

**SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA, LEGON**

**THE EXPERIENCES OF MOTHERS CARING FOR PRETERM
BABIES AT HOME: A STUDY IN THE ACCRA METROPOLIS**

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**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA,
LEGON IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR
THE AWARD OF MPhil NURSING DEGREE.**

JUNE, 2013

DECLARATION

I hereby declare that, except for references to other people's work which have been fully acknowledged, this thesis resulted from my own original research. No material in this write up has been presented either in whole or in part to any other institution for the award of any other degree or certificate.

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DEDICATION

I dedicate this research to Zack, Malik, Alswell, Osborne and Blossom. Looking forward to greater times ahead with all of you, I love you all.



ACKNOWLEDGEMENT

I would like to express my heartfelt thanks to the Almighty God for giving me the knowledge, strength and favour to finish up this thesis.

I sincerely express my gratitude to the participants who availed themselves to share their lived experiences with me.

To my supervisors I say God richly bless you for your relentless efforts which enabled me to come up with this work especially Dr. Patience Aniteye and Dr. Prudence P. Nyaledzigbor of School of Nursing University of Ghana, Legon.

I would also like to thank the Acting Dean and all the lecturers of the School of Nursing, University of Ghana, Legon, for their guidance and support.

I wish to extend my gratitude to Professor Gerri Lasiuk of University of Alberta, Edmonton, Canada for her contribution towards this thesis.

I thank the staff of the Neonatal Intensive Care Unit (NICU), the staff of the Out Patients' Department (OPD) of the Department of Child Health and the Biostatistics Unit of the Obstetrics and Gynaecology department of the Korle-Bu Teaching Hospital. Finally, I would like to acknowledge Mrs. Dorothy Aikins for supporting and encouraging me through the difficult times.

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ABSTRACT

The expectation and hope of every pregnant woman is to deliver a healthy baby without any complication at the end of the pregnancy. Studies have shown that when a mother gives birth to a preterm baby, it generates feelings of despair, grief and anxiety. Preterm babies are babies born before 37 completed weeks of pregnancy for gestation regardless of gestational age or birth weight. Preterm birth is an important perinatal health problem globally that needs to be given major attention. The objectives of this study were to explore the experiences of mothers caring for preterm babies at home, identify the major challenges and coping strategies of these mothers and to determine the information needs of mothers caring for preterm babies. A qualitative exploratory and descriptive method was used in the study. The study was conducted at the Department of Child Health, Neonatal Intensive Care Unit (NICU) Clinic of Korle-Bu Teaching Hospital Accra, Ghana. The target population for this study was all mothers who had delivered preterm babies, admitted at the NICU and discharged home with babies between the ages of 3 to 12 months at the time of the study. Purposive sampling technique was used to recruit nine mothers. Data were collected using face-to-face interviews and transcribed verbatim. Data were analyzed using content analysis of the phenomenon being studied.

The findings of the research indicated that mothers caring for preterm babies at home had an array of challenges including feeding, temperature control and attitudes of significant others. Their coping strategies included a reliance on the support of family and significant others and religion. Additionally, the findings of the study revealed that mothers with preterm babies desired more health education and support than they received. Finally, recommendations were made for nursing administration, nursing practice, policy makers and future research.

CHAPTER ONE

1.0 Introduction

In this chapter, the researcher set out to provide a background of the study out of which the problem statement developed. Based on this problem statement, the research questions emerged and the research objectives were developed with the aim of using the research process to meet them. Finally, operational definition of terms used in this study was duly explained.

1.1 Background to the Study

Preterm babies are babies born before 37 completed weeks of pregnancy or gestation regardless of gestational age or birth weight (WHO, 2009). These babies are classified as high-risk neonates. High-risk neonates are those in whom the levels of growth and development are less than normal neonates (Fraser & Cooper, 2003). High-risk neonates are newborns, regardless of gestational age or birth weight. They have greater-than-average chances of morbidity or mortality because of conditions or circumstances associated with birth and the adjustment to extrauterine life. These neonates are classified according to birth weight, gestational age and predominant pathophysiologic problem (Hockenberry & Wilson, 2009). The high-risk neonates who are classified according to birth weight are: Low Birth Weight (LBW); Very Low Birth Weight (VLBW), Extremely Low-Birth Weight (ELBW), Appropriate-for-gestational-age (AGA), Small-for-date (SFD), Intrauterine Growth Restriction (IUGR), Symmetric Intrauterine growth restriction (SIUGR), Asymmetric IUGR and Large-For-Gestational Age (LGA) infants. LBW are infants who weigh 2500grams (5.5 pounds) or less at birth regardless of gestational age, Very Low- Birth Weights (VLBW), are infants with birth weights of 1500grams (3.3 pounds) or less. Extremely low-birth-weight infants are infants whose birth weight is less than 1000g

(2.2 pounds). Appropriate-for-gestational-age infants are infants whose weight fall between the 10th and 90th percentiles on intrauterine growth curves (AGA), Small-For-Gestational-age (SGA) or Small-for-date (SFD) infants are those rate of intrauterine growth were slowed and whose birth weights fall below the 10th percentile on the intrauterine growth curve. Intrauterine growth restriction is found in infants whose intrauterine growth are restricted and sometimes described as small-for-date (SFD). Large- For- Gestational age (LGA) or Large- For- Date (LFD) infants are babies whose weights are above the 90th percentile on the growth chart (Fraser & Cooper, 2003).

The lesser the gestational age of preterm babies, the more problems they have. Usually preterm babies are not discharged home after assessment at the labour ward. They are transferred to the Neonatal Intensive Care Unit (NICU) where holistic and optimal care is provided to enhance the chances of survival of these babies, since the lesser the weights of these babies the more complex their outcomes.

Preterm birth is an important perinatal health problem globally. Low income countries, especially those in Africa and Southern Asia have the highest incidence of preterm birth, although, North America also has high numbers in terms of preterm birth. It was estimated that in 2005, 9.6% (12.9 million births) of all births globally were preterm (Beck, Wojdyla, Say, Betran, Merialdi, Requejo, Rubens, Menon & Van Look, 2010).

Africa and Asia alone had 11million of all the preterm births approximately (85%). However, lowest preterm births were found in Europe (Beck et al, 2010).

In the USA, about 15% of pregnant women are likely to deliver preterm babies, while in the UK about 18% of all pregnant women are likely to deliver preterm babies (Goldenberg, Culhane, Jams & Romero, 2008). The survival rate of preterm

babies delivered in high income countries is better than those in low income countries.

Furthermore, a study carried out in USA indicated that 5% of all preterm births occur in less than 28 weeks (extreme prematurity), 15% of preterm deliveries occur at 28-31 weeks (severe prematurity), 20% also occurs at 32-33 weeks (moderate prematurity) and 60-70% of them are born at 34-36 weeks (Goldenberg et al, 2008).

A total of about 33,577 preterm babies were delivered in Ghana in 2010 (WHO annual report, 2009). The number of preterm births in a country has significant consequences for the society, the economy and the family as a whole. Despite the technological advancement and the efforts of health care providers, the numbers of preterm births in relation to the total number of births continue to increase (March of Dimes, Peristatistics, 2006). This accounts for the large numbers of preterm babies that are discharged from the Neonatal Intensive Care Unit (NICU) for continuation of care at home. This phenomenon happens every year in Ghana. Korle-Bu Teaching Hospital (KBTH) is the largest teaching hospital in the southern part of Ghana and the number of preterm births has increased from 440 (6.1%) in 2006 to 1,132 (10%) in 2010 with an average of 94 preterm babies admitted to Neonatal Intensive Care Unit per month (Bilinla, 2010).

In many instances, the exact cause of preterm birth is unknown. However, there are several predisposing factors leading to reduction in gestational period in expectant mothers. These include previous obstetric history, maternal age, social class, multiple pregnancies, antepartum bleeding, premature rupture of membranes, infections, smoking, alcohol intake and maternal diseases in pregnancy such as hypertension and diabetes mellitus, (Fraser & Cooper, 2003 & Ling, Lian, Ho & Yeo, 2009). Additionally, certain factors on the part of the foetus account for the

delivery of preterm babies and these include placental insufficiency, Rhesus diseases and congenital abnormalities (Fraser & Cooper, 2003 & Ling et al., 2009).

The problems of preterm babies are numerous ranging from physical, behavioural, psychomotor and emotional (Holditch-Davis & Miles, 2000). Preterm babies have problems with respiration, temperature regulation, infection control, feeding and general ill health (Ball & Bindler, 2008).

These babies are managed in the Neonatal Intensive Care Units since their survival rate is perceived to be high in specialized units due to the high quality of care they receive (Holditch-Davis & Miles, 2000). The purpose of NICU is to give optimal nursing care to high-risk neonates in order to preserve their lives. Ideally, every hospital should have a NICU to care for high-risk neonates. However, in some hospitals in Ghana these facilities are not available therefore seriously ill neonates and preterm babies are transferred to other facilities where specialized care could be obtained.

Preterm babies should be managed in a Neonatal Intensive Care Unit (NICU) before they are finally discharged home for continuity of care (Rudolph, Kamei & Overby, 2002). Firstly, the preterm baby should be helped to establish and maintain respiration since the respiratory centre is not well developed.

Maintenance of body temperature is important in preterm babies. The high-risk infants whose weights are less than normal have difficulty in maintaining normal body temperature because the body surface area is disproportionate to the body weight. Thus the amount of subcutaneous fat (adipose tissue) is less than that which is required to conserve body heat (Kliegman, Behrman, Jenson & Stanton, 2007).

Preterm neonates therefore lose more heat than they produce. As part of the management plan, preterm babies are placed in incubators where temperature and

circulating air is controlled, or placed under radiant heater. They can also be wrapped in blankets to provide warmth. Research carried out in Australia showed that, the best way to keep a baby warm is by Kangaroo Mother Care (KMC) method where mothers are made to keep their babies on their chest through a specially made carrier (Nirmala, Rekha & Washington, 2006). In addition, infection should be prevented in the NICU since they are prone to infection because they cannot manufacture enough antibodies (Kliegman et al, 2007). Maintenance of aseptic techniques by proper hand washing and complete sterilization or disinfection of equipment and supplies are the most important things that should be encouraged in neonatal intensive care units. In addition, provision of optimal nutrition is vital since the increase in weight of preterm babies is determined by the quality of feed given (Sweet & Derbyshire, 2009). The nutritional requirement of the preterm infants depends on the individual rate of metabolism, body weight and gestational age. Feeding should commence immediately after delivery. (Kliegman et al, 2007). Furthermore, the preterm infant must be generally observed so that any deviation from normal is reported. The vital signs, skin colour, stools and the weight are the most important to be observed (Rudolph et al, 2002).

The challenges associated with the care of preterm babies at home are enormous. Low birth weight is a major public health problem globally, and the burden that this condition brings is considerably higher in low and middle income countries than in high income countries (WHO, 2009). The morbidity and mortality associated with preterm babies after discharge from NICU have long term adverse effects on parents with preterm babies as well as the infants. This morbidity often extends into later life resulting in physical, psychological and economic costs (Miles & Holditch-Davis, 1997).

Physically, infants who are born prematurely have high incidence of developing cerebral palsy, sensory deficits, learning disabilities, respiratory illnesses, sight and hearing problems, behavioural and psychomotor problems (Miles & Holditch-Davis, 1997). Sight and hearing problems are present in about one in every four of preterm baby born with birth weight below 1.5 kilograms. Infants who have undergone early screening and treatment for retinopathy in prematurity have improved in their long-term sightseeing as compared to those who have been screened and treated in later years. However, an increase in low-birth weight has a subsequent increase in prevalence of retinopathy of prematurity (Kliegman et al, 2007).

Psychologically, mothers of preterm babies have been found to have enormous traumatic symptoms long after their babies have been discharged from NICU. The care of the babies and unpleasant memories as a result of experiences has lead to this. A study carried out by Jotzo and Poets, (2005) showed that traumatization accounted for 77% of mothers with preterm birth one month after, and 49% showed traumatic symptoms after one year of the delivery. A study by Lindberg & Ohrling (2008) indicated that families could not spend time together as a result of prolonged stay of mothers in NICU leading to a sense of loneliness among the family members since they could not stay at home to care for the rest of the family especially, older siblings.

According to Bhutta, Cleves, Casey, Cradock and Anand, (2002), behavioural and psychomotor problems of preterm babies are seen as they advance in age especially during the school going ages. They have numerous disabilities which cannot be treated but can be managed. They have higher incidence of motor impairment and this affects how well they perform at school. Research showed that over 30% had developmental coordination disorder (DCD). Some are over active, easily

distractible, impulsive, disorganized and lack of persistence. Attention deficit hyperactivity disorder (ADHD) accounted for 8.9% of all preterm children (Kliegman et al, 2007). Slow brain development occurs due to intrauterine growth restriction (IUGR) and leads to poor intelligent quotient (IQ) and developmental skills. These disabilities are some of the predictors of maternal stress that they must learn to live with as coping strategies.

Nevertheless, prematurity can be prevented when intervention to reduce the morbidity and mortality rates of preterm birth are directed to all women of child bearing age. Problems such as social deprivation, poor maternal nutrition and substance abuse (smoking and alcohol) if addressed can reduce the rate of preterm births if not prevent them (Ling et al., 2009). Also, quality antenatal care is important and should be made accessible to all women.

1.2 Statement of the Problem

The expectation and hope of every pregnant woman is to deliver a healthy baby without any complication at the end of the pregnancy. However, mothers who deliver preterm babies become dissatisfied about the weight of their babies since in a typical Ghanaian culture babies are admired when they are plump ('big baby'). Usually, preterm babies are underweight and therefore much time and care are needed to enable them gain weight.

Additionally, the delay in naming the baby creates disappointment, worry, despair, anguish and stigmatization to the mother and the entire family. In a typical Ghanaian culture, the naming ceremony is performed on the eight day of delivery where friends, well-wishers and families would want to see and hold the named baby and welcome the baby into the world. The mother feels stigmatized when a small, skinny and unhealthy baby is presented at the ceremony. As a result, the naming ceremony

is postponed till the infant gains weight. Also, the socio-cultural practices in Ghana influence the way preterm babies are taken care of at home and in effect have either negative or positive effects on the babies as well as their mothers.

Furthermore, the cost of caring for preterm babies after discharge is very high. Economically the whole family is affected since much effort and time are needed in caring for preterm babies at home. Mothers who cannot afford the services of caregivers need to stay out of work to care for their preterm babies until they gain weight and develop normally. Mothers thus become financially drained out since they need the working hours to be visiting physicians and other health team members for follow-up and continuity of care. The researcher observed that the challenges of managing preterm babies at home are numerous, ranging from social, economic, physiological and psychological. Physiologically, preterm babies encounter numerous problems such as respiratory, maintenance of body temperature, exposure to infection and difficulty in feeding.

Additionally, there are no support groups for mothers with preterm babies to share their pain, experiences or interact with other mothers with similar problems.

Over all, the problems of preterm babies are enormous. Meanwhile, preterm births are on the ascendency with time. The preterm birth at Korle-Bu Teaching Hospital spanning the period 2006 – 2010 show a steady increase as depicted by table one below:

Table 1: Normal and Preterm Deliveries from 2006 - 2010

Year	Total Babies	Total Preterm Babies	Percentage (%)	Average Monthly Preterm Delivery
2006	7, 227	440	6.1%	37
2007	7,775	726	9.3%	61
2008	10,721	1199	11.2%	100
2009	10,783	971	9.0%	81
2010	11, 287	1,132	10%	94

Source: Biostatistics Unit of Korle-Bu Teaching Hospital.

Given the enormity of problems of caring for preterm babies, the more preterm babies are born the more the problems.

There might have been many problems confronting mothers in their homes following delivery of preterm babies which might have been taken for granted. Therefore, there is the need for this study to be carried out purposely to explore the lived experiences of mothers taking care of preterm babies at home in the Accra Metropolis.

1.3 Purpose of the Study

The purpose of this study was to explore and describe the experiences of mothers caring for their preterm babies at home in the Accra Metropolis.

1.4 Objectives of the Study

The objectives of the study were to:

- Describe the experiences of mothers caring for preterm babies at home.
- Identify the major challenges and coping strategies of mothers with preterm babies at home.
- Determine the information needs of mothers caring for preterm babies at home.

1.5 The Significance of the Study

The knowledge envisaged to be gained from this study, will enhance the quality of care provided to babies at the Neonatal Intensive Care Unit (NICU). It will provide useful insight into mothers' knowledge level about the care of preterm babies and offer avenues for health education. It will also provide suggestions to policy initiatives to enhance practice and management of preterm babies in Ghana. Again, findings from this study will serve as the basis for developing guidelines for educating mothers with preterm babies during discharge. Finally, the findings of this study will unearth other areas for further research and ultimately help improve both psychological and social dimensions of issues that affect mothers with preterm babies in Ghana.

1.6 Operational Definition of Terms used in the Study

Experience: The everyday practical life of mothers caring for their preterm babies at home.

Mothers: Nursing mothers who have delivered preterm babies and discharged home from the Neonatal Intensive Care Unit of Korle-Bu Teaching Hospital.

Preterm babies/Prematurity: Babies born between 32 to 34 weeks of gestation or pregnancy regardless of their weight.

Low Birth Weight: Babies with birth weight below 2.5 kilograms.

Very Low Birth Weight: Babies with birth weight of 1.5 kilograms or less.

Neonatal Intensive Care Unit (NICU): The unit where high-risk neonates including preterm babies are care for.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents a detailed review of the literature related to the topic. The review was organized based on the questions that the researcher sought to answer.

These included:

- What are the experiences of mothers caring for preterm babies at home?
- What are the major challenges and coping strategies of mothers caring for preterm babies at home?
- What are the information needs of mothers caring for preterm babies at home?

A computer search for related literature was done using databases such as of pubmed, hinari, psych INFO, Google, web of science. The following key words were used: [(preterm babies) OR (premature infant)]; [(expectation) OR (feelings) OR (experience) OR (stressors) OR (coping)] OR [(knowledge) OR (information needs)]. Limitations were applied by searching for articles from the year 2000 to date.

2.1 Experiences of mothers with preterm babies

Flacking, Ewald and Starrin (2007) conducted a study on experiences of becoming a mother and breastfeeding infants after discharge from a neonatal unit. It was a grounded theory approach with twenty-five mothers whose infants had received care in seven neonatal units in Sweden. The data collection was through interview with mothers between one to twelve months after discharge. The data were collected from three university hospitals and four in the chosen country hospitals.

The researchers found that the mothers were emotionally exhausted due to suppressed feelings such as fear of losing the babies, anger towards staff or shame about feelings of being rejected as mothers who could not live up to the expectations of being good mothers. Also, the mothers of the preterm babies expressed feelings of relief when the infants were discharged from the intensive care unit. It was also found that the mothers developed different coping strategies for mothering by identifying the needs and behaviours of the infants. They tried to imitate the staff about care of preterm infants so that they could be good mothers. Additionally, many mothers felt insecure on how to interpret their infants' behaviour and how to care for them but later became familiar with the infants' behaviour and gained confidence as mothers to nurse them. Furthermore, the cultural norm of "good mothering" was attached to breastfeeding. The breastfeeding experience was a strong symbol of maternal-infant bonding. According to the researchers, positive experiences of breastfeeding led to feelings of trust and pride in the mother-infant relationship while negative experiences led to feelings of distrust and shame in the mothers. The study was appropriate since a large sample was used even though it was a grounded theory approach. However, the findings of the study could not be generalized even though the study was carried out in different hospitals in Sweden.

The current study sought to know the experiences of care of mothers with preterm babies at home. This area has been sparsely studied in West Africa and in Korle-Bu, Teaching Hospital, the largest teaching hospital in Ghana. Hence the need for this study to be conducted to identify and address the concerns of mothers who had delivered preterm babies and are caring for them at home is important.

A study was carried out in Sweden on the experiences of mothers and fathers of preterm infants by Jackson, Ternstedt and Schollin (2003). A phenomenological

approach was used. Seven selected sets of parents of preterm infants born at 34 weeks of gestation without any congenital defect were recruited. They were interviewed 1-2 weeks after the delivery of the infants, and at 2, 6 and 18 months of age. It was established that internalization of parenthood was regarded as a time-dependent process with four codes of words such as “alienation”, “responsibility”, “confidence” and “familiarity”. These words were used during the interviews and questions asked on them described how mothers and fathers of preterm infants played their parental roles concerning the child in relation to insecurity, adjustment and the relationship with the infants. With regards to differences in experience, mothers had more responsibilities and control over the care and needs of the infants while the fathers also described and explained how confident they were leaving the infants in the care of the NICU nurses during admission and the mothers when the babies were discharged. According to the authors, fathers do not normally participate actively in the routine care of their infants except a few. Fathers would normally want to cuddle, and talk to their infants simply because of their nature of work. However, some fathers tried to balance responsibilities between work and family life. The positive aspect of parental experience was seen when the infants could be removed from the incubator at the NICU sometimes and discharged home due to the fact that the infant looked normal like a full term baby. Parents became happy and relieved because they were no longer in the hospital environment. The phenomenological approach of parenthood experience structured together by “alienation” “responsibility”, “confidence” and “familiarity” was based on the expectations of the parental role, infant’s condition of health and the health care environment. However, those factors were influenced by one’s cultural beliefs. The study appeared innovative and original because it provided an avenue for fathers to participate in the care of preterm babies.

The fathers with preterm babies showed how caring they were at the Intensive Care Unit during admission of the babies. However, not much of the fathers' experiences were explained.

In the current study, the researcher's aim was to explore the lived experiences of mothers caring for preterm babies at home. This was because at the Neonatal Intensive Care Unit (NICU), some of the babies would not have been on admission for a longer period and thus mothers would not have had much experience to share. Most of the literature review dwelt on studies of preterm babies at NICU and in Europe. Therefore, the need to conduct the current study which focuses on care of preterm babies at home is imperative.

Another study was carried out by Lindberg and Ohrling (2008) on experiences of having a prematurely born infant from the perspective of mothers in Northern Sweden with the aim of describing the mothers' experiences of having prematurely born infant. The focus of the study was on the birth itself and during the time immediately following the birth. The study was conducted in collaboration with neonatal intensive care unit (NICU) in Norrbotten. A descriptive qualitative method was used. Six mothers with premature infants born between 28 to 34 weeks who needed care at the Neonatal Intensive Care Unit were used. However, mothers were interviewed at the time the children were 3 years old. The data were analyzed by content analysis. It was found that mothers with prematurely born infants were not initially ready for the birth of premature babies therefore, it took time for them to consider themselves as mothers. Again, they felt anxious and separated from their infants in NICU while they were kept in the incubators. This led to a stressful experience by mothers of premature babies. Also their social roles as mothers could not be played well since they could not have time for other children at home.

However, the mothers felt supported by the hospital staff because they were equipped with knowledge and involved in the care of the infants. According to the mothers, the support they received from their partners made their situation less stressful. The limitation of this study was that, the mothers might have forgotten some of the lived experiences they encountered and therefore might not be able to share vividly their experiences because the 3-year period that elapsed after delivery of a preterm was too long. This study explored the experiences of mothers with preterm babies between the ages of three months and at most one year since their lived experiences can easily be remembered. The longer the time elapse between their experiences and the time of interview the lesser the chances of recollection. The element of recall bias must be taken care of.

