequate support from her relatives. This finding implies that irrespective of one's marital status, the delivery of a newborn with a congenital anomaly draws empathy from one's relatives to help in supporting the hospitalized child and mother. There is also no researched literature that is contrary to this revelation.

The demographic profile of the mothers, particularly their younger maternal age, low educational attainment, and lack of formal income, reflects the critical social determinants that influence neonatal outcomes. While previous studies (Ameen et al., 2018; Taye et al., 2018) have statistically linked such factors to higher rates of congenital anomalies, the lived experiences described here highlight how these socio-economic vulnerabilities not only contribute to the occurrence of anomalies, but also shape mothers' experiences of care-giving, access to care, and emotional resilience.

### **Participants' Lived Experiences of Delivering and Hospitalizing their Newborns with Congenital Anomalies**

In this study, mothers recounted their delivery and hospitalization experiences with great emotion and openness which generated three major themes and 15 sub-themes. The three major themes are mixed feelings and emotions, healthcare concerns and responsibilities, and support system and support needs.

#### ***Mixed Feelings and Emotions***

This major theme emerged as one of the significant experiences of the mothers, including its subthemes like feeling shocked, feelings of worry, felt scared, anticipation of blame, and faith with hope during hospitalization. The mothers reported experiencing an array of these mixed feelings and emotions on learning that their newborns were sick with a rare medical condition that required surgery if they were to survive. This left many of the mothers confused, helpless, and out of control; wondering what could have befallen them to give birth to newborns with such abnormal appearances. This situation was worsened by the fact that they had no earlier knowledge of the existence of such congenital anomalies, and neither were they identified during their antenatal visits. Additionally, the failure to detect such anomalies during antenatal suggests

a low quality of antenatal care and ultrasound scan services, especially in LMIC's where resources for improving such services maybe inadequate or unavailable. The emotional shock from seeing external anomalies like gastroschisis acted as a phenomenological rupture that challenged the mothers' previous expectations of normal birth and motherhood. In Husserlian terms, this constitutes a "bracketing" of normalcy, where the everyday understanding of childbirth was suspended, and a new uncertain horizon of meaning emerged.

**Feeling Shocked.** All the mothers reported experiencing the unexpected shock upon seeing the physical condition and abnormal appearance of their newborns, typical of external congenital anomalies like gastroschisis and omphalocele, where babies are born with their intestines protruding outside the abdomen. This significant shock triggered a range of emotional responses, like disbelief and confusion, leading the mothers to question the circumstances that surrounded their pregnancy, babies' births and their hospitalization. This finding was similarly documented by Rozensztrauch et al. (2020) who noted that the parents of a hospitalized newborn may not only feel overwhelmed by the hospitalization experience, but also experience the initial emotional shock of seeing their baby sick with a rare health condition. In this present study, the shock was exacerbated by the mothers' cultural beliefs, where some of them like Brenda were quoted attributing their newborns' sickness to evil supernatural forces, consequently causing them to feel more disappointed, helpless and out of control over their newborns' illness and hospitalization.

**Feelings of Worry.** Worry was another significant emotion that deeply affected the mothers' and their newborns' hospitalization experience. The worrisome experiences narrated in this study emphasized the mothers' anxieties about their newborns' health, survival prospects and family stability. This finding was similarly documented by Seyedrasooli et al. (2020) who noted

that after the birth of a newborn with a congenital anomaly, the parents often experience overwhelming worry and anxiety at the failure to have a healthy baby. The mothers' stories in this study revealed a profound sense of vulnerability and anxiety, as many struggled to comprehend their newborns' rare illnesses, the unusual medical and surgical interventions, and the impact of this rare experience on their family stability. Martha's emotional journey in the ambulance highlighted the urgency and seriousness with which she perceived her situation upon realizing that her baby was critically ill and needed immediate healthcare interventions.

**Feeling Scared.** Feelings of being scared and fearful were the other significant and strong emotions that resonated with all the mothers' experiences in this study. This finding was similarly noted by Staver et al. (2020) in their study about mothers whose newborns were hospitalized in a Neonatal Intensive Care Unit (NICU). The mothers in this study reported feeling scared of the critical health condition they saw their newborns in, and this conveyed a deep sense of impending loss of the lives of their newborns. The mothers' emotional breakdowns and tears while recounting their experiences vividly illustrated the intensity of their fears and worries, making their stories relatable to others who have faced similar threats of losing their newborns to such fatal, but less publicized health conditions.

**Anticipation of Blame.** The anticipation of being blamed as a result of giving birth to a newborn with a congenital anomaly added another layer of complexity to the mothers' emotional burden. In cultures where such health conditions are stigmatized, mothers often worry about being judged and blamed for giving birth to an abnormal baby, which reflects their inner conflict and struggle to preserve family identity, stability, and acceptance. Jalia's quote in this study underscores the mother's sense of relief in not being subjected to such blame, criticism, and

judgment from relatives; a phenomenon that is crucial for mothers' emotional support and comfort during such traumatic experiences.

Additionally, the anticipation of blame also implies that some cultures still hold stigma for mothers who deliver newborns with complex health conditions like congenital anomalies. This finding is consistent with those of Commander et al.(2021) and Seyedrasooli et al.(2020) who similarly documented that some cultural beliefs surrounding congenital anomalies can exacerbate the emotional stress and strain experienced by mothers through stigmatization and blame.

**Faith with Hope, during Hospitalization.** Amidst the distress and challenges that mothers encountered during their newborns' hospitalization, they reportedly found solace in praying and the prayers of their families, having hope and faith that their newborns will one day be completely cured. This was observed when the newborns started showing signs of improvement in their health, leading the mothers to feel hopeful. Martha's quote captures this change from being desperate, to having a more positive outlook, which portrayed the mothers' ability to adapt and become resilient in the face of their newborns' challenging experiences. This finding was similarly documented by Kidane et al. (2020) when they discovered that engaging in faith and spiritual activities was helping to positively boost the mothers' mental health states when they faced the uncertainty of their newborns' survival during hospitalization. Overall, this theme of mixed feelings in the mothers' experiences highlights the complex dynamics of feelings and emotions that can interact in mothers when they are faced with medical hardships like the hospitalization of their newborns.

