

**UNIVERSITY OF GHANA  
SCHOOL OF AGRICULTURE  
DEPARTMENT OF FAMILY AND CONSUMER SCIENCES**

**EXPERIENCES OF PARENTS WITH PRETERM CHILDREN IN ACCRA, GHANA:  
COPING RESOURCES PARENTS USE.**

**THIS THESIS/DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF  
GHANA, LEGON IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR  
THE AWARD OF MPhil IN HOME SCIENCE DEGREE**

**BY  
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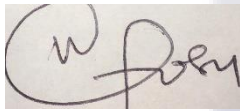
## DECLARATION

I, Alberta Korlekie Opoku-Mensah, hereby declare that this research was carried out under the supervision of Dr. Vivian Tackie-Ofosu and Dr. Sheriffa Mahama. With the exception of references to other people's work which have been acknowledged, this thesis was done entirely by me. I further affirm that this work has never been submitted either in whole or part for any degree in this University or elsewhere.



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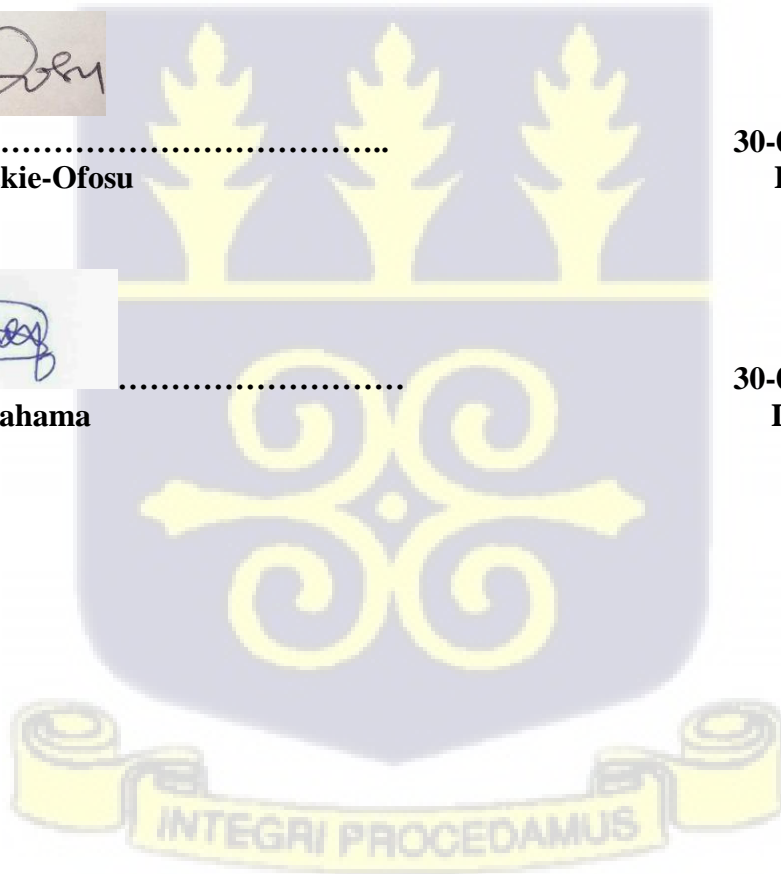
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## ABSTRACT

The continuous rise in preterm births in Ghana has led to the country's inability to achieve Millennium Development Goal 4 – which is, reducing the mortality rate of children under age five. Unfortunately, the exact cause of preterm birth is still unknown. Preterm birth is associated with poor developmental outcomes and low chances of survival for children, leaving parents and families of the affected children with mixed feelings and stress. Complications associated with preterm infants (such as their vulnerability to infections, inability to breastfeed and low weight) cause parents to fear losing the baby. This study investigated the coping resources available to parents with preterm infants at home. The study employed a qualitative approach that is, using an exploratory descriptive design and data collected at one point in time. The study location was the Department of Child Health at the Korle-Bu Teaching Hospital (KBTH). A total of 19 mothers, purposively selected, were used for the study. Data was analyzed using thematic content analysis. The predetermined themes data was organized around were: mothers' experiences during hospitalization, mothers' post-NICU experiences, coping resources parents used and support systems. 17 sub-themes emerged from the interviews conducted. The findings showed that resources such as money, taking time off work, faith, space, inner strength, among others made caring for their preterm less difficult and ensured the survival of their infants. Based on the findings, it was recommended that the government should add most Neonatal and Intensive Care Unit (NICU) charges to the National Health Insurance Scheme (NHIS) and the Ghana Under-five Health Policy. The findings of this study meaningfully add up to existing literature on preterm birth in Ghana.

Keywords: preterm, coping, resources, Korle-Bu Teaching Hospital, experiences, ABC-X model, experiences, NICU,

## DEDICATION

I dedicate this thesis to my God and my parents, Mr. and Mrs. Opoku-Mensah. I love you.



## ACKNOWLEDGEMENT

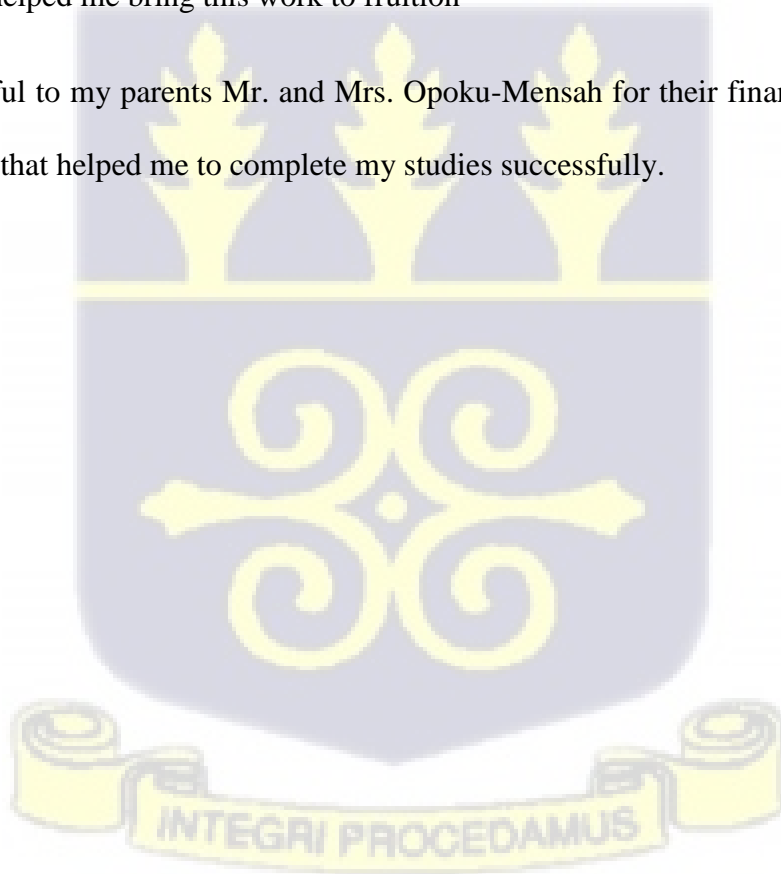
This work was accomplished by the help of the Lord Almighty whose grace and mercies saw me through my education. I am forever grateful to God.

I also want to appreciate my supervisors, Dr. Vivian Tackie-Oforu and Dr. Sheriffa Mahama of the Department of Family and Consumer Sciences, who devoted their time, knowledge and energy to supervise this thesis. I appreciate their constructive criticisms, encouragement and support towards me.

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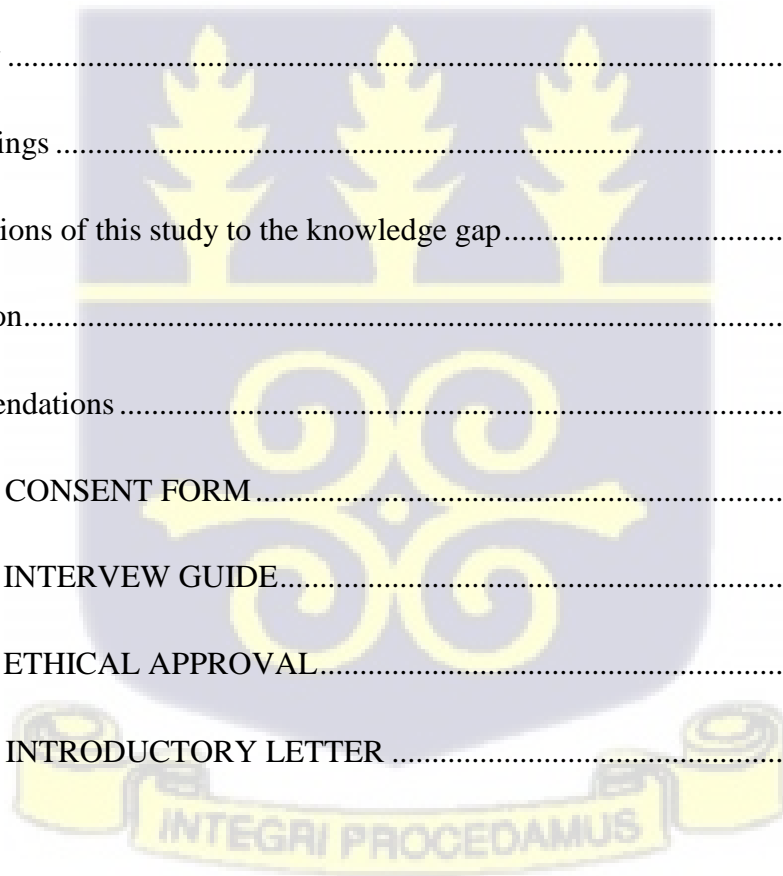
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## LIST OF ABBREVIATIONS

BDP	Bronchopulmonary Dysplasia
GARH	Greater Accra Regional Hospital
KBTH	Korle-Bu Teaching Hospital
KMC	Kangaroo Mother Care
NHIS	National Health Insurance Scheme
NICU	Neonatal and Intensive Care Unit
U.S. A	United States of America
UK	United Kingdom
UNICEF	United Nations Children Emergency Fund
WHO	World Health Organisation



## CHAPTER ONE

### 1.0 INTRODUCTION

#### 1.1 Background of the Study

Preterm births continue to be the major cause of perinatal mortality which drive neonatal mortality worldwide. Over the years, about 15 million preterm babies are delivered yearly, with Africa and Asia recording the highest of over 11 million cases (Blencowe *et al.*, 2013). In a developing country such as Ghana with limited resources, the preterm birth rate rose from 9.3% in 2006 to 18.3% in 2016 (Adu-Bonsaffoh *et al.*, 2019). The country was ranked 25th in the world in 2013 with regard to preterm birth rate (Ghana Factsheet, 2014). With such high record of preterm birth, coupled with inadequate resources contributed to the country's inability to achieve Millennium Development Goal (MDG) 4 which is, reducing under-five child mortality rates.

The World Health Organization [WHO] (2012), defines preterm birth as, “the delivery of an infant before 37 weeks of gestation”. The cause of preterm birth is still unknown (Chen *et al.*, 2019), however, there are risk factors believed to be associated with the issue. They include; maternal demographic characteristics like education, economic status and type of work, pregnancy history and characteristics, stress, genetic and biological marker, maternal conditions like hypertension, malaria, vaginal bleeding and infections, among others.

The burden of preterm birth is not limited to its impact on neonatal morbidity and mortality. Prematureness also causes much impairment in health, which may have long lasting consequences like developmental challenges, lifelong disease, among others (Monangi *et al.*, 2015). Moreover, there is a considerable bulk of literature confirming that, preterm infants face high risk of health conditions like hypertensive disorders, diabetes, and obesity, usually discovered during their adulthood (Monangi *et al.*, 2015).

Recent research suggest that having a preterm infant is associated with diverse stress on the parents (Baía *et al.*, 2016; Howe *et al.*, 2014; Ionio *et al.*, 2016; Koliouli *et al.*, 2016). One of such is the hospitalization of infants at the Neonatal and Intensive Care Unit (NICU). The preterm infant may have complications such as low birth weight, infant's inability to breastfeed, vulnerability to infections, respiratory and gastrointestinal problems, low survival chances rising from immature organ systems and long-term developmental delays (Soleimani *et al.*, 2013).

The 'stress experience' continues even after the baby has been discharged from the NICU (Busse & Stromgren, 2013). Observations made by Baía *et al.* (2016) suggest that mothers experience more stress levels since they are the immediate caregivers. The period of discharge is critical for them to settle at home and take up responsibilities to ensure the baby's survival (Boykova & Kenner, 2012). Dashti *et al.* (2015) argued that quite a number of infants discharged from the NICU are sent back on admission.

Also, factors such as parents' perception of parenthood, perception of the child, perception of oneself, which is mostly influenced by sociocultural practices affect parent's experiences, and how they cope with having and raising a preterm baby (Lang & Diener, 2020). For example, in some Ghanaian culture, preterm birth is perceived as a product of witchcraft attacks. With such sociocultural construct, pregnant women who dream about preterm birth run to their spiritual authorities for deliverance (Aziato *et al.*, 2016). Additionally, preterm infants, unlike the full-term infants, are usually tiny at birth. Hence, their parents usually express their dissatisfaction towards them in various forms (Ionia *et al.*, 2016).

Despite the great disparities in preterm mortalities across the globe, most of the existing literature on preterm birth are much conducted in developed countries like the United States, Finland, France, and Netherlands (Gueron-Sela *et al.*, 2015; Koliouli *et al.*, 2016; Schappin *et*

*al.*, 2013; Walani, 2020). Even with studies that were done in developing countries like Ghana, the focus was on treatment outcomes of preterm infants (Abdul-Mumin *et al.*, 2020), obstetric determinants of preterm delivery in various hospitals (Adu-Bonsaffoh *et al.*, 2016; Aseidu *et al.*, 2019; Axame *et al.*, 2020), with few studies on experiences and coping strategies these mothers use (Suraji, 2013; Velit & Akum, 2018). This highlights a huge gap in information and knowledge of literature, especially in the area of coping resources mothers with preterm use, as Ghana is considered as a low resource country.

In addition, the first early years of parenting a preterm infant is more time-consuming and maybe arduous than parenting a full-term baby (Howe *et al.*, 2014), hence, the need to identify how mothers cope. This study therefore sought to identify coping resources which parents with preterm infants in Accra, Ghana, use.

## **1.2 Statement of the Problem**

Preterm birth has been revealed to be associated with developmental complications and related issues with coping strategies that parents employ during care. The continuous rise in preterm births led to Ghana's inability to achieve MDG 4 which is, reducing under-five child mortality rates. Unfortunately, the exact cause is still unknown. The birth of a preterm infant is associated with mixed feelings, stress and complications such as vulnerability to infections, inability to breastfeed and low weight which heighten parents' fears of child mortality. These factors, coupled with other demands of preterm childcare, easily affect the parenting of such infants. Research shows that the day-to-day care of parenting a preterm child is more laborious and maybe difficult than parenting a full-term baby hence, the need to identify how parents cope. This study therefore sought to identify coping resources which parents with preterm infants in Accra, Ghana, use.

### **1.3 Aim of the Study**

This study aimed to investigate the coping resources parents with preterm infants use in Accra.

### **1.4 Research Objectives**

The specific objectives of this study were to;

1. Explore the experiences of parents with preterm infants during hospitalization and at home.
2. Investigate the resources used by parents to cope with preterm care.
3. Examine the support systems available for parents with preterm infants.

### **1.5 Research Questions**

The research questions were;

1. What are the experiences parents with preterm infants have when hospitalized and at home?
2. How do parents use resources available to them to cope with preterm care?
3. What are the support systems parents had in caring for their preterm infants?

### **1.6 Significance of the Study**

1. The study will give insight into how parents with preterm infants cope with their experiences. It will help appropriate bodies such as the Department of Social Welfare,

Ministry of Health, as well as Ministry of Gender, Children and Social Protection to find ways to help parents in such situations of their parenthood.

2. Also, the study will add up to the few works of literature available on preterm birth in low and middle-income countries like Ghana, especially regarding the resources mothers use in coping with the situation.
3. Finally, the study, when published, will help other mothers who may be new to parenting a preterm baby, to identify resources that can help them cope better. In the case of certainty about having a preterm birth, they can adequately plan for parenting during pregnancy.



## CHAPTER TWO

### 2.0 LITERATURE REVIEW

#### 2.1 Introduction

This chapter probes into the relevant literature that relate to the subject under study. The areas to be discussed are; an overview of preterm birth, experiences of parents with preterm infants (both at NICU and at home), challenges of parents with preterm infants, coping resources and support available to parents, theoretical framework and the conceptual framework.

#### 2.2 Overview of Preterm Birth

Preterm, according to WHO (2012) is defined as, “the birth of a baby before 37 weeks of gestation”. The period of gestation is categorized into three stages. These include; moderately preterm (33 to 36 weeks), very preterm (28 to 35 weeks), and extremely preterm (28 weeks and below) [WHO, 2012]. The majority of preterm infants are born between the 32<sup>nd</sup> and 37<sup>th</sup> week of gestation (Howson *et al.*, 2012). Adu-Bonsaffoh *et al.* (2019) affirm this claim in their research which indicated that, out of the 1,478 preterm births that occurred from 1<sup>st</sup> January to 31<sup>st</sup> of December 2015 in Korle Bu Teaching Hospital, 79.5% (that is 1,175) were born within 32-36 weeks, with 15.95% (235) between 28-31 weeks. Only 4.6% (which is 68) were below 28 weeks gestation. The majority of children born after 25 weeks have high chances of survival if properly cared for at the Neonatal and Intensive Care Unit (NICU) (Cao *et al.*, 2021). However, a baby born prematurely at 32weeks in a low-income country has 50% survival chances as against infants born at 24 weeks in high-income countries. This is due to lack of resources and low quality of specialized care in these countries (Howson *et al.*, 2012).

Furthermore, preterm infants are also called “high-risk neonates” (Suraji, 2013). They have a greater risk of morbidity and little survival chances (Suraji, 2013), leading to their hospitalization at the Neonatal Intensive Care Unit [NICU] (WHO, 2012). At the NICU, preterm infants are sustained in an incubator and given respiratory and nutritional support (Blencowe *et al.*, 2013). They also tend to have low birth weight (weight below 2.5kg) which makes them prone to neonatal mortality (Owusu-Ansah, 2018). More so, complications that arise from preterm birth has been recorded as the leading cause of neonatal mortality (Blencowe *et al.*, 2013; Lawn *et al.*, 2010). In 2010, there were approximately 11,500 preterm births in Ghana, out of which about 7,800 preterm-related deaths were recorded (WHO, 2012). Similarly, a study conducted in the Tamale Teaching Hospital by Abdul-Mumin *et al.* (2021) discovered that out of the 8,377 preterm infants that were admitted to the NICU, about 1,126 died (representing 13.4%). Almost half (49.6%) of these deaths were attributed to preterm birth complications, with 21.7% being caused by birth asphyxia, 14.6% as a result of neonatal infections, and 8.2% being congenital anomalies.

Nonetheless, infants that survive these complications are faced with lifetime developmental consequences (Blencowe *et al.*, 2013; Global Moms Challenge, 2012). They are at risk of poor cognitive, physical and social outcomes in childhood which sometimes continues through adulthood. Those who escape these neurological disabilities tend to have more difficulties in terms of academic achievement (Twilhaar *et al.*, 2018). They also experience lifetime learning disabilities which surface later in adulthood (American College of Obstetricians and Gynecologists, 2019). Also, most preterm infants are faced with breathing difficulties and are put on life support systems. They suffer breathing complications like Respiratory Distress Syndrome which is characterized by high chances (73%) of death (Abdul-Mumin *et al.*, 2020). Other preterm infants suffer from Bronchopulmonary dysplasia (BPD) which is the common cause of lung impairment in children (Northway, 1990 cited in Jobe, 2011). BPD has lifelong

respiratory complications on these children, leading to breathing difficulties and damage of lung tissues (Mourani *et al.*, 2015). Some other preterm infants may also need long-term technological support while some continue to have serious medical issues (Mourani *et al.*, 2015).

The health outcome of preterm infants is an interplay of maternal risk factors, NICU experiences, and the home environment, thus, some environmental factors can either aggravate or reduce complications (McManus & Poehlman, 2012). It has been documented that preterm infants in developed countries where there are adequate resources are able to pull through some of these complications as compared to their counterparts in developing and underdeveloped countries (Do *et al.*, 2020). The complications faced by preterm infants pose some stress on their parents, hence, affecting their psychological health. They remain unsure about possibilities and ways of survival of their preterm baby. This is the reason why this study is necessary to serve as a guide for those yet to navigate the path of parenting for preterm children.

### **2.3 Risk Causes of Preterm Birth**

Despite the vast research carried out in the field of preterm births, there is still a gap as to the main cause of spontaneous preterm labor. Some risk factors that have been identified to be associated with preterm birth are discussed below. They include: sociodemographic characteristics of mothers, pregnancy history, pregnancy characteristics, behavioral risk factors, maternal infections and conditions, as well as race, biological and genetic markers.

#### **2.3.1 Sociodemographic Characteristics of Mothers**

The sociodemographic characteristics of mothers include their socioeconomic status, educational attainment, maternal age and type of work. All these characteristics affect the

likelihood of having a preterm baby (Blenconwe *et al.*, 2013). In an empirical study conducted in Canada on spontaneous preterm birth, a univariate analysis was run on factors like maternal age and educational status, which revealed to be significantly associated with the likelihood of having a preterm delivery. Also, pregnant women's engagement in heavy physical workload is a likely cause of preterm birth (Van Beukering *et al.*, 2014) as it leads to intra-abdominal pressure causing early contractions of the uterine (Beaucage-Gauvreau *et al.*, 2011). With regard to maternal age, women who are 35 years and above are considered advanced maternal age women (Goisis *et al.*, 2017). These women have high risk of preterm birth (Goisis *et al.*, 2017). Similarly, some other research (e.g., Blenconwe *et al.*, 2013; Carolan & Frankowska, 2011) have shown positive influence between advanced maternal age and the risk of preterm delivery. However, how these characteristics lead to preterm birth has not been identified.

### **2.3.2 Pregnancy History**

Women with their first child being preterm have the likelihood of having another preterm child as compared to those who had full-term infants. Nonetheless, the mechanism to explain this risk factor has not been discovered (Goldenberg *et al.*, 2008; Schaaf *et al.*, 2012). Usually, if the first preterm birth is as a result of infections, it is more than 2.5 times likely to have another preterm birth during the next pregnancy (Blencowe *et al.*, 2013; Goldenberg *et al.*, 2006). This happens when infections repeat in subsequent pregnancies (Blencowe *et al.*, 2013; Goldenberg *et al.*, 2006). However, Aseidu *et al.* (2019) in their research revealed that the history of preterm delivery was not significantly associated with subsequent preterm delivery. Their finding could possibly be attributed to the fact that, in their study, most of the preterm cases were provider-initiated labor. On the contrary, Purisch and Gyamfi-Bannerman, (2017) posited that the recurrent rate of having a previous preterm birth and current preterm birth is 15% to 50% especially if the previous birth was spontaneous labor.