Sweet (2008) conducted a study on expressed breast milk as a 'connection' and its influence on the construction of 'motherhood' for mothers of preterm infants. It was a qualitative interpretive phenomenological study using a longitudinal approach in an Australia Metropolitan hospital's neonatal intensive care unit (NICU). The study sought to answer the research question: what is the lived experience of parents breastfeeding very low birth weight infants? The aim of the study was to explore the experiences from the perspectives of both mothers and fathers. The sample size was 10 mothers and 7 fathers altogether, 17 parents who wanted to breastfeed their preterm (VLBW) infants. Data were collected through 45 semi-structured individual interviews at different times. The data were analyzed through thematic analysis. Six themes were identified as: the intention to breastfeed naturally; breast milk as connection; the maternal role of breast milk producer; breast milk as the object of

attention; breastfeeding and parenting the hospitalized baby and the demise of breastfeeding.

The findings of the study revealed that breast milk was one of the best ways that the preterm infants could be physiologically and emotionally connected to the mother while the infants were on admission. It was also noticed that expressed breast milk was the only way that could create a bond between the preterm infants and their mothers since they (infants) are in constant care of the hospital staff. Finally, the results of the study revealed that the bond and interconnectedness between mother and preterm infants had made breast milk very valuable in the lives of the mothers and in the motherhood roles they play.

The findings of the study had implications for healthcare practice as far as breastfeeding was concerned. Breastfeeding success was found to create and enhance self-esteem and the sense of parental abilities in some families. It is therefore imperative to find more positive avenues of connecting mothers and their preterm infants in the neonatal intensive care environment to support breastfeeding practices.

The qualitative approach used for the study was appropriate. However, the findings cannot be generalized since the sample size was small. Exclusive breastfeeding has been found to be the most important source of nutrients for infants and its success enhances bondage of mother and infants. The current study adopted a qualitative approach to explore the lived experiences of mothers of preterm infants. The findings would inform nursing practice and encourage baby-friendly policy in Ghana.

Another qualitative study was conducted by Erlandsson and Fagerberg (2004). The objective of the study was to describe how mothers of premature or sick mature babies experienced the care and their own state of health after birth in postnatal care and neonatal co-care ward. The study was conducted in Sweden using Husserlian phenomenological approach. Six mothers were interviewed using semi-structured and opened ended interview guide. The study was conducted in a neonatal ward using the concept of co-care and part-care. The data were analyzed based on Husserlian phenomenology.

The researchers found that mothers of premature infants wanted to be close to their babies at the hospital and also wanted to be given constant information about the health status of their babies at all times. Additionally, it was found that separation of babies from the mothers affected the feelings and realization of the motherhood role. This consequently had negative influence on the health status of the mothers of preterm babies. Again, the mothers perceived their stay at the hospital as one event and could not differentiate between the experiences in the maternity ward and the neonatal ward but rather saw it as an event. The researchers suggested that the mothers also needed to be cared for while on the ward. It was again reported that the mothers were given the chance to work on their babies practically which created a bond between the mothers and the babies. The findings proved that the mothers who experienced the co-care felt good and confident in them and as a result could manage any situation in relation to care of the babies. Furthermore, those who were separated from their babies developed feelings of guilt and abandonment of their babies. Mothers felt bad leaving the babies in the unit and staying at home at night. Some of the mothers felt disconnected from their babies due to part-care because they did not

co-operate with the staff for their needs to be understood. Those who received part-care felt sorrowful and neglected because of frequent changes of staff which made it difficult them to identify with the needs of the mothers.

According to the researchers, the study design was such that they could not draw conclusions about the co-care and the part-care. However, they were able to outline the implications of the study and suggested that means should be identified for mothers of premature and sick babies to be brought together and treated as individuals by taking time to listen to them, talk to them and provide support.

On the whole, the study was useful because it threw more light on the experiences of mothers. The importance of the co-care and part-care was identified and valuable recommendations were made. However, the sample was so small that generalization was not possible to other settings.

The current study seeks to know about the experiences of mothers of preterm babies at home rather than at the hospital. Studies on mothers' experiences of care of preterm babies' care after discharge are scarce and this gap is addressed in the present qualitative study. It is important to focus on and to identify the experiences of these mothers at home because in the hospital their lived experiences of the babies on care is limited since they do not actively take part in the care of their babies due to complexity of the care of preterm infants at the unit. Additionally, much information cannot be received about their experiences at the hospital level since some of the babies are discharged within few days of hospital stay. To date, no research has been conducted on the area under study in Ghana. It is therefore imperative to conduct this study to enable the health care professionals realize the

importance of improving the quality of care received by mothers and babies in the intensive care unit.

Another study on fathers' lived experience of caring for their preterm infants was conducted by Lundqvist, Westas and Hallstrom (2007). The aim of the study was to highlight fathers' experience of caring for their preterm infants. An inductive design with hermeneutic phenomenological approach based on van Manen (1997) was used where thirteen fathers were interviewed. The study was conducted in the Neonatal Intensive Care Unit (NICU) in southern Sweden. The interview was conducted between one to three months after the babies were born. Themes such as "feelings of distance" and "feelings of proximity" were identified while subthemes such as "living beside reality", "becoming an outsider", "living with worry", "returning to reality", "becoming a family" and "facing the future" were identified.

The authors of the study found that fathers with preterm babies were overwhelmed by the infants' needs of actual medical treatment. As a result, they were in a state of emotional imbalance and could not face the realities of life. The fathers felt they were physically present but emotionally they were absent since they felt lonely. Additionally, the fathers were worried about the survival of their preterm babies and also empathized with their partners' situation. As a result, they felt that there was the need to show positive attitudes towards their partners to support them. According to the authors, the fathers with preterm infants readily received information from the staff when they gained grounds to face the realities of the situation of their preterm infants. The findings of the study showed that fathers of the preterm infants expressed how supportive the friends, family and the staff were to them. As a result, they felt encouraged to live in the present. Furthermore, the authors identified that

the fathers of preterm infants were pleased about spending time with their infants either alone or together with their partners as a family. Finally, the findings showed that the fathers of preterm infants felt secure when the preterm infants' condition improved and the doubts about their survival reduced. The fathers became closer to and happier with their preterm infants and began living in the future.

The study of fathers' lived experience of caring for their preterm infants might help health professionals to provide quality care in their clinical areas. It was also emphasized that Health professionals should be sensitive to the role of fathers caring for their preterm infants.

It is always assumed that fathers do not directly participate in the care of preterm infants but this study has shown otherwise. From the study it was concluded that fathers' concerns were paramount in the care of preterm infants. Studies such as this one are scarce in African countries therefore there is the need for further studies on fathers experience with preterm infants.

Additionally, Kipchumba (2008) carried out a study on mothers' experiences and perceptions of kangaroo mother care during hospitalization of their preterm babies. The study was conducted in a hospital in Johannesburg, South Africa. The purpose of the study was to understand the mothers lived experience and perception towards 24-hour kangaroo mother care (KMC) during hospitalization of their preterm babies. It was a qualitative design which used a phenomenological approach. Data were collected from nine mothers through in-depth unstructured interviews. The data were analyzed using Collaizzi's (1978) step to phenomenological data analysis. Three themes were identified during the analysis of data. These included; 'it is a bond

between me and my child', 'nurse-patient interaction' and 'it is tiring and exhaustive'.

The findings of the study showed that all the mothers were highly satisfied with the KMC method because, it enabled them closer assesses to their babies through bonding. As a result they were able to observe the growth and development in their babies with time. Further, the KMC was found to provide warmth and comfortable environment for the babies due to maternal body temperature which in turn enhanced maternal satisfaction despite the daunting task of carrying them on the chest.

In conclusion, it was suggested that kangaroo mother care should be incorporated in all the levels of health training institutions as it has been found to be beneficial to both mothers and their babies. The practice of the KMC had been introduced in Europe and America a long time ago but in Sub-Saharan Africa the adoption and implementation of the practice of KMC has been recent.

From the literature reviewed, much has not been done in the area of mothers experience in Africa, therefore, the need to further conduct the current study is pivotal.

In another qualitative study, Hollywood and Hollywood (2011) conducted a study on the lived experiences of fathers of premature babies on a neonatal intensive care unit in Dublin, Republic of Ireland. The aim of the study was to explore the lived experiences of fathers with premature babies on a Neonatal Intensive Care Unit, to highlight the varying degree of experiences that fathers encounter while maneuvering through such a turbulent and intense experience and to raise awareness amongst health care professionals in relation to the experiences of fathers whose

infants were care for in the NICU. A qualitative phenomenological approach was used for the study. Non-probability purposive sampling was used to elicit information required to understand the phenomenon. Five fathers were recruited and interviewed and the data were analyzed based on the work of Van Manen (1990) who introduced a six step approach to assist with analysis within phenomenological design. In all, five themes and three subthemes were identified after the analysis of the data.

The results of the study showed that the fathers of premature babies experienced great anxiety as evidenced by the hospitalization of the premature babies and the outcome of the babies in the neonatal intensive care unit. Also, the findings revealed that the fathers of premature babies felt helpless and feared the unknown when they saw the premature babies for the first time in the incubators. Additionally, the fathers became emotional with the realization of becoming a father to premature babies and the new roles associated with it. According to the authors, sharing of information and the positive nature of care by the health professionals were found to be important and beneficial to the fathers in the study. However, the information sharing was found to have both positive and negative effects on the fathers of premature babies because there was inconsistency in the information sharing by the health professionals due to different staff they come in contact with. Furthermore, the researchers noticed that mothers of premature babies were seen to be actively and directly involved in the care of their premature babies than their fathers at NICU; the fathers felt they were considered to be second parents of the premature babies. Finally, the findings of the study showed that fathers' occupation had a negative influence on the level of care provided by fathers to their premature babies at NICU. The effect of distraction of

work was a cause of concern to the fathers whose babies were hospitalized at the NICU.

In conclusion, highlights of the experiences of fathers of premature babies at the neonatal intensive care unit creates an awareness of the need for health care professionals to consider the unique roles that fathers of premature babies play in NICU. The strength of the study included the acknowledgement of roles of fathers with premature babies during such difficult times at the NICU. The study was relevant since the design made it possible for the lived experiences of fathers to be highlighted. However the findings of the study cannot be generalized since the number of participants was small.

2.2 Challenges and coping strategies of mothers

Furthermore, Singer, Fulton, Kirchner, Eisengart, Lewis, Short, Min, Kerckmar and Baley (2007) conducted a study in Cleveland, Ohio. The aim of the study was to compare the severity and determinants of stress and coping in mothers of 8-year-old very low birth weight (VLBW) and term children varying in medical and development risk. It was a longitudinal, controlled, prospective study where 3 groups of mothers with very low birth weight infants were compared from birth till 8 years with term children. 110 high-risk VLBW, 80 low-risk VLBW and 112 term children's mothers participated in the study. Conceptual model of family adjustment was used to view VLBW as stressful life event that may negatively affect families across multiple biopsychosocial domains. This model noticed that stressors and resources may change with time. However, race, maternal education, multiple birth socioeconomic status and other stressful life events were considered as confounding variables and their effects were examined statistically after mothers were

interviewed. Analysis of variance (ANOVA), analysis of covariance ANCOVA), multiple analysis of covariance (MANCOVA), Kruskal-Wallis test, Pearson and Mantel-Haensezel x tests were used to analyzed the data.

The researchers found that those high-risk VLBW children had more neurological and medical risks at birth and low IQ at 8years than low-risk VLBW and term children. 19% of the high-risk VLBW, 9% of the low-risk VLBW and 2% of term children had IQ of greater than 70. This implied that there was no significant difference in the score of the data. Also, the mothers of very low birth weight were different from mothers of term infants because they reported more concerns on their children's health, less parent-child conflict and attained fewer years of additional education. Furthermore, mothers of high-risk VLBW children were found to experience the highest family and personal problems and used less denial and mental disengagement in coping than mothers of low-risk VLBW and term children. Thus the mothers had developed coping strategies that would help them manage the stressors associated with parenting. Additionally, the mothers had lower consensus with marital/partner relationship, divorce rate, parenting competence and psychological distress symptoms. However, multiple birth, low socioeconomic status, low intelligent quotient (IQ) and mental retardation in the infants were found to add to maternal stress.

The findings of the study were appropriate to the topic since the researchers elaborated on the stressors and the coping mechanisms of the mothers. Also, the topic for the research was appropriate and the duration of the study was appropriate since it was a longitudinal study. Nevertheless, there were limitations in this study. Even though, the study was on parenting, data were collected on fathers who were not recruited for the study because they were not reliable. Another limitation was

that, measures of family impact were based on self-report obtained from the data and not from objective measurement. In contrast, the method of the current study was qualitative and not quantitative and sought to explore the stressor and describe the coping strategies of mothers who were caring for their preterm babies at home.

In conclusion, the survival rate of very low birth weight children is mainly due to increased technological advancement in medical care. However, it is associated with long-term positive and negative effect on maternal and family outcomes.

Jones, Rowe and Sloan (2008) carried out a study on the stress and coping in fathers following the birth of preterm infants in Australia. The purpose of the study was to investigate the stress experience of fathers of preterm infants during the infants' hospitalization. The specific aim of the study was to examine fathers' stress, coping style and their access to, use of and satisfaction with the social support resources during their infants' hospitalization in NICU. The research questions that were asked were; what levels of stress (emotional exhaustion) were experienced by fathers? What were the coping strategies used by fathers of preterm infants? What were the resources of support identified by fathers of preterm infants? How satisfied were fathers with the support they were receiving? A descriptive design was used based on Lazarus and Folkman's model of stress and coping. The participants were fathers of preterm infants recruited from metropolitan hospital in Queensland, Australia. Most of the infants were admitted to NICU after delivery and then transferred to Neonatal Special Care Unit (NSCU). The infants who were included in the study were those in stable condition determined by the nursing staff. Twenty one (21) fathers with the age range of 23 to 44years old were used for the data collection. The data were collected in two forms from each participant. A questionnaire was developed using standardized measures of Maslach Burnout Inventory (MBI)

subscale of emotion exhaustion for the aspect of stress and coping. A semi structured interview was also used to examine social support. Two forms of interviews were used. First, the participants were asked about their experience of having preterm babies and secondly, they were asked about the different resources of support they had received such as emotional, social, informational and practical in order to identify the rate of satisfaction.

The findings showed that, nineteen participants were employed and two unemployed at the time of the study. Again, nineteen of the fathers were married while two were single. It was noticed that thirteen of the fathers had children for the first time, while the remaining eight had other children ranging between one and five. Additionally, sixteen fathers had single-ton infants while four fathers had multiple birth babies in the Neonatal Special Care Unit (NSCU).

One multivariate outlier was found and the scores were identified as extreme scores and that participant was dropped from the quantitative aspect of the study so twenty fathers were finally used. The mean total score ($M=11.96$, $SD=7.08$) for emotional exhaustion was compared with means from the general population. Six fathers were in the clinical range. The mean total score for parenting competences was just above the mid-point of the scale ($M=41.25$, $SD=9.60$) indicating that fathers on average slightly agree with the statement about their parental competence. The subscales of the cybernetic coping scale showed that fathers used accommodation coping skills the most ($M=11.19$, $SD=4.14$), followed by symptom reduction coping strategies ($M=10.19$, $SD=3.01$). Coping designed to change the situation was the next used ($M=9.33$, $SD=3.15$), with devaluation ($M=7.46$, $SD=3.17$) and avoidant ($M=6.57$, $SD=2.20$) coping strategy used the least frequently. Furthermore, a series of t-test was conducted to determine if there was a significant difference between coping

strategies used. It was revealed that there were statistically significant differences between the changing the situation and accommodation ($t(20) = -3.14, p=.005$); accommodation and devaluation, $t(20)=4.07, p=.001$; accommodation and avoidance, $t(20)=4.63, p<.001$, with accommodation being used more frequently than changing the situation, devaluation and avoidance. Also, there were significant differences between devaluation and symptom reduction, $t(20)=-3.80, p=.001$, and avoidance and symptom reduction, $t(20)=5.85, p<.001$, with the strategy of symptoms being used more frequently than avoidance or devaluation. Finally, fathers used “changing situation” more than “avoidance” ($t(20) = 3.22, p=.004$). Accommodation and changing the situation also had a negative correlation with emotional exhaustion ($r=.49, p= .022$).

With the qualitative aspect of the findings, four major sources of support were identified as; social, emotional, practical and informative. It was found that families were the major sources of social, emotional and practical support, although friends were also a major source of emotional support and partners a major source of emotional support.

The research designs (mixed method) was appropriate. The use of both qualitative and quantitative approaches threw more light on the phenomenon under investigation. However, the sample for the quantitative design was small so there could be no room for generalization.

Garel, Dardennes and Blondel (2006) undertook a qualitative study on mothers' psychological distress 1 year after very preterm childbirth in France. The objectives of the study were to assess mothers' physical and psychological health, their perception of their child's health and development and their difficulties with children

from 2 months post discharge to 1 year after very preterm delivery. The study population included all mothers who delivered before 33 weeks amenorrhea between November 1998 and November 1999 in a Parisian maternity unit and between February 2000 and February 2001 in a maternity unit in Rouen, France. Twenty-one (21) mothers were used for the study. Semi-structured interviews were conducted by a Clinical Psychologist at the women's home.

The study showed that, the main difficulties reported by the mothers were fatigue, depressive mood, anxiety, physical symptoms, withdrawal and feeling of guilt. Fourteen mothers mentioned fatigue caused by activities such as work and lack of sleep. Depressive affects were seen in sixteen mothers and this was revealed by the tone of voice of the mothers and tears during the interviews. Most mothers' depressive affects were associated with the child's health and development. Also, feeling of guilt was observed in eleven mothers about the very preterm delivery. They thought they did something wrong to have caused them to deliver earlier. Again, anxiety was seen in fourteen mothers in form of worries and fear. This was mainly due to the children's health and development. Ten mothers experienced sleepless difficulties caused by fatigue and a tense marital relationship. Additionally, all the mothers gave mixed descriptions about their perceptions of the child's behaviour. They mention positive behaviour as happiness and sociability and the negative behaviour as restlessness and demanding behaviour. Furthermore, eight mothers reported challenges showing that the delivery of the preterm had been traumatic event. This manifested as post-traumatic symptoms such as avoidance or recurrent experience. Again, it was revealed that mothers used defense mechanisms such as denials, idealization and rationalization in order to be able to cope with the difficulties.

The study again showed that, most mothers had physical symptoms such as migraines, backache, weight gain or loss, digestive pain, colon problems, allergy, circulation problems and asthma. They were treated and discharged. However, none of the mothers ever visited a psychiatrist or psychologist. Finally, the study tried to find out about the baby's development and health at age one. It was observed that the children's motor development were satisfactory. The medical follow-up seemed satisfactory. However, five children were rehospitalized for major systemic infections and later discharged. One limitation of the study was that the inclusion criterion of the study was one year after delivery of preterm babies was too long since some mothers have forgotten some of their experiences.

Davis, Edwards, Mohay and Wollin (2003) carried out a study on the impact of very premature birth on the psychological health of mothers. A quantitative survey design was used with a population of sixty-two mothers of singleton preterm infants born at less than 32-week gestation at a tertiary referral hospital in Australia. Data were collected between May 2000 and February 2001 using structured questionnaires. The objective of the study was to examine the correlation of maternal depressive symptoms at one month following the birth of preterm baby after infant admission to neonatal intensive care. The hypothesis to be tested was maternal depressive symptoms at one month post- premature birth as associated with a previous history of depression, limited formal education, limited social support (from family and/or nursing staff), high levels of stress, limited use of coping strategies and infants of low gestational age, birth weight and Apgar score. The instrument used was a survey questionnaire booklet which contained a number of previously validated research instruments These included: Edinburgh Postpartum Depression Scale (EPDS); Stress scale of the Depression Anxiety and Stress Scale (DASS);

Social Support Interview (SSI); Nurse Parent Support Tool (NPST) and Coping Health Inventory for Parents (CHIP) The data was analyzed by Chi square, *t*-tests and Man-Whitney for non-normally distributed variables. The findings of this study revealed that, the mothers were mild to moderately stress up. They were somewhat satisfied with their coping efforts and reported receiving high levels of support from the nursing staff.

Bivariate associations showed that family social support scores, previous history of depression, infant birth weight and Apgar scores were not statistically associated with the EPDS scores. Also maternal stress scores, education, nurse support scores, the infant's gestational age were associated with the EPDS scores and were used in the logistic regression model. Scores on the EPDS ranged from 1 to 22, and 40.3% mothers scored ≥ 12 on the Edinburgh Postpartum Depression Scale. Overall, the logistic regression model was significant $\chi^2(3, 36.271)$ thus $p < 0.001$. The relationship between maternal stress and depressive symptom reached statistical significance such that a one-point increase in stress score increased the risk of depression by 14%. The relationship between a mothers' perception of support provided by nursing staff and depressive symptomatology also reached statistical significance, so as nursing support decreased by a point, the risk of depression increased by 6%. Depressive symptomatology was also associated with educational status. The risk of depressive symptoms was significantly higher in mothers who had completed primary/some secondary education compared to those mothers completing secondary education. There was a similar trend for mothers who had completed primary and some secondary education compared to tertiary educated mothers but this did not reach statistical significance. No significant difference was found between the prevalence of depression and those mothers completing secondary education and

tertiary educated mothers ($p = 0.598$). Neither gestational age of the infant nor maternal coping scores were statistically significant when entered into the final logistic model. The results of this study and the conclusions made were well outlined for better and deeper understanding.

2.3 Information needs of mothers

A qualitative descriptive study to investigate the feelings and expectations of mothers of preterm babies at discharge was conducted by Rabelo, Chaves, Cardos, and Sherlock (2007). Bardin's framework was used to collect data from 11 mothers of preterm babies from Neonatal Intensive Care Unit (NICU) in Fortaleza, Brazil from December 2004 to January 2005. During content analysis, four themes emerged from the data: (a) the moment of hospital discharge, (b) maternal doubts, (c) preparation and instructions for discharge and (d) instructions sought after by the mothers. The researchers found that, the mothers of preterm babies were elated at discharge because of the relief of the burden of caring for other siblings and relatives staying at home. However, many were anxious and insecure about caring for the preterm babies at home because they did not acquire the skills that would enable them care for the babies at home. This development occurred because they were only made to observe the procedures but not to participate in the care of preterm babies at the Neonatal Intensive Care Unit. Also, the researchers found that the basic activities such as bathing, changing of diapers, breast feeding and administration of medication were observed to be more complex for the mothers of preterm babies since they were not conversant with such activities while the babies were on admission. This was because the mothers were not given the chance to directly care for the babies during their stay in the hospital.

Furthermore, the researchers realized from the statements made by the mothers of preterm babies that, they received little or no information on follow ups and health education on care of preterm babies at discharge to enable them provide adequate care to their babies at home. As a result the mothers were inefficient and less equipped in caring for their preterm babies at home. This led to the anxiety and fear in the mothers when they were left to care for their babies after discharge. During the interviews, it was observed that some of the mothers of preterm babies had entirely forgotten the instructions they received at discharge on care of preterm babies at home so there was the need for manuals or handbooks on care of preterm babies to be provided.

