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THE LIVED EXPERIENCES OF MOTHERS REGARDING CARE OF THEIR HOSPITALISED PRETERM BABIES

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DECLARATION

I, Rosinah K. Ncube, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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DEFINITION OF TERMS

• Care
  Carrying out routine practices such as changing the baby’s nappy, sponging the baby’s body, feeding the baby (Lupton & Fenwick, 2001) as well as interacting with the baby.

• Preterm baby
  Babies born before 37 completed weeks of pregnancy or with fewer than 259 days, also referred to as premature babies (Valero de Bernabe, Soriano, Albeladejo, Juarranz, Calle, Martinez & Dominguez-Rojas, 2004).

• Phenomenology
  “Is an umbrella term encompassing both philosophical movement and a range of research approaches. In general, phenomenology is the study of phenomena, their nature and meanings. The focus is on the way things appear to us through experience or in our consciousness. The phenomenological researcher aims to provide a rich textured description of ‘lived experience’” (Finlay & Ballinger, 2006:263).

• Experience
  “Encounter, know, endure, and suffer. Undergo refer to encountering situations, conditions etc. in life or to having certain sensations or feelings. Experience implies being affected by what one meets with”.
  (http://www.dictionary.reference.com/browse/experience)

• Kangaroo mother care
  “Kangaroo is derived from the practices similar to those of the marsupial care, in which the baby is kept warm in the maternal pouch close to the breasts for unlimited feeding.
Kangaroo care is defined as skin-to-skin contact between a mother and her low birth weight (LBW) infant in a hospital setting. The term Kangaroo mother care (KMC) was adopted during the first International workshop on Kangaroo Care in Trieste” (Kirsten, Bergman & Hann, 2001:443).

- **Baby-Friendly Hospital Initiative**


- **Stillbirth rate**

  Late foetal deaths after 24 weeks of gestation, as expressed per 1000 live and stillbirths (Cartlige & Steward, 1995).

- **Perinatal mortality rate**

  “The number of stillbirths and deaths in the first week of life per 1000 live births.” (WHO, 2006b:13).

- **Early neonatal mortality rate**

  Deaths occurring within the first week of life as expressed per 1000 live births (WHO, 2005).

- **Late neonatal mortality rate**

  Deaths occurring after the first week but before 28 completed days of life (WHO, 2005).
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>BFHI</td>
<td>Baby-Friendly Hospital Initiative</td>
</tr>
<tr>
<td>KMC</td>
<td>Kangaroo mother care</td>
</tr>
<tr>
<td>SCBU</td>
<td>Special care baby unit</td>
</tr>
<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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<tr>
<td>NICU</td>
<td>Neonatal intensive care unit</td>
</tr>
<tr>
<td>LBW</td>
<td>Low birth weight</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
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ABSTRACT

INTRODUCTION AND BACKGROUND

Trends in neonatal care aim to minimise separation of the baby from the mother, as shown by initiatives such as Kangaroo mother care, the Baby-Friendly Hospital Initiative and the Humane Neonatal Care Initiative. These were developed in an effort to promote the well-being of both the mother and the baby, with proven positive effects on reduction of neonatal mortality and maternal health benefits. The maternal benefits include parental sense of fulfilment and confidence in caring for the baby (Ruiz-Pelaez, Charpak & Cuervo, 2004) and reduction in breast and ovarian cancer (UNICEF, 2010).

Most preterm babies are born with low birthweight (LBW), and are often admitted to the neonatal unit for provision of warmth and technological support (Tilokskulchai, Phattanasiriwethin, Vitchitsokun & Serisathien, 2002). This leads to separation of babies from their mothers, which may delay the attachment process and be painful for the parents since it increases their anxiety and fear (Hall, 2005).

AIM OF THE STUDY

The aim of this study was to explore and describe the lived experiences of mothers regarding care of their hospitalised preterm babies.

METHODOLOGY

Research design

A qualitative, explorative design which is contextual in nature was utilised to conduct the study in a phenomenological approach. In-depth interviews were conducted twice with eight mothers of hospitalised preterm babies.

Setting

The study was conducted in the Special Care Baby Unit of Princess Marina Hospital, a Government referral hospital in the capital city of Gaborone, Botswana.
DATA ANALYSIS

The interviews were transcribed verbatim and the data were analysed according to the steps for analysing phenomenological transcriptions as described by Colaizzi (1978:59-61) and Hycner (1985:280-294). Trustworthiness was ensured according to the criteria described by Guba and Lincoln (1989).

FINDINGS

Mothers were shocked by the delivery of a preterm baby, since they did not expect to deliver ‘too soon’. The neonatal environment increased the mothers’ fear and anxiety and delayed development of a relationship between mothers and their babies. Support from staff, other mothers in the neonatal unit and family members enabled the mothers to overcome their fear and eventually to develop an emotional connection with their babies since they could cope with their difficulties and challenges.

IMPLICATIONS OF THE STUDY

The findings of this study demonstrate that there is a need for adequate staff support of mothers while providing care to their preterm babies. The quality of care provided to mothers and their preterm babies could be improved by ongoing communication with the mothers while in the neonatal unit, since this promotes their confidence and competence. This in turn enables positive interactions between mothers and their babies and promotes mother-infant attachment.

KEY WORDS:
Lived experience, mothers, care, preterm infant, neonatal unit
ACKNOWLEDGEMENTS

This study would have not been achieved without the Power of God Almighty who strengthened me even when things seemed bleak. Indeed nothing is impossible with Him.

Thanks to my family, who have been supportive throughout my study period. I would like to extend my sincere gratitude to my husband Moses, who supported me by encouraging me, taking care of our son and ensuring that our house was well taken care of in my absence; our son Obakeng, who was courageous although deprived of the love of a mother for the period that I was away from home; and my sister, Mrs Magowe, who was patient enough to assist us with the care of our son.

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# TABLE OF CONTENTS

**DECLARATION** .............................................................................................................................................. I

**DEFINITION OF TERMS** ................................................................................................................................ II

**ABBREVIATIONS** ....................................................................................................................................... IV

**ABSTRACT** .................................................................................................................................................. V

**KEY WORDS:** ............................................................................................................................................. VI

**ACKNOWLEDGEMENTS** ............................................................................................................................ VII

**CHAPTER 1: INTRODUCTION** ...................................................................................................................... 1

1.1 INTRODUCTION AND BACKGROUND ....................................................................................................... 1

1.2 GLOBAL INITIATIVES ................................................................................................................................ 4
  1.2.1 Kangaroo mother care .................................................................................................................... 4
  1.2.2 The Baby-Friendly Hospital Initiative ......................................................................................... 5
  1.2.3 Humane Neonatal Care Initiative ............................................................................................... 6

1.3 BACKGROUND TO THE STUDY ................................................................................................................. 6

1.4 PROBLEM STATEMENT ............................................................................................................................ 7

1.5 RESEARCH AIM ........................................................................................................................................ 8

1.6 RESEARCH OBJECTIVES ........................................................................................................................ 9

1.7 RESEARCH QUESTION .......................................................................................................................... 9

1.8 CONCLUSION ........................................................................................................................................... 9

**CHAPTER 2: REVIEW OF THE LITERATURE** ................................................................................................. 11

2.1 INTRODUCTION ..................................................................................................................................... 11

2.2 HISTORICAL OVERVIEW OF NEONATAL CARE ................................................................................... 11

2.3 TRENDS IN NEONATAL CARE .............................................................................................................. 13
  2.3.1 KMC ................................................................................................................................................. 14
    2.3.1.1 Cost savings .......................................................................................................................... 16
    2.3.1.2 Other benefits of KMC .......................................................................................... 16
  2.3.2 The Baby-Friendly Hospital Initiative ......................................................................................... 17
  2.3.3 The Humane Neonatal Care Initiative ........................................................................................... 24

2.4 THEMES ARISING FROM THE REVIEW .................................................................................................. 26
  2.4.1 Struggling to mother ....................................................................................................................... 26
  2.4.2 Neonatal environment ..................................................................................................................... 27
  2.4.3 Mother’s role-claiming strategies .............................................................................................. 27
  2.4.4 The role of breastfeeding ............................................................................................................. 28
  2.4.5 Establishing connections and forming relationships with their baby ......................................... 28
2.4.6 Support systems for the mother of a preterm infant .............................................................. 29
  2.4.6.1 Support from nursing and medical staff ........................................................................... 29

2.5 CONCLUSION .......................................................................................................................... 30

CHAPTER 3: RESEARCH METHODOLOGY .................................................................................... 31

3.1 INTRODUCTION ........................................................................................................................ 31

3.2 CHOICE OF QUALITATIVE DESIGN ...................................................................................... 31

3.3 HISTORICAL OVERVIEW OF PHENOMENOLOGY .................................................................. 32
  3.3.1 Preparatory phase ............................................................................................................... 32
  3.3.2 German phase .................................................................................................................... 33
  3.3.3 French phase ...................................................................................................................... 34

3.4 SCHOOLS OF PHENOMENOLOGY ......................................................................................... 35
  3.4.1 The Duquesne school ........................................................................................................ 35
  3.4.2 The interpretation of phenomena - Heideggerian hermeneutics ......................................... 36
  3.4.3 The Dutch school .............................................................................................................. 36

3.5 DESCRIPTIVE PHENOMENOLOGY ....................................................................................... 37

3.6 STEPS OF DESCRIPTIVE PHENOMENOLOGY ..................................................................... 39
  3.6.1 Phenomenological reduction (bracketing) ........................................................................ 39
  3.6.2 Intuiting ............................................................................................................................ 39
  3.6.3 Analysis phase .................................................................................................................. 40
  3.6.4 Descriptive phase ............................................................................................................ 40

3.7 RESEARCH PROCESS ................................................................................................................. 40
  3.7.1 Study population .............................................................................................................. 40
  3.7.2 Sampling and sample size ............................................................................................... 41
  3.7.3 Choice of participants ..................................................................................................... 42
    3.7.3.1 Gaining access to the organisation ........................................................................... 42
    3.7.3.2 Gaining access to the participants ........................................................................... 42
  3.7.4 Setting ............................................................................................................................. 42

3.8 ETHICAL CONSIDERATIONS ................................................................................................. 43
  3.8.1 Ethical approval ............................................................................................................... 43
  3.8.2 Informed consent ............................................................................................................ 43
  3.8.3 Use of transcribing equipment ......................................................................................... 44
  3.8.4 Researcher-participant relationship ............................................................................... 44
  3.8.5 Management of sensitive information and need for support ......................................... 44

3.9 PILOT STUDY ............................................................................................................................ 45

3.10 DATA COLLECTION ................................................................................................................. 46
  3.10.1 Qualitative research interview setting ............................................................................... 46
  3.10.2 Preparation of the researcher ......................................................................................... 46
3.10.3 The researcher as instrument ................................................................. 46
3.10.4 In-depth interviews ............................................................................. 47
3.10.5 Developing rapport ............................................................................... 48
3.10.6 Stages of rapport between the interviewer and interviewee ...... 48
  3.10.6.1 Apprehension ............................................................................ 48
  3.10.6.2 Exploration ............................................................................... 48
  3.10.6.3 Cooperation ............................................................................... 48
  3.10.6.4 Participation ............................................................................... 49
3.10.7 Unstructured observation ................................................................. 49
3.10.8 Formulating the question .................................................................. 49
3.11 THE SCIENTIFIC RIGOUR OF THE STUDY ........................................ 49
  3.11.1 Credibility ..................................................................................... 50
  3.11.2 Transferability ............................................................................... 50
  3.11.3 Dependability ................................................................................ 50
  3.11.4 Confirmability ................................................................................ 51
3.12 TRANSCRIPTION OF DATA ................................................................. 51
3.13 PREPARATION OF DATA FOR ANALYSIS ..................................... 51
3.14 DATA ANALYSIS ............................................................................... 52
  3.14.1 Introduction ................................................................................... 52
  3.14.2 Stages of analysis .......................................................................... 53
    3.14.2.1 Stage one: Interview transcripts .............................................. 53
    3.14.2.2 Stage two: Delineating units of general meaning ..................... 53
    3.14.2.3 Stage three: Extracting units of relevant meaning ..................... 53
    3.14.2.4 Stage four: Clustering units of relevant meaning and/or formulating categories. 53
    3.14.2.5 Stage five: Determining central themes from clusters of meaning 54
    3.14.2.6 Stage six: Description of themes ........................................... 54
3.15 CONCLUSION ...................................................................................... 54

CHAPTER 4: PRESENTATION OF FINDINGS ........................................... 56
  4.1 INTRODUCTION ................................................................................... 56
  4.2 THEMES THAT EMERGED ................................................................. 57
    4.2.1 A life uncertain - my baby’s vulnerability ...................................... 58
    4.2.2 An unfamiliar and intimidating environment ............................. 62
    4.2.3 Experiences of interaction with medical and nursing staff .......... 65
      4.2.3.1 Positive interactions with medical and nursing staff ................. 65
      4.2.3.2 Negative interactions with medical and nursing staff .............. 69
    4.2.4 Overcoming fear: Emotional connection ...................................... 73
4.2.5 Enabling support network ............................................................................................................. 76
4.3 CONCLUSION ....................................................................................................................................... 79

CHAPTER 5: DISCUSSION OF FINDINGS, RECOMMENDATIONS AND CONCLUSION ...................... 80

5.1 INTRODUCTION ..................................................................................................................................... 80
5.1.1 A life uncertain - my baby’s vulnerability .................................................................................. 80
5.1.2 An unfamiliar and intimidating environment .............................................................................. 83
5.1.3 Experiences of interaction with medical and nursing staff ...................................................... 86
5.1.4 Overcoming fear: Emotional connections ................................................................................. 91
5.1.5 Enabling support network ........................................................................................................... 95
5.2 THE NEED FOR KNOWLEDGE ......................................................................................................... 97
5.3 IMPLICATIONS OF THE STUDY ....................................................................................................... 98
5.3.1 Implications for mothers of a preterm baby ............................................................................. 98
5.3.2 Implications for staff working in neonatal units ........................................................................ 98
5.4 LIMITATIONS OF THE STUDY ......................................................................................................... 99
5.5 RECOMMENDATIONS .......................................................................................................................... 100
5.5.1 Need for future research ............................................................................................................ 100
5.5.2 Mothers of preterm babies ........................................................................................................ 101
5.5.3 Managers and health professionals providing neonatal care ................................................. 101
5.5.4 Health training institutions ...................................................................................................... 103
5.5.5 The health system ...................................................................................................................... 103
5.6 CONCLUSION ....................................................................................................................................... 104

REFERENCES ............................................................................................................................................. 106

APPENDICES ............................................................................................................................................ 122

APPENDIX A: INFORMATION SHEET FOR PARTICIPANTS ................................................................. 122
APPENDIX B: CONSENT FORM FOR CONDUCTING THE STUDY ..................................................... 123
APPENDIX C: ETHICS APPROVAL LETTER ......................................................................................... 125
APPENDIX D: INTERVIEW SCHEDULE ................................................................................................. 127
APPENDIX E: TRANSCRIBED INTERVIEW .......................................................................................... 128
APPENDIX F: EXAMPLE OF ANALYSIS ............................................................................................. 136
APPENDIX G: LETTER TO CONFIRM REPRESENTATION OF TRANSCRIPTIONS ............................ 171
APPENDIX H: CATEGORIES AND THEMES EMERGING FROM THE DATA ..................................... 172
CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION AND BACKGROUND

Every year more than five million neonates die worldwide, most in developing countries where neonatal mortality is responsible for 50-70% of the infant mortality rate (Klingenberg, Olomi, Oneko, Sam & Langeland, 2003:293). According to Paul (2006:7), about 60-80% of neonatal deaths occur among low birthweight (LBW) infants and the mortality risk is higher among preterm babies. An LBW baby is defined as a “baby with a weight less than 2500 grams due to intra-uterine growth retardation or preterm birth or both” (Klingenberg et al., 2003:293). A preterm baby, often referred to as a premature baby, is a baby born before 37 completed weeks or at less than 259 days of gestation (Valero de Bernabe et al., 2004; Leonard & Mayers, 2008).

LBW is a problem worldwide since it is associated with high neonatal infant mortality and morbidity rates. LBW is found in approximately 10% of all live births and 50% of all neonatal deaths in developing countries. Morbidity associated with 5-10% of LBW infants results in neonatal complications including intraventricular haemorrhage, hypoglycaemia, leukomalacia and neonatal seizures (Tessier et al., 2003).

The risk of death in the neonatal period is six times greater in developing countries than in developed ones (WHO, 2006b). In Africa the risk of neonatal death is highest, with an average of 41 neonatal deaths per 1000 live births. The highest risk occurs in the sub-Saharan regions of western, middle and eastern Africa, which have between 42 and 49 neonatal deaths per 1000 live births. The neonatal mortality rate for Latin America and the Caribbean is 15 per 1000, ranging from 14 per 1000 live births in South America to 19 per 1000 live births in the Caribbean (WHO, 2006b). In sub-Saharan Africa the prevalence of human immunodeficiency virus (HIV) infection is high, and babies of women with advanced-stage HIV are at increased risk of LBW, preterm delivery and intra-uterine growth restriction (Klingenberg et al., 2003).

LBW preterm babies are often incapable of stabilising their body temperature on their own since they lack brown fat. This predisposes them to hypothermia; therefore they must be cared for in an environment that keeps them warm (Cinar & Filiz, 2006). The environment in the neonatal unit is warm and incubator temperatures are set according to the baby’s weight. They are vulnerable to many complications, such as respiratory problems because they lack surfactant which lowers the surface tension in the alveoli and prevents total collapse of the alveoli on expiration, neonatal
jaundice, patent ductus arteriosus, feeding problems and neonatal infections (Lau, 2001; Perinatal Education Programme, 2009). Preterm infants are therefore separated from their mothers since they are often unable to survive on their own and need to be assisted technologically in the neonatal care unit (Tilokskulchai et al., 2002).

Lupton and Fenwick (2001) argued that research studies into motherhood demonstrated certain ideas of what is regarded as a good mother. Good mothers are expected to bond with their children and always be there for them (Lupton & Fenwick, 2001). They are expected to consider their infant’s needs more than their own and to be able to cope with loss of sleep, have less time for themselves and perform other activities that involve caring for a baby (Lupton & Fenwick, 2001). According to Lupton and Fenwick (2001) these ideas refer to healthy babies who do not require admission in the hospital after birth.

Mothers who have delivered premature babies find difficulty in bonding with their babies in the first few days after the birth because they are separated from their babies, who are admitted to the neonatal unit (Tilokskulchai et al., 2002). Separation from a child is painful for the parents since it increases their anxiety and fear (Hall, 2005). Mothers are not yet ready for motherhood when they deliver a preterm baby, and caring for a delicate baby is stressful and may even affect the mother’s ability to care for her baby (Aagaard & Hall, 2008).

The involvement of mothers in the care of their babies while they are admitted to the neonatal unit is thought to improve mother-baby attachment and moderate psychological distress (Erlandsson & Fagerberg, 2005). Neonatal nurses are therefore faced with the challenge of providing the best developmental care for preterm infants, and are also expected to assist the mother through an unexpected start to motherhood and towards feelings of being a real mother to her preterm baby (Aagaard & Hall, 2008).

Mothers who respond to the needs of their babies develop a relationship with the baby and are able to develop secure attachment (Karl, Beal, O’Hare & Rissmiller, 2006). Schenk, Kelley and Schenk (2005:515) describe attachment as “an interactional process that seems to flow in one direction, beginning with acquaintance and moving over time toward attachment. Attachment behaviours are characterised by ‘proximity’, or seeking and keeping the infant close, by the reciprocity of verbal and nonverbal communication and by the development of positive/love feelings and commitment”. The relationship between the mother and the baby affects the child’s physical and mental development (Tilokskulchai et al., 2002). An immediate attachment process is reported to occur if the mother has positive feelings towards the infant at birth. It involves
wanting the baby, seeing the baby at birth or soon after and having physical contact with the baby at birth. Maternal factors that can hinder attachment include a traumatic birth experience, poor maternal health, lack of social support, father not taking part in the baby’s care, having children at home while in hospital, being dependant on drugs, and high stress levels (Schenk, Kelley & Schenk, 2005).