Another risk, which is of concern, is short intervals within pregnancies. That is a close interval below 6 months can lead to preterm birth. This occurs when the first pregnancy depleted a lot of body nutrients, and when the mother's body has not adequately replenished the body stores for the next pregnancy. This is consistent with a study by Jeena *et al.* (2020) who found out that delaying another pregnancy for a longer period reduces the risk of preterm birth. Furthermore, mothers' nutritional statuses can lead to the birth of a preterm (Blencowe *et al.*, 2013). That is, mothers with low body mass index before pregnancy are at high risk of preterm birth (Shen *et al.*, 2015).

### **2.3.3 Pregnancy Characteristics**

Multiple pregnancies (birth to twins and triplets) are at the risk of being delivered prematurely. Research indicates that about 60% of twins are born prematurely because of preeclampsia, and maternal and fetal disorders (Blencowe *et al.*, 2013; Goldenberg *et al.*, 2008). A study in Missouri reported that multiple gestations account for 15-20% of preterm births (Purisch & Gyamfi-Bannerman, 2017; Romero *et al.*, 2006). Also, the use of assisted reproductive technologies which cause multiple gestations were also identified to increase risk of preterm births (Blencowe *et al.*, 2013).

Again, mothers who experience excessive stress (from economic hardship, marital problems, whatsoever) during pregnancy are at risk of having preterm births. Though not a fully established fact, it is believed that when women are stressed, they are exposed to the serum concentration of inflammatory markers like C-reactive protein, leading to early delivery of infant. (Suwardewa *et al.*, 2022). This is similar to what Christiaens *et al.* (2015) discovered in their study which showed that depressive symptoms during pregnancy are significantly associated with preterm birth.

#### **2.3.4 Behavioral Risk Factors**

Furthermore, behavioral risks like the use of tobacco, smoking, and alcohol intake during pregnancy can also lead to preterm births (Janisse *et al.*, 2014). The use of cocaine and heroin by pregnant women have been significantly associated with high preterm birth rates in developed countries like the United States (Bailey *et al.*, 2012; Goldenberg *et al.*, 2008). Christiaens *et al.* (2015) likewise reported in their study that, there is a significant relationship between smoking and alcohol usage, and the likelihood of experiencing a preterm delivery.

#### **2.3.5 Maternal Infections and Conditions**

Intrauterine infections amount to 25-40% of preterm births. Most preterm births at 21-24 weeks have been associated with intrauterine infection. The microorganisms which cause these infections are mostly found in the amniotic cavity. These microorganisms get to the uterus by ascending from the vagina and cervix, thus causing infections, which lead to premature delivery of a baby (Blencowe *et al.*, 2013; Watts *et al.*, 1992). In addition, bacterial vaginosis can also lead to preterm birth. Bacterial vaginosis is the change in the microbial ecosystem of the vagina, and this disorder causes changes in the pH of the vagina from 4.5 and above (Sabour *et al.*, 2018). Black women in the US and UK are three times more likely to have bacterial vaginosis than white women. Though not proven, it may go a long way to explain the disparity in preterm birth rates between white and black women (Goldenberg *et al.*, 2005; Peebles *et al.*, 2019). It is worthy of note that, maternal conditions such as severe hypertensive disorder (preeclampsia and eclampsia) are the commonest reasons for preterm birth in Ghana (Aseidu *et al.*, 2019). Also, vaginal bleeding, especially in the first and second trimesters can also lead to preterm birth (Alijahan *et al.*, 2014).

### **2.3.6 Race, Biological and Genetic Markers**

Other risk causes of preterm birth are race, biological and genetic indicators. The disease and disorders mechanism for preterm birth is likely genetic. Studies have revealed that, women with female siblings who had premature infants are 80% likely to also have preterm infants (Dean *et al.*, 2013). Also, people, especially females who were born prematurely, have higher chances of having preterm infants themselves (Requejo *et al.*, 2013). It has been recorded over the years that, mothers from a black lineage (which includes the African American and the Afro-Caribbean) have higher rates of giving birth to preterm children as compared to whites, which is 16% against 10% respectively (Glass *et al.*, 2015). Population-based research of births in Missouri cited by Purisch and Gyamfi-Bannerman (2017) showed that black women have three times higher possibilities of giving birth to preterm infants, however, the mechanism is unknown.

To conclude, it has been realized that the mechanism by which most of the risk factors cause preterm birth has not been fully explored or studied. It has therefore affected the adoption of suitable interventions aimed at reducing the rate of preterm births globally. Therefore, chances of having more parents bear preterm infants and the accompanying stress remains a challenge. In order to assist new mothers with preterm to identify resources to ease their stress experiences both at NICU and after discharge, this study sought to find out how families cope with the issue.

### **2.4 Experiences of Parents with Preterm Infants**

Experiences of parents with preterm birth can either be positive or negative (Sawyer *et al.* 2013). However, many parents with preterm recount more of negative experiences dealing with

their predicament (Garti *et al.*, 2021). Korja *et al.* (2012) highlighted in their meta-analysis study that the kind of experience (be it positive or negative) which parents gain with their preterm infants at the NICU and homes may affect their relationships in later years. They found a relationship between experiences of parents and development of social and emotional problems in children as they grow up.

Moreover, Garti *et al.* (2021) in their qualitative descriptive study in a middle-income country, based on 11 participants, Garti *et al.* (2021) establish that most experiences of mothers with preterm infants were challenging and overburdening. The involved participants expressed their negative experiences with preterm birth, especially within the first year of post-delivery period. Some of these negative experiences recounted include a period of sleep deprivation as they felt obliged to be awake most of the times to keep an eye on the baby. These mothers wanted to be sure their infants were still breathing after being taken off life support systems when discharged (Boykova, 2016).

Furthermore, mothers tend to have mixed feelings after discharge from NICU. They are excited going home after a long stay at NICU, but same time anxious and worried about how to take care of their fragile infants without support from healthcare professionals at home (Granero-Molina *et al.*, 2019). They expressed constant worry about their infants' condition and development when returning home (Hall *et al.*, 2013; Griffin & Pickler 2011; Phillips-Pula *et al.*, 2013). Even though mothers view the home as a safe haven and a familiar environment where they can rightfully exercise their authority, long hours of being indoors for the sake of nurturing a preterm baby could lead to depression. Such depression emanates from the stress of isolation from the outside world and boredom. This study, therefore, sought to find out how these mothers use the resources at their disposal to cope with such experiences with preterm infants.

In addition, a study conducted by Granero-Molina *et al.* (2019) showed that mothers' experiences of preterm births become more challenging after they have been discharged. This is because, the impacts of the negative experiences they go through at the NICU tend to affect their homecare of their preterm infants. Unconsciously, they administer their preterm childcare role as though they are being monitored by health experts, as being done at the NICU. Also, the mothers set goals for themselves and try hard to attain them, as perceived as expected of a good mother (Green *et al.*, 2021). When they fail at these expectations, they feel incompetent as mothers. They therefore remain stressed by caring for their baby for at least two years. When discharged, some mothers also find it difficult to maintain a secure attachment with their preterm infants because they get used to health professionals performing caregiving roles in their stead. As a result, they shift their preterm childcare roles to other family members, while they go about other duties (Green *et al.*, 2021).

Again, some mothers gain various experiences with relation to feeding their preterm infants. Feeding is essential for the growth of infants, especially the preterm infants. Many health institutions like WHO and United Nations International Children's Emergency Fund (UNICEF) endorse exclusive breastfeeding as the optimal feeding for the first six months of every baby's life (Binns & Lee, 2014). Breastmilk feeding can either be direct (that is, from breast to the baby) or indirect (that is, pumped and fed from bottle or spoon) However, the recommended feeding practice among the two types is the direct feeding. Where it is impossible for direct feeding, the indirect method could be used as an alternative (Düzeltici & Arslan, 2022). Early introduction of foods for preterm infants other than breastmilk poses some threats to the baby's health. They include: the risk of obesity, diabetes, diarrhea, pneumonia, and sometimes, infant mortality (Brahm & Valdes, 2017).

Regardless of these risk factors, about 85% of mothers with preterm infants fail to comply with exclusive breastfeeding (Karmaus *et al.*, 2017). Research on feeding patterns in young infants

in Iran revealed that, some mothers expressed various reasons why they could not do exclusive breastfeeding. Majority of the respondents indicated that, they had insufficient milk. Sometimes, mothers, with the notion of insufficient milk, employ artificially made feeding formula as substitute for natural breastmilk (Shiva & Nasiri, 2021). Also, some mothers are unable to do exclusive breastfeeding as an effect of the infant separation in the early postnatal period during the period of hospitalization at NICU. During that period, some mothers are unable to breastfeed their preterm baby, hence, leading to a gradual decrease in the supply of milk (Shiva & Nasiri, 2021). Those who are able to breastfeed successfully feel fulfilled, knowing their direct contribution to the child's health, while those who encounter problems with feeding carry a feeling of guilt (Breivold *et al.*, 2019).

For the preterm, it is recommended that the introduction of solid foods can begin when the baby weighs 5kg, and can feed on a spoon (Barachetti *et al.*, 2017; Department of Health-UK, 1994). Unlike the guidelines for full-term infants' introduction to solid foods, there are no specific age recommendations for preterm (Palmer & Makvides, 2012). Again, the European Society of Pediatric Gastroenterology, Hepatology & Nutrition Committee revealed that, in the advanced European countries, the introduction to solid foods to a preterm should not be before 17weeks and not after 26weeks (Agostoni *et al.*, 2008; Barachetti *et al.*, 2017). This is because the risk of infections from complementary feeding is high due to exposure to infected water, feeding equipment, and even the food itself. These infections are not limited to only preterm infants but also full-term infants. This was demonstrated in a study conducted in the UK, involving 18,818 full-term infants where there was an increased risk of hospitalization as a result of diarrhea or lower respiratory tract infections in infants fed who were exclusively breastfed for less than four months (Quigley *et al.*, 2016). Early initiation of solid foods among preterm can lead to the development of food allergies, as preterm infants are known to have increased gut permeability (Chiale *et al.*, 2021; Robertson *et al.*, 1982). This can lead to

readmission of preterm infants, causing a repeat of NICU experiences that initially mothers had, and hence, affecting family resources.

Fathers, on the other hand, had quite different experiences with preterm birth. There were some who felt the whole preterm birth experience was out of control, and hence, caused them to isolate themselves from the journey of caring for the child (Provenzi & Santoro, 2015). Others also claim they would have loved to be fully involved, but for the unfriendly nature of the NICU to fathers. In a qualitative study conducted in Ghana on nine fathers on their experiences of caring for preterm infants by Adama *et al.* (2017), they lamented on their sidelined role in caring for their preterm, both at the NICU and after discharge. According to them, the NICU was not father-friendly, and as the name suggests, Mother and Baby Unit. Besides, the health care professionals did not make them feel welcome at the NICU, therefore, they lacked the opportunity to be involved in pre-discharge education and practical training in preterm childcare at the NICU. In effect, the fathers lack the requisite knowledge to support the preterm mothers in the supposed collective effort in caring for a preterm baby. They lack confidence and are sometimes filled with fear when attempting to cater for the child, considering the tiny and fragile nature of most preterm. To avoid hurting the infants, the fathers recount how they rather stayed away from such attempts like carrying them (Adama *et al.*, 2017).

Nonetheless, some fathers revealed that, they later had to learn to bond with their preterm infants through activities like spending time together, cuddling the baby as a way of caring, and taking them for a walk in the park. They acknowledge how fulfilling and joyous such moments were (Benzies & Magill-Evans, 2015). Candelori *et al.* (2015) confirm parents who show positive care experiences, regardless of their preterm situation, have better parent-child interaction

All these studies discussed above, however, failed to explore how parents were able to navigate through such challenging and difficult moments, using the resources at their disposal. Meanwhile, the availability of resources and how they are used is critical to effective parenting. This research, is therefore aimed at an exploration of the coping mechanisms of parents at the NICU and home, with utilization of the resources available to them.

#### **2.4.1 Parental Stress**

It is important to reiterate that, stress cannot be ruled out from the experiences of parents when a preterm baby is born. If not well-handled, the stress can break down families (Veronez *et al.*, 2017). The entire situation poses some sort of threat to the health of families involved, especially regarding their psychological wellbeing (Flacking *et al.*, 2012). Upon being informed about the minimal survival chances and high risk of disabilities associated with preterm births, anxiety eventually builds up into mental stress for the parents. They are gripped with fear and become anxious about what is next for their infants (Watson, 2011).

Another stressing factor is the weight of the baby. Parents tend to have an expectation of how infants should look when born, and if their baby falls short of that expectation, they get disappointed and discouraged. A study conducted in Portugal affirms the related stress that a baby's weight brings upon the parents. It revealed that, extremely low birth weight was cause for anxiety in parents, with the greater effects on mothers than fathers (Baía *et al.*, 2016). Likewise, the hospitalization period also comes with its associated stressors, where parents are not able to take up traditional roles of parenting. Mothers tend to feel that healthcare professionals are assuming their caregiving roles and making them more like the second parent to the baby. The fathers, however, usually remain indifferent about whether the mother or health professional assume the caretaker role (Baía *et al.*, 2016).

Moreover, lack of social support after delivery of a preterm baby can heighten stress levels among parents. This explains why Hispanic and Black American mothers have higher rates of stress after a preterm birth. They tend to lack social support and find it difficult to seek help due to stigmatization (Gateau *et al.*, 2021). All these stress situations, if not handled well, can influence the parent-child relationship (Suttora *et al.*, 2014), affecting the neurobehavioral and socioemotional development of the child (Lean *et al.*, 2014). In a research conducted in Ghana on the experiences of how mothers care for their preterm infants, it was discovered that preterm birth even goes beyond the preterm child, affecting other siblings, in terms of academics and interpersonal relationship (Suraju, 2013). Most mothers spend almost all their time caring for the preterm child, losing concentration on caring needs of their other children. This is similar to Aagaard's *et al.* (2015) study, where they realized that combining the care of other children with preterm infants can be highly stressful for mothers, as it creates relationship issues with other children. A review of articles found that, parents of preterm experience a sense of loss of control when it comes to parenting responsibilities, because their minds are occupied with ensuring the survival of the baby (Mu *et al.*, 2009).

Even though preterm-related stress is experienced by both parents, research shows that mothers tend to experience higher stress levels than fathers (Ionia *et al.*, 2016). This is explained by Kuhlman and Annandale (2012), who ascertained that the stress levels are higher in women because they are the immediate caregivers and experience almost all the happenings at the NICU. On the contrary, Treyvaud *et al.* (2014) observed in their study that more fathers than mothers experience a high level of stress in the first months of the preterm birth. This could be attributed to the father's role as the financial provider, coupled with the demand of their constant availability to support their partners. A meta-analysis of stress among parents with preterm revealed that, fathers' stressors were associated with their inability to understand the needs of preterm infants, whereas mothers' stressors included infants feeding and lack of

emotional support from partners (Schappin *et al.*, 2013). The above studies discussed dwelt only on the experiences of parents, and failed to explore how these parents are coping with this major change in their lives with the resources available to them. Thus, this study sought to fill that gap by investigating resources parents with preterm use to cope with the situation.

## **2.5 Challenges faced by Parents with Preterm**

Velit and Akum (2018) conducted research in the Bawku Municipality of Ghana, where they assessed the various challenges faced by parents with preterm. They grouped the identified challenges into four main themes, which were: physical, economic, sociocultural, and spiritual. They employed a qualitative approach using exploratory descriptive design. Twenty-one mothers were sampled for the study. The tools for data collection were interviews, focus group discussions and direct observations of study participants in their homes.

The researchers observed that, mothers experienced physical challenges such as exhaustion, weight loss and little time for themselves. They had difficulties combining the care of preterm infants with the care of other children. Premji *et al.* (2017) agree with Velit and Akum (2018) on how challenging it is for mothers in caring for their preterm ones, especially when they need to cater for other older children. Mothers described the care of preterm infants as tiring and laborious due to its effects on their general appearance as women.

Aside the physical challenges posed by preterm caregiving, Velit and Akum (2018) identified economic challenges. Their research revealed that, some mothers had to quit their job in order to get time and take care of their infants, hence, relying solely on the income of their partners. This made their partners feel overburdened with cost of care of the preterm infants. Lakshmanan *et al.* (2017) agree with Velit and Akum (2018), as proven in their study on this

subject matter. They found that, some mothers had to withdraw from their jobs to give full attention and time to their infants, leading to full reliance on their partners' incomes.

In terms of sociocultural challenges, it was found out that some women were, as a matter of culture, required to bath concoctions for four months before they could have marital affair with their partners. Mothers complained about how this led to infidelity on the part of their husbands. This is similar with a study where mothers posited that, the whole situation affected their relationship with their partners. They needed to put in more effort in becoming intimate with their partners again (Lundqvist *et al.*, 2019). Another sociocultural challenge reported was the mothers' inability to perform naming ceremonies for their preterm infant on culturally stipulated period. That was due to reasons such as long period of hospitalization, small size of the baby and their inability to carry out religious activities.

In Velit and Akum's (2018) study, some respondents hinted at feelings of loneliness as a challenge. The researchers could have categorized that and other related feelings as emotional challenges. However, they rather chose to capture it under sociocultural challenges, which to some extent, could be regarded as a shortcoming to their work. The emotional challenges faced by preterm mothers should have been widely explored since it goes a long way to even affect family relationships (Lasiuk *et al.*, 2013). Aside that, Velit and Akum (2018) failed to explore how mothers coped with the challenges they identified as a cue to determining whether they will experience a maladaptation or a bon-adaption of the crisis' experiences.

Another study was carried out in Ghana by Suraju (2013) on the experiences of mothers caring for preterm infants at home. The study used a qualitative approach with nine participants. In her study, she identified some challenges mothers in Ghana face with preterm care at home. The challenges identified were themed into physical, sociocultural, financial and feeding difficulties. Mothers expressed how traumatic and time-consuming preterm care was for them.

They explained that the preterm birth affected their social lives because they could not engage in social activities due to the demands of the preterm childcare. Others also withdrew from social activities due to fear of stigma on infants' size. It was also revealed that, mothers had to delay naming ceremonies which are usually held on the eighth day after delivery, because of long stay at the NICU. Moreover, even after discharge, their infants still looked tiny and deemed unfit to be out-doored. The researcher further reported on financial constraints as a major challenge for the interviewed mothers. Even though they were all working, they had to put their jobs on hold and focus on caring for their infants. This put pressure on the little money coming from their partners and plunged them into economic difficulty.

In addition, Suraju (2013) identified that, mothers had challenges when it comes to feeding their preterm infants. The feeding challenges were attributed to undeveloped sucking and swallowing reflexes. Padovani *et al.* (2011) in their study on perceptions of breastfeeding in mothers of infants born preterm found that, exclusive breastfeeding was difficult for mothers upon being discharged. It was noted to be so because of the introduction of other foods to the children during their stay at NICU. Similarly, Boykova (2016) in her study, identified some challenges posed by breastfeeding to preterm infants. Mothers discussed that breastfeeding was a challenge as infants have to constantly feed to gain weight and they were readmitted as a result of their inability to gain weight.

In a longitudinal study on factors affecting breastfeeding outcomes at six months in preterm infants, it was found out that exclusive breastfeeding was affected by mother-baby separation at the NICU due to infection prevention (Wang *et al.*, 2019). Another challenging moment for mothers is the introduction of solid foods. Most children experience gastrointestinal problems, excessive vomiting and constipation. It results in difficulty for the baby to eat, which as well becomes worrying for the mother (Grundvig *et al.*, 2020). Although Suraji's (2013), study probed into detail challenges mothers with preterm infants faced, the study was without

limitation, the sample size used for the study was too small, hence results albeit insightful cannot be generalized.

## **2.6 Coping Resources available to parents with preterm**

Paynter *et al.* (2013) define coping as the strategies used by a family to manage stressors. For parents with preterm infants to be successful in coping with experiences and stressors as discussed in previous paragraphs, resources at families' disposal can be a major determining factor. These could be the available material and non-material possessions that can be used to achieve a goal. Koliouli *et al.* (2016), in their study, explored and analyzed the different paternal stress, post-traumatic stress symptoms and the coping strategies used by French fathers with preterm infants. The study employed a quantitative approach using 45 fathers with preterm infants. It was conducted at a university hospital in Toulouse. Data for the study was collected using three questionnaires. For the coping strategies, participants were made to answer a Coping Health Inventory for fathers. This had three different subscales grouped as follows: family integration, cooperation and optimism as a subscale, and social support, self-esteem and psychological stability as another subscale. The last subscale was medical communication and consultation.

A five-point scale was used to determine fathers' coping strategies. The result of the study was analyzed using Statistical Package for Social Sciences (SPSS). Researchers found that fathers' age was significantly related to the type of coping strategies they used. Older fathers tend to use coping strategies like social support or communication with medical staff than younger fathers. Fathers in the study also used more of family integration than all the other coping strategies. In their study, Koliouli *et al.* (2016) found that stress and post-traumatic stress disorders did not affect the kind of coping strategies fathers used. Even though the study used

a quantitative method, the sample size was small to have generalized findings. Again, the study focused only on the hospitalization period where infants were still on admissions, and this could have influenced fathers' coping strategies. Also, other factors such as resource availability could have influenced the coping strategies used by fathers, but were not explored. This is a more reason this study is useful in identifying the resources available and used by parents, both at NICU and at home.

Again, Sih *et al.* (2014) conducted a study in South Africa on coping strategies mothers with preterm infants used. It was a qualitative study which used 12 mothers who had their infants still on admission at the NICU. The research aimed to explore and describe the coping strategies used by these mothers. They discovered that mothers resorted to prayers as a means of intervention to ensure the survival of their preterm children. They believed that their beliefs in a supernatural power will ensure their infants' survival at the NICU, and that, God would relieve them of the trauma they were going through as mothers. Other participants also mentioned that their ability to touch their infants and cuddle them helped in coping with the stress of delayed motherhood. Most often than not, these infants are in incubators, hence, creating a separation between them and their mothers. Getting to touch and cuddle them, therefore, was a moment of bonding and attachment for the mothers and their infants. Sih *et al.* (2014) pointed to the mothers' ability to understand infants' needs as a trusted coping strategy. Identifying and understanding the baby's needs was considered a great relief for the mothers because, according to them, it enhanced their caregiving roles. Sih *et al.* (2014) did a good work and established concrete findings supported by other literature, however, their study was just limited to the hospitalization period, after which stress levels may increase. As established already in this paper, the parental stress continues after hospitalization, with a likelihood of heightening. This study, therefore, aims at filling the gap by exploring how parents are coping with the stress after discharge, considering the resources they use.