It was recommended by the researchers that, parents should be ready for any eventuality that might occur as a result of delivery of preterm babies. The researchers emphasized on the need for mothers to participate actively in the care of preterm babies while on admission so that they would be conversant with the basic skills and knowledge in caring for preterm babies before they are discharged home. This would reduce their anxiety levels and increase their confident levels of managing the babies at home. Again, the researchers emphasized on the preparations and instructions given to mothers on discharge. It was stressed that instructions given to prepare mothers for the babies' discharge should be clear, concise, simple and easy to understand. Stress and anxiety could affect the learning process at the time of health teaching so factors that could impede their ability to learn should be avoided. Thus, they must be given the necessary attention and encouragement to enable them play the maternal roles such as permitting them to actively participate in the care of babies at the hospital. Additionally, they stressed on the need to consider the

mothers' socioeconomic, cultural background and appropriate language when giving them health education.

The researchers concluded that, the hospital staff should involve mothers in the care of the babies at the NICU in order to increase their confidence and security levels and reduce the doubts in them so that they can take care of their babies at home. They reiterated that the participation of the mothers would create an affective bonding which is healthy for both mothers and babies. For the intended purpose (feelings and expectations) of the mothers the design used for the study was appropriate as it afforded the mothers the opportunity to talk in detail about their experiences with preterm babies after discharge. The size of the participants was also appropriate for the chosen design considering the amount of qualitative data that the researchers might have gathered. The study highlighted the importance of involving mothers of preterm babies in their care of babies while they were on admission so that the mothers could acquire the skills of caring for their babies at home. They also stressed on the need to print manuals on care of preterm babies that would serve as a guide on discharge. In the same vein, the current study sought to identify the knowledge needs of mothers on care of preterm babies at home so that the appropriate information would be given to the mothers during health teaching. The previous study was limited to Brazilian speaking participants so the views of non-Brazilian speaking women were not captured. The current study used English and "Twi" (local Ghanaian language) speaking women to capture a wide spectrum of information.

Broedsgaard and Wagner (2005) conducted a study on how to facilitate parents and their premature infants for the transition home. The study was carried out in Copenhagen University Hospital, Denmark. The aim of the study was to ensure that

parents of premature infants were feeling independent when discharged home, to educate and meet the parents' need for information while at the neonatal units and to prepare them for going home with the premature babies. The interventions put in place were programmes offered to mothers during their infants' admission at the intensive care unit and during discharge to enable them care for their babies at home. Two distinct methods were used to collect data. Quantitative non-experimental survey and qualitative exploratory descriptive methods as semi-structured questionnaires and focus group interview were used to elicit information on parents' experiences. 37 families participated in the study, 18 families were involved in the focus group interview while 37 families filled the questionnaires. The study was carried out for two years and evaluated for one year after the intervention. The quantitative data were analyzed by using descriptive statistics (numbers and percentages) while the qualitative data was analyzed separately according to the themes developed from the interviews.

It was found out that, 73% of the families were satisfied with the information they received from the health visitors on care of premature infants. Also, 95% of the families in the study stated that they received adequate support and guidance from the coordinators, 94% felt that the intervention put in place was beneficial and were pleased with the continuity of care they had for their premature infants especially when they were discharged home.

Findings from the qualitative design showed that the parents of premature infants perceived most of the intervention initiatives as a measure that increased the support they needed to care for their infants during hospitalization and following discharge. Again, the intervention programmes the parents received increased their confidence

levels in caring for their premature infants at home. Finally the parents were well prepared to cope with consequences that the delivery of premature babies brought. This was made possible through the availability of written materials for parents to provide the knowledge that they needed to enable them care for the babies at home.

There are limitations with the study. As a quantitative study the 37 families who participated in the study were small. For the findings to be generalizable, a larger sample should have been used.

Boykova (2008) carried out a study in Russia focusing on follow-up care of premature babies and evaluation of parental experiences and associated services. A descriptive correlational design was used with a theoretical framework of Kenner Carole known as “Kenner’s Transition Model” as a standardized research instrument-Kenner’s Transition Questionnaire (TQ). The sample was a purposive convenience sample of 32 mothers of premature infants who had been hospitalized at NICU in Saint Petersburg, Russia. The purpose of the study current was to explore the experiences of parents of prematurely born infants after hospital discharge. The specific objectives of this study was to explore the parents’ experiences at home when caring for their premature babies, identify possible relationships between the parental experiences and gestational age and describe parents’ perceived evaluation of services provided for their baby and themselves once they arrived home with their preterm baby after hospital discharge. Data were collected from May to October in 2006; one month after the mothers had been discharged. Spearman’s rank order correlation was used to analyze the association between scores on the TQ subscale (Parent-Child Role, Information Needs, Stress and Coping, Social Interaction and Grief) and the gestational age. Analysis of data was done by using the statistical package for the Social Sciences for windows software (SPSS, version 11). The open-

ended questionnaires were evaluated using the constant comparative method for qualitative research analysis. Themes and categories were developed to establish the findings.

It was found that parents of premature infants were adequately prepared for the care of their premature infants after discharge. The study indicated that 81.3% had knowledge on care of premature infants, 68.8% also expressed the competence to take care of their preterm babies, 75% stated that they knew how to feed their infants and 84.4% said they knew when to seek medical attention by calling the doctor. Despite the fact that mothers of premature babies had basic knowledge and skills on care of infants, they still needed more information about the routine care of premature infants. The study showed that 81.3% of mothers needed information on behavioural patterns of their infants, 62.5% on eating, 34.4% on safety and 34.4% on sleeping patterns of the infants. From the quantitative analysis, 50% of mothers said they had information on care from relatives and 40% of information from other sources. Others also said they received information from physicians (37.5%), 15.6% from friends and 6.3% from nurses. At home, spouses, relatives, friends, nurses and physicians were found to be good sources of support for mothers of premature infants. Furthermore, the quantitative results showed that there was no significant relationship among the five categories of Kenner's Transition questionnaire (TQ) and the infants' gestational age. All the correlation coefficients were found to be low and therefore there was no statistical significance at the 0.05 level. However, there were two significant positive correlations between birth weight of preterm infants and grief. The mothers of premature infants who had higher number of home visits expressed adequate knowledge of care than mothers who had lesser home visits and higher evaluation services. Parents were happy to have home visits as compared to

taking their infants to see the clinicians. In Ghana no evaluation has been done on the information needs of mothers with preterm infants after discharge to know how well mothers could care for their infants. They are only left to struggle and care for their infants. Therefore, there is the need for this study to be carried out in order to reduce the level of ignorance in mothers caring for their preterm infants at home.

Lui, Chao, Huang, Wei and Chien (2010) conducted a study on the effectiveness of applying empowerment strategies when establishing a support group for parents of preterm infants. The objectives of the study were to apply empowerment strategies to the establishing of a support group for parents of preterm infants who were recently discharged home and to examine its effectiveness in terms of self-efficacy, perceived stress and depression among the parents. A quasi-experiment (quantitative) design was used. Seventy (70) participants were recruited from NICU at a medical centre in northern Taiwan. Parents whose infants' gestational ages were less than 37 weeks and whose infants were expected to be discharged home within one week were included in the study. The participants were divided into two equal groups, the intervention and the control groups. Among the 70 participants, 15 were fathers (intervention group: 7; control group: 8) and 55 were mothers (intervention group: 28; control group: 27). A total of 12 sessions were conducted during the period of April to November, 2005 in order to attain the sample size. The concept of empowerment used were; partnership, participation, collaboration, awareness, sense of control, self- efficacy, self-help, meeting personal needs, access to resources and personal action. Liu et al. (2010) developed strategies and activities to address the key elements of the named concepts above. Partnership between parents and health professionals were initiated before they were discharged home and were maintained throughout the process. These initiatives were carried out by the health professionals

in order to define the needs and the problems, to provide information and to help solve the problems of the parents. Participation and collaboration by the parents were encouraged through parent-to-parents and parent-to-health professional dialogue which helped to create a supportive environment. Data were collected by structured questionnaires including variables such as gender, age, educational level and work status. The data were analyzed by examining the characteristics between the two groups using Student's *t*-test and the Chi square test.

In the study, it was found that applying empowerment strategies to support group for parents of preterm infants was effective when self-efficacy increased in the use of resources to solve child- caring problems. Also, empowerment strategies were found to decrease depressive symptoms among parents with infants with Very Low Birth Weight (VLBW) but not among parents without VLBW. The intervention that was used during the study did not reveal any significant effect on self-efficacy when performing parental roles. Therefore the intervention group had a higher score for self-efficacy when performing parental roles.

The study by Liu et al. (2010) showed the effectiveness of a support group that applied empowerment strategies to decrease parental depressive symptoms and increase parental self-efficacy when using resources for parents of preterm infants. The intervention also showed effectiveness in decreasing perceived stress among parents of preterm infants with VLBW.

Mok, and Leung (2006) carried out a study on nurses as providers of support for mothers of premature infants. The aim of the study was to explore the supportive behaviour of nurses as experienced by mothers of premature infants in Hong Kong. It was descriptive design with convenient sampling of thirty-seven mothers recruited from the neonatal intensive care unit (NICU) of a regional hospital. 'Nurses Parent

Support Tool' (NPST) comprising of four categories was used. These included Communication information support, emotional support, parent esteem support and quality care-giving support. After the development of the tool, thirty- seven questionnaires were answered by mothers and six mothers among the participants were interviewed to identify the support and non-supportive behaviour. The data were analyzed using Pearson's correlational coefficient to examine relationships among the demographic data and types of support. The qualitative aspect of the data was analyzed using content analysis. Kappa statistic was also used to differentiate the agreements between perceived importance and actual received support of the mothers.

The findings of the study showed that 77% of the mothers rated the various support they received as important. Again, there was a significant mean difference between perceived and received nursing support. The result of the study showed that parents desired more nursing support than they received especially, in the area of supportive communication and the given information. According to the authors, emotional support was rated less important since the mothers did not receive much of it. The results of the qualitative data indicated that communication and information support, emotional support, affirmation and encouragement (esteem support), the involvement in the care of infants and the quality of care given to the infants were found to be important for the mothers of premature infants.

In conclusion, the authors found that the parents of premature infants desired more nursing support than they received, especially, in the area of supportive communication and giving of information.

Ferecini, Fonseca, Leite, Dare, Assis, and Scochi (2009) carried out a study on the perceptions of mothers of premature babies regarding their experience with a health education programme. The objective of the study was to assess the perception of mothers of premature babies on the experience they had in a health education programme. Qualitative observational method was used with thirty-eight mothers recruited from the neonatal intermediate care unit of the university hospital of Ribeirao Preto, Sao Paulo. Mothers whose babies were on admission from June to November 2007 and delivered below 37 weeks were selected to participate in the study. Data were collected through organized and systematic educational groups using survey. Thematic analysis of the data identified four major themes.

The findings of the study showed that all the mothers who participated in the study regarded the health education programme as important to the care of premature babies because they were able to ask questions which favoured development of confidence in the mother for child care. Also the findings revealed that mothers found the written materials (booklets) as learning guide for the mothers and the significant others in the family which adequately prepared them for hospital discharge to enable them care for the premature babies at home. Additionally, the health education programme helped the mothers to interact among themselves and shared their experiences. According to the authors, the programmes helped the participant to relax and relieved of the tension experienced in the course of care. Finally, the result of the study revealed that through interaction and sharing networking among the mothers was enhanced.

In conclusion, the authors noted that the health education programme was beneficial and therefore it should be expanded to include the participation of other family members and significant others. In Ghana no study has been conducted on the

experiences of mother caring for preterm babies. The impact of preterm babies' care on mothers' health has also not been investigated. It is therefore imperative and appropriate to carry out this study.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter set out to describe the research design chosen to answer the research question. The chapter describes the research setting, target population and sample as well as the procedure for data gathering. Data analysis, ethical considerations and measures used to ensure methodological rigour are also highlighted.

3.1 Study Design

A qualitative research design is the overall plan for addressing the research questions, including specifications for enhancing the integrity of the research (Polit, Beck & Hungler, 2001). In phenomenology the aim is to gain a deeper understanding of the nature or meaning of everyday experiences (Van Manen, 1997). The focus of this study was the experience of mothers caring for preterm babies at home. A qualitative naturalistic descriptive exploratory design was used in this study in order to explore the lived experiences of mothers with preterm babies at the Department of Child Health of the Korle-Bu Teaching hospital as well as give in-depth description of data obtained. This approach was necessary because no research about mothers' experiences with preterm babies has been carried out in Ghana. There was the need to carry out this research on the lived experience of mothers with preterm babies at home to fill the gap.

3.2 Research Setting

The study was conducted at the Department of Child Health, Out Patients' Department (OPD) of the Korle-Bu Teaching Hospital (KBTH) where mothers were recruited from the NICU clinic. The hospital was founded on 9th October, 1923. The then governor, Gordon Guggisberg laid the foundation for the Hospital in 1921 and

was officially opened on 1923. It is the second largest hospital in the West African sub region.

The hospital is located in Accra, the capital of Ghana. It is specifically in the Ablekuma South Sub-Metro District, and about 0.5km from the Korle-Lagoon. It covers an area of about 441 acres. Currently, the hospital operates as an autonomous body but under the Ministry of Health and the Teaching Hospital Act (Act 525). Korle-Bu Teaching Hospital is the only tertiary hospital in the southern part of Ghana. It is the only hospital affiliated to the College of Health Sciences, University of Ghana. The hospital is the premier and leading National referral centre. It has one of the best facilities that train health professionals in the country such as; Nursing and Midwifery Training College, Public Health Nursing School, School of Peri-operative and Critical Care Nursing, Ophthalmic Nursing School, School of Allied Health Sciences, School of Medical Laboratory Technology, University of Ghana Dental School, University of Ghana Medical School and School of Radiologic Technology. The hospital has expanded with a bed capacity of 1600 and a staff strength of 3500, comprising 390 doctors and dentists, 1035 nurses, 40 pharmacists, a number of health service administrators, laboratory technicians and technologists, biostatisticians and other categories of staff.

The average daily out-patients' attendance is 1500 and an average of 150 people admitted daily. The hospital has eighteen (18) clinical departments and centres. These include the Obstetrics and Gynecology, Surgery, Child Health, Polyclinic, Oral Maxillofacial Surgery, Medicine, Radiology, Pharmacy, Radiotherapy and Ear, Nose and Throat (ENT). Others are Haematology, Microbiology, Eye Clinic, Reconstructive Plastic Surgery and Burn Centre, Cardiothoracic Unit (CTU), Chemical Pathology, Clinical Psychology Department and the Mortuary. The

corporate mission of the hospital is to provide quality tertiary health care, teaching, research and outreach services.

The Department of Child Health was built in 1960 to offer specialized care to children from the southern part of Ghana with referrals from other hospitals. The vision of the Child Health Department is to continue to maintain the lead as the first class children's Hospital in Ghana offering specialized care. Its objective is to provide good quality care to children and significant others, be well equipped both in human and material resources, to renovate the whole block and to make admitted children to the hospital comfortable.

The Department is made up of three-storey. The third (3rd) floor has east and west wings. The east wing has 26 beds with 6 incubators, and the west has 30 beds. The second floor has a 54-bed capacity, while the first floor has 25 beds with 4 incubators and a non-functioning theatre. The ground floor is made up of an emergency room, the Out Patients' Department and 7 consulting rooms and a research unit. The emergency room has 20 beds. The ground floor also has a pharmacy unit, records unit, mini-laboratory and Public Health Nurses' unit. The staff strength of the department is 238. Out of this number, 60 are Doctors, 126 Nurses, 8 Pharmacists, 5 Pharmacy Technicians, 3 Dispensing Assistants, 25 Health Care Assistants and 11 Record Officers.

Clinics are run from Monday to Friday except on public Holidays. The OPD runs specialist clinics on different disease conditions weekly. The NICU clinic is run on Fridays. The main function of the NICU clinic is to assess the growth and development of preterm babies. The clinic is run by one (1) consultant, one (1) specialist, two (2) resident doctors and one (1) House officer. In addition, the OPD is managed by 11 competent Nurses, three (3) Health Care Assistants and four

orderlies. The average daily turnover is between 60 – 90 babies and children. The researcher chose this setting for recruiting mothers for the study because of accessibility and availability of mothers with discharged preterm babies attending NICU clinic.

The Neonatal Intensive Care unit (NICU), which is presently a unit under department of Child Health of the Korle-Bu Teaching Hospital is Located on the 3rd floor of the Maternity Block of the Department of Obstetrics and Gynaecology. NICU was established in 1962 as part of the Maternity block of the Department of Obstetrics and Gynaecology. It was initially designed to admit only preterm babies delivered on the maternity block and referred preterm babies from other Regional and District Hospitals. Currently, NICU admits all new born babies born at term or preterm with any congenital abnormality or sick for care. The NICU has four (4) cubicles with twenty-two (22) incubators and twenty (28) cots. The unit has ten (10) monitors, which help the staff to monitor the vital signs of the babies. The unit is managed by two neonatal consultants, four (4) resident doctors, six (6) house officers, ten (10) nurses and four (4) health care assistants.

3.3 Target Population

The target population is the total group of participants in whom the investigator or researcher is interested (Polit, Beck & Hungler, 2001). The target population for this study comprised mothers who had delivered preterm babies, whose babies were admitted and cared for at the Neonatal Intensive Care Unit (NICU) and later discharged home. The babies were between 3-12 months old and were attending the NICU Clinic at the Korle-Bu Teaching Hospital on Fridays. The mothers were 18 years and above. The researcher chose babies between the ages of 3-12months because at this period after birth the mothers could vividly recollect their lived

experiences and share them. These mothers were chosen as the target population because almost all mothers who deliver preterm babies in the Accra Metropolis have their babies managed at the NICU Clinic after they have been discharged from the Neonatal Intensive Care Clinic at the Korle-Bu Teaching Hospital.

3.4 Sample Size and Sampling Technique

Sampling is the process of selecting a portion of the population to represent the entire population (Polit, Beck & Hungler 2001). In qualitative study, the final size of the sample is determined during data collection when saturation is reached. Meaningful data are collected till no further question is needed to be asked. Purposive sampling was used. This non-probability sampling strategy is common to qualitative research and based on the premise that the researcher's knowledge of the topic area enables her to identify individuals who can be informative and can contribute meaningfully to the objectives of the study. While it will not allow generalization of the findings to all mothers of preterm babies, this study offers valuable insights into mothers' experiences. A total of nine (9) mothers with babies born before 37 completed weeks of gestation or pregnancy (preterm babies) were used for the study. Mothers who were 18 years and above and had delivered preterm babies and admitted at the Neonatal Intensive Care Unit ((NICU) of the Korle-Bu Teaching Hospital and had been discharged home were used. Mothers whose preterm babies were between the ages of 3-12 months, who were willing to participate in the study and fell within the inclusion criteria, were selected for the interview and confidentiality was assured. Out of the nine selected participants, six mothers spoke English while three mothers spoke "Twi" (a Ghanaian language from Ashanti and Eastern regions) because that was the language they could speak well to enhance easy communication between them and the researcher. The researcher

speaks and understands these languages fluently. It was also important to ensure that the best informants were selected to address the research question of the study. After interacting with the participants, they were given information sheets (Appendix B) which officially explained details of the research. Participants who willingly accepted to be part of the study were given consent forms (Appendix C) to sign. Participants were asked questions to confirm their understanding of the research information given to them (Appendix D). The answers given convinced the researcher that participants had understood the research information. In every qualitative research, the goal is to achieve quality data in each interview (Polit & Beck, 2004). Based on that, a small sample size was used in this research. Saturation was reached after nine participants had been interviewed. Saturation is the stage when no new information (themes) is emerging during the interviews (Mayan, 2009).

3.5 Pre-test

The data collection instrument (which was in the form of a topic guide for a semi-structured interview) was pre-tested at the Ridge Hospital using three (3) mothers. Following the pre-test, questions which were ambiguous were reframed and redundant questions were deleted from the topic guide.

3.6 Data collection

Data collection is the gathering of information to address a research problem meaningfully (Polit & Beck, 2004). In a qualitative inquiry, data collection and analysis occur concurrently. The steps of collecting data are peculiar to each study and are dependent on the research design and methods of measurement (Polit & Beck, 2004). Data may be collected from participants through interview, observation, testing, measurement or the use of a combination of these methods. In

research, the researcher is involved in the process of data collection either by collecting the data herself or supervises the data collection process (Polit & Hungler, 2004). In this study, the focus of the data collected was on mothers with preterm babies who fell within the inclusion criteria. They were recruited from the Department of Child Health, NICU clinic. Mothers who were willing to share their experiences were recruited with the help of NICU clinic nurses after they had been informed about the purpose of the study. Written permission was sought from the NICU clinic in-charge through the Head of the Child Health Department. The NICU clinic in-charge introduced the researcher to the mothers with preterm babies. The researcher then introduced herself and established rapport. The interviews were conducted after the whole study and its importance and implications were explained to the participants with the help of participant information sheets (Appendix B). Those who could read were given the participant information sheet to read. Those who willingly agreed to take part in the study were asked to sign consent forms. A venue and date for the interview were then arranged with the participants. The participants were informed that there might be two sessions of the interview each lasting between 45 minutes to one hour. Each participant was interviewed once lasting approximately 45-60 minutes.

In this research, data were collected by interviewing the participants using guiding questions (Appendix E). Additionally, probing questions were asked for clarification in cases where information was not forthcoming (Mayan, 2009). The questions were in two parts. Part "A" included short demographic questions which were used to establish rapport with the participants and helped them to relax in order to gain confidence to talk. Participants were relaxed and able to express themselves during

the interview. Part “B” included the guiding questions for the main interview. They were interviewed until there was no new information to be given (data saturation).

An interview guide in a semi-structured form (Appendix E) was used. The data were collected through face-to-face interviews. The questions were open ended and exploratory in nature. This encouraged the participants to share their lived experiences while caring for their preterm babies at home. After asking each question, the participants were allowed to express themselves without interrupting them except when it became necessary to do so. Probing questions were also asked because it helped them bring out all the needed information which they forgot to include in their initial descriptions. Questions were exhaustively answered by the participants so there was no need for second interviews since saturation was reached. On the whole, nine participants were interviewed. Seven out of the nine interviews were conducted in the various homes upon request by the participants while two were conducted at the hospital in an office provided for the researcher by the NICU clinic in-charge. The interviews were tape-recorded and transcribed verbatim. In the course of the interviews, the researcher observed and noted down all the non-verbal actions and gestures of the participants in the field diary as field notes.

3.7 Data analysis

Data analysis is the systematic organization and synthesis of the research data and the testing of research hypothesis using those data (Polit & Beck, 2004). Qualitative data analysis refers to the categorization and ordering of information in such a manner so as to make sense of the data and writing a final report that is true and accurate (Mayan, 2001). Qualitative analysis is a very tedious activity that requires insight and rapt attention. The data were analyzed using content analysis because it was identified as appropriate for the analysis of the interview scripts. It is the

process in which reading, thinking, writing and rethinking happens almost simultaneously (Mayan, 2001).