In their study on attachment behaviours in mothers of premature babies, Tilokskulchai et al. (2002) found that mothers of LBW infants experienced a higher incidence of psychological distress during the neonatal period as a result of their infants’ prematurity. Some mothers were afraid of touching their infants, thinking that they would infect or harm them, while others demonstrated emotional conflict such as being happy to see the baby and also sorry because the baby was too small. There were, however, individual differences in maternal attachment behaviours towards their infants when the following were observed: touch, inspection, facial expression and verbalisation. These women were reported to be less confident in their role as parents because they had to deal with infants who were not easy to care for since they were sick and were born before the expected date. Consequently, the bonding of these mothers and their babies may be affected (Tilokskulchai et al., 2002).

Mothers therefore need to be supported in order to cope with these difficulties to facilitate bonding with the baby. Nurses who take time to build a relationship with the mother and try to understand what she is going through will develop a trusting relationship with her and will become aware of her need for information and support. If the staff in the neonatal unit are willing to get to know the mother, they are able to support the mother emotionally which helps her to feel welcome in the unfamiliar environment of the neonatal unit. This supports the mother in her role change (Baker & McGrath, 2009). The mother has to be supported in learning her maternal role in order to develop confidence in caring for her infant. Care that enhances a trusting relationship between the mother and the nurses helps the mother to gain confidence and also helps in her role change. The long-term outcomes of the infant are influenced by the support that the mother receives in developing her maternal role. Mothers who are confident in taking care of their babies are sensitive to their baby’s needs and are in a position to raise healthy children (Baker & McGrath, 2009).
1.2 GLOBAL INITIATIVES

Globally, several initiatives have been developed in an attempt to prevent separation of mother and baby and to promote the well-being of neonates and assist maternal coping and competence in the care of their baby. Initiatives that were developed include kangaroo mother care (KMC), the Baby-Friendly Hospital Initiative (BFHI) and the Humane Neonatal Care Initiative.

1.2.1 Kangaroo mother care

According to Nyqvist et al. (2010:820), KMC is defined as a “standardised protocol based care system for preterm and LBW infants and is based on skin-to-skin contact between the preterm baby and the mother”. The baby is placed in skin-to-skin contact in an upright position, on the mother’s chest with both flexed arms and legs and the head turned to the side and secured so that the baby does not fall out of the kangaroo position (Nyqvist et al., 2010). KMC is used in health care institutions where equipment and human resources are available and are of an acceptable quality but are not adequate enough to cater for demand. It may also be used as an alternative to the use of incubators (Kirsten, Bergman & Hann, 2001), and has been reported as reducing the pain response to heel lance in full term and moderately preterm infants (Johnston et al., 2008).

Various studies found that one of the effects of KMC is prolonged duration of breastfeeding, stability of breast milk production, and increase in the number of feeds per day. KMC increases the level of competence of mothers, especially when started early. Mothers prefer skin-to-skin contact because it allows infants to be close to them and this makes them feel more at ease, fulfilled and satisfied than when their baby is cared for in an incubator (Kirsten, Bergman & Hann, 2001). Roller (2005:210) stated that “early interruption in the acquaintance process combined with concern about the newborn survival and long term prognosis can interfere with the maternal-infant attachment process”. KMC permits the mother to hold her preterm baby and this has a positive effect on maternal confidence; mothers are ready to take their infants home earlier than those who do not practice it (Roller, 2005).

According to Affonso, Brosque, Wahlberg and Brady (1993), as cited in Roller (2005), KMC was found to promote maternal-infant attachment and helped mothers to develop their identity in the role when they practised KMC in a tertiary-level intensive care nursery in the United States of America (USA). KMC was also found to be a “warm, calming, positive and bonding experience for mothers who delivered preterm babies as it calmed their jittery babies” (Roller, 2005:215).
The Baby-Friendly Hospital Initiative

The BFHI was developed by UNICEF and the WHO in order to protect, promote and support breastfeeding. Breastfeeding is important for the health of the mother and the baby. Breastfed infants have fewer episodes of gastro-intestinal disease, respiratory diseases, acute otitis media and urinary tract infections (Naylor, 2001). In the ten steps of successful breastfeeding, step four states that mothers should be assisted to initiate breastfeeding within one hour after the birth of the baby. Breastfeeding provides nipple stimulation provided by suckling, which increases maternal oxytocin levels, causing uterine contractions and decreasing postpartum bleeding. The elevated oxytocin level also contributes to the enhancement of maternal feelings and has a role in the bonding or attachment process (Naylor, 2001; UNICEF, 2010).

Step seven advocates the practice of rooming-in, allowing mothers and infants to remain together for 24 hours a day. If the mother and baby are together, the mother’s response to indications of readiness for feeding of the infant is quick. A quick response to an infant’s need promotes the infant’s sense of security and helps the secretion of milk as it stimulates the let-down reflex. It also helps mothers to become familiar with the “unique behavioural characteristics of their infants and allows infants to become familiar with the visual, auditory, olfactory and tactile stimuli of mothers” (Naylor, 2001:482). This promotes the attachment process between mothers and their infants (Naylor, 2001).

BFHI has been a successful strategy since it has benefits both for the mother and the baby. It promotes rooming-in and promotes mothers’ sensitivity to their babies’ needs as they are with their babies all the time. Mothers who breastfeed recover faster from childbirth and are less likely to suffer from postpartum haemorrhage and breast cancer (Department of Health of South Africa, 2010; UNICEF, 2010).

Preterm babies are nursed in incubators and often require interventions such as intravenous lines and nasogastric tubes, which are new to the mother. These create a barrier between the mother and the baby and may delay bonding. The mother who is new to the neonatal unit may be afraid of the equipment and take time to adjust to the environment. If the mother spends most of her time with the baby, with explanations of the equipment to the mother and involving the mother in decision-making concerning her baby’s care, this will help her to adapt more easily to the environment and become attached to her preterm baby (Aagaard & Hall, 2008; Lee, Long & Boore, 2009).
1.2.3 Humane Neonatal Care Initiative
The Humane Neonatal Care Initiative developed by Levin (1999) states that in order to improve the psychological and medical care in neonatal units for sick newborns, mothers and their babies should stay together for 24 hours a day. Staff members who are taking care of the baby should be able to take care of the mother and should meet the mother’s psychological needs. The mother and the infant should be considered as a closed ‘psychosomatic system’ which cannot be separated. Everyday ward rounds should concentrate on the needs of both the infants and mothers (including, for example, an obstetrician and other specialists as appropriate).

The initiative advocates for rooming-in, which could be beneficial to preterm babies and their mothers who are usually separated from each other as the vulnerable infant is admitted to a high technological unit while the mother is admitted to a separate unit. The initiative advocates for healthy family members, for instance father, grandparents and/or helpers, to be allowed to visit the mother and baby during a prolonged stay in hospital. Levin (1999) suggested that allowing relatives into the neonatal unit will serve as a source of support for the mother, who is separated from her family while in hospital with her infant. The family will also have an opportunity to get to know the baby and establish a relationship with him/her while in hospital (Levin, 1999).

1.3 BACKGROUND TO THE STUDY
Botswana’s National Census (2001) (latest available) reported that the total population of Botswana was 1,680,863. The crude birth rate per 1000 was 28.9 whereas the infant mortality rate per 1000 live births was 56. The under-five mortality rate in Botswana has increased over the past years according to WHO (2006a) statistics. In 1980 the under-five mortality rate was 84 per 1000 live births; in 1990 it decreased to 58/1000 live births, whereas in 2000 it increased to 101/1000 live births; by 2004 this increased to 116/1000 live births. Botswana is faced with the challenge of reducing infant mortality in order to achieve Millennium Development Goal four, which aims to reduce child mortality by two-thirds by the year 2015.

According to Mogobe, Tshiamo and Bowelo (2007), routine health statistics showed that in 2004 there were 36,000 live births and 600 neonatal deaths in Botswana. This translated to a national mortality rate of 16.6 neonatal deaths per 1000 live births. The proportion of neonatal deaths differed for each facility, with a range of 21 to 56 deaths per 1000 live births (Mogobe, Tshiamo & Bowelo, 2007). The facility that recorded the highest number of neonatal deaths was a referral hospital. Of the 36,000 live births in 2004, 4668 or 13% weighed less than 2500gm (i.e. were in
the LBW category). In 2008 the neonatal mortality rate was 16/1000 live births whereas the infant mortality rate was 26/1000 live births (WHO, 2010). According to the WHO (2010) the causes of neonatal mortality in Botswana were presented as follows: preterm - 42%; asphyxia - 19%; infection - 18%; congenital - 13%; tetanus - 1%; diarrhoea - 0%; and other - 7%.

1.4 PROBLEM STATEMENT

Princess Marina Hospital is a Government referral hospital in Botswana’s capital city of Gaborone, with specialist doctors including obstetricians, gynaecologists and paediatricians. Women from clinics, primary hospitals and district hospitals in the southern part of the country are referred to this institution for further management if they have complicated pregnancies.

The researcher, who is teaching in the Diploma in Midwifery programme and often accompanies students on clinical practice in this institution, has observed that the common causes of preterm birth in the institution are pre-eclampsia, antepartum haemorrhage and HIV/AIDS. The HIV/AIDS rate is reported to be 23.9% among the adult population aged 15-49 years, although women aged 15 years or more comprise 60.7% of the total population of adults of that age with HIV infection (Population Reference Bureau, 2007). A study of risk factors for very premature and very small for gestational age infants in Botswana by Parekh et al. (2011) highlighted high blood pressure, HIV infection and a history of poor obstetric outcome.

Mothers who deliver a preterm baby in Princess Marina Hospital are hospitalised with their babies, but in separate units. The babies are admitted to the hospital’s special care baby unit (SCBU) for technological support and the mothers are admitted to the postnatal ward. The researcher’s assumption is that since the hospital has been declared as baby friendly, rooming in should be practised, including as far as possible for preterm infants. Where this is not possible, free access to the neonatal units should be encouraged. The evidence for the positive effects of the baby friendly hospital initiative has been outlined above. Separation can affect the attachment process between mother and baby (Lee, Long & Boore, 2009; Schenk, Kelley & Schenk, 2005; Tilokskulchai et al., 2002), especially if the mother is sick and not able to visit the neonatal unit to interact with her baby.

Mothers at Princess Marina Hospital are only allowed limited involvement in the care of their babies: they are able to be with the baby every three hours when they may feed, change their nappies and interact with them. Mothers then return to the postnatal ward in order to allow the nurses to carry out their nursing duties. The researcher has observed that the psychological needs
of mothers of preterm babies are not adequately attended to, since nurses in the SCBU are often very busy and mothers do not stay in the unit long enough to ask questions. The availability of nurses to answer mothers’ questions is also limited. On a recent visit to the neonatal unit it was also noted that there was a personnel shortage. Nurses in Botswana leave Government institutions for alternative employment, as has also been reported in other countries. Many nurses work for periods overseas, which affects the availability of personnel. According to the Ministry of Finance and Development Planning (2003:306), as stated in the National Development Plan 9, “most health facilities are still faced with problems of staff shortages, both in numbers and skills to enable them to carry out the intended health care services at an acceptable quality”.

In order to try and reduce the infection rate in the neonatal unit, only mothers are allowed to care for the baby, and other relatives - including fathers - are not allowed to handle sick babies, even if the mother is sick or has passed away. This can lead to emotional distress in the father or the sick mother. Padden and Glenn (1997) support family-centred care in neonatal units, since taking care of a medically delicate infant is an endless trauma for parents. In order for parents to cope, they need to develop their parenting role in the alien environment of the neonatal unit. Parents need to adapt to their role change both as individuals and as a couple after the birth of their newborn baby. Fathers are especially important as a source of support for mothers who have a major role of taking care of the newborn infant (Gray, Lovejoy, Piotrkowski & Bond (1990), cited in Lee, Miles & Holditch-Davis, 2005). As a woman from the Setswana culture, the researcher is aware of the exclusion of fathers from the care of their infants by the Setswana culture. This is also true in relation to access to the SBCU.

Mothers of premature infants show fewer attachment behaviours when compared to those of full-term infants due to premature infants’ less responsive behaviours. The disappointment and confusion experienced by mothers of premature babies coupled with a complex technological environment may frighten the mother, who will not feel confident to touch her baby (Tilokskulchai et al., 2002). This affects the attachment process of the mother and her baby, which can be aggravated by separation of baby and mother.

1.5 RESEARCH AIM
The aim of the research study was to explore and describe the lived experiences of mothers regarding care of their hospitalised preterm babies.
1.6 RESEARCH OBJECTIVES
The research objectives of the study were as follows:

- To describe the experience of mothers who are separated from their vulnerable/sick preterm babies soon after birth.
- To explore the mothers’ experiences of interaction with their preterm babies within the neonatal environment.
- To describe the experience of mothers from their perspective of mothering in the neonatal unit.

1.7 RESEARCH QUESTION
The following is the research question that motivated this study:

What is the lived experience of mothers regarding care of their hospitalised preterm baby?

1.8 CONCLUSION
Neonatal mortality in developing countries is high compared to the developed world. The sub-Saharan regions of western, middle and eastern Africa have the highest neonatal deaths per 1000 live births (WHO, 2006b). Botswana as a developing country located in sub-Saharan Africa has a high prevalence of HIV among pregnant women; this increases the neonatal deaths since babies born to women with advanced HIV disease give birth to LBW babies and preterm babies who have the highest neonatal mortality (Creek et al., 2010; Klingenberg et al., 2003).

Babies with LBW, including preterm babies, are admitted in the neonatal unit for technological support and are separated from their mothers. Separation of the baby from the mother and the technology in the neonatal unit affect the interaction between mother and baby, which may delay bonding between them and increase the mothers’ distress. KMC, BFHI and the Humane Neonatal Care Initiative were developed worldwide to advocate rooming-in of mothers, since this could moderate the mothers’ psychological distress and promote bonding between the mother and her preterm baby.
There is limited research in Botswana on the nature of mothers’ experiences when caring for a preterm infant who has been admitted to a neonatal unit. This study explores and describes the lived experiences of mothers regarding care of their hospitalised preterm babies.
CHAPTER 2: REVIEW OF THE LITERATURE

2.1 INTRODUCTION
An overview of the literature is presented in this chapter, which discusses the history of neonatal care, initiatives that have been developed to promote the well-being of both mother and baby, and findings of previous studies on experiences of mothers regarding care of their preterm babies. The initiatives that have been presented aimed at reducing neonatal mortality and moderating the psychological distress experienced by mothers through their involvement in the care of their preterm babies. A further literature review of phenomenological studies is presented with the discussion of findings in Chapter 5.

The criteria that were utilised in searching the literature were as follows: The data bases selected included EBSCOhost-Academic search premier, Africa-wide, CINAHL, Health Source-consumer edition, Health source-nursing academic edition, Medline, Psych articles and Psych INFO, Pubmed, Ovid and Google Scholar. The key words and search terms used were: lived experience, mothers, care, preterm baby, neonatal unit, phenomenology, kangaroo mother care and Baby-Friendly Hospital Initiative. Particular focus was given to studies from the African continent.

The review of the literature revealed no study of mothers’ experiences of having a preterm baby in a neonatal unit in Botswana. A few studies have been conducted in African countries, including South Africa, Nigeria and Zimbabwe, but most studies in this field have been conducted in developed countries. The studies were mainly qualitative, using a variety of approaches: phenomenological, ethnographic, longitudinal and grounded theory. One study was a meta-synthesis conducted using a meta-ethnographic approach. The meta-synthesis evaluated 14 qualitative studies on mothers’ experiences of having a preterm baby in the neonatal unit. A few studies using a quantitative design compared the experiences of mothers of preterm babies with those of mothers of full-term babies, comparing the nature of attachment of the mothers.

2.2 HISTORICAL OVERVIEW OF NEONATAL CARE
Prior to the availability of life-saving technology premature babies were born at home, as were full-term infants. If they were alive they were cared for by their parents with the help of midwives and physicians (Goldberg & Di Vitto, 2002). During the Siege of Paris in the Franco-Prussian war of 1870-1871, following the death of many preterm infants action was taken to rescue infants born prematurely. The low birth rate, high infant mortality rate, stable decline in
birth rate and need to preserve the lives of all infants, even those born prematurely, resulted in the need to develop an incubator. The incubator was developed by French obstetrician Tarnier in the 1880s as a way to keep premature infants alive; its development resulted in a survival rate of 85% for infants weighing less than 1500g. Although the number of babies dying due to prematurity decreased, many preterm infants were left with disabilities (Davis, Mohay & Edwards, 2003). Avery and Litwack (1983), cited in Goldberg and Di Vitto (2002), reported that during the late 1800s investigations were carried out in Berlin and Helsinki to find solutions for the problems of premature infants such as poor temperature control, difficulties in feeding and susceptibility to infection.

In the 1880s when neonatal care was introduced in hospitals, mothers were separated from their preterm infants and not involved in their care, mainly due to the fear of infection of babies by their mothers. At this point in history no antibiotics were available. There were complications as a result of the treatment of infants; for example, oxygen therapy was introduced in the 1930s and high oxygen concentrations resulted in partial deafness of some neonates (Davis, Mohay & Edwards, 2003). Excessive oxygen use is also associated with other problems such as retinopathy of prematurity (Chen & Smith, 2007).

Respiratory problems of neonates were said to be caused by germs, with parents as carriers. Parents were not allowed to touch their infants. In an effort to describe the pathogenesis of hyaline membrane disease, aspiration was described. There was the fear that if an infant aspirated some liquid their respiratory condition would worsen, and this led to withholding all food or fluids for up to four days. This in turn increased the likelihood of severe acidosis, dehydration and spastic diplegia, which lowered the neonatal survival rates (Davis, Mohay & Edwards, 2003).

Despite efforts to improve the survival of the child, maternal mortality did not improve. It was then realised that the only solution was to hospitalise women for childbirth. In the post-war era there were new developments in the care of premature babies since maternity hospitals had evolved. These positively influenced the mothers’ involvement in the care of their premature babies during the 1950s and 1960s. The earliest human contact for premature infants was through invasive medical procedures. The cost of highly trained staff and the specialised equipment for premature infants resulted in neonatal intensive care units (NICUs) being situated in regional medical centres rather than in the local hospitals. This still led to the separation of mothers from their infants, as they had to remain in their local hospitals (Davis, Mohay & Edwards, 2003). The separation of infants was reported to have been strenuous for the fathers,
who had to visit the mother in one hospital and the baby in another, and this was compounded by large distances between the hospitals. The environment and high technology of the neonatal unit was frightening to parents when they visited their infants (Goldberg & Di Vitto, 2002).

According to Davis, Mohay and Edwards (2003), researchers began to challenge the longstanding practices of hospitals of separating a baby from his/her mother. This led to increased contact between parents and their infants. Davis, Mohay and Edwards (2003) reported that a study by Schaffer conducted in 1999 brought about a tremendous change, as it revealed that the developmental progress was seen as being influenced by biological characteristics including prematurity, as well as the social or physical environment in which development occurred. This acknowledged that the infant affects the parent, and therefore that there is reciprocity of parent and infant influences acting together in a mutually dependent system (Davis, Mohay & Edwards, 2003).

In the 1970s there was an increase in studies that resulted in the recognition of the importance of early contact between the mother and her infant in order to enhance bonding, which led to the understanding of the need for early contact of mother and infant. This encouraged rapid acceptance of the theory of bonding and the practice of rooming-in, and allowed infants to stay with their mothers, providing the most reasonable, less expensive way of making sure that mothers had adequate contact with their infants (Davis, Mohay & Edwards, 2003).

Goldberg and Di Vitto (2002) stated that in the 1970s an experiment was reported from Stanford University Medical Center where mothers were allowed in the NICU to interact with their infants. When non-handling of infants was compared with handling by parents, no increase in infection rates was observed and it was recognised that parental contact was not harmful to infants. Caregivers then began to question the separation of babies from their parents, and this resulted in more research conducted on the effects of contact between mothers and babies (Goldberg & Di Vitto, 2002). This concurs with what Davis, Mohay & Edwards (2003) reported, when they stated that parents were allowed to stay with their babies after the understanding of the importance of early contact of the mother and her baby.