### *Healthcare Concerns and Responsibilities*

Healthcare concerns and responsibilities is another significant theme that surrounded the mothers' experiences of delivering and hospitalizing their newborns. From this major theme, several subthemes emerged and these were financial woes, load of care-giving responsibilities, and causality. The mothers' accounts revealed these several healthcare concerns and challenges as some of the unanticipated care giving burdens that challenged their traditional notions of maternal responsibility. These challenges added more stress to the psychological strain mothers were already experiencing in coming to terms with the reality of their newborns' sickness.

**Financial Woes.** Many of the mothers reported facing financial difficulties like the inability to afford basic items like food and sanitary pads, consequently making them feel more inadequate and anxious of about their ability to take charge of their newborns' hospitalization. Mothers like Irene expressed their worry over the costs related to their baby's treatment, such as the need for ultrasound scans and theatre supplies, revealing their financial vulnerability in handling their newborns' hospitalization expenses. This finding is similar to what Commander et al. (2021) noted when the respondents acknowledged that hospitalizing their newborns' with a congenital anomalies would subject them to heavy financial burdens associated with their treatment costs.

**Load of Care-giving Responsibilities.** Some mothers in this study reported failing to have a good night sleep due to the need of constantly monitoring their newborns' who had medical tubes connected to their bodies. These kinds of care-giving demands and responsibilities left many of the mothers emotionally and physically exhausted as they cared for their hospitalized babies. This finding is similar to what Fontoura et al., (2018) documented in their study describing the hospitalization experiences as one that is marked by overwhelming

financial, physical and social demands. Sharon's quote highlights the impact of these overwhelming care-giving demands and responsibilities, while also emphasizing the mothers' love and determination to prioritize their newborns' care, even at the cost of their own comfort and rest. These experiences demonstrate how far mothers can go to make sure that their babies are effectively cared for, despite the hospitalization hardships they encounter. This serves as a reminder of the power of maternal love and compassion in the face of profound difficulties that families experience.

**Unknown Cause of the Anomalies.** The other subtheme that emerged from the mothers' narratives was the healthcare concern of how the mothers got to deliver sick newborns with congenital anomalies yet expected healthy babies. For many of the mothers, this experience was unexpected and unprecedented, thus the search for answers about the causes of these congenital anomalies dominated their minds. Mothers like Brenda and others expressed their need for more knowledge and understanding about congenital anomalies, which led them to link their newborns' health conditions to existential fears like witchcraft, and sicknesses they encountered during pregnancy. This revelation portrayed that the quest for more knowledge and understanding of their newborns' sickness maybe both reassuring and calming, but also a potentially additional source of psychological stress to the mothers since they had no prior knowledge about the existence of congenital anomalies.

### ***Participants' Support Systems***

During their newborns' hospitalization, the mothers faced several challenges and subsequently relied on their support systems like family members, relatives, nurses and doctors, and the peer mothers to cope with their challenging experiences. Despite the emotional toll and caregiving burden, mothers in this study demonstrated adaptive resilience by forming informal peer

networks and valuing familial and professional support. Their narratives suggest that healing and coping were not only clinical but relational, and the support from peers (other mothers) and nurses was pivotal in mitigating psychological distress and promoting resilience. From this major theme, several other subthemes emerged, and these included; peer support, relationship with nurses, and familial support.

**Peer Support.** This support from fellow mothers was notable when the mothers experienced financial difficulties to purchase certain expensive medicines. In response, the mothers decided to collaborate together and pooled resources to enable them buy such expensive medicines like amino acids. These financial constraints and other medical hardships encouraged the mothers to work together, consequently strengthening their peer relationships in the process. Justine's quote highlights the collaboration and unity that emerged when the mothers faced similar medical hardships despite hailing from different religious, tribal and cultural backgrounds. It was also revealed that mothers who lacked relatives as caregivers relied on fellow mothers for support in running errands like buying for them items out of the hospital premises. This phenomenon demonstrated the mothers' ability to establish comradeship, unity and peer support for one another whenever they faced similar medical hardships. The value of such support systems was also acknowledged by Kidane et al., (2020) in their study of Rwandese mothers who were caring for their hospitalized newborns with gastroschisis.

**Relationship with the Nurses.** In this study, several of the mothers acknowledged being helpfully supported by their attending nurses, although one mother encountered a rude and harsh experience with the nurse in-charge. Justine and Jalia's quotes highlight their contentment with the healthcare services, alluding to the sensitivity and concern that nurses portrayed in getting the mothers' concerns addressed. This implies that despite experiencing a wide range of conflicting

feelings and emotions during their newborns' hospitalization, mothers were still able to recognize and appreciate the nursing care that was provided by the nursing staff. This consequently reflected the mothers' ability and potential to trust and establish supportive relationships with their attending nurses and doctors, a finding that was similarly documented by Yu et al. (2019).

The one mother who reported experiencing rude remarks from the nurse in-charge appeared so disappointed in the nurse and this implies that negative interactions though few, often have lasting emotional consequences in a high-stress environment. This is a revelation of the moral authority that nurses carry and ought to reflect upon during their communication with vulnerable mothers and nursing practice in general, in order to exercise emotional intelligence during difficult experiences.

**Familial Support.** All the mothers in this study indicated receiving various forms of help and support from their family members, and relatives. This support ranged from receiving physical items like food, finances, and soap, to receiving spiritual support like comfort, encouragement and prayers. Many of the mothers regarded their spouses, siblings and parents as being caring and supportive, despite being unable to fully meet the mothers' support needs like finances to buy all the expensive drugs, and other theatre supplies for the newborns' surgery. This implies that although the family members could not meet all of the mothers' support needs during their newborns' hospitalization, the mothers were still thankful and appreciative of the love, support, and contributions they received.

**Support Needs.** Several mothers acknowledged receiving different kinds of support like food, money, and encouragement during their babies' hospitalization. However, despite receiving these different kinds of support, mothers still echoed their desire to have more support extended to them in the form of hygienic washroom facilities, counseling services, meals,

financial assistance, and health education on how to handle their fragile babies. This is a revelation that much as mothers desire to have their newborns cared for, and treated to recovery, they still desire more support from the health workers like counseling, and health education on how to effectively perform their mothering roles and responsibilities to the hospitalized newborns.