The audiotaped data were played and transcribed verbatim and those in “Twi” were translated to English. The field notes (recorded observations of participants) were read and added to the data on the same day of the interview. The interview data were compared script by script across all the interviews. In doing this, the researcher was able to verify the accuracy of the transcripts. The transcribed data were read several times in order to get insight and in-depth meaning so as to bring ideas, thoughts and words together to help come out with themes and sub-themes.

Concepts, ideas, and words identified within the data were noted as open coding was done.

Concepts are labels placed on discrete happenings, events and other instances of phenomena (Strauss & Corbin, 1990). Phrases were coded by writing them in the margins of the transcribed data. The most common and similar phrases were copied and pasted in different files and the files were named according to the codes. Related codes were grouped as themes. Themes and categories were named from the various files created and concepts checked to ensure that they fit into the categories. In the course of the analysis, both manifest and latent content analyses were used from the beginning of the data collection until the interviews ended. In the manifest content analysis, certain specific words and quotes that were expressed by the participants were reported verbatim. However in the latent content analysis coding and categorization of primary patterns were identified in the data. This approach enabled the researcher to seek the meaning of specific passages within the context of the transcribed data.

In all, six major themes were identified (after putting some categories together based on their similarities in ideas) and twenty-five sub-themes emerged under these main categories.

3.8 Methodological Rigour

In qualitative research, the issue of rigour is important. Rigour refers to the steps taken to ensure that the study findings are trustworthy (Polit, Beck & Hungler, 2001). The researcher demonstrated the sense of trustworthiness in the study. The terms used to describe rigour in qualitative research include; credibility, dependability, confirmability and transferability (Polit, Beck & Hungler, 2001).

Credibility includes activities that increase the probability that credible findings will be produced. Credibility was ensured by allowing the participants adequate time to narrate “their stories” and to express their in-depth understanding of the phenomenon under study. The participants were made comfortable before the interview began. During the interviews, the researcher repeated certain phrases and words mentioned by the participants so that they could clarify what they really meant and also asked questions for conformation purposes. As a result, the researcher ensured that the reality of the lived experiences of the participants who were caring for their preterm babies at home was earnestly represented. Each interview recorded was played back for the participants to listen and confirm the exact information they wanted to divulge.

In qualitative study data **dependability** refers to data stability over time and over conditions (Polit, Beck, & Hungler, 2001). Dependability was attained because the researcher met the criterion for credibility. Dependability here means whether replication of the study will come out with similar findings with other groups in a similar context (Polit & Beck, 2004).

Confirmability refers to the neutrality or objectivity of the data (Polit & Beck, 2004). The researcher ensured that she was mindful of her own attitude and professional knowledge about the topic under study in order not to impose them on the participants' data. Also, the researcher's feelings, ideas and professional views were separated from those of the participants.

In order to ensure confirmability, the researcher kept an audit trail (which is the detailed recording of the research interview transcripts; raw data field notes including the date and the time of interview, how consent was obtained and the process of the interview) so that others can follow to confirm the findings. The transcripts of all the interviews, field notes and drafts of the final report were given to the researcher's supervisors to inspect.

Transferability is the extent to which the findings from the data can be transferred to other settings or groups (Polit & Beck, 2004). The researcher ensured transferability by asking herself such questions as whether the findings were applicable, useful or important to a similar group or any practice setting? The researcher ensured transferability through thick detailed descriptions of the research design so as to make replicability possible.

Thorough descriptions of the research setting or context and other processes were given in the form of written field notes. Areas for future study have been suggested by the researcher.

3.9 Ethical Considerations

In scientific research where human beings are used as participants, they cannot be taken for granted therefore, certain cautions must be exercised to ensure that their rights as human beings are protected. For this reason ethical approval for the study was obtained from the Institutional Review Board of the Noguchi Memorial Institute

of Medical Research, University of Ghana, Legon (APPENDIX F). In addition, informed consent was sought from the participants prior to the interview. Introductory letters from the School of Nursing were sent to the Chief Executive Officer of the Korle-Bu Teaching Hospital, the Director of Nursing Services in-charge of the hospital as well as the Director of Nursing Services in-charge of the Department of Child Health to obtain permission to recruit participants from the Korle- Bu Teaching Hospital. An explanation of the study was given to the participants. To ensure voluntary consent, participants were assured of the confidential nature of their data. They were also informed that their privacy would be protected by the use of pseudo-names on the demographic data so that they would not be identified.

Additionally, they were informed of the right to withdraw from the study at any time without specification of reason. They were further assured that, their refusal or withdrawal will not in any way affect the care they were receiving from the Korle-Bu Teaching Hospital. The purpose, objectives of the study, specific expectation concerning participation and potential costs and benefits were explained to the participants. The only people who had access to the recorded information on tape were the researcher and the supervisors. The tape and the transcribed information were stored under lock and key and it was only the researcher and the supervisors who had access to them.

3.10 Data management

The demographic data were separated from the main interview data to make sure that linkages between them were not made. The interview materials (tape and transcripts) were kept under lock and key in the researcher's custody. Only the researcher and her supervisors had access to them. The transcripts would be kept for five years

following completion of the study and if they are needed for further analysis, ethical clearance will be obtained.

CHAPTER FOUR

FINDINGS

4.0 Introduction

The chapter first presents the profile of the nine (9) mothers who participated in the study. This comprises succinct and overarching characteristics of relevance to the topic being investigated.

Nine mothers were used for the study. Seven (7) of them were interviewed in their various homes in the Accra metropolis while two (2) were interviewed in a quiet office provided by the hospital. The mothers were between the ages of 27 to 41 years with the mean age of 35 years. They were all married and were staying with their husbands except two mothers whose husbands live and work outside the country. Most of the mothers had children apart from the preterm babies. Three of the mothers had three children while another three had two children. Only one mother had four children. Two out of the nine mothers had given birth for the first time thus the preterm babies. Three mothers had multiple-ton births while the rest of the mothers had singleton births. All the nine mothers were literates; seven of them had had formal education to the tertiary levels, one junior high graduate and one middle school leaver.

All the mothers were Christians with the exception of one Muslim. They were all Ghanaians mostly Akans by ethnicity. The mothers fell within the working class and were all working before they delivered the preterm babies. However, six of them were self employed while three were secretaries working with different organizations in the country.

The mothers' gestational ages ranged between 32 to 34 weeks and the birth weights of the preterm babies ranges between 1.2kg to 2kg. Their period of hospital stay

ranged between 4days to 31days at the Neonatal Intensive care unit (NICU) of Korle-Bu Teaching Hospital.

A detailed table of demographic data of participants is presented in appendix A table three.

The findings following exploration of the experiences of mothers caring for their preterm babies at home after having been discharged from the Neonatal Intensive Care Unit of the Korle-Bu Teaching Hospital are now presented. These findings were derived from interviews with nine participants as well as and non-verbal information obtained and written as field notes during the interviews. The field notes elucidated the interviews and were complementary of the interview data. From the analysis, six major themes emerged. These were:

- Care of preterm babies
- Perceptions of prematurity among mothers and attitudes of significant others
- Mothers' health and well-being
- Challenges
- Support
- Coping strategies

Each of the major themes had sub-themes under them. These are presented in table two below.

Table 2: Major themes and their corresponding sub-themes

Themes	Categories/Sub-themes
1. Care of preterm babies	<ul style="list-style-type: none"> • Feeding • Temperature control • Infection prevention • Observation
2. Perceptions of prematurity among mothers and attitudes of significant others	<ul style="list-style-type: none"> • Perceptions of mothers • Attitudes of husbands • Attitudes of In-laws • Attitudes of family members • Attitudes of friends
3. Mothers' health and well-being	<ul style="list-style-type: none"> • Fear of losing baby (anxiety, grief and worries) • Sleep deprivation • Inability to maintain personal hygiene
4. Challenges	<ul style="list-style-type: none"> • General challenges of mothers • Information needs of mothers • Socio-cultural challenges • Financial challenges • Feeding challenges of babies • Weight gain • Challenges of siblings
5. Support	<ul style="list-style-type: none"> • Support from husbands • Support from In-laws • Support from extended families • Support from friends
6. Coping strategies	<ul style="list-style-type: none"> • In-depth understanding of babies' needs • Religious beliefs

4.1 Care of Preterm Babies

This section deals with how mothers were caring for or nursing their babies at home after they had been discharged from the Neonatal Intensive Care Unit (NICU) of the Korle-Bu Teaching Hospital. All the nine participants were able to narrate how well they cared for their preterm babies at home.

i Feeding

The feeding experiences of mothers were explored to determine how well the preterm babies were fed because feeding in preterm babies is important. All the nine mothers were able to feed their babies through diverse means until they gained appreciable weight. Feeding of the babies was an overarching or daunting task for the mothers. The mothers put in much effort to make sure the babies gain weight. Feeding at frequent intervals with small quantities of food during the day and night was the major experience of the mothers. Even though most Ghanaian mothers derive satisfaction from breastfeeding their babies, the experience with preterm babies was exceptional and overwhelming. Most mothers (five) exclusively breastfed their babies either by putting the babies to the breast or expressing the breast milk and using cup and spoon to feed the babies. However, three (3) mothers used the combination of breast milk and formula (artificial feeding) to feed their babies. While one mother decided to use complementary feeding (feeding the preterm baby with only formula). Due to economic constraints a mother decided to wean her baby when she could not purchase the formula food for the baby. Below are typical statements made by some mothers who exclusively breastfed their babies:

When I came home I was breastfeeding exclusively and because the babies were put on multivitamins, I realized my baby was most of the time always hungry so I started when she was about 3, we spent 3 weeks at NICU so we came home about a month or two; they taught us at NICU how to use the cup and spoon to feed the baby so for me I did not use formula milk, I used the breast milk exclusively till about 9 months so I was putting her on the breast and I was using the breast milk to feed her with the spoon

Mother C1, age 34.

Yeah! Initially when I came, we were told to feed like 2 hours interval and a top up with a spoon but we were not told the measurements so I just feed her and give her the top up with the spoon and sometimes it's just like 10mls after breastfeeding for the top up. And anytime I give her the top up she feels like she want to vomit so I

make sure I give her the breast milk more. I do not give her any other artificial milk apart from the breast milk.

Mother B1, age 41.

Some mothers used the combination of breast milk and formula as methods of feeding:

I was giving him the breast milk and sometimes I used to add the formula (points to the formula container) because I could not combine expressing the milk and giving to him to suck so when I give him the breast milk then I will add the formula so that was how I was going about it.

Mother E1, age 30.

For the first month, I only gave him breast milk until I realized that, the breast milk alone wasn't enough for him, because he usually cried after breast feeding him. So his father bought him SMA (formula) to try him on but he didn't like it, so he bought lactogen (formula). So within a day, I feed him with it, once in the morning and once in the afternoon. But in the evening I made sure I gave him enough breast milk before he sleeps.

Mother I1, age 40.

The only mother who decided to feed her multiple-ton babies on formula alone also stated:

We were feeding them with Nan1 when they were having their health problems so when we came from the hospital a day later, we changed to cow and gate (lifts the container up) which is a product known in the UK but is not known in the Ghanaian market, is now been introduced. But is one of the good baby foods that you can give and ours is the one that has colic relief medications in there so it helps the children to belch well, to bring out the gas wherever the concentrated milk is concerned so it helps. Cow and gate is what we have been giving them ever since and we give them water

Mother A1, age 34.

A mother expressed how she fed her preterm baby when she noticed the breast milk alone was not sufficient:

As I said earlier, I gave him formula food for some time, and then gave him the breast milk for sometime then I realized it was not enough for him when he was 4 months old so I started giving him porridge and when he takes that he will sleep for a long time.

Mother H1, age 27.

All the participants who were used for the study were able to feed their babies well.

However, the mothers expressed the process of feeding their babies as difficult task

yet they were able to do a good job and this could be testified from their weight gains as seen in the growth monitoring chart presented by the mothers during interviews with them.

ii Temperature control.

All the mothers had knowledge about the provision of warmth to their babies. According to the mothers, they closed their bedroom windows, wore the babies warm clothing and wrapped them with blankets and cot sheets to provide warmth. A special way of providing warmth in preterm babies was the “kangaroo mother care” (KMC). This method was identified to be the best way of keeping babies warm depending on the weight of the babies. Among the mothers who used the “KMC” the babies’ temperatures were reportedly within the normal range and there were no signs of heat loss in them. The mothers were seen to be physically and emotionally attached to the babies due to the skin-to-skin contact the KMC provided. However, not all the mothers used the kangaroo mother care (KMC).

Some mothers described how they provided warmth to their babies:

On the baby, you always have to cover him and my mother was also helping me because of my first experience and she was also coaching me in some of the things. I was using about 2 or 3 cot sheets to wrap him always until it got to a stage that I used only one because when the baby is growing, you will see it yourself whether your baby is gaining or losing weight. After covering him with the cot sheet, you should not expose the foot. So formally, I wear him this sleeping overall so that the whole body will be covered and I even stopped this not quite long ago.

Mother D1, age 34.

I used a thick cloth to cover the whole body after wearing him his dress excluding his face, then, wear him a cap and put him in his cot in the room, we do not come out. So immediately he has his bath, we give him his medication, wrap him and put him in his cot then he sleeps.

Mother H1, age 27.

The mothers whose babies' birth weights were within the ranges of 1.2kg and 1.5kg used both the KMC and other methods of keeping the babies warm. One of them said:

I just wrapped the baby using the blanket. We were taught how to do it (KMC). So you make sure baby is wrapped up nicely and kept warm. For me I did not open my windows; always my windows were shut until she was a month or two old. Also at NICU, they have a special cloth that they have done for mothers so before you come home they make sure you buy one and they teach you how to use it well so when you come home just put the baby in front of your chest and tie it as you have been taught.

Mother C1, age 34.

I wrapped him and put him on the bed or used the Kangaroo method.

Mother F1, age 35.

The mothers were anxious about their babies' progress in terms of growth and development. Due to increased anxiety in the mothers, they adhered to the health teaching they received at the NICU before being discharged home. During the interviews with the mothers the preterm babies' temperatures were within the normal range.

iii Infection prevention

Infection prevention was one of the most important measures that the mothers employed in caring for their preterm babies since their immune systems were low. The adoption of new lifestyles of infection prevention practices to enable their babies receive maximum protection from infections was quite an experience for them. During the interviews with the mothers, none of the babies had any observable infections. This might be due to quality of care rendered by the mothers. Only one mother reported the re-admission of one of her multiple-ton babies to hospital due to gastroenteritis after two weeks of discharge. Additionally, some of the areas in the

Accra metropolis were mosquito-prone zones but the babies never had malaria. They were physically healthy with signs of progress; adequate growth and development was observed in them at the time of the interviews with the mothers. During reviews at the hospital, emphases were laid on the infection prevention practices for the purpose of preventing the re-admission of the babies to the hospital unit.

One participant narrated how she prevented people (family and friends) from seeing her preterm baby. She said:

Yeah! I do not allow people to touch her and I make sure I clean the place up, I wash and change her cot sheet often and keep the windows always closed, so the window was not opened to collect dust and some other things. And I make sure with the medicine; I wash that small cup with warm water before I give her the medicine.

Mother B1, age 41.

Another mother whose baby weighed 1.8 at birth explained:

Washing of hands, washing and ironing of his clothes, always try to do things yourself because someone else might not wash the hands which might bring infection.

Mother F1, age 35.

One mother who was knowledgeable about infection prevention explained:

We are particular about it since we went to Korle-Bu because of the gastroenteritis and all that. So what we do is anytime we change the baby's diaper, you wash your hands with soap. And there are times because it quick and there is nobody around we use the carex (hand sanitizer) so that is what we use to clean your hands, so you can quickly feed the baby then put one down and feed the other one then, later you wash it proper. Their bottles are sterilized; I have a sterilizer before, I had the sterilizer. I was boiling them in boiling water for 5minutes, then I use a teat to pick them up to keep it clean then. We bought the sterilizer so we are still using the sterilizer to sterilize everything of theirs. Their clothing's are washed and rinsed with dettol (a type of antiseptic lotion commonly used). Their room is mopped every morning and every evening and their cot sheets are also changed morning and at night because we have heard it and all that. There is also a mosquito net around their cot which we take off around 7- 8 am and put it back at 6pm after they have their bath. They are in their net so they only come out when they have to eat after that they go back into their mosquito net. So that is how we keep them

Mother A1, age 34.

iv Observations

Observation remains one of the vital measures of caring for preterm babies especially at home. The characteristic features and clinical manifestations of preterm babies as were explain to the mothers during discharge made the mother quite observant. The mothers were found to be anxious and expressed grief and worries about the outcomes (size) of their babies. As a result some of them were vigilant and could not sleep at night. They kept wake to observe the babies and to report any abnormality. Others expressed doubts about the survival of their babies hence the need to keep watch over their babies. It was revealed that neither observable infection nor post-discharge complications were noticed in the preterm babies until the time of data collection.

It has not been easy and is like 24 hour work. You always have to be vigilant and keep an eye on her because we were told from NICU that we have to be observing their breathing so most of the time you have to keep the baby to be near you because is not like a full term baby when baby is asleep, is asleep.

Mother C1, age 34.

We came home and we were suppose to go for review in 2 weeks so within the first week, then I realized one day that my baby has constipated and the stomach had protruded a little and he was feeling very uncomfortable and I tell it was not an easy thing. I was very worried and did not know what to do. I also did not have any of the telephone numbers of the nurses so I could ask her but I use the little experience that I had in normal babies to encourage myself that it was as a result of weight gain. So I would wait for some few more days and even that I could not sleep observing him day and night to see what is going on and whether he was breathing or whether it could affect him in any way.

Mother G1, age 40.

As I said earlier on, the baby could sleep from morning till evening because you might think that once a while baby would open his eyes and look around to observe something but he was not like that always asleep..... Even sometimes, you have to go and touch the baby and see whether he is breathing because he is a preterm baby. Instead of putting him in a baby's cot, I said no rather I wanted to sleep by him alone because I just wanted to observe something.

Mother D1, age 34.

4.2 Perceptions of Prematurity among Mothers and Attitudes of Significant

Others

Out of this major theme emerged five other sub-themes which were

- i. Perceptions of mothers
- ii. Attitude of husbands
- iii. Attitude of In-laws
- iv. Attitude of family members
- v. Attitude of friends

i Perceptions of mothers

Most of the mothers perceived their preterm babies to be “abnormal”; prematurity to them was an abnormality. As a result most of the mothers felt embarrassed taking the babies out. Others felt the babies were too small for people to see and make derogatory statements so the preterm babies were kept indoors for some time before allowing families and friends to see them.

Some of the mothers who were embarrassed expressed:

Initially, I did not want anybody to see him because when you come I will tell you he is asleep so people were like anytime you go to see her baby, she will say he is always asleep.

Mother H1, age 27.

Hmm! When I took her home initially, it was difficult for me because of the size of the baby. When anyone visited me and wanted to look at her, I felt embarrassed and the like and so, anyway, I wrapped her and kept her in the room and was gradually caring for her. It was worrying me but it is now better. At first due to the size of the baby when we went for weighing, I felt embarrassed looking at the other babies

Mother I1, age 40.

Most mothers equated their preterm babies to abnormality and had these to say:

When I was discharged home with this preterm baby, it was difficult for me because with the normal babies I could get someone to take of the baby for me. You cannot give him to somebody to help you carry him, like it happens in normal babies where you can give the breast milk whiles you also take a nap, but it's not like that in

abnormal babies. If he was a normal baby, I could have had people helping me in bathing and other stuff but now I do everything myself

Mother G1, age 40.

The premature babies are different from the normal babies because the premature baby every 15minutes; you have to feed the baby instead of maybe 30minutes for the normal baby. Also because the baby is too small, you have to take very good care of him or her so that the baby will meet up with the normal standard. It is slightly different from the normal babies because, for instance in prescription of medicine, when the baby is a normal baby and like 4 months, they can prescribe 2.5mls but when it is a preterm baby you will be told to give 1.5mls to the baby.

It is like always, you have to reduce anything to be given to a preterm baby.

Mother D1, age 34.

ii Attitudes of husbands

Attitudes are habitual modes of thought or feelings of people living in a community.

The attitudes of husbands appeared to influence the way mothers were caring for their preterm babies at home. Most of the mothers had good attitudes from their husbands towards their preterm babies, thus their husbands' attitudes towards them were positive. Most fathers whose wives delivered preterm babies showed some form of concern. Eight mothers were so grateful about their husbands' attitudes towards them except one mother whose husband remained aloof and unconcerned during the first three months of care of the baby. The husband disliked the baby when he noticed the baby was preterm.

The mothers whose husbands showed positive attitudes towards them while caring for their preterm babies had these to say:

There is no conflict between the family and me. My husband has no problem with this baby. My husband was happy since the baby had been delivered and there was nothing he could do. He did not complain about the baby but always encouraged me to take good care of the baby.

Mother I1, age 40.

He was also very supportive because he said that once he is a human being who has been born, then there is no problem.

Mother F1, age 35.

A mother whose husband disliked the baby when he noticed he was preterm expressed:

Well, initially, when you look at the weight of the baby at 1.7kg like I said, even my husband said the baby was too small so he wanted us to be out of the hospital because he did not believe that the baby was going to survive. He had so much doubt because; he had not seen something like that before. So he was always complaining that “the baby is too small” and I will say “why are you saying this because gradually it will be well” and he will say “he is too small for my liking. As he is saying this, if you look at his face, it’s like bringing hell back. But when he was 3 months, he was then picking up. Then, he started taking photos of him. I then asked him that but you said he was too small so why do you want to take a photo of him? And he said; now he is growing well. Then I also became happy because, he was also happy since I was very sad when he was behaving like that previously. I think the little problem that I have with him was when we had the baby and the baby was too small. It’s like there was no sign of happiness reflecting on his (husband) face and I was hurt because I went through the trauma. So I was expecting that he will be encouraging me as my mother was doing...

Mother D1, age 34.

iii Attitudes of In-laws

In this research, most of the mothers interviewed did not mention their In-laws. The delivery of preterm babies was not made known to the in-laws except a few of them. The delivery of the preterm babies was kept secret from all the family members including some of the in-laws of the mothers of the preterm babies. Only four mothers said their husbands were able to inform their parents and siblings about the delivery of their preterm babies. A mother expressed that she was not congratulated by her in-laws. The In-laws did not say anything in the presence of the mothers. People around them told the mothers what their In-laws had been saying about them. This was confirmed by the following statements from a mother whose preterm baby’s birth weight was 1.7kg:

Even though they did not tell me directly, they asked my husband that why 7 months baby? In our Akan tradition, when you give birth at 7 months then it is a taboo or something. So I went through this trauma even though they did not tell me all this. And my husband said it was not my fault and that it is one of those things. I heard that someone's baby was 1.3kg and she was able to take care of the baby and it survived so I put that in my mind that I will not listen to them but always concentrate on the baby. And now when they see the baby, it's like they are ashamed of themselves. So now if I do not tell you this is the preterm baby you will not know. My in-laws, comparing them to when I had the first two, immediately they heard that I had delivered, they came to visit us but when they heard that it was a premature baby, for 3-4 months, we just heard them say we will come and visit but they never came to visit us. So my husband said we should have the naming ceremony in the church so that we will not allow them to come. But I said, "We should forget about them because two wrongs do not make a right". So we should just allow them to come. So they came and when they came they were not even too happy about their grandchild even though I forced myself to give him to my mother in-law. She took him for just some few seconds and gave him to their house help. (She became quiet for some time and folded her arms). Socially, another time with my same in-law, we sent somebody to have something fix for them and when he went, they were saying so many things that "delivering a 7 month baby is a taboo". And he came to tell us that it was not a good attitude from them. What about if we had lost the baby, will she be happy? As a woman you would not normally have a problem with your family. And even that, it will just be maybe 10% but the problem will always come from your in-laws and sister in-laws. So that is the only problem.

