

UNIVERSITY OF CAPE COAST

EXPERIENCES OF MOTHERS WITH PRETERM BABIES ON SUPPORT  
SERVICES IN NEONATAL INTENSIVE CARE UNIT AT TECHIMAN  
HOLY FAMILY HOSPITAL

BY

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## DECLARATION

### Candidate's Declaration

I hereby declare with certainty that this thesis is the outcome of my own original research and that no part of it has been presented for another degree in this University or elsewhere.

Candidate's Signature ..... Date: .....

Name: Dominic Bachegejoa Apedani

### Supervisors' Declaration

We hereby declare that the conduct and presentation of this thesis were supervised in accordance with the guidelines on the supervision of the thesis outlined by the University of Cape Coast.

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## ABSTRACT

Hospitalization of a preterm baby presents significant burden to parents especially the mother. This study explored the experiences of mothers of preterm babies on support services in the Neonatal Intensive Care Unit (NICU) at the Techiman Holy Family Hospital. The study utilised an explorative descriptive qualitative case study design with homogenous purposive sampling of mothers of preterm babies admitted in the NICU. In-depth interviews were conducted with a semi-structured interview guide until data saturation was reached. The interviews were audio taped, transcribed and analysed using thematic content analysis. The findings showed that mothers were generally provided with tangible (sleeping room, mattresses, bath rooms and toilets) and intangible support services (counselling, and health education) from nurses and doctors in the NICU. However, these support services were not adequately available to meet the needs of the mothers. The findings also showed that the few support services that were available in the unit were accessible and acceptable by mothers. Nonetheless, certain factors were identified that could positively or negatively affect effective utilization of support services including attitude of staff, experiences and skills of staff, attitude of mothers, communication and feedback and early discharge. Based on the findings of the study, it is recommended that the hospital management should take steps to refurbish the NICU and institute policies that allow interdisciplinary collaboration among staff such as doctors, nurses, counsellors, dieticians, social workers and health promotion officers in providing holistic care to preterm mothers.

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## DEDICATION

This research work is dedicated to my wife, Joyce Awudanjong, my children Nestor and Jefferson.

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## LIST OF ABBREVIATIONS

BFHI	Baby-Friendly Hospital Initiative
CAM	Complementary and alternative medicine
CHAG	Christian Health Association of Ghana
CS	Cesarean section
ENC	Essential Newborn Care
FCC	Family Centred Care
GA	Gestational Age
HIRD	High Impact Rapid Delivery
IMNCI	Integrated Management of Neonatal and Childhood Illnesses
IRB	Institutional Review Board
KMC	Kangaroo Mother Care
LMP	Last Menstrual Period
LPIs	late-preterm infants
NICU	Neonatal Intensive Care unit
NIPU	Neonatal Intensive Parental Unit
PPROM	Pre-labor Premature Rupture of Membranes
RISE	Rural Initiative for self-empowerment
SDG	Sustainable Development Goals
SVD	Spontaneous Vagina Delivery
THFH	Techiman Holy Family Hospital
UCC	University of Cape Coast

## CHAPTER ONE

### INTRODUCTION

#### **Background to the Study**

The experience of preterm birth is an unanticipated predicament for parents especially mothers (Altimier & Phillips, 2016). When preterm birth occurs, the role of parents is often replaced by technology and mothers have to entrust the care of their vulnerable infants with uncertainties into the hands of Neonatal Intensive Care Unit [NICU] staff (Ardal, Sulman & Fuller-Thomson, 2011; Roberts, 2005).

Preterm birth is defined as childbirth occurring at less than 37 completed weeks or 259 days of gestation (World Health Organization [WHO], 2018). A study based on data from 184 countries suggests a worldwide estimate of 15 million preterm births for the year 2015, representing 18 percent of all live births, and currently more than 15 million preterm births worldwide, with 5 percent in several European countries and 12 percent in the United States (Blencowe et al., 2013). However, there is a dramatic survival gap between high income and low-income countries, with more than 90 percent of the infants born before 28 weeks' gestation surviving in the former, while only 10 percent or less survive in the latter (Howson, Kinney, McDougall & Lawn, 2013).

Other researchers have reported that approximately, 11 million (85%) out of 12.9 million worldwide estimates of preterm births in 2005 were found in Africa and Asia, while about 0.5 million occurred in each of Europe and North America (excluding Mexico) and 0.9 million in Latin America and the Caribbean. The highest rates of preterm birth were in Africa and North America, 11.9% and 10.6% of all births, respectively while a recent Greek

epidemiological study shows a similar increase in the country over two-fold within the past three decades, accounting for 9.62 percent of live births in 2008 when the rate in 1980 was 4.66 percent. (Baroutis et al., 2013; Beck et al., 2010).

Several reasons account for the admission of preterm infants in the Neonatal Intensive Care Unit (NICU) including prematurity, sepsis, and respiratory difficulty. Parental experience especially mothers of these infants can be particularly distressing because of the struggle with an unfamiliar and potentially threatening environment of an intensive care unit which to a larger extent affects the development of parenting roles (Cleveland, 2008; Padovani, Carvahó, Duatre, Maertinez & Linhares, 2009).

Psychological support and other support systems for NICU mothers drastically reduce their feelings of stress. Mind-body interventions, which constitute a major portion of the overall use of complementary and alternative medicine (CAM), can also provide support. These techniques are designed to enhance the mind's capacity to affect bodily function and symptoms (National Center for Complementary and Integrative Health [NCCIH], 2015).

Evidence on supportive services for mothers of preterm babies shows that some interventions which were implemented during hospitalisation and post-discharge such as the Newborn Individualised Developmental Care Assessment Program, Kangaroo Mother Care, and the Infant Behavioral Assessment & Intervention Programme improved mothers' self-efficacy to care for their preterm babies (Nygqvist et al., 2010). Also, similar studies that were focused on pre and post-hospitalisation interventions such as Creating Opportunities for Parent Empowerment (COPE) and the Mother-Infant Transaction Programme (MITP) both of which sought to bridge the transition from the neonatal intensive

care unit to home revealed that mothers who had these supportive services while in the neonatal intensive care unit experienced less stress and better empowered to care for their babies than women in the control groups (Koldewijn, 2010; Kynø, Ravn, Lindemann, Smeby & Torgersen, 2013; Melnyk et al., 2006).

Again, other studies that were conducted to evaluate parent-to-parent peer support revealed that mothers who participated in peer support experienced less stress, reduced anxiety, and depression. The programme primarily consisted of educational parental support-group meetings and the parent buddy programme where individual parent-to-parent support, primarily telephone support given by a parent experienced with the NICU to a parent of preterm infant (Preyde & Ardal, 2003; Roman et al., 1995).

Mothers and fathers, whose infants are admitted to a NICU, perceive their preparation as very important. In other studies, mothers reported that a tour of the NICU was a stressful event; some mothers stated that they were shocked at the size of some of the very preterm infants. However, findings show that although it is stressful, acquainting mothers with the NICU is beneficial. Also, all of the parents who had received the neonatal unit information booklet found it helpful in assisting them to cope with the stress of the NICU (Raeside, 1997; Turan, Basbakkal & Ozbek, 2008).

Relatedly, other researchers reported the effects of family-centred care, skin-to-skin care, and breastfeeding support on the stress of mothers of preterm babies in the NICU. The findings of these studies generally show that these supportive services were relevant in reducing the stress of parents. The family-centred nursing practice encompasses nurses' role of giving confidence to

mothers by supporting them emotionally, promote mother-infant attachment, and provide information devoid of medical terminologies on infant care to the mothers. Breastfeeding policy guidelines as well as systematic breastfeeding training for the staff were commonly available and effectively utilised. Seventeen NICUs in one of the studies that was conducted in Denmark recommended starting breast milk expression within 6 hours after birth, and mothers were encouraged to double pump to ensure that breast milk was available to the babies. Also, most NICUs in Denmark initiated skin-to-skin contact, the first time the parents were in the NICU, and daily skin-to-skin contact was estimated to last for 2-4 hours in 63% and 4-8 hours in 37% of the units ( Maastrup, Bojesen, Kronborg & Hallström, 2012; Turan, Basbakkal & Ozbek, 2008).

However, limited studies took into account a relevant dimension of enquiry on the views of mothers concerning whether support services exist in the NICU or not and what constitutes appropriate support services to them in the NICU. It is suggestive that patients' participation and choice of care as well as evaluating the care received in nursing are paramount to their psychological, physical and physiological wellbeing (Morgan & Yoder, 2012). Therefore, research that elicits the views of parents about the treatment they receive at NICU is required.

Again, most studies that have investigated the issue were experimental and quantitative in nature and mostly conducted in Europe, American and other countries with high financial resources. Limited research has been conducted on the issue in African and other countries with low financial resources including Ghana (Bergh, et al., 2012).



Limited studies also looked at the holistic view of the support services to see how they can complement each other to meet the needs of mothers of preterm babies in the NICU. This is equally a major gap in the literature that warrants further studies to assess qualitatively the supportive services available to mothers in NICU. Given the gaps in international literature that have been outlined, it is important that research that focuses on parents' perspectives, using qualitative approaches are required to understand the phenomenon in countries with low financial resources. Therefore, this study that seeks to explore mothers' experiences in Ghana is important.

Preterm births in Ghana continue to increase with consequences of neonatal deaths. Neonates comprise 38% of childhood mortalities under age 5 in underdeveloped countries like Ghana. Other researchers have maintained that a high number of neonatal deaths are caused by prematurity and not much decline in the newborns' proportion of under-five mortality has been achieved (Parga, Udofia & Punguyire, 2011; Siakwa, et al., 2014).

This trend is more apparent in the Brong Ahafo Region. A study conducted by Waggeh (2016) revealed birth asphyxia, neonatal sepsis, and prematurity as key determinants of neonatal mortality. However, it appears Ghana's effort to tackle prematurity-related neonatal deaths has focused more on only the preterm babies such as Essential Newborn Care (ENC), the Baby-Friendly Hospital Initiative (BFHI), the Integrated Management of Neonatal and Childhood Illnesses (IMNCI), and High Impact Rapid Delivery (HIRD) with little evidence on supportive services for parents especially mothers which will improve their self-efficacy to care for their preterm babies (Bergh et al. 2012). This is a gap irrefutably worthy of exploration.

## Statement of the Problem

Although modern advances in perinatal medicine have occasioned a significant increase in the survival rates of preterm infants over the last decades, what remains substantial and problematic is the emotional distress of the parents produced by preterm birth and its subsequent hospitalisation to the Neonatal Intensive Care Unit. Devastating as this problem may be in most NICUs in Ghana, not enough attention has been paid to the well-being of the whole family to ensure that when babies are going home, they are discharged to parents who have been provided enough care and support to demonstrate their resiliency and readiness to care for all their baby's needs (Bouras et al., 2015; Hall, Phillips & Hynan, 2016).

As posited by Meijssen, Wolf, Koldewijn, van Baar and Kok ( 2011), during and after hospitalisation of a preterm baby, care for the fragile preterm infant often places a burden on the parents, particularly on the mothers who in general play a major role in caregiving. However, few studies have evaluated the availability and efficacy of support services and interventions for women in preterm labor and care for preterm babies in NICUs in Ghana. Women in preterm labor who have been treated with tocolytic medications often results in additional stress due to the separation from home and family, lack of privacy, hospital discomfort environment, restricted activities, and the anxiety about preterm birth and the baby's outcome (Heaman & Gupton, 1998; Kao, Hsu, Tien & Chen, 2017).

In Ghana, Preterm deaths continue to pose danger to Ghana's efforts in achieving the Sustainable Development Goal number 3 (SDG 3), which aims to end preventable deaths of newborns and children under 5 years of age by

2030 with all countries looking to reduce neonatal mortality to at least as low as 12 per 1000 live births and under-5 mortalities to at least as low as 25 per 1000 live births. Gyasi (2017, November 16), reported that the Director of Rural Initiative for Self-Empowerment [RISE], an NGO in Ghana indicated that in 2015 alone, an estimated 128,000 babies were born prematurely in Ghana and an estimated 8,300 neonatal deaths in 2015 were associated with prematurity.

The Brong Ahafo Region has consistently recorded increased neonatal mortality rates between 2014 and 2016 recording the highest values of 5.8%, 7.6% and 8.7% of 1000 live births as against the Ashanti Region with the lowest values of 1.2%, 2.0%, 2.6% recorded within the same period (GHS, 2016). Undoubtedly, mothers of these preterm babies in the Neonatal Intensive Care Units often suffer hopelessness and will require support services that will enable them to cope with their fragile neonates. Unfortunately, most health facilities in Ghana lack simple care and quality services for mothers (Parga et al., 2011).

Also, despite the large body of knowledge on the efficacy of support services for mothers of preterm babies in the NICU in other parts of the world, limited previous studies have examined the experiences of mothers of preterm babies on the support services for preterm babies in Neonatal Intensive Care Unit in Ghana. It is against this background that this study seeks to explore mothers' experiences about supportive services they receive in the NICU of the Techiman Holy Family Hospital (THFH) in the Bono East Region.

### **Purpose of the Study**

The purpose of this study was to explore the experiences of mothers on support services in the NICU of the THFH of the Bono East Region.

Specifically, the study will; describe the support services available to mothers in the NICU of THFH, identify the extent of utilisation of these support services available to mothers in the NICU of THFH and describe factors that facilitate or hinder effective utilisation of available support services to mothers in the NICU of THFH.

### **Research Questions**

1. What support services are available to mothers of pre-term babies in the NICU?
2. What is the extent of utilisation of support services available to mothers in the NICU?
3. What factors hinder or facilitate the utilisation of support services for mothers in the NICU?

### **Significance of the Study**

This study provides insight into the support services that are available to mothers of preterm babies in NICU as well as bring to bare the factors that facilitate or hinder effective utilisation of available support services for mothers and their babies in the NICU of the THFH. The findings of this study will help the facility, policymakers and programme implementers to design evidence-based supportive services for mothers of preterm babies. Additionally, the availability of evidence of this study at the regional level will be relevant in documenting issues affecting NICU services in the region. Ultimately the findings of the study will inform services delivery that will impact on the regional efforts in improving maternal and child health.

### **Delimitation**

This study was delimited to mothers with preterm babies who had gestational age less than 37 weeks and are on admission in the NICU of the THFH. Mothers of preterm babies whose gestational ages did not fall in the range of fewer than 37 weeks were not included in the study.

### **Limitations**

The findings of this study may be applicable to only settings that are similar to the study area. Another limitation of this study is the fact that mothers' length of stay in the NICU may influence their experiences of support services differently. Finally, participants' previous NICU experience, their professional background as well as their relationship with NICU staff could also influence the care they receive which can greatly affect their experiences differently.

### **Organisation of the Study**

The study was planned into five (5) chapters. Chapter one is essentially an opening chapter that focused on the general concepts and what is currently known about the subject matter, that is support services at NICU. The chapter includes background information, statement of the problem, the purpose of the study, research questions, significance of the study. It also captures the delimitation and limitations of the study.

Chapter two reviews pertinent theoretical and empirical literature with respect to the study. It summarised the status of current research, theories, and models and identify gaps in literature that require to be addressed.

The third chapter deals with the methodological aspects of the study. It included the research design, the study area, population, sampling procedure, data collection instruments, data collection procedure, data processing and analysis, ethical issues and how they were addressed. The fourth chapter covered a detailed presentation of the study results, starting with the socio-demographic characteristics of participants and discussion of the study findings. It takes into consideration the findings of the present study against the findings of previous studies related to the topic. Finally, chapter five entails a summary of results, conclusions, and recommendations drawn from the study.

## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

This study explored the experiences of mothers with preterm babies on support services available in the Neonatal Intensive Care Units [NICU] of the Techiman Holy Family Hospital [THFH) of the Bono East Region. Specifically, the study; described the support services that are available to mothers in the NICU of THFH, identified the extent of utilisation of support services available to mothers in the NICU of THFH and described factors that facilitate or hinder effective utilisation of available support services to mothers in the NICU of THFH.

This chapter focuses on a review of some theoretical, conceptual and empirical studies by other authors relevant to the study. As posited by Hart (2018), the review of literature helps in instituting a conceptual and theoretical orientation to the research problem; it develops the significance of the research and it is a means to discover new information. The chapter, therefore, reviews relevant literature using following search terms; "support services", "mothers of preterm babies "or "parents of preterm babies and "Neonatal Intensive Care Unit" in electronic databases such as; EBSCOhost, Hinari, Pubmed and google scholar. The boolean operators, wild cards and database vocabulary helped to combine and refine search results. Publications of studies in English within the past ten years both globally and locally on support services for mothers of preterm babies were retrieved. However, relevant articles that are beyond ten years were also considered. Other non-published grey materials such as textbooks, and secondary data from the study area were also sought in this study.

### **Concept of Preterm Birth**

Prior to the 19<sup>th</sup> century, the concept of preterm was understood as infants without vitality and coined as "tiny new-born" with a lot of uncertainty regarding whether their frailty reflected immature development or some kind of hereditary taint (Heshmat, 2010). Cone as cited in Rukweza, Haruzivishe, Gidiri & Nziramasangae, (2017) also proffered that the words preterm and premature were not equivalent to what they mean now, and the diagnosis of prematurity was solely on the basis of birth weight of less than 2300 grams as was first mentioned by Alexandre Gueniot, between 1832 and 1935, while the care of neonates including premature babies was also regarded traditionally as the reserve of the province mothers who were assisted by midwives, mothers who breastfeed for other mothers (wet nurses), and "wise" grandmothers.

According to Harrison and Kositsky (as cited by Rukweza, et al., 2017) in the 1940s, nurses dominated in the care of premature babies while mothers and physicians were not allowed to touch the preterm babies. The nurses employed techniques such as gavage feeding, maintaining warmth, and watching for apnea as they care for such babies. However, the 1950s saw the insurgence of medical interventions including exchange transfusions for jaundice, gastrostomies for feeding, new antibiotics, mist inhalations and oxygen use for respiratory distress syndrome, which made the physicians' role become more important. Following these interventions, some series of disasters such as blindness brain damage and other handicaps occurred which at the time necessitated a lot of research into preterm birth and premature baby care. Also, following the numerous concerns, neonatal intensive care units were subsequently established (Heshmat, 2010).