### **Application of the Theoretical Framework**

Qualitative descriptive phenomenology as postulated by Edmund Husserl was used to unravel the detailed experiences of the mothers whose newborns were delivered and hospitalized with congenital anomalies. Descriptive phenomenology uses three frames of reference to study a lived-experience in its pure and universal sense, and these were applied in studying these mothers' experiences. The three frames of reference are creating a "live-world plane of interaction" between the researcher and participants, ensuring transcendental subjectivity (which is maintaining neutrality and openness to the participants' realities), and the identification of eidetic essences, which are the universal truths in a lived experience.

The first frame of reference, creating a real-world plane of interaction, was established by fostering a conversational environment between the researcher and the mothers. The two parties engaged in extended one-on-one interactions (interviews) to actively listen and clarify the narrated experiences while recording them using a phone recorder. The second frame of reference, ensuring "transcendental subjectivity," was applied in bracketing the researchers' personal opinions and biases, while also interviewing mothers using semi-structured, open-ended questions to remain neutral to their experiences. The third frame of reference, identifying the eidetic essences or universal truths about the mothers' lived experiences, was applied in analyzing the mothers' narratives to discover the common features and themes that cut across the

mothers' experiences. These three frames of reference enabled the exploration and description of the mothers' lived experiences in this study.

### **Recommendations**

Nurses and other healthcare professionals should provide comprehensive health education to women of reproductive age regarding congenital anomalies, including their potential causes, prevention strategies, and methods for early detection during antenatal visits. These educational sessions should be integrated into routine antenatal care and delivered in a supportive manner. Additionally, nurses must be prepared to offer reassurance and psychological support, as increased awareness of congenital anomalies may inadvertently heighten maternal anxiety.

Healthcare workers should adopt and strengthen family-centered care approaches when managing newborns hospitalized with congenital anomalies. This should include continuous communication of the newborn's health status, active involvement of mothers and their family members in care processes and decision-making, and provision of empathetic support to reduce maternal stress and anxiety during their newborns' hospitalization.

Nurses should establish collaborative partnerships with mothers to ensure care is holistic, addressing not only the medical needs of the newborns but also the emotional and practical needs of the mothers. Creating such supportive environments enhances maternal confidence and competence in performing their care-giving roles and responsibilities. It also enables the nurses to implement a holistic care process that attends to the mothers' needs and concerns as well.

Literature has shown that it is possible to do prenatal screening, detection and diagnosis of congenital anomalies during pregnancy. Nurses and nurse leaders should collaborate closely with other departments, such as radiology, to strengthen prenatal screening, detection, and

diagnosis of congenital anomalies during antenatal visits. The information from ultrasound scans and other screening tools should be effectively communicated to expectant mothers, alongside guidance on the appropriate delivery facilities for such high-risk pregnancies. This collaboration can lead to timely referrals, appropriate preparation, and improved clinical outcomes.

Given the mental health challenges mothers face during their newborns' hospitalization with congenital anomalies, nurses and psychosocial counselors should focus on providing family centered counseling services. These interventions should focus on emotional processing, resilience building, and coping strategies to strengthen the mothers' ability to perform their parental roles with confidence and self-esteem.

Nurses and other healthcare professionals should receive regular trainings like Continuous Medical Education (CME) programs on assessing and supporting the physical and emotional well-being of mothers following the birth and hospitalization of newborns with congenital anomalies. Such training should equip healthcare staff with the requisite knowledge and skills to conduct tailored mental health assessments and interventions.

In collaboration with cultural and religious leaders, nurses and nurse leaders should organize community outreach programs aimed at reducing stigma, misconceptions, and blame directed toward mothers and families of children born with congenital anomalies. These initiatives should promote cultural sensitivity, raise awareness, and foster community support systems that encourage acceptance and inclusivity.

### **Limitations**

One of the limitations of this study was that some of the probing questions used in the interview portrayed a conflict of interest where the researcher's role would sometimes conflict with the employee role during data collection. The other limitation of this study is that its

findings cannot be automatically transferred to other settings because it aimed to explore the individual mothers' experiences, as they encountered them, and thus the use of these findings should be with caution. Another limitation was the inability to totally eliminate selection bias towards mothers whose newborns had externally visible congenital anomalies, as opposed to those with internal congenital anomalies. Lastly, several of the mothers interviewed used their local languages to give particular information for expressing themselves fully and this can be prone to social desirability bias.

### **Areas of Further Studies**

First and foremost, there is a need for more research on the root causes of congenital anomalies in low-income and resource-limited settings, with particular attention to genetic, environmental, and nutritional risk factors. Understanding these determinants could guide the development of context-specific preventive strategies and inform antenatal care interventions that are both cost-effective and scalable. Secondly, further studies should focus on maternal psychosocial support and therapeutic interventions for mothers of newborns with congenital anomalies. The research should evaluate counseling approaches, emotional support systems, and structured guidance programs to determine their impact on maternal mental health, care-giving confidence, and mother-infant bonding during hospitalization.

There is also a relative absence of studies exploring family dynamics and paternal perspectives in the context of congenital anomalies. Current literature emphasizes maternal experiences, but future research should investigate how newborn illnesses like congenital anomalies affect marital relationships, paternal involvement, and overall family functioning. Finally, more attention should also be directed towards the experiences of bereaved mothers whose newborns do not survive hospitalization. This includes exploring the grief processes,

coping mechanisms, cultural dimensions of bereavement, and the long-term psychological effects of neonatal loss due to congenital anomalies. Such research is essential for designing culturally sensitive, scalable interventions to support recovery and resilience in affected families.

### **Conclusion**

The birth and hospitalization of newborns with congenital anomalies presents mothers several challenges that affect their physical and emotional well-being, care-giving capacity, and financial stability. This study revealed that mothers often rely on family members and extended relatives for support, including peer support from fellow mothers, and maintaining good relationships with health workers so as to cope with this difficult experience of caring for hospitalized newborns with congenital anomalies. To address the challenges mothers experience during their newborns' hospitalization, healthcare professionals and other stakeholders should create supportive environments and interventions that offer more comprehensive care to both the sick newborn and the attending mother. This can help mothers to effectively adjust and cope with their maternal identity and responsibilities in a complex healthcare setting.