Mother D1, age 34.

A 30-year old mother wanted her In-laws to wash their hands before carrying her preterm baby but they never did because they thought it was not necessary. They thought it was their grandson so there was no need for them to wash their hands before carrying the baby. The in-laws were offered water to wash their hands and the reason explained to them but they did not. This is what she has to say:

Sometimes my in- laws will come and would hold the baby but I am not happy about that but when you say it they will be offended. They will just be talking about you saying; she is just staying in the house without going to work, just being in the house spending on their son's account, now you are in the house just putting on weight, just like our other in law in the house, so it's like as if you do not want to do anything you want to be in the house and it very hurting but you cannot say anything about that and I know, something they say a lot. Initially when they came to visit and I asked them to wash their hands before touching the baby, then they go like does that mean we are not clean or what so they have been saying all these things and I know they say them and sometimes when they come here the comments. They will make as if you do not have anything to do.

Mother E1, age 30.

iv Attitudes of family members

Family members play important roles in the lives of nursing mothers and their babies. When a child is born into a family, they become happy and would like to see the baby. However, most family members were not allowed to see the preterm babies except the close ones. These family members exhibited so many negative attitudes towards mothers with preterm babies. The mothers were not happy about the attitudes that were put up by the family members. Some ended up teasing the mothers and their babies after visiting them. Some of the mothers had many sad stories to tell:

When my siblings come around they say “oh your baby is like an old lady” and things like that. So I make sure I feed her to gain some weight for them to at least see some changes. For now, a close one like my mother wants to carry her. Even when she is going outside she wants to carry her out and she was like can I take the baby out... So when will you grow up so we will carry you. And sometimes there are some words that come out of her mouth like; so when will all these potholes fill up (bony face)? And all those things and with all those words when you hear them it's not that easy but I just accept it.

Mother B1, age 41.

Another mother with a similar problem had this bad experience to share:

A lot of things like; are you the only nursing mother that you always keep in-doors and absent yourself from any family gathering. They sometimes say that it's only one baby and you go like I have to concentrate on the child so when they become two or three then you will not even look into our faces. When I came home and they heard my baby was preterm, they said ‘this baby could look like a mouse, throw him away’. Do you think he can survive? But what I heard was; is he a lizard or what, and will he survive?

Mother H1, age 27.

The attitudes of extended family members did not have any negative impact on a mother whose aim was to make sure the baby was developing well:

They said so many things but because I was focusing on my child I did not worry too much

Mother F1, age 35.

v Attitudes of friends

Friends form part of everyday life; without friends life cannot be meaningful. About five of the mothers who were interviewed expressed how helpful and supportive some of their friends were while four said negative things about their friends. Four mothers with preterm babies did not invite their friends to their homes. Some friends asked the mothers of the preterm babies why they were not invited while others kept quiet over the issues and gossiped saying many negative things about the babies to the hearing of the mothers. Despite the joy of having babies, mothers were annoyed by some comments and remarks friends and others made about their infants. This was confirmed by the following statements:

A mother whose baby's birth weight was 1.7kg refused to allow friends to see her preterm baby:

When we came home from the hospital there was one lady who does not stay with us, she comes to help us and go so when we came home, she was expecting that we would give her the baby to observe or something. But right from the hospital then back to the room for about 2 weeks and we did not allow her to touch the baby and she said so many things because we have kept the baby from her. And we also did not tell her the problem about the baby. So because of that she told other tenants in the house that we do not want her to see the baby. So sometimes you will be in the room and somebody would want to see the baby then my husband will say "nobody will see the baby till she is due for naming". So there were so many speculations from people but we stood on our grounds.

Mother D1, age 34.

Some mothers were harassed by friends and family about their babies' naming ceremonies:

People were like; have you really named the baby and we said yes. They will complain; why did not you call me? Why did you do that?

Mother C1, age 34.

One mother left her matrimonial home to live in her parent's house for three months in order to avoid friends and well-wishers from seeing her preterm baby. She was

surprised to know how friends had information on the naming ceremony of her preterm baby. Many friends called her to find out why they were not invited to the naming ceremony. She said:

Honestly, I am staying away from them so I do not even want them to come around. That is why I am staying away from home. So I do not open my doors for them because I know when they come, it will just be talking all along. So there will be nothing important to talk about and they would come in their numbers too, just to come and see what is happening and get something to say so that is why I have moved from my home and I am staying elsewhere to make sure she is fine.

Mother B1, age 41.

4.3 Mothers' Health and Well-Being

This section deals with the effects that the delivery of preterm babies had on the mothers. All the mothers in this study experienced both physical and psychological effects after delivery.

i Fear of losing baby (anxiety, grief and worries)

Almost all the mothers interviewed were anxious, worried and feared that they could lose their babies in the course of care. This was due to the sizes of the preterm babies as well as clinical manifestations of prematurity such as breathing pattern, sleeping pattern of babies, feeding behaviours' as well as general conditions of the babies. Two mothers expressed doubts about survival of their preterm babies. Despite the anxiety and worries, they received encouragement and support from their husbands, extended families and friends to enable them care for the preterm babies at home.

A 27-year old mother whose first baby was preterm expressed her fears and worries:

It is very difficult because you cannot touch him; he is small and has very feeble body so it is difficult to handle him and you have to be careful he does not break any part of the body. I am beginning to experience high blood pressure because when I hear him cry then I become alarmed since I do not know what actually the problem is. I always think I can lose the baby but I do not want to think that way so my pressure is always up and has created fears in me. I had fear because initially he

was very small and I always had a feeling that I could lose the baby because he was too small as compared to other preterm babies. So I was always hopeless and that made me have fear every day. I am always frightened about him and worried especially when he is crying. Sometimes you wake up as many as five times during the night to feed him and other things too. I sometimes have that feeling of grieve because of the size of the baby

Mother H1, age 27.

This mother in her anxiety expressed how distressed she was. She could visit the clinic even when it was not time for review. She said:

There are times that the baby is breathing funny and you have to rush her to the clinic thinking something is wrong, but you go and they check and they tell you baby is fine. You cannot just leave her. Sometimes you think she is fine, the next minute you think this baby is acting funny so it's better you seek medical attention than stay here with her and everything becomes too late. So you go all the way to clinic, wait and wait and wait, they check her up and sometimes there is really nothing wrong with her but at least you at peace that baby is fine. Most of us actually thought we were going to lose the baby because we were not hopeful from the beginning. Because you do not know what is going to happen next and you would not know who to call so the only thing you have to do is to drive all the way to NICU to see a doctor.

Mother C1, age 34.

This mother was so sad and wept because of the size of the baby. She felt she would have been relieved if the baby had died. She said:

The first time I saw my baby I could not touch him. When we came home for instance, I will sometimes stand by his bed and watch him for a long time even when he is crying very low nobody hears him and I will just wonder whether my son will grow well. That feeling of apprehension is really there but God takes care of them. Initially, I felt he was not growing so when we go for review I ask other mothers how they were able to cope then they will encourage me. Initially, I had this grief in me which could make me cry about his weight and size or sometimes, such evil thoughts like why not the baby die so I can be free and later you will regret and ask for forgiveness but now I am okay.

Mother G1, age 40.

This mother was so worried about the survival of her baby because of the large amount of money she had spent on the baby since discharge. She expressed:

With this one, pointing to the baby, I have been troubled. When she was small, I feared for her life and prayed that she lives. I do not want anything bad to happen to

her, so the slightest sound coming from her; attract my attention and immediate care. I was also scared that looking at the very high expenses already spent on her wellbeing, she needed to be given every attention in order for her to survive

Mother II, age 40.

ii Sleep deprivation

Puerperium is the 6-week period within which nursing mothers are expected to rest and sleep in order to recover from all the stressors associated with delivery. However, all the nine mothers interviewed never had rest since they had to care for their babies both during the day and night. According to the mothers, they never had good sleep because of frequent feeding, especially at night. Some of the mothers could get up as many as five times during the night to feed the preterm babies with the hope that they would gain weight. Sometimes, the preterm babies were not sleeping immediately after feeding so, they had to keep wake and observe the babies until they fell asleep.

A mother whose first baby was preterm explained why she could not sleep at night.

She said:

There were times that you had to wake up ````at midnight for 5 or 6 times to breast feed him. Sometimes I also feel dizzy then when I report I will be given treatment and told to rest but I cannot have enough rest as I should because of the baby. Sometimes you wake up as many as 5 times during night to feed him and other things too.

Mother H1, age 27.

One of the mothers who had prolonged fertility treatment and delivered a preterm baby described how stressful it was when she was not getting enough sleep. She complained:

When we came home it was stressful because I could not get enough sleep, I had to feed him every 3 hours with cup and spoon little by little so when I sit down to feed him I do that for long hours until he is done before you can also have some sleep. Initially, when we came home I always had sleepless night because sometimes I can feed him at night and wait till maybe 2am before he would belch before I can put him

down for him to sleep and sometimes he does not sleep immediately. Also once he is not asleep, I cannot also sleep. I would have to wait till he sleeps and that is another big problem for me. Even if I feel sleepy, I still have to wait for him to sleep. Initially, I had bodily pains and weakness, always feeling sleepy and you cannot sleep as you used to do

Mother F1, age 35.

One mother who knew the importance of rest and sleep but could not sleep because of anxiety associated with her preterm baby said:

I used to have time for myself; having a nap, sleep most of the time in the afternoons when I am free I take a nap, I could not do all that, I could not sleep sometimes even at night I could not sleep. Sometimes when even I am asleep, I will be thinking what is going on with the baby so sometimes I am awake with my wide eyes and watching her to make sure she is fine. I will rather be awake and make sure she is fine than sleep and not know what is going on so I had lack of sleep

Mother C1, age 34.

All the nine mothers interviewed did not have good sleep during the night. They all managed to sleep at shorter intervals during the day in order to maintain a good state of health.

iii Inability to maintain personal hygiene

In the African cultural system, safe delivery is perceived as a sign of victory over death. Nursing mothers are therefore supposed to dress and groom themselves in white clothing. However, because of the tedious nature of the task of caring for preterm babies at home, some of the mothers could not groom themselves well as expected. Others also became so engaged with their preterm babies to the extent that they were not able to maintain their personal hygiene in a satisfactory manner.

One of the mothers delivered twins and was always busy caring for her preterm babies at home and as a result could not maintain personal hygiene noted how tedious caring for them was to her:

You lose yourself because then, you are in a hurry to do something and you do not have that time to make sure you are looking good. Sometimes, I even forget I have not had a bath and I quickly have to go to town and remember that Oh I have not even had a bath. There are times that I go to town wearing bathroom slippers and I have to find some slip-on to buy because I forgot. You are not yourself anymore; you do not make sure you are looking good, like how is my hair? You do not have that time anymore to even go to the salon, you cannot. You are in a hurry to do something and you do not have that time to make sure you are looking good.

Mother A1, age 34.

Two of the mothers thought caring for their preterm babies was more important than grooming themselves. All that they were interested in was to make sure that the babies developed well without any complications. The two mothers remarked:

And even myself; my hair I do not think of going to the salon to do my hair or anything. I have only two clothing that I am okay with because everything is about the baby how to make sure the baby is okay and has gained weight.

Mother B1, age 41.

In fact, sometimes you do not think about yourself. So some of the things like polish up your face, dress well, you cannot do it because you will breastfeed. Some way, somehow and sometimes you are even in the bathroom and he will be crying so when you come out, you do not have the time to polish your face and even to use pomade. I do not remember the last time I used pomade or polish my face unless maybe I am going to church and I would use lip gloss. Apart from that, when I am in the house, I do not have the time because I will be in the bathroom and he will be crying and you do not have the time to do all these things so having time for yourself is out when you have a premature baby. So how you dress, put on your clothes, all will change until maybe he grows to a certain stage.

Mother E1, age 30.

4.4 Challenges

In this section, three challenges are discussed. The findings revealed three categories of challenges. These included challenges of the mothers, the challenges of the preterm babies and challenges of the siblings of preterm babies.

i General challenges of mothers

The reportedly tedious care rendered to preterm babies by the mothers, coupled with inexperience brought about a lot of challenges in the course of care. Some

participants described caring for preterm babies as traumatizing and time consuming. Despite these challenges faced by these mothers, they did not give up; they tried hard to care for their preterm babies until their developmental progress was noticed.

The mothers expressed different views on their experiences of care. The challenges the mothers encountered included; physical, socio-cultural and economic challenges.

These were confirmed by various experiences:

A mother who had delivered a preterm baby after 15years of marriage spoke at length about her experiences:

Yeah! It has been so it's hectic and sometimes I ask myself a whole lot of questions and I just want to understand why I have to get a preterm baby. You are still feeding the baby and the baby is not growing and you feel like so when will the baby grow, you cannot do anything, you cannot leave the baby to anybody because you have to take care of the baby yourself and make sure that everything is clean and neat and you know you have people around so I have to run away from my house to hide myself somewhere because if I have to go home, I do not think it will be easy for me. I am just like a single parent so I have to do everything on my own and myself do not like people doing things for me so I have to combine all those things; my personal, my baby, my work and everything so it hasn't been easy and you have to go to the NICU clinic every week because they have to make sure the baby gains some weight.

Mother B1, age 41.

A mother who needed someone to help her at home while she concentrated on her preterm baby could not find help. She shared her experience in a different way:

It has not been easy and is like 24 hour work. For me I will say it's a lot of work a lot, a lot of work because breastfeeding her using the cup and spoon. It takes quite a while because one minute she is playing and the next minute she wants to sleep you have to stop everything and get her and make sure she is put to bed or you need to change her nappy, most of the time you are busy with her either feeding her or when she is playing and start crying you have to carry her or she just wants you to carry her so it's just busy, busy, busy then its evening then the next morning so it's like that on and on. It's like we have been through something we have not been through before and it's like if not for the baby, I would not have been aware of baby being born and looking that small so I think it has really changed our way of thinking as well. Taking care of her, it has been difficult especially, if you are alone and you have to take care of her all by yourself. Sometimes I need help to get something done, for instance if I have to pick up my son from school and I have taken the baby

for review, sometimes I spend the whole day there and I cannot get anybody to pick him up, it worrying trying to get someone to help you out a bit and I do not have anyone with me to help me out I do everything on my own because most family members are working and they are busy doing their own stuff.

Mother C1, age 34.

One of the mothers was unwell after delivery and needed some time to recover but then had to care for the preterm baby and two other children. She described her experience as a traumatic one since she did not get emotional support from her husband. She wept as she shared her experience:

It is very difficult taking care of the premature baby. What was difficult for me was the trauma that I went through. I was expecting much support because I went through a lot of trauma so I thought my husband will support me. When it happened like that, we did not explain it to some people so we just told them that I have delivered so they knew that I had delivered but they did not know whether it was a normal baby or a preterm baby. In the beginning, I did not have anybody around me apart from my mother and she would also not stay with me forever so when my mother left, then it became a big problem for me. Because I have to take care of this one with the other two, including the man so that was a problem for me at that time.

Mother D1, age 34.

Another mother narrated how she, a mother whose preterm baby weighed 1.5kg thought her In-laws could help her care for her baby but could not give the baby to them because of the information she was given after discharge. She struggled to care for her baby as follows:

It was not easy! That was my first time to have a premature baby and when I came home; my mother was not with me and the baby was too small and yet I had to take care of him myself so it was not easy for me and my husband was not also around by then. I had to do everything myself such as bathing. During the night I had to feed him too and he was used to the spoon so I did not find things easy when I came home from NICU. On the first day, I gave the baby to a woman but because he was too small, she could not so I had to carry him, bath, feed and do everything myself before I could also bath and take in something and then sleep. This continued like that so every morning I had to bath, feed, and clean him because I could not give him to my in-law then cook myself since my mother was not around. I will say that it has been like a new big experience for us which had made us to enter into this new world and given us lots of experiences. So it has been a whole lot of new experiences for us, especially for me. Sometimes it is not easy but you have to try your best to

take care of the premature baby, like feeding him, taking care to make sure he is fine, doing well, go to the hospital at the right time, and make sure he is happy and he is healthy

Mother E1, age 30.

ii Information needs

All the mothers who delivered preterm babies needed information to enable them care for their babies since caring for preterm babies is different from that of full term babies. However, it appeared they were not given enough information on care of the preterm babies after discharge. Some mothers were not happy with the brief period within which health teaching was done on the ward before discharge while others thought it would have been better if they were given contact lines to call for more information when the need arose. Also, others described the hasty manner of health teaching which they soon forgot and said it would have been better if they were given handouts well outlined on care of preterm babies so that they could refer to them when they forget the process of care.

In a frustrated manner, a mother explained her view:

You know sometimes, I feel like I have the doctor's number or a nurse so I can call to find out in case sometimes I do not understand something and sometimes the feeding. The baby will just be crying and I could just call a doctor or a nurse to find out something; what can I do? Maybe the baby will be crying and like you do not have such opportunities to call. Is just not easy sometimes because you do not have enough experience and like you have become a doctor yourself now.

Mother B1, age 41.

Some mothers who felt they were not well informed on care and outcomes of care of preterm babies expressed their views:

Yes and No because, yes they told us what we needed to know, no because personally they did not inform me much about what to look out for in their health changes like growing up changes, there was no much information on that. What to look out for

and what to worry about, they gave us the basics but there is more to it than just the basics.

Mother A1, age 34.

The only thing they said was when you come home make sure you continue to give the medicine you were giving him, make sure you do not expose him to the public, make sure you clean everything and they were saying it verbally so assuming I just want to see my baby then I will just say Ok because I just want to see my baby and go home since I am already tired coming all the way to that place so I just want to see him and go. The nurses also confirmed that was true that the mothers only thought of seeing the baby so we just nod as they talk to us but when we take them home, and then we forget. So most of the time some of the mothers do not ask questions they just collect their babies and go home then when they get home they realized they have forgotten everything but for me if I did not understand, I did ask questions. So NICU was really a challenging place and the place needs to be take care of very well.

Mother E1, age 30.

I think it was because it was my first time and we were given a lot of lecture at the NICU and each lecture took about 5 minutes so sometimes by the time you get home you have forgotten all they said. So you end up trying to do what you think is okay and even when you come home, they do not even give you any contacts they do not do that; so you cannot even call a nurse to say can I do this or that no that communication is not there so when you are discharged, that is the end of it. Because you do not know what is going to happen next and you would not know who to call so the only thing you have to do is to drive all the way to NICU to see a doctor and that will also take hours but if at least there is a number then, you can call to say this is the symptom or this is that. Can I bring the baby or is it normal or something? So at least that anxiety can come down a bit but when you are discharged from NICU, that contact is cut so whatever is wrong with you, you have to travel all the way; so imagine you are outside Accra.

Mother C1, age 34.

iii Socio-cultural challenges

a Social challenges

The nine mothers who were interviewed did not have any meaningful social lives after the delivery of the preterm babies. They became isolated and cut off from social gatherings by the constant and tedious care of the preterm babies. Some of the mothers did not enjoy their leisure times. All their social activities were sacrificed

into care. Due to the stigmatization associated with preterm babies and attitudes of friend and families, some mothers did not inform some family members and friends about the birth of the babies. For these reasons, they preferred being in-doors to make time available to care for their babies.

An extrovert mother whose social life was centred on her twin-babies and had to forego her social pleasures had this to say:

I do not even have a life anymore, I used to go out to dance sometimes sit with friends and talk, sometimes go and sit at the play ground put the small boy there, read. It's not like that anymore because then they need the extra attention, time, care, love. Like I said before everything is extra for them so you need to do that and you do not have a life you try as much as you want, but it's still not, "you do not have a life". Your life sort of surrounds them, you cannot just get up and go like a term baby where at a certain age, you can just get up and go and make sure the nanny will take care of her. It is not like that with them, is either you go to town and back immediately or you carry them along to wherever you are going so the inconveniences, that's all. It's not fun when you feel isolated, you feel nobody comes to you and that is what happens because then, there are times that you are left with just the babies and you cannot go anywhere. You do not have a social life, even if somebody has to talk to you, it has to be on the phone and there are times that you even would not get a phone call and with that sometimes you cannot just pick because your hands cling on the baby so you feel you have been separated from the world for a while especially when you cannot go out with them and all that. You feel left out.

Mother A1, age 34.

Other mothers who felt frustrated narrated:

You cannot take her out too so I cannot go anywhere; always indoors. It's very challenging because I could not go anywhere, always at home with her. When I had to go out, I had to really consider whether it is really necessary and if it's not, then I will not go. When I find out and it's not very necessary, I will not go. I will rather stay at home with her and I think it has affected her a bit because I do not take her out so when she sees strangers, she is a bit withdrawn. I used to go out a lot and like a naming ceremony, party or to the beach. I used to like the beach a lot; when it's my birthday I call 6 or 8 of my friends we prepare food and we go to the beach to have fun but now I cannot do it and I have not tried to do that since I gave birth to her but I used to do that a lot. I like to go to the beach a lot, sitting there with friends, attend parties, dance but now I am not doing it. I have not been able to do that since I gave birth to her but now I am hoping that I will do that soon. I used to go out for party with friends but when I had her, I think they knew it but they think I would not come so they will not even call or invite me so I felt isolated.

Mother C1, age 34.

I cannot attend family meetings these days and everybody complains about that. The baby is still young so I cannot expose him by taking him out always. I cannot go to church as I used to. I cannot go for programmes because I cannot take him along so that he will not be exposed to the weather. I was a chorister but now I cannot go for practice and I cannot robe too. I am always in-doors which is quite worrying. I usually go out for parties, weddings, funerals of friends but now I cannot go out any more and I am always in-doors. I am always in-doors I only go to church on Sunday since I cannot go for evening church service for Bible class and stuff because the baby is too small. Especially, going for church service and also I wanted to enroll onto a programme too but because of the baby I just could not combine them so I have stopped. I cannot read any book, not even the Bible. I have access to the internet but because of the baby if there is anything I want to find out on the net I cannot. I cannot watch movies as I used to, I cannot watch programmes on the television these days. So I cannot just have the time to do all these things I used to do. I could not continue to do other things. I cannot go to church, browse, visit friends, go out with my husband, and go for parties and others...

Mother H1, age 27.

b Cultural challenges

In Ghana, naming ceremony is very important as far as the identity of the baby is concerned. Every newborn baby is given a name on the eight-day of delivery. However, with preterm babies parents found it difficult to name them because they were too small to be exposed. Due to stigmatization surrounding the birth of preterm babies, they thought it would be prudent to name the babies after they had gained weight. Additionally, most of the babies were not discharged early from hospital therefore they are in the hospital by the seventh day.