## **2. 6.1 Preterm care and coping resources in Ghana**

Not many research has been conducted in Ghana on how parents with preterm cope. The few studies conducted in Ghana identified that mothers adopted two main coping strategies which included, religion, and in-depth understanding of infants' needs (Suraju, 2013). The religion aspect is the mothers' ability to trust God to help them care for their infants. They believe in God to help them nurse their preterm infants without any complications. Also, the in-depth understanding of baby's need is the mothers' ability to identify what the baby needs at a particular point in time. These findings by Suraju (2013) is supported by Velit and Akum (2018), who also found two coping strategies of mothers. They are: understanding the needs of the baby and religious beliefs. They found that, mothers were more religious and trusted their faith in a supernatural power to help them overcome their challenges. Additionally, mothers found a good understanding of their infants' needs very relieving, as it helped enhance their preterm childcare. Both Suraju (2013) and Velit and Akum (2018) did not explore how the availability and utilization of resources influenced preterm childcare by parents.

Coping can be successful or become maladaptive depending on the resources available to the family (Boykova & Kenner, 2012). The approach people use to cope is largely dependent on the resources at their disposal (Westman, 2013). The coping resources people use affect their coping methods and the strategies they employ (Brooten *et al.*, 2001 cited in Kilpatrick *et al.*, 2014) thus, coping becomes stressful when people lack the required resources to go through the event (Repetti & Wang, 2017). For instance, people with spiritual resources like faith, beliefs and prayer would tend to adopt religion as a coping strategy in their moment of difficulty as compared to someone who does not have those resources because they do not believe in religion. Some of the resources families and individuals use to cope during stressful moments have been identified and discussed below.

### **2.6.2 Spiritual Resources**

Spiritual resources are the religious beliefs and practices employed to reduce the emotional difficulty one experiences in times of stress, aimed at making those moments more bearable (Saad & de Medeiros, 2012). Some of such resources include prayer, faith, meditation, etc. Prayer is described as an intimate communication with a higher deity to implore or petition for something or someone (Saad & de Medeiros, 2012). In most of the articles reviewed on coping strategies in various countries, especially in Africa, it was seen that most families and mothers resorted to prayers as a way of managing demands they faced (Sih *et al.*, 2014; Suraju, 2013; Velit & Akum, 2018).

Faith, as a spiritual resource, is the inner courage that works as a shelter to help an individual go through difficulties. Faith and prayer help people connect to a higher source of power with the assurance that, they will have interventions from there. They resort to dependence on God to help them overcome their plight (Suraju, 2013). This shows that mothers going through stressful moments do not downplay the power of a spiritual resource like prayer. It is consistent with Assimeng's (2006) assertion cited in Suraju, 2013 that, the daily life of the African is knotted around spiritual principles and practices. He described religious beliefs as guidelines to which people belonging to a certain religion observe. When people exercise their belief in the supernatural, they tend to get some comfort and expect some supernatural interventions in their stressful moments.

Additionally, several studies have proven spirituality to be associated with improved levels of psychological and physical health (Jim *et al.*, 2015). Research shows that spiritual resources have become one of the commonest coping resources people use in times of crisis (Saad & de Medeiros, 2012). When compared to the Western World, for instance, African Americans tend to rely on regular prayer, Bible study, and the consumption of religious media as means of

coping during times of difficulty. Frequently, they use prayer as an approach to feel emotionally, mentally, and spiritually sheltered (Gona *et al.*, 2016). Therefore, people with these spiritual resources will employ religiosity as a coping strategy to help cushion them in stressful moments like preterm birth.

### ***2.6.3 Finance as a coping resource***

Financial hardship is a source of strain that may impact the health and well-being of parents with preterm infants (Chaney *et al.*, 2012). Parents in the Western countries pay up to over £32,153 on healthcare expenses throughout the first year of raising a preterm child (Petrou & Khan, 2012) bringing a strain on family monetary resources. In a research article on experiences of mothers with preterm infants in Ghana, mothers expressed their concerns about financial difficulties. This was due to payment of most of the medications required for the treatment of the infants, even though they were registered on the National Health Insurance Scheme (NHIS) (Lomotey *et al.*, 2020). They found out that, mothers had difficulties in paying hospital bills. The respondents expected that the NHIS would cover most of the expenses but to their disappointment, that was not so (Lomotey *et al.*, 2020). Ghana's NHIS was introduced in 2001 to replace the cash and carry system of payment of health services as part of the country's Strategy of Poverty Reduction (Azaare *et al.*, 2020). The policy was to help deliver accessible, affordable and good quality healthcare to all Ghanaians, especially the poor and most vulnerable in the society (Azaare *et al.*, 2020). Therefore, it is not surprising that mothers looked forward to the NHIS as a support to the financial debt they had to pay at the NICU. However, because the NHIS is unable to cover the greater percentage of hospitalization-related costs for the preterm families, there is little left for the caregiving role at home, hence, making it difficult to cope with the preterm situation. Families who tend to have good financial standing, however, have an upper hand in dealing with the stress since they are able to easily

afford their infants' needs. They therefore adopt a coping strategy that is more financially inclined, as compared to others who are financially challenged.

## 2.7 Social Support

Cobb's (1976) cited by Cohen and McKay (2020) defines social support as "information leading a person to believe that he or she is cared for and loved, esteemed and valued or that he or she belongs to a network of communication and a mutual obligation" (page 38). Bi *et al.*, (2022) also defines social support as an individual's awareness of the availability of help or from others in their social network group. In Velit and Akum's (2018) study, they explored some support mothers received as they went through the care of their preterm infants. According to some respondents, they got support from their husbands, in-laws, friends, extended family, and religious groups. Some also reported of never receiving any support from their partners; they went through the whole experience by themselves. Others also declined support from friends due to reasons such as shame about their infants' weight, and a means of preventing infections. Lack of social support, however, has been identified as a cause of maternal distress in mothers with preterm infants (Ballantyne *et al.*, 2013) In the same vein, Granero-Molina *et al.* (2019) revealed that, restriction of visit as a way to prevent infection affects the social relationships of parents. It also leads to a feeling of loneliness and isolation (Boykova, 2016). Despite the given support in many cases, mothers still had great difficult moments sharing what they were going through, because, they felt no one understood their situation (Boykova, 2016).

Also, grandmothers have been identified as major social support in caring for preterm infants, regardless of the delivery outcomes (Gupta *et al.*, 2015). They provide physical, emotional, and informational support to parents after childbirth (Aubel, 2012; Moyer *et al.*, 2012). Even

though social support is key in overcoming emotional stress, research by Adama *et al.* (2020), showed that support from grandmothers in the care of preterm infants rather led to extra morbidity and readmission. This was due to the consistent use of herbal concoctions to help stimulate infants' growth and as a form of protection for the child. Besides, they become hindrances to exclusive breastfeeding, dwelling on the notion that, the preterm baby will be extremely thirsty without water. Fernández-Medina *et al.* (2021) concur with Adama *et al.* (2020), opining that grandmothers, though supportive, raise issues of conflict due to differing views on caring for preterm infants. Therefore, not all social support can be considered positive by the recipient, as held in the Social Support Theory. The theory posits that, if there is a difference between what receivers expect from the providers in terms of the perception of the type of support that should be given, the recipient might not be happy with the support provided (Shumaker & Brownell, 1984 cited in McClure, 2013).

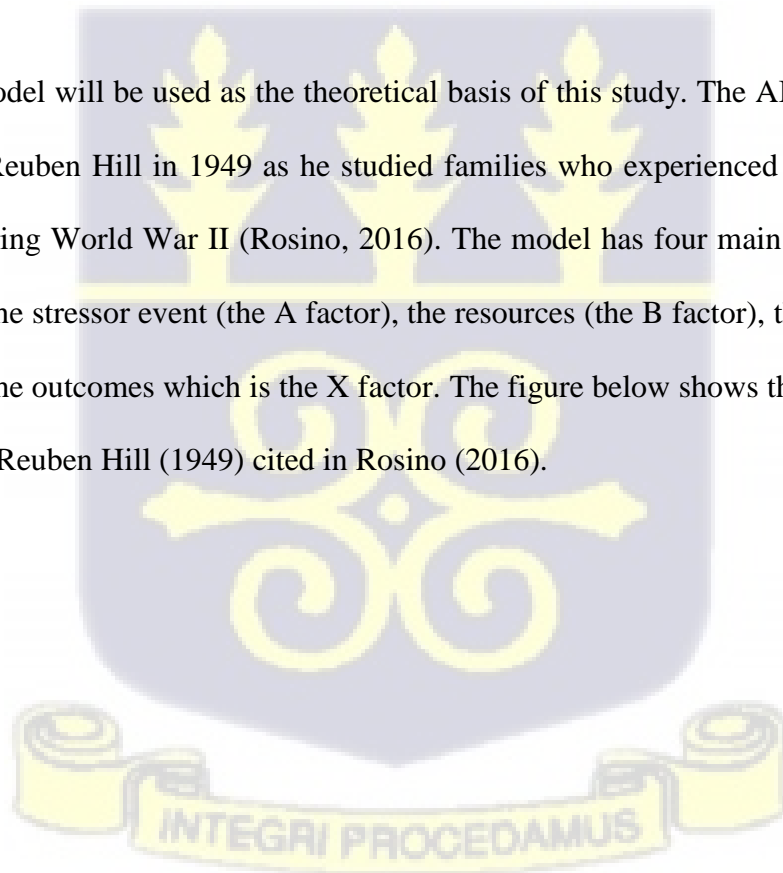
In addition, parent-to-parent support has been identified as essential, as parents expressed that getting to know the experiences of other parents and how they pulled through the stress experience was a "breath of fresh air" to them (Fernández-Medina *et al.*, 2021). This gives parents a sense of confidence and help them positively cope with caring for the preterm baby (Fernández-Medina *et al.*, 2021). Also, mothers in an empirical study suggested the need for support from families who have once raised a preterm baby, rather than any other person, this was a way of helping them know that they are not in the situation alone (DeHoff *et al.*, 2016). Parents expressed getting other parents who had similar experiences helped them to learn few things from their experiences, hence reducing stress at home (especially the stress stemming from inadequate resources). However, in a social support conceptual analysis paper, it was argued that, the fact that a person has similar experiences does not mean the person can provide the needed support to another in a similar situation (Langford *et al.*, 1997 cited in Graven & Grant, 2014).

Support can also be a good coping resource where healthcare providers increase parents' confidence in taking care of their infants by doing regular follow-ups and home visits (Adama *et al.*, 2016). In a research on mothers' experiences after discharge from the hospital, with a moderate to late preterm baby in Norway, it was revealed that mothers were able to cope successfully when there was a constant follow-up by Public Health nurses (Breivold *et al.*, 2019).

It is worth noting, however, that the lack of social support conversely has some positive impact on mothers. It helps them to develop confidence in caring for their infants (Leahy-Warren *et al.*, 2012).

## **2.8 Theoretical Framework**

The ABC-X model will be used as the theoretical basis of this study. The ABC-X model was developed by Reuben Hill in 1949 as he studied families who experienced the absence of a male figure during World War II (Rosino, 2016). The model has four main components and these include: the stressor event (the A factor), the resources (the B factor), the meanings (the C factor), and the outcomes which is the X factor. The figure below shows the ABC-X model as designed by Reuben Hill (1949) cited in Rosino (2016).



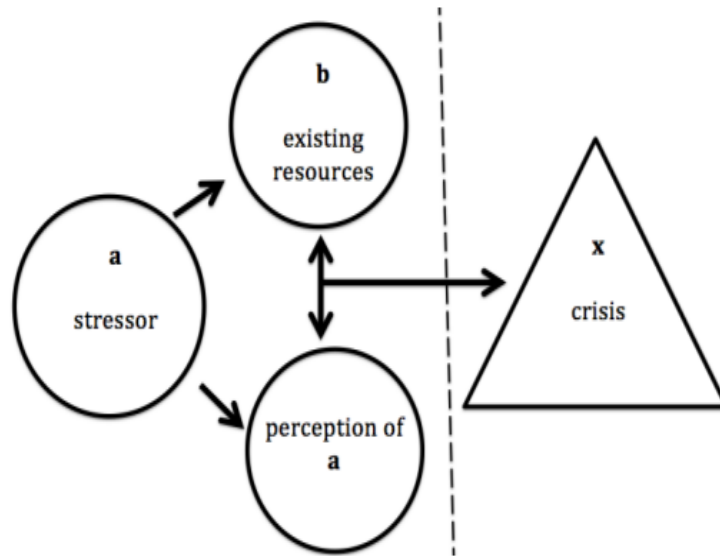


Figure 1: ABC-X Model by Hill (1949)

### 2.8.1 The A Factor (The Stressor Event)

According to Rosino (2016), a stressor event is defined as an occurrence, positive or negative, that changes the family or has the potential to change the family system. They can be generated internally or externally. Those that are generated internally can be managed by the family, while the externals are situations beyond the control of the family. Boss *et al.* (2016) grouped the stressors into three main categories, namely: normative or non-normative, ambiguous stressor events, as well as volitional and non-volitional stressor. The normative stressor events are events which can be foreseen and sometimes tend to be traditionally expected. Normative stressors hardly end up in crises since they are, somehow, anticipated by families. However, the non-normative stressors come unexpectedly, and hence, could be difficult to handle (Boss *et al.*, 2016). An example is a preterm birth. Another type of stressor event is the ambiguous stressor events, where families are not able to give meaning to what is happening and do not know when it will end (Boss *et al.*, 2016). For instance, the case of a preterm birth where the

family is unable to tell what exactly is happening and remain uncertain about the survival of the baby. It goes a long way to affect how they cope, unlike when the issues surrounding the stressor event are clear, and hence, making it possible for families to identify needs and resources that will help them cope better (Boss *et al.*, 2016).

Finally, there are the volitional and non-volitional stressor events. A volitional stressor event is one which is caused by the family –that is, they willingly made the situation occur, therefore, they have an upper hand in dealing with it. The non-volitional events are those that families do not have control over; they come by surprise (Boss *et al.*, 2016). An example is the case of a preterm, where families do not expect such, and hence are taken by surprise. The non-normative, ambiguous and non-volitional stressor increase families' stress and make them prone to crises if not handled well. Preterm birth falls under these types of stressors, and as proven by research, turns out very stressful, for both mothers and the entire family.

Also, stressor events can be classified according to specific durations– that is, whether the stressor event will continue for a while or last for a short period. Either of them may lead to chronic or acute stress for the family (Boss *et al.*, 2016). Preterm birth is associated with lifelong complications and developmental delays which can be a source of chronic stress to families and drain resources. Even with that, the outcome might not change but families have to live with the effects of the condition. For families whose preterm infants have manageable complications and can be treated at the NICU, the event is a short time. Again, stressors can be grouped according to their density (Boss *et al.*, 2016), based on whether the stress event is in isolation or coupled with other events. If other events occur at the same time, it increases the stress level as compared to dealing with just one stress event (Boss *et al.*, 2016). In this instance, preterm birth comes with different stressors which tend to make dealing with it a bit more complex.

### 2.8.2 *The B factor (Resources)*

Resources are materials at the family's disposal that help prevent families from being stuck in the crises. It helps families in solving the issue at hand, and gives them a better coping strategy (McCubbin & Patterson, 1983 cited in Rosino, 2016). For a family to go through a stressful event such as preterm birth, some resources are very important. These include family resources (adaptability, wealth, and many others) and community resources (Rosino, 2016)

A family resource such as adaptability is an important resource to help manage stressful events. Adaptability is the family's ability to remain calm in a stressful situation and adjust to the event if it requires change (Hobfoll & Spielberger, 2003 cited in Prawitz *et al.*, 2013). It enables family members to go through that process of change successfully. In a situation of preterm birth, families who have the resource of adaptability can change jobs, if possible, to help care for the baby. Families that are unable to change as a result of holding on to strict and traditional ways of doing things might experience a dysfunction. For example, in a research conducted by Suraju (2013), a respondent complained of other children not ready to adapt to the shift of attention to the preterm baby. As a result, their performance in school was negatively affected, and in effect, that became a source of stress for their parents.

Another useful resource is communication. This is when family members can express feelings and thoughts adequately for the intended meaning to be well-understood (Hobfoll & Spielberger, 2003 cited in Prawitz *et al.*, 2013). Communication helps families to share feelings and moments of difficulties so that there can be mutual support.

Community resources, though not owned by families, are available to the families. They include religious groups, governmental institutions and social support (McKenry & Price, 2005 cited in Kong & Jeon, 2018). Social support is a key resource that helps prevent the breakdown of families as they go through crises. McCubbin & Patterson (1983) cited in Rosino, (2016)

define social support as an "interpersonal relationship between families and other people outside the family unit". Social groups provide three main forms of support. They are emotional support, esteem support, and networking (that is, giving a sense of belonging to the family members in order not to make them feel burdened with whatever crises they experience). These resources, when available to the family, can help them pull out successfully in stressful events like preterm birth.

### **2.8.3 The C factor (Meanings)**

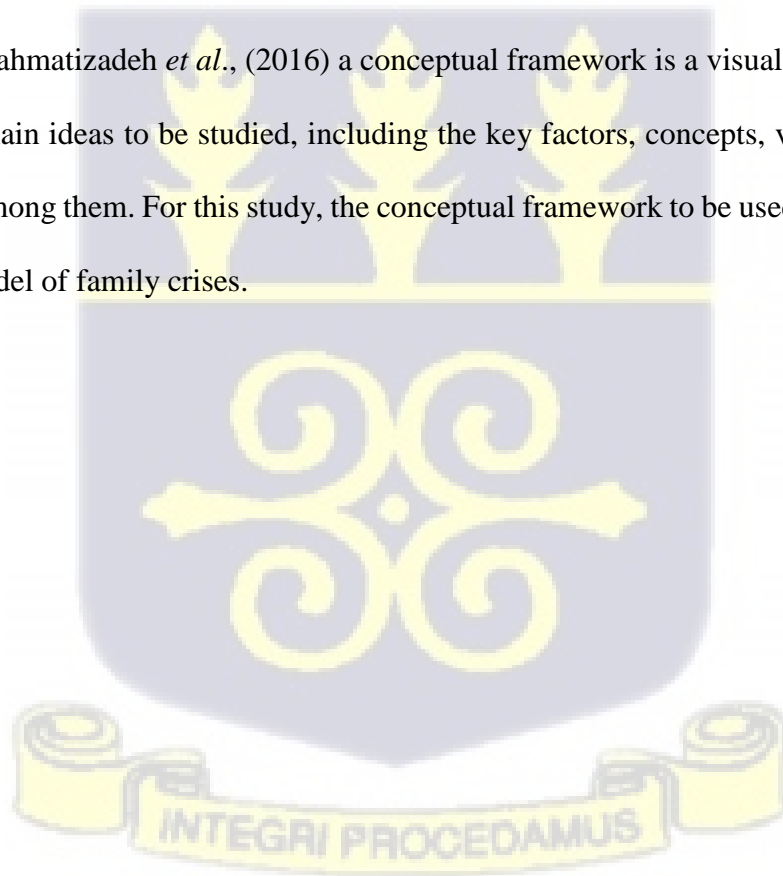
It refers to families' perception of crises which comes their way and the views they form concerning the situation, as they interact with one another. According to Hill (1958) cited in Rosino, (2016), the meanings which family members attach to stressful events are as a result of the family values they hold on to, their past definitions, and experiences used in dealing with crises. Patterson (2002) cited in Boss, (2016) also came with an idea that families organize perceptions about the stressors, their identity as a unit, and their world view. Each family has its definition of what is a stressful event. For one family, a preterm birth may not be a very stressful event, especially if they have already experienced it. However, some families may find preterm birth very stressful even when they have experienced it before. The definitions families give to the event at hand tell if it would be stressful condition or not (McKenry & Price, 2005 cited in Kong & Jeon, 2018). Families that have mastered the act of overcoming challenges adjust easily to stressful situations, hence, less likely to cause a breakdown of the family unit. Families who have a positive world view are more able to cope and adapt to their stressful event (Madden-Derdich & Herzog, 2005 cited in Boss, 2016).

#### **2.8.4 The X factor (Outcome)**

When a stressful event pulls more resources from a family such that it affects roles, the family then faces crises (Hill, 1958 cited in Rosino, 2016). The outcome of a stressful event occurs in a continuum – that is, from maladaptation to bon-adaptation to the positive. Maladaptation is a process where families are unable to merge stress events and their ability to meet that event, while bon-adaptation is the family’s ability to see the difference between the stress and how they would be able to meet the demands of the stressful situation. The resources at the family’s disposal and meaning they attach to the event they experience can help them either pull out of or enter into crises.

### **2.9 Conceptual Framework**

According to Rahmatizadeh *et al.*, (2016) a conceptual framework is a visual presentation that describes the main ideas to be studied, including the key factors, concepts, variables, and the relationships among them. For this study, the conceptual framework to be used is adopted from the ABC-X model of family crises.