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## Appendix A: Consent Form

**Title of research study:** The Lived Experience of Mothers whose Newborns are Hospitalized with Congenital Anomalies in a Tertiary Hospital in Central Uganda

**Principle investigator, contact information, and affiliation:** This research study is being conducted by Mr. Joseph Olimporera for the completion of a master's degree in nursing from Uganda Christian University. You can contact Joseph Olimporera on +256775918235 or +757326446, or [olimporeraj@gmail.com](mailto:olimporeraj@gmail.com). Uganda Christian University, P.O. Box 4, Mukono, Uganda.

**Introduction and purpose of study:** This research is about a conversational interview regarding your experience as a mother caring for your hospitalized newborn with a congenital anomaly. The purpose of the study is to explore the lived experience of mothers whose newborns are hospitalized with congenital anomalies.

**Description of the research:** A qualitative phenomenology study.

**Subject participation:** You have been selected to participate in this study because you are a mother caring for your newborn who is hospitalized with a congenital anomaly. You are therefore invited to participate in an interview conversation about your experience. The researcher will guide you through the interview as your responses are recorded using a phone recorder. The interview period and audio recording will approximately take 30 to 40 minutes.

**Potential Benefits:** As a participating mother, you will be given a token of appreciation for engaging in and contributing to this study after the interview. This will be ten thousand Ugandan shillings for sparing your time to participate in the study.

**Potential Risks and Discomforts:** There are no known physical risks involved in participating in this study. However, there is a chance that you might feel sad or angry when discussing your

experience during the interview. To mitigate such feelings and emotions, a social worker will be contacted to engage you respectfully and offer you counseling support.

**Confidentiality:** Any information you share will remain confidential and undisclosed at all times. In any publications or reports, your true names as a participating mother will not be disclosed or identified in order to protect your privacy and ensure the confidentiality of the information shared. The phone recordings will be secured using a password-protected phone and computer that are only known to and accessible by the researcher.

**Rights of participants:** Your decision to participate in this study or not to participate will not affect the healthcare services you are entitled to receive in the hospital. When you decide to participate, you will still be free to withdraw from the study when you feel it is necessary.

**Contact information for ethical concerns or to withdraw consent:** This research study has been reviewed and approved by Uganda Christian University's Research Ethics Committee. In case of any concerns or inquiries, you may contact the research study supervisor, Dr. Grace Nakate Mary, on +256772439526 for more information regarding this research.

**Authorization statement:**

I have read this consent form, and I agree to be a participant in this study. I have been given the opportunity to ask questions regarding the study, and I have received the answers to my questions. I acknowledge that I am aware of what this study involves, that I am at least 18 years old, and that I have received a copy of this informed consent form.

**Signatures**

**Participant's Signature**.....**Date**.....

**Researcher's Signature**.....**Date**.....

### **Appendix B: Interview Guide**

1. Please talk to me about yourself, i.e., name, age, address, marital status, number of children, educational level, employment, and health status.
2. Tell me about your pregnancy and delivery experience.
3. What were your initial thoughts and reactions when you learned that your baby has a health issue and needs to be admitted?
4. Tell me about the reaction of your family members when they realized that your newborn is sick with such a problem.
  - a. Husband's reaction,
  - b. Siblings' reactions,
  - c. Your parents' reaction,
  - d. Your in-laws' reaction
5. How did you feel regarding the reactions of the following people?
  - a. Your husband,
  - b. Your parents,
  - c. Your siblings,
  - d. Your in-laws
6. Please describe for me the challenges you have encountered so far with your newborn's hospitalization.
7. What are your thoughts and feelings regarding the challenges you have encountered during the hospitalization of your newborn?


8. Please describe your feelings and reactions about the effect of the hospital environment on your ability to care for your baby.

**Follow-up interview questions**

9. What support do you think a mother with your experience or in a similar situation would like to have?
10. Is there anything else that you would like to further discuss or share with me regarding your experience of caring for a hospitalized newborn with a congenital anomaly?

**Thank you for participating in and contributing to this research study.**

## Appendix C: Hospital REC Approval

TELEPHONE: +256-41554008/1 FAX: +256-414-5325591 E-mail: <a href="mailto:admin@mulago.or.ug">admin@mulago.or.ug</a> Website: <a href="http://www.mulago.or.ug">www.mulago.or.ug</a>		MULAGO NATIONAL REFERRAL HOSPITAL P. O. Box 7051 KAMPALA, UGANDA
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IN ANY CORRESPONDENCE ON THIS SUBJECT PLEASE QUOTE NO.....

19 March 2024.

**Dr. Joseph Olimporera**  
 Principal Investigator  
 Uganda Christian University.

Dear Mr. Olimporera,

**RE: ADMINISTRATIVE CLEARANCE TO CONDUCT A STUDY AT MULAGO NATIONAL REFERRAL HOSPITAL.**

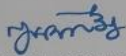
The Administration and Management of Mulago National Referral Hospital is pleased to inform you that you have been offered clearance to conduct the study titled **MHREC 2713: “The Lived Experience of Mothers whose Newborns are Hospitalized with Congenital Anomalies in a Tertiary Hospital in Central Uganda”**.

The above clearance is granted to you on the following conditions;

- That you will follow the research ethical processes
- Agreed to comply with all institutional policies and regulations of Mulago National Referral Hospital
- Agreed to provide end of study report and acknowledge Mulago hospital in all publications

Administrative clearance is valid for one (1) year effective from 19 March 2024 to 18 March 2025.

By copy of this letter, we reiterate our commitment to support this study.

  
 DR. BYANYIMA ROSEMARY  
 AG. EXECUTIVE DIRECTOR  
 MULAGO NATIONAL REFERRAL HOSPITAL.