Some participants who could not name their preterm babies on the eighth day because they had not gained weight felt stigmatized because of their social status and narrated their disappointments as follows:

Because they were all expecting to see the babies with this kind of big expectation and I did not know it's preterm and people will still want to find out what happened or this and that and that, so I have to avoid all those things. Some will understand but I know some will just complain because even after 4 weeks still, my father was saying no; you have to give the baby a name and I said no. She has to gain eem, weight (she laughs) before giving the name so they said no and I said okay, since she was born on Friday and they told me on Wednesday, I have to call the pastor and

just pray over the name and just that. So after that I knew a lot of people will say eh (she pause) we heard that you had a naming ceremony and I said that it's just a small thing and they are like for us to come and take in a small coke that you did not want us to come so I said, that is not the reason because she is still under treatment so I have to like finish all those things but once she is on this earth, I have to give her a name that is why. So I know some people are still expecting their out-dooring. I am trying to adjust myself to the family but it's not easy and it's an experience.

Mother B1, age 41.

For over 3 months she was not named because, you think your baby is too small and people will come and look and they will say a lot of stuff so you want the baby to look bigger and fine before you name her and all that. And that is worrying. when I brought baby home I used to like I said we could not name her till after 3 months even then she was too small so what we did was, we really isolated her we only invited not extended family we did it like close family thing just named her and I think we really isolated ourselves and people were like; have you really named the baby? And we said yes. They will complain why you did not call me, you did not do that and when I am going out and it's very necessary, I do not go with her just to make sure my presence is felt for some time and then by 10, 15 minutes, I am out of the place and I am back home. I do not take her out.

Mother C1, age 34.

One mother, who could not remember specifically when she named her preterm baby, stated how she did it without her church members' involvement:

It took us I think 2 to 3 months before he was named and even that I did not do it at church I did it in the house because it was just announced in church that our sister has delivered and that was all.

Mother E1, age 30.

iv Financial challenges

Financial costs of caring for preterm babies were one of the numerous challenges that the mothers were confronted with even though they were all within the working class. The cost of care had become expensive because all the nine mothers interviewed had stopped working and the burden of care had been shifted unto their husbands. Six of the nine mothers were self employed while three of them were secretaries. Some said because they were referred to other special clinics like Eye, Ear, Nose and Throat (EENT) they found it difficult paying the bills. Additionally,

the cost of review by means of transportation had created a lot of financial burden for them:

I had to stop work, look after them in the house and it was a bit of stress. Oh cost, it is a lot of cost taking care of these children especially when you want good care for them. It's a lot of cost and we believe in comfortability of the children so then you will incur a lot of cost with that. When Daddy goes to work and I have to go to the hospital, then we have to pick a taxi and they are two so we need a drop and a waiting taxi at that and I have to go with the Nanny because she has to help out and you can't just go to any clinic around because we are told they have not been discharged from NICU and when you go to a clinic nearby, then they are like Oh these children are special children so take them back to Korle-Bu. You have to always go to Korle-Bu from Adenta always refer back to Korle-Bu apart from the weighing and their normal community checks and it's a lots of cost. Well, I had to stop work actually, I am a caterer and I trade a little too in the market. I had to stop going to the market right there and then and I have not picked up yet. I do not know how long it's going to take me to pick up and my catering. It has really affected me financially. Caring for them has really affected me a lot because I could do better than I was doing at that time because I was aiming high. So financially, it brought me down, down to zero ground. As much as it has affected me work wise, financially everything is so tied up and sometimes you think someone actually stood somewhere and actually tied your opportunities.

Mother A1, Age 34.

Another mother complained:

It is expensive and sometimes you do not get the money to do it, or sometimes the money is not ready. Sometimes they give you an appointment and the money is yet to come before and you will not be able to attend clinic on your appointment date so you have to go later on. I used to own a shop but I could not do that so I kept the shop close for 7 months and I think we sat down as a family and we decided to give the shop out for rent. I import stuff and I network and I have people I distribute to so I do not even get people to order for the stuff anymore. I am able to make the distributions so I think now I am not able to do what I used to do. I am self employed but when I had only one child, I wake up in the morning, get him ready, take him to school, go to the shop until I had my baby and since then I am at home and I have not been able to do that at all. Even when I said I will operate from home, I was still not able to do that because most people that I give my stuff to work in the offices. I cannot go carrying my baby and the stuff to the offices and all that so I think it has really affected my work. I was thinking of expanding my business and I now have to start all over again when I am really ready.

Mother C1, age 34.

It is very expensive and we spend a lot of money. Financially, because sometimes it becomes very difficult for us since I have also stopped work for now. I remember when I used to work, things were not all that difficult since I always support with the

little I could get but now all the burden is on him now. I have really been affected especially concerning my work. I have really been affected financially. I am into this credit business so sometimes when I analyze the monies I have in debt, I become worried because I have stayed home for too long and I still cannot until he is 6 months. So the greatest effect is the financial aspect. It is really a problem because the entire burden has been laid on my husband. It is only the financial difficulties that make it difficult, otherwise, it is a good experience.

Mother G1, age 40.

One of the respondents, a secretary who had to resign from the company that she was working with because they would never give her anything beyond the maternity leave expressed:

It is not easy because even where I am working, I had to resign to be able to stay at home because they will not give you more than 3 months. So I have to resign and stay at home and take care of him. That really cost a lot, like when going for review, it has to be a taxi. When you get there (hospital) you have to buy medicines that are expensive, various laboratory investigations that you have to run and sometimes these investigations take weeks. I remember when I was asked to do Eye, Ear, Nose and Throat (EENT) investigations and this took me a whole week because I was just being tossed round and round come here today, there tomorrow and all that. So you can imagine how much that will cost just moving up and down. I have stopped work and I am in the house now because I cannot leave my child with somebody. Preterm babies are very delicate and the expenses and the investigations you have to do and all that. So I should rather stay at home and take care of him till he is fully okay. I also had my own business aside my work and I am not able to go for my rounds anymore which also brought some income. I had to resign from my work. So I have lost those opportunities.

Mother E1, age 30.

v Challenges of babies

In the next section, challenges in relation to the babies are presented.

a Feeding challenges of babies

One of the numerous challenges that the mothers encountered in the care of their preterm babies was feeding. Some of the babies could not feed well because their sucking and swallowing reflexes were not well developed. As a result, they got tired easily and would not suck enough breast milk or formula to gain weight. This

problem made the mothers very anxious since it was through feeding that the babies could gain weight. Even though, the mothers were not to introduce bottle feeding, some of them were forced to do so. Additionally, some of the babies slept for longer hours and therefore could not be frequently fed by their mothers. Two mothers who had had no previous experience of feeding preterm infants shared their experiences:

When we came initially if you do not wake him up, he can be sleeping from morning till evening so I made sure that every 15minutes, I would take him and breastfeed him and I was doing this for quite a long time.

Mother D1, age 34.

Well, sometimes he will not eat when he is awake so I wait till he is sleeping then I will put the bottle in his mouth then he will eat before he will sleep again. There are times that when he eats he will not even open his mouth but I force it on him then when he is able to take a little, he will sleep.

Mother H1, age 27.

b Weight gain

One of the aims of care in preterm babies is weight gain and this can be achieved through frequent feeding. However, two mothers' preterm babies' weights were found to be static on two occasions at the NICU clinic when they went for review. As a result, the mothers were anxious and frustrated. Hence there was the need for the mothers to increase the frequency of feeding the babies.

One mother explained:

For the first time I went for review, the weight was still the same. When we were coming from NICU, she was 1.3kg though when I gave birth she was 1.8kg and after 2 weeks when we went back, her weight was still the same 1.3kg and I was telling the doctor that I knew the baby eats well and I can see I feed her but she was still not gaining weight so it was also sort of a worry to me because I did not understand why I feed the baby well and she eats well and still not gaining weight. As I am saying, sometimes you know you are feeding the baby and you are expecting the baby to gain more weight and the weight is not going up as you are expecting so sometime I feel like, I should buy the milk because I feel the milk is heavier than the breast milk.

Mother B1, age 41.

Another mother expressed:

When I went for the first review, I was told that I did not feed him well because the weight was low so I was cautioned that I will come on admission if I do not improve on the weight.

Mother G1, age 40.

vi Challenges of siblings

Siblings of the preterm babies also had their challenges since they were not given much attention by their mothers. This was because the mothers were busy caring for their preterm babies at home. This created psychological and emotional problems for other children and in turn caused displeasure to the mothers.

A mother narrated how her 6-year old son was emotionally and academically affected by the delivery and care of the preterm baby. She said:

Okay Mummy does not love me anymore or Mummy has neglected, me she loves the babies more than she loves me. He Woo! (She exclaimed). It has affected him so much. His education sometimes, he feels left out sometimes. He is not doing well in school. The first 3quarter they came, it was not easy; his education was bad his results were so bad it was not that fun. Outgoing, happy go boy he was, he was so coiled and every time my Mummy this and my Mummy that. But he is now adjusted to it. It was tough but we got in fast to help the situation.

Mother A1, age 34.

Another mother whose 15-year old and only son felt neglected said:

He is in school so the first time he came and was happy to come and see his sister it's like something so tiny and he wanted to carry her and I said he should please not, so he was standing and looking at her and when she was crying he said ayah, 'your face is like an old lady'. So the way he was looking at her I was wondering what was going through his mind but you can see that he was not too comfortable with what he was seeing because he was expecting that he would see his sister and this and that and that so the next day he said; I want to carry her and I gave her to him and he was just looking at her and I said, do not worry in a few months time you would start running with her'. He is coping but sometimes if he wants me to do something for him like if he is hungry and I tell him Oh 'Joshua' the baby, then he would be like oh the baby so what about me? As if he is not important so I say you are but I have to give the baby some extra time. He is not too comfortable because he has to eat and to be also served his food. So lucky he is not with me now so anytime he comes around he tries to, so he is coping well.

Mother B1, age 41.

A 3-year old boy who developed separation anxiety because he felt left out by the changes he noticed in his mother's behaviour reportedly reacted this way:

It has affected him because I used to do everything for him and he would not allow anybody to help him out so when I was away especially when baby was at NICU, I had to go early in the morning and come back in the evening, he was always asking of me he was not eating because he has a problem with eating; he was not eating so when baby came home, it was like I was giving the new baby all the attention and I was not focusing on him and sometimes I just transfer my stress on him; I shout even if not necessary when I am tired or stress or something but now baby is playful so they play together but before it was challenging for him as well.

Mother C1, age 34.

In the preceding sections, the arrays of challenges experienced by mothers with preterm babies were highlighted. The section that follows outlines the form of support the mothers received from people.

4.5 SUPPORT

i Support from husband

Almost all the nine mothers who were interviewed received both economic and social support from their husbands, In-laws, extended families and friends. The various supports the mothers received encouraged them to take care of their preterm babies at home. All the mothers received support from their husbands except one mother who did not receive any physical and emotional support from her husband but received support from her family and friends. Other children (siblings) in the family were sometimes taken care of by their fathers to enable the mothers take full charge in the care of the preterm babies at home.

Mothers who received support from their husbands had these to say:

My husband for some reason has fitted in so well because he comes back from work, he goes straight to the kitchen, washes his hands with soap and he comes to carry them. Sometimes you can see I am stressed and he will help me bath the child or put one baby to bed before he comes to eat. There are times that he will just sit with us, try and play with the baby or help you to sterilize the bottle or help you do something.

Mother A1, age 34.

He was also very supportive because he said that once he is a human being who has been born, then there is no problem. He was not bothered because he wanted me to have enough time for the baby. So he was doing things for himself while I also took care of the baby. Well, he does everything and since he was not complaining I think he is okay with that. I had no help from anyone; it was only my husband that helped me in everything.

Mother F1, age 35.

Sometimes my husband has to go to the kitchen because he cannot wait anymore because he wants his food and I will ask him to please help himself since the baby is not yet done. So he goes to the kitchen to serve himself and make sure the other child is fed.

Mother C1, age 34.

The only mother whose husband was not supportive expressed:

My husband said the baby was too small so he wanted us to be out of the hospital because he did not believe that the baby was going to survive. He had so much doubt because; he had not seen something like that before. So he was always complaining that “the baby is too small” and I will say “why are you saying this because gradually it will be well” and he will say “he is too small for my liking..... I was expecting a 100% support from my husband but I did not get it until the baby was 3 or so months old. I was expecting much support because I went through a lot of trauma so I thought my husband will support me. I thought my husband would encourage me that “all will be over and you will walk soon” but instead he said if you cannot walk then let me get you a wheelchair which sounded like he wanted me to be like this forever meanwhile I was not born like this. So it was my mother who came in and said No! No! Do not go and buy any wheelchair; she will walk and then in 3 days I was able to walk. Well, he was not expecting that because he has not seen something like that before. And he thought instead of giving birth to the preterm baby he would have been happy if I had a normal baby. It is now that he is showing some form of happiness. And also when we came home from NICU he never touched the baby he will just look at the baby and turn back. So I was not happy with it at all.

Mother D1, age 34.

ii Support from In-laws

Almost all the mothers who were interviewed did not mention any support they received from their in-laws except two mothers whose in-laws were very supportive. This was confirmed by the following statements:

Well, I think they help me with household chores a bit, preparing food for me so that I can also pay more attention to the baby, so with food, washing up a bit yes they help me out with that.

Mother C1, age 34.

Another mother whose in-laws helped her to care for her baby said:

One of my in-laws asked me to move into her place for sometime so I can come back later when the baby becomes matured because where I was staying was a compound house and also because of the way the baby was small. So we went with her to stay in her house so she helped me take care of the baby well.

Mother H1, age 27.

The mother in question narrated the support she received from her in-laws with her previous deliveries as compared to this preterm delivery. She said:

My in-laws, comparing them to when I had the first two, immediately they heard that I had delivered, they came to visit us but when they heard that it was a premature baby, for 3-4 months, we just heard them say we will come and visit but they never came to visit us. So my husband said we should have the naming in the church so that we will not allow them to come. But I said, "We should forget about them because two wrongs do not make a right". So we should just allow them to come. So they came and when they came they were not happy about their grandchild even though I forced myself to give him to my mother in-law. She took him for just some few seconds and gave him to their house help. She became quiet for some time and folded her arms.

Mother D1, age 34.

iii Support from extended family members

All the nine mothers who participated in the study expressed how supportive their families were when they delivered the preterm babies. Some mothers had physical, emotional and financial support, while others received only physical support. The forms of support they received encouraged them to care for their babies.

The mother who received both physical and financial support from her elder sister and her cousin said:

A cousin of mine who comes to help bath the children when it is stressful and I need extra hands so she is more involved, she is more involved, she comes to take care of them while I am doing something else and then we end up finishing quickly (point to a relative). She is affected a little because then when I go to the hospital or I go doing something, she has to come and take care of the younger boy or she has to come home and make sure Daddy's food is done and make it ready and there are times she has to come and do that. Money wise yes, the preterm babies are given milk from the United Kingdom. Like I said, my big sister brings them in bulk every 6 months. With the supply, they have their diapers in abundance, their wipes, everything for 6 months. So that there is nothing like eventualities and then the food is in good supply and sometimes there is money coming in for their upkeep.

Mother A1, age 34.

The mothers who received both emotional and physical support from their family stated:

My mother was so supportive. She was advising me that people give birth to 1.8kg but it did not survive and he is a boy and normally they say the boys do not normally survive especially for the 33 weeks so my mother was the one who really encouraged me. Well, my family was very supportive towards us.

Mother D1, age 34.

Another reported:

Well, sometimes my sister comes to visit and help me over the weekends then she leaves on Sunday. They also helped by coming to help me sometimes. And my mother came to stay with me for about 2 months when I came home but she had to leave when she also started work.

Mother H1, age 27.

The only mother who found her older daughter and family as sources of support said:

My first born is almost 11 years old so she is the one who actually helps me a lot in all the house chores; I have taught her everything so she can cook, wash and do other things which has helped me all this while. My elder sister when she comes around, she will grace us with some money but with the other members I will say it is just their time which is maybe 3 weeks then one will show the face. As I said earlier on, at least after every 3 weeks, any of them could come and visit us with or without a token so it like that.

Mother G1, age 40.

iv Support from friends

Most of the mothers who were interviewed received support from their friends and loved ones in the form of gifts and money. These helped the mothers to care for their babies. However, some mothers prevented their friends from visiting them so they could not receive any support. This was due to their attitudes towards the preterm babies and a measure of infection prevention. The mother who had a good interpersonal relationship with her friends received support in the form of gifts and money from her friends. She noted:

Some friends come and they are like they are so beautiful, sweet babies, used clothing and baby shoes, baby stuff, sometimes someone will say Oh have these for the babies maybe money, and there are times that close friends come around to help. Maybe just come around and hold them whiles you quickly have a bath or quickly cook for the house or something.

Mother A1, age 34.

One mother allowed her friends to visit and support her during and after she had named her preterm baby. She observed:

It was after we had named the baby that people could come and give you something (gift) to push you up. Few ones actually came to visit and helped me during the naming ceremony.

Mother H1, age 27.

A mother who received emotional support from her friends by way of encouragement and gifts mentioned:

The only help was that friends will say “try and take care of him because preterm babies need care so if you are able to do that he will be fine”. They also brought baby clothes, soap and other things.

Mother F1, age 35.

In the ensuing section, the strategies the mothers used to cope with the experiences they were going through following delivery of preterm babies are presented.

4.6 Coping Strategies

Faced with the daunting task of caring for preterm babies, the mothers developed coping strategies that helped them care for the preterm babies at home after discharge from hospital. Two kinds of coping strategies were adopted by the mothers.

i In-depth understanding of babies' needs

While the mothers were caring for their preterm babies they tried to find ways to deal with the stress they were going through by developing a deeper understanding of the needs of the babies since it is only the mothers who would know, understand and appreciate the needs of their babies. The mothers understood their babies' behaviour because they could recognize and identify their cries for wet diapers, hunger or attention. This strategy helped them to cope well with their preterm babies.

A mother who could identify the needs of her preterm baby narrated how she coped:

Oh, I think we have coped very well. So far we have managed ourselves so well; we have cultivated a joint family way of making things easy for us. We have found a way around the stress to release some of the tension. Sometimes you want to play music for them to just listen, and there are times, you clap, you dance like a crazy person and they are all excited so then you are okay with that.

Mother A1, age 34.

A mother who studied her baby to identify her needs in order to cope with the stress of care explained:

I think that I go according to her pace now that she is growing up. So I think that I do it as and when it's needed it's not like first that the anxiety was there, now I am a bit relaxed so I can tell when she needs food then I give her, I change her diapers I know when she needs what because she make certain sounds. When she needs her cup and she sees her cup around then she will cry out then I know she needs water so the anxiety and the attention is a little bit gone down than when she was a real baby. It's getting to know her because if you know her it's easier. If you know the baby, there is some little stuff she would do to tell you she wants that or this so if you know

all that it's a little bit easier for you. So that is what I do, getting to know her and knowing her more than I know what she wants.

Mother C1, age 34.

Similarly, a mother who was able to identify her baby's needs found it rewarding and helpful:

Now I know she needs food more so I have to feed her on time and make sure she takes the food. Wrap her well to keep the temperature. Generally, I just accept it and make sure I do what I have to do and what they tell me to do. I follow the advice we were given on discharge to get her well and gains weight.

Mother B1, age 41.

ii Religious beliefs

The mothers in this study used religious beliefs as coping strategies to enable them care for their babies. They trusted in God as their help and a mediator in the course of caring for the preterm babies. The following statements buttress the use of religion for coping purposes:

I always pray to God for His strength towards me to enable me to take care of him.

Mother F1, age 35.

Two other mothers narrated:

It is all about prayer. I always pray that God should give me wisdom and a good heart to help me take care of him and lo and behold He did that for me and I have been able to take care of him.

Mother H1, age 27.

I just thank God. It has been like that till today and prayer also helps. God has been faithful.

Mother G1, age 40.

A mother who used her philosophy in life as a coping strategy maintained that:

Well, how I overcame all this process, I put something in my mind and I realized that it's life. It's like that; it does not go straight as you want. Because it is rough and smooth so whatever you encounter in life, you always thank God for that especially if you are a Christian and then you continue doing the normal things that you do. So I think I had a great experience.

Mother D1, age 34.

In summary, this chapter analyzed nine interviews conducted on mothers caring for their preterm babies at home. Six major themes and twenty five sub-themes emerged during the analysis. These major themes were: care of preterm babies; perceptions of prematurity among mothers and attitudes of significant others; mothers' health and well-being; challenges; support and coping strategies.

The findings of this study revealed that five mothers exclusively breastfed their preterm babies, three mothers used complementary feeding while one mother used only artificial feeding as breast milk substitute. All the nine mothers employed various methods of providing warmth to their babies. As a result their temperatures were within the normal range at the time of interviews. Also the findings of the study showed that none of the babies had any observable infections. During the interviews with the mothers, almost all the mothers showed some form of anxiety, grief and worries about the outcomes of their babies and also expressed doubts about the survival of their babies.

Preterm babies were perceived to be abnormal babies and as a result the mothers felt embarrassed sending their babies out. Additionally, eight out of nine mothers experienced good attitudes from their husbands while caring for their babies at home. Some in-laws, extended family members and friends showed positive attitudes towards the babies while others showed negative attitudes towards the preterm babies.

The delivery and care of preterm babies was found to have had psychological, physiological and physiological impact on the health of the mothers. The findings also revealed three categories of challenges encountered by the mothers during the

care of their babies. These were: challenges of the mothers; challenges of the babies and challenges of siblings of preterm babies.

Furthermore, almost all the mothers received psychological, socio-economic and physical support from their husbands, in-laws, extended families and friends. Finally, all the nine mothers developed coping strategies that helped them due to the daunting task of caring for their preterm babies at home.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 Introduction

This chapter discusses the findings of the study in relation to the literature reviewed.

The purpose of this study was to explore and describe the experiences of mothers caring for preterm babies at home after discharged from hospital in the Accra metropolis. To enable the researcher carry out the investigation successfully, the following specific objectives were set. The study set out to:

- Describe the experiences of mothers caring for preterm babies at home.
- Identify the major challenges and coping strategies of mothers with preterm babies and
- Determine the information needs of mothers caring for their preterm babies at home.

The detailed discussions of the findings of this study are presented according to the following research themes; care of preterm babies, perceptions of prematurity among mothers and attitudes of significant others, mothers' health and well-being, challenges, support, and coping strategies.