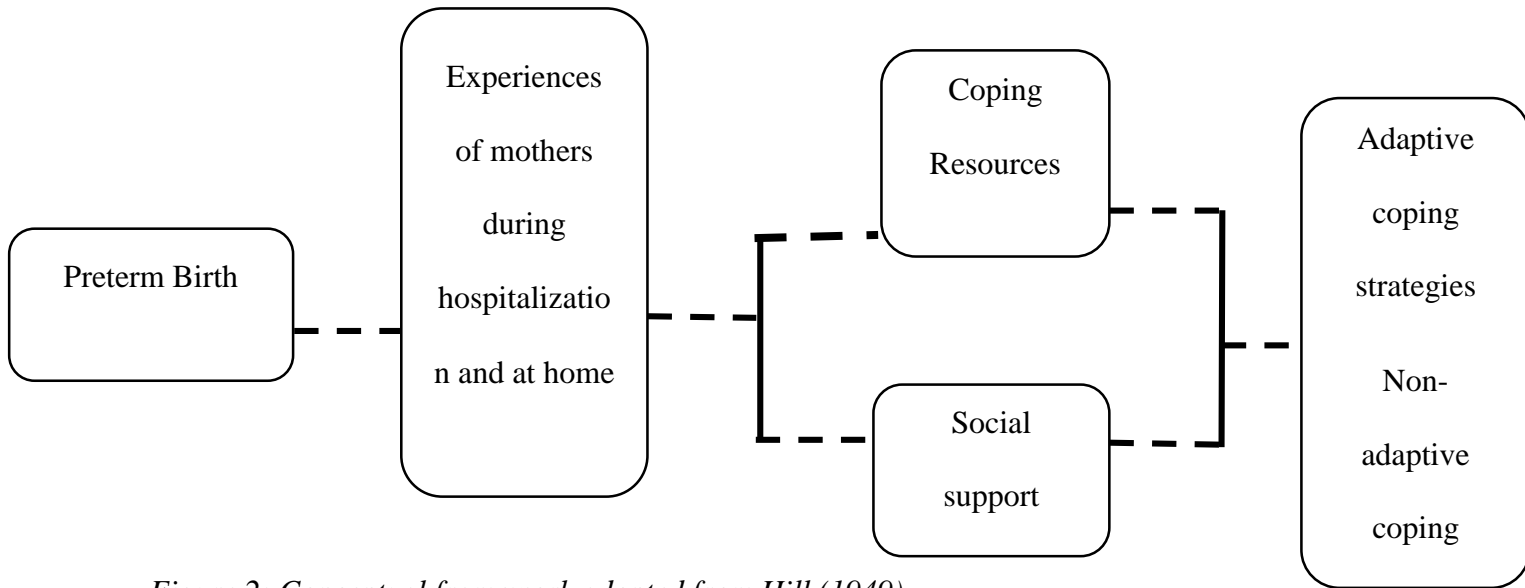


Figure 2: Conceptual framework adopted from Hill (1949)

### 2.10 Conceptual Framework Explained

From the conceptual framework, it is assumed that preterm birth could lead to challenging experiences as explained in literature (e.g. Boykova, 2016; Garti *et al.*, 2021; Green *et al.*, 2021). These experiences require certain resources to manage them. It is also assumed that the available resources if managed adequately could result in adaptive coping strategies. On the other hand, if the resources are difficult to come by, could lead to non-adaptive coping strategies and put families with preterm into a maladaptation as explained in the theory. The broken lines signifies that the relationships are abstract and yet to be established.

### 2.11 Summary

From the above concepts and theories discussed, it has been noted that, parents with preterm children experience a great deal of stress. In order to navigate through the stressors, the available and utilization of resources at the disposal of the preterm parents remain significant. Also, families are able to settle on a coping strategy based on the resources available to them.

## CHAPTER THREE

### 3.0 METHODOLOGY

This chapter focuses on the study design, the study location, and the target population for the study. It also discusses the sampling technique, the data collection instruments and procedures, data analysis and presentation, and methodological rigour of the current study.

#### 3.1 Study Design

A research design is a plan that describes how, when and where data are collected and analyzed (Creswell, 2014). This study employed a qualitative approach using exploratory-descriptive design. This approach helps to uncover the details of events or experiences of parents with preterm babies (Hunter *et al.*, 2018). This also allows researchers in analyzing and interpreting rarely evaluated phenomena. This helped researcher investigate the descriptive experiences of parents with preterm birth and resources they used to cope. A qualitative approach allowed the researcher to explore details of parents' experiences during hospitalization and at home, resources they employed as coping strategies for preterm infants, and the support systems they had to ease their burdens. Also, because limited studies have been done concerning coping resources available to parents with preterm children, the approach was useful in exploring such areas (Austin & Sutton, 2014).

#### 3.2 Study Location

The study location was the Department of Child Health at the Korle-Bu Teaching Hospital (KBTH). KBTH was set up in October 1923 and currently the largest teaching hospital in

Ghana and the 3<sup>rd</sup> largest in Africa (Suraju, 2013). It is in the Ablekuma South Sub-Metro District, and approximately 0.5km after the Korle-Lagoon. It has affiliations with the University of Ghana Medical School and the major referral centre in Ghana (Suraju, 2013). KBTH has several units. Some are Medicine, Child Health, Surgery, Emergency unit, Pathology, and many others. The Department of Child Health was established in 1964 under the leadership of Dr. Susan De-Graft Johnson (Taylor, 2017). The unit runs specialty clinics which include Neonatal follow-up clinics on Fridays (Taylor, 2017). Parents with discharged preterm infants attend this clinic (Suraju, 2013). Again, KBTH was chosen because they had enough facilities and resources that take care of preterm babies. Therefore, most preterm cases are referred there.

### **3.3 Target Population**

The target population refers to the total set of entities for which data is used to make inferences (Lavrakas, 2008 cited in Malenya *et al.*, 2017). The target population was all parents who had delivered preterm infants, cared for at the NICU, and attended the Neonatal follow-up clinic at KBTH. The infants chosen were between three to 18 months old. The choice of target population was mainly due to time factor. As more time passes, people easily forget vital details of various happenings. Hence, mothers of such fairly younger infants were more likely to easily recall and give vivid account of their experiences with the preterm birth.

### **3.4 Inclusion Criteria**

Parents at age 18 and above, with preterm infants within three to 18 months old, discharged from the NICU, attended Neonatal follow-ups at the department of child health (KBTH) and could speak English were qualified to be included in the study. This is because by the third

months, most infants would have been discharged, while their mothers as well would have gained some caregiving experiences at home. The parents were required to be 18 years and above, because the focus of the study was on adults, not adolescents. They were also expected to be proficient in English, that is, the proficient language of the researcher.

### **3.5 Exclusion Criteria**

Parents with infants who were still on admission at the NICU, those below 18 years, and those who could not speak English were not included in the study. This is because the study focus was not on adolescents, and those who were still on admission did not have any post-NICU experience. Language would be a barrier if respondents could not speak English.

### **3.6 Sample Size**

Sampling is choosing a part of a population to obtain information or learn something from the population (Taylor, 2005 cited in Farrokhi, & Mahmoudi-Hamidabad, 2012). The sample size refers to the number of entities that are chosen from a population from which data is collected (Lavrakas, 2008 cited in Dumicic, 2011). Appropriate sample size must be employed in the selection of respondents for the study. The sample size for this study was determined based on the research design, objectives of the study, and the point of saturation.

Adler and Adler (2012) recommended that, for a qualitative study, a sample size of 12 and sixty participants can be used, hence, a total of 19 mothers were used for the study. At the point of saturation, 19 mothers had been interviewed for the current study. These 19 mothers were 18 years and above, and delivered preterm infants, admitted at the NICU, discharged and attended neonatal follow-ups at KBTH. They had preterm infants between the ages of three and 18 months and were willing to offer information for the study.

### **3.7 Sampling Technique**

A purposive sampling technique was used to recruit participants for the study. Purposive sampling is a non-probability sampling technique that involves identifying and selecting individuals or respondents based on their experience about the phenomenon of interest (Cresswell & Clark, 2011). Mothers were selected based on having delivered a preterm baby, admitted at the NICU and have been discharged, yet attend NICU clinic for review.

### **3.8 Data Collection Instrument**

An interview guide was used to collect data. An interview allows the researcher to get detailed experiences of other people and the meanings they attach to their experiences (Seidman, 2006 cited in McGehee, 2012). A semi-structured interview guide was used for the study. The semi-structured nature of the interview guide allowed the researcher plan around a group of open-ended ideas.

#### ***3.8.1 Instrument for Data Collection***

A semi-structured interview guide with open-ended questions, based on research objectives, was used. The interview guide had sections on;

Section 1: Demographics e.g. Age, Gender of parent, Educational Level, Number of other children

Section 2: Some experiences with preterm birth, e.g., tell me about your experiences with having a preterm child. How was the family's reaction when they first learnt that the baby was premature?

Section 3: Challenges being faced at home, e.g. what have been some of the challenges associated with parenting a preterm baby at home?

Section 4: Coping with baby at home, e.g. what things (resources) have helped you cope with parenting a preterm?

Section 5: Support systems available to family, e.g. after discharge whom or where did you turn for support?

Adapted from (Suraju, 2013; Carrion *et al.*, 2016; Kelly, 2016)

### **3.8.2 Pre-test**

The interview guide was pre-tested with five mothers in the Greater Accra Regional Hospital (GARH). The choice of hospital was due to the fact that GARH has NICU and a child health service (Aseidu *et al.*, 2019). The pre-test interviews lasted between 20 to 40 minutes. It helped the researcher to confirm the clarity of questions. It also helped practice and improve interviewing skills before the actual data collection. From the pre-test, the researcher realized that some of the questions needed to be merged and others taken out.

### **3.9 Ethical Consideration**

In scientific research where humans are used as participants, certain cautions must be exercised to ensure the protection of rights. For this reason, ethical approval for the study was sought from the College of Basic and Applied Sciences Review Board and the KBTH Institutional Review Board. An introductory letter from the KBTH Institutional Review Board was sent to the Head of the Department of Child Health to obtain permission in recruiting participants from the NICU clinic. An explanation of the study concerning the purpose, objectives, specific

expectation concerning participation, as well as potential costs and benefits were provided to the participants in order to seek their voluntary consent. Participants were assured of the confidentiality in the collection of data. They were assured that their privacy would be protected using pseudo-names on the demographic data, in order for them not to be identified. Additionally, they were informed of the right to withdraw from the study at any time without specification of reason. They were further assured that, their refusal or withdrawal will not in any way affect the care they were receiving from the KBTH. Participants were assured that all COVID-19 protocols would be observed. The tape and the transcribed information are stored under lock and are accessible by only the researcher and the supervisors.

### **3.10 Procedure for Data Collection**

After ethical clearance had been obtained, and an introductory letter sent to the Department of Child Health, permission was sought from the Head of Department of the Child Health Unit, the NICU in-charge nursing officer and the Matron in charge of the NICU clinic. The researcher then introduced herself to the nurse who oversees the NICU clinic, and she in turn introduced the researcher to the mothers with preterm infants. Mothers who were willing to share how they cope with parenting a preterm baby were recruited with the help of the NICU clinic nurse after they had been informed about the purpose of the study. They were given the participant information sheet to read. Those who willingly agreed to take part in the study were asked to sign consent forms. The data was collected from mothers with preterm infants who fell within the inclusion criteria, because the fathers were not willing to participate in the interviews. Mothers who agreed to participate in the research were interviewed face-to-face before their clinical sessions at a designated place in the hospital which was assigned to the researcher. An interview guide was used to collect data. Interviews lasted between 25 to 45 minutes. Data was collected using an audio recorder per the permission of the participants.

### **3.11 Data Analysis and Presentation**

In a qualitative study, data analysis occurs concurrently with data collection, hence, thematic content analysis was used to analyse data. Thematic content analysis is a descriptive presentation of qualitative data (Anderson, 2007 as cited in Aarah-Bapuah, (2015). This involves observing the transcribed data to classify themes that sums up all the views collected (Anderson, 2007 as cited in Aarah-Bapuah, (2015). Recorded audio from the interview were transcribed verbatim. Verbatim transcription was useful to ensure that data was not lost. The researcher first read through the transcripts and read over again to get familiar with the data. Similar codes that were identified were categorized and re-categorized as the study progressed. Sub-groups were named and grouped under predetermined themes. The predetermined themes were: mothers' experiences during hospitalization, mothers' post-NICU experiences, coping resources parents used and support systems. 17 sub-themes emerged from the interviews conducted

During the review of literature, it was realized that most literature on preterm birth had similar themes (Baía *et al.*, 2016; Suraju 2013; Velit & Akum, 2018). The themes that were highlighted in such studies included experiences regarding preterm caretaking at either NICU or home, challenges mothers faced, and various coping strategies. This study therefore adopted predetermined themes similar with the aforementioned. Data was coded manually by the researcher and presented using tables where appropriate. Quotes from respondents were added to support discussions

### **3.12 Methodological Rigour**

Methodological rigour is a way researchers determine integrity and authenticity of a qualitative research process (Prion & Adamson, 2014). Rigour is essential to help render the research work

true and worth contributing to knowledge. Therefore, trustworthiness is seen as a more appropriate way for evaluating a qualitative study using four main criteria. These are credibility, dependability, transferability and confirmability (Lincoln & Guba, 1985 cited in Cope, 2014). The researcher demonstrated trustworthiness in this regard.

Credibility ensures that the study actually measures the intended purpose and that, the results of the study accurately reflect the social reality of the participants (Maher *et al.*, 2018). Credibility was achieved by giving the respondents enough time to describe their experiences with the preterm birth and resources they used to cope, allowing them to share their in-depth understanding of the subject under study. During the interviews, the researcher repeated some phrases cited by the respondents so that they could explain what they really meant. As a result, the researcher ensured that the realities of how the respondents discharged from NICU coped with their preterm infants at home using available resources were carefully represented.

Transferability refers to the ability of qualitative study to be transferred to another context (Maher *et al.*, 2018). Most qualitative studies are context-specific; hence, findings might not be transferable. However, similar results can be obtained (Maher *et al.*, 2018). The researcher provided a detailed outline of methodology to help others produce similar findings should they apply the same method.

Furthermore, dependability is when the study process describes sufficient details to help another researcher repeat the work (Maher *et al.*, 2018). This was achieved as research provided a logical, traceable and clearly documented process of research work. Therefore, other researchers can access documents of the current study to produce a replica of the study.

Lastly, confirmability is concerned with proving that data and interpretation of results are not made up of researcher's thoughts, ideas and perceptions but mainly obtained from respondents (Polit & Beck, 2012). The researcher achieved this by keeping an audit trail of audiotapes, field

notes, transcripts, interview questions, consent forms, and all other relevant documents regarding the study. These will be made available for any future auditing of the study for confirmatory purposes.

### **3.13 Limitation of the Study**

The limitations of the study were;

1. The main target population were parents; however, only mothers participated in the study. This is because when the fathers were approached, they said the mothers were mostly with the infants and would be in a better position to give detailed descriptions of what happened. However, this challenge is not enough to refute the valuable contributions this study has made to knowledge.
2. There is limited literature on coping resources parents used in preterm care especially in developing countries like Ghana.

### **3.14 Conclusion**

This chapter looked at the methodology for the study. The study adopted a qualitative approach using exploratory descriptive design. The study location was KBTH, specifically the Child Health Unit in the Greater Accra Region of Ghana. The target population was parents with preterm infants between three to 18 months, who have been discharged from the NICU and attending NICU clinics for reviews. An interview guide was used to collect data from respondents and data was analysed manually. Four themes were discussed, and 17 sub-themes emerged from transcribed data.

## CHAPTER FOUR

### 4.0 RESULTS AND DISCUSSION

#### 4.1 Introduction

This chapter presents the findings, interpretation of the findings, and discussions of the data collected from 19 participants. The findings of the study sought to investigate the coping resources parents with preterm infants use in Accra and also answer the following research questions;

- a) What are the experiences parents with preterm infants have when hospitalized and at home?
- b) How do parents use resources available to them to cope with preterm care?
- c) What are the support systems parents had in caring for their preterm infants?

The findings are categorized under the following themes: demographic characteristics of participants, mothers' experiences during hospitalization, mothers' post-NICU experiences, and coping resources and support systems available to parents, considering the ABC-X model of family crises (Hill, 1949).

#### 4.2 Demographic Characteristics

The demographic characteristics of the participants are presented under the following sub-headings: age, occupation, educational background, number of children, gestational age, infants birth weight, and infants' gender. Table 1 below presents the demographic characteristics of 19 mothers who were interviewed.

**Table 1: Demographic characteristics of participants**

Characteristics	Frequency
<b>Mothers' Age*</b>	
20-24	1
25-29	2
30-34	7
35 and above	9
<b>Mothers' Educational Levels*</b>	
Junior High School	2
Senior High School	7
Tertiary	10
<b>Mothers' Employment Status*</b>	
Not working	2
Self-employed	7
Formal employment	7
Students	3
<b>Number of other Children*</b>	
None	8
1- 2	4
3 and above	7
<b>Infants' Gestational Age*</b>	
Extremely preterm (< 28weeks)	0
Very preterm (28-32 weeks)	13
Moderately preterm (33-36 weeks)	6
<b>Infants' birth weight**</b>	
Low birth weight (< 2.5kg)	12
Very low birth weight (<1.5kg)	10
Extremely low birth weight (< 1kg)	0
<b>Gender of infants**</b>	
Male	10
Female	12

\* Total number of mothers who participated in the study = 19

\*\*Total number of children of the mothers =22

#### **4.2.1 Mothers' Age**

The participants in this study were aged 23 to 46 with a mean age of 34.05 years. Majority of the mothers (nine) were 35 years and above. According Goisis *et al.* (2017), women within that age range are considered advanced maternal age women. Such women are highly at risk of having preterm infants (Goisis *et al.*, 2017). Other research (e.g., Carolan & Frankowska, 2011; Blenconwe *et al.*, 2013) similarly showed a positive relationship between advanced maternal age and the risk of preterm delivery.

However, research by Saloojee & Coovadia, (2005) cited in Goisis *et al.*, (2017) which was conducted in Finland revealed otherwise. In their study they found that advanced maternal age was not directly linked to the mother's chances of giving birth to a preterm baby. The findings of that study (Saloojee & Coovadia, 2005 cited in Goisis *et al.*, 2017) are consistent with this current study because high blood pressure was identified as the main cause of preterm birth among the women interviewed – including women at advanced maternal age and below.

#### **4.2.2 Mothers' level of education and occupation**

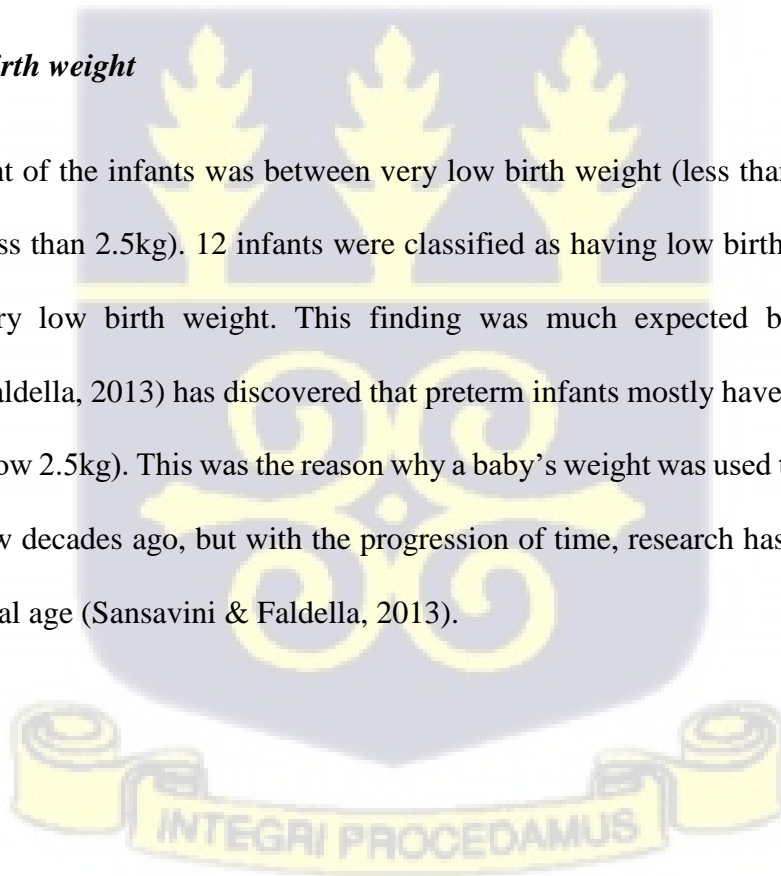
With regard to education, two of the mothers were Junior High School graduates, seven were Senior High School Graduates, and 10 were degree holders. Therefore, all 19 participants were literates. Even though most of the mothers (14) were employed at the time of the interview, only six had started working and the students among the participants had deferred their program due to the preterm birth. This is similar with the findings of Lakshmanan *et al.* (2017) who mentioned that some mothers had to put their job on hold to get time for the baby.

#### **4.2.3 Gestational age of the pregnancy**

The preterm infants are categorized according to the weeks of pregnancy before delivery. They are; moderately preterm (33 to 36 weeks), very preterm (28 to 35 weeks), and extremely preterm (28 weeks and below) [WHO, 2012]. Gestational ages of infants in the current study ranged between 28 and 36 weeks. 13 participants had their infants being very preterm (28 to 32 weeks) and six of them were moderately preterm (33 to 36 weeks). Global studies (e.g., Adu-Bonsaffoh *et al.*, 2019; Howson *et al.*, 2013) on preterm birth showed that most infants are more likely to be moderately preterm. However, findings in the current study showed that most of the infants were very preterm. The factors that might have accounted for this were not covered in the current study.

#### **4.2.4 Babies' birth weight**

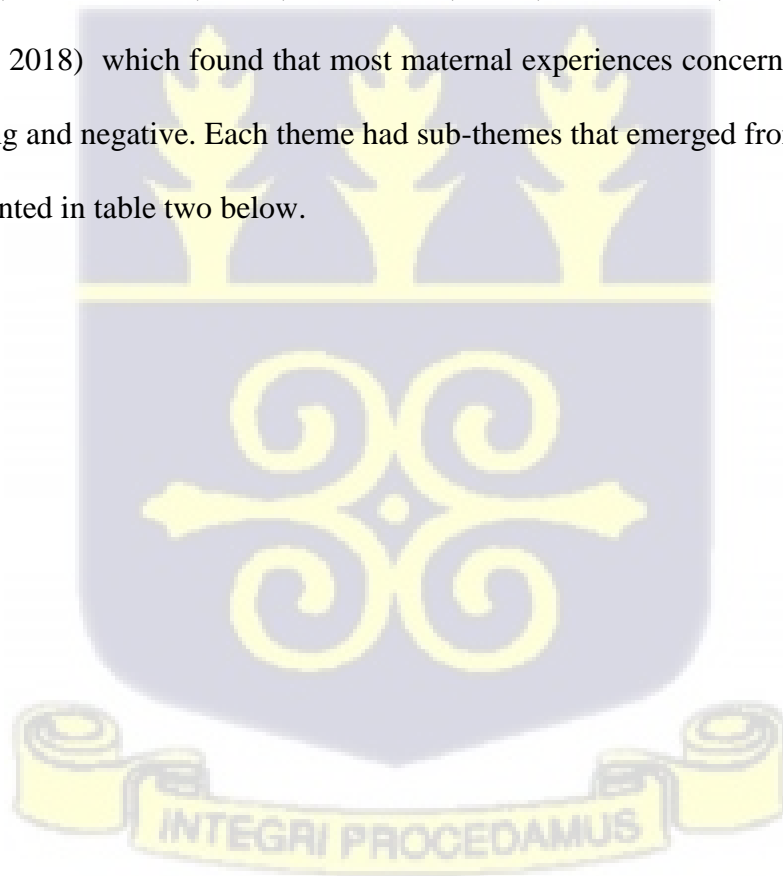
The birth weight of the infants was between very low birth weight (less than 1.5kg) and low birth weight (less than 2.5kg). 12 infants were classified as having low birth weight and nine infants had very low birth weight. This finding was much expected because literature (Sansavini & Faldella, 2013) has discovered that preterm infants mostly have low birth weight (i.e., weight below 2.5kg). This was the reason why a baby's weight was used to classify infants as preterm a few decades ago, but with the progression of time, research has improved to the use of gestational age (Sansavini & Faldella, 2013).