Copied to;

1. In-charge – Pediatric surgical Unit MNRH.

Vision: “To be the leading centre of Health Care Services”



# UGANDA CHRISTIAN UNIVERSITY

## School for Research and Postgraduate Studies

*"A Centre of Excellence in the Heart of Africa"*

### REGULAR SUPERVISION REPORT

Supervisor's Name: **Dr Grace Nakate**

Student's Name: **Olimporera Joseph**      Reg No: **RM21M11/002**

Date of Submission of Work to Supervisor: **31/10/2024**

Date of Meeting that Discussed the Work: **10/05/2024 - 3/10/2024**

### SUPERVISORS COMMENTS ON STUDENT'S WORK AND RECOMMENDATION FOR ACTION

Date	Comment area	Supervisor's feedback	Action done	Page Number
Jan 2022-May 2024		Meet weekly on Zoom with cohort	Regular feedback given in writing and verbal in class	
30/01/2022-16/02/2024	Chapter 1	-Select the research study topic -Create literature review matrix and submit to faculty for approval -Make a clear outline of key concepts in Idea papers 1and 2 -Make chapter one outline -Describe major sections in chapter One i.e. <ul style="list-style-type: none"> <li>✓ Introduction</li> <li>✓ Background</li> <li>✓ Study purpose</li> </ul>	-Selected research study topic -Reviewed literature review through matrix and submitted to the supervisor -Outlined and edited concepts in Idea paper 1and 2 transferred them to chapter 1. -Listed the major sections in chapter 1 using correct grammar, following a chronological order and followed APA 7 standards.	11-20

		<ul style="list-style-type: none"> <li>✓ Study objectives</li> <li>✓ Research questions</li> <li>✓ Significance of the study</li> <li>✓ Theoretical frame work</li> <li>✓ Define variables and key terms</li> <li>✓ Use APA, grammar, correct spelling, and clear hand writing</li> </ul>		
22/02/2022-2/03/2024	Chapter 2	<ul style="list-style-type: none"> <li>-Reviewed concepts in Idea paper 3 &amp; made a clear outline</li> <li>-Create literature review outline</li> <li>-Make introductory paragraphs and summaries for each premise</li> <li>-Use appropriate headings and titles</li> <li>-Summarize critical gaps</li> </ul> <p>Use APA 7, apply correct the grammar, correct spellings</p>	<ul style="list-style-type: none"> <li>-Edited major concepts in Idea paper 3 and formulated premises to guide chapter 2</li> <li>Created an outline of key concepts to add in chapter 2.</li> <li>Analyzed and organized literature into premises made paragraphs.</li> <li>-Edited different premises in chapter 2 &amp; discussed critical gaps identified</li> <li>Edited the literature review section basing on APA standard, &amp; correct grammar</li> </ul>	21-35
	Chapter3	<p>Methodology</p> <ul style="list-style-type: none"> <li>-Outline the major concepts in methodology as Idea paper 4</li> <li>-Describe <ul style="list-style-type: none"> <li>✓ Study design</li> <li>✓ Population and setting</li> <li>✓ Sampling method and size</li> <li>✓ Inclusion and exclusion criteria</li> <li>✓ Ways of improving study's integrity and trustworthiness</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>-Reviewed concepts in Idea paper 4, got them approved</li> <li>-Transferred the content from idea paper 4 to chapter 3</li> <li>-Described all sections in chapter 3 using APA 7 and applying correct grammar and spellings (study design, sampling method)</li> <li>-Described the exclusion &amp; inclusion Criteria. Described measures for ensuring Study's integrity and trustworthiness</li> </ul>	43-50

		<ul style="list-style-type: none"> <li>✓ Setting description</li> <li>✓ Data collection techniques</li> <li>✓ Where data will be collected &amp; stored</li> <li>✓ Describe theoretical Framework and its application</li> <li>✓ Describe data analysis methods</li> </ul> <p>-Ethical considerations</p> <ul style="list-style-type: none"> <li>✓ Permissions</li> <li>✓ Consent</li> </ul>	<p>-Described the tools for use in data Collection and how to apply them.</p> <p>-Described data safety and protection methods to use</p> <p>-Descriptive phenomenology application explained</p> <p>-Described the Colaizzi data analysis technique and how it was to be used. Got approval from faculty.</p> <p>- Described ethical considerations to use &amp; got approval from faculty</p>	
11/03/2024		Subject the completed research proposal to Turnitin	Subjected the proposal to Turnitin, and got a score 9%	
14/03/2024		Submit proposal to UCU REC for approval	Research proposal submitted to UCU REC and got approval	
19/03/2024		Submit proposal to Mulago REC	Submitted to Mulago REC and got approval	
<b>May -October 2024</b>		<b>Met twice weekly on Zoom with cohort</b>	<b>Regular feedback given in writing and verbal in class</b>	
10/07/2024-10/08/2024	Chapter 4	<p>-Describe study results by transcribing all audio narratives to word document</p> <ul style="list-style-type: none"> <li>✓ Code all similar narratives</li> <li>✓ Synthesize similar statements</li> <li>✓ Remove redundant statement</li> </ul>	<p>-Transcribed all audio data into a word document as was required by supervisor.</p> <p>-Color coded similar narratives and synthesized them to form themes and sub-themes</p>	50-65
19/08/2024-8/9/2024	Chapter 5	<p>Describe sections in this chapter based on study findings, correct grammar, APA formatting and clear handwriting.</p> <ul style="list-style-type: none"> <li>✓ Discuss and summarize findings</li> <li>✓ Draw recommendations and conclusion</li> </ul>	<p>-Discussed and described study findings using correct grammar and APA 7 headings.</p> <p>-Identified study recommendations from the study results</p> <p>-Identified study limitations and described areas for further study</p>	66-80

		✓ Identify study limitations		
10/9/2024	Reference List	Correct all citations and proof-read the reference list	- cross-checked and corrected all citations and references	81-86
20/9/2024		Subject the completed research report to Turnitin.	Subjected the report to Turnitin, and got a score of 4%	
3/10/2024		Submit the completed research report to external examiner	Submitted to the complete research report to the external examiner	



**STUDENT'S SIGNATURE**

Cc Head of Department  
Cc Co-supervisor (if there is one)



**SUPERVISOR'S SIGNATURE**



# UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa

UGANDA CHRISTIAN UNIVERSITY  
SCHOOL OF RESEARCH & POSTGRADUATE STUDIES

## DISSERTATION CORRECTION COMPLIANCE REPORT BY THE CANDIDATE (POST VIVA FORM)

**Date:** 19<sup>th</sup>/08/2025

**Name of Candidate:** Olimporera. Joseph    **Reg. No:** RM21M11/002

**Title of Dissertation:** The Lived Experience of Mothers whose Newborns are Hospitalized with Congenital Anomalies in a Tertiary Hospital in Central Uganda