2.3 TRENDS IN NEONATAL CARE

Neonatal care is an integral part of the health care system worldwide. Several initiatives have been developed internationally to promote the well-being of neonates and reduce neonatal morbidity and mortality, with an emphasis on parental involvement and the mother and infant
unit staying together. In 2006 the WHO reported that over 130 million babies were born every year and more than 10 million infants died before their fifth birthday (WHO, 2006b). Neonatal mortality is described by WHO (2006b) as death occurring during the first four weeks after birth, whereas perinatal mortality includes both deaths in the first week of life and foetal deaths (stillbirths).

Worldwide there are over 6.3 million prenatal deaths per annum, and almost all of these occur in developing countries. Globally the under-five and infant mortality rates are decreasing at a faster pace than the neonatal mortality rate, which represents an increasing proportion of child deaths (WHO, 2006b). More than half of approximately 7.5 million infant deaths in the world occur in the first four weeks after birth. Ninety-eight per cent of these occur in developing regions and 28% in least developed countries. Overall there are 30 neonatal deaths per 1000 live births, 5/1000 in developed regions, 33/1000 in developing regions and 42/1000 in least developed countries. In the neonatal period more deaths occur in the first few days after birth. Early neonatal mortality represents about 75% of neonatal mortality, and this applies to all regions of the world (WHO, 2006b).

Uthman (2008) stated that more than 20 million infants worldwide, representing 15.5% of all births, are born with LBW, and 95.6% of these neonates are born in developing countries. The neonates have to be cared for in incubators to assist thermoregulation, requiring specialised nursing care, and this overwhelms the health care system - especially in developing countries where there is a lack of equipment and shortage of manpower (Ruiz-Pelaz, Charpak & Cuervo, 2004).

2.3.1 KMC
An effective health care technique called KMC was developed in Instituto Materno Infantil, Bogota, Colombia in 1978 (Kirsten, Bergman & Hann, 2001; Nyqvist et al., 2010). It was developed as an ambulatory care for LBW infants where there had been high morbidity and mortality caused by overcrowding and sepsis, especially in neonatal settings of poorer countries. KMC involves skin-to-skin contact of the baby’s chest with that of the mother or whoever is caring for the baby. The baby wears a bonnet and a nappy and is kept in an upright position for 24 hours. The carer sleeps in a semi-sitting position (Roller, 2005; Ruiz-Pelaez, Charpak & Cuervo, 2004). “KMC affords the mother and infant an opportunity to get to know one another in a profound and synergistic way” (Roller, 2005:216). Kirsten, Bergman and Hann (2001), Ruiz-Pelaez, Charpak and Cuervo (2004) and Tessier et al. (2003) reported that KMC historically has three essential components:
Kangaroo positioning (skin to skin contact): Skin-to-skin contact of the mother and infant may start early after the baby’s condition is stabilised or later.

Kangaroo feeding: An infant who is held in the kangaroo care position stimulates lactation and is able to breast feed on demand (Leonard, 2004). The infant feeds on the mother’s breast only and formula is provided to a preterm infant if the infant is not gaining weight.

Kangaroo discharge: The mother practices continuous skin-to-skin contact at home provided that the infant is well and growing on the mother’s milk and there is adequate follow-up.

KMC has subsequently been implemented in other countries, including Vietnam, Brazil, South Africa, Asia, Latin America and other countries in Africa, as well as in industrialised countries including France, Sweden, the United Kingdom and USA. The use of KMC as an option to incubator care was supported by the WHO, which developed its implementation guidelines (Ruiz-Pelaez, Charpak & Cuervo, 2004).

KMC has advantages both for the mother and the neonate, as stated by Kirsten, Bergman and Hann (2001); Nyqvist et al. (2010); Ruiz-Pelaez, Charpak and Cuervo (2004); Tessier et al. (2003) and Whitelaw (1990). Advantages of KMC include provision of warmth to neonates with LBW who cannot regulate their body temperature, especially where there are no incubators - the infant’s temperature remains within normal range; it is used as a form of transport for babies who need warmth before reaching the hospital; parental sense of fulfilment and confidence as they provide skin-to-skin contact with their preterm infants, especially when started early; promotion of bonding and breastfeeding; preparing a family for a successful discharge from hospital; and reduction of morbidity and length of hospital stay among LBW infants. Physiological effects of KMC on the infants include increase of the respiratory rate by five breaths per minute, increase of oxygen saturation by 2%, and decrease of apnoea and periodic breathing (Charpak et al., 2005; Feldman, Eidelman, Sirotta & Weller, 2002).

KMC has long-term effects on infant development and on the parenting process. According to Feldman et al. (2002:16), premature birth “exposes the infant to a range of developmental risks and premature babies often show lower cognitive and motor skills that persist into later childhood”. KMC is reported to be contributing to the “premature infant’s cognitive development as it integrates rhythmic, sensory and tactile components into the mother-infant contact” (Feldman et al., 2002:17). Mothers who provide KMC are reported to have positive feelings towards the infant and feel satisfied with their role as parents. KMC has an effect on the attention
span of the infant and on the development of the infant both physically and mentally. It is also argued that mothers may have a lower risk of depression in the postnatal period because they are actively involved in the care of the infant. The effect of KMC on infant state organisation may assist the infant to be more alert during mother-infant interaction, which results in increased maternal involvement (Feldman et al., 2002).

A study by Feldman et al. (2002) comparing KMC and traditional care in terms of parenting outcomes and preterm infant development found that after KMC mothers looked at their infants more, touched the infant more frequently, had positive feelings towards their infants and became more alert to their infant’s cues. Mothers who provided KMC provided a better environment for their infants at six months. The study also found that infants who received KMC were “more socially alert and their Bayley developmental scores at six months were higher in the mental and motor domains” (Feldman et al., 2002:23). KMC has been found to be helpful in early child development and in assisting the mother to assume her parental role in the first six months after the birth of the infant.

Feldman et al. (2002) also argued that maternal and infant behaviour influence each other in a continuous manner to shape the infant’s development. Premature infants who receive KMC are more alert than others and KMC assists mothers to be sensitive to their infants’ needs, resulting in the improvement of the mother’s caring capabilities and better development of the infant (Feldman et al., 2002).

### 2.3.1.1 Cost savings
KMC enables the infant to be discharged the infant at a lower weight, it reduces length of hospital stay and the increase in bed occupancy results in lower costs. Nyqvist et al. (2010) stated during a conference on KMC that Mokhachane from Johannesburg, South Africa, demonstrated that the KMC method produced a safer discharge of high-risk, very LBW infants at a weight of >1650g than the previous discharge weight of >1800g. This is an important factor in a setting with a low-income population, limited resources, HIV/AIDS-related problems and migration problems in a community.

### 2.3.1.2 Other benefits of KMC
Charpak et al. (2005) reported that benefits of KMC include the reduction proximal noise as the infant is carried on the mother’s chest and most noise is absorbed by the parent’s skin and clothes. Therefore the continuous kangaroo position reduces the stress that the infant is exposed to in the NICU, and because of the reduction in stress the baby gains weight and mental
development is optimally influenced. Nyqvist et al. (2010) reported that KMC improves the infants’ neurobehavioral development, promotes participation of the father in the infant’s care, as fathers can take turns in carrying the infants in the skin-to-skin position, and prevents feelings of separation anxiety. In a study conducted by Tessier et al. (2003) the KMC intervention was reported to have a positive effect on the hearing and speech of infants when compared with those in a control group.

### 2.3.2 The Baby-Friendly Hospital Initiative

UNICEF and the WHO adopted the BFHI in accordance with the Innocenti Declaration of 1990 on the prevention, promotion and support of breastfeeding. The BFHI was launched in 1991 by UNICEF and the WHO. This was to ensure that all institutions providing maternal and newborn care promote breastfeeding (UNICEF, 2010). Since the launching of the BFHI it has been implemented in different countries in the world and 15 000 facilities in 134 countries have been awarded baby-friendly status. A maternity facility is declared baby-friendly if it does not allow the mothers to give babies any form of breast milk substitutes nor allow mothers to give bottles and teats to babies (UNICEF, 2010).

South Africa, a neighbouring country to Botswana, had its launch of the BFHI in 1994 in Bloemfontein. Since 1995 the Department of Health has become actively involved in the implementation of BFHI in South Africa (Department of Health, 2010). Different health facilities have been declared as baby-friendly since its launching. Since 1998 there has been an annual assessment of health facilities in order to declare them baby-friendly, and by 2004 a total of 140 out of 480 health facilities with maternity beds had been assessed and declared as baby-friendly (Department of Health, 2010).

Although the BFHI has been implemented in different developing countries, the HIV and AIDS pandemic has affected its implementation, especially in Botswana, Kenya, Namibia and Uganda (Latham, 2001). A study conducted by Latham (2001) revealed a decline in actions to protect, support and promote breastfeeding since policies on HIV/AIDS and the prevention of mother-to-child transmission affected the status of protecting, supporting and promoting breastfeeding in all four countries.

Out of 84 maternity settings in Botswana, seven were declared as baby-friendly over the period 1993-1996. Since 1998 the Government has been implementing Integrated Management of Childhood Illnesses under the Ministry of Health, and the programme is supported by the WHO in
five districts, namely Francistown, South East, Kalahari South, Kalahari North and Mahalapye. The programme incorporates breastfeeding messages (Latham, 2001).

Latham (2001), in a study entitled ‘Current status in protection, support and promotion of breastfeeding in four African countries: Actions to protect, support and promote breastfeeding in Kenya, Namibia, Botswana and Uganda’, strongly recommended that the Government of Botswana, UNICEF and the WHO, as funders of the project, should protect, support and promote breastfeeding. Botswana was also urged to consider exclusive breastfeeding for mothers who are HIV positive in order to reduce infection of babies, especially in poorer communities.

The Ministry of Finance and Development Planning (2003) in the National Development Plan 9 of Botswana reported that in order to promote breastfeeding among mothers, the Maternal Protection Law that provides a one-hour break for working mothers who are breastfeeding was endorsed. The National Breastfeeding Authority was initiated to be responsible for the efforts to protect, promote and support breastfeeding. It is reported that the regulations on the marketing of breast milk substitutes have been revised in order to apply to the situation of Botswana and to incorporate the current issues on HIV/AIDS and the feeding of infants/breastfeeding. It was reported that the findings of a study conducted to evaluate infant feeding practices in the country were used to revise the infant feeding guidelines and in developing the national infant feeding policy (Ministry of Finance and Development Planning, 2003).

According to UNICEF (2010), 10% of infants in Botswana were born with LBW over the period 2003-2008. None of the children had early initiation of breastfeeding, although 34% of children were exclusively breastfed until the age of six months. Setty (2006) reported that after the 2000 review, which demonstrated that there was a decline in the support of breastfeeding by the governments of Botswana, Kenya, Namibia and Uganda as the countries are mostly affected by the HIV/AIDS pandemic, action had to be taken. The United Nations agencies came up with the HIV and Feeding Framework for Priority Action. This was to address the misunderstandings about HIV and breastfeeding, since it was realised that governments were of the opinion that HIV-positive mothers who breastfed would infect their babies. The review also reported that officials from different sectors, such as staff from the United Nations and officials from Ministry of Health, overlooked the benefits of breastfeeding for all babies. The United Nations suggested that governments should strategise and develop priority actions for addressing issues relating to exclusive breastfeeding and replacement feeding in HIV-affected areas. The governments’ goal is to ensure safe feeding practices for all infants as much as reducing the transmission of HIV from the mother to the child. In order to achieve the goal, all health care officials are expected to make
sure that effective breastfeeding strategies are employed, and they also have to coordinate the activities (Setty, 2006).

The United Nations framework also recommended that governments should enforce the International Code of the Marketing of Breast Milk Substitutes. Mothers who are not aware of their HIV status should be discouraged from using breast milk substitutes until their infants are six months of age (Setty, 2006). According to Setty (2006), the WHO and UNICEF set a standard in order to ensure optimal breastfeeding of babies. Whenever possible mothers should exclusively breastfeed their babies, that is without giving them food and liquids, including water, until the baby is six months of age. The reason for this is that breast milk is best as it contains all the nutrients and helps the baby to grow. Another recommendation in the United Nations framework is that mothers who are HIV positive should be supported in order to make an informed decision about infant feeding and be able to succeed in carrying it out. HIV-positive women should be supported by counselling them and educating communities through the use of media so as to decrease the stigma surrounding HIV infection (Setty, 2006).

The Ministry of Health (2011) conducted an assessment of the status of Botswana in implementing the Global Strategy which aims at achieving optimal infant feeding through the use of the World Breastfeeding Trends Initiative tool. The Ministry (2011) reported that 40% of babies in Botswana are breastfed within one hour of birth, and 20.3% of babies from zero to six months are exclusively breastfed. There is a low coverage of BFHI in Botswana, which is not implemented adequately and with limited monitoring. The Ministry of Health (2011) also reported that of the 34 hospitals providing maternity services that were assessed for BFHI status, there was no facility in the country that has been declared as baby-friendly, as none of them have yet met the global and national criteria. There is no skill training of workers in the 34 hospitals providing maternity services, and as a result BFHI is not sustained; however, the country has the capacity to implement and monitor BFHI as there are systems in place.

The gaps that were identified as affecting the effective implementation of the strategy include the following: health workers have not been trained in BFHI and those who have been trained have since left Government institutions, which affects implementation of the strategy at district level; BFHI training has not been included in the basic training of health workers; lack of ownership and monitoring of the strategy in facilities; the assessment of the BFHI quality of hospitals and maternity facilities has not been conducted for the last four years; and implementation of BFHI has not been monitored for its effectiveness (Ministry of Health, 2011).
The Ministry of Health (2011) made the following recommendations for Botswana in order to be able to implement the strategy effectively: include BFHI in the basic training of health workers; train all hospitals’ staff in order to comply with the status of being baby-friendly; restructure BFHI by conducting an assessment of hospitals and maternity facilities every three years; come up with a plan in order to advocate for the resources; develop a BFHI training plan for both pre-service training and in-service training of health workers; include BFHI as a requirement for facilities to report upon when discussing their performance; and to develop and implement a monitoring plan. It is worth noting that the BFHI was referred to by the Ministry of Health (2011) as Baby and Mother Friendly Hospital Initiative (BMFHI) in their report.

The benefits of BFHI, according to the Department of Health of South Africa (2010) and UNICEF (2010) are:

- Breastfeeding babies are less likely to suffer from serious illnesses such as gastro-enteritis, asthma, eczema, respiratory and ear infection;
- Reduction in infant mortality rate as a result of fewer deaths caused by gastro-intestinal and respiratory infections; and
- Reduction of maternal deaths since there is less bleeding after delivery, and it also protects against osteoporosis, breast and ovarian cancer.

In order for a setting to promote breastfeeding among mothers it has to observe the following ten steps, as listed by UNICEF (2010) and described by Naylor (2001):

1. **Have a written breastfeeding policy that is routinely communicated to all health care staff.**

   If the institution has a written policy, this will serve as a guide for all the workers in the institution and will communicate the intention of the administrators with regard to BFHI. The policy will assist the administrators in budgeting for staffing, training of staff, provision of supplies and revenue. The policy should apply to all departments in a hospital setting, but not only to staff in maternity settings since all health workers deal with mothers who are breastfeeding in one way or the other.

2. **Train all health care staff in skills necessary to implement this policy.**

   Naylor (2001) reported that this step has been of great help to the success of BFHI because most health workers were not trained on BFHI during their pre-service education. Naylor (2001) stated that although 18 hours of training of staff on the
promotion of breastfeeding does not seem to be enough to cover the most difficult situations, if the material is well presented, staff will gain a lot of understanding of the promotion of breastfeeding. Staff also gain the skill needed to assist mothers and infants to get good initiation of breastfeeding. Hospitals are not necessarily expected to train the staff on promotion, protection and support of breastfeeding, but can send them for training within communities where training on BFHI is offered.

3. Inform all pregnant women about the benefits and management of breastfeeding.

The decision of breastfeeding should be made by the mother. Mothers should not be forced to breastfeed against their will. The mother should be informed about the advantages of breastfeeding for both herself and the baby and be made aware of other feeding options. The mother should also be informed about the physiology of lactation.

4. Help mothers to initiate breastfeeding within an hour after birth.

Naylor (2001) reported that there are many advantages of early initiation of breastfeeding, as the nipple stimulation that occurs when the infant suckles increases the oxytocin levels of the mother. Oxytocin causes the mother’s uterus to contract, which decreases bleeding of the mother during the postpartum period. Lactation is maintained if breastfeeding is effective. Naylor (2001) stated that if the infant sucks from the mother’s breasts initially before the infant is subjected to the procedures within the hospital setting, there is a high chance of success in breastfeeding since the infant starts sucking while the breast is still soft. The immediate breastfeeding helps the infant to get colostrum, which helps to boost the infant’s immune system. Although it is advocated that infants should be fed within an hour of birth, infants should not be forced to feed but should be offered the breast and can feed at the time that they are ready to do so. However, if the infant does not start feeding within the first hour then skin-to-skin contact can be initiated, which helps in bonding and the duration of breastfeeding.

5. Show mothers how to breastfeed and how to maintain lactation even if they should be separated from their infants.

Despite the mother’s past experiences of breastfeeding, mothers tend to succeed in breastfeeding if they are assisted in the initiation of it. Mothers should be informed about how to prevent a decrease in breast milk even if she is separated from her infant, such as when she has to work while breastfeeding. She should be informed about expressing
breast milk. The mother should also be informed about how she should safely store the milk.

6. Give newborn infants no food or drink other than breast milk unless medically indicated.

In order for the mother to maintain lactation she should breastfeed the baby. Breastfeeding is also advantageous since breast milk is rich in antibodies for protecting the infants against infection. Breastfeeding reduces the incidence of gastro-enteritis which is common in non-breastfeeding infants. Healthy infants feed from the mothers’ breasts for six months without taking any supplements which may interfere with the infant’s appetite. Infants who should receive supplements should be referred to physicians as they should follow the supplementation guidelines.

7. Practice rooming-in - allow mothers and infants to remain together 24 hours a day.

When infants are kept with their mothers in the same place, mothers will respond to the infants’ readiness for feeding. Responding to the infant’s need for feeding promotes the infant’s sense of security and also helps in the projection of milk as it stimulates lactation. This results in adequate milk supply. When infants are kept with mothers, mothers are able to respond to their infants’ cues and infants are able to recognise their mothers’ voice and other responses such as eye contact. This promotes bonding and attachment between mothers and their infants.

8. Encourage breastfeeding on demand.

Infants should not be fed on schedule if they are healthy and born at term. These infants feed frequently after the first day of birth. This encourages the secretion of milk from the breasts. Infants should be treated as individuals since their appetite differs. Mothers should be able to know when their infant is ready to feed in order to prevent upsetting the infant.

9. Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.

Pacifiers are not permitted for healthy infants as they may affect the infant’s interest in suckling from his/her mother’s breast. The process of lactation is affected once the infant does not suckle from the mother’s breast. Early sucking helps the infant to get used to the characteristics of the mother’s breast. Some infants experience difficulties in switching from the pacifier to the breast and this may affect the infant’s interest in
breastfeeding. The pacifiers may also serve as a source of infection to the infant if they are not cleaned after falling on the floor or ground.

10. Foster establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.

If the mother is referred to a breastfeeding support group, she will have an opportunity of meeting with other mothers who are breastfeeding or who are experienced in breastfeeding. Other mothers may help the mother in solving the problems she may be faced with while breastfeeding. Mothers in the breastfeeding groups are more likely to breastfeed their infants for longer periods, at least for the first six months of the infant’s life. Where there are no support groups in the community to refer mothers to, hospitals can start breastfeeding support groups.

A study was conducted by Nyqvist and Kylberg (2008) on application of the BFHI to neonatal care, including suggestions by Swedish mothers of very preterm infants, and demonstrated that the ten steps to successful breastfeeding are also relevant for mothers of very preterm infants. The initiative needs to be clarified with additional information in order to guide mothers of preterm infants, and the guidelines for breastfeeding support must be based on the mother’s point of view. The mothers suggested additional steps for preterm infants. Mothers in this study reported that even though they were provided with information on breastfeeding, they could hardly remember the information - probably due to the shock of premature birth - and it was recommended that a breastfeeding expert should assist the mothers. The mother’s unique situation should be considered and her feelings of vulnerability after the shock of premature birth and grief of loss of a normal pregnancy should be respected and treated with sensitivity. Mothers should be shown empathy, given time and encouraged in a way that does not make them feel stressed or forced to breastfeed. The importance of early basic information about lactation and breastfeeding was emphasised. Antenatal classes should cover the benefits of breastfeeding, breastfeeding techniques and possible problems that the mother is likely to encounter (Nyqvist & Kylberg, 2008).