5.1 Care of Preterm Babies

During the data collection and analysis it was realized that mothers expressed confidence in the ability to care for their babies at home. The sub-themes that emerged under care of the preterm babies included feeding, temperature control, infection prevention and observation. Feeding was the greatest concern. Feeding was the overarching task for the mothers. They could sit for hours feeding the babies during the day and at night. Some of the mothers could wake up as many as five times during the night feeding their babies with the hope that they would gain

weight. Sometimes the babies would not open their mouth to suck because their swallowing and feeding reflexes were not well developed. As a result, they easily got tired and lacked the strength to breastfeed. The task of feeding is now discussed in details.

i Feeding

The methods of feeding used were exclusive breastfeeding and complementary feeding. However, one mother decided to substitute her breast milk with artificial feeding to enhance the growth and development of her babies because they were multiple-ton babies. She also felt the breast milk would not be enough. Growth and development were noticed in the preterm babies as shown in their weight gain through their growth monitoring records. Exclusive breast feeding is the best known and acceptable method of feeding babies globally. The World Health Assembly and UNICEF adopted a global strategy for infants and young child feeding in 2002 to draw the attention of the world on the impact of feeding on the nutritional status, growth and development, health and survival of infants and young children. Exclusive breast feeding is the feeding of infants solely on breast milk for six months without water or artificial feed (Ball & Bindle, 2008). Breast milk is considered to be the most suitable food for the infants especially in the first six months of life because it prevents babies from getting diarrhoea. A baby's own mother's milk is the best for all LBW infants of all gestational ages. Strong evidence shows that exclusive breastfeeding is associated with lower incidence of infections and better long term outcomes (WHO, 2006). With the introduction of Baby-friendly Hospital Initiative (BFHI) launched in 1992 with the aim of transforming maternity facilities to improve standard of care, health teaching during discharge of preterm babies from NICU in terms of exclusive breastfeeding had improved. The staff of NICU of the

Korle-Bu Teaching Hospital, place so much emphasis on exclusive breastfeeding. In Ghana, all the teaching hospitals, regional and district hospitals as well as health care centres are practising the Baby-friendly Initiative where nursing mothers are taught how to practise exclusive breastfeeding.

The findings on care of preterm babies as described earlier in this study are consistent with the study conducted by Sweet (2008) on expressed breast milk as ‘connection’ and its influence on the construction of ‘motherhood’ for mothers of preterm infants. She found that the mothers of preterm infants were connected to their babies through breast milk. Even, when the infants were on admission at the NICU expressed breast milk was found to create physiological and emotional connection between the infants and the mothers while the infants were in constant care of the NICU staff. In Africa, the joy of motherhood is derived from the satisfaction of putting the baby to the breast or giving breast milk in whatever form. For an African mother to substitute her breast milk, it could be as a result of factors contributing to the inability of the mother to put her baby to the breast (Hockenberry & Wilson, 2009). Breast feeding has been found by a research carried out by Buckley & Charles (2006) to be beneficial to both babies and their mothers as opposed to bottle feeding. The authors found that infants who were breastfed had fewer infections and less gastrointestinal tract (GIT) disorders, better cognitive as well as neurological and visual development. The study also found that putting babies directly at breast improved oxygen saturation and better coordination of sucking and swallowing. Additionally, the study showed that breastfeeding improved breathing pattern in infants. Furthermore, it also increased body temperature due to skin-to-skin contact between the mother and the infant. Breast milk enhances nutritional and immunological properties of the baby. To the mother, the study

showed that breast milk reduces the risk of breast engorgement and improves maternal health during and after puerperium and also associated with positive psychological effect. The current research findings therefore, corroborate with those of Buckley and Charles (2006).

ii Temperature control

Neonatal hypothermia is defined as abnormal thermal state in which the neonate's body temperature drops below 36.5°C (97.7°F). When there is progressive reduction in temperature, it leads to adverse clinical effects ranging from mild metabolic stress to death (WHO, 1993). Temperature control is pivotal in care of preterm babies to prevent infant morbidity and mortality. Temperature control was one of the basic and important tasks that were employed to provide warmth to the preterm babies. The mothers did all they could to conserve energy in the babies by covering them with blankets and other articles and the intervention showed how well mothers understood this need in the fragile infants. Others used the Kangaroo Mother Care (KMC) in addition to the usual methods of keeping them warm. KMC is the practice where preterm and very low-birth-weight (VLBW) infants are kept warm by placing them on the chest to get skin-to-skin contact between the mother and the baby. It is a low cost, standardized method that promotes the health and well-being of preterm and VLBW infants. Even though, Sub-Sahara Africa is warm they did all they could to conserve energy in the preterm babies. In Ghana, infants are usually strapped at the back of their mothers to provide warmth but there was the need to adopt the KMC method. Even though the KMC method has been adopted in Ghana, it is practised only in very low birth weight (VLBW) babies (Naaso, Bonzie, Bawa, Rooyen & Bergh, 2009). This method of care had been researched into and was found in several studies that it can reduce morbidity and mortality in preterm and LBW infants

(Pattinson et al., 2006; Nyqvist et al., 2010 & Nirmala et al. 2006). KMC was initiated at the Instituto Materno Infantil in Bogota, Colombia by Dr Rey in 1978. In Ghana, KMC has been adopted by the health institutions and implemented due to the benefits derived from it. This method is briefly practised and as the infants gained weight, they preferred strapping them at their back since that is the culture of Ghanaians. This practice of strapping infants at the back is believed to create a bond between infants and their mothers.

The study's findings on temperature control are consistent with the work of Kumar et al. (2009) which showed that the risk factors for neonatal hypothermia (sub-normal temperature) differ with mothers of newborn babies. The study found that, a combination of physiological, behavioural and environmental factors put all neonates at risk irrespective of the gestational ages. Several socioeconomic, cultural and systemic factors that pertain to neonatal care potentially expose neonates to a high risk of hypothermia, even in warm climate zones.

iii Infection prevention

Infection prevention was another important concern of the mothers interviewed. They tried to observe all the measures of infection prevention to make sure the preterm babies did not get infections since their immune systems were under developed. As a result no observable infections were noticed in the babies. Again, the babies were observed closely by their mothers for abnormalities to be reported to enhance early detection and management. In relation to prompt medical attention and management, none of the preterm babies had developed any complications after discharge at the time mothers were interviewed. Although health care providers are striving to improve the quality of care rendered to preterm babies at the intensive care unit and at home, much improvement in quality of care could be achieved if the

nursing and medical staff utilize the standardized guidelines that are internationally accepted to increase the survival of preterm babies in the country.

5.2 Perceptions of Prematurity among Mothers and Attitudes of Significant

Others

Most of the mothers perceived their preterm babies to be abnormal. Prematurity to them was an abnormality. As a result, they felt embarrassed taking their babies out. With time as developmental progress was observed in the babies, the mothers expressed joy in mothering and confidence in the care the babies were receiving from them. The attitudes of husbands and significant others appeared to influence the social lives of mothers and the way they cared for their preterm babies. Most husbands showed positive attitudes towards their wives; the mothers received encouragement from their spouses while caring for their babies. However, some in-laws, extended family members and friends showed negative attitudes towards the delivery of the preterm babies by passing derogatory comments about the babies. As a result the mothers suffered many emotional reactions including worries and sadness, heightened concern for their babies and stigmatization. This study findings are consistent with the study findings of Lee, Norr and Oh (2005) on the emotional adjustment and concerns of Korean mothers with premature infants. In the Korean study, the mothers showed emotional distress while caring for their infants. They showed concerns about their babies' well-being; breathing, feeding and sleeping. Furthermore, some mothers expressed worries about the infants' growth and development. The developmental delays in the infants in terms of size and weakness heightened the mothers concern and this made the mothers keep the infants away from others to see because of potential stigmatization. It was also found that because

of the Korean mothers' cultural beliefs that negative thoughts could lead to negative consequences, they internalized their feelings and distress leading to isolation and depression.

5.3 Mothers' Health and Well-Being

The care of preterm babies had a negative effect on mothers' health and well-being. They were anxious, grieving, worried and feared that they could lose the babies. They had doubts about the survival of the babies. Again, the mothers were deprived of sleep because of frequent intervals of feeding. According to the mothers, they never had good sleep because they were feeding the babies during the day and at night with the hope that they might gain weight. Meanwhile the mothers were supposed to rest during the puerperium which is the six-week period within which nursing mothers are expected to rest and sleep in order to recover from all the stressors associated with child birth to prevent post partum blues. Also, in Ghanaian cultural system, safe delivery is perceived as sign of victory over death. Nursing mothers are therefore mandated by culture to dress and groom themselves in white clothing and beads and other ornaments (Nukunya, 2003). However, due to the tedious nature of the task of caring for preterm babies at home, some of the mothers could not groom themselves as expected. Others were unable to maintain their personal hygiene due to the burden of care of these babies.

These findings are consistent with the findings of the study carried out by Lee, Norr, and Oh (2005) on emotional adjustment and concerns of Korean mothers of preterm infants. They found that the mothers expressed much concern about the health of their infants while others were worried and anxious about the size and development of their infants. They suffered negative emotional reactions such as self-blame,

concerns for the infants and fear of stigmatization. Due to stigmatization, they refused to show their small and weak babies to others. The mothers also internalized their feelings due to cultural beliefs that negative thoughts lead to negative consequences so they did not express the stress they were going through and avoid verbalizing their negative emotions. As a result they felt isolated and depressed.

Mothers all over the world are passionate about their babies than fathers because of the bond between them (Buckley & Charles, 2006). Parenthood forms an integral part of ordinary family life because of the bond between parents and their infants. However, the burden of care is much on mothers than fathers as mothers are directly responsible for the care of infants (Nukunya, 2003). A study was conducted by Jackson, Ternstedt and Schollin (2003) which sought to determine the differences between the experiences of mothers and fathers of preterm babies in Sweden. It was noticed that mothers had more responsibilities and control over the care and needs of the infants than fathers. The fathers expressed how confident they were leaving the infants in the care of the NICU nurses during admission and the confidence they had in the mothers. According to the authors, fathers do not actively participate in the routine care of their infants, though, there are exceptions. The authors further stated that fathers would normally want to cuddle and care for the infants sometimes simply because of their nature of work. However, some fathers tried to balance responsibilities between work and family life. In Ghana, the burden of care of both preterm and term infants solely rests on the mothers. Fathers do little when it comes to direct responsibility and care (Nukunya, 2003). The findings of the current study revealed that fathers encouraged their spouses to care for the babies but were not directly involved in the care of babies. However, they offered assistance when necessary.

The findings of the study by Garel et al. (2006) showed some similarities with the findings of the current study. According to Garel et al. (2006), the main difficulties that were reported by the mothers were fatigue, depressive mood, anxiety, physical symptoms, withdrawal and feeling of guilt. Fourteen mothers mentioned fatigue caused by activities such as work and lack of sleep. Depressive affects were also seen in sixteen mothers and this was revealed by the tone of voice of the mothers and tears during interviews. Most mothers' depressive affects were associated with the child's health and development. Also, the feeling of guilt was noticed in eleven mothers about the preterm delivery. They thought they did something wrong to have caused them to deliver earlier. Again, anxiety was seen in fourteen mothers in terms of worries and fear. This was mainly due to the children's health and development. Ten mothers experienced sleepless difficulties caused by fatigue and a tensed marital relationship. In the current study, one of the challenges that the mothers encountered was sleep deprivation. Some mothers were almost moved to tears during the interviews with them. The daunting task of care of preterm babies especially feeding throughout the day and at night caused the mothers sleepless nights. There was the need for frequent feeding to enable the preterm babies to gain weight. Feeding was one duty emphasized by the nursing staff during health teaching upon discharge of preterm babies from the intensive care unit. Growth and development can be achieved in preterm babies only when they are well fed (Hockenberry & Wilson, 2009). Knowing the benefits of feeding babies there was the need for mothers to deprive themselves of their sleep and feed the babies for optimal results.

5.4 Challenges

The findings of this study revealed numerous challenges faced by mothers of preterm babies during care at home. The challenges ranged from general challenges of the

mothers, information needs, socio-cultural, financial, feeding, weight gain and challenges of siblings. Nevertheless, the mothers expressed happiness when they noticed improvement in the growth and development of the preterm babies. One may argue that these challenges could have been prevented if the babies were delivered at term. The statements made by the mothers during the interviews showed that they were not prepared for the preterm delivery. However, looking at the predisposing factors of preterm delivery, there was the need to accept the situation and live with the challenges that go with it. In Ghana it is common knowledge that pregnant mothers prepare for the delivery of babies a few months ahead before the baby is born. Pregnant mothers work hard and save money in preparation for the arrival of the new baby only for the mothers to deliver preterm babies when they have not saved enough money for the arrival of the babies. As a result financial burden was one of the paramount challenges that the mothers mentioned. The financial costs of caring for preterm babies were overemphasized by the mothers. They had to stop work to care for their preterm babies. Apart from that, the cost of medical bills and transportation to the hospital made mothers of preterm babies over burdened financially.

Furthermore, information needs were other concerns of the mothers. They had inadequate skills and knowledge that would equip them to care for the preterm babies at home. The care of preterm babies is different from care of term infants. Mothers need adequate information on care to make them feel secure and confident about care of their babies at home. Mothers tend to encounter challenges of care where they are not adequately taught what to do. Additionally, mothers of preterm babies were socially isolated from the society because they did not want others to see the small and unhealthy babies to avoid stigmatization. As a result, they kept the

baby indoors and could not tell significant others about the delivery of the babies. They could not also attend social and religious gatherings like church services, parties, and family gatherings. They could not visit and others could not visit them. The mothers internalized their feelings leading to stress which they expressed during the interviews. Culturally, preterm babies could not be named on the eighth day of delivery as the culture of Ghanaians demand (Nukunya, 2003). This was attributed to prolonged hospital stay of the babies, developmental delay in baby after discharge and stigma associated with preterm birth. Babies could not be exposed for others to see. The mothers protected the babies from potential hazards like exposure to infection from strangers, friends and family members. In the Ghanaian culture, babies are exhibited for everybody to see and welcome during the naming ceremony. Also, gifts and other valuables are presented to the baby and the family (Nukunya, 2003). Even though the preterm babies were given names, it took the parents some months to do so. They had to wait for the babies to grow and put on weight.

In addition to the above, the babies also encountered challenges such as poor feeding and slow weight gain due to physiological problems of preterm birth. This negatively affected the mothers' psychological state of health resulting in anxiety and worries. Finally, the siblings of preterm babies encountered challenges because attention was diverted to the newly born babies. Mothers had no time to care for other children in the family as well as their husbands. Some of the children developed separation anxiety. Others did not do well at school because of the little attention they received from their mothers especially. Consequently, it caused displeasure to the mothers.

Findings of a study conducted by Lindberg and Ohrling (2008) corroborate the findings of the current study. The study by Lindberg and Ohrling showed that mothers with preterm babies were not ready for transition when they were

discharged home because they could not consider themselves as mothers. Also, it was found that mothers with preterm babies were anxious and stressed up because they were separated from their hospitalized infants and other children at home. Additionally, their social roles as mothers could not be played well since they could not care for other siblings of the preterm infants at home. However, the mothers received some form of support from their spouses by taking the responsibility of care of the other children at home.

Findings of the current study are in contrast with the findings of a study conducted by Ferecini, Fonseca, Leite, Dare, Asis and Scochi (2009) on perceptions of mothers of premature babies regarding their experience with a health education programme. According to the authors, the findings of the study showed that mothers of premature babies were able to learn and developed confidence to care for their babies when health education programme was organized for them. The use of written materials (booklets) as a guide for care was given to the mothers. This helped mothers and significant others to provide quality care to their babies and therefore prevented infections in the babies. The participants felt the programme prepared them adequately for discharge. Furthermore, the findings of the study showed that the programmes created an avenue for mothers to share their experiences and fostered greater interaction among the participants and nurses. However, the findings of the current study showed that mothers with preterm babies were not adequately prepared to care for their babies at home. Written materials (booklets) were not given to participants even though some mothers suggested the use of written materials as a guide for care.

5.5 Coping Strategies

Despite the multitude of challenges faced by mothers at home, they found reasons to live by developing coping strategies that strengthened them as they cared for the preterm babies. “Coping is the effort to control, reduce or learn to tolerate the threats that lead to stress” (Feldman, 1994) Coping was largely religious-based. Ghana is a secular country but the people are highly religious. The mothers trusted in God as their source of grace, help and a mediator in the course of caring for the preterm babies. Assimeng (2006) noted that everyday life of the African is intertwined with religious beliefs and practices and described religious beliefs as statements to which members of a particular religion adhere to. Notably, religion performs certain basic social and psychological functions which include integrating people into the society and helping people to withstand challenges they face. Another means of coping was the mothers’ reliance on in-depth knowledge and understanding of their babies’ needs during the initial stages of care. The mothers were able to identify the exact needs of the babies that made them comfortable and prevented them from crying unnecessarily. The level of care changed as the mothers nurtured their babies. Mothers understood the babies’ behaviour because they could recognize their cries for wet diaper, hunger or attention.

These findings support the findings of a study conducted by Vasquez (1995). The studies found that parents gathered special resources that helped them cope with their infants at home through information. Mothers asked the medical and the nursing staff questions about infant care. Again, they protected the infants from potential hazards by keeping the infants from strangers, friends and close families. They also avoided derogatory comments and insults from friends and families by isolation. The results also showed that they developed strategies and defense mechanisms to protect

the infants. The strategies they adopted were to develop cues about the likes and dislikes of the infants and their behaviours to guide them in the care of babies because they could recognize their needs.

The current study also showed that, many participants coped well with their babies by drawing emotional strength from God. In many parts of the world people get religious when they are ill or are befallen by mishap (Hill & Pargament, 2003; Cummings & Pargament, 2010).

A study by Singer et al. (2007) sought to find out mothers' psychological distress one year after very preterm childbirth identified that, mothers of high-risk VLBW children experienced the highest family and personal problems and used less denial and mental disengagement in coping than mothers of low-risk VLBW and term children. Thus the mothers have developed coping strategies that would help them manage the stressors associated with parenting. Additionally, the mothers had lower consensus with marital/partner relationship, divorce rate, parenting competence and psychological distress symptoms. However, multiple birth and low socioeconomic status were found to contribute to the maternal stress. Furthermore, low intelligent quotient (IQ) and mental retardation in the infants during the developmental stages were found to add to maternal stress. Some of the findings were in line with the current study. In all, the findings of the study some elements of coping were identified. This is because coping is necessary in order to have control over challenges that befall human beings

In contrast, a study by Sloan et al. (2008) identified stress and coping in fathers following the birth of preterm infants. The qualitative aspect of the study showed four major sources of support namely; social, emotional, practical and informative.

The study found that families were the major sources of social, emotional and practical support, although friends were also a major source of emotional support and partners a major source of emotional support. The quantitative aspect also found that fathers had less levels of stress because they used accommodation as coping strategies. These findings were different from the findings of the current study because fathers were the participants in the study in question. However, in Ghana, fathers are not directly involved in the care of babies. According to the findings of the current study, major responsibilities of care rested on mothers but financial burden rested on the fathers.

5.6 Information Needs of Mothers

Information on care of preterm baby at home after discharge is pivotal. All the mothers in the study needed information to enable them care for their babies. Care of preterm babies is different from care of term infants. Care of preterm babies requires special skills and knowledge received from medical and nursing professionals by mothers before discharge. To provide optimal care for preterm babies, mothers with such babies require pertinent, adequate and useful information to enable them carry out the daunting task efficiently. From the data gathered during the interviews mothers were not given enough health teaching to enable them care for the preterm babies. Some mothers were not happy with the brief period within which health teaching was done at the intensive care unit before discharge while others thought it would have been better if they were given contact lines to call for more information when the need arose. Furthermore, other mothers described the hasty manner of health teaching which they soon forgot and suggested that it would have been better if they were given handouts (booklets) well outlined on care of preterm babies so

they could refer to when they forget the process of care. The women also complained that there was no follow-up (home visit) by health care providers to assess the level of growth and development in the babies.

The findings from the current study are consistent with the findings of Rabelo et al. (2007). They investigated the feelings and expectations of mothers of preterm babies at discharge. Four themes emerged from their data and included “the moment of the discharge” “mothers’ knowledge and questions” “mothers’ preparation and orientation for discharge”. They found that mothers of preterm babies were elated at discharge because of relief of the burden of caring for other siblings and relatives staying at home. However, many of them were anxious and insecure about caring for the preterm babies at home because they did not acquire the skills that would enable them care for the babies at home. This happened because they were only made to observe the procedures but not to participate actively in the care of the preterm babies at the Neonatal Intensive Care Unit (NICU). Also, the authors found that undertaking basic activities like bathing, changing of diapers, breast feeding and administration of medication were more complex for the mothers of preterm babies because they did not have the opportunity to carry out such activities while the babies were on admission. Furthermore, the authors found that the mothers received little or no information on follow up and health education on care of preterm babies at discharge to enable them provide adequate care to their babies at home. Consequently, the mothers were poorly equipped to care for their preterm babies at home. This led to the anxiety in the mothers regarding caring for their babies after discharge. During the interviews, it was observed that some of the mothers of preterm babies had forgotten the instructions they received at discharge on care of

preterm babies at home, so there was the need for manuals or handbook on care of preterm. It was recommended by the authors that, parents should be ready for any eventuality that might occur as a result of delivery of preterm babies. The authors underscored the need for mothers to participate in the care of preterm babies while on admission so that they would be conversant with the basic skills and knowledge in caring for preterm babies before they are discharged home. This would reduce their anxiety levels and increase their confidence to manage the babies at home. Again, the authors emphasized on the preparations and instructions to be given to mothers on discharge. They highlighted that instructions given to prepare mothers for the baby's discharge should be clear, concise, simple and easy to understand. It has been indicated that stress and anxiety could affect the learning process at the time of health teaching (Rabelo et al., 2007). It is therefore imperative that factors that could impede the ability of the mothers to learn should be avoided. Thus, the mothers should be given the necessary attention and encouraged to enable them play their maternal roles by permitting them to actively participate in the care of babies while at the hospital. The authors further noted that it is important to consider the mothers' socioeconomic, cultural background and appropriate language background when giving them health education. It is important that health providers who are passionate, empathetic and knowledgeable should be made to counsel the mothers with preterm babies so that the effects of health education would be realized. Basically, in Ghana health teaching at the hospital level is done in the language that the mothers understand in order to care for the preterm babies at home. However, the educational background of the mothers plays an important role in the education of the mothers. It is believed that the higher the level of education, the better the understanding of the health education by the mothers. It is recommended that

mothers in low socioeconomic class as well as enlightened mothers should be visited (follow up) frequently to assess the level of developmental progress in their babies.

The best way of acquiring skills and knowledge is through observation and direct participation in the care while the babies were on admission. At the Korle-Bu Teaching Hospital, where the research was conducted, the hospital protocol only allowed mothers to visit the babies and breastfeed if possible but not to handle them since procedures at the unit were complex for the mothers. It would have been appropriate if mothers directly took part in the care of babies at NICU because they would be eventually caring for these infants at home. Again, information given to the mothers in the current study seemed not to be adequate and sometimes health teaching was not well done to equip the mothers for care of their preterm babies at home.

Again, the current study's findings are in contrast with the findings of the study conducted in Hong Kong by Mok and Leung (2006) which showed that all mothers received some form of support from the nurses at the neonatal intensive care unit while on admission. However, there was a significant difference between perceived and received nursing support. According to the authors, the parents of premature infants desired more nursing support than they received especially in the area of supportive communication and the giving information. The study showed that, most of the time the mothers of premature infants relied on the NICU nurses to explain the information or message given by the medical staff, especially when the infants were sick. The findings of the study showed that the nurses' support was the source of mothers' strength as evidenced by the concerns and listening ear granted to the mothers by the nurses at the NICU. The concerns and listening ear by the nurses

form important components of caring that the mothers received at the hospital. As professional nurses it is our duty to develop a “listening ear” in order to address the psychological concerns of mothers with preterm babies not only at home or on admission but when they come for review.