An infant is considered preterm if born before 37 weeks' gestational age and very preterm if born before 32 weeks' gestational age. Preterm births can further be categorised into moderately preterm (33 to 36 completed weeks of gestation), very preterm (less than 32 weeks) and extremely preterm (less than 28 weeks) (Lawn, Gravett, Nunes, Rubens & Stanton, 2010 ; Pennell, Whittingham, Boyd, Sanders & Colditz, 2012).

The most extensively used definition of preterm birth was carved by the World Health Organization (WHO) as any birth before 37 completed weeks of gestation or fewer than 259 days since the first day of the woman's last menstrual period (LMP). This is further subdivided on the basis of gestational age (GA) as extremely preterm (less than 28 weeks), very preterm (28–<32 weeks) and moderate or late preterm (32–<37 completed weeks of gestation) (Howson, Kinney & Lawn, 2012).

Physiologically, the final months and weeks of pregnancy are very crucial for full maturity of organ systems such as the brain the lungs and liver of the growing embryo. These developments and maturity of organs which often take place during the final weeks of pregnancy will prepare the infant for the capability to sustain extrauterine conditions. When preterm birth occurs, challenges of breathing, crying, sucking, milk digestion, blood pressure control, glucose metabolism and regulation of body fluids are very imminent within the first few days of the baby's life which can result in serious disability or death (Butler & Behrman, 2007; Rukweza, e tal., 2017).

Preterm births are broadly categorised into spontaneous preterm birth where there is a spontaneous onset of labour or following pre-labour premature rupture of membranes (PPROM)) and provider-initiated preterm birth where

induction of labour or elective cesarean birth takes place before 37 completed weeks of gestation for maternal or fetal indications. The spontaneous preterm premature rupture of the membrane can result from the interplay of factors that cause the uterus to contract early before 37 completed weeks of gestation. These may be due to environmental factors, maternal history of preterm birth, genetic factors, advanced maternal age, multiple pregnancies, short inter-pregnancy intervals, and low maternal body mass index (Requejo et al., 2013).

Medically and non-medically indicated preterm births are related to early induction of labour or cesarean birth. Medical indications include pregnancy complications such as placental abnormalities (e.g. placenta preavia), multiple gestations, maternal diabetes, pre-eclampsia and pre-existing conditions such as high blood pressure, asthma, thyroid and heart disease. Other studies have implicated physical and emotional stress as causes of preterm birth (Agbla, Ergin & Boris, 2006; Blondel, Macfarlane, Gissler, Breart & Zeitlin, 2006; Muglia & Katz, 2010; Plunkett & Muglia, 2008; Requejo et al., 2013).

According to the American College of Obstetrics and Gynecologists (2016), women with short cervix, previous preterm birth, short interval between pregnancies, history of certain types of surgery on the uterus or cervix, certain pregnancy complications, such as multiple pregnancy and vaginal bleeding, lifestyle factors such as low pre-pregnancy weight, smoking during pregnancy, and substance abuse during pregnancy are risk factors for preterm deliveries. Other risks for spontaneous preterm births also include black race, periodontal disease, and low maternal body mass index.

### **Prevalence of Preterm Births and Admissions in the NICU**

It is estimated that premature births account for about 8% of total births in developed countries and up to 25% in developing countries (Pennell et al., 2012). In Australia, preterm births account for approximately 21,000 (8.4%) out of about 300,000 babies born in each year while the United State of America is lingering around 500,000 infants, or 11.7% of all live births born prematurely (<37 weeks' gestation) each year. These preterm births often require prolonged hospitalisation with evidence of an increase in mortality rates and health complications especially with decreasing gestational age which possesses intense stress to families (Lakshmanan et al., 2017).

Whereas 60% of preterm births happen in South Asia and sub-Saharan Africa, the United States and Brazil took a centre stage among the top 10 countries with the highest number of preterm births. In the United States, for instance, about one in 12 of all births is a preterm baby with approximately half a million yearly. Yet, the burden remains highest in the regions with the least human resources of which West Africa is one. Out of the 11 countries with preterm birth rates of over 15 percent, nine (9) are sub-Saharan Africa countries placing preterm birth as a global problem that requires collective and coordinated global action (Kinney, Lawn, Howson & Belizan, 2012; Lakshmanan et al., 2017; Pennell, et al., 2012).

Also, the United Kingdom has the highest rate of premature birth in Western Europe with 7% of babies born preterm (less than 37 weeks' gestation) with survival rate directly proportional to gestational age and birth weight. Among neonates admitted in the NICU, very low birth weight infants have the

longest average length of hospital stay and the highest rates of morbidity and re-hospitalisation in the first year (Gar et al., 2016; Swanson et al., 2012).

Each year, over 400 000 babies are admitted to NICU in the United States. However, out of these 400 000, about 27% of late-preterm infants (LPIs) (those born between 34 weeks to 36 weeks) are admitted to the NICU and re-hospitalised within the first 2 weeks post discharge. This invariably increased health care cost of about 3 times than full-term infants during the first year of life. These researchers, Samra et al., 2015; Boykova & Kenner, 2012; Murdoch and Franck, (2012) also established that suboptimal outcomes in LPIs, including unnecessary readmission, are not always the direct result of the prematurity but lack of engagement and support for parents ).

Again, over the past decade, the percentage of Neonatal Intensive Care Unit (NICU) admissions in China increased by a third from 19.7 to 26.2 %. However, parents are not allowed to enter the NICU during the infant's entire stay, with the care of these infants provided exclusively by medical specialists which is seen as an unfair practice on both the newborn infants and their mothers (Hei et al., 2016).

In general variations in prevalence rates exist between high, middle and low-income countries with 11.8%, 11.3% and 9.3% respectively (Blencowe, et al., 2013). Blencowe et al. (2013) added that relatively high preterm birth rates are seen in many individual high-income countries where they contribute substantially to neonatal mortality and morbidity. Of the 1.2 million preterm births estimated to occur in high-income regions, more than 0.5 million (42%) occur in the United States and in Southeastern and South Asian countries, accounting for 13.4% of all live births.

A study conducted in Ghana to investigate determinants and outcomes of preterm births in the Korle-bu Teaching Hospital revealed that out of 7801 single births that were included in the study, 1478 (18.9%) gave birth to preterm babies. The distribution of the causes of these preterm births included 879 (59.5%) spontaneous and 599 (40.5%) provider-initiated preterm deliveries. The spontaneous preterm births constituted 139 (9.4%) women with preterm premature rupture of membranes (PPROM) and 740 (50.1%) with spontaneous onset of labour without rupture of membranes. Among the 1478 preterm babies, 737 (49.9%) and 741 (50.1%) were males and females respectively (Adu-Bonsaffoh, Gyamfi, Bannerman, Oppong & Seffah, 2019).

The Techiman Holy Family Hospital also recorded similar values of preterm deliveries within the period between January 2018 and March 2019. Out of a total of 2,757 neonates admitted in the NICU, about 500, constituting 18.1% were born prematurely while mortality stood at 118 (4.3%) with majority of the mortality cases being those born preterm (Hospital Administration and Management System [HAMS], 2019).

### **Management of Preterm Birth and Prevention**

WHO (2018) has recommended guidelines useful in managing preterm labour and preterm births which include the use of steroids which are capable of crossing the placenta to cause the lungs of the baby to mature fast. Where the amniotic sack breaks before the onset of labour, antibiotics are given to prevent infection while magnesium sulfate is given to prevent future neurological impairment of the infant. Other interventions outlined by WHO include thermal

care, feeding support, kangaroo mother care, safe oxygen use, and other treatments to help babies breathe more easily.

On the other hand, other obstetric therapeutic steps involved in the treatment of preterm labour include bed rest, hydration, sedation, uterine activity monitoring, and tocolytic agents, all of which require hospitalisation (Goldenberg, 2002). Other researchers are pointing to a contrary view to bed rest that rather than benefit to the mother or baby, absolute bed rest is perceived as a negative experience for the mother, and it can have an adverse impact on the fetus (Lederman et al., 2013; Maloni, Brezinski-Tomasi & Johnson, 2001). The physiological and psychosocial changes of absolute bed rest can be accompanied by maternal feelings of fear, lack of control, powerlessness and anxiety (Kao et al., 2017; Lederman et al., 2013).

Another relevant intervention in preventing preterm labour and birth is the management of pregnant women at higher risk of preterm birth including women with pre-existing conditions such as diabetes, thyroid disease, heart disease, asthma, pre-eclampsia, antepartum hemorrhage, and multiple pregnancies. Also, identification and treatment of structural abnormalities (e.g. cervical cerclage, cervical pessary) are equally helpful in the management of women in preterm labour (Requejo et al., 2013).

Again, it is important to promote antenatal and skilled birth care for all women, educate them on smoking cessation, reduction in exposure to secondhand smoke and other pollutants and advocacy for policies to support safe motherhood and universal access to antenatal care, workplace policies regulating working hours and strenuous working conditions, professional and hospital policies to regulate infertility treatments and to reduce caesarean

section rates and early induction of labour (Requejo et al., 2013). Similarly, Kinney et al. (2012) also outlined five interventions of preterm birth to include smoking cessation, decreasing multiple embryo transfers during assisted reproductive technologies, cervical cerclage, progesterone supplementation, and reduction of non-medically indicated labor induction or cesarean delivery.

There is growing evidence that reducing risks in the preconception period improves the health of the pregnant woman and also contributes to the prevention of preterm birth (Dean et al., 2013). Dean et al. again indicated that preconception care encompasses broader initiatives such as women's education and empowerment, and more targeted health interventions such as vaccination and micronutrient supplementation in schools, primary health care facilities or community centers with support from husbands, health care providers, youth leaders and community volunteers in achieving healthier outcomes for mothers and babies.

More specifically, preventing pregnancy in adolescence by ensuring universal access to primary and secondary education for girls and provision of family planning services to adolescents is viable in preventing 15% of first adolescent pregnancies (DiCenso, Guyatt, Willan & Griffith, 2002). Relatedly, Oringanje et al. (2016) opined that multiple interventions such as health education and contraceptive-promoting interventions significantly lowers the risk of unintended pregnancies among adolescents.

It is estimated that 17% of teen unintended births are at higher risk for preterm delivery, and these mothers are more likely to have a second baby within 2 years of the first birth, which increases the likelihood of second preterm delivery (Shapiro-Mendoza, 2016). Therefore, prevention of unintended

pregnancies and promoting of appropriate spacing after a previous live birth or pregnancy loss through family planning decreases the risk for prematurity in subsequent pregnancies significantly (Dean et al., 2013).

### **Global and National Policy Interventions for Preterm Births**

Available evidence points to the fact that a greater portion of preterm babies who are born at less than 28 weeks will require neonatal intensive care services to survive, and similarly, preterm babies 28 to 32 weeks will also need special newborn care at a minimum. However, the quality and availability of these services in many low- and middle-income countries remain a challenge. These challenges give credence to the long-term consequences in survivors of preterm births in low and middle-income countries (Blencowe, Cousens, et al., 2013). Likewise, 43% of the estimated 0.9 million preterm babies surviving with neurodevelopmental impairment are from middle-income countries with marked impairment associated with survivors born extremely preterm; however, there is increasing evidence that all premature babies regardless of gestational age are at increased risk (Blencowe, Lee, et al., 2013).

In efforts to curtail the burden of preterm births especially in low-income countries, several organisations have made concerted efforts in tackling preterm birth care and prevention. These organizations among others include the Bill and Melinda Gates Foundation, Global Alliance to Prevent Prematurity and Stillbirth, March of Dimes, National Institute of Child Health and Human Development (NICHD) and the World Health Organization (WHO) working collaboratively to harness recent advances in science and technology and growing global political will from many countries to identify novel solutions that will speedily translate research results into effective global health action.



Common on the agenda of these organisations is to advance the visibility of and advocacy and investment in the research required to drive global change in the burden of preterm birth (Howson et al., 2013).

World Prematurity Day which is currently observed in more than a hundred (100) countries was founded in 2008 and formally launched in 2011 as part of efforts to amplify the awareness of the burden of prematurity and institute measures to ameliorate the debilitating effects of preterm births on families. The day was celebrated again in the year 2018 across many countries including Ghana with the theme "Working together: Partnering with families in the care of small and sick newborns" (International Medical Products, 2018).

The celebration of Prematurity Day in Ghana was marked with a lot of activities including health education in various radio stations in the Ashanti, the Bono and the Bono East Regions. Health personnel from various districts of these regions were dressed in purple colours to commemorate the day, notably among focal persons within the Bono and Bono East Regions who coordinated the celebration of the event were the pediatricians of Dormaa Presbyterian Hospital, Dr. Adoma Fokuo and Dr. Jacqueline Asibey of Techiman Holy Family Hospital. The occasion also highlighted the burden of preterm births in the country which stood at 128,000 premature births every year (GNA, 2016).

The following models were used to guide the study; Systems Model of Premature Birth, the Family Integrated Care Model and the Donabedian Quality Care Model (Beaton, 1984; Donabedian, 1980; 2002; Patel, Ballantyne, Bowker, Weightman, & Weightman, 2018; O'Brien et al., 2013).

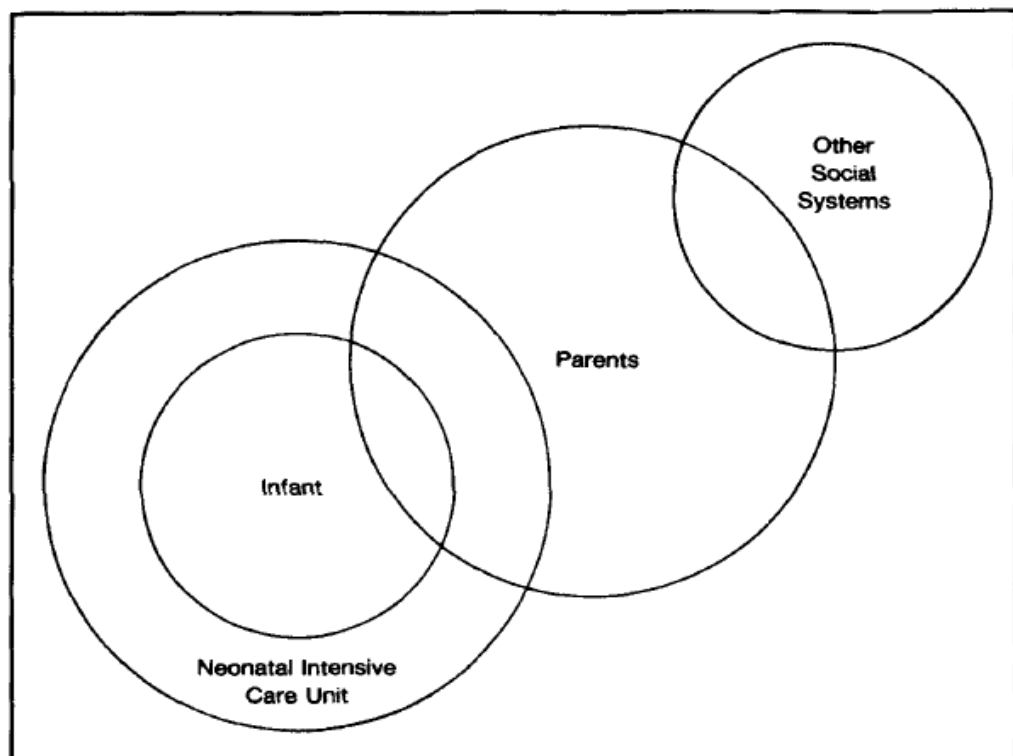
### **A Systems Model of Premature Birth (Beaton, 1984)**

The model viewed preterm birth within the context of three major interrelating and intersecting components: the infant, the parents, and the neonatal intensive care unit. The preterm infant is seen as a subcategory of the intensive care unit who is confined to the unit with little movement or interaction outside the unit. From the model, the newborn is more a part of the neonatal intensive care family constellation than his/her own family. The parents' only source of contact with their infant is through the neonatal intensive care unit. However, parents interact with both the NICU and other social systems outside the NICU. Therefore, their experiences of a crisis of premature birth will depend on their interactions with other social systems, and their experiences within the NICU particularly related to their infant. At the intersection of each component, there is an opportunity for either success or failure in terms of adaptation to the crisis of premature birth and the establishment of a healthy relationship with their infants ( Beaton, 1984).

The model also has fundamental questions in assessing the supportive needs of parents of preterm babies in the NICU. These include:

- What support systems or strategies are currently available to parents within the neonatal intensive care unit and the community? How effective are these support systems in meeting parental needs?
- What policies, rules, and regulations within the NICU are either tangibly or intangibly unsupportive of parents?
- What helpful strategies are currently used to familiarise parents with the neonatal intensive care unit, its equipment, rules, and regulations?

- What documented and useful methods are available to assess parent-infant interactions and coping abilities?
- What policy interventions and practices are routinely used to promote parent-infant interaction?
- What provision is made for the evaluation and revision of strategies used to promote parent-infant interaction? Is feedback from parents and staff sought and used in order to improve services to parents and their infants?
- What is the current knowledge level of the NICU staff regarding the determinants of parent-infant interaction, crisis resolution, and appropriate intervention strategies?
- What resources are available to the NICU to develop and institute a parent-infant programme?



**Figure 1: Systems Model of Preterm Birth**

Source: Beaton, 1984

The System Model of Preterm Birth was utilised in a study conducted to evaluate NICU care programme which involved 61 mothers of preterm infants hospitalised in the NICU and 42 mothers with term infants in a normal newborn nursery as a control group. The researchers conceptualised 5 dimensions of support for the NICU mothers to include: early contact with preterm parents to discuss the infant's condition, parental assessment of coping abilities done by social workers immediately after NICU admission, emotional support and guidance through inter-professional conferences, fostering frequent parent-infant interaction by ensuring unlimited parental visits and daily assessment of parental status during daily ward rounds. The findings of the intervention revealed no significant differences in the stress levels and coping abilities among the two groups (Dillard, Auerbach & Showalter, 1980). Inferring from the findings, it could be said that the programme was able to relieve mothers of the stress of preterm birth and helped them gained better coping abilities as their colleagues with normal term babies.

This study is in line with the systems model and seeks to examine what support services are available to mothers, how effective mothers put to use the support services available to them and what factors within the NICU or outside NICU hinder or facilitate effective utilisation of support services.

### **The Family Integrated Care (FICare) Model**

The Family Integrated Care Model by O'Brien et al. (2013) emerged from the “humane” care model in which parents provided nursing care for the infants (except for respiratory care and administration of intravenous fluid and medication), while nurses provided teaching and guidance to parents. The

FICare Model was developed for the Canadian NICU, to completely integrate parents into the NICU care team. The principle of FICare is that in the NICU, families should be supported, educated, and empowered to provide as much of their infant's care as they are able. The model has four domains which include; educational support, environmental support, inter-professional support and psychosocial support which are necessary to provide social, psychological, and physical supports that enable greater parents participation in the care of their baby (O'Brien et al., 2015).