The study found that anxiety about the infant’s condition and insensitive treatment of infants by individual nurses had a negative influence on the mothers’ let-down reflex and affected their lactation process. It was then suggested that effective communication with mothers while in the neonatal unit is important (Nyqvist & Kylberg, 2008). The acceptance of the mother’s breastfeeding problems and decisions will help the mother to tolerate the situation but will not
decrease her desire to breastfeed. The study emphasised that the presence of the mother in providing care to her preterm baby, such as holding and bonding, should be recognised as important, even if she is not able to breastfeed (Nyqvist & Kylberg, 2008).

Nyqvist and Kylberg (2008) advocated that all professionals concerned should have adequate knowledge about preterm infants, breastfeeding and nutritional questions, since effective support of mothers is necessary when they begin breastfeeding and expressing milk and when they encounter problems with milk production. Breastfeeding should be commenced as soon as possible and the infant should be allowed to suckle before receiving supplementation, and be given the time he or she needs before starting to suck and be allowed to suck until satisfied. Mothers felt that the father’s presence should be supported without restrictions since the father is the mother’s main supporter in infant care giving. An infant’s birth is the birth of a new family who needs to be together, and mothers found it stressful to be in hospital alone, especially at the beginning when the baby was in intensive care (Nyqvist & Kylberg, 2008).

A step that encourages early, continuous and prolonged mother-infant skin-to-skin care without unnecessary restrictions cannot be left out, since it offers mothers an opportunity to stay with their infants for 24 hours a day. Mothers were separated from their infants even though rooming-in is the most important way of promoting breastfeeding. Mothers stated that they found it very difficult to leave a small, vulnerable ‘preemie’ as they regarded it as inhuman (Nyqvist & Kylberg, 2008).

2.3.3 The Humane Neonatal Care Initiative
The Humane Neonatal Care Initiative was developed by Levin and launched in Tallin Children’s Hospital, Estonia, in Stockholm in 1999. The model’s key concept is that an infant and the mother should not be separated (Levin, 1999; Nyqvist, 2005). The nurse has the task of serving as a facilitator of the maternal role, with strict, defined functions related to the procedures that require professional education. Levin (1999) identified 11 steps to be followed by health professionals in neonatal units in order to improve the psychosocial and medical care of sick newborns:

- The mother should be allowed to stay with her sick baby for 24 hours a day.
- All staff members who are caring for the preterm baby should be able to take care of a mother and should meet the mother’s psychological needs.
- The staff should assist mothers to breastfeed and should be informed about the techniques of expressing breast milk.

- Mothers’ psychological stress should be reduced throughout their hospitalisation period.

- Newborns to be fed with breast milk unless there are medical reasons not to.

- Newborns should be fed by a tube and mothers should be allowed to feed their babies if the baby cannot suck from the mother’s breast.

- Examinations and tests performed on the newborn babies should be minimised.

- Mothers should be allowed to kangaroo care their babies and use of technical care to be reduced.

- Hostile treatment of newborns should be reduced.

- The mother and the infant should not be separated and the ward rounds should meet the health needs of both mother and baby.

- If the mother and the baby have been in hospital for a long time, healthy family members such as the father and grandparents should be allowed to visit them while in hospital.

Levin was supported by Kennell (1999), who was of the opinion that neonatologists should review their policies with regard to neonatal care as mothers were separated from their infants. Kennell (1999) used an example of Professor Levin and his staff, who involved parents in the care of babies in a special facility where care was provided for preterm babies and other disabled infants. Since there was shortage of nurses, mothers were asked to come and care for their infants and to stay in hospital until the infant’s discharge. Levin and his staff observed a decrease of infection among infants, with less need of antibiotics and intravenous fluids when most babies were cared for by their mothers and having less contact with staff members, who served as a guide for mothers and gave medications (Kennell, 1999). It was reported that weight gain was faster among preterm babies, breastfeeding was promoted, and there was an improvement in social and psychological development. Mothers recovered from childbirth quickly, developed confidence in caring for their infants, and mother-infant attachment was promoted (Kennell, 1999). Levin promoted the importance of BFHI being incorporated in the care of sick premature babies as it promotes rooming- in, mother-infant attachment and success in breastfeeding (Kennell, 1999). Kennell (1999) argued that keeping mothers and babies together enhances growth and
development of the infant as well as bonding of mother and baby. Mother-infant bonding prevents parenting disorders such as abuse, abandonment, failure to thrive and neglect.

The Initiative advocates for mothers to breastfeed their infant. Preterm breast milk has more protein, nitrogen, chloride, sodium and less lactose than term milk. The bacteriostatic and bactericidal factors in mother’s milk, which include lactoferrin, lysozyme, complement and lymphocytes producing immunoglobulins A, G and M and colonisation with non-pathogenic flora, is the reason for breastfeeding preterm infants. This results in less infections and reduced incidence of necrotising enterocolitis in breastfed premature infants (Kennell, 1999). Kennell (1999) stated that it is suggested that the reduced incidence of the severity of retinopathy in preterm infants is the result of the long-chain fatty acids present in human milk. The other main reason (Kennell (1999) mentioned as to why preterm infants are recommended to breastfeed is that they tend to have lower levels of oxygen during feeding, but oxygenation is better maintained when the baby breastfeeds than when bottle-fed.

The above initiatives were developed and are implemented all over the world to promote the well-being of both the mother and the neonate during hospitalisation in the neonatal unit. A number of studies have been conducted on the experiences of mothers in relation to their preterm infants, and the studies have been incorporated into the themes outlined below.

2.4 THEMES arising from the review

2.4.1 Struggling to mother

In a study by Lee, Long and Boore (2009) it was found that many mothers did not know what to do or how to mother their tiny ill infants in the neonatal unit. Some mothers could not have immediate contact with their babies because of ill health. They had to wait several days before interacting with their baby because of problems associated with a high-risk pregnancy and/or caesarean section.

Giving birth to a preterm baby made mothers feel like they were in a different world; they experienced despair and grief (Lupton & Fenwick, 2001) and it was described as being in an ‘alien world’ (Aagaard & Hall, 2008; Hall, 2005). The mothers had to make efforts in order to cope with the extreme anxiety that they were feeling, which could be due to their infant’s appearance, being connected to wires and surrounded by machines (Aagaard & Hall, 2008; Miles, Holditch-Davis, Burchinal & Nelson, 1999). Separation of the mother from the baby such as staying at home made mothers feel guilty and abandoned, and staff shifts made it difficult for the mothers
to express their needs (Aagaard & Hall, 2008; Elandsson & Fagerberg, 2005). Initially mothers did not feel like they were mothering, since they could not meet their babies’ physical needs and were also not yet ready for motherhood. Mothers did not feel close to their babies because they did not feel like mothers (Lupton & Fenwick, 2001). Mothers felt as if they were real mothers when they were involved in the care of their preterm babies (Aagaard & Hall, 2008; Lupton & Fenwick, 2001).

2.4.2 Neonatal environment
Mothers were frightened by the technological environment of the neonatal unit and the medical equipment attached to their babies separated them physically from their infants. The mothers were scared of the equipment, which prevented them from feeling attached to their infants for some time (Lee, Long & Boore, 2009). Reid (2000) reported that mothers felt frightened and abandoned when seeing the neonatal unit for the first time. Mothers had difficulty in coping with the busy and unfamiliar environment of the neonatal unit, with the equipment that was new to the mother, busy staff with expert knowledge, skill and the medical terms that they use (Aagaard & Hall, 2008; Johnson, 2008; Lupton & Fenwick, 2001). The sound, sight and smell of the environment horrified the mothers; they wanted to be informed of what was happening (Aagaard & Hall, 2008; Hall, 2005; Reid, 2000). Mothers reported that they had to abide by the regulations of the neonatal unit (Aagaard & Hall, 2008; Lupton & Fenwick, 2001).

2.4.3 Mother’s role-claiming strategies
In a study on mothers’ lived experiences of co-care and part-care after birth, their strong desire to be close to their baby meant that mothers needed to work hand in hand with the staff, and to agree with them so that they could be involved in the care of the baby (Elandsson & Fagerberg, 2005). As mothers developed confidence in caring for their infants, they felt that they knew their baby better than the nursing staff and were able to suggest to the nursing staff what they felt was causing pain to their infants (Lupton & Fenwick, 2001). A mother would voice her concerns and felt that the nurses should listen (Aagaard & Hall, 2008; Heermann, Wilson & Wilhelm, 2005), or she might fear that mentioning her wishes, questions or concerns would result in her being regarded as a difficult mother (Aagaard & Hall, 2008; Hurst, 2001a; Hurst, 2001b).

When they have a baby in the neonatal unit, mothers showed a number of strategies to provide safety for their infants. This included trying to reach an agreement by discussing issues with the health personnel, asking to speak to the authorities, building supporting relationships with other mothers and seeking support from spouses, partners, families and friends. Through vigilant watching and negotiated actions mothers began to understand the health challenges and risks
that the infant was facing (Aagaard & Hall, 2008; Heermann, Wilson & Wilhelm, 2005: Hurst, 2001a). Mothers wanted to be provided with information on prematurity, their babies’ specific health problems, treatment needs and prognosis so that they could evaluate their babies’ care needs and be able to guard against whatever might hold danger for their infants (Hurst, 2001b). Mothers wanted to know their infants’ medical condition and the functions of monitoring equipment used (Lupton & Fenwick, 2001). They wanted to interact with their infants as much as possible as they touched and stroked them while on humidicribs, and this helped them to get connected to their infants even though they still depended on the support of staff for success (Hurst, 2001a; Lupton & Fenwick, 2001).

2.4.4 The role of breastfeeding
Breastfeeding and expressing breast milk for their babies helped mothers to feel that they were building a relationship with them. While in the neonatal unit mothers developed a greater sense of competence in caring for their babies and felt they knew them better than nurses did (Lupton & Fenwick, 2001). Mothers were more likely to describe their infant as their baby if they had been able to hold the baby, having had skin-to-skin contact with them. Mothers were happy and developed a loving relationship with their baby if they breastfed and had an influence on the infant’s care (Heermann, Wilson, & Wilhelm, 2005; Lee, Long & Boore, 2009).

2.4.5 Establishing connections and forming relationships with their baby
Mothers wanted to get to know their infants by trying to realise the unique characteristics of their infants, since this helped them to perceive their infants as unique individuals (Lee, Long & Boore, 2009). Mothers who could not be with their babies in the neonatal unit brought toys from home for their baby and audio tapes for nurses to play to their babies. This enabled them to feel close to their LBW infants emotionally (Lee, Long & Boore, 2009). The first holding of the baby was reported by mothers as an important moment which made motherhood real (Reid, 2000). As mothers gained competence and reassurance, they felt connected to their infants (Heermann, Wilson & Wilhelm, 2005; Lupton & Fenwick, 2001). Mothers interacted with their infants and were willing to connect to their infants (Lee, Long & Boore, 2009). They reported that they were able to hold their infants when the baby’s condition improved, and that they managed to develop a relationship with the baby after participating in their care (Lee, Long & Boore, 2009).
2.4.6 Support systems for the mother of a preterm infant

2.4.6.1 Support from nursing and medical staff

Support from nursing and medical staff is an important aspect for the successful outcome of the mother’s experience and the preterm infant’s eventual discharge. In a grounded theory study in which 26 Taiwanese mothers were interviewed, it was found that medical staff provided mothers with information on the infants’ conditions and treatment, while nurses provided explanations to the mothers and offered them emotional support. This allowed mothers to perform their parental role in the neonatal unit (Lee, Long & Boore, 2009). A longitudinal study conducted by Miles et al. (1999) found that mothers needed assistance in caring for their baby while the baby was admitted to the neonatal unit and even after hospital discharge.

Mothers felt that being treated as a unique person, being comforted and supported was reassuring (Elandsson & Fagerberg, 2005). Mothers had difficulty in establishing relationships with staff who were ignorant and did not respect their child’s needs (Aagaard & Hall, 2008; Hall, 2005). Davis, Edwards, Mohay and Wollin (2003) reported that there was a relationship between the mothers’ perception of support provided by the nursing staff and depressive symptomatology. When nursing support decreased, the risk of depression for the mother increased by 6%, thus demonstrating the importance of support of the mother by the staff. This contributes to maternal well-being during the postpartum period while her preterm baby is admitted to the neonatal unit.

Mothers reported that some nurses encouraged them to become more actively involved in the care for their infants (Heermann, Wilson & Wilheim, 2005). Mothers were encouraged to conduct simple procedures by staff, such as taking the infants’ temperature, weighing them and giving medications such as vitamins. This gave the mothers a sense of being a mother (Lupton & Fenwick, 2001). Mothers reported less worry after having an opportunity to talk to staff. Mothers felt supported by staff when they explained how to take care of the baby to them, and when showing them how to perform caring activities. Mothers appreciated being allowed to decide how much they wished to be involved in their infants’ care (Lindberg & Orhling, 2008).

The support of family members enabled the mothers to cope with their role change (Lee, Long, & Boore, 2009). Parents whose baby was admitted supported each other, and the support they received from spiritual beliefs provided mothers with hope during difficult times (Lee et al., 2009). Some of the greatest sources of stress for parents are the appearance of a fragile, sick baby and fears for their baby’s survival, alteration of parental role and separation of the parents.
from their baby due to the baby’s hospitalisation (Davis et al., 2003). When mothers have a baby in the neonatal unit and are supported by a spouse or parents they tend to experience less maternal depression and greater parenting experience (Davis et al., 2003). Mothers’ coping strategies while their baby was admitted to the neonatal unit included seeking social support and communicating with other mothers whose babies were hospitalised, relying on religious faith and focusing on the infant (Davis et al., 2003; Hughes, McCollum, Sheftel & Sanchez, 1994). Support from the spouse during the period of hospitalisation of the infant also enhanced the mothers’ coping abilities (Davis et al., 2003).

2.5 CONCLUSION

Although in the last 50 years there has been a significant change in the approach to care of the preterm infant, and recognition of the critical role that the mother plays in a satisfactory outcome for the vulnerable neonate, there remains a need for this important topic to be further studied in the African context. Trends in neonatal care have evolved, which include KMC, BFHI and the Humane Neonatal Care Initiative; these advocate for prevention of separation of the infant from the mother in order to promote the well-being of both. This literature review has highlighted that there are challenges in the implementation of the BFHI, especially in Botswana. The BFHI promotes breastfeeding, which facilitates bonding between the mother and the baby, reduces neonatal mortality from gastro-intestinal disease and also protects the mother from osteoporosis, breast and ovarian cancer.

The benefits of rooming-in, early and regular responsive contact between mother and preterm infant for both the mother and the preterm infant have been described. A number of studies have been conducted on the experiences of mothers with regard to the care of their preterm infants. However, these studies have been conducted mainly in developed countries and there is limited information with respect to the African context. The literature reviewed found no study conducted in Botswana on the lived experiences of mothers regarding care of their hospitalised preterm babies.
CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION
In this chapter the research methodology is presented, the type of qualitative research design and method of data analysis. Descriptive phenomenology as the philosophical underpinning for this study is described. The steps that were followed in collecting and analysing data, ethical considerations and steps to ensure the trustworthiness of the study are described.

3.2 CHOICE OF QUALITATIVE DESIGN
The study was qualitative, explorative and contextual in nature. A phenomenological approach was used for this study. The main aim was to explore and describe the lived experiences of mothers regarding care of their hospitalised preterm babies. Baker, Wuest and Stern (1992:1356) stated that “the main goal of phenomenological research is to describe the world as experienced by the participants of the enquiry in order to discover the common meanings underlying empirical variations of a given phenomenon”.

Phenomenology is derived from the Greek word phenomenon, which “means to show itself, to put to light or manifest something that can be visible in itself” (Morse, 1994:118). It requires that a phenomenon be described rather than being explained or having its related causes looked for, and it concentrates on the things as they reveal themselves (Sadala & Adorno, 2002).

“Phenomenology is a philosophical approach to the study of phenomena and human experience” (Holloway, 2008:179). It is used to explore the lived experiences of people. Morse (1994: 118) states that “Husserl who is the father of phenomenology considered phenomenology to be all three: being a philosophy, an approach and a method”.

Phenomenology is defined by Husserl (as cited in Earle, 2010:287) “as a discipline that seeks to describe the manner in which the world is constituted and experienced through conscious acts” or the study of phenomena as shown by conscious acts, as Koch (1995) describes it. Anything that presents itself to consciousness is of interest to phenomenology. Human beings have access to the world through consciousness. Being aware of some aspects of the world is being conscious. Phenomenological research is the study of essences; this means that it always tries to answer the question: What is the nature or meaning of something? (Van Manen, 1990). In this study the
question was: What are the lived experiences of mothers regarding care of their hospitalised preterm babies?

As a philosophy, phenomenology is a way of approaching the world and the lived experience. It allows the researcher to describe the structure of an experience as presented to consciousness without assumptions (Connell, 2003). As a research method it is a process of re-examining what Husserl termed the ‘things themselves’ (cited in Connell, 2003). Phenomenology “is a rigorous, critical, systematic investigation of phenomena” (Streubert & Carpenter, 1999:48). Its purpose is to explain the essence of lived experiences of a phenomenon as well as looking for a united meaning. This can be described as identifying the essence of a phenomenon - its precise description through the everyday lived experience (Baker, Wuest & Stern, 1992; Streubert & Carpenter, 1999).

3.3 HISTORICAL OVERVIEW OF PHENOMENOLOGY

Phenomenology has a philosophical origin. As a movement it has three phases: the preparatory phase, German phase and French phase (Holloway & Wheeler, 1996; Munhall, 1994).

3.3.1 Preparatory phase

During the preparatory phase Frank Brentano (1838-1917) wrote about phenomenology as an investigation. He was the first philosopher to discuss the concept of intentionality, which implies that human beings cannot be separated from the world (Munhall, 1994; Van Manen, 1990). Holloway and Wheeler (1996:116) stated that “intentionality is a way of describing how in consciousness the mind directs thoughts to an object”. It can be described as the relationship between people and the events surrounding their lived experiences or, more simply, one’s awareness of an object or an event in their lives (Drew, 2001; Dowling, 2007; Earle, 2010). There is always an intentional relationship with the things that make up our everyday lives (Drew, 2001).

The other philosopher who contributed towards the preparatory phase was Carl Scarpf (1848-1936), who had the opportunity to describe the phenomenon before testing the behaviours with the method. Scarpf contributed to the preparatory phase by explaining that phenomenology could be studied with the rigour of experimental and scientific techniques (Munhall, 1994).
3.3.2 German phase

Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976) dominated the German phase of the phenomenological movement (Holloway & Wheeler, 1996; Munhall, 1994). Husserl believed that the study of philosophy should have a new humanism and not only rigour. He argued for the creative attempt to get a meaning through the study of human experience. He linked the scientific enquiry of observation and experiment and the concept of phenomenological intuiting and reduction. Experience is closely involved with imagination, suggesting a relationship with something real such as an event, whereas reduction is a process which suspends attitudes, beliefs and assumptions so as to adequately examine what is present (Holloway & Wheeler, 1996; Holloway, 2008; Munhall, 1994).

According to Holloway (2008) and Morse (1994), Husserl termed the philosophical reduction as epoche, meaning ‘suspension of belief’. There are two stages in this eidetic reduction from particular facts to general essence. Bracketing is the name given by Husserl to this process of suspending belief. The researcher has to examine her attitudes, beliefs and assumptions to bracket them out and prevent them from influencing the research. This is done in order to investigate the phenomenon from a new way of perceiving things (Moustakas, 1994; Priest, 2002).

Husserl placed more emphasis on the concept of ‘essences’, referring to the true being of something - the inner essential nature of something - since it is that which makes something what it is. (Munhall, 1994; Van Manen, 1990). Munhall stated “Another important aspect of Husserl’s philosophy was phenomenological intuiting which is considered to be a direct grasping of the essential structure of phenomena as they appear in consciousness” (1994:288). From Husserl’s work arose the concepts of intersubjectivity and live world, the world of lived experiences. Intersubjectivity means that the human researcher needs the other, such as the participant or the reader, in order to develop a dialogic relation with the phenomenon (Munhall, 1994; Van Manen, 1990). The live world is the world of lived everyday experiences. Phenomenological research can help us recognise that which is around us through a new way of looking at things (Munhall, 1994).