#### **4.2.5 Delivery outcomes**

Two out of the 19 mothers had multiple births<sup>1</sup> and the rest had single births. Eight of the mothers had given birth for the first time, and the outcome of that pregnancy was a preterm baby, while 11 of the mothers have had children already.

The findings of the study which were obtained from 19 participants were grouped under four main themes, namely; mothers' experiences during hospitalization, mothers' post-NICU experiences, coping resources, and social support available to mothers. The experiences shared by mothers indicated the overwhelming challenges and burdens they experienced at each stage of their journey with preterm birth. These findings are consistent with other studies (e.g. Boykova, 2016; Fowler *et al.*, 2019; Garti *et al.*, 2021; Green *et al.*, 2021; Taylor, 2016; Trumello *et al.*, 2018) which found that most maternal experiences concerning preterm birth were challenging and negative. Each theme had sub-themes that emerged from the interviews. These are presented in table two below.

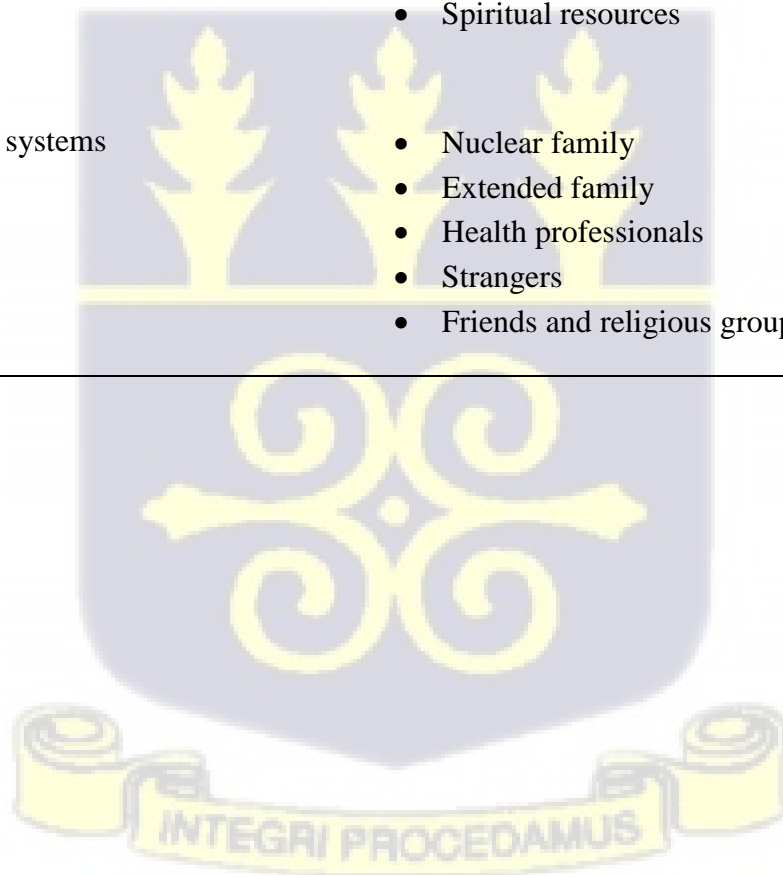


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<sup>1</sup> Multiple births are births with multiple outcomes such as twins and triplets

**Table 2: Major themes and their corresponding sub-themes**

Themes	Sub-themes
Mothers' experiences during hospitalization	<ul style="list-style-type: none"> <li>• Mothers' experience at NICU</li> <li>• Reaction from the family</li> </ul>
Mothers' post-NICU experiences	<ul style="list-style-type: none"> <li>• Baby's health at home</li> <li>• Variations in parental care roles</li> <li>• Underdeveloped body organs of infants</li> <li>• Inadequate resources</li> <li>• Preterm care and work</li> <li>• Differences with families about infants' needs</li> </ul>
Coping resources	<ul style="list-style-type: none"> <li>• Time resource</li> <li>• Emotional resources</li> <li>• Material resources</li> <li>• Spiritual resources</li> </ul>
Social support systems	<ul style="list-style-type: none"> <li>• Nuclear family</li> <li>• Extended family</li> <li>• Health professionals</li> <li>• Strangers</li> <li>• Friends and religious groups</li> </ul>



### 4.3 Mothers' Experiences during Hospitalisation

This section focuses on mothers' experiences at the NICU and families' reaction to the preterm births when infants were still on admission.

#### 4.3.1 Experiences of Mothers at NICU

Mothers with preterm infants explained their many experiences right after their preterm birth, especially at the NICU. Their infants tend to be labelled as high-risk newborns (Suraju, 2013). Such children are vulnerable to infections and have low survival chances (Suraju, 2013). Most often, the infants are hospitalized at the Neonatal Intensive Care Unit (NICU) where they are sustained in an incubator with respiratory and nutritional support systems (Blencowe *et al.*, 2013). At the NICU, mothers expressed how they form their experiences from factors such as the unexpected baby's size; medical procedures, uncertainty of infants' survival, family's reaction, among others. These factors and many more tend to traumatize mothers right from the birth of preterm infants. For this study, the researcher analyzed the factors that formed mothers' experiences.

##### 4.3.1.1 Unexpected long stay at the NICU

Every mother's expectation is to go home shortly after delivery of their baby. With preterm birth, however, there is a prolonged stay. All the 21 infants were admitted to the NICU, immediately after delivery. Most mothers expressed how stressful that was for them.

Describing her frustration, a mother said:

"It wasn't easy... we slept in NICU for two months... for cry, I have cried" (P8, 37years, 30 weeks)<sup>2</sup>.

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<sup>2</sup> **P** represent participant code; **years** relates the participants age at the time of the interview; **weeks** refer to the duration of pregnancy

Another mother lamented:

“They were taken to the NICU and actually we suffered there...right from the delivery room... I didn't even see their faces; they took them to the NICU” (P3, 31years, 31 weeks).

Most often, preterm infants are admitted at the NICU for adequate health monitoring, to help ensure their survival. It is usually an unexpected event for these mothers as shared by them. They narrated how it led to emotional loss and shock for them, such that they resorted to crying as an outlet for letting out frustration. According to Santos *et al.* (2015), the environmental factors at the NICU affect preterm infants' physiological and psychological developments, hence cause infants to stay at the NICU for a longer period . For example, loud noises from equipment in the NICU can lead to negative physiological effect on the baby such as increased heart rate, sleep apnea, increased blood pressure, decreased oxygen saturation, among others, affecting their mothers' emotional health.

#### 4.3.1.2 Uncertainty of baby's survival

Despite the long stay at the NICU, the mothers revealed that there was no certainty of survival of their infants. Most of the infants relied on life support machines for survival due to undeveloped respiratory system (Aagaard *et al.*, 2015; Sorte, 2018). Literature (Tamene *et al.*, 2020) has it that, Africa has the poorest survival rates of preterm in the world, and the preterm infants are 13 times likely to die as compared to full-term infants. The fears of child loss added up to the mothers' stress as characterized in their comments, some of which are shared below.

For example, a mother shared her experiences of seeing others lose their infants:

... I saw it with my eyes how a baby close to my [twin] kids died, and they wrapped him and then the next day another baby closer to my kids died again.... I was going mad, what will happen to my infants (P3, 31years, 31weeks, emphasis added).

A mother also commented,

“The doctors were not giving us good assurances of whether they will survive or not”  
(P19, 29years, 31weeks).

The comments from the participants highlighted the psychological threats that mothers deal with, in addition to the physical inconveniences of a preterm birth. They seemed very concerned when they saw other mothers lose their infants. The respondents described how they felt helpless, powerless, and uncertain of their infants’ survival as they witnessed what was happening to others at the NICU. Misund *et al.* (2014) cautioned that this experience, if not handled well, could lead to psychological disorders such as maternal depression (which often lasts the first year of post-delivery) and other mental disorders in the long term.

According to WHO (2018), over half of neonatal deaths are attributed to preterm birth and its associated complications, giving these infants less likelihood of existence. A study conducted at the Tamale Teaching Hospital (Ghana) by Abdul-Mumin *et al.* (2021) discovered that out of the 8,377 preterm infants that were admitted to the NICU, 1,126 died. These deaths were due to complications arising from preterm births. Another study conducted in Ethiopia by Tamene *et al.* (2020), also discovered that the low chances of survival of preterm infants could be attributed to poor quality of care in hospitals. Even though they identified conditions such as respiratory distress syndrome, sepsis and necrotizing enterocolitis accounting for 71% of the deaths at the NICU, they argued that, those deaths could have been prevented if there were available resources such as oxygen plantation at the NICU.



#### 4.3.1.3 Unmet expectations on baby's appearance

Mothers shared some experiences with regard to the preterm baby's appearance at the NICU. Pregnant women traditionally expect to have a plump baby when delivered (Nukunya, 2003 as cited in Suraju, 2013), however preterm infants are exceptional. Preterm or unexpected infants, by their physiology, look fragile and may appear unattractive compared to full-term infants (Ionio *et al.*, 2017). They often appear very small. Almost all the mothers (18) in this study stated how terrified they were with their infants, and yet, doctors had to perform procedures on them as they would on full-term plump infants.

A mother shared her experience:

If you haven't experienced some before, it can be terrifying for you as a mother. Looking at how the baby is tiny and if they want blood sample, they will take ...which they do more often... This baby's veins are very small, very tiny, you can't even see it. They have to be piercing until they get it. Those are some of the things that make the parent sorrowful a bit (P14, 38 years, 28 weeks).

A mother also stated:

"I didn't know people give birth for the infants to be tiny like that" (P1, 31 years, 34 weeks).

The mothers described how the appearances of their infants surprised them, probably influenced by their cultural expectations of how new-borns must look. Hence, they turned out disappointed and discouraged when their preterm infants fall short of their expectation. A study conducted in Portugal posits that, baby's size increases stress levels in parents, with the greater effect on mothers than fathers (Baía *et al.*, 2016). The respondents in this study confirmed how emotionally stressed they became as medical procedures were being performed on their infants. They were gripped with fear and anxiety. Their narratives signalled tough and incredulous moments for mothers at the NICU, as expressed in comments below.

“It was quite traumatic and difficult for us” (P19, 29 years, 31 weeks).

Preterm birth is described as a traumatic and stressful event for families, especially mothers (Baía *et al.*, 2016; Ionio *et al.*, 2016; Schappin *et al.*, 2013), and poses some threats to the health of these mothers (Lefkowitz *et al.*, 2010 as cited in Ionia *et al.*, 2016). They have to deal with their loss of hope in giving birth to a full-term baby (Mendelsohn, 2005 as cited in Baía *et al.*, 2016), coupled with inconsistencies in their infants’ response to treatment at the NICU and the unattractive appearance of the infants (Baía *et al.*, 2016). It tends to make mothers feel guilty and blame themselves for bringing such sufferings on their infants (Flacking *et al.*, 2012; Griffin & Pickler, 2011). Also, the NICU environment, medical procedures, and constant loss of lives of other infants, explained by the mothers, increased their emotional burdens during the hospitalization period. This is consistent with the findings of Lean *et al.* (2018) who opine that, mothers feel helpless in their desire to protect their preterm infants from medical procedures.

#### **4.3.1.4 Disorganized family resources**

The mothers described how resources became limited due to the fact that they had never envisioned a preterm birth and its associated costs (Howe *et al.*, 2014; Ionio *et al.*, 2016). Hence, there was little or poor planning at the time of delivery of the preterm baby. However, an antenatal clinic was instituted to educate pregnant women and their families on pregnancy-related issues so that they are properly prepped for eventualities (UNICEF, 2021). This study did not examine whether mothers of the preterm infants attended the clinic or not. Nevertheless, it was evident that all the mothers (19) were not prepared for the preterm event.

For example, a mother narrated:

I just woke up one Thursday, feeling some pains, abdominal pains, thinking that it was a normal pain so I need to see the doctor for medications. I just took paracetamol at home, and then on Friday morning, the pains were still severe. I needed to come to the hospital. When they examined me, they said it was labour... I had to call my family for them to bring my luggage and things because I was going to the labour ward... I didn't feel happy because my time was not due... (P3, 31 years, 31 weeks).

Nearly half of the mothers (eight) expressed how the unexpected delivery they experienced made them feel everything was out of order. This led to a disruption in their lives and took a toll on their families and their resources. A 31-year-old mother with a very preterm baby<sup>3</sup> expressed quite wryly:

“It wasn't easy at all because we didn't anticipate that. So, everything becomes disorganized” (P16, 31years, 30weeks).

Mothers, after birth, often anticipated taking their infants home after delivery only to be told that the baby would be admitted, hence, leaving their expectations thwarted. The suddenness of the event often makes them disorganized, as they must draw resources from unplanned sources to care for the baby at the NICU. For example, a 31-year-old mother narrated how much she had to spend on acquiring oxygen for the baby. The oxygen cost GHs 10 per hour and the baby was put on oxygen for one month three weeks totalling GHs 11,760. This cost did not include NICU facility bills, medication, laboratory tests, among others.

She narrated:

...the baby was on oxygen for one month three weeks, that one too every hour is 10 cedis. If you calculate then a day is 240 cedis multiply by 30 days then, three weeks.... I was also buying some drugs which were about 180 cedis, and the baby needs it every 14 days so we were hitting over 13,000... (P8, 37years, 30 weeks).

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<sup>3</sup> infants who were born within 28 and 32 weeks of pregnancy

In Ghana, there is the Free Maternal Health Care Policy where pregnant women enrolled on the NHIS have premium access to free comprehensive maternal healthcare up to three months post-delivery (Azaare *et al.*, 2020). The mothers however expressed the huge cost the birth of the baby posed on the families' income. This was as a result of NICU cost that was not covered by NHIS, such as baby on life support systems, frequent laboratory tests, transportation cost, among others. All these inconveniences, as indicated by the mothers, put unexpected pressure on their resources. They were forced to look for resources, especially money, to help their infants survive – indeed, that was distressing for mothers as they described. These findings are supported by Trumello *et al.*, (2018) who articulated that, parents tend to have negative experiences with having a preterm birth because they never anticipated the situation.

#### **4.3.2 Reaction from Family**

Another factor that formed some of the experiences of mothers during hospitalization was the reaction from the family. This captures reactions mothers received from other family members, especially the extended family. The family is a complex social unit where an individual finds himself or herself. What affects one member of the family, directly or indirectly, affects other members, and interactions within the family unit affect the behaviours of all members of the family (Crossno, 2011). The family is therefore seen as a whole system rather than an individual element (Gilbertson & Graves, 2018), yet, members of the family react differently to similar situations due to individual differences (Bonanno & Burton, 2013).

In Ghana, the family system is a bit complex. Although Ghanaian families are increasingly becoming nuclear, the extended family relations cannot be side-lined when it comes to developmental milestones like marriage and childbirth (Dzramedo *et al.*, 2018). When a

woman is pregnant, there are high expectations of her giving birth to a full-term baby. When such does not happen, the extended family tends to get disappointed with the birth outcomes. This understanding underpinned the researcher's interest in examining how families react to the birth of preterm infants.

The findings showed that family members had some traumatic experiences and expressed varying reactions to the birth of preterm infants. The reactions from family members had some sociocultural implications. Members of the extended family (grandmothers, siblings among others) expressed some emotions towards the birth of the child; they were disappointed, ambivalent, or worried. Mothers, as they recounted, had to deal with the disappointed reactions from family members as well as their own disappointments.

#### **4.3.2.1 Worry and anxiety from extended family**

It is expected for family members to sometimes get worried and anxious when a preterm baby is born. The findings showed that few (eight) participants had their extended families overly concerned about their infants' health, especially in situations where the doctors kept postponing their discharge dates.

A mother narrated her experience:

“They were postponing the discharge dates; they [family members] became worried. So, every day they keep asking me what was happening” (P10, 30 years, 33 weeks).

Another mother also shared:

“Everyone was worried...” (P16, 31years, 30 weeks).

Preterm birth comes with a display of lots of emotions. These emotions, such as anxiety, worry, hopelessness, helplessness, frustrations, among others, tend to play out as a result of the stay

at the NICU, baby's health conditions, neonatal characteristics, health professionals' reactions, among others (Obeidat et al., 2009 cited in Galeano & Carvajal, 2016). The findings indicated that, the birth of a preterm baby does not only affect the parents, but also the entire family. The mothers explained how there was increased anxiety on the part of the extended family members since the mother and the baby were not discharged after stated dates. Family members became excessively concerned about when the chapter of waiting to see the fate of the child will end. However, incessant expression of their worry seems to have affected the mothers and made them lose their faith in the baby's survival. Other members of the family of the mothers were also gripped with worrying about the infants' health, and when the infants will be discharged from the NICU. They wondered if the infants will get any better even after the long period of hospitalization. They made this judgment due to how fragile and tiny the infants looked regardless of the health treatment that was being provided for them at the NICU.

#### **4.3.2.2 Disappointment from family members**

Mothers explained that the extended family members expressed disappointment when their expectations of a healthy delivery were not met. They also revealed how comments made by doctors tend to contribute to their hopelessness. Four mothers shared how disappointed their families were.

A mother shared that her family was disappointed, had this to say when the researcher followed up to understand her assertion:

According to the doctor taking care of me, the things he said, we all lost hope and were disappointed as a family. When I was even here, some told me to come home. [They said] since the baby won't survive what am I doing here (P8, 37years, 30 weeks).

As mothers described, it seemed the comments from the doctors had a powerful effect on them and their families regarding their preterm infants. The family relied on the doctors' information for hope in the survival of the child. In instances where the families saw the doctors' comments to be discouraging, the families lost hope. When families felt disappointed and hopeless, they eventually discouraged the mother from holding on in hope of baby's survival. In this study, the mothers expressed how they were directed by some relatives to leave the baby at the NICU and return home to their normal lives.

Obeidat et al.'s (2009) work which was cited in Galeano and Carvajal (2016) also found that parents and families become disappointed, worried, and even scared especially when there is no assurance of the survival of the baby from healthcare professionals.

#### **4.3.2.3 Insensitive comments**

Mothers narrated how some insensitive comments from family members affected them. Derogatory comments from family members tend to put mothers in a situation of hopelessness. Drawing from family systems theory, the family is meant to provide adequate support and comfort for the mother during crises (Crossno, 2011). Nonetheless, the study showed that most of the relatives of the mothers, out of their disappointments, made comments which caused the mothers to have regrets. The mothers (two) narrated how their relatives made them feel as though they had given birth to something less of a human. Consequently, mothers felt ashamed of themselves, feeling guilty, and regretted the entire birth experience.

A thirty-six-year-old mother commented about what her brother told her:

“... our last born told me to go and throw the baby away because she was too tiny...I even lost hope” (P12, 36 years, 32 weeks).

This narrative shows how some family members of the participants felt disappointed when they saw how the baby looked and felt getting rid of the baby was the best option for the family. In Africa, due to stigmatization, some communities have the practice of dumping infants who have visible disabilities (Ojedokun & Atoi, 2012). Even though it is a criminal offense, it is mostly done to permanently erase the shame families might face and ensure social acceptance (Alichie, 2015). A study in India also showed that newly born infants are thrown away as a result of pressured traditions and the societal definition of how new-born infants should look (Alichie, 2015). Therefore, it was not surprising some extended family members of the participants encouraged mothers to discard the infants. Such negative comments from relatives might be from their attribution of preterm infants to infants born with visible disabilities. This is consistent to the findings of Hall (2015), who found that preterm mothers waver from hope to hopelessness because of family members' reactions to the preterm event.

#### **4.3.2.4 Discomfort and uncertainty with the handling of baby**

Participants recounted how some family members, especially grandmothers, demonstrated discomfort and hesitation with handling the infants, although it was culturally expected from them to assist with caretaking for newly born infants. In the Ghanaian context, childbirth and childcare have a communal value attached to them (Maposa & Rusiaga, 2012). Older female relatives like grandmothers are traditionally expected to help with childcare, especially when the mothers are first-time mothers (Adama *et al.*, 2020). They are perceived to have in-depth knowledge and understanding of childcare, even though their approaches might not be the recommended healthcare practices (Adama *et al.*, 2018). In this study, mothers' support systems such as grandmothers were afraid to handle the infants though they were experienced in childbirth and childcare. This is because of how small and fragile the infants were. So, for

some mothers (two), even though the infants' grandmothers were available, they had to do everything related to the baby themselves. One of them was a first-time mother.

They shared their predicaments as follows:

“My mother-in-law who is taking care of me said she has not taken care of a preterm baby before. She was scared of everything, everything she was afraid, so I had to do most of the things myself” (P5, 29 years old, 31 weeks).

“...my mum even though gave birth to eight was even scared to handle her” (P12, 36 years, 32 weeks).

According to the mothers, grandmothers of the infants saw them to be too frail and tiny to handle. This could be as result of their traditional expectations of how they perceived newborns to look like at birth. Thus, they see preterm infants as a deviation from the normal expectations of how infants have to look like. Also, they refrained from the preterm caregiving, possibly because they lacked experience in taking care of such infants, and did not want to risk doing something which could hurt or worsen the baby's condition. Without doubt, it added to the stress the mothers were experiencing already. This finding is consistent with research conducted in Ghana by Adama *et al.* (2017), where Ghanaian fathers of preterm children discussed how they were afraid to carry their infants because they appeared fragile, and hence, did not want to hurt them by carrying them.

#### **4.4 Mothers' Post -NICU Experiences**

Another major theme identified in this research was mothers' post-NICU experiences. These are experiences mothers gained while parenting their preterm infants at home. Mothers articulated how challenging these experiences were after being discharged from the NICU. From the interviews, six sub-themes emerged under experiences mothers face as they take care of preterm infants after NICU. They are the baby's health at home, differences in parental care

roles, underdeveloped body organs, inadequate resources, preterm care and work, and family differences.