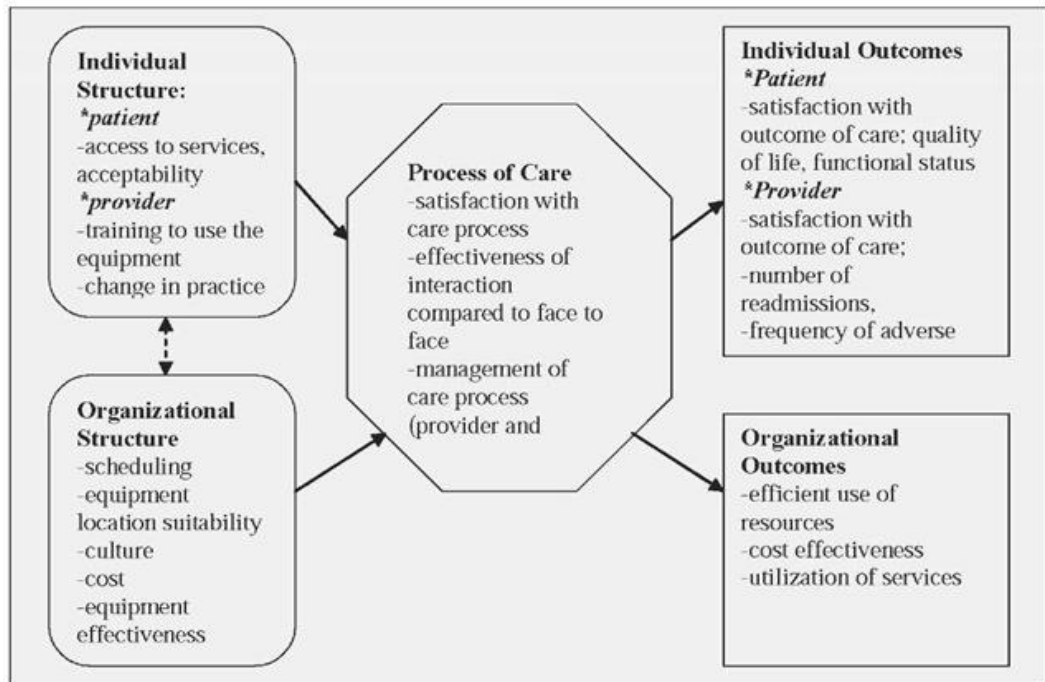
In a pilot case-control study of the FICare programme which was conducted at the Mount Sinai Hospital, Toronto, mothers in the cases group of the family integrated care had their stress scores significantly reduced. There was also a significant increase in the rate of breastfeeding at discharge which resulted in significant weight gain in infants on the Family Integrated Care Model compared with control infants. In effect, the feedback regarding programme implementation from the parents and nurses was very positive (Staub, Baardsnes, Hébert, Hébert & Newell, 2014).

The FICare Model of care has advantages of potentially improving infant outcomes, decrease parental stress and anxiety, and using minimal resources including duration of oxygen therapy, incubator care and length of hospitalisation in the NICU. The improvement of neonatal outcomes by FICare significantly reduces mortality and morbidity post-NICU discharge. In addition, FICare aims to increase the confidence and capability of parents to care for their fragile preterm infants when they go home, which may reduce the need for post-discharge support for families, outpatient clinic visits, re-hospitalisations, and other health care utilisation (O'Brien et al., 2015).

### **Model of Quality Care**

The Donabedian's Structure-Process-Outcome Quality of Care Model assumes the existence of three essential factors in assessing quality: structure, process and outcome and how these domains impact on quality health care. For Donabedian (2002), the structure is defined as the places where medical care takes place and may include the features of the system, the service provider or the patient. Process refers to the set of activities that take place inter-professionally as well as between professionals and patients. It includes technical and interpersonal aspects. Outcomes are the consequences on the health and well-being of individuals and society (Donabedian, 1980) and include clinical outcomes, quality of life and satisfaction with the care provided.

In this study only the constructs of structure and process were adapted from the model since the study focus does not seek to measure the outcome of quality care, the outcome was not included. A large volume of the literature revealed that the model has been used extensively to study the concept of quality health care. Voyce, Gouveia, Medinas, Santos and Ferreira (2015) applied the Donabedian's Model to examine nurses' perceptions of the quality of nursing care provided in an Emergency Department of the Obstetrics and Gynecology/Birthing Unit of the Algarve Hospital Centre. However, the researchers assessed the perception of the homogeneous population which may be a major pitfall in terms of internal consistency and multidimensionality of quality.



**Figure 2: Model of Quality Health Care**

Source: Donabedian, 1980

## Support Services for Preterm Mothers

### Psycho-Social Support

Psycho-social support encompasses giving both medical and social information to preterm mothers from inter professionals, providing emotional support and helping to initiate a good bonding process between preterm babies and their mothers (Pehrsson & Eriksson, 2002). Pehrsson and Eriksson further revealed that greater percentage of parents (92%), received inter professional care following the admission of their babies in the NICU. These inter professionals included; 81% of physicians, 64 % of nurses, 70 % of children's nurses and 40% of hospital social workers. Usually, these inter professionals participated in planned meetings with the parents of preterm babies while the hospital social worker contacted almost all the parents (86%) for early information about the temporary allowance and travel expenses that the hospital

pays to mothers with preterm babies. Issues of the parents' accommodation during the child's stay at the hospital were also attended to by the social worker.

With regards to assisting parents to cope with emotional reactions, Pehrsson and Eriksson (2002) revealed that 89% of the parents reported to have received emotional support/counseling during their babies hospitalization in the intensive care unit, 45% of the parents had planned and regular meetings with a hospital social worker during the intensive care period, while only 17 % reported such contacts during the later period of care.

Similarly, Fowlie and Mchaffie ( 2004) in their study to evaluate how mothers are supported in the neonatal intensive care units in the United Kingdom indicated that counseling through organisations, such as the Premature Baby Charity (BLISS) was also offered to mothers in all NICUs that were included in their study.

Also, a qualitative study that explored mothers' experiences of receiving counselling/psychotherapy on a neonatal intensive care unit revealed that counselling was provided in a quiet room on the NICU, telephone support was also available for mothers who were unable to travel to the NICU. The therapist was often a qualified counsellor/psychotherapist assisted by a Sister nurse in NICU. Also, a nurse working on the NICU met and talked to parents in that role to be able to identify mothers who may benefit from further support so that an appointment can then be made for them (Parker, 2011).

Coughlin, Gibbins and Hoath (2009), identified five core measure sets for evidence-based developmental care for NICU parents and their preterm babies. The researchers looked at protected sleep for parents and babies, pain and stress assessment and management, developmental activities of daily living,



family-centered care and the healing environment. For protected sleep, the behavioural state is highlighted by the researchers as a foundation for all human activities. Only when an individual is physically, behaviourally and emotionally prepared for interaction can caregiving activities occur without injurious effects. The attributes pertaining to protected sleep encompass assessment, documentation, and utilisation of infant state to guide care delivery. The corresponding criteria include specific interventions that promote sleep and educate families about the importance of sleep in the hospital as well as post-discharge at home.

Pain and stress assessment and management is a second core measure the researchers considered as a supportive measure for parents of preterm babies. Attributes and corresponding criteria specific to pain and/or stress assessment and management are: routine assessment and documentation of pain and stress with an established pain/ stress tool, management of pain and stress before, during, and following all painful procedures with subsequent documentation of interventions and a return of the infant's pain scores to pre-procedural baseline and involvement in and sharing of a pain and stress management care plan with parents (Coughlin et al., 2009).

Non-pharmacological relaxation techniques such as deep breathing and guided imagery were key components of cues programme designed for mothers of preterm babies to reduce the stress associated with NICU admission. These interventions were found to be effective in the management of anxiety. These interventions were often offered by trained psychologists or counsellors (Feeley, Zelkowitz, Westreich & Dunkley, 2011).

### **Parent-To-Parent Support**

According to Gooding et al. (2011), peer support explains a supportive continuous engagement of families who had previous NICU knowledge and experience with new parents in the NICU. The engagement offers a valuable source of information, hope, advice, and support, especially when parents connect with other parents whose infant has or had a similar condition. The researches in this study explored the origins and advances in Family-Centered Care in the NICU and identified various delivery methods of peer support in the NICU. The researchers explicated that linking current NICU parents with former NICU parents allows for the parent to parent education sessions in groups to engage in activities such as scrapbooking nights, and initiatives in which former NICU parents volunteer to provide bedside or telephone support to new NICU parents. Relatedly, Pearson and Anderson (2001) found peer support as an important support system that was offered to them, mothers expressed peer support as very comforting and offered them the opportunity to interact with parents going through the same emotions. They described the information given during formal peer interaction as covering everything that mothers were going through which helps them feel more normal in one's feelings and reactions to stressful/new adjustments.

A relevant widely used concept of psychosocial support for preterm mothers in NICU is Kangaroo Mother Care (KMC) which is cost effective and gives mothers a sense of control over their stressful situation related to preterm birth. Studies have shown that mothers are able to regulate a preemie's temperature better through kangaroo mother care than incubators (Baley, 2015; Boundy et al., 2016; Smola & Lawson, 2019). A study conducted by Grahams

foundation (2018) to assess the effect of Kangaroo Mother Care on the infant and mother revealed that regular heartbeat in neonates was strongly linked to the practice of kangaroo care while parents also regain their control and confidence by practising kangaroo care. Other benefits of Kangaroo care to the mothers as highlighted by the Grahams Foundation included the following; helps mothers to get to know their preemies and armed mothers with the knowledge to be able to detect when things go wrong with the child, helps to stimulate milk production hormones making it easier to pump milk for preemies and to breastfeed, plays a role in reducing rates of postpartum depression related to maternal anxiety and finally, promotes attachment, and reactive pathways in the brain associated with mental and emotional health.

In a related study which sought to evaluate the impact of Kangaroo Mother Care (KMC) and discharge planning as well as family-centered care on the families of preterm babies admitted in NICU, it was revealed that the majority of family respondents who kangaroo-cared their babies found that this activity provided the highest level of comfort. Health care providers also indicated the importance of kangaroo mother care with 67% of a total of 502 respondents rating it as highly effective in reducing parental stress, 73% as highly effective in providing comfort to parents and 80% as highly effective in facilitating parent/infant bonding. Surprisingly, in their study, only 8% of staff stated that kangaroo care was routinely performed in their units. Regarding discharge planning, family respondents noted the confusion and lack of preparation for and at discharge time. Parents indicated in written comments that they felt ill-prepared to deal with what they would face at home. Fifty-eight percent of a total of 216 parents felt that discharge preparation did not begin

until a week before discharge and 35% felt that it never commenced at all (Samra et al., 2015).

Social support is another significant form of support for parents of preterm babies in the NICU. The researcher conceptualised social support as the structural elements of formal (professional) and informal (family) social networks and the functional elements of informational, instrumental, emotional, and appraisal support. Social support and social influence have also been used in research addressing families of preterm infants and are a source of self-efficacy (Samra et al., 2015).

### **Breastfeeding Support**

A mixed method study conducted in Sweden by Ericson, Flacking and Udo (2017) to evaluate the experience of mothers with preterm babies on telephone-based breastfeeding support to the preterm mothers revealed that mothers felt satisfied with the support and had the sense of being involved in the care of their babies. They also asserted that mothers felt more empowered in the mothering process of their babies as a result of the breastfeeding support provided by the breastfeeding support team. This proactive support was compared in the study with reactive support which was more associated with contradictory experiences where the mothers had the opportunity to call for support but also found it difficult to determine when to use the support. The study results indicated that although there were positive aspects of both proactive and reactive support, providing only reactive support may be inadequate for those most in need of support as they may be the least likely to access it. Mothers expressed that they felt positively motivated any time the nurses encouraged them that they were still good mothers capable of caring for

their preterm babies amidst difficulties in breastfeeding their babies unaided. The encouragement and support boosted the self-confidence of the mothers (Ericson et al., 2017).

Similarly, a survey that was conducted to evaluate nurses' perspective of lactation-based support to preterm mothers revealed that more than half (n = 71, 50.7%) of the nurses reported having provided lactation-based support and care during their previous shift. However, less than half (46.5%) of participants gave education related to breast pumping and 38% gave support on lactation-based equipment/supplies as against a higher number of nurses constituting 73.2% who reported to have checked expressed breast milk in the refrigerator/freezer for proper labeling and expiration. These findings possibly will mean that another relevant breastfeeding supports ranging from education using audiovisuals, assisting with supplies such as breast pumps and also demonstrating techniques in breastfeeding were not emphasised in nurses' efforts to support mothers to breastfeed their preterm babies (Froh, Dahlmeier & Spatz, 2017).

Sisk, Quandt, Parson and Tucker (2010) in a study regarding breastfeeding support for mothers revealed that mothers were supported with milk expression using hospital-grade electric breast pumps obtained at the hospital, other supportive interventions where patient instructions provided in an audiovisual format such as DVD was also found useful to mothers in the study.

However, a study conducted to evaluate mothers' experiences on hands-on breastfeeding support where nurses hold mothers' breast to put into the babies' mouths and help position the babies revealed mothers' disapproval of the

support. Some of the study participants reported that the nurse pushed one of the child's arms behind the back while they were breastfeeding. The mothers questioned the reason for this, as they thought the baby liked to use the arms to play with the breast while sucking. Other mothers also felt their privacy was overly compromised by nurses, exposing their breast when other mothers and fathers were around. Instead of the hands-on breastfeeding support mothers preferred breastfeeding guidance to be given to them, for example, that nurses sit beside them and spend more time sharing information and practical advice (Weimers, Svensson, Dumas, Navér & Wahlberg, 2006).

### **Environmental/Physical Support**

Mothers in preterm labour were orientated to the NICU when a decision was made for their admission into the unit which allowed them to familiarise themselves with the NICU environment and staff. Decision-making concerning medical or nursing procedures and other routines of the unit were often discussed with mothers before they were implemented. Written information about the neonatal unit where appropriate (describing specific conditions or procedures) was also beneficial to mothers (Fowlie & Mchaffie, 2004). Fowlie and Mchaffie further argued that routine contact between the neonatal unit and social services may allow financial support to be provided to the parents. Similarly, reports intimate that Canada has a universal health care system whereby antenatal, intrapartum, postnatal, and neonatal care are provided to all of its citizens under a national health scheme and in Japan, the cost of care for preterm infants is fully covered by the national health scheme (Isayama et al., 2012).

Another germane measure was the healing environment which encompasses the physical, human and organisational elements required for safe and salutary hospital experience. The criteria include the measurement and maintenance of recommended light and sound levels and assurance of physical and auditory privacy for families; promotion of effective communication, collaboration, and caring behaviours among the healthcare team and documentation of evidence-based policies, procedures and resources to sustain the healing environment over time (Brown, Ohlinger, Rusk, Delmore & Ittmann, 2003; Ohlinger, Brown, Laudert, Swanson & Fofah, 2003; Johnson, Abraham & Parrish, 2004; Coughlin et al., 2009).

Relatedly, a study conducted to describe a paradigm shift occurring in neonatal intensive care suggested that care in NICU should shift focus limited to healing the baby's medical problems towards a more holistic focus, requiring effective partnerships with families known as Neonatal Intensive Parenting Unit (NIPU). This demands comfortable rooms and beds, provision of meals, bathrooms and showers, laundry facilities, access to computers and Wi-Fi, kitchens where families can store and prepare meals, and lounge space where families can gather for peer-to-peer support and education sessions (Hall et al., 2017).

Similarly, a cluster randomised controlled trial conducted to evaluate Family Integrated Care Model in Canada and Australia reflected what Hall et al. found. Each NICU provided a lounge and sleep room for the exclusive use of parents, as well as amenities to facilitate parents spending extended periods of time in the hospital. Comfortable reclining chairs are provided in the NICU for parents to provide kangaroo care while still being able to interact with other

parents and staff, and breast pumps are available to facilitate breast feeding (O'Brien et al., 2015).

Nevertheless, most NICUs environment in middle and low income countries appear to be under resourced. In a study conducted by Bergh, et al. (2013) to monitor the progress of implementation of KMC in Ghana found that the environment of most health care facilities was inadequate to allow mothers with preterm babies to remain in hospital for a longer period of time because family support for their daily needs would be required which cannot be met because of the resources constraints of most NICUs in Ghana.

### **Educational Support to Mothers**

A study to evaluate a programme designed to ensure positive parenting in the NICU involved mothers being educated on the development of the fetus. What the baby was like before birth was covered, including tactile and auditory senses, development of the vestibular, reflexes, movements and muscle tone development. Implications of early childbirth on each of these sensory systems and the supportive ways in which parents can interact and care for their baby were exhaustively discussed (Pearson & Anderson, 2001).

A systematic review on interventions that helped support, communicate with and inform NICU parents included education on breastfeeding, kangaroo care, baby-massage, emotional coping skills, active problem solving, and effective communication and exchange of information with NICU. Other strategies included ensuring organised support groups, maintaining environments that allow for parent-to-parent support, psychotherapy and journal writing (Brett, Staniszevska, Newburn, Jones & Taylor, 2011).



Other researchers have found information needs of parents to include more information with regard to parenting preterm infants and what it entails. Some parents suggested the provision of a small handbook that gave them new additional information regarding their babies' development and support needs, as well as a list of contact details of parental resources for preterm infants (Wang, Briere, Xu & Cong, 2019).

### **Family Centered Care (FCC)**

This programme focused on the family's role as the center of the healthcare delivery system which is grounded on collaboration between caregivers in the NICU and parents of preterm babies to deliver care through respect, effective communication, and participation. The American Academy of Pediatrics has recommended FCC as a very relevant supportive concept for neonatal care. The concept recognises parents as fundamental members of the NICU team and allows for parents' presence during the conduct of attending physician rounds (i.e., presentations and ward rounds discussions) to enable them to contribute to the care of their preterm babies (De Bernardo, Svelto, Giordano, Sordino & Riccitelli, 2017).