Heidegger was the second influential philosopher in the German phase, and is considered the founder of this phase. His main concern was to ask questions about the nature of being (Munhall, 1994). “Heidegger’s philosophical concerns were ontological, he aimed for understanding of ‘Being’ itself, seeking to uncover the understanding of the meaning of ‘Being’ as ‘hermeneutic’ designating it as interpretive rather than descriptive process. The philosophy requires the researcher to know the nature of existence or Being. Being is conceptualised as ‘being-in-the-
world’. Human being cannot exist except in the framework of an encompassing world” (Mackey, 2005:181). ‘Being in the world’ refers to the way human beings exist and act and the way they are involved in the world (Dowling, 2007; Van Manen, 1990).

“For Heidegger time is the horizon from which entity is understandable in its meaning. Being in the world reminds us that our lives are unified and connected within the whole of our significances and involvements. Because human involvement is the clearing that makes all meaning possible, the participants’ experiences and the meaning of these experiences cannot be separated from the whole of that person’s world” (Johnson, 2000:139). Interpretive phenomenology considers that all human experience is rooted in time, and that the experience of time is important to an understanding of Being, and ways of being. Time is experienced and given meaning within the individual’s life world (Mackey, 2005).

Being in the world means that a person does not only exist but that he belongs somewhere (spatial). ‘Spatiality’ places a person in a location. Being in the world has a characteristic of belonging somewhere. Heidegger called the spatial situation the ‘there’. “From the position of ‘the there’ the person is always either bringing something close to them (‘here’), or experiencing it as remote (yonder)” (Mackey, 2005:185). To be situated in the world in a state of care reveals one’s being. The concept identifies the person in the world both in time and space. It is important that the interpretive nurse researcher place the participants’ experiences in space (Mackey, 2005).

Interpretive phenomenology requires the researcher to accept and value the descriptions by the participants as their reality and understanding of the phenomenon. Interpretation starts when the researcher “engages with the phenomenon as his prior awareness, attention and anticipation is directed towards the phenomenon” (Mackey, 2005:182). The researcher continues to listen to and read the descriptions of the participants and interpretation continues as the researcher becomes immersed in the data. However, the researcher has to go “beyond the literal meaning of the participants’ words, but has to pursue the fore structures and the thematic meaning held in the data” in order to achieve understanding (Mackey, 2005:182).

3.3.3 French phase

Three philosophers who are recognised in this phase include Gabriel Marcell (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961). Marcell viewed phenomenology as an introduction to the analysis of being. “Sartre’s goal was to understand. To understand is to change, to go beyond oneself. Sartre expanded phenomenology as an alternate
research method and as a method of inquiry” (Munhall, 1994:289). For Merleau-Ponty phenomenology is considered as an experience of time, space, body and human relationships. It is Merleau-Ponty who made it clear that the effort of described lived experience is explained by phenomenology (Holloway & Wheeler, 1996; Munhall, 1994).

Merleau-Ponty developed the concept of embodiment, the urgency of perception and the need to concentrate on lived experience. He described phenomenology as: “the study of essences, a transcendental philosophy that questions facts about our world more adequately, and a philosophical stance or position that attempts to describe experience as it is lived without concern for how it came to be the way it was” (Munhall, 1994:290). Merleau-Ponty, in Munhall (1994), stated that people experience the world around them by perception, and was of the opinion that perception is an individual’s experience which is dependent on the situation and the external stimuli being recognised (Munhall, 1994).

3.4 SCHOOLS OF PHENOMENOLOGY
According to Holloway and Wheeler (1996) and Morse (1994), there are different schools of phenomenology although their main goal is the same: to gain knowledge about phenomena. The different schools are presented below.

3.4.1 The Duquesne school
This is guided by the ideas of Husserl (eidetic structure), and focuses on the description of phenomena. The goal of eidetic phenomenology is the description of the meaning of an experience as described by those who have experienced the phenomenon since they have a meaning attached to it. In this school of phenomenology the researchers bracket their presuppositions, reflect on the experiences described and intuit or describe the essential structures of the experiences under study.

The description of the meaning of the experience can be achieved by the process of laying aside the natural world in order to view or see the phenomenon as it is in its essence. Reduction is the process of looking at the experience objectively without biases or pre-existing knowledge or conditions that one can bring to a description (Morse, 1994).
3.4.2 The interpretation of phenomena - Heideggerian hermeneutics

The second school deals with the interpretation of phenomena (Heideggerian hermeneutics). Heidegger’s believed that the things of the world should speak for themselves. He asks: What is the nature of [being] of this being? Heidegger was of the opinion that human experience should be interpreted and be understood, not just by describing it. “He argued that hermeneutics [understanding] is a basic characteristic of human existence. Indeed the term hermeneutics generally refers to the art and philosophy of interpreting of the meaning of an object such as text, work of art, human utterances and so on. It should be noted that in interpretative phenomenology bracketing does not occur. For Heidegger, it was not possible to bracket one’s being-in-the world. Hermeneutics presupposes prior understanding on the side of the researcher” (Van Manen, 1990:221). Researchers who utilise the Heideggerian philosophy realise that they can only interpret something according to their beliefs, experiences and preconceptions, which is regarded as part of the research process and cannot be left out (Lowes & Prowse, 2001).

3.4.3 The Dutch school

This school, which combines the description and interpretation of phenomena, has been described by Van Manen (1997) (as cited in Earle, 2010:289-290) as an active and ongoing interplay of six distinct research activities:

1. **Turning to the phenomenon of interest to the researcher**
   “It requires that the researcher be committed to the making sense of phenomenon that he is interested in. Husserl used the term ‘bracketing ‘to describe how researchers must put aside any pre-existing knowledge or assumptions they may have about the phenomenon, however Van Manen (1997) questioned whether it is possible for researchers to truly put aside their knowledge of the subject. He mentioned that it is unnecessary for one to bracket the information that they have but to be responsive in making their knowledge of the phenomenon explicit” (cited in Earle, 2010:289).

2. **Investigating the experience as we live it rather than as conceptualised**
   “Van Manen (1997) suggested that it is necessary for the researcher to become immersed in the phenomenon in order to develop a deep understanding of the nature of the lived experience and find meaning in the experience” (cited in Earle, 2010:290).

3. **Reflection on the themes which characterise the phenomenon**
   Reflection is considered as the first means of discovering the essence of an experience.
Themes are considered to give meaning to the phenomenon. Meaning is obtained from the individual themes that are originating from the experience being investigated.

4. Describing the phenomenon through the art of writing and rewriting, as outlined by Van Manen (1997:30, cited in Earle, 2010:290):

This means being clear about the meaning of something. Writing and rewriting involves making something open or giving appearance and body to thought. It is through the process of writing and rewriting the themes that the meaning of the lived experience is recognised.

5. Maintaining a strong and orientated relation to the phenomenon

The researcher must be aware of the phenomenon and must aim at interpreting it according to the lived experience.

6. Balancing the research context by considering the parts and the whole, as described by Van Manen (1997:31):

“The researcher has to have clear research plans and has to have a clear picture of how the study will proceed and how he will organise the text and work out specific details during the research process” (cited in Earle, 2010:290).

3.5 DESCRIPTIVE PHENOMENOLOGY

The phenomenological tradition utilised in this study is descriptive or transcendental phenomenology. Husserl’s descriptive phenomenology was the philosophical underpinning for the study of the lived experiences of mothers regarding care of their hospitalised preterm babies. In phenomenology the nature of the phenomenon is investigated, and a phenomenon is described as something that is experienced consciously (Polit & Beck, 2006).

Polit and Beck (2006:219) stated that “the descriptive phenomenologist insists on the careful description of an individual’s ordinary conscious experience of everyday life, a description of things as people experience them”. The researcher explored the lived experiences of mothers regarding care of their hospitalised preterm babies. Transcendental phenomenology is a qualitative method of describing the meaning of an individual’s experience (Roller, 2005). According to Earle (2010:287), transcendental phenomenology “relates to the way knowledge comes into being in consciousness and is seen as the rigorous human science of all conceivable transcendental phenomena”.
Van Manen (1990:184) stated that “for Husserl phenomenology is a discipline that aims at describing how the world is constituted and experienced through conscious acts. Phenomenology must describe what is given to us in the immediate experience without being obstructed by the pre-conceptions and theoretical notions”.

It is mentioned that “Husserl (1970) believed that subjective information should be important to scientists seeking to understand human motivation because human actions are influenced by what people perceive to be real” (cited by Lopez & Willis, 2004:727). Husserl believed that there are distinctive elements that are common to people with any lived experience (cited in Lopez & Willis, 2004). The distinctive elements are referred to as universal essences. For a description of the lived experience to be considered a science, there should be commonalities identified in the experience of the participants so that description is possible. The essences are regarded as a representation of the true nature of the phenomenon being studied (Lopez & Willis, 2004).

The researcher utilised descriptive phenomenology since she explored the lived experiences of mothers. The mothers had some things in common. They had delivered a preterm baby, who had to be hospitalised. During hospitalisation their baby was cared for by the nurses and doctors, and whatever happened to the mothers in regard to their delivery of a preterm baby and being involved in the care of the baby while in hospital had meaning for them. The researcher wanted to describe the meaning of that experience without having to neutralise the phenomenon under study with her preconceived ideas. This was achieved by the steps of descriptive phenomenology as presented below.

The study is descriptive in that the question is: What are the lived experiences of mothers regarding care of their hospitalised preterm babies? Mothers who had their preterm babies cared for in the neonatal unit had to describe their experience. The mothers’ narratives were analysed according to the methods of Colaizzi (1978) and Hycner (1985). Findings were reported as theme clusters with examples of participants’ comments that supported these (Lopez & Willis, 2004).
3.6 STEPS OF DESCRIPTIVE PHENOMENOLOGY

Throughout the study the researcher utilised the four steps of descriptive phenomenology, as outlined below.

3.6.1 Phenomenological reduction (bracketing)

An assumption with descriptive phenomenology is that for any human experience there are distinct essential structures that make the phenomenon, regardless of who experiences it (Morse, 1994). Morse (1994) and Van Manen (1990) stated that the essential structures require phenomenological reduction. Swingewood (1991) stated that bracketing is “interpreted as a method whereby all ideas about the external world and its objects such as those acquired through society, culture and history are abandoned by consciousness” (cited in Lowes & Prowse, 2001:472). Through bracketing the research discovers the true meaning or the essence of lived experience. The researcher bracketed any preconceived ideas that she had about the lived experiences of mothers regarding care of their hospitalised preterm babies by discussing things with the supervisors so that the lived experiences of mothers could be presented as described by the participants without being influenced by the researcher’s beliefs (Dinkel, 2005; Kleiman, 2004; Koch, 1995; Morse, 1994; Munhall, 1994; Polit & Berg, 2006; Van Manen, 1990).

3.6.2 Intuiting

According to Streubert and Carpenter (1999), intuiting requires the researcher to be completely absorbed in the phenomenon of interest in order to gain information from the participants’ descriptions. The researcher has to pay attention to what the participants have said without any objections. The researcher has to feel what it would be like to live in the participant’s world (Swanson, 1990). Biases, beliefs and assumptions are acknowledged and suspended. The researcher examines the data in an imaginative way until she understands the phenomenon. The researcher has to ensure that she is not immersed in the phenomenon, which might distract her from looking closely at the participant’s experiences (Dinkel, 2005).

The researcher remained open to the meanings as attributed to the phenomenon by the mothers caring for their hospitalised preterm babies in the neonatal unit (Polit & Beck, 2006). The researcher explained the phenomena as she observed them; she put aside assumptions about the care of a hospitalised preterm baby and listened to the mothers. This allowed the researcher to identify the essence or real intended meaning of caring for a hospitalised preterm baby (Holloway, 2008).
3.6.3 Analysis phase
Dinkel (2005:9) stated that analysing “involves identifying the essence of the phenomenon as presented by participants. Essences are described as concepts or themes that give common meaning and understanding to the phenomenon under investigation. Relationships and connections among and between essences are explored.” The researcher extracted significant statements from data shared by participants. These were then categorised in order to get a clear sense of meaning of the experience of caring for a preterm baby in the neonatal unit. This was enhanced by utilising the steps of analysing data from the transcribed interviews, as described by Colaizzi (1978) and Hycner (1985).

3.6.4 Descriptive phase
The exact components or essences that are described and are common to the phenomenon are isolated and relationships identified. The overall goal of this is to formulate a description of the phenomenon and to describe the essential parts based on essence clarification and formulation of themes (Dinkel, 2005; Streubert & Carpenter, 1999).

The researcher described the lived experiences of mothers who were caring for their hospitalised preterm babies, as presented in Chapter 4 (Polit & Beck, 2006). The researcher described the experiences of the participants by utilising quotes from the data as provided by the participants (Swanson, 1990).

3.7 RESEARCH PROCESS

3.7.1 Study population
The population for this study were mothers who had delivered a preterm baby and whose baby was admitted to the neonatal unit in Princess Marina Hospital. Mothers were Batswana from the different tribes of Botswana. Mothers were able to communicate in Setswana and were aged between 22 and 30 years. They were able to give autonomous informed consent according to the law of Botswana.

The researcher selected the inclusion and exclusion criteria in order to determine which mothers of preterm babies would be included in the study and to control the number of those that qualify to be included in the population (Polit & Beck, 2010). The rationale for the selection criteria were based on the current definition of a preterm infant; the period of time decided upon was to ensure that the mother had sufficient ‘experience’ of the ICU unit to be able to reflect on her
experiences; and the singleton criteria was based on the assumption that the mother’s experience would be different for multiple preterm infants.

Inclusion criteria were as follows:

- A mother who had delivered a baby before 37 weeks of gestation;
- Her baby was in the hospital for more than 5 days; the baby’s condition had improved if the baby had been very ill, and the mother was not too anxious for an interview;
- They had delivered a singleton;
- They were able to communicate in Setswana or English (Mothers were comfortable speaking in Setswana); and
- They were willing to participate in the study.

Exclusion criteria were the following:

- Mothers who did not deliver a preterm infant, but whose baby was admitted to the neonatal unit;
- Mother who delivered a preterm baby with congenital abnormalities; and
- Mothers who delivered multiple preterm babies.

3.7.2 Sampling and sample size

Purposive sampling was used to select participants for the study, this method being based on the assumption that the researcher’s knowledge about the population can be utilised to select the cases to form the sample (Polit, Beck & Hungler, 2001). Participants were those from whom the researcher was likely to best gain information about the central focus or purpose of the study (Burns & Grove, 2005). It is stated that “phenomenological studies are typically based on samples of ten or fewer study participants” (Polit, Beck & Hungler, 2001:248). In this study eight mothers were interviewed twice: the first interview was conducted after recruitment of the mother to the study and the second just before the baby was discharged. Participants were recruited until the point of data saturation. Data saturation occurs when further sampling does not uncover new ideas important for the development of the study, and no new categories or themes emerge during analysis, which shows that data collection is complete (Holloway, 2008).
3.7.3 Choice of participants

3.7.3.1 Gaining access to the organisation

The researcher gained access to the organisation where data were collected by asking for permission from the Hospital Superintendent, Principal Nursing Officer and Nursing Officer in charge of the neonatal unit. This site was chosen because it is the biggest neonatal setting in the southern part of the country. The authorities were informed that they would be provided with a copy of the study findings (Shenton & Hayter, 2004).

The researcher also informed the hospital authorities that there is a likelihood of mothers being emotionally distressed during interviews, and arrangements were made with the social workers for counselling of the mothers. The time schedule was shared with them and they were informed that data will be anonymous to prevent linking information with any of the participants (Shenton & Hayter, 2004).

3.7.3.2 Gaining access to the participants

The researcher asked the nurse who was on duty to introduce her and inform the mothers about the study that the researcher was undertaking. The nurse then left the researcher to talk to mothers about the study. The researcher informed mothers that she was aware that their time was precious, and that their cooperation in what was to be discussed would be appreciated. The researcher established whether the mother was willing to spare some time for her; if the mother agreed, the researcher informed her about the study and its purpose and asked her if she would like to participate. The researcher spent time with mothers, chatting with them in order to build trust with them (Shenton & Hayter, 2004).

3.7.4 Setting

The setting of the study was the SCBU in Princess Marina Hospital, which is a referral hospital in the capital city of Gaborone. The SCBU admits babies from within the city as well as preterm babies from different clinics and district hospitals in the southern part of the country. The unit is very busy and has five cubicles with 45 beds and a maximum capacity of 60 beds. There is an Intensive Care Cubicle within the unit where sick babies are nursed whether or not preterm. Babies in this cubicle are critically ill and sometimes on ventilators.
3.8 ETHICAL CONSIDERATIONS

3.8.1 Ethical approval

The study was approved by the Human Research Ethics Committee of Faculty of Health Sciences of the University of Cape Town (HREC REF: 332/2010). Written permission to conduct the study was obtained from the Ministry of Health of Botswana through the Health Research and Development Unit. The management of Princess Marina Hospital were informed about the proposed study and written permission to conduct the study was sought from the Institutional Research and Ethics Committee. Written permission was also obtained from the sisters in charge of the SCBU and postnatal ward where in-depth interviews were conducted.

The study was conducted in accordance with the Declaration of Helsinki 2008 (http://www.wma.net/en/30publications/10policies/b3/index.html).

3.8.2 Informed consent

After permission to conduct the study was granted, the researcher informed the potential participants about the study. Before making the decision to participate in the study, potential participants were informed about the ethical considerations (Brink, van der Walt, & van Rensburg, 2006). Once the participants had agreed to take part in the study, an opportunity was provided for any questions, and once these were satisfactorily answered, written informed consent was obtained. “Written consent to participate must include the participant’s right to refuse to answer a question, to stop the interview at anytime and re-schedule or withdraw from the study without consequence” (Donalek, 2005:125).

**Autonomy:** The participants were informed about the study and its purpose, and told that they had the right to withdraw from the study at any time they wished without any penalty.

**Beneficence:** The participants were informed that discomfort that they may encounter might be emotional distress, especially during interviews when asked to tell stories of their experiences. They were informed that arrangements would be made to assist mothers who needed referral.

**Anonymity and confidentiality:** The participants were informed that the information obtained from them would be kept confidential. Their names would not be used but rather codes to eliminate the possibility of linking the information to any of them. The participants were given numeric codes as participants. The codes were used throughout the study: for the first interview the information was labelled participant 1, first interview with the date; the second interview for participant 1 was labelled participant 1, second Interview with the date, etc. All the transcriptions were also labelled and stored in a computer which could be accessed by the researcher alone.
**Justice:** Each woman was treated fairly. Women who delivered preterm babies and met the criteria for inclusion in the study were afforded a chance to participate. Even if a woman met the inclusion criteria, she was not forced to participate in the study if she was not willing to do so.

**Benefit:** The participants were informed that the study would not benefit them directly but that the information obtained through the study may influence nursing practice, therefore benefiting mothers and preterm infants in future.

### 3.8.3 Use of transcribing equipment

The participants were informed that the researcher would utilise a digital audio recorder to record their responses while collecting data in order to capture all that they were saying. This would allow the researcher to make an accurate transcription of the mother’s words.

After sharing the above information with the participants who decided to participate in the study, written consent was obtained as the participants understood the implications of the consent for both the researcher and themselves.

### 3.8.4 Researcher-participant relationship

The researcher established rapport with the participants during the time that informed consent was obtained. Informed consent was obtained in a quiet room in the postnatal ward and the relationship was maintained throughout the data collection process. The researcher spent time with the participants as she checked on them every day in the hospital after the first interview until the time of the second interview, in order to promote their trust in her. The relationship was terminated after completion of data collection.