SN	COMMENTS BY EXTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	To align the acronyms in alphabetical order	Aligned the acronyms in alphabetical order	Appearance of the acronyms on ( <b>Page ix</b> )
2	Clarify between philosophical underpinning and	Re-worded and specified the theoretical framework used to	Specified the theoretical

	theoretical framework used	inform the study	framework used. <b>(Pages 15 and 76)</b>
3	Methodology still written in future tense	Methodology has been re-worded to reflect the past tense since the study was completed	Use of past tense in methodology section. <b>(Pages 43-49)</b>
4	Remove similarities in the inclusion and exclusion criteria. Consider excluding mothers who never consented and those who had critically ill babies.	Added mothers who had critically ill babies to the exclusion criteria, and those who never consented.	Exclusion criteria has been re-worded appropriately. <b>(Page 44)</b>
5	Remove the repeated methods' section that is re-appearing in chapter four introductory paragraph.	Removed the redundant statements that were re-appearing in both chapter four, and chapter three	Replicated information removed from chapter four on <b>(Page 50)</b>
6	Re-word some themes and subthemes to directly reflect the study's main question and objective.	Changed the wording of particular themes and subthemes to directly reflect the study's objective.	Re-worded some themes and subthemes e.g from blame, to anticipation of blame. From causality, to unknown cause of the anomalies. From hope with faith, to Hope with Faith in the Amidst of Hospitalization. <b>(Pages 54, 55 and 56)</b>

SN	COMMENTS BY INTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	Demographic characteristics in qualitative research should not be typically grouped together, but rather separated by each characteristic	Re-drawn Table 1 to separate and portray the demographic characteristics as individual characteristics.	<b>(Page 51)</b>
2	Some recommendations are not directly linked and supported by the study findings	Removed the recommendations that had no direct link to the study results.	<b>(Pages 77 and 78)</b>
3	You mention using an android phone for recording, but this is not addressed in the ethics sections. Did participants consent for recording?	Clarified and added the issue of using an android phone recorder into the ethical considerations' section.	<b>(Page 49)</b>
4	Some subthemes appear repetitive and unnecessarily broad. Review and consolidate overlapping themes to create a more focused discussion.	Consolidated the several kinds of support i.e from spouses, in-laws, parents and siblings into one subtheme (familial support) in chapter five discussion of findings.	<b>(Page 75)</b>
5			

SN	COMMENTS BY VIVA VOCE PANNEL	ACTION TAKEN	INDICATOR
1	Literature review is too broad with an excessive focus on the burden of congenital anomalies, rather than the mothers' lived experiences during hospitalization.	Scaled down on the literature that broadly focused on the burden of congenital anomalies. Increased on the literature of mothers lived experiences during hospitalization.	A scaled down literature review on the burden of congenital anomalies i.e <b>(in premise one)</b>  <b>Pages 21-28</b>
2	Many sections of the literature are overtly, descriptive, rather than analytical and critiquing. A more critical discussion of research gaps could strengthen it	Re-analyzed the literature review in a more analytical and critical manner. And also discussed more research gaps.	Research gaps identified and discussed on <b>Pages 31, 35, 39, and 41</b>
3	Apply the theoretical framework in all sections of the study.	Applied the theoretical framework to chapter four and five as well.	<b>Pages 52, 66, 76</b>
4			
5			

Candidate's Name : **Olimporera Joseph**

Signature:



Supervisor's Name: **Dr. Grace Nakate**



Signature:

# TurnitinOriginalityReport

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The Lived Experience of Mothers whose Newborns are Hospitalized with Congenital Anomalies in a Tertiary Hospital in Central Uganda Submitted by JosephOlimporera A Research Proposal Submitted in Partial Fulfillment for the Requirements of a Masters Degree in Nursing Science Uganda Christian University ChapterOne: Introduction Becoming a mother is one of the main events that occur in a woman's life with maternal identity often associated with the joy for giving birth. However, Begin Match to source 17 in source list: [https://ijsstr.com/wp-content/uploads/2023/03/4\\_October-2018.pdf](https://ijsstr.com/wp-content/uploads/2023/03/4_October-2018.pdf) with a congenital anomaly End Match baby. Begin Match to source 17 in source list: [https://ijsstr.com/wp-content/uploads/2023/03/4\\_October-2018.pdf](https://ijsstr.com/wp-content/uploads/2023/03/4_October-2018.pdf) with a congenital anomaly End Match can cause anxiety, stress and depression which negatively impact the mother's mental health status (Abuidhail et al., 2017; Staver et al., 2020). A congenital anomaly is defined as a structural or functional malformation or defect that develops in a baby while still in the womb and usually detected at birth (Yu et al., 2019). Giving birth to an infant with complex congenital anomaly not only negatively impacts the infant's health, but also influences the mother's subsequent interactions with her family and

newborn. The impact further extends to the mother's physical, emotional and spiritual wellbeing (Staver et al., 2020). In Uganda however, there is minimal literature that describes mothers' experiences of giving birth and caring for newborns with congenital anomalies (Mumpe-Mwanja et al., 2019). Silvio et al. (2018) noted that it is also essential to incorporate mothers and their families into the care process while attending to their hospitalized newborns. Undertaking such a study might help to identify the challenges, concerns and the possible support or care that can be rendered to these mothers so as to cope with this difficult experience. Owing to the impact of congenital anomalies on newborns and their mothers, it is important to explore the lived experiences of Ugandan mothers whose infants are born with

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at Begin Match to source 17 in source list: <https://ijsstr.com/wp-content/uploads/2023/03/4.October-2018.pdf> **birth** End Match, but can also be diagnosed antenatally or later in a baby's life (Yu et al., 2019). The anomalies can develop as single birth defects, or in association with others as a complex syndrome arising from parental gene's incompatibility (Ekwochi et al., 2018; Yu et al., 2019). A baby born with a congenital anomaly often requires specialized care and attention from health workers and the newborn's mother, thus their consequent hospitalization. The initial hospitalization period, which is often prolonged, separates them from their existing family and community support systems which potentially increase the mother's stress (Fleck et al., 2017). The majority of women who deliver newborns with congenital anomalies are from