Unrestricted presence of mothers of preterm babies in the NICU, parental involvement in infant caregiving, and open communication with parents as tenants of FCC are important to parents (De Bernardo et al., 2017). Consistent with De Bernardo et al.' work, Greisen et al. (2009) showed that though unrestricted parental presence is not yet uniformly established in most NICUs across countries, in Sweden, Denmark and the UK, 90% of NICUs allowed parents the access to their babies at any time, 75% of NICUs each in

the Netherlands and Belgium also allowed mothers access to their babies while 71% of NICUs in France allowed mothers access to their babies. Yet, at variant to what De Bernardo et al. recounted, Greisen et al. also found that only 30% of NICUs each in Italy and Spain allowed unrestricted visits by mothers while most NICUs in China still use the separation policy or traditional care model, where parents are not permitted to enter the unit during the child's hospitalization until the child is ready for discharge (Wang et al., 2019).

Lachman, Jayadev and Rahi (2014) have asserted that parents' expectations are beyond just the survival for their babies. Parents are as vulnerable as their babies and their experiences of support are essential components of care. Lyndon, Jacobson, Fagan, Wisner and Franck (2014) have demonstrated that parents expect NICU staff to be reliable, consistent and skillful in order to meet their safety concerns. Mothers also expect to be included in decision-making concerning the care of their babies.

### **Inter-Professional Support**

In a cluster randomized controlled trial conducted in Canada and Australia, education for parents of preemies was provided in sessions with small groups for at least five times per week. During these sessions, parents discussed medical care of preterm infants, preterm newborn development, coping within the NICU, preparation for discharge, and how they can interact with their infant more effectively. These sessions were led by inter-professionals such as lactation consultants, dieticians, pharmacists, respiratory therapists, mental-health professionals, and physiotherapists. Appropriate educational materials including handouts and reference materials were also provided to mothers after

education sessions. Information provided in the education sessions is reinforced at the bedside by nursing staff ( Bracht, Leary, Lee & O'Brien, 2013; O'Brien et al., 2016). Mock and Leung (2006) also posited that nurses can boost parental self-esteem and confidence in the NICU by encouraging visiting, teaching parents how to care for their child and involving them in decision making.

A qualitative study conducted in Prontolinda, Brazil to explore the influence of family support groups on parents of preterm babies and NICU workers, revealed that the support group included weekly educational meetings led by interdisciplinary NICU staff, including a neonatologist, nurse, psychologist, and breastfeeding expert. Parents reported that the support group provided them with information, which helped reduce their anxieties; emotional support; confidence; an opportunity to share their experiences with other group members and gain strength; and mutual learning (Buarque, Lima, Scott & Vasconcelos, 2006).

### **The Extent of Utilization of Available Support Services**

In a study conducted to describe and evaluate a parent education programme known as parents' circle programme which was meant to support parents as they psychologically process their experience of having an infant in the NICU, the study illuminated that families who took part in the study reported the programme helped them gain perspective on their situation, feel supported, learn key developmental concepts, locate hospital and community resources, and optimise interactions with their fragile infant (Pearson & Anderson, 2011). Pearson and Anderson reported that participants in the

programme were able to initiate an Infant Care Plan (ICP) and pasted it at their infant's bedside to help them participate fully in the care of their infants and to be able to practice whatever education has been given to them by the NICU staff.

In a study that described the views of mothers on the care received during NICU admission, parents cited the kind and caring nature of the staff, and the emotional support they provided as positive aspects of NICU care. Some parents likened it to belonging to the same family with the staff, a demonstration of empathy which made it easier for them to cope. A substantial number of parents commended the nurses for treating their role on the neonatal team as more than just a job; they felt that neonatal nurses went out of their way to provide emotional support and beyond their functional duties to care for both the parents and baby (Russell et al., 2014).

In a similar qualitative enquiry that sought to examine mothers' expectation of care in NICU, mothers described nurses as having caring attitude towards their babies. They also expressed nurses' communication with parents to be helpful in reducing stress and allowed for effective interactions with their babies. The positive communication was viewed as an outstanding locus of a supportive and fulfilling encounter between parents and caregivers and nearly all the parents reported that the caring nature of the staff was primordial for the interactions they developed with their baby. Parents also described nurses' gentle attitude towards them as relevant in helping them to overcome the strangeness in the Intensive Care Unit (Guillaume et al., 2013). Wang et al. (2019) also revealed that doctors and nurses provided parents with information and updates on their babies' conditions. This support was exceptionally crucial

and viewed as relevant care from the staff. Parents also perceived healthcare professionals to be a valuable source for emotional support during this time.

Blomqvist, Frölund, Rubertsson and Nyqvist (2013) also found the extent of use of KMC to be associated with access to space, a quiet atmosphere and being able to maintain privacy in NICU, and the opportunity to stay overnight at the NICU. The parents appreciated that the hospital furniture was appropriate for their special needs, such as comfortable armchairs and height-adjustable beds.

Again, a study conducted to examine mothers' experiences of kangaroo mother care uptake revealed that the extent to which mothers' practice KMC was influenced by their acceptance of KMC and their belief in the benefits. Mothers who perceived KMC as means of creating bonding between mother and infant demonstrated high uptake (Anderzen-Carlsson, Lamy & Eriksson, 2014).

### **Factors that Hinder or Facilitate Effective Utilisation of Support Services in the NICU**

Problems relating to quality health care according to Shah, Warre and Lee, (2013) may arise from variations in practice including; underuse, overuse, or misuse of available health care services within the health care environment as well as disparities in quality of care which can either hinder or facilitate care delivery.

In a systematic review that examined the needs of preterm mothers in NICU, the following were described by mothers as facilitating factors to integrating them into the NICU care: communication of information, parental

involvement in infant care, protecting the infant, individualised care, and positive interaction with the NICU staff (Chertok, Mccrone, Parker & Leslie, 2014). Mothers of NICU infants desired to be perceived positively by the nursery staff but often feared that voicing their opinion would increase their infant's vulnerability. Three studies described the mother's fear of becoming labeled by the nurses as being non-cooperative and felt they needed to be submissive to the nursing staff to maintain good relationship (Fenwick, Barclay & Schmied, 2001; Hurst, 2006; Lupton & Fenwick, 2001). In another related study conducted to evaluate parents' satisfaction in the neonatal intensive care unit, the majority of parents in the study cited good interpersonal relationship with staff as one of the most important factors affecting their satisfaction with the neonatal intensive care unit (Russell et al., 2014).

The attitude of staff as a facilitating factor of mothers utilisation of support services was also demonstrated in the work of Parhiz, Birjandi, Khazaie and Sharifzadeh (2016) where interviews revealed that some of the mothers thought the follow-up of Skin-Skin Care at the NICU was incidental, depending too much on the attitude and competence of the individual nurse who was on duty. Mother expressed that the nurses were very encouraging which made them kept on with the care of their preterm babies in the NICU.

However, other researchers have identified and described diverse barriers to effective utilisation of support services in NICU. Lupton and Fenwick (2001) discovered that in some cases nurses were found to inappropriately limit the parent's contact with their infants and mothers seldom get the opportunity to practice what they have been thought concerning the care of the infant. They reported an incident where the mother of a stable, 34-week

gestation was restricted to the number of times to hold and cuddle the infant. During the study, there were additional claims of several mothers arriving at the NICU to visit their infants and being told that the NICU was closed. These actions resulted in feelings of anger and frustration on the mother's part.

In other studies, mothers saw rules and regulations that prevented family members especially grandmothers from touching the baby in the NICU as real barriers to developing normal mother-baby relationships and self-efficacy to help in the care of their babies. Some women found it distressing to tell their mothers not to touch their grandchild which is seen as a barrier to integrating their baby into their family (Swanson et al., 2012). Mothers in this study also cited a lack of privacy and obtaining an effective breast pumping as hurdles that mothers had to overcome to move from initiation to maintenance of breastfeeding after receiving an education. However, adjusting to changes in social interactions, managing time, and having positive attitudes toward pumping were seen as facilitators to the effective utilisation of breastfeeding supports (Sisk et al., 2010). In this same study, mothers expressed difficulty recalling the pumping instructions given to them verbally and in written format as a hindrance to the effective utilisation of the teachings they received from staff regarding breastfeeding.

According to Smith, Bergelson, Constantian, Valsangkar and Chan (2017), impaired uptake of KMC by mothers was attributed to insufficient explanation of the concept by providers, mothers, fathers, and families in the study expressed concerns that they were simply told to perform KMC without explanation on why or how to do so, which attracted the feeling that KMC was forced on them. The issue of inadequate explanation was also mirrored in other

studies where mothers expressed concerns that during hot climate seasons, parents observed during KMC that their infant became irritable due to the heat which is a clear demonstration of inadequate understanding about the importance of KMC (Quasem et al., 2013) while Hadian Shirazi, Sharif, Rakhshan, Pishva and Jahanpour (2015) held the opinion that nurses have deficient knowledge regarding NICU care to meet communication and other needs of preterm mothers in NICU.

Other researchers identified top five barriers to KMC practice expressed by mothers to include issues with facility resources such as space reclining chairs, negative impressions of staff attitudes, fear of hurting the infant, lack of help with KMC practice and other obligations on the part of mothers and low awareness of the benefits of KMC on the infant's health. Top enablers to KMC practice for mothers included mother-infant attachment, feelings of confidence or empowered to practice KMC, and support from family, friends, and other mothers (Seidman et al., 2015).

A qualitative study conducted to explore health professionals' attitude and practices in supporting preterm mothers to breastfeed their infants in the NICU revealed that Nurses were focused more on carrying out medical orders for the infants as part of their routine responsibilities allocated to them. When interviewed, none of the staff referred to any tasks that concerned the mothers such as assisting them in breastfeeding or pumping as part of their job. This attitude of staff often pushed mothers to the periphery of NICU care (Shattnawi, 2017). The researcher also found out that nurses were judgmental about the mothers' inability to satisfy their infant's nutritional needs. Negative feelings from the nurses about the nutritional adequacy of breast milk affected the



mothers' confidence in their abilities to breastfeed. According to Shattnawi, another barrier that is associated with staff attitude was the skills of staff in supporting preterm mothers. Nurses expressed that they relied on their background and little experiences when giving any information but their teaching is not based on any up to date courses that were taken. This often leads to many contradicting points of view expressed by nurses.

Closely related, Blomqvist et al. (2013) found that staff attitude could also be a barrier to KMC. In their study, mothers reported that NICU staff did not have enough time to help to position the infant on a parent's chest, which resulted in delayed and shorter KMC sessions. The researchers also cited mothers' own physical limitations, such as pain after a caesarean section and backache rendered KMC difficult. Lack of support from family members was also mentioned by Blomqvist et al. where mothers reported that the Swedish University Hospitals did not permit the presence of family members. This made mothers the sole caregivers at the NICU which limited the extent of KMC, as it was difficult to perform KMC 24 hours a day alone. However, there were parents who stated they did not have problems at all providing their infants with KMC in NICU.

Feeley et al. (2011) also implicated feasibility challenges, such as mothers' different visiting patterns and language preferences when providing the programme to mothers as a group while their infant is hospitalised in the NICU as factors that hinder effective uptake of the support intervention. One intriguing barrier that was also expressed by mothers was a lack of bonding between mothers and their preterm infants possibly due to fear, stigma, shame, guilt, or anxiety associated with the birth and in some instances the fact that

some mothers may not want to keep the baby at all (Smith et al., 2017; Waiswa et al., 2010).

In a study conducted to develop, implement, and evaluate a parent education and support programme that enhances family-integrated care in a Canadian Neonatal Intensive Care Unit (NICU), a total of 39 mothers of infants born at 35 or fewer weeks' gestation were enrolled in the pilot programme to examine the development, implementation, and qualitative assessment of the education component of a family-integrated care programme. The majority of the mothers felt that the time and length of the sessions worked well, but there were days when it could be difficult to attend depending on their infants' feeding schedule or specific needs. Mothers of twins felt that there would probably never be a good time as one or other of the infants would always require attention (Bracht et al., 2013).

Other researchers have maintained that communication and feedback can either hinder or facilitate mothers' support in the neonatal setting. A survey assessment of strength and weakness of patient-staff communication in NICU of University Hospital in Sweden showed that nurses and doctors met the communication needs of parents by using a simple language that was understood by all parents. Nurses and doctors also kept regular information flow, explained all procedures and gave feedback to mothers after procedures. Parents reported that the communication made a difference to them and fostered their full utilisation of NICU routines (Wigert, Dellenmark & Bry, 2013).

However in a qualitative enquiry that involved interviews of mothers on their experiences of strength and weakness of parent-staff communication in the NICU at the same study site, parents expressed that communication with staff

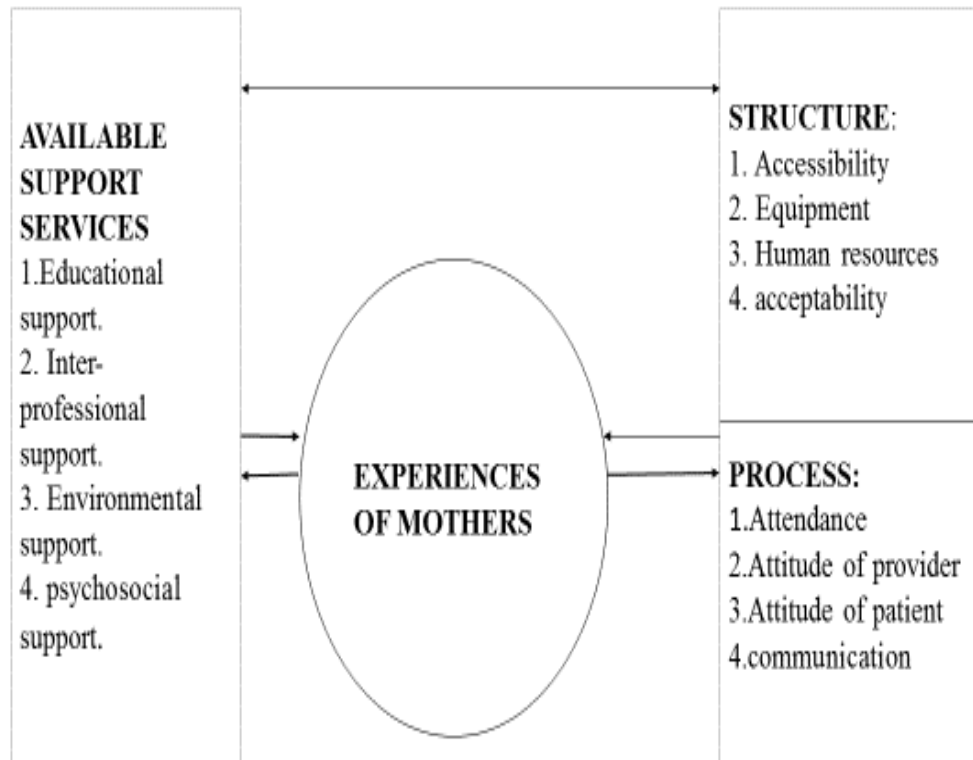
meant that mothers were powerless and have little input in their care or the care of their babies; they were dependent on the staff and adapted themselves to being forced to take responsibility for communication and seeking to participate in the care of their babies (Wigert, Blom & Bry, 2014). Wigert et al. also found that the most important weakness in information-giving reported was that information was incomplete and infrequent. Some parents also indicated doctors used medical terminologies that were hard to understand.

Discharge planning which aims at ensuring that parents are adequately prepared to play independent roles in caring for their babies as they transit from the NICU to home is important for parents. Even though the goal of health care in the NICU is to ensure that babies are discharged early enough to reduce the chances of nosocomial infections, mothers often reported their unpreparedness to take up parenting roles following discharge from the NICU. A study conducted in Western Australian tertiary neonatal clinical care unit to explore parents' readiness for discharge revealed that parents felt they were often rushed to be discharged due to a requirement to make bed spaces available (Aydon, Hauck, Murdoch, Siu & Sharp, 2018). Likewise, other researchers reported that some parents at the time of discharge experienced a heightened anxiety because they feared doing something wrong or harmful to the infant in the absence of highly specialised setting of the NICU (Setiawan, Mannix & Sweet, 2019).

### **Conceptual Framework**

The conceptual framework was derived from the FICARE by O'Brien et al. (2013) and the Donabedian Quality care (1980) models by using some of the constructs of the models such as; experiences of mothers of preterm babies,

psychosocial support services, educational support services, inter-professional support services, environmental support services as well as structural and process elements of support for mothers in the NICU.



**Figure 3: Conceptual framework adapted from Ficare and Donabedian Models**

Source : (O'Brien et al 2013 ; Donabedian, 1980)

The study was conceptualised from the point of view that support services for mothers of preterm babies can be viewed under psychosocial, environmental support, inter-professional support, and educational support which are the four main domains of the family integrated care model. Therefore, all four domains of the model were useful in this study. The structure and process domains of the Donabedian model were also included in the framework, however, since the study does not have an objective to measure the outcome of mothers' experiences of support services, it was not included in the framework. In this framework, the four domains in the FICare model will answer the first

research question of the study which is to explore what support services are available to mothers of preterm babies in the NICU while the structure and process domains of the Donabedian Model will answer the second and third research questions of the study which sought to identify extent of utilisation of available support services and explore factors that facilitate or hinder effective utilisation of support services for mothers of preterm babies.

### **Chapter Summary**

The concept of preterm birth is understood to mean a baby born less than 37 completed weeks of gestation. The models reviewed in this study revealed relevant approaches to supporting parents of preterm babies in the NICU. The family integrated care spelled out four main domains of support services for mothers which included psychosocial support, educational support, inter-professional support, and environmental support. The systems model of care explains how three levels of systems; the NICU, the parents, and social networks work together in order to ensure better preterm admission outcomes.

Donabedian quality care model explains three levels of care which included "the structure" "process" and "outcome". In this study only the first two phases were useful. The evidence clearly suggests that any of the models could be used to guide this study but the FICARE Model and the Donabedian Quality Care Models were adapted for the conceptual framework.

Again, the empirical review conducted revealed various support services that are important to mothers and their preterm babies and the strategies that are needed to optimise care and reduce the stress levels of mothers. The extent of

utilisation of support services, as well as factors that affect the utilisation of support services, were evident in the literature review.

## CHAPTER THREE

### RESEARCH METHODS

This study explored the experiences of mothers with preterm babies on support services available in the Neonatal Intensive Care Units [NICU] of the Techiman Holy Family Hospital (THFH) of the Bono East Region. Specifically, the study; described support services that are available to mothers in the NICU of THFH, identified the extent of utilisation of support services available to mothers in the NICU of THFH and described factors that facilitate or hinder effective utilisation of available support services to mothers in the NICU of THFH. This chapter is organised into study design, study setting, population and sample size, sampling procedure, data collection instrument and process, data analysis, ethical considerations and methodological rigour.