#### ***4.4.1 Baby's Health at Home***

In assessing parents' experiences with the baby's health, the factors that emerged from the interviews were: good health, readmissions, temperature regulation, and infants' nutrition.

##### **4.4.1.1 Good health**

All the participants (19) mentioned that they adhered to the health teachings they were taught at NICU before being discharged and during reviews. The instructions included washing hands before touching the baby as well as using hot water to wash infants' clothes and feeding utensils.

Mothers shared:

... I wanted to abide by whatever I was told because I was scared that if I do not comply, we can be readmitted ... His health is good, he wasn't sick. It was he falling sick that scares me but he doesn't fall sick. He is very tough (P13, 39 years, 28 weeks).

"I was careful to obey the things they tell us when we come for review because I have suffered. I make sure her stuff is kept well ... even at six months she looks small and cute, but she is healthy" (P11, 35 years, 32 weeks).

Mothers articulated that their infants were healthy because they followed all instructions that doctors gave them on the care of preterm infants. They did that to avoid readmission and escape a repeat of the uncomfortable experiences their infants went through at the NICU. Furthermore, the trauma they might have experienced at the NICU possibly took a toll on family resources, and they did not want to have a recurrence of such experience, hence, the need to adhere to doctors' instructions. Also, uncertainties about the outcome of readmission

cautioned parents to be extra careful in their preterm parenting. Research has indicated that preventing preterm readmissions help reduce cost and further health burdens on infants and the family at large (Perkins *et al.*, 2015).

#### 4.4.1.2 Readmission

Preterm infants are vulnerable to infections due to immature physiology. Hence, any little unhygienic practice from the mother could cause infections. These include poorly washed feeding utensils, touching baby with dirty hands, among others. Out of the 19 participants, two mothers reported that they were readmitted as a result of infections.

A mother said:

“At three months she run a temperature and the doctor said it was an infection so she was admitted for one week” (P17, 38years, 36weeks).

Another mother also expressed:

“At first, she fell sick and was admitted to ER [Emergency Room], later she fell sick again and was admitted to Child Health...There was an infection” (P18, 32years, 36weeks).

One mother suspected that the infection was a result of mixed feeding. It could also be attributed to poor handling and cleaning of feeding utensils.

It was not surprising that out of the 19 participants interviewed, only two had been on readmission. It comes as no surprise because, Escobar *et al.* (2006) (as cited in Celik *et al.*, 2013) reported that only about 30% of preterm infants are readmitted due to infections. Also, with readmissions, Ralser *et al.* (2014) reveal that infections are the major cause. This mostly occurs during the first critical period of life of preterm infants. This is mostly observed in preterm infants born at 36 weeks gestation and most common among baby boys than girls

(Escobar et al., 2006 cited in Celik *et al.*, 2013). The research revealed that that the two infants who were readmitted were born at 36 weeks gestation, however, they were both girls.

#### 4.4.1.3 Temperature Regulation

Mothers further expressed their views on health, with regard to temperature control. They understood the necessity to provide warmth to the infants. Some participants disclosed that they put two or more clothes on their infants for the sake of keeping warm. A more unique way of retaining heat among preterm is the Kangaroo Mother Care (KMC). Full-term infants can better regulate their body temperature, compared to preterm infants. Preterm infants are not able to maintain their body temperature because they usually have little fat on their bodies, making it extra hard for them to keep warm (Brodsky & Quinn, 2014). This makes them feel cold often as their bodies are not yet ready to sustain a normal body temperature (Brodsky & Quinn, 2014).

The 19 participants indicated that they provided some warmth for their infants. Nearly half of the mothers (seven) used the KMC method, and a majority of them (12) either overdressed the infants or wrapped them in clothes. Mothers who did not practice the KMC approach complained of rashes or a rise in the baby's body temperature.

A mother made this statement:

“In the beginning, we used to overclothe him. The overall attire, we could wear two for him... so he was picking gradually, even at three months they praised us at the review clinic that we were taking care of him well...” (P1, 31 years, 34 weeks).

Another mother who overdressed her baby complained:

...this is what I have studied my child and seen, that when we overdress her, her temperature rises. The doctor told us to buy a thermometer at home to monitor the temperature. If it is more than 37.5 then we have to take her to the hospital but if it is 37.5 then we can give her paracetamol syrup. But as I studied that, I don't allow a lot of things to be worn for her, unless it is cold, but if the temperature changes and she

becomes warm maximum is 37.4, or 37 or 37.2, and that is normal (P5, 29 years, 31 weeks).

Mothers who overdressed their infants explained that their infants tend to experience overheating, heat rashes, and constantly cry as they felt uncomfortable with the temperature. Temperature regulation tends to be difficult when infants are overdressed. This is because the mothers usually do not know the temperature in the room and the required clothing that gives the baby the normal thermal insulation for the prevention of overheating. This finding supports the study of Young *et al.*, (2013) who stated that, when infants are overwrapped and overdressed, there are high chances of overheating, heat rashes and excessive crying. It could even result in death due to the increase in their thermal insulation.

In contrast to overwrapping and overclothing of preterm infants, the KMC method is the optimal provision and regulation of temperature for preterm infants. In the current study, some mothers explained how they used the KMC method to regulate the temperature of their preterm infants.

A mother explained how she did the KMC method:

“...you have to carry them on your chest as a kangaroo. Because they were tiny and very small, you cannot bath for them. They need heat when they are tiny...” (P3, 31 years, 31 weeks).

Another mother also shared a similar experience:

“We were doing something called, KMC, Kangaroo Mother Care, so most at times you tie the baby on your chest...” (P14, 39 years, 28 weeks).

The KMC is when the baby is put in between the breast of the mother who should be bare-chested to ensure skin-to-skin contact and provide warmth for the baby by covering herself and the baby with a cloth (Feldman *et al.*, 2002 as cited in Pouraboli *et al.*, 2018). It is done to

produce warmth for the baby who has low-fat content, and therefore unable to maintain body temperature. The KMC also helps mothers and their infants to bond and form attachments (Altimier & Phillips, 2016). Additionally, the KMC method has been recorded to be essential in neuroprotection (Altimier & Phillips, 2016). This is a strategy for preventing neuronal cell deaths in preterm infants, and ensures optimal development of the brain. Again, research has shown that KMC, when practised for six hours per a week, aids preterm brain development and seen as an ultimate healing environment (Altimier & Phillips, 2016).

#### **4.4.1.4 Baby's nutrition**

The final sub-theme under baby's health is the baby's feeding. The mothers (19) mentioned that the issue of feeding was critical for the weight gain of their preterm infants. Infant feeding is directly related to infants' physical growth. Early postnatal nutrition during the early life of a preterm baby has a substantial effect on their brain growth and growth of other parts of their bodies (Düzeltici & Arslan, 2022).

According to Cheah (2017) breastmilk is regarded as the best nutrition for new-borns and especially preterm infants. Despite the numerous advantages of exclusive breastfeeding such as decreased risk of infections and reduced rate of infant (Siziba *et al.*, 2015) some mothers in the current study did not practice it. Results from this study indicated that half (10) of the mothers exclusively breastfed their infants either by putting them at the breast, using the cup and spoon method or the bottle-feeding method. The remaining nine, for various reasons, combined breastmilk and infant formula to feed their infants.

A mother who exclusively breastfeeds her preterm baby verbalized:

“I am trying to do exclusive breastfeeding and the baby feeds well, just take a look; the baby looks fine with just the breastmilk. The improvements are encouraging” (P16, 31years, 30weeks).

Another mother who breastfeeds exclusively using the cup and spoon method expressed:

“He was not taking any formula, it was only the breastmilk, which I have to pump and use a cup and spoon to feed him” (P14, 38years, 28weeks).

Participants expressed varying ways of feeding their infants to ensure that they put on weight and were commended at NICU review clinics. Mothers who were breastfeeding exclusively said they saw improvement in their infants’ weight. This is consistent with research by Asadi (2019), who expressed that, exclusive breastfeeding has a significant cause in adequate weight gain among preterm infants after birth. However, many used the spoon and cup method, because according to them, the infants got used to that method when they could not suck well while at the NICU.

Also, some of the mothers (nine) stopped the exclusive breastfeeding, even though it is the recommended feeding option, because of the difficulties they faced in feeding their infants.

A mother with triplets expressed her reason for not doing exclusive breastfeeding:

“...because of their number we are unable to do exclusive breastfeeding” (P19, 29 years, 31 weeks).

Another mother who had twins shared similar reason:

“With twins... at least we have to add an after meal<sup>4</sup> ....as a breastmilk substitute, in case they are not satisfied with the breastmilk” (P3, 31years, 31 weeks).

One mother also shared how breastmilk was not enough to satisfy her baby

We do cup and spoon, he takes the breastmilk but when he is not full, I top up for him... we used to take pre-NAN<sup>5</sup>. It was later changed to NAN 1<sup>6</sup>, so now he takes NAN 1, if I give him the breastmilk and he is not satisfied then I will top up with the NAN 1 (P6, 46years, 32weeks).

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<sup>4</sup> After meal is an infant formula, the participant used to feed her preterm infants

<sup>5</sup> Pre-NAN is a Nestle branded infant formula for preterm

<sup>6</sup> NAN is a Nestle branded premium starter infant formula

Another mother also gave her reason as:

“I gave her both breastmilk and NAN because my milk was not flowing so I do top up with NAN” (P12, 36years, 32weeks).

According to research (Palmer & Ericson, 2019), mothers with preterm infants breastfeed to a less significant extent compared to those with full-term infants. This could be due to lack of encouragement and support from health professionals. In a study conducted in Iran, the researchers discovered various reasons why mothers were not exclusively breastfeeding their preterm infants. These reasons include the mothers’ perception that breastmilk was insufficient, decreased supply of breastmilk, difficulty in breastfeeding due to multiple births, and stress factors resulting from long hospitalization at the NICU (Shiva & Nasiri, 2021). This finding is similar to responses mothers in this study cited as to why they were not breastfeeding their infants exclusively. Again, a study in Canada on breastfeeding among preterm found that over 80% of mothers partially breastfeed their preterm infants due to challenges encountered during breastfeeding (Dosani *et al.*, 2016). The challenges include reduced breastmilk flow due to anxiety and stress from preterm caregiving (Dosani *et al.*, 2016). Again, other mothers do not exclusively breastfeed due to lack of confidence to breastfeed, lack of adequate information on breastfeeding, and perceptions of insufficiency of breastmilk (Zukova *et al.*, 2019). However, failure to breastfeed exclusively can affect maternal-infant attachment formation and bond. This can lead to loss of sense of motherhood and difficulties in establishing mother-infant relationships (Palmer & Ericson, 2019).

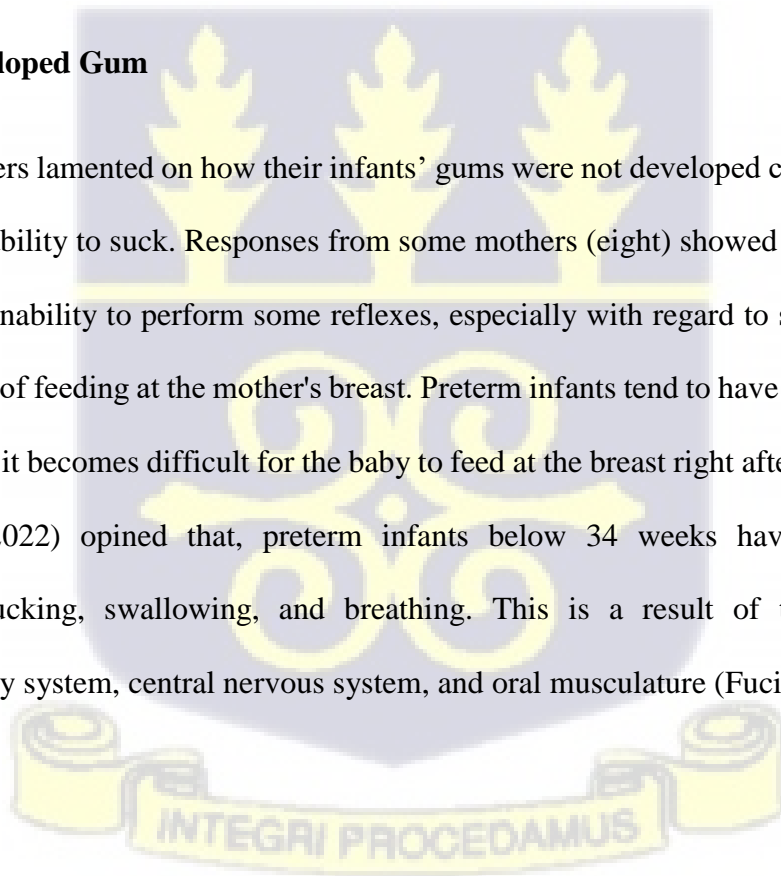
#### **4.4.2 Underdeveloped body organs**

Another challenging experience mothers faced after discharge from the NICU was the underdevelopment of their infants’ body organs. Preterm infants are exposed to several

developmental challenges compared to full-term infants (Do *et al.*, 2020; Johnson *et al.*, 2019; You *et al.*, 2019; Woythaler *et al.*, 2019). They have an increased risk of physical, cognitive and socio-emotional delays. This is a result of the underdevelopment of some body organs to support this functioning (Chung *et al.*, 2020). Research has shown that the birth of preterm infants in developing countries are more susceptible to delays as compared to their counterparts in developed countries due to lack of adequate resources to support the normal functioning of the infants, as well as cultural differences (Do *et al.*, 2020). The current study found some challenges preterm infants faced due to poor development of some organs. There were challenges with feeding due to undeveloped gum, delay in developmental milestones such as sitting, and disproportioned body size as against age. They are further elaborated in the subsequent paragraphs.

#### **4.4.2.1 Undeveloped Gum**

To begin, mothers lamented on how their infants' gums were not developed completely, hence affecting their ability to suck. Responses from some mothers (eight) showed that infants were faced with the inability to perform some reflexes, especially with regard to sucking. Sucking is a baby's way of feeding at the mother's breast. Preterm infants tend to have immature organs for sucking and it becomes difficult for the baby to feed at the breast right after birth. Düzeltici and Arslan, (2022) opined that, preterm infants below 34 weeks have difficulties in coordinating sucking, swallowing, and breathing. This is a result of the undeveloped cardiorespiratory system, central nervous system, and oral musculature (Fucile *et al.*, 2019).



This assertion was affirmed by the participants of this study who commented as follows.

A mother said:

“I am hoping that by four months she will be able to suck well on the breast, then I will do up to 6 months. But if she doesn’t suck herself then at least 4 months I will start giving her formula” (P16, 31 years, 30 weeks).

Another mother shared her plight:

“...because of their gum was not fully developed, sucking was a problem, so we do cup and spoon where we expressed the breastmilk into a cup and fetch with teaspoon for her” (P11, 35years, 32weeks).

The feeding challenge, under discussion, is noted to have affected the nutritional needs of the infants, hence weight and growth deficit – an issue which the mothers found very worrying. This is consistent with a study by Currie *et al.*, (2019) which showed that, preterm infants’ inability to coordinate sucking and breathing causes them to be at risk of dehydration and insufficient caloric intake, leading to constant weight loss. Some mothers resorted to the cup and spoon method, but that was still a problem, because, the infants got used to the cup and spoon so much that they refused to feed at the breast.

Research has shown that mothers with preterm infants experience difficulties in initiating breastfeeding at the breast due to sucking difficulties (Aytekin *et al.*, 2014). This is why such mothers stick to other feeding methods like the cup and spoon to ensure continuity of exclusive breastfeeding method. That method, however, comes with its own challenges such as difficulty in feeding outside home, insufficient milk intake and increased risk of choking (McKinney *et al.*, 2016). Nonetheless, the method has been proven to be physiologically safe. It is hygienic and non-invasive (Aytekin *et al.*, 2014).

#### 4.4.2.2 Baby's size and appearance after discharge

Additionally, the sizes of the infants were of great concern for all the 19 participants, even after discharge. In the Ghanaian society, infants are typically accepted when they look fleshy (Nukunya, 2003 as cited in Suraju, 2013). Mothers expressed that they expected their infants to gain some weight upon being discharged. However, their infants still had small body sizes as compared to full-term infants of the same age. This ordeal made them worried and ashamed, hence their quest to conceal the baby in excessive clothing. Some had to wait for as much as six months before organizing their child's naming ceremony. That might have posed some psychological health challenges to the mothers to the extent that, for one interviewee, when something as small as a handkerchief fell, she thought it was her baby.

A mother described her ordeal as:

"...carrying them was a problem because they were very tiny... We felt embarrassed to let people come and look at them and they felt like we were telling them that they are witches or something" (P3, 31 years, 31 weeks).

Another mother shared:

"When I was coming for review, I will wrap him tightly because I was shy and because I hadn't given birth to a baby like that before" (P13, 39 years, 32 weeks).

A mother who tends to be affected psychologically by her baby's size exemplified:

Because when they are very tiny, you are holding the baby and something falls off your hand, you presume that it is the baby that has fallen ...because they are very, very tiny. Assuming my handkerchief falls, there is that kind of panic, thinking I have made the baby fall (P14, 38 years, 28 weeks).

Also, a mother who was affected by the baby's size expressed:

"...because she was very tiny, we had the naming ceremony 3 weeks ago and she is seven months now" (P12, 36 years, 32 weeks).

From the narratives, mothers shared how they were trying their possible best for the infants to look plump after NICU, yet to no avail, despite all the recommended feeding practices they

adhered to. They expressed how psychologically unstable the look of their infants made them. The mothers had hoped that their infants would gain some weight, but it looked like all their effort to see that reality was void. This finding is in conformity to Suraju's (2013) research work on the experiences of mothers in the care of preterm infants. She examined preterm infants in Accra and found out that, infants' weight negatively impacted mothers and posed some threat on their psychological wellbeing, because, the mothers were often anxious and visibly worried.

When it comes to preterm weight gain, several factors are observed. Some studies associate preterm weight gain to their nutrition (Liu *et al.*, 2019). Others suggested that the inability of preterm infants to gain adequate weight could be attributed to health problems related to digestion (Namiiro *et al.*, 2012). However, there is a study which has shown that mothers' ability to do the KMC method could promote weight gain in their preterm as it provides stability in physiological functioning (Irianti *et al.*, 2021). The KMC method was practiced by few mothers in this study, but no further exploration was done to ascertain the validity of Irianti *et al.*'s (2021) findings.

#### **4.4.2.3 Delay in developmental milestones such as sitting**

A mother expressed how her baby delayed in sitting as compared to her other full-term children.

“Even my first two children, sat and even walked earlier. But when she was four or five months she could not sit well, we are almost seven months and she is now trying to sit” (P11, 35 years, 32weeks).

Infancy is a dynamic period of growth and changes in infants. There are certain milestones which give parents a confirmation of growth in their children (Darrah,& Kembhavi, 2022).

Ideally, a baby, by five to six months, should have gained progressive stability in sitting (Darrah,& Kembhavi, 2022). However, with the cases of preterm infants, some still have an immature central nervous system to support that milestone at five or six months (Chung *et al.*, 2020). This is because they tend to have a variety of neurodevelopmental challenges leading to developmental delays. Therefore, they experience slower growth in developmental milestones as compared to full-term infants.

#### ***4.4.3 Variations in Parental Care***

Mothers realized some variations in the care of their preterm infants and full-term children. Unlike the full-term infants, the preterm ones need special attention and care. Over half of the participants (11) who had other children revealed that there have been some changes in roles or activities performed in the care of the preterm as compared to their full-term children.

A response from a mother with other children:

“The new roles were the first three months doing kangaroo mother care. That was the different thing, making sure that she is always warm... taking care of this baby is expensive compared to my other kids” (P17, 38 years, 36 weeks).

A mother expressed her difficulty:

Parenting has been a bit of a challenge because I have to be extremely careful with her care. With my first child my in-law was around so parenting him was not difficult but with this current baby, I want to take care of her myself (P16, 31 years, 30 weeks).

One mother added:

“Parenting this one has been difficult as compared to the first child, because there were no complications with that child” (P15, 39 years, 32 weeks).

Another mother shared her sufferings:

“I have suffered in taking care of this one, right from NICU” (P12, 36 years, 32 weeks).

There were some role alterations when it came to care roles for a preterm and a full-term baby. For some mothers, the difference was KMC feeding which was not done for their full-term children. Again, they explained that the cost of raising preterm infants was expensive in terms of their feeding, health complications, and many others. The preterm infants needed more attention and extra care.

#### **4.4.4 Inadequate Resources**

Some mothers cited that; resources needed to ensure fruitful care of the baby was a problem for them. These resources help people deal with their traumatic events (Brooten *et al.*, 2001 cited in Kilpatrick *et al.*, 2014). Hence, if it is not sufficient, it becomes worrying and stressful, thus making it difficult for mothers to cope (Repetti & Wang, 2017). Some of these inadequate resources mothers identified included finance, time, social support, and the infants' clothes. These have been explained subsequently below.

##### **4.4.4.1 Escalating cost of care**

The birth of a new-born tends to come with some cost; however, the cost becomes higher when the baby is preterm. This is because, preterm is an unplanned event, which comes with extra healthcare costs such as, weekly or monthly visits to the hospital for reviews depending on the baby's condition, buying of prescribed medications to sustain the health of the baby, readmissions, among others. Some mothers (nine) who were interviewed expressed how the whole issue of managing a preterm baby led to their bankruptcy. Others also asserted that parenting a preterm baby is a waste of money.

A mother disclosed:

I have incurred a lot of costs and my husband has been the one paying for it and he has been complaining o... The cost we have incurred is more than 10,000 cedis. So, if you go and ask for money again then he gets bored. It has pulled all the money from home. (P4, 40years, 32weeks).

Another complained:

Just that it is a waste of money, you will spend a lot... it has cost you so much that the money you wanted to use for a project now you cannot even do it. Health insurance coverage is just small money. (P11, 35 years, 32 weeks).

One mother added:

“But now all my money is finished, I don’t even have money to start my business” (P12, 36 years, 32 weeks).

Apart from the incurred cost at the NICU, the home care of preterm infants came with additional cost, especially with frequent visits to the hospital for reviews. Parents described that they were overwhelmed with money they had spent on their preterm infants. The cost involved was overwhelming for some of the parents and plunged them into serious financial crises. The mothers complained that the NHIS did not cover most of the laboratory tests they ran during reviews, which also put much pressure on their family’s financial resources. Some lost their business capital and other budgeted money. Again, some mothers explained how it affected their family’s bond, as frustration from the financial burden set in on the part of their partners. In an empirical study on preterm mothers’ experiences in a Mother and Child Unit in Ghana by Lomotey *et al.* (2020), mothers expressed how burdensome the financial demands of preterm caregiving were, despite their enrolment on the NHIS. It leaves them with little to no money to finance other needs of the preterm child, hence making it difficult for them to cope with their plight of a preterm birth.