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End Match folic acid, good nutrition and antenatal care is inadequate (Ajao & Adeoye, 2019). The mothers face an abnormal and often frightening birth experience that is characterized by fear, worry, guilt, depression, and feelings of being out of control (Staver et al., 2020). Unlike mothers who deliver healthy infants, those who birth infants with congenital anomalies experience heightened stress that underscores the need for adequate counseling of such mothers. Interventions to address the early loss of the maternal role, reduce psychological distress, and improve mother-infant interactions are often needed and have shown to improve maternal satisfaction with the care process (Holditch-Davis et al., 2014; Staver et al., 2020). The global

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incidence of congenital anomalies is estimated

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at 3-7% but

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actual End Match figures amongst different countries vary. In Uganda, a descriptive cross-sectional study was conducted over 4 months at Mulago Hospital and estimated a prevalence of 440 per 10,000 live births with congenital anomalies (Mumpe-Mwanja et al., 2019). The most common congenital anomalies occur in the cardiovascular system at 32.3%, musculoskeletal anomalies at 18.8%, and chromosomal anomalies at 10.9%. The anomalies of central nervous system are estimated to be at 9.6%, while those of the gastrointestinal tract are at 6.9%. Congenital anomalies of the genital system are estimated to be at 5.3%, while those of the eyes, head and neck are estimated at 5.3%. The anomalies of the respiratory system are at 4.2%, while those affecting multiple systems are estimated to be at 4.2%. The least number of defects has been noted in the renal and urinary system where they are approximated to be at 2.8% (El Awady et al., 2021). The impact of congenital anomalies

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lies not only in their contribution to

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and neonatal

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mortality but

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also lead to

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disability in children

End Match while negatively impacting the mother's mental health and emotional wellbeing (El Awady et al., 2021). According to a study in Sweden, Bruce et al., (2014) noted that the majority of mothers reported a desire for more support than what they received, despite having reported that they also received adequate services from health workers. Other mothers reported feeling disappointed with the care process due to having few opportunities for speaking about their infant's health and progress with health workers. As a result, this study aims at exploring and describing the lived experience of Ugandan mothers whose infants are hospitalized with congenital anomalies. Statement of the Problem Birthing a newborn with a congenital anomaly and their subsequent admission is considered a traumatic event to the mother and her family as it presents them significant challenges and stress during their initial hospitalization period. Global studies indicate that maternal distress in particular, is a common phenomenon during this period and its symptoms range from feelings of denial, guilt, and sadness to anxiety, uncertainty, and depressive symptoms. One study conducted in Mulago in 2019 estimated the prevalence of congenital anomalies at 440 per 10,000 births for all the 754 newborn admissions registered in 4 months. However, the impact of these anomalies on Ugandan mothers and their newborns is not known. It is thus important to explore the lived experiences of mothers whose newborns are hospitalized with congenital anomalies to recognize their emotional responses, needs, concerns and the support they require to cope with the experience.

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Ahiabile.pdf?isAllowed=y&sequence=1 **Purpose of the Study This study** End Match seeks

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Ahiabile.pdf?isAllowed=y&sequence=1 **to explore the** End Match lived experience

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End Match Ugandan mothers, whose newborns have been hospitalized with a congenital anomaly and the possible support and care they would require to cope with this challenging experience. Research Question What is the lived experience of mothers whose newborns are hospitalized with congenital anomalies in an antenatal referral hospital in Central Uganda? Study Objective The objective of this study is to explore and describe the lived experiences of mothers during the hospitalization of their newborns with congenital anomalies.

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Ahiabile.pdf?isAllowed=y&sequence=1 **Significance of the Study The findings from this study** End Match may increase nurse leaders' awareness of the adverse mental health states in mothers whose newborns are hospitalized with a congenital anomaly. This could consequently urge them to institute mental health therapeutic interventions that can support the mothers to cope with the difficult experience. The study findings may also be used to evaluate current support given to these mothers for improvement. The study results may also be used to plan for training of staff who work with these mothers so that they are better prepared to provide holistic care to the newborns and

their mothers. As regards nursing practice, the findings of this study may help nurses to enhance their knowledge and perception of how mothers feel about their infants' hospitalization. This can be in terms of recognizing mothers' emotional responses, thoughts, and feelings regarding their infants' hospitalization experience.

Additionally, the findings may help nurses to recognize the concerns and needs of mothers whose newborns are delivered and hospitalized with congenital anomalies. The study findings may also be used by nurses to identify the kind of help and support mothers have received and support they would like to receive during this experience. Lastly, the study findings may be used to offer better support to future mothers who may encounter a similar experience of delivering a newborn with a congenital anomaly. Theoretical Framework Used in this Study The philosophical root underpinning this study is the qualitative descriptive phenomenology as postulated by Edmund Husserl. In this phenomenology philosophy, three frames of reference are emphasized for studying a lived experience