A research methodology explains the designs and methods a researcher employs for a study. It also discusses the strategies through which the goals of the research are attained (Polit & Beck 2008). This study used a qualitative methodology, a naturalistic paradigm involving the use of semi-structured interviews.

#### **Research Design**

The research design was a qualitative exploratory descriptive case study. According to Yin (2013) case studies can be exploratory, descriptive, or multiple-case studies. Creswell, (2007) asserted that an exploratory descriptive case study design explores a single phenomenon, while the multiple case studies explore multiple cases within the same study. The fundamental goal of an exploratory descriptive qualitative case study design is to conduct an in-depth

analysis of an issue, within its context with a view to understanding the issue from the perspective of participants where the researcher explores, understands and presents the participants' perspectives and get close to them in their natural setting through interaction with them to generate data (Mills, Harrison, Franklin & Birks, 2017).

Therefore, this design was employed because it allowed the exploration of support services for mothers of preterm babies, beliefs or factors that hinder or facilitate effective utilisation of available support services for mothers. Also, the design was appropriate to the research objectives and will help to elicit clear responses from the participants.

Merriam and Tisdell (2015) have opined that exploratory descriptive case study design is a pliable approach which allows the researcher to deal with complex social components and study a phenomenon as a whole or divide it into parts according to the researcher's focus and needs. Yet Creswell (2007) has also pointed out some limitations of the design such as; the necessity and difficulty of selecting the exact case before the beginning of the research and commitment of time and money to complete the study.

### **Study Area**

The study was conducted in the Neonatal Intensive Care Unit of THFH. This facility is one of the Christian Health Association of Ghana (CHAG) in the Bono East Region which operates within the National Catholic Health Services. The hospital is located in the commercial town of Techiman along the stretch of road linking the south to the northern regions. The 330-bed facility provides primary and secondary levels of healthcare to the people of the region and beyond. Due to the location of the hospital, it is highly accessible to all its



catchment areas as well as travellers, and market women traveling along this road network. The NICU has staff strength of 15 nurses which comprised registered general nurses (RGN), registered midwives (RM), nurse assistant clinical (NAC), one paediatric nurse and one paediatrician. The unit is subdivided into two units, one unit is where unstable preterm babies who require some procedures such as oxygen therapy, phototherapy and other medically-indicated procedures that require close monitoring are received. The place is not spacious and there is a limited number of 10 monitors, 5 incubators and 4 warmers. The other section of the unit is meant for babies with stable conditions. Mothers are free to visit their babies at any time, 24 hours per day, and could stay as long as they desired, mothers are provided with plastic chairs placed by the baby cots where the women sit to breastfeed their babies. Bathrooms and toilet facilities are available to the mothers. The fathers' presence on the ward to visit their infants was limited to specific hours in the morning. Other family members such as siblings and grandparents were not allowed to enter the NICU to see the infant but per hospital policy, the mothers can meet relatives outside during visits.

### **Study Population**

The population of interest in this research study was all mothers of preterm babies admitted in the NICU of THFH. This is because the researcher assumed that the mothers would have had sufficient experience of the NICU to enable them reflect on their experiences on support services in the unit. Also, there is an increased evidence that patient and family health care experiences are increasingly recognised as important indicators of the quality of care (Isaac,

Zaslavsky, Cleary & Landon, 2010; Price et al., 2014). Therefore, a sample of this population was required, which was appropriate to the design of the study, as well as financial and time constraints as also asserted by Moule and Goodman (2009).

All mothers with preterm babies born less than 37 completed weeks' gestation and have their babies admitted in the NICU for at least three days were considered. Mothers who speak either Twi or English were also included in the study. Mothers who delivered their babies after a gestational age of 37 completed weeks were not included. Mothers of preterm babies who were on admission for less than 3 days were excluded in this study. Also, mothers who could not speak either English or Twi were also excluded from the study.

### **Sample Size**

Speziale and Carpenter (2007) are of the view that in a qualitative enquiry a sample size of two to ten participants is appropriate or until data saturation. However, Polit and Beck (2008) have maintained that sample size in a qualitative research is based on data saturation. It also depends on the type of study, purpose of the study, how findings will be used, and what resources including time available to carry out the study. In this study, a total of 16 participants from the study population made up the sample size. This was determined after the 16th participant was interviewed and no new or relevant information emerged hence, signifying data saturation.

### **Sampling Procedure**

The study employed homogenous purposive sampling with sample size relatively small and based on data saturation (Polite & Beck, 2008). Purposive sampling involves personal judgment in choosing cases that will help answer research questions or achieve research objectives. It also involves a strategy where the researcher handpicks the cases or type of cases that will contribute to the information needs of the study whiles data saturation on the other hand, explains the point in data collection when no new or relevant information emerges, and therefore, no more data need to be collected. The study used homogeneous purposive sampling because it intended to gain in-depth knowledge from mothers with similar characteristics in terms of their experiences of support services in the Neonatal Intensive Care Unit whiles their preterm babies are admitted in the NICU as suggested by other researchers (Etikan, Musa & Sunusi, 2016; Polit & Beck, 2008). Therefore, considering the population characteristics and the objectives of this study, homogeneous purposive sampling was more appropriate.

Subsequent to the approval of this study by the Institutional Review Board of the UCC, the researcher proceeded to the hospital where concurrent approval from the Medical Director was given and the researcher introduced to the NICU. This made it possible for the researcher to get acquainted with the unit and also established rapport with staff and patients of the unit including the potential participants of this study. After the ward in-charge introduced me to the mothers, I took the opportunity to declare my intentions to them and finally those who fell within the inclusion criteria and accepted to participate in the study were considered and time and place for interviews were agreed upon.

## Data Collection Instruments

Background information form was used to collect participants' demographics such as age, educational level, occupation, religion, marital status and parity. The gestational ages of participants' babies before birth was also taken to help in the description of the participants. This was followed by the use of a semi-structured interview guide to collect data through an individual in-depth interview from participants, field notes and observations were also used in collecting data. The content of the guide was mainly open-ended and probing questions based on the research objectives and the literature review as suggested by Hudelson (1994) and Kielmann, Cataldo and Seeley (2012) in the design of an interview guide. For example, a question like "tell me your experiences about support services in this unit" was asked which allowed participants to express themselves.

Interview guides are most commonly used in qualitative study designs as they enable the researcher to uncover and explore the participants' opinion and present strengths such as suitability for the exploration of perceptions of the participants regarding sensitive issues, the ability to adapt questions to probe the context and meaning of responses. There is also two-way communication between the researcher and the interviewee which allows for clarification of the participants' responses (Moule & Goodman, 2009; Polit & Beck, 2008). Yet the use of semi-structured interview guide may be liable to loss of standardization and comparability, probes differ from one participant to another which can be recipe for bias than structured guide. Also, it requires a skillful interviewer to be able to probe participants and can sometimes be time consuming (Galletta, 2013).

Pretesting of the interview guide was done using two participants at the NICU of Sunyani Regional Hospital since the unit had similar characteristics with the study area. This was done to help the researcher to make good changes to the initial interview guide and test his interviewing skills. Additional probes were added to the initial interview guide after the pre-testing was done. This is consistent with Burns and Grove (2010) who hold the opinion that it is better to pre-test instruments on smaller sample to help you identify and correct errors before applying it to the actual sample.

According to Creswell (2014) and Miles, Matthew, Huberman, Michael and Saldana (2014), methodological rigour is important because the researcher's perceptions and interpretations become part of the research, hence it is important for the researcher to declare his/her reflexive stance and adopt journaling method to reduce biases. These measures were adopted in this study to ensure credibility, dependability conformability and transferability as also asserted by Shenton (2004). Shenton explains these trustworthy principles as credibility; is the extent of fairness and authentic show of reality. Credibility was employed in this study by ensuring that another analyst reviewed the findings of this study. Also, participants who met the inclusion criteria and could give in-depth information were carefully recruited and finally, member checking was done by contacting the participants after the data transcription and coding to confirm that transcripts were the exact expressions of the participants.

Dependability is the stability of data over time and under different conditions. This was maintained by ensuring that same interview guide was used to collect data from participants and the transcripts were subjected to the same coding and theming process. Also, the research setting, methodology,

research design and the background of the participants who were used for the study were described in detail. The research supervisors were involved at every stage of the study and all documents were also kept for audit trail. Also my personal experiences as a nurse about the NICU environment and my reflections at certain stages of the research were recorded to avoid the influence of my positionality on the research.

Transferability is the potential for findings to be transferred to other settings or groups. This was ensured by a detailed description of the research design, setting, methodology and the background of the participants who were used for the study.

Finally, Shenton explains confirmability as the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning. This was upheld by immediately transcribing the interviews to avoid mixing of data. Participants were asked to confirm the information they gave during the interviews after transcription.

### **Data Collection Procedures**

Approval for the study was sought from the Institutional Review Board of the University of Cape Coast. Following their approval, the researcher then presented an application letter and the ethical approval letter to the authorities of THFH which was concurrently approved. Participants consent for participation was obtained after the research process was fully explained. An in-depth personal interview was then conducted with individual participants at their convenient appointed time using a semi-structured interview guide. The interviews were conducted in the ward in-charges' office in Twi and English.

The researcher himself interviewed mothers who could speak English while the research assistants interviewed mothers who could only speak Twi because of language barrier. Open-ended questions were asked and participants were allowed enough time to express themselves, the questions were probed where necessary and participants were given the opportunity to ask questions for clarification. Responses were then audio taped, replayed later and transcribed verbatim. Interviews lasted between 30-50 minutes per participant.

The demographic data was however taken before the interview responses were audio taped. This was for the purpose of maintaining confidentiality of the participants. Pseudonyms were assigned to participants in order to maintain their anonymity. As asserted by Creswell (2007), all observations during the data collection were written in the field notes which helped the researcher to cross check and validate the transcripts during the data analysis.

An informed written consent was also obtained from participants after explaining to them, the research process, the voluntary nature of the study and their right to withdraw at any stage of the study. Participants were assured that their rights to privacy and confidentiality would be protected. To ensure privacy and confidentiality respectively, interviews were conducted in the nurses' office and the demographic information of participants was not included in the audio tapes. As much as possible, labels were used to represent participants and no participant was named in any report of this study.

Also, recordings were audio taped by the researcher with only the research team having access to the audio recorder. Transcribed data was also put on the principal investigator's laptop protected with a password while the

recorder and the field notes were put in a drawer under key and lock. Only the principal investigator and the supervisors had access to this information. The audio tape recorder after analysis will be kept for five (5) years before recordings will be deleted from the recorder.

### **Data Analysis**

Qualitative data were analysed using thematic content analysis with the aid of NVivo (Computer Assisted Qualitative Data Analysis Software [CAQDAS] version 9) as described by Hilal and Alabri (2013). This approach allows the researcher to appropriately analyse views of mothers on availability of support services for mothers of preterm babies, the extent of utilisation of available support services and factors that hinder or facilitate effective utilisation of support services from the in-depth interview. The software has features such as character-based coding, rich text capabilities and multimedia functions that are crucial for qualitative data management and improvement in the accuracy of qualitative studies (Bazeley & Jackson, 2013; Zamawe, 2015).

The audiotaped recorded interviews were transcribed verbatim after a minimum of three times repeated listening and translated into English by a multilingual interviewer. The transcripts were cross-checked, edited and validated by listening to audio files and comparing with field notes to ensure they matched with the unique codes and responses of participants. Interview transcripts were stored using Microsoft Office Word. The researcher developed a folder for the interview transcripts under the navigation view of the Nvivo software. The data was therefore imported into the created folder. The researcher again developed nodes using Tree nodes. The researcher then coded the data by highlighting the text via the mouse and pulled the highlighted text



to the identified node. When the cursor is located over the node, the highlighted text changed color and the relevant node linked with the text shows up on the Coding Stripe to the right of the browser. This allows assigning multiple codes to the same chunk of the text as well by going through the same process (Saldaña, 2013). The researcher then developed concepts, categories, and themes at the end of the coding process. The analysis, therefore, followed Braun and Clarke (2006) six phases; familiarization with the data including transcribing, coding, searching for themes, reviewing themes, defining and naming themes and reporting findings.

### **Chapter Summary**

The study used the naturalistic paradigm with a qualitative descriptive exploratory case study design. Purposive sampling was used to select mothers of preterm babies in the Neonatal Intensive Care Unit of Techiman Holy Family Hospital of the Bono East Region. Participants were interviewed using a semi-structured interview guide till data reached saturation. However, there are limitations of the methods used in this study such as the inability to generalize the results since the findings of the study may only be peculiar to the Techiman Holy Family Hospital.

## CHAPTER FOUR

### RESULTS AND DISCUSSION

The purpose of this study was to explore the experiences of mothers on support services in the neonatal intensive care units of the Techiman Holy Family Hospital [THFH] of the Bono East Region. Specifically, the study will; describe support services available to mothers in the neonatal intensive care unit [NICU] of THFH, identify the extent of utilisation of support services available to mothers in the NICU of THFH and describe factors that facilitate or hinder effective utilisation of available support services to mothers in the NICU of THFH.

This chapter encompasses a detailed description of the findings that emerged from the analysis of the responses of study participants regarding their experiences on support services in the Neonatal Intensive Care unit (NICU) based on the specific objectives guiding this study. The chapter begins by providing a description of study participants followed by a detailed presentation of the findings that emerged from this research.

#### **Study Results**

##### **Description of Study Participants**

The essence of describing the study participants is to understand key characteristics of preterm mothers who had their babies admitted in the NICU of the THFH who participated in this study. However, to ensure confidentiality, participants' individual characteristics were described in general rather than specific terms. Mothers who participated in this study voluntarily consented to take part after the research process was explained to them. The participants did not receive any form of financial reward for participating in the study. Mothers

who participated in the study had spent more than three days in the unit and in a better position to tell their own experiences of the unit. They were particularly happy and willing to participate in the study because they felt the study will evoke policy changes in the hospital that will help mothers of preterm babies admitted in the NICU. The demographic data of the participants is presented in table1 and table 2 below;

**Table 1: Demographic characteristics of the babies**

<b>Part.NO.</b>	<b>Weight at birth (kg)</b>	<b>Sex of baby</b>	<b>Number of days on admission</b>
P1	2.0 and 2.1	Male &female	1 week
P2	1.1	Male	3 weeks
P3	1.2	Male	4 days
P4	1.1	Female	4 weeks
P5	1.2	Female	4 weeks
P6	1.0	Male	4 weeks
P7	1.5	Male	3 weeks
P8	1.0	Female	1week 4days
P9	1.3 and 1.2	Male &female	4weeks
P10	1.2	Female	2 weeks
P11	0.8	Female	3 weeks
P12	1.6	Female	4 weeks
P13	01.2 and 1.0	Male&Female	2 weeks
P14	3.0	Male	1weeks
P15	2.0	Male	3week
P16	2.1	Male	4 weeks

Source: Author's Construct, (2019)

**Table 2: Distribution of socio-demographic characteristics of Participants**

<b>Part. NO.</b>	<b>Age (years)</b>	<b>Parity</b>	<b>Gestation age</b>	<b>Mode of delivery</b>	<b>Marital status</b>	<b>Level of education</b>	<b>Occupation</b>	<b>Religion</b>
P1	39	G5P5	32wks	SVD	Married	JHS	Trader	Muslim
P2	19	G1P1	34wks	C/S	Married	Primary	Farmer	Christian
P3	17	G2P2	34wks	SVD	Married	JSS	House wife	Muslim
P4	25	G3P3	34wks	SVD	Married	Tertiary	Teacher	Christian
P5	42	G5P5	31wks	C/S	Married	No formal education	Farmer	Muslim
P6	37	G1P1	24wks	C/S	Married	SSS	Hair Dresser	Christian
P7	25	G1P1	32wks	C/S	Married	JHS	Seamstress	Muslim
P8	25	G2P2	31wks	SVD	Married	SHS	Trader	Christian
P9	35	G6P6	26wks	SVD	Married	Primary	Farmer	Christian
P10	32	G1P1	24wks	SVD	Married	Tertiary	Entrepreneur	Christian
P11	26	G1P1	24wks	SVD	Married	Tertiary	Civil Servant	Christian
P12	33	G3P3	26wks	SVD	Married	Tertiary	Civil servant	Christian
P13	28	G3P3	26wks	SVD	Married	JHS	Farmer	Christian
P14	18	G3P3	28wks	SVD	Married	No formal Education	House wife	Muslim
P15	39	G2P2	28wks	SVD	Married	JHS	Seamstress	Christian
P16	36	G3P3	34wks	SVD	Married	Tertiary	Civil servant	Christian

Source: Author's construct, (2019)

Out of the mothers of preterm babies who were admitted at the NICU of THFH, sixteen (16) participated in the study. The ages of the preterm mothers ranged from 17 to 42 years and 31.25% were first-time mothers. Their educational levels ranged from no formal education to tertiary education. It was revealed that 45.75% had primary to junior high education, 31.25% had Tertiary education while 12.5% had Senior High Education and same percentage of 12.5% had no formal education at all.

The gestational age of the babies ranged from 24 to 34 weeks. Three mothers gave births to twins and three mothers also experienced four previous preterm deaths. One mother had two while the other two each had one previous preterm death. Sixty-nine percent (69%) of the mothers gave birth through Spontaneous Vaginal Delivery (SVD) while 25% had caesarean birth. There were 9 boys and 10 girls in the study, including three set of twins. The birth weight of the babies ranged from 0.8kg to 3.0kg with 78.94% lower than 2.0kg. The length of neonatal hospitalisation ranged from 4days to 4weeks.

There were 3 main themes and 11 sub-themes which emerged from the study analysis. Table 3 below shows the themes and sub-themes.