### 3.8.5 Management of sensitive information and need for support

During the time of obtaining consent to conduct the study the researcher liaised with the social workers in Princess Marina Hospital about the possibility of referring certain clients to them if the need arose. A letter was written to the social work department giving details of the anticipated number of participants both for the pilot study and the main study. The social workers were consulted before the commencement of data collection so that any client needed counselling could be referred immediately. No clients were referred to the social workers for counselling, and the researcher communicated with the social workers to inform them that data collection was complete and thanked them for offering to help.
3.9 PILOT STUDY

According to Holloway (2008:187) “a pilot study in qualitative research is a small scale trial run of a larger research project carried out within the same approach, within the setting and with a small number of participants chosen through the same criteria as those in the research”. The pilot study was conducted to help the researcher to familiarise herself with the data collection tool and to detect problems that could be encountered during the main study (Wilson, 1993) such as environmental disturbances. The pilot study also helped the researcher to refine the questions and identify a satisfactory area for the interviews. A pilot study was carried out in the SCBU at Princess Marina Hospital and the postnatal ward. Two mothers who met the criteria for inclusion were approached to be interviewed. The mothers were purposely selected in the SCBU during feeds, and those mothers who showed interest in participating in the study were given details of the study before written informed consent was obtained. Mother-infant interaction was then observed in the SCBU and field notes were taken. In-depth interviews were conducted in a quiet room in the postnatal ward. Each mother was interviewed twice.

The first interview was conducted immediately after obtaining consent. One participant was in the hospital for seven days with the baby admitted to the neonatal unit, whereas the other baby was in the neonatal unit for more than 21 days. The second interview was conducted upon discharge of one baby, whereas the other participant was interviewed just before discharge of the baby. The first interviews were the longest and lasted up to an hour, whereas the second interviews were short, with the shortest lasting 25 minutes. The main question, which was: “Tell me about your experience of having your baby cared for in the neonatal unit” did not yield much information, so the researcher had to gain information through the use of prompts which expanded upon this. Based on those interviews, the research questions were refined.

The participant’s audio-recorded data were kept by the researcher, away from the research setting. The participants were given codes, which were Participant A and Participant B. This protected the confidentiality of the data and prevented the linking of data with any of the participants. The audio-recorded data remained anonymous and transcriptions were coded. Data in the computer were kept confidential; the computer was only utilised by the researcher, and stored in a protected file. Other data on paper, like consent forms, were kept in a locked place to prevent access by anyone.
3.10 DATA COLLECTION

The researcher utilised in-depth interviews as a primary method of data collection. A digital audio recorder was used to record the participants’ responses (Holloway & Wheeler, 1996). Interviews were conducted in a quiet room in the postnatal ward in order for the mothers to feel free to talk about their experience. This also protected the participants’ confidentiality. A second interview was conducted just before discharge of the baby for the purposes of clarification and checking of some information (Andrew & Halcomb, 2009). Each interview lasted approximately 30 minutes.

Although observation as a data collection tool is not required in phenomenological studies, the researcher observed the mother-infant interaction during feeds (Holloway & Wheeler, 1996), in order to enhance understanding of the mothers’ lived experiences of interaction with their infant. Field notes were written by the researcher to record her observations. These were not analysed, merely used to inform the data analysis and facilitate the rich description of the lived experience. For example: The environment where preterm babies were admitted was observed together with mother-infant interaction, so when mothers mentioned something about the neonatal unit environment, the researcher was better able to engage with the mother’s descriptions. Field notes were written by the researcher to record her observations.

3.10.1 Qualitative research interview setting

The interviews were conducted in a room in the postnatal ward. The room was quiet and enabled the participants to be open during interviews. The interviews were terminated when the participants could not share anything more about their experiences.

3.10.2 Preparation of the researcher

The researcher personally collected data from the participants. Her experience as a midwife meant that she was comfortable in this setting, and this promoted rapport between herself and the participants. The participants were interviewed carefully and with empathy. This enabled the participants to trust the researcher, and they were willing to share their experiences without any inhibitions.

3.10.3 The researcher as instrument

In qualitative studies the researcher serves as an instrument to collect data. The researcher has the quality of listening attentively and becomes empathetic towards participants (Leonard, 2004). Sorrell and Redmond (1995:1118) stated that “the interviewer as the research instrument uses responses of the participants to guide data collection, probing for further information as needed
for depth and clarity. The researcher maintains control of the interview but there must be sufficient flexibility to respond to important content responses and general non-verbal cues from the participant”.

The researcher directed the interviews by asking questions. She paid much attention to the participants’ responses, including non-verbal cues like facial expression, talking quietly, especially when the participant showed concern about what they were talking about. Through this the researcher was able to show empathy, by leaning towards the participants and other non-verbal responses, e.g. nodding the head when participants were talking, to show concern and care. The researcher also clarified certain questions when participants showed lack of understanding.

3.10.4 In-depth interviews

Individual in depth interviews were used by the researcher to create meaning from the experiences of mothers regarding care of their hospitalised preterm babies. Sorrell and Redmond (1995:1118) stated that “phenomenological interviewing is concerned with the uncovering of knowledge related to specific phenomena”. The interviews commenced with the question: “Tell me about your experience of having your baby cared for in the neonatal unit”, which is a broad first question, as recommended by Dicicco-Bloom and Crabtree (2006).

The participants were informed that they had the right to refuse to participate, the right to refuse to answer a question, and that they could withdraw from the study at any time they wished to do so without any penalty. The researcher had to decide when to intervene during an interview, such as when the participant was going astray or giving information that was not related to the phenomenon under study. The researcher also had to encourage the participants to continue talking when more information was needed on a certain aspect, to change to a new subject by asking another question, or encourage the participant to elaborate on the current one (Price, 2002).

Probe questions (after Bernard, 2000, as cited in Price, 2002:276) were utilised. The researcher utilised the echo probe by repeating the respondents’ last words and invited them to continue or elaborate on what they were talking about. The researcher also encouraged the participants to say more about the phenomenon by utilising the ‘tell me more’ probe (Price, 2002). The researcher remained silent even when the respondent was not saying anything in between the responses. This helped to encourage the participants to reflect on what they were talking about and to continue saying more on the same topic.
3.10.5 Developing rapport
During in-depth interviews the interviewer has to develop rapport with the interviewee. The interviewee should trust the interviewer, who has to respect the interviewee and the information she shares. The interviewer has to ensure that the interview occurs in a comfortable environment which enables the interviewee to share their personal experiences in exactly the way they happened. “It is through the connection of many ‘truths’ that interview research contributes to our knowledge of the meaning of human experience” (Dicicco-Bloom & Crabtree, 2006:316).

3.10.6 Stages of rapport between the interviewer and interviewee

3.10.6.1 Apprehension
In this stage both the interviewer and the interviewee do not know what to expect because of the new environment. The main aim is to encourage the interviewee to open up and talk. The interviewee is offered an opportunity to think about what the interviewer is saying in order to answer. The interviewer responds by prompting the interviewee, but avoids leading the interviewee’s responses (DiCicco-Bloom & Crabtree, 2006). Although the researcher allowed some pauses as the participants were telling their stories, she used prompts as appropriate in order to elicit certain information.

3.10.6.2 Exploration
The interviewee describes her/his experience and during this process both the interviewer and the interviewee pay attention to each other; as they share information, bonding develops between the two. The researcher who served as the interviewer listened to the participants and allowed them to talk (Dicicco-Bloom & Crabtree, 2006).

3.10.6.3 Cooperation
The interviewee feels free and is not scared of offending the interviewer. The interviewee derives pleasure from the interview process. The interviewer questions the interviewee to clarify certain points, and the interviewee may correct the interviewer as they attempt to understand the interviewee’s experience. This is the time to ask questions that could initially have been too sensitive (Dicicco-Bloom & Crabtree, 2006).
3.10.6.4 Participation
This shows the extent of the rapport established between the interviewee and the interviewer. The interviewee assumes the guiding role and provides the interviewer with information (Dicicco-Bloom & Crabtree, 2006).

3.10.7 Unstructured observation
The researcher utilised observations to gain insight into the interactions between the mother and her preterm baby. The researcher was able to develop a complete understanding of the influence of the neonatal environment on the mothers’ care of their hospitalised preterm babies (Mulhall, 2003).

3.10.8 Formulating the question
Each participant who consented to participate in the study and was ready to share their lived experience was asked the following question:

“Tell me about your experience of having your baby cared for in the neonatal unit”.

The following questions were asked as ‘prompts’ when necessary (as adapted from Padden & Glenn, 1997):

- Can you describe your feelings when you first saw your son/daughter?
- Since you first held him/her, how have your feelings changed?
- Describe anything in the neonatal unit that strongly affected you, for example: made you feel happy or sad, frightened/reassured?
- Tell me about your interaction with the medical/nursing staff in the neonatal unit.
- If you would have anything to make this time easier for you and your family, what would it be?

3.11 THE SCIENTIFIC RIGOUR OF THE STUDY
Validity or trustworthiness in qualitative research identifies its truthfulness or how much the findings of the study are true to what was intended (Holloway, 2008). Trustworthiness refers to the following: credibility, which is the same as internal validity; dependability, which relates to reliability; transferability, which can be matched with external validity; and conformability, which deals with the presentation (Holloway, 2008; Rolfe, 2006). Guba and Lincoln (1989) provide foundations for ensuring trustworthiness, outlined below.
3.11.1 Credibility

“It is linked to the ‘fit’ between the social reality of the participants and their representation by
the researcher. It corresponds to internal validity” (Holloway, 2008:238). Credibility requires
taking the findings to the participants for verification and peer debriefing (Holloway, 2008). It
refers to the confidence in the truth of data (Polit, Beck & Hungler, 2001). The researcher
enhanced the confidence in the truth of the data by utilising two methods of data collection: in-
depth interviews and observation. The researcher also spent as much time with the participants
as possible in order to build trust with them and this is referred to as prolonged engagement.
After the first interview the researcher visited the participants and their babies every day in the
hospital until just before the baby was discharged, when the second interview was conducted
(this took about three to four weeks). Credible data collection that focused on data that were
relevant to the phenomenon being studied was carried out as the researcher kept detailed field
notes. Peer debriefing was enhanced because the researcher’s work was evaluated by the
supervisors who have expert knowledge in research. The researcher also utilised the participants’
codes while presenting the findings in order to ensure credibility (Graneheim & Lundman, 2004).

3.11.2 Transferability

This is the extent to which the findings of the data can be transferred to other settings (Polit, Beck
& Hungler, 2001). Participants were purposively selected for the study and those who could
provide adequate information with regard to the phenomenon being studied were selected.
Although data were collected from eight mothers whose babies were admitted in the neonatal
unit, and are therefore not generalisable, the findings may be transferred to other settings in the
country where neonatal care is provided. Transferability also involves presenting an accurate
description of the lived experience of mothers regarding care of their hospitalised preterm babies
which other future mothers of preterm babies may recognise (Leonard & Mayers, 2008).

3.11.3 Dependability

This refers to “the consistency of data over time and requires an audit trail and peer debriefing”
(Holloway, 2008:238). Verbatim transcriptions and detailed field notes provided an audit trail
(Leonard & Mayers, 2008). “Field notes are ‘analytical in themselves’ in that they contain
immediate and later perceptions and thoughts about the research participants” (Rose & Webb,
1998 as cited in Tuckett, 2005; Tuckett, 2004b cited in Tuckett, 2005:31). They were utilised by
the researcher in order to engage with the data. Field notes were a further data source that
contributed to data triangulation as they were used together with transcriptions from the
interviews (Tuckett, 2005).
3.11.4 Confirmability
This refers to the way data are presented, for instance, being presented in an objective and neutral manner such that different people would agree about their relevance or meanings (Polit, Beck & Hungler, 2001). It demonstrates that the researcher has represented the reality of participants and has contextualised the study.

The researcher ensured that the findings of the study came directly from the data collected to ensure confirmability and an ‘audit trail’ which will enable readers to understand the methodology that was followed (Holloway & Wheeler, 1996). The researcher bracketed her preconceived ideas about the lived experiences of mothers regarding care of their hospitalised preterm babies, and described the experiences as shared by the participants (Polit & Beck, 2006).

3.12 TRANSCRIPTION OF DATA
Interviews were transcribed immediately after they took place in order to identify omissions and spot errors while the interview was still fresh in the memory (Booth & Booth, 1994). All interviews were transcribed verbatim. This allowed the researcher to be familiar with the data while transcribing it. Verbatim transcriptions were important in order to arrange the data into texts and to be in a position to analyse them. This allowed the researcher to capture the pauses, laughter, tears, distractions and occurrences of verbal and non-verbal communication during an interview, as recommended by Hycner (1985).

3.13 PREPARATION OF DATA FOR ANALYSIS
Data were prepared for analysis by translating them from Setswana (the interviews were conducted in Setswana) to English and the researcher typed all the translated data. The Setswana interviews were listened to by a colleague who is a neonatal nurse to verify that the researcher represented the participants accurately while transcribing the data. This was done since the researcher’s supervisors do not speak Setswana. After typing the data, which were arranged according to first and second interviews of each participant interviewed, the data were read, and re-reading of the data allowed the researcher to reflect on the data, which were then ready for analysis. Information that was obtained through observation of mother-infant interaction also enabled the researcher to analyse the data. According to Creswell (2003), the general first step before analysing data after organising them involves reading through all the data in order to obtain a general sense of the information, and to start making notes on general thoughts about
the data. Each interview was read through in order to reflect on the significant statements pertaining to the research question.

3.14 DATA ANALYSIS

3.14.1 Introduction

Qualitative data analysis is defined as “making sense out of text and image data. It involves preparing the data for analysis, conducting different analysis, moving deeper into understanding data, representing data and making an interpretation of the larger meaning of the data” (Creswell, 2003:190). According to Creswell (1997, cited in Starks and Trinidad, 2007:1375), phenomenological data analysis involves the “coding of data from the phenomenological inquiry in which specific statements are analysed and categorised into clusters of meaning that represent the phenomenon of interest”.

Data were analysed according to (Colaizzi, 1978: 59-61) and (Hycner, 1985:280-294):

1. After interviewing the participants, the researcher transcribed the data. The researcher repeatedly read the participants’ descriptions, and listened to the audio recordings in order to familiarise herself with their words. This enabled the researcher to gain a sense of the participants’ meanings.

2. The researcher then returned to participants’ descriptions and focused on words and sentences that seemed important for the phenomenon under study. Every sentence and paragraph was examined closely for significant statements. The statements were isolated and presented as general statements, which Colaizzi (1978) terms “extracting significant statements” and Hycner terms “identifying units of general meaning”.

3. The researcher took each significant statement and made sense of it by utilising the terms as mentioned by the participant, which is referred to by Colaizzi (1978) as “formulating meanings”, whereas Hycner (1985) terms this “units of general meaning”.

4. The process was repeated for each interview and the meanings were organised as clusters of themes and referred back to the data to confirm and validate the emerging patterns.

5. Each theme contained descriptions of participants’ feelings and ideas, and the themes were described as the step called “exhaustive description” by Colaizzi (1978).
6. The researcher then formulated a description of participants’ feelings and ideas, which Colaizzi (1978) describes as an “equivocal statement of identification of the fundamental structure of the phenomenon”.

3.14.2 Stages of analysis

3.14.2.1 Stage one: Interview transcripts
During this stage of the analysis process, the researcher read through the transcribed data. Reading through the data several times enabled the researcher to get a sense of the information as verbalised by the participants. The researcher then noted her reflections against the transcript text. An example of the analysis process is provided in Appendix F.

3.14.2.2 Stage two: Delineating units of general meaning
In this stage the researcher went back to the interview transcripts and extracted sentences or phrases and words pertaining to the phenomenon of caring for a hospitalised preterm baby, noting the significant non-verbal communication in the transcript in order to get the meaning of what the participant was saying (Hycner, 1985). Units of general meaning are defined by Hycner (1985:282) as “those words, phrases, nonverbal or para-linguistic communication which express a unique and coherent meaning”. The researcher tried to stay as close to the original data as possible in order to avoid deviating from the participants’ meaning.

3.14.2.3 Stage three: Extracting units of relevant meaning
The researcher extracted words or sentences relating to the phenomenon under study. Colaizzi (1978) calls this process “extracting significant statements”, whereas Hycner (1985) states that the researcher addresses the research question to the units of general meaning in order to check whether what the participant has said is relevant to the phenomenon of interest. This means that statements not relevant to the question were omitted.

3.14.2.4 Stage four: Clustering units of relevant meaning and/or formulating categories
During this stage the researcher examined each individual unit of relevant meaning in order to get the essence of what each unit meant in relation to the context. The researcher then identified those units of relevant meaning which tended to cluster together, or “whether there seemed to be a common theme or essence that united several discrete units of relevant meaning” (Hycner, 1985:287). The researcher considered the context here, including non-verbal communication, since that differentiated some clusters. Since the researcher’s judgement was exercised and there was a possibility of the researcher’s presuppositions being imposed, the supervisors checked on the researcher’s judgements to verify the clusters. It is important to note that some of the units
of relevant meaning were listed under separate clusters. The researcher went back and forth from the interview transcript to the units of relevant meaning to the clusters of themes, as recommended by Hycner (1985). There was a possibility of overlap of some clusters (Hycner, 1985), and those categories which seemed redundant were excluded.

**3.14.2.5 Stage five: Determining central themes from clusters of meaning**

The researcher examined all the clusters of themes to determine if there was one or more central theme/s which expressed the essence of those clusters (Hycner, 1985). This was done for every interview. The researcher looked for themes common to most interviews, putting together those that clustered to develop a general theme. The researcher identified five central themes, as follows:

- A life uncertain - my baby’s vulnerability;
- An unfamiliar and intimidating environment;
- Experiences of interaction with medical and nursing staff;
- Overcoming fear: Emotional connections; and
- Enabling support network.

**3.14.2.6 Stage six: Description of themes**

Each theme that the researcher identified following the steps above contained the descriptions of participants’ feelings and ideas, and the themes were described; Collaizi (1978) refers to this as an “exhaustive description”.

**3.15 CONCLUSION**

The qualitative research design utilised is a typical research approach to describe the lived experiences of mothers regarding care of their hospitalised preterm babies. Descriptive phenomenology was utilised to explore and describe the meaning of the experiences without neutralising the phenomenon with the researcher’s beliefs and assumptions. The steps of descriptive phenomenology were followed in order to adequately describe the meanings attributed to the phenomenon of caring for a preterm baby by their mothers. The steps include phenomenological reduction, intuiting, the analysis phase and the descriptive phase. During the analysis phase the researcher extracted significant statements from the data shared by the participants, which were then categorised in order to get a clear sense of the meaning of caring for a hospitalised preterm baby. This was made possible by utilising the steps of analysing data
CHAPTER 4: PRESENTATION OF FINDINGS

4.1 INTRODUCTION

This chapter discusses the themes that emerged from the data during the process of data analysis. Mothers described their lived experiences of having their preterm baby cared for in the neonatal unit. Eight mothers who delivered a preterm baby were interviewed twice. The first interview was conducted five days after admission of the preterm baby, at which point the researcher believed that the mother was not too anxious to be interviewed. The second interview was conducted just before the baby was discharged home although one participant whose baby died was interviewed before she was discharged. Though the researcher felt that the participant should not be interviewed for fear of the possibility of emotional distress, the participant insisted that she be interviewed. The researcher avoided prompting the participant for more information but asked the participant to tell her experience. The participant however did not develop emotional distress.

All babies of participants in the study were admitted to the SCBU in the hospital, although not all of them were born there. Participant 1 (P1) who was 27 years old, P2 who was 28, P3 who was 27, P5 who was 30, P6 who was 27 and P8 who was 30 delivered their preterm babies in the institution where the data were collected. The babies were admitted to the SCBU for prematurity and its complications, such as patent ductus arteriosus. P4, a 23-year-old woman whose baby was nursed in the SCBU, delivered in another hospital and was referred from outside Gaborone. P4’s preterm baby was delivered with a birthweight of 1000g and the baby was referred with chronic lung disease. P7, aged 30 years, delivered in the institution where the data were collected after being referred from a clinic in Gaborone for premature labour.

P3’s baby was admitted to the intensive care cubicle for severe prematurity, and the baby died. P8’s baby was also admitted to the intensive care cubicle, recovered, and was transferred to the premature babies’ cubicle where he was nursed in the incubator. Other preterm babies were nursed in incubators and radiant warmers in the premature babies’ cubicle to stabilise their condition for the first 24 hours. The babies remained in incubators while on intravenous fluids, receiving oxygen, until their conditions were stable or they weighed 1300g. Then they could be nursed in cribs in another cubicle for weight gain. Two of the babies were transferred to the kangaroo room situated in the postnatal ward for a few days before they were discharged home. In the kangaroo room participants provided KMC for their babies, although they still went to the
neonatal unit to weigh the baby and get the baby’s medications. This prepared mothers for the discharge of the baby.