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[the live-world plane of interaction](#) End Match between the Begin Match to source 1 in source list:  
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[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
[researcher and participants](#) End Match,  
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[transcendental subjectivity](#) End Match (which  
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is End Match the  
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[neutrality and openness to the reality of others](#)  
End Match), and the identification of eidetic essences or universal truths (Wojnar & Swanson, 2007). Begin Match to source 1 in source list:  
[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
The "live-world plane of interaction" End Match" between  
the Begin Match to source 1 in source list:  
[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
[researcher and participants](#) End Match involves making extended one-to-one engagements and contact with the objects of research through  
which Begin Match to source 1 in source list:  
[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
[the meaning of lived](#)  
End Match experience Begin Match to source  
e 1 in source list:  
[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
[may be unraveled](#) End Match. According to Begin  
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[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
to End Match Wojnar & Swanson, (2007), this concept also emphasizes that the engagements Begin Match to  
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[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
[must involve attentive listening, interaction, and](#)  
End Match participant Begin Match to source 1 in source list:  
[http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
[observation](#) End Match so as  
Begin Match to source 1 in source list: [http://www.researchgate.net/publication/233426638\\_Kumar\\_A.\\_\(2012c\).Using\\_phenomenological\\_research\\_methods\\_in\\_qualitative\\_health\\_research\\_International\\_Journal\\_of\\_Human\\_Sci5134](http://www.researchgate.net/publication/233426638_Kumar_A._(2012c).Using_phenomenological_research_methods_in_qualitative_health_research_International_Journal_of_Human_Sci5134)  
[to create a representation of reality](#) End Match. Transcendental subjectivity refers to the constant assessment of  
Begin Match to source 11 in source list:  
[https://repository.up.ac.za/bitstream/handle/2263/83518/Sesheba\\_Exploring\\_2021.pdf?isAllowed=y&sequence=2](https://repository.up.ac.za/bitstream/handle/2263/83518/Sesheba_Exploring_2021.pdf?isAllowed=y&sequence=2) [the impact of the researcher on the inquiry](#) End  
Match, with a focus on neutralizing all preconceived opinions, biases and prior knowledge about the phenomenon under study (Wojnar & Swanson, 2007). This  
concept emphasizes the process of remaining neutral and open minded to the reality of participants' experiences, which is achieved by bracketing all personal  
values, preconceptions, prior knowledge and personal biases about the phenomenon under study. The identification of eidetic essences or universal truths refers to  
analysis of participants' accounts to identify the common features that are considered representative  
Begin Match to source 6 in source list: [http://ugspace.ug.edu.gh/bitstream/handle/123456789/8794/Victims with Voices The Conceptualisation, Lived Experiences and Resilience of Victims of Intimate Partner Violence in the Upper West Akyem District of Ghana - 2016.pdf](http://ugspace.ug.edu.gh/bitstream/handle/123456789/8794/Victims_with_Voices_The_Conceptualisation,_Lived_Experiences_and_Resilience_of_Victims_of_Intimate_Partner_Violence_in_the_Upper_West_Akyem_District_of_Ghana_-_2016.pdf)  
[of the true nature of](#) End Match a  
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[phenomenon under investigation \(Lopez & Willis, 2004\)](#) End Match). For a  
Begin Match to source 7 in source list: [http://www.sagepub.com/millsandbirks/study/Journal\\_Articles/Qual\\_Health\\_Res-2004-Lopez-726-35.pdf](http://www.sagepub.com/millsandbirks/study/Journal_Articles/Qual_Health_Res-2004-Lopez-726-35.pdf) [description of](#)  
[the lived experience to be considered as science, commonalities in the](#) End Match experiences  
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[participants must be identified, so that a generalized description is possible. The](#) End Match universal  
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[35.pdf](#) [essences](#) End Match or truths  
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Match then Begin Match to source 7 in source list: [http://www.sagepub.com/millsandbirks/study/Journal\\_Articles/Qual\\_Health\\_Res-2004-Lopez-726-](http://www.sagepub.com/millsandbirks/study/Journal_Articles/Qual_Health_Res-2004-Lopez-726-35.pdf)  
[35.pdf](#) [considered to represent the true](#) End Match structure  
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Match lived experience (Lopez & Willis, 2004). Descriptive phenomenologists thus use 4 main steps to uncover the universal essential structure of a lived  
experience phenomenon. These include (a) bracketing, (b) intuiting, (c) analyzing and (d) describing (Polit & Beck, 2017). Bracketing refers to the  
Begin Match to source 21 in source list: <https://tutorsonspot.com/questions/data-analysis-eukseq/> [holding in abeyance](#) End Match  
Begin Match to source 21 in source list: <https://tutorsonspot.com/questions/data-analysis-eukseq/> [preconceived beliefs, opinions](#) End Match,  
biases Begin Match to source 21 in source list: <https://tutorsonspot.com/questions/data-analysis-eukseq/> [about the phenomenon under study](#) End Match so as  
Begin Match to source 21 in source list: <https://tutorsonspot.com/questions/data-analysis-eukseq/> End Match confront the subject matter on its own terms  
and in a state of pure consciousness. Begin Match to source 18 in source list: Ngenye, Liza, Kreps, Gary. [This means that the researcher must actively strip](#)  
End Match off. Begin Match to source 18 in source list: Ngenye, Liza, Kreps, Gary. [his or her consciousness of all prior expert knowledge as well as](#)  
[personal biases](#) End Match about. Begin Match to source 18 in source list: Ngenye, Liza, Kreps, Gary. [the](#) End Match phenomenon under study (Lopez & Willis,  
2004). Intuiting refers to the process of being open to the meanings attributed to the phenomenon by those who have experienced it. As participants'  
Begin Match to source 8 in source list: Harmon, Carla Armstead. [accounts are](#) End Match being  
Begin Match to source 8 in source list: Harmon, Carla Armstead. [generated, the investigator's intuition is "fed" by more and more data through attentive](#)  
[listening, deep critical reflection about commonalities across participants](#) End Match' narratives. Begin Match to source 8 in source list: Harmon, Carla  
Armstead and concerted effort to understand "what it must be like" End Match" (Wojnar & Swanson, 2007). Begin Match to source 8 in source list: Harmon, Carla  
Armstead. [p.176](#) End Match). Analyzing refers to Begin Match to source 8 in source list: Harmon, Carla Armstead. [the](#) End Match process of examining  
participants' accounts so as to identify common features that represent the essential structure of the lived experience. It involves reading participants transcripts to  
extract significant statements that are then categorized into themes to form an exhaustive description of the structure of the lived experience (Shosha, 2012). The describing step  
marks the end of descriptive phenomenology investigation and presents a theoretical model representing the essential structures of phenomenon under  
study. According to Polit & Beck (2017), it is during this step that the phenomenon's structure is defined and described.  
Begin Match to source 9 in source list: Dambra-Candelaria, Laura Marie. [if the true structure of the phenomenon is identified, then anyone who has](#)  
[experienced the phenomenon should be able to identify](#) End Match their Begin Match to source 9 in source list: Dambra-Candelaria, Laura Marie. [own](#)  
[experience in the proposed description \(Wojnar & Swanson, 2007\)](#) End Match). Operationalization of Begin Match to source 9 in source list: Dambra-Candelaria,  
Laura Marie. [the](#)  
End Match Theory The concept Begin Match to source 9 in source list: Dambra-Candelaria, Laura Marie. [of](#) End Match