**Table 1: Themes and Sub-themes**

Support services available	Environmental support <i>-accommodation</i> <i>-Sanitary facilities</i> Psychosocial support <i>-Kangaroo mother care</i> <i>-Access to child</i> <i>-peer support</i> <i>- husband support</i> Health education support <i>-Breastfeeding</i> <i>-Infection prevention</i> <i>-Cord care</i> Inter-professional support <i>-Doctors</i> <i>-Nurses</i>
Extent of support service utilisation	Acceptability Accessibility Caring
Factors that hinder or facilitate effective utilisation of support services	Attitude of mothers Attitude of staff Early discharge Communication Feedback

Source: Field Survey (2019)

**Research Question 1: What are the available support services for preterm mothers**

The first objective of the study sought to explore preterm mothers' experiences of support services available in the NICU. Support services refer to wide spectrum of health care services and facilities within the NICU or the hospital system that are tailored not only to the neonate admitted but also to the

mothers of these preterm babies. These services include infrastructural needs of the mothers, care from interdisciplinary workforce ranging from NICU nurses, pediatricians, dieticians and physiotherapist. It also includes psychological needs such as counseling and health education which includes parents' participation in care, useful educational materials, and preparation for discharge related to feeding, hygiene, bathing, elimination, airway secretion, the way to pick up the baby, affective bonding and signs and symptoms of risk. To address this objective, participants were asked to describe their experiences of support services available to them. Four main themes describing support services were identified based on the responses; environmental support psychosocial support, health education and inter-professional support.

### **Mothers description of environmental support**

Mothers had mixed feelings as far as their experiences of environmental support is concern. All the participants confirmed the availability of accommodation and sanitary facilities for mothers. However, mothers felt that these facilities were not adequately available to meet the number of mothers who were in the unit with their preterm babies. A participant stated:

*...when I was admitted they showed us a yard at the back of the unit where we can sit to eat. That same yard is where we have our sleep in the night, frankly, that place is too small and can only accommodate six persons... (Mrs. p4).*

Participants also said sometimes when they are many in the unit, some were compelled to sleep outside. A participant stated:

*...even where to sleep has been my worry, there is no place to sleep. During the night I do sleep on the floor in front of*

*the pharmacy. There's no canteen where you can find some food to buy, unless you go outside the hospital before you can get food to buy... (Mrs.p5).*

The participants described these facilities not only as inadequate but also discomforting adding to their already stressed state relating to the birth of a preterm baby.

*There are few mattresses that we have to put on the floor, sometimes when we are many, I had to put my cloth on the floor and sleep, the next day you will have pain all over your body. I cried on my husband to come and take me home because this place is very disgusting. It's like the staffs or the hospital management don't care for the wellbeing of mothers (Mrs. P13).*

Another participant also stated:

*There are plenty mosquitoes in the room, even for the days, I have spent here I had malaria as a result of that (Mrs. P8).*

A participant also described sanitary facilities in the unit. She stated;

*In fact, we are using the same bath house and of course look at the number of people using one toilet and two bath rooms, you can imagine, very appalling but we are managing because the hospital is not your home... (Mrs. p 12).*

### **Mothers' description of Psychosocial support**

Another theme that emerged was psychosocial support from the NICU nurses, doctors, peers and family members. Mothers described how they were



worried following an unanticipated preterm birth but with the help of staff, other mothers of preterm babies and sometimes family members they gained some hope about their preterm babies. A mother stated:

*One mother who was a victim of preterm even advised me on the preterm babies, she told me when they discharged the baby, the husband rejected the baby because the baby was too small at that time, but now the baby is really heavy. It has really encouraged me... (Mrs. P13).*

Mothers also indicated that the staff were able to offer some form of counseling to the mothers. A mother said:

*Initially, when I delivered, I was frightened and anxious to see the baby, so I told the nurse I don't like the baby, but one nurse advised me, the child will grow well and put on weight. This nurse too always comes to me to talk to me and find out how the child is thriving... (Mrs. P7).*

They also described access to their babies as relevant in relieving them of their worries. A mother stated:

*...every time and every day I do have access to the child if only I have disinfected my hands... (Mrs.5).*

Another mother also described spousal presence as a relevant social support to mothers.

*My husband is permitted to come here any time and apart from him no one has been allowed to enter here. If my husband comes in and I need to do something outside, my husband stays behind to look after the baby until I return.*

*The staff at the NICU are always around, and in case they need something for the wellbeing of the child they tell me and I will go and get it for them (Mrs.P1).*

A Participant also expressed how they were introduced to Kangaroo Mother Care (KMC) by peers and how the practice has supported her psychologically.

*Some relatives came in here, so when she saw me in tears and sad, she told me they admitted her baby here, she too delivered at 26 weeks + 6 days, a very beautiful girl. She really advised and talked to me a lot and she even said the only thing that helped her keep the baby alive was KMC, so she really advised me to always do KMC for the baby. Since I started, I can see that I am now relieved of the fear that I was having about my baby... (Mrs. P4).*

However, participants bemoaned the absence of professional counseling services in the unit. This was a narrative from a participant;

*I have not been counselled as I came to this hospital and I think it will be good if a counsellor is here to counsel patients. Even this morning I told the nurses to check my BP for me because what I was going through was not easy so they told me to go to postnatal because they don't have the apparatus here, but when I went I could not check because they were busy attending to their patients and could not attend to me... (Mrs. P4).*

Another mother expressed how her psychological needs were not attended to by the NICU staff:

*I have not received any support to relieve me of the stress I am going through. In fact, I am very anxious and depressed, because some babies lost their lives and because of this, it's heart-breaking whenever I hear my name being mentioned. I do think may be something bad has happened to my babies. They really don't think of our wellbeing, their attention is only on the babies because after I was discharged from the maternity ward, I have not been asked to go for review (Mrs. P9).*

#### **Participants' description of health education as a form of support**

The third theme that emerged was health education. Health education needs of preterm mothers is an important role that should be played by all NICU professionals. Participants described array of topics that were discussed with them during their baby's admission. The participants also demonstrated understanding of education on breast feeding, cord care, kangaroo mother care and infection prevention. A participant stated;

*We are told to put the baby on your chest and place the head in between your breast [KMC]it helps to maintain bonding between the baby and the mother. They taught us how to do it... (Mrs. P10).*

A mother also stated the display of visuals on hand washing at vantage point;

*...they are doing well the moment you enter here they will tell you to wash your hands or use hand sanitizer before you touch the baby, there are protocols around on hand washing. They are really doing well in that area (Mrs. P12).*

Another participant stated that knowledge on cord care and home care for jaundice was relevant to them:

*...also, they told us we shouldn't apply any medication on the umbilical cord of the new born and we should only apply the alcohol they have given us and do exclusive breastfeeding. Moreover, they told us to send the child out whenever the morning sun arises (Mrs. P7).*

Participants also indicated that education needs of the mothers were not adequately met. The participants made the following comments:

*...For the morning devotions and education session there are particular nurses who have devoted their time in leading and if they are off duty no one comes to lead it, so I think there should be other staff to support in case those nurses' that lead always are not around. The schedule for the education session always changes but not fixed... (Mrs. P5).*

### **Inter-professional support to preterm mothers**

Participants reported that only nurses and doctors attended to their babies but with little attention to the mothers. They were however unable to distinguish between the nurses and doctors especially the males and also had

similar identity challenge when it comes to the other categories of staff such as counsellors, nutritionist, and social welfare workers. The following views were expressed by the participants:

*I cannot differentiate the staffs in here, the only staffs I can recognize are those who delivered me, that I can say they are midwives apart from that I don't know the differences in the staffs here (Mrs. P1).*

Another one stated examples of other professionals who do not extend their services to NICU:

*...for dieticians and physiotherapist, they have never visited us here. For the doctors and the nurses, I have made a lot of friends with them and I am receiving a lot of information from them, I quiet remember one of the nurse said she was going to check my child's RBS. Without knowing what RBS was, I asked the nurse and she explained everything to me and I understood it (Mrs.P4).*

Participants felt that mothers should also be reviewed especially by doctors and other health personnel. A participant made the following statements:

*...I believe it would have helped if mothers in here are also to be attended by the doctors even if we are discharge. Recently, after morning devotion, we asked the staffs that, after we the mothers have been discharged if we fall sick or don't feel well we don't even know who to report to and*

*where to go for medication and it's like the staff concern are not on us... (Mrs.P5).*

Another mother emphasised on the need for other professionals to visit mothers in NICU:

*...but those who have studied in the area may even know some other food products which are cheaper in the market for lactation mothers to use. The other professionals need to visit the NICU mothers, we need them, nurses cannot do all these things... (Mrs.P12).*

## **Research Question 2: What is the extent of utilisation of available support services**

The second objective was to examine the utilisation of support services available to mothers. This explains mothers' views concerning support services accessibility to mothers, the experience and commitment level of staff in helping mothers to utilise support services. It also explains the expression of the level of satisfaction with available support services. To be able to obtain the views of participants on the extent of utilisation of available support services, the participants were asked to describe the extent to which they utilised the available support services. Three (3) main themes were identified from the participants' responses: care received from staff, acceptability (breast feeding, KMC) and accessibility (hand washing).

### **Staff were caring**

Caring also emerged strongly in mothers' description of their experience on extent of utilisation of support services. Mothers expressed that staff were

caring which helped them to utilise the services available. The following views were expressed by the participants:

*The pediatrician has been here three times since I came here, when she comes for rounds and gets to you she speaks Twi if you cannot speak English, she speaks to each mother; maame, do you put the child on your chest? How often? if you go home can you do it, she speaks to them about it maybe they don't understand and they don't ask. Dr. (Name) also tells us; have you been doing the KMC? Be doing it for me okay!!(Mrs.P12).*

Another participant saw nurses being caring through supporting her to breastfeed the baby. She stated:

*...for the first time of feeding my babies I had no idea of how to go about it, but one of the nurses approached and gave me directives to feed my babies and this has really helped me... (Mrs. P9).*

Another mother stated nurses being caring in terms of given them appropriate information and reassuring them. She said:

*...for the first week on admission, I was always with tears. In fact, if it is that time I could not sit with you to talk like this because I was really depressed. The doctors told me the child has developed (NEC) a condition in which I need not feed the child for one week. I don't know your medical terms but the stomach of the baby was just going down like that. Sometimes I just enter and see my child lying helpless and I*

*am unable to help the situation than to cry. Seriously Dr.(Name), I don't know whether you know her but she is the one that has been consoling me since I came here. She has told me a lot and any time there is any challenge and I called her she always attends to me(Mrs.4).*

### **Acceptability of support services**

Mothers acceptability of support services was another theme that emerged. Mothers expressed their satisfaction with support services as well as their level of resilience gained following utilisation of support services. Mothers were generally satisfied with education on breastfeeding. Mothers made the following direct statements:

*I think all information received here is going to support my child wellbeing, e.g. how to breast feed my child effectively, how to cater for the child and how to eat and get enough breast milk (Mrs. P14).*

*The education has helped me, initially I never knew you need to position the baby in a prone position after giving breast milk and how to position the child when breast feeding the child. Initially I thought what they taught us won't help but when I put all into practices its really helping the wellbeing of the child... (Mrs.P13).*

Mothers also expressed acceptance of kangaroo mother care. A mother makes this statement:

*...being first time mother I think that the breastfeeding teachings and how to handle a preterm baby has really*



*helped me. I can see that I am now feeding my baby well and things are getting better. I feed every two hours and like I said earlier, I also do the KMC as I have been instructed (Mrs. P11).*

Another mother stated reasons why she practices KMC and her ability to express breast milk after education:

*...I really practice it [KMC] every day because I don't want to get my child infected. Also with regards to the breastfeeding I think we have slow learners; for me I can now express and breast feed my child well but other mothers are still being supervised. I think that all what they offer us or ask us to do is important that is why they ask us to do (Mrs.P10).*

### **Accessibility of support services**

All the participants expressed that the few services that were available in the unit were accessible to all mothers. Notably participants expressed access to hand washing facilities. Below were some of the expressions made by participants:

*...as for the infection prevention mothers in here are truly patronizing it. Any mother who comes into the ward from outside is going straight to wash the hands, in fact we are even over using the soap, you wash when you want to breastfeed, you wash when you visit the wash room and if anything of yours falls down and you pick it up you have to wash your hands before you can touch the baby (Mrs. P4).*

*I also think that the nurses are doing well with the hand washing materials, they even have hand sanitizers at vantage points for us use so that we don't contaminate our babies (Mrs. P11).*

### **Research Question 3: What factors facilitate or hinder effective utilisation of supportive services**

The third objective was to describe factors that facilitate or hinder effective utilisation of support services. This looks at barriers or enablers which may range from cultural or religious considerations, issues of communication, feedback, costs and interpersonal relationship between mothers and health care providers that can affect care delivery in the NICU. Views from the participants produced four themes namely: staff skills, attitude of mothers, attitude of the staff and communication. According to participants, attitude of staff was seen as both an enabler to their support as well as a barrier. Some staff presented good demeanors that allowed mothers to approach them when they needed help while others appeared unfriendly to mothers. The participants also expressed views about skills of staff as barrier to their support. Attitude of some mothers also stood as a hindrance to effective utilisation of support services. Participants felt that some mothers are not cooperative. Language was generally expressed as a factor that facilitated effective health education, communication was done in mothers' local language and mothers who did not understand the language were given interpreters. Mothers also had mixed feelings concerning the skills of staff, some of the mothers expressed that the staff are skillful in addressing needs of mothers and their babies. Others also doubted the skills of the staff especially nurses. Also, participants felt that feedback was an issue that adds up

to their stress, staff failed to give them feedback on corning procedures carried out on their babies.

### **Staff attitude**

Some of the participants described the attitude of the staff as positive depending on the individual nurse you are dealing with. They expressed that some of the staff have good interpersonal relationship that allowed mothers seek help from them. A mother stated:

*Some of the staff are really good but everyone has his/her bad side. For my observations, some are doing well and some need improvements. For instance, morning devotion and the teaching is only a reserve of some nurses, if those nurses are not on duty, it is not done for us (Mrs.P4).*

However, participants expressed that other staff also have undesirable attitude towards mothers. The participants made the following statements:

*In fact, we, mothers here, we know the nurses we approach when we need something and not all of them. For some of them when you approached them the way they will react to you, you will get scared approaching them the second time (Mrs. P4).*

Another mother stated:

*Some are good on the job but some of them, the way they talk to the mothers and the way they even attend to the baby you can see clearly that they are not professionals. You go to call them if there is an issue about the baby and they are so*

*relaxed to attend to you so how will you have the courage to go and tell them about your own problems. As for you the mother they don't consider your welfare here... (Mrs.P11).*

Another participant commented on how some nurses were reluctant to attend to them anytime they needed them:

*some of the babies with vomiting problems, so the specialist instructed that the nurses always feed these babies and when the mothers go to call them, they (nurses) tell them have you not been taught how to breastfeed your baby? Go ahead and breastfeed meanwhile feeding a patient is part of the job. All they do is to give medications and that is all. even here in NICU the nurses are better than those in maternity, ooh the way they talk to the patient, to the extent that student nurses don't even talk well to patients (Mrs.P12).*

Participant expressed that some staff are not skillful. A participant recounted this:

*...you know the mother I told you needs counselling; her baby has problem of vomiting. So the quantity of the feed was reduced from 5mls to 2.5mls, when this nurse came and fed the 5mls she still went ahead to draw aqua, the moment she started pushing it in the baby started vomiting and the sp02 started coming down so if you don't get a skillful person it can affect you (Mrs. 12).*

### Attitude of preterm mothers

Participants generally expressed that the attitude of mothers could also be a factor but much of the problem had to do with the staff. A participant stated:

*...all the mothers here even fear the nurses so we all comply in whatever instruction is given to us. The problem is the nurses and the student nurses. Some of them think that we are all illiterates here. I read a lot about this preterm birth since I have been here and I know what they are supposed to do for my child and what they are not supposed to do (Mrs. P11).*

However, there were other mothers who cited some instances of mothers' conduct as hindrance to their support. Below are the opinions expressed by the participants

*At times some of the mothers skip the education lessons. I think the education session helps and if they teach us well, I think some attitudes of the mothers can prevent the nurses or staffs to stop the education lesson because everyone comes from different background and having different attitudes too (Mrs. P16).*

Another mother stated:

*...even speech, how some women will speak to the nurses but it still depends on the individual, some of the nurses may be fine with it and still attend to you but some of them will ignore you when you don't talk well to them (Mrs. P10).*

Participants also expressed that some mothers do not heed to instructions. A mother said:

*...some mothers too sometimes put those in charge of the education off, because during the education session is where you do see some of the mothers going to take their baths and also going to breast feed their child. So when they are now teaching us such people will now come with a lot of distraction (Mrs. P4).*

Another mother said:

*...in fact, some mothers can sleep a lot, the nurses keep on calling them and they don't care. Some too they will be asked not to bring bucket but they will bring (Mrs. P12).*

### **Communication and feedback**

All participants expressed that language was generally a facilitator in the unit since communication was done in the local language devoid of medical terms. Also, in instances where some mothers could not speak Twi, nurses looked for people to interpret for them. The views of the participants regarding factors that affect utilisation of support services included:

*The staffs educated us well and I do understand everything that they taught us in the local language (twi). We are always given the opportunity to ask questions too (Mrs. P7).*

Another mother stated assistance given to mothers who do not speak Twi or English:

*They use Twi here and those who do not understand they interpret. There was this woman who speaks only Hawsa, the nurses looked for someone to interpret (Mrs. P2).*

However, feedback was said to be inadequate. Nurses failed to give feedback to mothers where necessary. A mother stated:

*I have had to send two samples to the laboratory for my baby. Even myself when I came I needed to do some labs, because of the folderless system, I did not get to know anything about my results. All that they told me was that the results were not good and I have to be taken to theatre. They had discussed among themselves and they did not tell me. I was there when a nurse came to tell me that at this time you will be taken to the theatre and I said ooh, I was hoping that my BP will go down and I will get additional two weeks which would have increase my baby weight. I told the doctor about it when I went into the theatre. As for feedback, it is bad. This incident happened at the maternity ward (Mrs. P12).*

Another participant said:

*For feedback here it is very bad, sometimes they will come and monitor your child, they will not tell you anything so when you move out and the call your baby name you start to*

*panic because you think something bad has happened to your baby (Mrs.P11).*

### **Early discharge**

Participants expressed that their babies were discharged from the NICU at the time they felt they were not adequately prepared to take independent roles in the care of their fragile babies at home.

A mother expressed this;

*One thing that may hinder me from benefitting counselling services from the staff is early discharge. They said my baby will be discharged soon but I don't know whether I will be able to take care of this baby. I for instance have been absenting myself from the education, this may hinder some of the required benefits (Mrs. P7).*

### **Discussion**

The previous section presented the results of the study. In this section of the chapter, the findings of the study were discussed in relation to previous researches and the theoretical framework of this study. The chapter also presented the implications for consistencies or inconsistencies of the study findings with previous studies to clinical practice.