#### 4.4.4.2 Time Constraints

Time was also a resource that some mothers (four) explained they do not have enough at their disposal. Childbirth puts some extra demand on the time available for mothers, however, the demand increases further in the case of a preterm birth (Howe *et al.*, 2014). Preterm infants need dedicated continual care, hence, their mothers stated how they spend a lot of time making sure the infants are well-taken care of. For example, after taken off life support, mothers fear to lose their child at the least negligence, so, they spend much time checking the child's progress and feeding to enhance weight gain. Consequently, the mothers are left with little or no time to care for themselves, their partners, and other family members.

A mother shared:

“The only challenge is getting maximum time for both of them...” (P3, 31 years, 31 weeks).

One mother also uttered:

“Time has been a challenge; I don't get time at all. I was supposed to be in school but see, I am here” (P10, 30 years, 33 weeks).

A mother, who had to put her work on hold to make time, expressed:

I have to stop the work, to get time for him and when I stopped too, I made time for him ...at the beginning, all my time was the baby. I wasn't minding them, my husband, I even ignored him for some time (P13, 39 years, 32 weeks).

Another, whose sleeping hours was affected, narrated:

“The infants determine the time for you, you cannot have time for yourself.... we do not have sleeping time” (P19, 29years, 31weeks).

Following the amount of time dedicated to parenting a preterm, some have equated it to a full-time job (Garti *et al.*, 2021). Mothers shared that they never found enough rest, and usually felt overburdened with the parenting of their preterm. They narrated how their interpersonal relationships had been affected due to time constraints, especially in terms of family bonds.

This is because they could not balance taking care of the preterm and meeting the emotional needs of other family members.

Again, the mothers indicated they found it difficult to balance their time with the care of the baby and their businesses. It affected them such that, they had to quit their jobs or put their businesses on hold, just to get enough time to take care of their infants. The time constraint associated with parenting preterm infants leaves their mothers stressed (Kumar & Aithal, 2020).

#### **4.4.4.3 Other limited material resources**

The lack of other material resources such as clothes, diapers and refrigerator also affected the preterm childcare.

A mother who needed a refrigerator commented that:

“We don’t have a refrigerator, so I don’t sleep. I have to express for her and she eats every 2hours, even at night, so I wake up every two hours to express.” (P5, 29 years, 31 weeks)

Another mother, who had need for baby’s clothes shared her plight;

Getting clothes for her wasn’t easy, so I used to have some toys clothes which I wear for her, because the clothes I shopped for her were too big, she wears half and a half will be hanging and I will use it to wrap her (P12, 36 years, 32 weeks).

Again, a mother who needed smaller diapers shared:

“Getting her pampers size has been very difficult because she is very small” (P15, 32 years, 34 weeks).

After discharge, some mothers shared how lack of some essential material resources (as cited earlier) affected their preterm childcare. This made parenting and caring for the infants difficult

and stressful for the mothers. Such predicament goes a long way to affect the family's pattern of interactions (Feldman et al., 2007 as cited in Necef, 2022).

#### 4.4.4.4 Inadequate Social Support

Even though social support is key in overcoming emotional stress (Adama *et al.*, 2020). Two mothers mentioned they had insufficient social support after being discharged.

A mother complained that:

“...I didn't have anyone to help me so I suffered. I do everything by myself...when you are feeling bodily pains and you have to sleep, the baby is now crying, you have to pick her up” (P11, 35 years, 32weeks).

The other mother also complained:

“Most often, my husband is not at home, so I do house chores then I have to take care of her alone and it is stressful for me” (P18, 32years, 36weeks).

It is very usual for mothers who have given birth to get support from extended family members. This is because, in Ghana and some part of Africa, childbirth is a social milestone where many people (especially the extended family members) desire to provide support to the new mother (Maposa & Rusiaga, 2012). However, with this study, some mothers indicated they did not get the usual support, and that could be attributed to the increasing inclination to the nuclear family system in Ghana (Kpoor, 2015). Sometimes, the mothers themselves failed to seek such social support from extended family members due to fear of stereotypical attitudes and non-acceptance of their preterm infants (Garti *et al.*, 2021). Meanwhile, social support is essential for mothers who have given birth. It helps them to get time for themselves and their infants. Hence, the absence of such support places extra burden on the mother, turning out as a stressful venture. Some of the interviewed participants expressed that, they had to do everything by

themselves, which was even more stressful for those who had undergone a caesarean section. This current finding is supported by (Ballantyne *et al.*, 2013) who posited that, the lack of social support can lead to maternal distress in mothers with preterm infants.

#### **4.4.5 Preterm care and work**

Another sub-theme on mothers' post-NICU experiences is how difficult it was for them to combine preterm care and their jobs. For mothers who were in formal employment (seven), they complained that the preterm care affected their productivity, because they had to take the infants to work since they were too small to be sent to a day-care.

One mother narrated:

“It affects productivity because sometimes she cries. She wants to eat so I've to take her and feed her before I continue whatever I'm doing, so it reduces my productivity at work” (P18, 32years,36 weeks).

Another mother shared;

“If he is hungry then he cries, if not he won't cry, so I will stop what I am doing and pick him up” (P6, 46 years, 32 weeks).

Mothers who were in formal employment had just three months of maternity leave and had to resume work. Due to the immature state of their preterm infants, it became difficult to enroll them in a day-care after the three months. In Ghana the International Labour Laws (ILO), Maternity Protection Convention, 2000 (No. 183) provides mothers with only a 12-week paid maternity leave whereas, in other countries like Sweden, mothers are entitled to almost 69 weeks of paid leave when a child is born (Ma, 2020). The mothers were therefore compelled to take the infants to work in order to give them the necessary care and attention as they narrated. Eventually, it affected their output at the workplace. This is consistent with Gateau

*et al.*'s (2021) finding that mothers had to withdraw from their jobs to give full attention and time for their infants. Velit and Akum (2018), in their empirical study in the Northern part of Ghana, also found that mothers had to put their jobs on hold or quit to get enough time for their preterm infants.

#### ***4.4.6 Differences in Understanding of Preterm Childcare***

The family's understanding of preterm childcare was a challenging experience that was identified from the interviews. The lack of understanding of the baby's needs on the part of other family members made the mothers insecure about trusting their baby in the care of others.

A mother expressed her concerns:

So, at first my mother-in-law and my husband used to complain that I was overfeeding her... When she cries then I will allow them to carry her and I stopped expressing the breastmilk down, for them to realize that I know what I was saying. So, when she is hungry and crying, I go and give her to them as if they want to make her stop crying and if she doesn't, they will be like oh she is hungry, express breastmilk for her. Then I will say no (P5, 29 years, 31 weeks).

Another mother also shared:

“Because most of the time, when with her, because of the preterm thing she needs to take multivitamins and it is not everybody who knows how to give it to her. So, I do almost everything by myself” (P17, 38 years, 36 weeks).

The mothers had better understand of their infants' needs (especially due to NICU lessons) than other family members. Due to the variation in childcare for preterm and full-term infants, there is usually disagreement between the mother and other family members who do not have much knowledge on both. According to a respondent, she had to allow situations to play out to enhance the peaceful atmosphere at home. Another mother, however, performed the preterm childcare roles for family members to understand that she knew the needs of the child better.

This finding is in conformity with Fleury *et al.*'s (2014) finding, which report that, families had difficulties in identifying and understanding the needs of preterm infants, and that caused behavioral differences between preterm and full-term children.

#### **4.5 Coping Resources**

The study adopted a model called ABC-X model which helped to explain the coping resources. The ABC-X model (Hill, 1949) has the B-factor as resources available to families which enable them to come out successfully in their stressful events like preterm birth. Some resources identified were time, finances, family bond, among others. They were categorized into four factors, which are time, material, emotional, and spiritual resources.

##### **4.5.1 Time Resource**

With regard to the challenges faced by parents with preterm, some time and pace to adjust to life with a preterm baby may go a long way to ease some of the challenges. Indeed, parents who were able to take time off work or other previous daily pursuits were able to cope with the challenges. For instance, time to set in place a daily schedule for feeding and other child-related activities, and time to adjust to other changes brought by the new birth. Parents who had extra time at their disposal attested to the usefulness of such, in managing the demands of preterm parenting. Such extra time comes by various means such as cutting off some daily pursuits and taking some time off work.

Even though 14 mothers were employed, eight had to put their work on hold to cope with the demands of childcare. Hence, time has been a useful resource that helped them cope with the stress of childcare of a preterm baby.

A banker who had resigned from her work narrated:

Time has helped me in a way. In my former place working, I have to leave home early, and then sometimes 9 pm I am not home. I used to be a teller at the bank, if everyone has not yet left, you the teller you are not going, you have to also balance. I don't know what I will have done, if I was still working. I resigned 2019 December, conceived him in 2020 and had him in 2020. I don't know how it would have been, how long they are going to give me that leave advantage. It would not be possible, and they are tiny, if it was a normal baby, 3 months I will have to resume work. So, I think being off my job for a while has helped me to take care of him till this time. I can rest but most at times (P14, 38 years, 28 weeks).

Another mother said that because she was self-employed (a caterer), she had all the time at her disposal to focus on childcare.

She recounted:

“Because I am self-employed, I get time to care for..., I even get time to rest, when she is full, I just have time” (P12, 36years, 32weeks).

Self-employed mothers shared how they were able to put their work on hold and made time to care for their infants, unlike those in formal employment. The flexible nature of their work granted them the time needed for themselves and their infants. Mothers after delivery spent at least a week to three months at the NICU, and for those employed in the formal sector, that would mean limited time for maternity leave. They would have to report to work after the usual three months of maternity leave, even if the baby has not recovered fully. Mothers entitled to lengthy maternity leave (like those in Sweden) get an appreciable amount of time to take care of themselves and their infants, unlike those in Ghana (Ma, 2020). It was therefore not surprising that one mother explained how she had to resign as a banker in order to get maximum time for her baby.

Undoubtedly, the availability of time plays out as a very useful resource for mothers in coping with the associated challenges. It is affirmed by Salin *et al.* (2020) who based on their research

in Finland posit that, time is the strongest resource that helps many to cope with the challenges of caring for a preterm.

#### **4.5.2 Emotional Resources**

Another resource that the mothers mentioned helped them cope is emotional resources. Several psychological theories point to the power of a positive mindset and perception of positive outcomes which helps one to cope with challenges (Krohne, 2002). Some of these theories include a sense of coherence (Antonovsky, 1979 as cited in Eriksson, 2022), hardiness (Kobasa, 1979 as cited in Henderson, 2015), self-efficacy (Bandura 1977 as cited in Iroegbu, 2015), optimism (Scheier & Carver, 1992 as cited in Segerstrom *et al.*, 2017), among others. In this study, mothers pointed out that their inner strengths, family bond and positive mindsets are instrumental in helping them cope with the challenges associated with having a preterm baby. They are explained below.

##### **4.5.2.1 Inner Strength**

Inner strength is an emotional resource that promotes the well-being of people in times of crises. It helps them to be firm and have the necessary stamina to deal with and overcome every challenge they are confronted with (Lundman et al., 2012). Inner strength is as a person's ability to remain calm and adjust to unpleasant situations that require change, by tapping strength from within. Some mothers (three) coped with the care of preterm infants by gathering strength from within to face the situation, hence deciding not to give up regardless of what they were experiencing.

A mother pointed out:

“The joy I had gave me the strength to do everything. I do everything” (P6, 46 years, 32 weeks).

Another mother who also tapped from her inner strength revealed:

“I’m somebody who doesn’t give up, it thus strengthens me... I just keep going” (P17, 38 years, 36 weeks).

Again, one mother said:

We just have to remain positive, that is very important. I believe they feel positive energy and when you are sad, they may also feel sad. Therefore, we are motivated with the strength we had that whatever they are going through, we will fight it together (P19, 31 years, 30 weeks).

The mothers shared how they encouraged themselves, stayed positive and strong for themselves, their infants, and their families. They indicated how they dwelt on their inner strength to keep persevering for the survival of their infants, hence, giving up was not an option. They explained how they resorted to a positive mindset amidst the challenges. According to Harzer and Ruch (2015) inner strength has a positive influence on reducing stress. They also emphasized that inner strength helps to deal positively with stressors.

#### **4. 5.2.2 Strong family bond**

Some participants mentioned that their strong family bond helped them cope with their preterm event. The way many family members were ready to assist in the preterm childcare strengthened the family ties. It relieved the mothers from solely bearing the difficulty of preterm parenting. The mothers attested to how the good support from family proved useful in coping with the stress of preterm parenting.

One participant cited:

“It looks like she has made us so tight” (P5, 29 years, 31 weeks).

The other indicated:

It has been a positive one, the whole situation has brought us together more. We do everything together when it comes to feeding, we feed together, carrying all of them together. In fact, we are in one room together, so the family bond has grown stronger (P19, 29years, 31 weeks).

As mentioned by some mothers, they found comfort in family relationships and cooperated with their partners to take care of their infants. It enhanced communication and strengthened couple ties amidst the challenges.

The findings conform to the research of Salin *et al.* (2020) who mentioned that, families' togetherness in coping with stressful moments is essential, since it helps family members share responsibilities, in order to avoid overburdening one person. It eventually leads to decreased stress levels. Also, they found that as families came together, communication among themselves was well enhanced. To a large extent, such moments could be refreshing for mothers with preterm.

#### **4.5.3 Material Resources**

Mothers who had material resources at their disposal explained how beneficial these resources were to them. Material resources are resources that are physical and available for use by everyone. In the data collected, four main material resources were identified, namely: finances, information, space, and medication.

#### 4.5.3.1 Finances

Cash was the means of payment for goods and services at the NICU. At home, participants attested to the relevance of financial resources in their children's survival. The availability of adequate money made coping with preterm parenting less stressful, as it enabled the mothers to access various needs. For some mothers (six), having money to pay their bills alone felt literally like escaping hell.

A mother articulated:

“There are a lot of costs, and if you don't have enough money, you suffer” (P8, 37 years, 30weeks).

A mother also described:

“If I didn't have money the baby might not have survived. He was super small, very small. At the NICU it was not easy, you are doing labs and buying drugs... doing labs and buying drugs” (P13, 39 years, 32 weeks).

Another mother recounted:

“Without finances, it would have been hell, especially when we came to KBTH. At the NICU, go and buy this, go and buy that, go and buy this. Everything we were buying, yet we had insurance, so it has helped” (P14, 38 years, 28 weeks).

The mothers explained how they survived the preterm situation, as a result of the availability of money. At the NICU, they had to pay for every single service their infants were offered, to ensure their survival. They believe that their ability to provide money was what caused their infants to be well-catered for at the NICU, and at home. This is due to the fact that they had enough to pay for their hospital bills, buy the infants' foods, go for regular reviews, and even buy good clothing for the infants.

#### 4.5.3.2 Information as a resource

Another material resource that participants stated being helpful, in coping, was their access to information. Some mothers searched for information on the internet, others made sure that they carefully followed all instruction given before being discharged from the hospital. It turned out very useful in taking care of their preterm baby. Out of the 19 respondents, 18 were first-time mothers of preterm infants, who saw the need to rely on available information to cope with the situation.

A mother voiced:

“Most of the time I am on the internet, I am on the internet searching for what to do at what time” (P14, 38 years, 28 weeks).

Another mother also aired:

“The doctors spoke to us and gave us information, so I followed suit what they said, and it helped me greatly” (P1,31 years, 34 weeks).

One mother recounted how she resorted to YouTube videos:

“We found a couple of videos on YouTube and some apps I cannot recall the names right now, that guides us on how to handle them, feed them.... knowing the acceptable temperature, change in complexion, and what it means” (P19, 29 years, 31weeks).

Another mother too verbalized:

When we come the things they tell us, that their care is difficult. If you leave their stuff anywhere, they will get infections. I was very careful about that because I have suffered. I made sure his stuff was kept well, or use hot water to wash and we have not been on readmissions (P11, 35 years, 32weeks).

The information provided by health professionals and some friends to these mothers was greatly beneficial, especially for those who had given birth for the first time. Majority of the mothers found it needful to adhere to the medical experts' advice in order to avoid the stress of readmission and ensure optimal growth of their infants. They also shared that, the information they received helped them with decisions they took regarding the caregiving of their infants.

Some mothers took the burden upon themselves to find adequate information on the internet as a top-up to understand some changes in their infants' health. This was not surprising because all the participants were literates, so, they could help themselves with the needed information concerning caring for their infants. Not only that, also, mothers in the age group of 20 years to 41 years are termed millennial parents and are such are exposed to technology at their time of parenting (Wolf, 2021). Therefore, they had the ability and skills to search for information on the internet. These findings are supported by a study conducted by Vasquez (1995) (as cited in Suraju, 2013) that parents cope with the care of their infants based on the amount of information they have at hand. Also, a study by Mok and Leung (2009) (cited in Mousavi *et al.*, 2016) showed that mothers felt relieved with the information given to them by medical staff because it gave them headway into the care of the preterm infants.

#### **4.5.3.3 Space as a resource**

The mothers indicated that space was another resource which was useful in helping them cope in parenting of their preterm. The space in a house is determined by the housing arrangements. Housing is important in child development, as children require a lot of space to enhance their development. The space in a house can make raising a child difficult or easy (Solari & Mare, 2012).

A mother stated how space has helped her coped with taking care of her preterm baby:

“Now I have enough space to sleep with her without getting scared of sleeping on her as it nearly happened when we were on admission” (P15, 32 years, 34 weeks).

A mother's stress increased as she nearly slept on her baby due to limited space. At home, she could sleep without the fear of sleeping on her baby because she had a larger sleeping space. According to Evans (2021), limited space at home can impact the behaviour and

socioemotional functioning of both parents and children. Evans (2021) stated that lack of space at home can increase stress among children and other family members such as parents.

#### **4.5.3.4 Availability and efficacy of drugs**

According to the research participants, another material resource which was beneficial in their preterm childcare was the medicine given to them upon discharge. Parents were happy as the drugs yielded results and contributed greatly to the infants' development. According to two mothers, the medications made their infants gain weight faster and helped them maintain the infants' health.

A mother asserted:

“The medicine they gave to her was very helpful” (P18, 32 years, 36 weeks).

Another mother affirmed:

“Some medications were given to them, so it makes them eat more, they are eager to eat whatever we feed them with. Because as they look tiny, the medications helped them to develop the body” (P3, 31 years, 31weeks).

The mothers exemplified the improvements they had seen and the high survival chances of their infants, as they continued to give them medications prescribed after discharge. Some also believed that the medications helped their infants feed well to gain weight. Garay-sevilla et al. (2011), in their empirical study, found that the use of medications was associated with coping in a positive manner. This is to say, patients who wanted to survive their ill-health issue complied by using medications given to them. This study also showed that mothers used medications as a resource to help ensure the survival and wellbeing of their children.

#### 4.5.4 Spiritual Resources

Some mothers resorted to spiritual resources to recover from their experiences at the NICU and home. Spiritual resources are the use of religious beliefs and practices to help reduce emotional difficulties (Saad & de Medeiros, 2012). Spirituality in the African context, especially Ghana, is the connection to a higher power (Acquah, 2011). Studies (e.g. Acquah, 2011; Bawa et al., 2022) have identified Ghanaians as very spiritual, with about 70% identified as Christians. Research again has indicated how Ghanaians have an external locus of control and attribute most events in their lives to a higher power and in most instances, God (Acquah, 2011). Interestingly, five out of 19 of the respondents attributed their means of coping to their belief in God, and the fact of His provisions, by faith and prayer.

One participant stated that:

“It has been God because I have faith in him that in all things, he can take care of my baby” (P8, 37 years, 30weeks).

And in the case of prayer, others (three) verbalized:

“... so, it was just prayers, you know sometimes when they are tiny like this it is only God, you always have to pray for them that God should strengthen their bones for them to grow...” (P3, 31 years, 31weeks).

“...I have prayed not small at all” (P15, 32 years, 34 weeks).

“We are just praying that they will get well, and they will be fine” (P6, 46 years, 32weeks).

Prayer and the belief in God gave the mothers hope that God will make their infants survive the conditions of a preterm birth. Thus, they moved from a state of hopelessness to hopefulness. This is consistent with a research conducted in South Africa by Sih *et al.* (2014), who found that mothers relied on God and prayed that God will restore their infants' health and ensure their survival. Arzani *et al.* (2015), in their empirical studies, found that people usually employ prayer to cope with any trauma they go through. This finding also concurs with Anderzen-

Carlsson *et al.*'s (2014) finding that, people's involvement in religious activities has a positive influence on their emotional relief to stress.

#### **4.6 Social Support System**

All the participants (19) had some form of support after the delivery of the preterm baby. Some received support while at the NICU, and others after being discharged. The mothers received various kinds of support from sources such as their biological mothers, in-laws, siblings, health professionals, husbands, friends, religious groups, and some strangers. Some had financial support, while some others had emotional support, and assistance with house chores, as well as valuable information on preterm childcare.

##### **4.6.1 Nuclear family**

One major support system the mothers had was their immediate nuclear family. The nuclear family is the closest relation mothers with preterm infants have, and mostly where they have their support from. Usually, the support from the nuclear family cannot be ruled out as mothers are expectant of it. It could be in terms of financial or emotional support, or help with household chores. All the participants (19) had their partners supporting them in various ways. Those with older children also had support from them.

A mother enunciated how her husband helped her with house chores:

“My husband is even more than a woman. He is very helpful, he can wash, now I don't even go to the market to buy foodstuff. He goes to do everything, anytime we want to prepare food, he will go and buy the food items...” (P3, 31 years, 31 weeks).

A mother also uttered how her husband provided financial help:

“We incur a lot of costs, and my husband has been the one paying for it” (P4, 40, 32 weeks)

Another woman disclosed how she received emotional support from her partner:

“...My husband encouraged me a lot because my hope was even finished” (P16, 31 years, 30 weeks).

A mother also explained how her daughter was of help to her:

“...My elder daughter is 16 years, so for some time she was the one cooking and then I took over not long ago” (P14, 38 years, 28 weeks).

According to the mothers, their husbands were their main support system before, during and after NICU. The respondents expressed they had great financial support from their husbands as they were the main providers of financial resources needed to take care of their infants, both at NICU and home. Additionally, the men supported their partners in overcoming their preterm-related trauma. The mothers found relief in the encouraging words from their partners. Husbands and older children took up household chores such as cooking in order to help the mothers get enough time to take care of themselves and their infants. This is similar to the findings by Suraju (2013) and Velit and Akum (2018), where they found that almost all their participants had some form of support from their husbands and older children in caring for their infants. In Suraju's (2013) study, she affirmed that the major bearer of financial responsibilities in childcare is the husband.