The findings of a study carried out by Broedsgaard and Wagner (2005) are in contrast with the current study’s findings. The study by Broedsgaard and Wagner sought to know the educational programmes during hospitalization of preterm infants, visit and orientation about the neonatal intensive care unit by the family’s health visitors and publication of relevant booklets for parents and health care providers. The findings showed that 73% of the families were satisfied with the information they received from the health visitors on care of premature infants. About 95% of the families in the study stated that they received adequate support and guidance from the coordinators, 94% felt that the intervention put in place was beneficial and were pleased with the continuity of care they had for their premature infants especially when they were discharge home. Additionally, findings from the qualitative part of the study showed that the parents of premature infants perceived most of the intervention initiatives as a measure that increased the support they needed to care for their infants during hospitalization and following discharge. The participants stated that the intervention programmes they received increased their confidence levels in caring for their premature infants at home. Finally the parents expressed that they were well prepared to cope with the consequences that the delivery of premature babies could bring. This was made possible through the availability of written materials for parents to provide the knowledge that they needed to enable them care for the babies at home. The fear, worries and anxiety exhibited by the mothers in the current study were as a result of lack of knowledge

and skills to equip them care for the babies. To the mothers, it was frightening to see a small baby and try holding it let alone bath the baby. If they were taught and made to handle the babies while on admission would have been skillful enough to care for them at home on discharge. However, mothers are not always allowed at the NICU for infection prevention purpose. Mothers are not allowed to stay long enough at the unit to enable them learn more skills. It is believed that when effective measures are put in place through collaboration with the health care providers and the stakeholders the mothers would be able to acquire enough skills and knowledge on the care of babies before discharge.

5.7 Support

Almost all the mothers who were interviewed received various forms of support from their husbands, in-laws, extended families and friends. This support encouraged them to care for their preterm babies at home. Eight mothers described the socioeconomic and emotional support they received from their husbands. During the interviews, only two mothers expressed how supportive their in-laws were. One mother stated that she did not receive any support from her in-laws. All the nine mothers expressed that the extended families were an immense source of support for them because they received physical, socioeconomic and emotional support from them.

The findings of the current study are in conformity with those of a study done by Sloan et al. (2008) on the stress and coping in fathers following the birth of a preterm infant. In this study, however, fathers were used as participants instead of mothers. The findings showed that fathers used accommodation as coping strategies and made efforts to change situations that seemed stressful. As a result they reported moderate level of stress. In the qualitative aspect of the study, four major sources of support

were identified namely; social, emotional, practical and informative. It was found that families were the major sources of social, emotional and practical support, although friends and partners were also the major source of emotional support. According to the authors there was no follow-up (home visit) by health care providers to assess the level of growth and development in the babies.

In the study by Sloan et al. (2008) partners were the major source of emotional support. Additionally, nurses and doctors were found to be supportive to most of the fathers since they provided them with informational support. Support for fathers appears to be essential since they also share the emotions of their wives, though they do not show them. It is therefore important to involve fathers in psychological counseling where available to reduce their level of stress. The current study showed that most of the husbands were financially burdened since their wives were not working as a result of the care of their preterm babies at home.

CHAPTER SIX

SUMMARY, CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS

This chapter highlights the summary and conclusion of the research work, the key findings and their implications for nursing administration, nursing practice, policy and research. In addition, recommendations based on the findings and limitations that confronted the study have also been presented.

6.0 Summary

In this study, the researcher sought to find out the experiences of mothers caring for preterm babies at home.

The research questions posed warranted the use of a qualitative inquiry. Use of an exploratory descriptive approach enabled the researcher to probe deeply and thus obtain in-depth and rich descriptive data on the experiences of mothers caring for preterm babies following discharge.

The research questions were:

- What are the experiences of mothers caring for preterm babies at home?
- What are the major challenges and coping strategies of mothers with preterm babies?
- What are the information needs of mothers caring for preterm babies at home?

The study was conducted at the Korle-Bu Teaching Hospital, Department of Child Health NICU clinic. The analysis of data yielded six major themes and twenty-five sub-themes all of which were directly related to the topic. The major themes were: care of preterm babies, perceptions of prematurity among mothers and attitudes of significant others, mothers' health and well-being, challenges, support and coping strategies.

Care of preterm babies covered how mothers cared for their preterm babies at home after they were discharged from the Neonatal Intensive Care Unit (NICU) of the Korle-Bu Teaching Hospital. The nine participants described how they cared for their preterm babies at home with respect to feeding, temperature control, infection prevention and observation of the babies.

Perceptions of prematurity among mothers and attitudes of significant others.

Most of the mothers perceived their babies to be abnormal. To them prematurity was an abnormality and as a result they felt embarrassed taking their babies out. The attitudes of significant others such as husbands, in-laws, family members and friends appeared to influence the mothers both positively and negatively and consequently impacted on the care of their preterm babies. Husbands and family members were found to be the major sources of inspiration and encouragement to the mothers during difficult times.

With the **mothers' health and well-being**, all the mothers experienced some form of physical and psychological problems after delivery and during care of their preterm babies. They feared losing their babies and as a result, became anxious. Also, they were deprived of their sleep due to night feeding of the babies. Maintaining personal hygiene was a problem.

The mothers cited numerous **challenges** during the interviews with them. They reported the over arching task of care of preterm babies. Some participants described caring for preterm babies as traumatizing and time consuming. Information needs was one of the challenges encountered by the mothers as it appeared they were not given enough information on care of preterm babies at discharge. Some mothers were not happy with the brief period within which health teaching was done on the ward before discharge while others thought it would have been better if they were

given contact lines to call for more information when the need arose. Others described the hasty manner of health teaching which they soon forgot and said it would have been better if they were given detailed handouts on care of preterm babies.

Socioculturally, the nine mothers did not have any meaningful social lives after the delivery of the preterm babies. They became isolated from social gatherings and other social activities by the constant and tedious care of preterm babies. Parents found it difficult to name their babies because they were too small to be exposed. Due to stigmatization surrounding the birth of preterm babies, they deemed it prudent to name the babies after they had gained weight. Furthermore, the cost of care was described as expensive because all the nine mothers interviewed had stopped working in order to care for their babies; the burden of care had therefore been shifted unto their husbands.

Besides the challenges of mothers, the babies also had their own challenges. Some of the babies could not feed well because their sucking and swallowing reflexes were not well developed. This problem made the mothers anxious since it was through feeding that the babies could gain weight. Finally, the siblings of the preterm babies also had their challenges since they were not given much attention by their mothers. This created emotional problems for the children and in turn caused displeasure to the mothers.

Support was another important theme that emerged from the interviews with mothers with preterm babies. All the mothers received psychological, socioeconomic and physical support from their husbands, in-laws, extended family members and friends. Husbands and family members were the major sources of support to the

mothers. Finally, all the nine mothers developed **coping strategies** that helped them manage the daunting task of caring for their preterm babies at home. The strategies included in-depth understanding of babies' needs and religious beliefs of the mothers.

6.1 Conclusion

Interacting with mothers with lived experiences of caring for preterm babies at home has been an important learning exercise for the researcher. The researcher was interested in gaining in-depth knowledge of the experiences of mothers with preterm babies. The findings of the study showed that mothers who have delivered preterm babies have challenges upon discharge to their homes. The challenges are diverse and enormous. They range from care of the infants to support the mothers require. Mothers need the support of both family and health professionals to enable them cope. The findings of the study must be given attention to help reduce infant morbidity and mortality rate as declared in the millennium development goal to be achieved by 2015. It is suggested that health care providers especially doctors and nurses should give parents adequate information about care of preterm babies at discharge. Follow-up care should be carried out by Public Health Nurses to enable them identify the challenges of care of preterm babies at home for possible solutions. The findings of the research indicate that mothers with preterm babies at home desire more health education and support than they received.

The need for further studies about this important topic is proposed so that effective guidelines to enhance quality of care of preterm babies in general can be developed in health care settings.

6.2 Implications for Nursing

6.2.1 Nursing Administration

The findings of this study have implications for nursing administration. When nurse managers know the strengths and challenges of mothers with preterm babies at home, they can institute measures that would facilitate better care and attention for these mothers. Public Health and Community Health Nurses can be assigned to the homes of the mothers for follow-up care so that their physical and psychological needs could be taken care of adequately. From the findings of the research, it is necessary for nurse managers to have a written protocol for educating mothers with preterm babies on discharge. Counseling rooms or cubicles should be available for mothers and staff of NICU to provide privacy. A proper discharge plan should be instituted and should include well outlined guidelines or information booklets stating how babies should be cared for at home. Furthermore, contact lines of Public Health Nurses can be made available to the mothers where necessary. Finally, in-service training for the staff of NICU and NICU clinic should be organized to equip them to provide quality care to babies and mothers during hospitalization and on discharge.

6.2.2 Nursing Practice

Nurses play an important role in advocating for the patients and their families under their care. In order to achieve the best outcome, nurses must understand the needs of patients and families not only from the health care providers' perspective but also from the perspective of the person going through the experience. From the findings of this study, it is clear that, mothers have not only physical needs but also social and psychological needs. Nurses are in a unique position to assist their patients to meet these needs. Knowledge acquired from the findings when widely disseminated should help practising nurses to appreciate the difficulties and challenges that

mothers go through with their preterm babies at home. This will help them to adopt a better approach to the discharge plan (health education) given to the mothers. The nurses at the Neonatal Intensive Care Unit (NICU) should know the needs of individual mothers and address them through a proper discharge plan. There should be a laid down protocol or a written protocol for educating the mothers with preterm babies who have been discharged from the unit for continuity of care.

The findings of this study can be used to create awareness in health care providers (doctors and nurses) about the demands of care for preterm babies at home. This will evoke insight and empathy on the part of the health professionals. This study on experiences of mothers with preterm babies at home was conducted to sensitize health care providers to the experiences that mothers with preterm babies encounter after they have been discharged home so that they can improve on the quality of care while their babies are on admission and when discharged. Finally, the findings of the study will stimulate the nurses at the NICU clinic to properly hand over the mothers and their babies to Public Health Nurses for continuity of care at home in a well organized follow-up care system in the community as was done in the past.

6.2.3 Policy

The Ministry of Health (MOH) in collaboration with the Korle-Bu Teaching Hospital need to address the issue of increase of preterm birth and low-birth-weight babies in Korle-Bu Teaching Hospital and other health care facilities in the country in order to achieve the Millennium Development Goals (MDG) four (4) by 2015. Additionally, adequate staff should be trained to bridge the gap between the ratio of health care providers to patients. Lastly, the Ghana Health Service (GHS) in collaboration with MOH need to support the implementation of the Kangaroo

Mother Care (KMC) in various health facilities to enhance the survival of low-birth-weight infants.

6.2.4 Future Research

Further studies aiming at investigating the experiences of parents (fathers and mothers) of preterm babies in the intensive care unit and at home would be an important under taking since this area of study has been scarcely researched into.

6.3 Recommendations

The following recommendations were made based on the findings.

- ***Infrastructural Development:*** Considering the fact that counseling of mothers with preterm babies on discharge is private and individualized, there is the need to build more permanent cubicles that can cater for the increasing number of parents for the provision of privacy
- ***Availability of Resources:*** The health care system is faced with inadequate resources and equipment which are needed for effective health care delivery. The findings of this study have provided evidence of lack of proper discharge plan and absence of follow-up care (home visits) at the Korle-Bu Teaching Hospital NICU. It is therefore recommended that the authorities of the hospital liaise with the government and other stake holders such as the Non-Governmental Organizations (NGO) to provide the Community Health Nurses (CHN) and the Public Health Nurses (PHN) with vehicles and other logistics to enable them visit (follow-up) patients and their families for continuity of care which is one of the elements of Primary Health Care.
- ***Follow-up care:*** Follow-up care is one of the important elements of Primary Health Care but it is not practised properly. There is the need to organize the follow-up care by the authorities responsible to enable the nurses identify the

physical, social and psychological concerns of mothers with preterm babies at home and address them.

- **Protocol:** A written protocol for guiding the health teaching and education of mothers on preterm care at home should be developed. This can be in the form of information booklets giving to mothers on discharge as part of the discharge plan to guide them as they care for their preterm babies at home.

- **Health Education of mothers**

Stress management should be discussed as part of the discharge plan through counseling by a qualified Clinical Psychologist in-charge of the unit. This will enable mothers to cope with the stressors and challenges associated with preterm care at home.

- **Mother Support Group:** There is the need for a mother support group to be formed where mothers with similar concerns can deliberate on issues and share ideas to enable them cope with the challenges associated with care of preterm babies at home. As a matter of importance, support groups should be organized in the hospital and mothers should be encouraged to join.

6.4 Limitations of the Study

Even though the study will contribute meaningfully to nursing practice, it has some limitations. The qualitative design permitted the researcher to use small sample size so that data collected could be analyzed conveniently. As a result, the findings cannot be generalized though, the findings were important.

Another limitation was that, some of the mothers could not speak English therefore some the interviews were conducted in “Twi” (Ghanaian traditional) language and later translated by the researcher. It is therefore likely that the true meaning of certain statements made by participants might have changed.

Additionally, once the study was conducted at the NICU clinic of the Department of Child Health of Korle-Bu Teaching Hospital in Accra, where participants were from only one geographical area in Ghana, the findings cannot be generalized to other populations.

Personal experience: The initial stages of the data collection were tough due to the difficulty in recruiting the participants. Most of the mothers initially contacted were not willing to share their experiences because some believed that babies are gifts from God so one needs not discuss the challenges associated with the care of preterm babies at home. Most mothers preferred internalizing the outcomes of preterm delivery than sharing it with others. With more contacts, some willing mothers were identified. The timing for the interviews kept changing since some of the participants were not responding to the telephone calls at the stipulated dates. Finally, the field work was cumbersome because almost all the participants' houses were neither numbered nor were streets names available, therefore, location of houses was difficult.

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APPENDIX A
DEMOGRAPHIC DATA OF PARTICIPANTS

Table 3: DEMOGRAPHIC DATA OF PARTICIPANTS

Name	Age	Marital Status	Number of Children	Education- al level	Religion	Ethnicity	Occupation	Birth weight	Gestation- al Age	Period of Hospital stay
Mother A1	34	Married	3	Tertiary	Christian	Fante	Caterer	1st-1.5kg 2nd-1.2k	34weeks	31days
Mother B1	41	Married	2	Tertiary	Christian	Ga	Business Woman	1.8kg	32weeks	12days
Mother C1	34	Married	2	Tertiary	Christian	Fante	Business Woman	1.5kg	33weeks	21days
Mother D1	34	Married	3	Tertiary	Christian	Akyem	Secretary	1.7kg	33weeks	14days
Mother E1	30	Married	2	Tertiary	Christian	Ga	Secretary	1.5kg	32weeks	29days
Mother F1	35	Married	1	Tertiary	Christian	Akyem	Secretary	1.8kg	33weeks	18days
Mother G1	40	Married	4	Tertiary	Christian	Fante	Petty Trader	1.4kg	32weeks	13days
Mother H1	27	Married	1	Junior High School	Moslem	Ashanti	Dress Maker	1.4kg	32weeks	30days
Mother I1	40	Married	3	Middle School	Christian	Fante	Hair Dresser	2kg	34weeks	4days

APPENDIX B INFORMATION SHEET

Study Title: The Experiences of Mothers Caring for Preterm Babies at home: A study in Accra Metropolis.

Principal investigator: Amanda Hafsa Suraju

Telephone number: 0244713052

I am MPhil Nursing student of the School of Nursing, College of Health Sciences, University of Ghana, Legon and conducting a study and would like you to take part.

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

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

You will be asked to read the interview text to correct errors or to add anything you think is important. The researcher will telephone you the day after each interview to make sure that you are doing well and to offer support if you need it. You are free to opt out of the study at any time if you wish. Your decisions to participate in the study or not will not in any way affect your medical attention at the NICU clinic.

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

Possible Risks and Discomfort: There is no harm involved in this study. If you feel uncomfortable participating at any time during the interview, you are free to opt out without hesitation. Some mothers may feel upset after talking about caring for their infants or break down into tears. If this occurs, support or assistance will be provided through counseling by the researcher.

Possible Benefits: There is no monetary or material reward in taking part of the study.

Talking about one's life with a support nurse can be a positive experience. Mothers may also feel good about being part of a study that is trying to improve quality of care provided to both mothers and babies at the Korle-Bu Teaching Hospital. Finally, the study will unearth other areas for further research and ultimately help improve both the psychological and social dimensions of issues that affect mothers with preterm babies in Ghana.

Compensation: There would be no compensation at the end of the study.

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

Contact for Additional Information

If you have any concerns about this study or about your rights as a research participant, please call the researcher on 233-244713052 /0201459037. OR email: eamandahafsa@yahoo.com.

Your right as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any question about your right as a research participant you can contact the IRB Office between the hours of 8am to 5pm through the landline 03022916438 or email address: nirb@noguchi.mimcom.org or HBaidoo@noguhi.mimcom.org . You may also contact the chairman, Rev. Dr. Ayete-Nyampong through mobile number 0208152360 when necessary.

APPENDIX C**CONSENT FORM**

Study Title: The experience of mothers caring for preterm babies at home: A Study in Accra Metropolis.

Principal Investigator: Amanda Hafsa Suraju, Master of Philosophy in Nursing student of the University of Ghana, Legon.

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

Supervisor 1: Dr Patience Aniteye

Supervisor 2: Dr Victoria May Adebayere

Consent: Please circle the appropriate answers

Do you understand that you have been asked to take part in this study?	Yes	No
Have you been given a copy of the information sheet?	Yes	No
Do you understand the information on the information sheet?	Yes	No
Has the benefits and the risks in participation been explained to you?	Yes	No
Are you aware that you are free to withdraw from this study at any given time?	Yes	No
Are you aware that your withdrawal will not affect the medical services you receive at NICU clinic?	Yes	No
Has the issue of confidentiality explained to you?	Yes	No
Have you had the opportunity to ask questions and discuss the study?	Yes	No
Do you consent to the interview being audio-taped?	Yes	No

Do you agree that this information can be used in future research? Yes No

I agree to participate as a volunteer.

.....

Date

Name and signature or mark of volunteer

If volunteer 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.

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 and signature of Person who obtained Consent

APPENDIX D**CONFIRMATION OF INFORMATION SHEET AND INFORM CONSENT**

Do you understand that you have been asked to take part in this study?

Have you been given a copy of the information sheet?

Do you understand the information on the information sheet?

Has the benefits and the risks in participation been explained to you?

Are you aware that you are free to withdraw from this study at any given time?

Are you aware that your withdrawal will not affect the medical services you receive at clinic?

Has the issue of confidentiality explained to you?

Have you had the opportunity to ask questions and discuss the study?

Do you consent to the interview being audio-taped?

Do you agree that this information can be used in future research?

APPENDIX E**INTERVIEW GUIDE**

Section A (demographical data)

1. Age
2. Marital status: married / cohabitation.
3. Number of Children
4. Educational level
5. Occupation
6. Religion
7. Ethnicity
8. Birth weight of baby
9. Gestational age
10. Length of hospital stay:

Section (B)

1. Please tell me about your experiences in caring for a preterm/premature baby at home.
 - What has it been like managing/premature preterm baby at home?
 - Tell me how you ensure warmth in the baby.
 - Tell me how you feed your baby.
 - What type of feed do you give your baby?
 - How do you prevent infection in the baby?
 - How do you generally care for the baby?
 - How long does it take you in caring for the baby on daily basis?

2. What has this experience been like for the family? What has been most challenging or difficult for you?
 - How has having and caring for a preterm baby at home affected your other children? Your spouse/ partner? Your extended family? Your role as a mother?
3. Are there any problems associated with caring for your baby?
 - Hospital visiting cost?
 - Loss of work?
 - Help with housework?
 - Changes in work and work productivity? (Lost employment, reduce working hours, loss of opportunity to progress).
 - Changes in your health status?
 - Leisure time activities?
 - Feelings of apprehension, anxiety, grief, loss of wellbeing, social isolation, family conflict?
4. How do you cope with your preterm/premature baby at home?
 - Do you get any help from family and friends?
5. Tell me how the nurses and the Doctors prepared you for the care of the baby at home.
 - Time to report for review.
 - What information were you given regarding; temperature control, provision of warmth, feeding, care of the fontanel, immunization, handling and the general care of the baby?

APPENDIX F
INTRODUCTORY LETTER

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

Telephone: 021-513255 (Dean)
 Ext. 6206
 021-513250 } Secretary
 028 9531213 }
Fax: 513255
E-mail: nursing@ug.edu.gh



P. O. Box LG 43
LEGON, GHANA

Our Ref:.....

Your Ref:.....

January 17, 2012

The Chief Executive Officer i/c,
Korle-Bu Teaching Hospital,
Accra

Dear Sir/Madam,

APPLICATION FOR SITE APPROVAL TO CONDUCT A RESEARCH STUDY

Title of the Project: The Experiences of Mothers Caring for Preterm Babies at Home: A Study in Accra
Metropolis

Researcher: Suraju Amanda Hafsa (MPhil Student)

This letter is to request your permission and assistance for practical attachment in the Department of Child Health for data collection in a research project on the Experiences of Mothers Caring for Preterm Babies at Home. An M'Phil research student at the School of Nursing, College of Health Sciences, University of Ghana, Legon will conduct the research.

Ethical Clearance has been obtained from the University of Ghana Medical School, Ethical and Protocol Review Committee.

The participants will be Mothers Caring for Preterm Babies at Home who attend clinic and counselling services at the Department of Child Health. Data collection will involve interviews with the Mothers Caring for Preterm Babies at Home at the Department of Child Health of the Korle-Bu Teaching Hospital

I kindly request your assistance in helping the researcher to access the mothers and if required, providing her with the necessary assistance. Attached is a copy of the Consent form and approval letter from the Ethical and Protocol Review Committee.

Thanks for your prompt consideration on this matter.

Yours faithfully,

Dr. Prudence P. Mwini Nyaledzigbur
Lecturer

Cc: The Director of Nursing Service, Korle-Bu
The DDNS i/c, Dept. of Child Health, Korle-Bu
The DDNS i/c, NICU, Korle-Bu

APPENDIX G

ETHICAL CLEARANCE

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979 *A Constituent of the College of Health Sciences*
University of Ghana

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 +233-289-522574
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 E-mail: nirb@noguchi.nimimr.ug
 Telex No. 2556 UGL GH

INSTITUTIONAL REVIEW BOARD



Post Office Box LG 561
 Legon, Accra
 Ghana

My Ref. No. DF 23
 Your Ref. No.

30th November, 2011

ETHICAL CLEARANCE

FEDERAL WIDE ASSURANCE FWA 00001824

IRB 00001276

NMIMR-IRB CPN 041/11-12

IORG 0000908

On 30th November, 2011, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) conducted expedited review and approved your protocol titled:

TITLE OF PROTOCOL : The Experiences of Mothers Caring for Preterm Babies at Home: A Study in Accra Metropolis

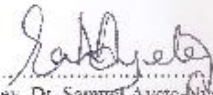
PRINCIPAL INVESTIGATOR : Saraju Amanda Halsa (MPhil Student)

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 1st December, 2012. You are to submit annual reports for continuing review.

Signature of Chairman: 
 Rev. Dr. Samuel Ayete-Nyampong
 (NMIMR – IRB, Chairman)

cc: Professor Alexander K. Nyarko
 Director, Noguchi Memorial Institute
 for Medical Research, University of Ghana, Legon