### **Participants' Demographic Characteristics**

Mothers of preterm babies who participated in this study voluntarily consented to do so. All participants had their baby/babies admitted in the NICU of Techiman Holy Family Hospital and have stayed in the unit from minimum



of four (4) days to a maximum of four (4) weeks. The long stay in the unit gave participants rich experience about the unit and other structures within the hospital that provide services to the unit. They shared these experiences with the belief that it could lead to enhanced safety and quality care for mothers and their preterm babies in the unit and in other facilities elsewhere. This background of the study participants places them in a position that they would be likely to disclose true experiences that reflect realities on the ground.

The results revealed that sixteen preterm mothers with an age range from 17 to 42 years, a minority of (5) mothers had given birth for the first-time while (11) were mothers of more than one child. Their educational levels ranged from no formal education to tertiary education. All the participants were married women and the majority (11) were Christians while the rest were Muslims. Also, 12 of the mothers gave birth through spontaneous vaginal delivery (SVD) while 4 had a caesarean birth. The gestational ages of the babies ranged from 24 to 34 weeks. Three mothers gave birth to twins and three mothers also experienced four previous preterm deaths. One mother had two while the other two each had one previous preterm deaths. There were 9 boys and 10 girls in the study, including three sets of twins. The birth weight of the babies ranged from 0.8 kg to 3.0 kg with 15 babies recording less than 2.0 kg.

#### **Participants' description of support services available in the NICU.**

Participants alluded to the fact that accommodation and sanitary facilities were available to them in the unit. However, they described the facilities as inadequate and of substandard quality. Participants often slept on the bare floor on their clothes because only six mattresses without beds were provided to them. This is consistent with Bergh, et al. (2013) who found the

environment of health care facilities as inadequate to allow mothers with preterm babies to remain in hospital for a longer period of time because family support for their daily needs would have been required and cannot be adequately met due to the under resourced nature of most NICUs in Ghana. This may be due to the fact that Ghana as a developing country has infrastructural challenges and the health sector may not be an exception. However, these findings appear to be at variant with what Hall et al. (2017) found in their study about environmental friendly NICU where the unit was equipped with enough decent sleeping rooms, bathrooms, beds, laundry facilities as well as provision of meals to parents. Families also had access to kitchens where families could store and prepare meals, and lounge space where families could gather for peer-to-peer support and education sessions. This implies that the facility is challenged with environmental needs such as infrastructure and logistics necessary in facilitating a comfortable stay of preterm mothers during the hospitalisation of their babies in the NICU. Even though most of what is seen in literature is of international standards and most health facilities in Ghana may not be able to provide, it is imperative that attention is paid to basic environmental needs such as rooms, beds, sanitary facilities and treated insecticides mosquitoes' nets especially for mothers who require longer stay in the unit with their babies.

Another support service that was revealed by participants was psychosocial support. Participants indicated that their interactions with other mothers with preterm babies, especially those with previous experience of preterm birth gave them a sense of emotional relief. Also, access to their babies and the practice of kangaroo mother care gave the mothers some sense of psychological relief. This is consistent with Pearson and Anderson (2011) who

found peer support as an important support system for preterm mothers. Mothers in Pearson and Anderson's study expressed peer support as very comforting because they had the opportunity to interact with parents going through the same emotions. Gooding et al. (2011) reported similar support with an expanded spectrum which involved linking current NICU parents with former NICU parents to allow for a parent to parent education. This also allows parents volunteers to provide bedside or telephone support to new NICU parents even when they are discharged.

The implication is that nurses will have to view peer support as an important concept and ensure that it is well coordinated in order to make sure mothers will not misinform or give false hope to one another which will have a rippling effect on them.

Some mothers also held the view that though nurses and doctors provided some form of counselling to them, they felt that professional counselling would have done them a great deal of good. This also agrees with other researchers who have maintained the position that mental health nurses, psychologists, and breastfeeding experts should be part of the NICU set up to provide routine support to preterm mothers (Buarque et al., 2006). Also, Parker (2011) reported that in a qualitative inquiry into psychosocial support for preterm mothers, counselling was provided by counsellor/psychotherapist as well as a NICU sister in a quiet room, telephone support was also available for mothers who were unable to travel to the NICU. A nurse working in the NICU has the opportunity to meet and talk to parents in that role so is able to see who may benefit from further support and an appointment can then be made for such mothers to meet a counsellor.

Participants reiterated that KMC and unlimited access to their babies as well as support from their spouses gave them a psychological relief. The practice of KMC promoted love for their babies and they were willing to always practice it. The findings on the Kangaroo Mother Care and the access to the child were also consistent with what Samra et al. (2015) found, where mothers rated Kangaroo Mother Care as an activity that provided the highest level of comfort to them. Health care providers in this study also indicated the importance of Kangaroo Mother Care with 67% of a total of 502 respondents rating it as highly effective in reducing parental stress, 73% as highly effective in providing comfort to parents and 80% as highly effective in facilitating parent/infant bonding. De Bernardo et al. (2017) also revealed unrestricted presence of mothers with preterm babies in the NICU, parental involvement in infant caregiving, and open communication with parents as a form of psychosocial support to preterm parents.

However, unlimited parental visit to NICU is a complete antithesis with the practice in China where parents are not permitted to enter the unit during the child's hospitalisation until when the child is ready for discharge (Wang et al., 2019). Unrestricted parental access to babies in NICU enables parents to adjust to the agony of preterm birth. It gives parents the opportunity to become part of the care process, gain bonding with babies and assess improvement in their babies' condition.

What is important is for health care providers to ensure effective education and availability of necessary facilities in NICUs that will safeguard parents stay in the NICU. Also, findings suggest that the psychosocial needs of preterm mothers are often not adequately addressed. This may be due to the fact

that the focus of care in most NICUs in Ghana appears to be linearly directed to the medical treatment or outcome of the baby with less attention placed on the parents. No wonder Lachman et al. (2014) asserted that parents' expectations in NICU are beyond just the survival for their babies. Parents are as vulnerable as their babies and their experiences of support are essential components of care.

In light of this, it is necessary that hospitals consider providing the opportunity for mothers to be reviewed by other cadre of staff such as counsellors, and mental health nurses in the clinical setting which will go a long way to better the psychological care rendered to mothers in the NICU.

Another support service described by participants was educational support. Participants received education on breastfeeding, KMC, cord care, and infection prevention. This is consistent with the findings of Brett et al. (2011) who emphasised that the educational needs of preterm mothers included breastfeeding, kangaroo care, baby-massage, emotional coping skills, active problem solving, and effective communication with NICU staff. However, in Brett et al.'s study, education was done in an organised support groups in an environment that allowed for parent-to-parent support, psychotherapy and journal writing which is at variance with findings from this study where education sessions were largely organised by nurses for all mothers in the unit. Participants felt that not all nurses were involved in the education and there was no formal arrangement for peer-to-peer interactions. It appears from the findings that peer teachings were also beneficial to parents which bring to point the need for mothers' involvement in education sessions instead of being viewed as mere recipients of knowledge from caregivers.

Participants also described inter-professional support to include nurses and doctors. This agrees with what Pehrsson and Eriksson (2002) found, where parents described that one or two inter professionals visited them in conjunction with their child's birth. Usually, these contact people participated in planned meetings with the parents. However, Feeley, Zelkowitz, Westreich and Dunkley (2011) maintained that trained psychologists and counsellors had provided their services to NICU such as deep breathing and guided imagery for mothers of preterm babies to reduce the stress associated with NICU admission.

Participants also indicated that nurses and doctors alone could not meet their needs because of the workload and inexperience of some nurses. Participants felt that the attention of nurses and doctors is on the babies and not the mothers. Even when mothers had challenges producing breast milk, nurses and doctors could not help them. They wished other specialised professionals such as nutritionists, physiotherapist and psychologists visited and interacted with them. This is in agreement with what Hadian et al. (2015) found in their study conducted to evaluate nurses' ability to meet the communication needs of preterm mothers in NICU. Nurses in Hadian et al.'s study expressed that they were deficient in knowledge regarding NICU care. They indicated they were often unable to answer questions from the mothers very well which left mothers dissatisfied with care.

This implication of the findings is that nurses and doctors alone are unable to meet the growing needs of mothers in the NICU. Nurses and doctors run a shift system with care focused more on the medical and nursing procedure on the sick preterm babies. It is important that care for preterm mothers is well

coordinated to include other professionals such as counsellors and dieticians whose services are equally needed in the NICU.

### **Participants' description of the extent of utilisation of support services**

Participants described how nurses were caring in their duties which aided them to utilise support services that were available to them in the unit. They described nurses and doctors as being caring to them and their babies. This agrees with Wang et al. (2019) who reported that doctors and nurses provided parents with information on their babies' conditions. They described the care of healthcare professionals to be a valuable source for emotional support. Mothers in another study described nurses as having a caring attitude towards babies and parents and communicated with empathy that made their interactions with the babies possible. Parents also reported that nurses' gentle attitude towards them helped them to overcome the strangeness in the intensive care unit (Guillaume et al., 2013). This implies that caring on the part of health caregivers is an important measure of patient satisfaction. Even though the unit had resource constraints and mothers did not receive a wide range of interdisciplinary care as per the Family Integrated Care Model for NICU care, the nurses and doctors per their caring attitude were able to assist some mothers to overcome their challenges. This is not surprising because Russell et al. (2014) reported that NICU parents commended the nurses for treating their role on the neonatal team as more than just a job; they felt that neonatal nurses went out of their way to provide emotional support and beyond their functional duties to care for both the parents and babies.

The participants also indicated that accessibility of support services allowed for effective utilisation. Mothers had access to hand washing facilities

and also, their unrestricted presence in the NICU allowed them to carry out KMC effectively. The parents felt it was safe to care for the infant with KMC at the NICU. These findings were supported by Blomqvist et al. (2013) who examined the extent of mothers' use of KMC as being facilitated by access to a private space, a quiet atmosphere, privacy and mothers' opportunity to stay overnight at the NICU. Parental access to appropriate hospital furniture such as comfortable armchairs and height-adjustable beds also aided them to perform KMC effectively.

However, Lupton and Fenwick (2001) found the contrary experience of mothers where in some cases nurses inappropriately limited the parents' contact with their infants and mothers seldom get the opportunity to practice what they have been taught concerning the care of their infant. This is not surprising because, Greisen et al. (2009) have also asserted that unrestricted parental presence is not yet uniformly accepted in most NICUs across countries. For instance, in Sweden, Denmark and the UK, 90% of NICUs allowed parents the access to their babies any time, 75% of NICUs each in the Netherlands and Belgium respectively allow parental access, 71% of NICUs in France and only 30% of units each in Italy and Spain allowed parents the access to their babies. However, most NICUs in China still use the separation policy or traditional care model, where parents are not permitted to enter the unit during the child's hospitalisation until when the child is ready for discharge (Wang et al., 2019). The implications of these findings suggest that unrestricted parental access to their babies in NICU is important. This allows mothers to participate in the care which is proven to be beneficial to mothers in terms of relieving them of stress related to preterm birth. It is important that efforts be made by health care



providers to ensure that available resources in NICU are made accessible to mothers and their babies. Even though there were environmental challenges such as lack of comfortable seats and beds to practice KMC, lack of breast pumping equipment in the unit, mothers' access to child and handwashing facilities influenced the extent to which they utilised the support systems. This probably explained why participants expressed access to describe their extent of utilisation of support services.

Again, participants expressed acceptability in describing the extent to which they utilised support services in the NICU. Mothers felt satisfied with breastfeeding teachings as well as KMC and were constantly practising whatever they were taught. This agrees with Chan, Labar, Wall and Atun (2016) assertion that the extent to which mothers' practice KMC was influenced by their acceptance of KMC and their belief in the benefits. Mothers who perceived KMC as a means of creating bonding between mother and infant demonstrated high uptake. Pearson and Anderson (2011) who also conducted an interventional study on supportive programme for mothers in NICU revealed that mothers who participated in the programme were able to initiate an Infant Care Plan (ICP) and pasted it at their infant's bedside to help them participate fully in the care of their infants and to be able to practice whatever education has been given to them by the NICU staff.

#### **Participants' description of factors that hinder or facilitate the effective utilisation of support services.**

Regarding factors that hinder and factors that facilitate the effective utilisation of support services, three themes out of the four themes could act as both facilitators and hindrances to mothers' utilisation of support services. These

three themes included the attitude of staff, attitude of mothers and communication and feedback. The fourth theme; early-discharge was described as a hindrance. Mothers described staff attitude as positive towards them in terms of encouragement, information and practical assistance to the mothers.

Mothers felt comfortable to interact and seek help from staff whom they felt had a positive attitude towards them and were readily available to assist them to perform activities such as breastfeeding and KMC. These findings agree with Russell et al. (2014) who found that parents' satisfaction in the Neonatal Intensive Care Unit was influenced by positive staff conduct that promoted a good interpersonal relationship between mothers and staff in the neonatal intensive care unit. Positive staff attitude was also expressed in a study involving NICU mothers who were being supported to practice skin-skin care [SSC]. Mothers felt that the extent of utilisation was highly dependent on the attitude of nurses. A participant in the study expressed this "One of the nurses was very encouraging. She said it [SSC] was very important and made me try, and thus I kept on, mainly because of her support."(Parhiz et al., 2017 p.5).

On the other hand, participants also expressed that some staff have a negative attitude towards mothers, these staffs were disrespectful towards them and failed to attend to mothers' needs. These contrary opinions expressed by the participants support what was reported by Blomqvist et al. (2013) where mothers averred that staff did not have enough time to help mothers to carry out KMC which resulted in delayed and shorter KMC sessions. Some mothers in the study who underwent a caesarean section [CS] reported that they were often in pain and could not perform KMC but nurses were not available to assist them. Shattnawi (2017) also found out that nurses were judgmental about the mothers'

inabilities to satisfy their infant's nutritional needs. Negative feelings from the nurses about the nutritional adequacy of breast milk affected the mothers' confidence in their abilities to breastfeed.

Another hindrance related to the staff attitude was a lack of skills. Some mothers expressed that some of the nurses lack the necessary skills to assist them to practice supportive interventions such as KMC and breast feeding. This confirms what Shattnawi (2017) reported about nurses' views concerning their ability to adequately support NICU mothers. Nurses in the study expressed that they relied on their background and little experiences when giving any information but their teaching was not based on any up to date courses in NICU care. This often leads to many contradicting points of view expressed by nurses. This is not surprising because Smith et al. (2017) revealed that impaired uptake of KMC by mothers was attributed to an insufficient explanation of the concept by providers. Mothers, fathers, and families in the study expressed concerns that they were simply told to perform KMC without explanation on why or how to do so, which gave them the feeling that KMC was forced on them. The implication is that nurses should be reminded of their unique position to help mothers handle the stress related to preterm birth by continuously developing maternal caregiving skills while in the NICU and be trained to talk and communicate effectively with the mothers to maintain and enhance mothers' confidence.

On the issue of mothers' attitude, participants described their attitudes as cooperative and were ever ready to carry out instructions given by health care givers. This is consistent with other studies where mothers were ready to adjust to changes in social interactions, managing time to attend to all programs and

having positive attitudes towards breast pumping and other interventions (Sisk et al., 2010).

However, participants also described the attitude of some mothers as a hindrance to the effective utilisation of support services. Mothers expressed that some mothers did not heed to instructions, arrived late during education sessions and some were also slow learners and could not remember what has been taught. These findings agree with other researchers. Bracht et al. (2013) found out in their study that it could be difficult for mothers to attend programs in the NICU depending on their infants' feeding schedule or specific needs. Mothers of twins felt that there would probably never be a good time as one or other of the infants would always require attention which prevented them from participating fully in teachings. Feeley et al. (2011) also implicated feasibility challenges, such as mothers' different visiting patterns and language preferences when providing the programme to mothers as a group while their infant is hospitalised in the NICU as factors that hinder effective uptake of the support interventions.

Also consistent with this study findings, Sisk et al. (2010) reported that mothers expressed difficulty recalling the pumping instructions given to them verbally and in written format as a hindrance to the effective utilisation of the teachings they received from staff regarding breastfeeding. The implications of these findings are that health caregivers will need to find healthy ways of assisting mothers to adapt to the NICU environment. Mothers probably behave the way they do because of deficiencies in communication and feedback which also emerged strongly in this study. Nurses and doctors need to be accommodative and treat mothers with empathy.

Communication and feedback were also described by participants as both a hindrance and a facilitating factor to effective utilisation of support services. Mothers expressed that all communications were done in the local dialect (Twi) which allowed mothers to express themselves freely. Medical terms that were not understood by mothers were often explained to them. However, mothers expressed that feedback was badly practised in the unit. They felt that communication was linear, they were often not given feedback and not made to be part of decision making concerning their babies. These findings are consistent with Wigert, et al. (2013) who reported that nurses and doctors met the communication needs of parents in the NICU by using a simple language that was understood by all parents.

In contrast to the findings in this study concerning lack of feedback, Wigert et al. reported that nurses and doctors also maintained regular information flow, explained all procedures and gave feedback to mothers after procedures. Parents reported that the communication made a difference to them and fostered their full utilisation of NICU support services. This implies that communication should be devoid of medical jargons and be tailored at individual needs of mothers taking into consideration their individual language preferences. Regular feedback should also be provided to mothers.

Participants also expressed that early discharge from the NICU will hinder them from receiving adequate support to be able to take care of their babies independently at home. This is consistent with a study conducted in Western Australian Tertiary Neonatal Clinical Care Unit to explore parents' readiness for discharge. The study revealed that parents felt they were often rushed to be discharged due to a requirement to make bed spaces available

(Aydon, et al., 2016). Similarly, Setiawan and Mannix (2019) also reported that parents often experienced heightened anxiety because they feared they cannot care for their babies at home without the support of NICU nurses. This implies that NICU health care providers will need to assess mothers' readiness for discharge and be able to establish follow up measures for preterm mothers when they are discharged from the NICU.

Finally, considering the models used as a conceptual framework to guide this study, it was evident that there is no single ideal model of care for preterm birth. This implied that nurses working in NICU will require any of these models to guide the care rendered to preterm mothers and their families. It was also revealing that the constructs of the Ficare and the Donabedian Quality Care Models were not adequately applied in the NICU care of the study area. This could probably be due to material and human resources constraints of the facility.