#### ***4.6.2 Extended family***

Also, support from the extended family was described by the mothers as vital. Extended family support is essential in the lives of mothers who have given birth, especially mothers with preterm. The burden of having preterm infants cannot be borne by the mothers alone. Family support helped the mothers to overcome some stressful experiences. In this study, over half of the mothers (13) had extended family members such as their mothers, in-laws and siblings be of help to them in varying ways, especially with household chores.

A mother who had support from her sister articulated:

“My sister helps with housework” (P4, 40 years, 32 weeks).

Another mother had support from her sister financially, she indicated:

“My sister has been around: she helps me even in terms of finances” (P8, 37 years, 30weeks).

One mother said how she had support from her mother:

“At least my mum supports in finances” (P10, 30 years, 33 weeks).

A mother also shared how she had support from her in-laws:

“My sister-in-law, my brother’s wife’s sister, came to help me because my mother was scared to bathe her” (P12, 36years, 32weeks).

Extended family members are very helpful after childbirth, especially in the case of preterm birth. Some extended family members helped not only in household chores such as cooking and bathing the infants, but also provided financial support and encouragement. According to the mothers, the preterm childcare took much of their time, hence, the family support meant so much to them. A quantitative study by Amorim *et al.* (2018) on the quality of life among parents with preterm infants showed that, the mothers’ contact with extended family members had a positive influence on their quality of life. It therefore implies that the lack of extended family support could have a negative effect on a family with a preterm baby. It could give the immediate family (nuclear family) an impression of unacceptance of the preterm baby on the part of the extended family (Moura *et al.*, 2017). This shows how significantly extended family support helps improve the mental health of such mothers (Emmanuel *et al.*, 2012).

#### **4.6.3 Health professionals**

Some mothers mentioned that they received support from the doctors and nurses at the NICU. Support from health professionals is vital in helping mothers with preterm infants to cope with the distress (Tajalli *et al.*, 2022). It was revealed in this study that, one major support from health professionals was the provision of useful and adequate information to the mothers. Information support is key for mothers with preterm infants because it helps to reduce their stress (Mok & Leung, 2006 cited in Mousavi *et al.*, 2016) and helps mothers cope better with childcare. This is because they might have had little or no information on preterm birth before facing its reality.

The mothers received information on how to care for their preterm infants, feeding strategies, ways to prevent infections, among others. They did not only receive information, but also emotional support. Due to the traumatic nature of the whole preterm birth experience, the mothers lost hope and resorted to crying as their expression of distress. The health professionals therefore occasionally offered counselling and words of encouragement to such mothers. Some mothers also received financial help from doctors.

Two mothers who had emotional support shared:

“The counsellor called me and asked what I have heard about my child... and she said she will be fine and said I should not cry because if I cry the baby becomes sorrowful” (P10, 30 years, 33weeks).

“The doctors realized that there was an issue, so they started advising me” (P13, 39 years, 32 weeks).

Others who had informational support also narrated:

“The health professionals give me suggestions on how to take care of her” (P17, 38 years, 36 weeks).

“The doctors spoke to us and gave us information, so followed suit what they said and it helped me greatly” (P1, 31 years, 34weeks).

One mother also expressed how she received financial support:

“...some doctors helped me to pay the rest of my bills” (P8, 37 years, 30weeks).

The findings of the current study confirm a study by Galeano and Carvajal, (2016) that, mothers are able to adequately care for their preterm infants because of the information they receive from healthcare professionals.

The emotional support that the mothers had at the NICU is very likely to have helped them calmed down, thereby became hopeful that their infants would survive. A study conducted in Iran by Arzani *et al.* (2015) showed that, emotional support from people helps boost the assurance of mothers’ ability to care for their preterm infants and reduces stress in childcare. Again, this study confirms a study in Iran which shows that emotional support helps mothers to be hopeful that their infants will survive (Heydarpour *et al.*, 2017). Mostly, doctors are known to provide more formal support like informational and emotional support (Suraju 2013), however, as revealed in this study, some received financial support from doctors.

#### **4.6.4 Strangers**

Additionally, some mothers had support from people they did not know. It was discovered in the study that strangers sometimes went to hospitals and paid for the hospital bills of people who could not afford them. Two mothers were privileged to have benefited from such benevolence while at the NICU. However, they did not get a chance to meet such benevolent people.

The mothers narrated:

“One man came to devote himself to pay for one of the twins' bills. Even though we don't know him o, we don't know him” (P3, 31 years, 31weeks).

“When I was discharged someone came to pay my bill for me and I didn’t even know or see the person” (P8, 37 years, 30weeks).

This finding is not surprising because, recently, a lot of anecdotal evidence show that many philanthropic activities have focused on helping mothers pay for hospital bills. This happenings at NICU are consistent with a study by Smith (2020) on how families experiencing stressful situations survived through the kindness of strangers. He found that families and their children coped better and survived with the kindness, goodwill, and help provided by these strangers.

#### ***4.6.5 Friends and religious groups***

Some mothers also had their friends and church members support them in diverse ways. A person's affiliation to a religious group is seen as a contributing factor to reducing psychological stress (Chatter *et al.*, 2015). Such affiliation helps members of the group to feel a sense of belongingness, since members of the group provide social support to others in times of crisis (Crescioni & Baumeister 2013). The church sometimes provides financial support, material support, or emotional support. Also, support from friends is deemed essential to mothers because it is associated with decreased levels of postpartum distress (Shaw *et al.*, 2013).

Three mothers from this study confirmed support from friends and church members, as cited below:

“... but the church, they have been so supportive in terms of finance, in my injection, someone bought two months injection worth 3000 for us for free” (P5, 29 years, 31 weeks).

“Even friends, someone will call you and tell you to take this and use it to buy a drug for the baby” (P8, 37 years, 30weeks).

“My church folks who encourage me” (P16, 31 years, 30 weeks).

Mothers received support from religious groups and friends. A mother had her friends supporting her with an amount of GHS 3,000. This is consistent with Velit & Akum's (2018) research which revealed that mothers received support from friends and religious groups.

#### **4. 7 Conclusion**

In conclusion, mothers formed various experiences at the NICU and home. These challenging experiences may disrupt the different roles performed in the family, hence, affecting family resources. Resources such as finances, adequate time, family bond and social support helped families to manage the challenging experiences. Some families were able to build resilience and adjust successfully with time, thereby restoring the family system. However, some were still facing challenges in restoring the family to its original system.



## CHAPTER FIVE

### 5.0 SUMMARY, CONCLUSION AND RECOMMENDATIONS

#### 5.1 Introduction

This chapter shows the summary of the research findings, conclusion and recommendations based on the findings of the study.

#### 5.2 Summary

Preterm birth is documented to come with associated stress that can put families in crises and for families to cope successfully, it will be dependent on the available family resources. However, research on coping resources used by families with preterm infants is limited in Ghana. Literature tends to focus on experiences, challenges and sometimes coping strategies. Yet for coping to be successful, there are certain resources required for families to employ in adjusting the crises. This research therefore sought to investigate those resources. A qualitative approach using exploratory-descriptive design was used to interview 19 (19) respondents using a semi-structured interview guide. Data was analyzed manually along four predetermined themes, which were: mothers' experiences during hospitalization, mothers' post-NICU experiences, coping resources parents used and support systems. 17 sub-themes emerged from the interviews conducted. The findings of this study showed that, mothers' experiences were organized around baby's health, family members' reactions, baby's nutrition, and NICU experiences. These factors tend to increase their stress levels. Also, it was found that mothers faced challenges in terms of inadequate resources for childcare, lack of social support and delayed developmental milestones, which in turn affected preterm parenting. Again, this study found some useful resources which mothers used to cope, such as: time,

material resources, emotional resources and spiritual resources. They explained that the resources helped them overcome stress and contributed to their infants' survival. Support from husbands, extended families, children, strangers and health professionals was of great benefit to the preterm mothers, as it enabled them care for the infants at NICU and at home well. The support came in various ways such as financial support, information accessibility and support in household chores.

### 5.3 Key Findings

1. The preterm birth experiences mothers formed started right after the birth of their infants. They formed these experiences from factors such as unexpected long stay at NICU, as well as the appearance and size of the infants. Additionally, family members' reactions such as insensitive comments discouraged the preterm mothers from pressing on in such moments.
2. Moreover, mothers shared some post-NICU experiences they had. They formed their post-NICU experiences around factors like infants' health at home, variations in parental care, preterm care and work, among others. With regard to infants' health, some mothers were readmitted, as a result of infections, and others had problems with exclusive breastfeeding. In terms of temperature regulation, the mothers used either the KMC method or overdressing.
3. Some mothers were also challenged in terms of finances, time, good clothing for the infants, and support system. As such, parenting the preterm infants became difficult which might have increased their stress levels. Some mothers were compelled by the situation to put their jobs on hold in order to make time for their infants. Others had their family relationships negatively affected.

4. Finally, the mothers explained how resources at their disposal helped them to navigate through the preterm birth event. They used resources such as time, money, medication, faith, inner strength and positive mind-set among others to cope with the care of preterm. These resources helped mothers manage the demands of parenting a preterm, made good decisions concerning childcare and helped their ‘tiny’ babies gained desired weight. Aside the aforementioned resources, some mothers overcame with the support and encouragement from doctors, strangers, partners and some extended family members. These support mothers had from the NICU and at home were essential in helping them cope with the hopelessness in preterm care.

#### **5.4 Contributions of this study to the knowledge gap**

In a resource limited country like Ghana, the management of resources are very crucial especially in the case of preterm birth. This study therefore addressed the minimal research on coping resources available to parents with preterm children. The few literature in Ghana and South Africa (Sih, 2014; Suraju, 2013; Velit & Akum, 2018), discovered that mothers coped with reliance on religion and insight in babies demands. The findings of this study discovered emotional resources (positive mindset and inner strength) as an important resource parents relied on. Again, material resources (space and efficacy of drug) helped mothers pull through various challenges.

Also, the findings of this study contribute to the social support mothers with preterm had during hospitalization. Various literature (Heydarpour *et al.*, 2017; Suraju, 2013) revealed that doctors usually provide formal support such as informational and emotional support. However, it was ascertained in the current study that doctors provided some financial support to mothers who were overwhelmed with the NICU bills.

## 5.5 Conclusion

The researcher was interested in investigating the coping resources parents with preterm infants use in Accra. The researcher wanted to know about the experiences of parents with preterm babies during hospitalization and at home. The findings of the study showed that parents with preterm babies are exposed to various factors such as unexpected long stay at NICU, infants' health at home, variations in parental care, among others which explained their experiences during hospitalisation and after discharge. Also, in answering the research question on resources used by parents to cope with preterm care, it was identified from the findings that, parents used resources at their disposal such as time, money, medication, faith and positive mind-set among others to cope with the care of preterm. Finally, the support system that was available to mothers as they expressed were from the nuclear family, health professionals, strangers, and others at the NICU and home was essential in helping them cope with preterm care.

## 5.6 Recommendations

1. The findings showed that financial resource was a challenge for most mothers and a vital resource that ensured baby's survival. In Ghana, the NHIS and the Ghana Under-five infant health policy, despite their numerous benefits, do not cover any large amount of NICU charges. Therefore, these policies should be expanded to include NICU charges, laboratory tests and medications, to help parents in such difficult moments.
2. Also, the findings of the study revealed how information was an essential resource that helped mothers to cope. It is therefore recommended that; the Ministry of Health should intensify information on preterm birth given to pregnant women during antenatal clinic. Pregnant women should also be encouraged to start planning towards delivery as soon as they start the antenatal clinic because there could be a possibility of a preterm birth

even though it is rarely anticipated.

3. Finally, it was identified that some mothers who were formally employed had to resign, while others had to take their infants to work. Therefore, the Ministry of Employment and Labour Relations should review labour laws regarding maternal leave policy in Ghana, for mothers who delivered preterm to apply for extended leave. Alternatively, maternity leave could be revised to at least 6 months in order to give mothers enough time for them and their infants to fully recover postpartum. Also, fathers should be granted paternal leave in order to support their wives, considering the relevance of their support, as revealed by this research.



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## APPENDIX A: CONSENT FORM

**Principal investigator:** Alberta Opoku-Mensah

**Telephone number:** 0261601929

I am MPhil Home Science student of the School of Agriculture, College of Basic and Applied Sciences, University of Ghana, Legon and conducting a study and would like you to take part.

**Purpose of the study:** To explore and describe the experiences of mothers caring for their preterm infants in the Accra Metropolis.

**Method:** To be part of this study, you must have been delivered preterm baby, admitted at the Neonatal Intensive Care Unit (NICU), discharged and caring for the preterm baby at home. The preterm baby must be between the ages of three months to 18 months. Also, mothers who can speak English and are 18 years and above would be involved in the study. You have the free will to decide whether you want to take part in the study or not. If you agree to take part, your cooperation will be needed. You will be given an agreement form, and you will have to give your consent by signing the agreement form. The researcher will interview you for at least one hour to understand resources available to parents and how they are coping with the event of preterm birth. There is no right or wrong answer; you are free to express any opinion or sentiments. It will be scheduled at your convenience. You may be interviewed twice. The second will be needed if an issue raised during the first interview session needs to be clarified. The interview will be tape-recorded and transcribed. You may ask to have the tape-recorder turned off at any time during the interview.

You will be asked to read the interview text to correct errors or to add anything you think is important. You are free to opt out of the study at any time if you wish. Your decisions to participate in the study or not will not in any way affect your medical attention at the NICU clinic.

**Benefits of the study:** this study will provide the opportunity for mothers to express how they feel about the event and how they are coping as this will be an opportunity for them to vent out built up emotions if any. Also, this study will help other mothers to know the right resources to help them cope easily with having a preterm baby.

**Possible Risks and Discomfort:** There is no harm involved in this study. If you feel uncomfortable participating at any time during the interview, you are free to opt out without

hesitation. Some mothers may feel upset after talking about caring for their infants or break down into tears. If this occurs, support or assistance will be provided through counselling by the researcher

**Confidentiality:** The venue and time will be arranged such that no one will hear of what you say. Your name will not be mentioned during the recording of the interview, when you give me personal information about yourself. Your name will only appear on the agreement form which will only be read by my supervisors and me. Your name will not be used when the results of this study are presented or published. Anything you tell the researcher will be confidential unless the law requires us to report it (A person tells the researcher that she intends to harm herself or the baby). All materials such as consent forms, audio tapes and transcripts will be stored in a locked cabinet, in a locked office for five years after the study is over. It will then be destroyed. If they are needed for further studies, ethical clearance will be sought. You are free to ask me any question at any point during the research for clarification.

**Compensation:** There would compensation (one pack of detergent per a participant) at the end of the study. Compensation will be done after respondents have finished interview session.

**Voluntary Participation and Right to Leave the Research:** Participation in this study is voluntary. You do not have to answer any question you do not want to without explaining why. You may withdraw from the study at any time without penalty.

#### **Contact for Additional Information**

If you have any concerns about this study or about your rights as a research participant, please call the researcher on 233-261601929. or email: [opokumensahalberta@gmail.com](mailto:opokumensahalberta@gmail.com)

#### **Your right as a Participant**

- If you have any issues on your rights as a participant you can contact the address below:

**Administrator, Ethics Committee for Basic and Applied Sciences**

**College of Basic and Applied Sciences**

**University of Ghana**

**P. O. Box LG 68**

**Legon – Accra**

**IP No.: 3014**

**Email: [ethicscbas@ug.edu.gh](mailto:ethicscbas@ug.edu.gh)**

Section C- VOLUNTEER AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and I am willing to give consent for me, my child/ward to participate in this study. I have not waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

\_\_\_\_\_  
Name of Volunteer

\_\_\_\_\_  
Signature or mark of volunteer

\_\_\_\_\_  
Date

**If volunteers cannot read the form themselves, a witness must sign here:**

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

\_\_\_\_\_  
Name of witness

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
Date

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

\_\_\_\_\_

Name of Person who obtained Consent

---

Signature of Person who obtained Consent

Date



## APPENDIX B: INTERVIEW GUIDE

### SECTION 1- DEMOGRAPHICS

Can you please tell me about yourself?

1. Age
2. Gender (use of ARS if multiple)
3. Occupation
4. Number of other children
5. Baby's month as at the time of interview
6. Marital Status
7. Educational Level
8. Gestational age
9. Baby's birth weight and gender

### SECTION 2 – EXPERIENCES

1. Tell me about your experiences with having a preterm child?
2. How was the family's reaction when they first learnt that the baby was premature?
3. How has managing the baby's health at home been like? Cries, temperature, bathing, diapered,
4. How has feeding the baby been/ care of the baby-how many times, what, exclusive, pattern
5. Have parental roles differed in any way with the preterm child?
6. Has been any readmission after discharge?

### SECTION 3- CHALLENGES

1. What have been some of the challenges associated with parenting a preterm baby at home? Developmental milestone
2. How has combining parenting a preterm and work been?

3. How has the whole event affected the family?

#### SECTION 4- COPING RESOURCES

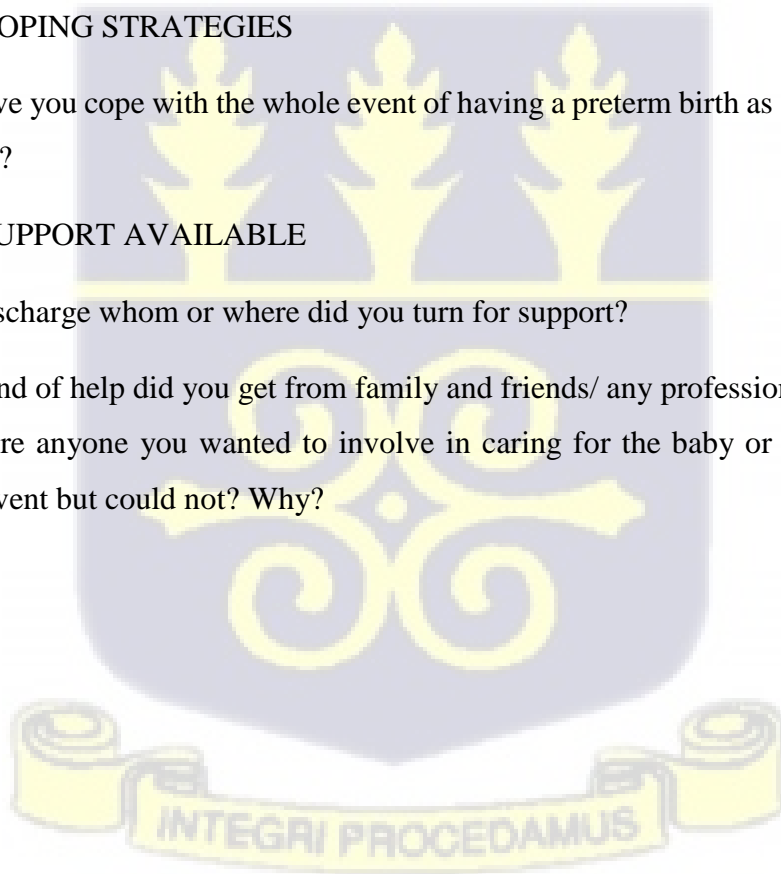
1. What things (resources) have helped you cope with parenting a preterm?
2. How were these resources obtained?
3. What other resources did you think would have made coping better if you had?
4. How did that affect parenting the child?
5. How has these resources helped in dealing with the event of preterm birth?
  - a) Time
  - b) Finances
  - c) Communication
  - d) Family bond

#### SECTION 4- COPING STRATEGIES

1. How have you cope with the whole event of having a preterm birth as an individual and a family?

#### SECTION 5- SUPPORT AVAILABLE

1. After discharge whom or where did you turn for support?
2. What kind of help did you get from family and friends/ any professional help?
3. Was there anyone you wanted to involve in caring for the baby or talk to about the whole event but could not? Why?



## APPENDIX C: ETHICAL APPROVAL

In case of reply the number  
And the date of this  
Letter should be quoted

My Ref. No.....

Your Ref. No.....



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14<sup>th</sup> May, 2021

ALBERTA KORLEKIE OPOKU-MENSAH  
DEPARTMENT OF FAMILY AND CONSUMER SCIENCES  
P.O. BOX LG 91  
UNIVERSITY OF GHANA

INSTITUTIONAL APPROVAL: KORLE BU TEACHING HOSPITAL-SCIENTIFIC  
AND TECHNICAL COMMITTEE/INSTITUTIONAL REVIEW BOARD (KBTH-  
STC/1RW00026/2021

Following approval of your study entitled "The birth of preterm Children and Socio-Cultural dimensions of How parents cope in Accra, Ghana" by the Korle Bu Teaching Hospital-Scientific and Technical Committee/ Institutional Review Board.

I am pleased to inform you that institutional approval has been granted for the conduct of your study in Korle Bu Teaching Hospital.

Please contact the Head of Department to discuss the commencement date of the study.

Please note that, this institutional approval is rendered invalid if the terms of the Institutional Reviewed Board/Scientific and Technical Committee approval are violated.

Sincere regards,

Dr. Ali Samba  
Director of Medical Affairs  
For: Chief Executive

## APPENDIX D: INTRODUCTORY LETTER

MEDICAL DIRECTORATE  
KORLE BU TEACHING HOSPITAL

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14<sup>th</sup> May, 2021

THE HEAD  
DEPARTMENT OF CHILD HEALTH  
KORLE BU

LETTER OF INTRODUCTION - ALBERTA KORLEKIE OPOKU-MENSAH "THE BIRTH OF PRETERM CHILDREN AND THE SOCIOCULTURAL DIMENSIONS OF HOW PARENTS COPE IN ACCRA. GHANA"

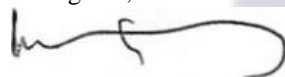
I have the pleasure to introduce to you the above-named Investigator from Department of Family and Consumer Sciences, University of Ghana, Legon. Alberta Korlekie Opoku-Mensah sought and has been granted approval to conduct a study entitled 'The birth of preterm Children and Socio-Cultural Dimensions of How parents cope in Accra, Ghana'.

She is to contact you to discuss the commencement date of the study.

Please verify her identity with a government issued National ID card and accord her the needed assistance.

Attached is the Scientific and Technical Committee and Institutional Review Board approval, which specifies the terms.

Sincere regards,



Dr. Ali Samba  
Director of Medical Affairs  
For: Chief Executive