### **Chapter Summary**

This chapter summarized the discussion of the results obtained from this study in relation to what is found in the empirical review and the conceptual framework underpinning this study. The study revealed mixed findings in relation to what is found in the literature review.

## CHAPTER FIVE

### SUMMARY, CONCLUSION, AND RECOMMENDATIONS

The study explored the experiences of mothers with preterm babies on support services in the Neonatal Intensive Care Unit (NICU). The specific objectives guiding this study were to: (1) explore the available support services for preterm mothers (2) describe the extent of utilisation of available support services and (3) explore describe factors that facilitate or hinder effective utilisation of support services for mothers with preterm babies. This chapter summarizes the results of the study per the research objectives as well as conclusions and recommendations made based on the key findings of the study. The chapter will also present the implications of the study findings to clinical practice, nursing education and future research.

#### **Summary of Key Findings**

The purpose of this study was to explore the experiences of mothers on support services in the NICU of the THFH of the Bono East Region. An exploratory descriptive qualitative case study design was used. Homogeneous purposive sampling was used to sample 16 mothers of preterm babies admitted in the NICU who were interviewed using a semi-structured interview guide. Ethical clearance was granted by the IRB-UCC and subsequent approval at the study site as well as participants informed consent was obtained. Data was analysed using thematic content analysis.

#### **Mothers' Description of Support Services**

Mothers with preterm babies in the NICU described the kind of support services they received. These support services included accommodation,

sanitary facilities, counselling from staff, peers, and family members, education on breastfeeding cord care, KMC, and infection prevention. Despite the support services received, mothers also expressed the need for more support than what was reported. Mothers also expressed that Inter-professional support was limited to doctors and nurses, and therefore there was a definite need for a wider scope of inter-professional's support to take care of the diverse needs of mothers in the NICU.

### **Mothers' description of the extent of utilisation of support services**

- Mothers generally expressed accessibility to their babies which allowed them to practice KMC, access to hand washing materials such as running water, soap and hand sanitizers to be used when the taps were not flowing. The accessibility allowed mothers to practice continuous hand washing and practised KMC during their stay in the NICU.
- The caring nature of nurses and doctors in the performance of their responsibilities especially staff attention for the preterm babies, the empathy they generally demonstrated towards mothers was outstanding. Mothers also accepted and practised KMC and breastfeeding.

### **Mothers' description of factors that hinder and factors that facilitate effective utilisation of support services**

The mothers expressed the following factors to positively influence the utilisation of support services: positive attitude, positive attitude of mothers and the use of local language as a language of choice in the NICU. On the other hand, lack of skillful staff, negative attitude of staff, poor feedback and early discharge were factors that hindered mothers utilisation of support services provided in the NICU.



## Conclusions

The following conclusions were made from the findings. The mothers in NICU expressed that they received both tangible and intangible support services during their hospitalisation in the unit. The mothers also said the support services they received benefited them, though the services were not adequately available. Inter-profession support was limited to only nurses and doctors and much of the care rendered was tailored to only the babies. The women described certain facilitating factors to the effective utilisation of support services to include, positive attitude of staff and mothers themselves and the local dialect as a medium of communication. On the contrary, factors such as poor feedback, early discharge, poor attitude of mothers and lack of skills of staff were expressed by the mothers as factors that hinder effective utilisation of support services in the NICU.

The findings of the study demonstrated that health professionals in neonatal settings have more than just a singular responsibility of caring for the preterm babies in NICU but more importantly, need to extend care to preterm mothers to ensure that they are physically and psychologically fit to support in the care of their preterm babies. The study concluded that without interdisciplinary collaboration among the health force to render holistic care and support to mothers and their preterm babies in the NICU, mothers' supportive needs will remain unmet. Also, without further improvement in NICU infrastructure, the supportive needs of mothers will be a mirage.

## **Recommendations**

### **Nursing Practice**

- In view of the findings that there were institutional barriers to support services such as poor attitude, poor feedback and lack of skills of staff, it is recommended that in-service training on therapeutic communication and professional role adjustment should be organised by the clinical coordinator of the hospital for nurses working in the NICU.
- The hospital management should ensure that the mothers whose babies are admitted to the NICU are routinely reviewed by counsellors, nutritionists/dieticians, and health-promoting officers.
- Nurses working in NICU should integrate mothers who have experienced previous preterm birth and have been assessed by caregivers to be properly adjusted into the NICU care by assigning old preterm mothers to new preterm mothers in the NICU to help in the psychosocial and educational needs of the new preterm mothers.
- Facilities such as descent accommodation, beds, treated insecticides bed nets, and some improved sanitary facilities should be provided in the NICU by the hospital management.

### **Education**

- In-service training and workshops on continuous professional development should cover the needs of mothers of preterm babies. Such programmes should target nurses working in the NICU since the majority of the nurses working in the unit are general nurses who have not received specialised education on neonatal and maternal care.

- Antenatal education, especially on birth preparedness, should incorporate lessons on what mothers should expect in an event of preterm birth and NICU admission. This will serve as the beginning point of mothers psychosocial and educational needs associated with preterm birth.

### **Policy and Planning**

- In view of the findings that mothers did not receive adequate support from the NICU, it is recommended that the hospital management should consider NICU support interventions such as Creating Opportunities for Parent Empowerment (COPE), the Mother-Infant Transaction Program (MITP) and the Family Integrated Care in NICU. Possible recommendations by the hospital management to relevant agencies such as the Ghana Health Service, Christian Health Association of Ghana to facilitate scaling-up such interventions in NICUs of other hospitals in Ghana as these programmes were successfully utilised in other countries such as Canada and Sweden.
- The management of the hospital should institute a NICU policy that encourages both parents to take active participation in the care of their babies. Particularly, fathers should be encouraged by the caregivers in the NICU to support mothers in caring for their preterm babies.
- Hospital management should liaise through the Members of Parliament, the Regional Ministers and other relevant stakeholders to benefit from special initiatives by the government such as "save a child, save a mother" initiative of the Rebecca Foundation which is into child and maternal health interventions across the country. Non-governmental

organizations such as UNICEF- Ghana, the World Vision should also be contacted to come to the aid of the hospital to refurbish the NICU.

### **Suggestions for Further Study**

- A quantitative based approach should look at the extent of utilisation of the available support services.
- This study should be extended to include nurses and hospital managers about their views on support services received by mothers in NICU.
- Another study should look at the views of mothers in NICU on support services across Ghana.
- Another study is needed to explore the views of nurses and mothers on discharge planning for families of preterm babies.

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## APPENDICES

### APPENDIX A: INFORMED CONSENT FORM

**Title:** Experiences of mothers with preterm babies on Support Services in Neonatal Intensive Care Units

**Principal Investigator:** Dominic Apedani Bachegejoa

**Address:** University of Cape Coast, School of Nursing and Midwifery, University of Cape Coast.

#### **General Information about Research**

This is a research study that seeks to explore experiences of mothers with preterm babies on support services in the neonatal intensive care unit with objectives of; describing what support systems are available for mothers in neonatal intensive care unit, identify the extent of utilization of support services and to describe factors that hinder or facilitate effective utilization of support services if there are any. Your participation will last for one month, during this period, individual personal interviews will be conducted with participants with each section lasting between 30-40 minutes. All interviews will be recorded for the purpose of this study.

#### **Procedures**

To find answers to some of these questions, we invite you to take part in this research project. If you accept, you will be required to: participate in an interview with Eunice Konadu Adai or myself. Eunice is an experienced nurse in this Hospital who has worked in so many units including the neonatal intensive care unit, she also speaks multiple languages especially the common languages that will be used in this study; English and the Twi language.

If you do not wish to answer any of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The

interview which will last for 30-40 minutes will take place in the unit in-charge's office if possible and no one else but the interviewer will be present. The information recorded is considered confidential, and no one else except myself, Eunice Konadu Adai and my supervisors will have access to the information documented during your interview.

### **Possible Risks and Discomforts**

Your participation in this study will not post any risk and discomfort to you. However, if during the interview you are not comfortable answering any question, you can refuse to answer without any consequences on your care or the care of your baby. Also, during the course of the interview if you need to breast feed your baby, you will be given an ample time to do so.

### **Possible Benefits**

Findings of this study will represent the voices of mothers of preterm babies concerning how they are supported in the neonatal intensive care unit which will inform management of the hospital to ensure that, empirical support systems are instituted in the neonatal intensive care unit to support mothers whiles they are on admission. It will also help the facility to know the challenges that affect effective utilization of existing support systems. Best practices that will be identify will be scaled up to other institutions in the Region and beyond to ensure that when mothers of preterm babies are admitted in the neonatal intensive care unit, their support will be paramount to health care givers.

### **Confidentiality**

Recordings will be audio taped with only the research team having access to the audio recorder. Transcribes will also be put on the principal investigator's laptop with password whiles the recorder and the field notes will be put in

drawer under key and lock. Only the principal investigator and the supervisors will have access to this information. The audio tape recorder after analysis will be kept for five (5) years before it will be deleted from the recorder. As much as possible labels will be used to represent participants and no participant will be named in any report of this study.

### **Compensation**

There will not be any special compensation for participating in this study, however at the end of the interview session, there will be water and soft drinks for your refreshment.

### **Voluntary Participation and Right to Leave the Research**

This study is absolutely voluntary without coercion or any form of force, participants are at liberty to opt out of this for their own personal reasons without prior approval from any one. Withdrawal from this study will not in any way affect nursing care for you or your baby.

### **Contacts for Additional Information**

In the course of this study, participants are at liberty to contact the following people

The principal researcher,

Dominic Apedani Bachegejoa

Tel: 0201122701/0247877898.

Email: apedanid@gmail

1<sup>st</sup> Supervisor

Dr. Ebu Enyan Nancy

Tel: 0541145193

Email: nebu@ucc.edu.gh

2<sup>nd</sup> Supervisor

Dr. Druye Adjei Andrew

TEL: 0503187902

Email: adjeidruye2@gmail.com

### Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00 am and 4:30 p.m. through the phones lines 0558093143/0508878309/0244207814 or email address: [irb@ucc.edu.gh](mailto:irb@ucc.edu.gh).

### VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title; **Experiences of mothers of preterm babies on support services in neonatal intensive care units** has been read and explained to me.

I have been given an opportunity to have any questions about the research answered to my satisfaction.

I agree to participate as a volunteer.

\_\_\_\_\_

Date Name and signature or mark of volunteer

#### 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.

\_\_\_\_\_

Date Name and signature of witness

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.

\_\_\_\_\_

Date Name Signature of Person Who Obtained Consent

## APPENDIX B: BACKGROUND INFORMATION FORM

Age of mother

Parity

Mode of delivery

Gestation age of baby before birth

Educational background of mother

Occupation of mother

Number of days on admission

Religion of mother

Weight of baby at birth

Sex of the baby

## APPENDIX C: INTERVIEW GUIDE

### SECTION B: GUIDING QUESTIONS

1. Can you tell me your experience about this unit or the hospital as a whole in terms of facilities that will promote your comfort and wellbeing while your baby is admitted here?
2. Can you tell me how you have been supported in terms of information on everything?
3. Can you describe how the health professionals and your family have supported you in terms of allaying you of any fears and anxiety?
4. Can you tell me about the various health workers who have attended to you while you are admitted here?
5. Can you tell me about the sort of information you have received from the various health workers?
6. Can you describe how you have benefited from support systems available in this hospital or unit?
7. How have you been supported in terms of breastfeeding your babies and carrying out skin- to skin care?
8. In your opinion what do think are some of the things that affect how mothers are supported in this unit?
9. Are there certain considerations you take beforehand that take possible cultural differences into account that can affect how you are supported here?

Thank you for your cooperation

**APPENDIX D: COVER LETTER FOR ETHICAL CLEARANCE**  
**FROM SCHOOL OF NURSING, UCC**



**UNIVERSITY OF CAPE COAST**  
**COLLEGE OF HEALTH AND ALLIED SCIENCES**  
**SCHOOL OF NURSING AND MIDWIFERY**  
**DEAN'S OFFICE**



Telephone: 233-3321-33342/33372  
Telegrams & Cables: University, Cape Coast  
Email: [nursing@ucc.edu.gh](mailto:nursing@ucc.edu.gh)  
Our Ref: SNM/I/4/Vol.1/59  
Your Ref:

UNIVERSITY POST OFFICE  
CAPE COAST, GHANA.  
6<sup>th</sup> December, 2018

The Chairman  
Institutional Review Board  
UCC

Dear Sir,

**APPLICATION FOR ETHICAL CLEARANCE TO CONDUCT RESEARCH: DOMINIC  
BACHEGEJOA APEDANI**

We forward herewith the attached application for ethical clearance from the above named level 850 Master of Nursing students with registration number SN/MNS/17/0014 of the School of Nursing and Midwifery for your consideration, please.

Thank you.

Yours faithfully,


Dr. Dorcas Obiri-Yeboah  
**DEAN**

**APPENDIX E: ETHICAL CLEARANCE LETTER FROM IRB, UCC**

UNIVERSITY OF CAPE COAST

**INSTITUTIONAL REVIEW BOARD SECRETARIAT**

TEL: 0558093143 / 0508878309/ 0244207814 C/O Directorate of Research, Innovation and Consultancy  
E-MAIL: irb@ucc.edu.gh  
OUR REF: UCC/IRB/A/2016/299  
YOUR REF:  
OMB NO: 0990-0279  
IORG #: IORG0009096



20<sup>TH</sup> FEBRUARY, 2019

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Mr Dominic Apedani Bachegejoa  
Department of Nursing and Midwifery  
University of Cape Coast

Dear Mr Bachegejoa,

**ETHICAL CLEARANCE – ID: (UCCIRB/CHAS/2018/66)**

The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for the implementation of your research protocol titled **Experience of Mothers with Preterm Babies on Support Services in Neonatal Intensive Care Unit**. This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

Please note that any modification of the project must be submitted to the UCCIRB for review and approval before its implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

Yours faithfully,



for: Samuel Asiedu Owusu, PhD  
**UCCIRB Administrator**  
ADMINISTRATOR  
INSTITUTIONAL REVIEW BOARD  
UNIVERSITY OF CAPE COAST  
Date: 21/02/19




**APPENDIX F: CONCURRENT APPROVAL FROM TECHIMAN**

**HOLY FAMILY HOSPITAL**

UNIVERSITY OF CAPE COAST

**INSTITUTIONAL REVIEW BOARD SECRETARIAT**

TEL: 0558093143 / 0508878309/ 0244207814 C/O Directorate of Research, Innovation and Consultancy  
E-MAIL: [irb@ucc.edu.gh](mailto:irb@ucc.edu.gh)  
OUR REF: UCC/IRB/A/2016/299  
YOUR REF:  
OMB NO: 0990-0279  
IORG #: IORG0009096 20<sup>TH</sup> FEBRUARY, 2019



Mr Dominic Apedani Bachegejoa  
Department of Nursing and Midwifery  
University of Cape Coast

Dear Mr Bachegejoa,

**ETHICAL CLEARANCE – ID: (UCCIRB/CHAS/2018/66)**


The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for the implementation of your research protocol titled **Experience of Mothers with Preterm Babies on Support Services in Neonatal Intensive Care Unit**. This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

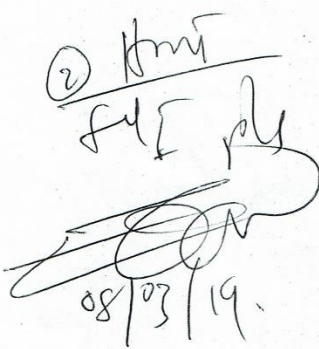
Please note that any modification of the project must be submitted to the UCCIRB for review and approval before its implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

Yours faithfully,

  
for: Samuel Asiedu Owusu, PhD  
**UCCIRB Administrator**  
ADMINISTRATOR  
INSTITUTIONAL REVIEW BOARD  
UNIVERSITY OF CAPE COAST  
Date: 21/02/19

  
08/03/19

## APPENDIX G: APPLICATION FOR ETHICAL CLEARANCE



UNIVERSITY OF CAPE COAST, INSTITUTIONAL REVIEW BOARD (UCC-IRB)

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University of Cape Coast  
College of Health and Allied Health Science  
School of Nursing and Midwifery  
5<sup>th</sup> December, 2018.

Thro;  
The Dean  
School of Nursing and Midwifery  
University of Cape Coast.

The Chairman  
Institutional Review Board  
University of Cape Coast  
Cape Coast.

Dear Sir/Madam,

### APPLICATION FOR INSTITUTIONAL REVIEW BOARD CLEARANCE

I wish to apply for ethical clearance to undertake a research study at Techiman Holy Family Hospital in the Brong Ahafo Region. I am a Master of Nursing student and would be grateful if you would review my research proposal on the topic: Experiences of mothers with preterm babies on support services in Neonatal Intensive Care Units.

I attached here the necessary documents for your perusal.

Yours faithfully


  
.....

Dominic Apedani Bachegejoa


(SN/MNS/17/0014)

UCCIRB  
VERSION: 2017

**APPENDIX H: INTRODUCTORY LETTER FOR PRE-TESTING OF  
INTERVIEW GUIDE**

 **UNIVERSITY OF CAPE COAST**  
**COLLEGE OF HEALTH AND ALLIED SCIENCES**  
**SCHOOL OF NURSING AND MIDWIFERY**  
**DEPARTMENT OF MENTAL HEALTH**

Telephone: 233-3321-33342/33372  
Telegrams & Cables: University, Cape Coast  
Email: [nursing@ucc.edu.gh](mailto:nursing@ucc.edu.gh)

 UNIVERSITY POST OFFICE  
CAPE COAST, GHANA.

Our Ref: SNM/DMH/R2/5  
Your Ref:

11<sup>th</sup> December, 2018

TO WHOM IT MAY CONCERN

Dear Sir,

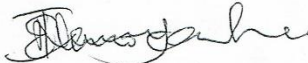
**INTRODUCTORY LETTER – DOMINIC B. APEDANI**

We write to introduce Mr. Dominic B. Apedani who is currently pursuing Master of Nursing at University of Cape Coast. He has successfully defended his thesis proposal and would like to pretest his interview guide in your facility.

We would be grateful for your assistance and cooperation.

Thank you.

Yours faithfully,

  
**Dr. Nancy I. Ebu Enyan**  
PRIMARY SUPERVISOR

*Hoffmans*  
*Approved*  
*[Signature]*  
*28/12/18*

*Research Center*  
*[Signature]*  
*03/01/19*

*Received*  
*3-1-19*  
*[Signature]*