All the participants volunteered to participate after being informed about the study that the researcher was undertaking by a nurse working in the unit. The researcher was introduced to the participants, after which she informed them about the study with the knowledge that they could provide her with information regarding her study (purposive sampling). The participants were interviewed in a private quiet room in the postnatal ward after consenting to participate in the study.

Participants were shocked by the unexpected delivery of their preterm baby. Their trauma was increased by the separation from their baby, who required nursing in the SCBU while the mothers were admitted in the postnatal ward. Although mothers had the chance to see their babies in the delivery unit, the babies were immediately taken to the neonatal unit where they were nursed in incubators.

Since mothers were involved in the care of their preterm baby, they went to the neonatal unit every three hours to interact, feed the baby, sponge the baby’s body and change the nappy. Initially the neonatal environment aggravated the participants’ fear and anxiety, since they were afraid of the equipment in the unit and other unexpected things that they saw there. This affected mother-infant interaction, but with the support of the staff, other mothers and their families, mothers eventually developed an emotional connection with their babies. The joy of being discharged from hospital was of utmost importance to the mother as she now had hope, since the baby she continued to feed had survived the initial traumatic and critical period in SCBU; however, mothers were anxious that something might happen to the baby while at home.

4.2 THEMES THAT EMERGED

Five themes that emerged from the lived experiences of the participants are described. These themes interlink with each other, and the experiences of the participants can be described as cyclical. The series of events which happened to the participants demonstrate how one factor affects another, such as the increase in the mother’s fear and anxiety when the baby’s condition deteriorated, or a decrease in fear when the condition improved. The themes are described as follows:

- A life uncertain - my baby’s vulnerability;
- An unfamiliar and intimidating environment;
- Experiences of interaction with medical and nursing staff;
- Overcoming fear: Emotional connections; and
- Enabling support network.

4.2.1 A life uncertain - my baby’s vulnerability

The birth of a preterm baby was a traumatic experience to the participants, who did not expect to deliver their baby too soon. They were denied the psychological preparation for the birth of their baby which happens during the last months of pregnancy. Participants were shocked by the sudden onset of the delivery and they experienced both emotional and psychological stress. They felt disappointed and frustrated because they could not carry their baby to term. Participants had to deal with feelings of uncertainty. They experienced fear and anxiety because they did not know whether the baby, born before his or her time, would survive. The baby looked so small and the physical appearance of the baby made participants afraid, because they did not expect to deliver such a small infant. The small size of the baby also suggested to participants that the baby was vulnerable. Since the delivery of the baby was unexpected, participants felt afraid when seeing the baby for the first time:

“After delivery ... after delivering him like I said I did not expect that the baby will be so small. I was scared because I was even feeling cold and took off the clothes that I was wearing.” (P7)

Participants yearned to handle the baby but were afraid of doing so since they thought that they did not know how to do it. They doubted their ability as they feared that handling could damage the baby. The participants felt incapable of handling the baby and felt that they could not do so because the baby was small. They felt that they were going to fail to assume their expected parental role, and this made them afraid since they were wondering how they were going to cope. Even though they were afraid initially, they eventually managed to handle the baby while performing the caring activities:

“Aah I was afraid of him, he was too small. I didn’t know how to handle him though I ended up handling him and changing his Pampers nappy.” (P1)

Participants were initially afraid of touching the baby, as they felt that this might hurt the baby since they looked so small and vulnerable. They described the baby as being “soft” and were unsure of how they could handle the baby without causing some pain or harming the baby.
“At first I was scared, seeing him ... wondering how aah am I going to handle such a very small baby? I also thought that ... the baby was ... very small and soft, handling him might hurt him since his hands are not yet proper.” (P1)

Although they wanted to interact with the baby, to touch and hold the baby, at the same time they were afraid as they did not want to cause any harm like “breaking him”. Participants described their baby as being “too thin”. The presumed vulnerability of the baby initially affected the interaction of the mother with the baby:

“I was afraid of touching him, wondering where I am going to touch him, whether touching him will break him or not ... the body was too thin.” (P7)

The participants did not expect or believe that their preterm baby would survive, mainly because it was their first time seeing such a small baby. To these participants the baby’s size was attributed to the baby’s prematurity, as previously mentioned, which made them fearful since they felt that the baby would not adapt well to extra-uterine life:

“I did not even expect that the baby will survive because it was my first time to see that ... as I was shown the baby that the baby can be born so small.” (P7)

The baby also looked different from other babies that the mothers had seen before, and since that was not a normal happening, they felt that the baby might not survive. The participants felt that even if the baby was alive, he or she might be alive only for a short period of time. The participants’ fear for the survival of the baby delayed the development of a relationship between them and their babies:

“Mmm! The baby was too small ... you could not believe that he will survive for a longer time. I used to see babies but I never saw a baby born that small. I was wondering how this one is like, wondering whether he will survive or not.” (P2)

Although separated from their infants, participants in this study were involved in the care of their preterm baby. The babies were sick after delivery or needed care to stabilise them while being nursed in incubators. Anxious about the outcome of the condition of their baby, their feelings oscillated between hope and hopelessness. Participants were hopeful that their baby would survive when the condition of the baby seemed stable. This was assumed when the baby was feeding well and gaining weight. They desired to be close to the baby by expressing their love to the baby and staying with the baby for a long time in the neonatal unit. When doing this they experienced less anxiety:
“Sometimes when you get there you feel like pouring your love to your baby, wanting to stay with him for a longer time.” (P2)

Participants were reassured when the condition of the baby improved, and they then felt that the baby would survive. When this happened they felt as if they had accepted the arrival of their preterm baby, although they still experienced anxiety about the baby’s condition, since it fluctuated:

“Yes today I have accepted that the baby is born, he will grow though his condition changes sometimes.” (P7)

The participants’ anxiety increased when their preterm baby’s condition deteriorated. The deterioration in the baby’s condition created a form of separation from the mothers and their baby since they became afraid of the baby, just like they were afraid of the baby initially when they first saw him or her:

“Sometimes when you find that his condition has changed, you want to leave immediately. Due to that change in his condition you become afraid of the baby just like the first time you saw him.” (P2)

The participants felt frightened when they realised that their baby had stopped breathing. They felt afraid as they thought that the baby was not alive and this made them very anxious about their baby’s condition and its prognosis. An increase in the mothers’ anxiety led to fear of the baby, which became a barrier to building a relationship with their babies:

“I was frightened because the baby was not breathing. I was wondering whether he was dead or what was happening to him.” (P4)

Participants felt afraid if any unusual thing was happening to the baby. One participant was frightened and became so anxious about the baby’s condition when she found the baby with secretions from the mouth and nostrils, as she thought that the baby was not breathing:

“He had a lot of foam from his mouth and yellow stuff from his nostrils. This is one of the things that frightened me as I was wondering aa if a person can have yellow stuff from his nostrils. When that was happening, I thought he is not breathing well, you see because aa, hee.” (P7)

The participants were worried about anything abnormal happening to the baby as this increased their concern about the infant’s well-being. They asked questions about whatever seemed to be
affecting the well-being of the baby in order to get clarity from the nurse. They wanted an explanation for whatever they did not understand:

“Last time I asked the nurse about the fact that my baby experienced eye discharges every time the light was put on and whether that does not affect him.” (P7)

When the baby was losing weight, the participants were worried because loss of weight could be a sign that the baby was unwell. The participants were worried until the baby started gaining weight again:

“You wonder whether the baby is sick or what could be the problem.” (P2)

The participants were concerned about the safety of their baby and were always on the lookout for anything that signalled danger to the baby. They had been informed that a preterm baby is sensitive and susceptible to infection and were cautioned about the importance of the cleanliness of the equipment. This made them alert to anything that was potentially harmful to the baby:

“They took the oxygen hood back to my baby after the other baby died, you see and this they did without cleaning the hood. I then complained to that lady that what they are doing is not good. They are causing bad luck to my baby.” (P4)

The participants went to the neonatal unit every three hours to interact with the baby and provide caring activities such as feeding, changing the baby’s nappy and cleaning the baby’s cord. This made them uncomfortable as they were always concerned about how they were going to find the baby when they got to the neonatal unit. They felt that it would be safer if they were allowed in the neonatal unit more often in order to ensure the safety of the baby, as they began to realise that nurses were not with the babies all the time. Participants felt that some of the babies who died, had done so because they had a problem which could not be promptly identified and there had been an inadequate response:

“Some babies lose their lives because they were not identified or seen. So when you are there ... going to the neonatal unit more often, I think it is safe. ... This would even assist nurses because I think some things happen when they are not aware. At first I thought they do not care, because I thought when somebody is allocated to the room, he or she has to be there full time observing the babies but it is not like that. They stay at the reception area while the babies are there.” (P7)
4.2.2 An unfamiliar and intimidating environment

When the participants arrived in the neonatal unit their fear was exacerbated by an unfamiliar and frightening environment. They were overwhelmed by the strange equipment that was used, especially that used to stabilise the baby’s condition within the first 24 hours after birth. The intravenous lines, feeding tubes and oxygen equipment made the participants afraid of touching the baby because they thought that something might go wrong if they did so; this affected mother-infant interaction. Seeing other sick babies was unexpected and added to the fear that they experienced in respect of their own infants:

“You might have seen your baby but seeing so many of them is scary because some of them have many drips with so many other things on their chest and nostrils.” (P7)

For some participants the incubator with the alarm was anxiety-provoking as they feared for their baby’s safety, not knowing how to open the incubator or how to work with it, which further increased their overall sense of fear. The incubator with its constant alarms and noise was frightening to participants, since their infant was inside the incubator and they did not understand what was happening. Participants were concerned about the safety of their baby while inside the incubator, especially during their first days in the neonatal unit when they did not know how to open it. The incubator initially prevented physical contact between participants and their babies:

“You know where those babies are ... isn’t it when you get there, you do not know the equipment, where the baby is and where the baby is kept. When you get there, the first thing that frightens you is the machine that the baby will be kept in, as it alarms since you will be wondering what is happening, you see.” (P5)

The strange and unfamiliar equipment used on the baby created more anxiety among the participants, especially if the equipment was not explained to them. Participants wanted to be informed about the equipment used on their baby and to be informed about the function of it in order to allay their anxiety:

“Sometimes you will find her on ... I do not know what battery it is. It used to be placed on her abdomen. I did not know what it was.” (P6)

Participants were frightened when they arrived in the neonatal unit since everything was unexpected, strange and overwhelming. They did not receive orientation to the SCBU environment, which seemed to increase their anxiety and fear of coping. They felt that they could have been prepared psychologically by being told what to expect when they arrived in the unit.
and be orientated to the unit on arrival. This overwhelmed the participants initially and affected their interaction with the baby:

“We could have been told that the people in the neonatal unit are different from those outside the unit. Do not be surprised by what you will see, because they do not breathe on their own, they are assisted to breathe. They have a breathing problem and others have heart problems ...” (P7)

When one participant was in the SCBU to interact with her baby she sometimes saw babies who were not alive since they were not breathing. This made her afraid because she felt that a mother should not have the experience of coming to the unit and finding her infant dead. She felt that babies who had died should be removed from the unit so that the other mothers would not have to deal with this as well:

“Other things which were frightening are babies who were dying. You will find a baby who has long died kept for a long time. It is you who will tell yourself that the baby is dead ... isn’t it that the baby has to breathe.” (P7)

The neonatal environment exacerbated the participants’ fear for the survival of their baby. They were worried when their babies lost weight, since they associated this with deterioration of the infant’s condition and the possibility that the infant could die. Their fear was fuelled by the belief that infants with very LBW were more vulnerable. The fear that participants experienced while in the neonatal unit delayed the development of a relationship with their babies:

“You will hear one mother saying my baby is weighing ... because at first I delivered him weighing one point four (1.4kg) and his weight dropped, dropped and dropped until he weighed ten something. I wondered if he would end up weighing 500g as his weight dropped or not? This is because I heard that some babies were weighing 650g and these are the babies who were going, even that of one point one (1.1kg). I also wondered aa if my baby is also going.” (P7)

While in the unit the participants met with other mothers who had babies there. Participants saw other mothers’ babies dying and this made them afraid as they thought that their baby might also die. Every time the participants went to the unit, they were worried that they might find their baby dead:

“What is frightening is that we are sleeping with other mothers who also have babies in the same room as mine. Sometimes when we come, maybe coming for a three o’clock
feed or any other time, you will find that baby dead. That is what frightened me thinking that maybe one day, when I come here, I will be told that my baby is no longer alive. Yes.”

(P8)

Although the technological environment was intimidating, as they spent more time in the unit and were informed about prevention of infection, they felt more reassured. The participants felt that their babies were in a safe environment, as the rooms were clean and it appeared as if there was a commitment to cleanliness and prevention of infection:

“It's ... where the babies are, is very clean. It seems as if they clean every time we leave. I have never seen that place dirty.” (P8)

Participants believed that the neonatal unit environment had less bacteria and or germs that could infect their babies while in there as it was clean. They felt satisfied with the cleanliness of the place and thought that their babies were less likely to be infected:

“Where my baby ... where they are admitted ... I was made happy by the cleanliness of the ... the way those women clean their areas. They clean; they make sure that they clean the place when we go. It is always clean to avoid bacteria ... to prevent bacteria and germs among the babies. The place has to be clean.” (P1)

The cleanliness of feeding utensils such as feeding cups also reassured the participants, who felt that their babies were safe from infection. The participants were informed that a preterm baby’s immune system is not well developed and the baby can easily be infected. So when they saw that the feeding utensils were sterilised and cleaned before and after feeding the baby, they felt that their babies were free from the likelihood of infection that could be caused by dirty feeding utensils:

“We have been taking what we use to clean the utensils from the neonatal unit and we take good care of them.” (P5)

“Mothers clean the feeding utensils for feeding babies but they are provided with sterilising pills to clean the utensils with.” (P8)
4.2.3 Experiences of interaction with medical and nursing staff

When the participants were in the SCBU they had varied experiences of interaction with staff members. While overall participants felt that staff members related well with them, there were participants who described poor interaction with the staff. Participants’ experiences of interaction with staff members have been categorised into positive and negative interactions.

4.2.3.1 Positive interactions with medical and nursing staff

Good interaction between staff and the participants in the SCBU allayed their anxiety and enabled them to develop competence in caring for their preterm baby. The participants were reassured when the staff members answered their questions and provided adequate explanations. When nurses offered explanation about what the participants needed to know, they felt that nurses were being considerate and thus interacting with them as they expected. Participants felt that nurses explained what they expected to know every time they requested this:

“There is good interaction this time. I am considering the fact that you will be asking the nurses about the condition of the baby, she will be patient enough to explain.” (P8)

The interaction that was perceived as good by the participants made it easier for them to provide their caring activities and to interact with the baby. Participants felt that the staff explained how they should take care of the baby and were pleased with the way they related to them:

“So there is good interaction with nursing staff. They explain to us how we should do things. There is no problem between us.” (P1)

Staff members who communicated well with the participants enabled them to realise that they were partners in the care. Participants felt that staff members informed them if they could not offer them assistance immediately when they called for help, and that they would do what the participants asked for as soon as possible if they were not held up:

“Most of the time when you call a nurse, maybe the baby unwell, it depends on what the nurse was doing. If he/she is still doing something, he/she will tell you that he/she is still busy and that you should wait for him/her. If he/she is not doing anything, he/she comes immediately to ... so there is good interaction with nursing staff.” (P1)

Although participants sometimes found it difficult to wait when they needed assistance, they appreciated that staff communicated with them when they could not offer them help immediately:
“There is good communication between the mothers and the nurses. It is only that sometimes it is very difficult to accept some situations as they come”. (P8)

When the participants were provided with information by staff members and shown how to take care of the baby, they felt encouraged as they were reassured and became confident in taking care of the baby. They were informed about the importance of washing hands before touching the baby in order to prevent the spread of infection. The participants for whom this was a first baby found the explanations of how to provide care for the baby very helpful:

“When you arrive in the unit ... especially with a premature baby ... because I did not know that you have to wash hands ... how to feed him. I did not know that I do not have to bathe him while still here. I was taught by doctors and nurses since the baby is my first baby. They taught me that I should wash hands before handling the baby and even after feeding the baby to avoid spread of infection.” (P2)

The participants were informed about the routine of the unit and when they were expected to come to the unit. They were told about feeding times in order for them to come to the unit then to feed the baby. This enabled mothers to fulfil their parental role as they provided care for their preterm baby:

“The other thing concerning interaction is that mmm, when you arrive in the neonatal unit for the first time they explain everything to you. They tell you that before you touch the baby you should wash hands and even before feeding the baby if you were sponging his body. They tell you feeding times, that feeding is done at 6am, 9am, 12 midday and 3pm, etc.” (P8)

The participants experienced less anxiety and were reassured when the nurses and doctors explained the condition of the baby to them and the procedures done on the baby. Explanation of the condition of the baby to the participants helped them to realise the seriousness of it and prepared them psychologically for complications that could occur. Explanation of procedures also allayed the mothers’ anxiety. This promoted mother-infant interaction as mothers felt that they were informed about the prognosis and condition of the baby:

“They did the chest X-ray and the head X-ray the following day. These they did at the same time. Then they told me that the X-ray revealed bleeding from the lungs. The way they told me the disadvantages of bleeding from the lungs ... I ended up accepting the situation though nowadays his condition has improved.” (P3)
The participants felt reassured when the doctors answered their questions in relation to their baby’s condition, the procedures and reasons for these. They wanted to know the causes of their babies’ conditions and felt reassured when doctors explained the possible causes. The participants were also reassured by the doctors when they explained the prognosis of the babies’ condition:

“Even when I ask them what something is, why they are doing something? They normally tell me. Yes I was even asking them last time when they were doing scan on his head. They explained to me why they were doing it.” (P4)

“The doctor explained to me what caused that. Why it is like that? I asked him what the dark colour in between was, and then he told me that the dark colour showing on the scan is blood that affected the brain. He then told me that the baby will be hopefully fine since he is on treatment. The next time they did the scan the colour was fading on the side, the dark colour was not so dark like before. So I asked him why the colour was not so dark. He said it shows that the baby is responding to treatment.” (P4)

Four of the participants felt that doctors were helpful and five of them felt that the nurses were helpful. Staff were perceived as helpful if they offered the participants what they needed, which could be in the form of explanation or provision of something that the participant needed to use while caring for the baby. Nurses and doctors were perceived as helpful if they provided satisfactory answers and assistance, but as unhelpful if they did not do so. The helpful nurses and doctors reassured the participants as they realised that they cared about their babies and wanted what is best for them. Helpful staff members enabled mothers to fulfil their parental role and to interact with the baby, and this was appreciated:

“Mmm! The way I see it in other words is that nurses and doctors are so helpful. If it was not for them maybe our babies would not be where they are. Yes, Ma. They provide us with whatever we have to utilise in caring for babies. They also explain how we should use them in providing the care.” (P1)

Participants felt that the doctors listened to them and respected their decisions as they were involved in the care. They felt that when they said something contrary to what the nurses were saying about the baby’s condition, the doctors listened. The participants had the courage to advocate for their babies and felt that the doctors were willing to help:
“Sometimes when I tell them that my baby is on and off, they listen to me. Last time they wanted to discharge the baby but I told them that the baby has changed. I did not want the nurse to do that on my behalf and they listened to me.” (P4)

Six of the participants were pleased with the way the doctors and nurses were taking care of their baby, especially when their baby was gaining weight. They were happy that the doctors and nurses had met their expectations and provided satisfactory care to their baby. This reassured them and gave them hope that their baby would one day be well:

“Aah! I feel great, I feel fine. I am just okay; I do not have problems with my baby as long as he is growing ... and well cared for. I am happy with his care. I mean that they have moved the baby from the prem cubicle to the intensive care one. While at the prem cubicle his health was deteriorating.” (P3)

Participants felt that doctors and nurses were taking good care of their baby and were happy with the care provided:

“They are doing well; there is nothing that I can say I am not happy about.” (P1)

Four of the participants felt that they were supported emotionally by staff members when they reassured them about the baby’s condition. They felt supported when staff members encouraged them to interact with the baby, even though they found difficulty in providing care due to their fear of touching the baby. This helped them to perform their parental role as nurses encouraged them not to be afraid of the baby, to touch the baby, feed the baby and perform other caring activities:

“I was afraid of him. I was seeing another person not knowing how I am going to handle him, change his nappy and even get used to him. It was a bit difficult but I ended up touching him. There is a nurse who told me not to be afraid of him because it is me who is going to take care of him while they show us how to take care of them.” (P1)

One participant experienced difficulty in interacting with her baby because she had lost her previous baby, who had been born prematurely the previous year. This had reawakened her memories of the loss, and raised fears that this infant too would die. She was counselled by the nurse and after being reassured, she was able to interact with her baby. The support the participant received from staff members enabled her to overcome her difficulties and interact with the baby:
“She then comforted me and told me to focus on the now and forget about the past. She said we should focus on the positive side and hope that the baby will be well. I felt better after talking to that nurse on the twenty-seventh.” (P8)

4.2.3.2 Negative interactions with medical and nursing staff

Although five of the participants felt that there was good interaction between them and the staff members, three of the participants felt that their interaction with the medical and nursing staff was not good at times, yet they acknowledged that some of the staff members interacted well with them. Due to the differences in interaction that staff exhibited, these participants found difficulty in trusting staff members, which also undermined the confidence of mothers when caring for their baby. The participants felt that some nurses, when they had their own personal problems, did not interact well with them:

“Hei! Myself I don’t think there is any interaction ... well this one and that one because we are from different families. Some would go ... and would come with their moods from home.” (P7)

Participants felt that there were nurses who interacted well with them, and those who did not interact with them the way they expected:

“The nurses are not the same, you see. There are those that treat us well and there are those that do not treat us well.” (P4)

One participant felt that she was not provided with information on how to take care of her preterm baby on her first day in the neonatal unit. The participant expected to have been shown how to provide care, and this made her feel helpless as she did not know what to do. Lack of information on how to care for a sick preterm baby affected the participant’s ability to interact with her baby as she was new in an unfamiliar environment:

“Heishi! No that which affects ... that which affected me the most was on my first day. When I arrived in the neonatal unit there was no, what is it..? We were not told anything about care of those babies.” (P7)

Two of the participants were concerned and upset when their baby had had a problem and the doctors and nurses delayed when they called them for assistance. This increased their anxiety as they felt that the staff “took their time” in responding to their request. Participants became concerned as they felt that it would be better if they were assisted at the time that they expected:
“Mmm! The other thing is when you call the nurse that will be working in an area at that particular time. He/she will behave as if he/she is tired. He/she will say no, I will check on you then he/she takes ... not knowing what you are calling him/her for. He/she comes at his own time so much that maybe if he attended you on time when you called him that would be better. They take their time.” (P7)

The participants were aware that staff members, especially doctors, also had responsibilities for other infants in the unit, and that the delay was sometimes caused by the need to provide treatment to other sick babies, such as resuscitation of a baby:

“Sometimes when you call them, they would seem as if they are delaying yet they also have a way of doing things since it is not only your baby. This can also hurt you if you do not understand the way the doctors function because with these small babies the doctors are always needed, you see.” (P5)

Two of the participants were dissatisfied with the care, especially when there was poor interaction between the mother and some of the staff members in the neonatal unit. Participants felt they did not get any help with the routine care, such as nappy changing, and that if for any reason the mother did not go to the unit at the appointed time, the infant might be neglected:

“Mmm! What made me sad is ... you will find your baby there ... not taken care of ... nappy not changed. If you happen not to go to the unit because you were not feeling well, by the time you go there to check on her, you will find the baby in the same sheets and the nappy not changed.” (P6)

Two of the babies were moved to the kangaroo room after their conditions had stabilised, so that the participants could provide KMC to their baby while waiting for the baby to gain weight. While in the kangaroo room participants were not happy with care the staff provided to their baby; they felt that the staff did not regularly check in on them in order to take care of the baby’s needs. This made them anxious because they felt that their babies were not given enough attention despite still being in the hospital:

“Can you see that ever since we came to that room, there is no nurse who has come there? This means that even if the baby can be feverish, or be ill, it is still one who has to go back there. I mean the baby is not discharged, when they say that the baby should go to the kangaroo room, they should make sure that they check on the baby every morning just like they do to those that are that side.” (P5)
Participants became more anxious and more fearful when the treatment of the baby was not explained to them, since they felt that they did not know whether a particular treatment (such as a blood transfusion) was helping the baby or putting the baby’s life in danger. They needed to know the reason for the treatment and whether it was expected to be effective. Although they felt that they did not know the reason for the baby’s treatment, they had to comply with what was expected of them because they were concerned about the baby’s well-being:

“When the baby is sick, they collect blood and tell you that they are collecting blood to check the baby’s blood group in order to give the baby some blood. They will never tell you why the baby is receiving blood, what happened to the baby’s blood. What happened or the baby does not have blood or has problems in order for you to understand. As a parent, since you want to protect the baby though you do not know whether you are putting the baby’s life into danger, they end up collecting blood from you to check the blood groups as they were saying and give the baby some blood without explaining anything to you.” (P5)

The participants also felt that they should be informed before the baby was commenced on treatment so that they were aware of the reason for giving it and could be involved in decision-making about it:

“Even when giving medications, they do not tell us what the medications are for.” (P6)

“You would find the baby on a drip yet you have not been told as a mother, not knowing what the baby lacks.” (P6)

The participants’ anxiety increased when they did not receive sufficient information about their baby’s condition and prognosis. They needed the staff to communicate with them about the baby’s progress while on treatment. The participants were concerned when the baby was not given anything orally as they were not given an explanation for this. They felt that explanations would help them understand the situation:

“I was wondering how the baby will survive, whether the baby will survive because of oxygen. So I asked other mothers by telling them that I have a baby who has not eaten for two days ... the first day ... yes, I saw him, but just looking at him and not doing anything. The following day ... not giving him any food but wondering aa if the baby will live?” (P7)

Participants felt that they had to be told before any procedure was done on the baby. They wanted the staff to explain the reasons for doing the procedure on the baby in order for them to know. The participants felt that they had to be told about the blood results:
“Even before collecting blood from our babies, they have to sit down with us and let us know. They have to explain that they are collecting blood and what blood is collected for so that the mother may know. When the results come, they have to tell the mother that since they collected blood, the results are like this and that.”  (P5)

The participants’ stress increased as they felt that they were not adequately informed of the baby’s progress while on treatment, unless they were able to observe an obvious improvement in the baby’s condition as a result of treatment interventions. They also felt that the staff members should communicate with them about the procedures done on the baby while they were not in the neonatal unit:

“All we do is to go, do what we are supposed to do and go back. They never tell us what has changed and what has not changed and how the baby is doing health wise. Yes.”  (P6)

“Sometimes you would find blood on the sheets, not knowing whether the baby was injected or what and they would not tell you.”  (P6)

Five of the participants felt that nurses were not helpful at a particular time when they needed assistance, and two of them felt that doctors were not helpful. Participants felt that they were not assisted properly when an option was suggested other than what they expected:

“Sometimes when the baby ... the feeding tube that she used to drink with was out and when you tell the nurse that it is out. He/she would tell you to feed your baby with a cup. Sometimes when lifting the baby to change the sheets, he/she would say, ‘lift that baby, she is yours’.”  (P6)

When doctors and nurses could not provide the participants with an explanation or answer their questions, participants became more anxious since they did not know what to expect. They felt disappointed as it seemed that doctors were not willing to provide explanations and the nurses seemed unable to assist:

“When you go to the nurse, the nurse asks you why you came to him/her yet you found the doctor attending to the baby. He/she will tell you that he/she does not know anything. When you tell the doctor that he/she is the one doing this and that, that he/she is the one to explain, he will refuse to tell you. You will end up giving up and the doctor is the one ... are the ones that I see putting up drips on babies.”  (P5)

Three of the participants felt that some nurses and doctors did not act responsibly while they were in the neonatal unit. They felt that they shifted their responsibility to others, especially
when asked to explain something. Due to lack of communication of some staff members with the participants, they asked the staff questions in order to understand; however, some nurses were not willing to explain but rather referred them to other staff members for explanations:

“Some did not care when we asked them. When you ask somebody: ‘Why is the baby like this?’ He/she says the doctors are the ones who know.” (P4)

The participants felt that they were pushed from one health professional to the other, and were unhappy at the way the doctors fobbed them off and referred them back to the nurses:

The doctors were also … when you come to the doctor and tell him that you found him doing this on the baby in order for him/her to explain what he/she was doing, he/she would tell you to go and ask the nurse.” (P5)

Three of the participants felt that they were not supported by staff members at a particular time when they needed their support. Participants felt that they needed to be told the reasons why the baby was admitted to the SCBU and be counselled, although they convinced themselves to try and cope with their situation. Lack of emotional support for the participants, such as no counselling by staff and showing concern and care, increased the mothers’ anxiety:

“I was not … I think I was not welcomed the first day. Even today there is no one who ever told me that you delivered a premature baby … because I thought I needed counselling, you see yet I told myself that I should be strong.” (P7)

When nurses talked to the participants in a manner that they felt was unacceptable, especially when the participant needed something and tried to ask for assistance, they were emotionally affected. This discouraged them because they expected staff to assist them in order for them to take care of the baby, whom they were looking forward to recover and gain weight:

“So when a person talks to you like that yet you want your baby to get well, to grow and be discharged from there you can end up being hurt if you are not able to control your feelings.” (P8)

4.2.4 Overcoming fear: Emotional connection

Initially the participants were shocked by the delivery of their baby because they did not expect to deliver so soon. Their parental process of psychological preparation was interrupted. They
were emotionally unprepared for the sudden onset of their delivery, which happened so quickly. When the participants first saw their small baby, they were surprised by the size of their baby:

“I did not expect to deliver such a small baby ... a baby that small.” (P2)

Participants who had previously delivered full-term babies were more affected by the trauma of preterm birth as it was their first time to deliver a preterm baby. Their expectation of the delivery of a normal-term baby disappeared immediately. Participants wondered why they delivered a preterm baby and were shocked, since it was unexpected:

“My experience is that I did not expect to deliver a preterm baby because it has never happened to me. It was such a shock to me.” (P7)

After seeing the baby for the first time, participants had difficulty in accepting the baby. They found it hard to understand and it was difficult for them to accept the baby because the baby was too small. They could not cope with the reality of the situation and reacted negatively, such as going away from the baby in order to avoid seeing him or her. They had questions, were emotional and uncertain and blamed themselves:

“I was wondering why it happened to me to give birth to such a baby ... to such a small baby, I became too emotional and left him.” (P2)

This participant could not cope with the situation and burst into tears. She could not think of this small infant as the baby that she had expected, and found it difficult to be convinced that this infant was indeed hers:

“I cried while looking at him wondering whether mmm thinking that he is not a baby even if people can say what.” (P7)

As time went on, the participants managed to overcome fear as they interacted with their infants. They were now able to touch and hold them. This created a sense of stability and connection:

“I felt happy that I was now able to hold my baby since it was not like the first time. Initially, I used to go to the neonatal unit and when I arrived there, I used to just stand next to him failing to touch him, and wondering what I am going to do. So I was now happy that I was able to hold the baby.” (P1)

One participant held her baby when she felt that her baby’s condition had improved as the baby was awake. Holding her baby offered the participant an emotional satisfaction as she felt differently from the time she could not touch or hold the baby:
“Mmm! I first held her when I saw that she was awake. That is the day I felt better. I mean that ... I felt as if I am becoming happy. It was a different feeling from what I felt before.”

(P6)

As the participants' feelings became more positive towards their baby, they began to accept them, and the fear of handling the tiny infants lessened. Holding the baby offered them an opportunity to accept them since their feelings towards the baby had changed. The initial feeling of fear and uncertainty had changed; they were able to accept and love their infant and wanted to be close to them all the time:

“My feelings have changed, since I said I was afraid of him at first but I have now accepted him. I manage to lift him when I get there. Even when I am in the room I miss him. I have accepted him and I love him.” (P2)

As the participants continued to interact with the baby, touching and handling them, they began to realise that although tiny and preterm, their baby was just like any other baby:

“You accept the baby as time goes on realising that the baby is fine.” (P5)

Being able to feed their infants made the connection with them real and tangible. Participants were able to touch them made their love for the infant a reality. The constant contact that the participants had with their babies as they interacted with them enabled them to develop a relationship with their babies:

“So when I started feeding him, I was able to touch him by then ... Hee! I gave him a lot of love.” (P3)

For the participant who had lost a previous baby, her fear that this infant too would not survive delayed the development of a relationship with her baby. This fear changed into love as she started to interact with her infant:

“I started loving him. At first I gave up because I had a baby who died.” (P8)

The participants loved their baby even more when able to observe their responses such as opening the eyes. Participants felt that even though they touched their baby before, they had a different feeling when they saw their baby’s response. This made them very happy and gave them hope that their baby would survive:

“So it was very nice, yes when I saw that because before, there was no sign of affection since I used to just look at him there. Even when I touched him before, I could feel that yes
he is alive but there was no ... But the day I saw him open the eyes aa I was not scared at all.” (P7)

Despite the initial fears, the love that developed between the participants and their babies connected them emotionally. The encouragement that the participants received from staff members enabled them to be emotionally connected with their babies:

“There is a nurse who told me not to be afraid of him because it is me who is going to take care of him while they show us how to take care of them. I ended up being acquainted with him until he was able ... we got used to each other.” (P1)

The participants felt that bonding had taken some time because the development of a relationship between them and the baby was delayed by different things such as fear and anxiety:

“As time went on and on ... since I already accepted him as a baby ... loving him, you see, yes. As time went on and on I ended up getting used to him.” (P5)

“I started having that love and I am attached to the baby.” (P8)

4.2.5 Enabling support network

Different support systems assisted the participants to cope with their difficulties while they were involved in the care of their preterm babies. The support that the participants received from staff members helped them to cope. The participants were able to perform caring activities for their preterm babies when they were provided with information and shown how to do so by staff members. This helped them to develop competence in providing care to their preterm baby. Staff members also reassured mothers when the baby’s condition deteriorated and counselled them when faced with difficulties in providing care. The support that the participants received from staff enabled them to develop a relationship with their baby and eventually to bond with them:

“They also encourage us and tell us that if he is like this, you do this and that. They tell us that the baby will survive and it is possible. They are the ones that are always counselling us.” (P2)

The participants felt reassured by staff members who counselled them when they had conflicts with other mothers in the unit:

“The other thing is that if someone hurt you ... those women who supervise how we take care of babies ... the nurses, they call you, sit down with you and talk to you in order to be reassured.” (P1)
The participants were advised, reassured and comforted by other mothers while in the neonatal unit. Participants were encouraged to touch and hold their baby by other mothers in the neonatal unit:

“Some mothers who were there are the ones that comforted me by saying, please touch him, kiss him. I started touching his legs and toes.” (P7)

Mothers who had been in the unit for some time served as support persons for others as they shared information with them on how to take care of the baby, and also reassured them since they had also had the same experience. The participants encouraged others to have hope and to pray and believe that their baby will finally be well. This helped them to overcome their fears and anxieties while caring for their baby and also in developing a relationship with their baby. Participants found the support of others very helpful:

“What is reassuring that side is us as mothers. As we are where our babies are admitted, sometimes arriving and others realise ... like at first I was afraid of that baby, a mother whose baby is next to yours ... hei she reassured me quite well by telling me that her baby was not like that before. That she did not expect that the baby will be the way he/she was at that particular time. She said relax and pray, knowing that this baby will be fine.” (P8)

The participants supported each other by advocating for one another and assisting each other when they were in the neonatal unit. Although the participant was supported by others, she would also support other mothers in different ways. Through the emotional support of others, mothers were encouraged not to give up hope even if the baby’s condition was not improving:

“Like now, when one mother is sad, I am able to tell her that I was in the same situation, do not be sad. It will be fine. Even if somebody’s baby is in a coma ... like there is a certain mother whose baby is in a coma ... this is the fourth day, but I always tell her that it will be fine.” (P7)

The participants also learnt to put their differences behind them and continued in their journey until they reached their destination. They were able to forgive others when they wronged them and focused on caring for their baby. Participants would go and call the other participant from the postnatal ward at night if they realised that she did not manage to come to feed her baby, especially when the baby was crying:
“If someone has wronged you, you have to forgive them and interact with them like if someone has not yet come to the unit and the baby is crying, you can go and call them especially at night.” (P1)

Family members supported the participants in this study during their hospitalisation with the baby, both socially and emotionally. This they did through visiting them while in hospital. When the participants were visited by members of their family they felt less isolated, and forgot about being separated from the family. This helped them to focus on the care of their baby:

“Their presence when they came to check on us ... when seeing them was of great importance as I would forget about my situation. I was not hurting much.” (P6)

The family members also reassured the participants, comforted them and encouraged them to have hope during difficult times by phoning them. Family members informed the participants about people who they knew been born prematurely in order to reassure them and to give them hope that their baby will also survive:

“My mother phoned me more often and telling me that I should not be scared because that baby survives just like the child of so and so. He/she was born premature and here he/she is working for him/herself. They do not have problems in life.” (P7)

Participants’ religious beliefs served as a source of support for them, since they trusted that God was with them. They prayed in order for God to intervene in their situations. The participants felt that God was with them as He answered their prayers:

“God is great because even when I was in labour ... I normally do not pray but after hearing that the baby is not alive. I talked to God and prayed seriously. I prayed and God answered my prayers.” (P3)

Participants completely surrendered everything to God when faced with difficulties. They used to pray and believed that God would not forsake them. This helped them to cope emotionally and psychologically:

“What reassured me is that I trusted in God, I used to pray and believe that it will be alright. Anything that will happen to me ... only God knows.” (P6)
4.3 CONCLUSION
The themes that have been described presented the lived experiences of mothers who delivered a preterm baby regarding their care. The participants were shocked, fearful and anxious as they had not expected to deliver “too soon”. They were uncertain as to whether their infants would survive, they were small and ill post-delivery. The participants were separated from their small, ill preterm babies, who needed technological support in the SCBU while they were admitted to the postnatal ward. The physical separation was stressful, but as they were able to become involved in the care of their preterm baby they became less anxious.

The unfamiliar neonatal environment increased the mothers’ fear and anxiety as it created a barrier between the participants and their baby. The equipment in the unit initially prevented mothers from touching and holding their baby as they were afraid of it. This delayed the development of a relationship between participants and their baby. The anxiety was also increased by the negative interactions that some staff members displayed while the participants provided care to their baby, such as lack of explanation of the baby’s condition, and treatment and procedures done on the baby. Support from staff, other mothers in the neonatal unit and family members enabled mothers to cope with their difficulties and challenges. The participants eventually overcame their initial fears and developed a relationship with their baby, which enabled them to be emotionally connected with them. The participants were confident and competent in caring for their baby before the baby’s discharge.
5.1 INTRODUCTION
Five themes emerged from the data as the lived experiences of mothers regarding care of their hospitalised preterm babies. These themes are presented in the context of the literature, and the researcher will dialogue with the literature to demonstrate how it supports the findings of this study, as comparisons are made and differences are noted. The chapter presents what the study adds to knowledge in the field, recommendations that arose from the findings, and also concludes the study.

5.1.1 A life uncertain - my baby’s vulnerability
The findings of this study reveal how the psychological preparation of the participants - which was not completed but interrupted - affected their readiness for delivery of their preterm baby. The participants expressed shock since the delivery was unexpected. They lost the valuable last weeks of their pregnancy, which could have helped in the process of their attachment with the unborn baby. Klaus and Kennell (1982) argue that a woman has to be psychologically ready for the delivery of the baby in order to easily accept the baby, since the attachment process commences during pregnancy. During pregnancy the woman undergoes certain changes, both physically and psychologically, and she has to accept the pregnancy in order to deal with the feelings of being a mother.

The woman will be aware of the growing foetus in her uterus and should accept the foetus as a separate individual. The first feeling of foetal movements helps the mother to accept the growing baby, and the mother then starts thinking of what the baby is going to look like. This helps the woman to accept the baby who is growing, and that is when the process of attachment starts (Klaus & Kennell, 1982). The trauma of preterm birth experienced by the participants in this study affected them in coming to terms with the birth of their preterm baby. This is supported by other research studies. The mother’s emotional and physical experiences in relation to her unexpected and traumatic birth may affect the attachment process. This occurs because the mother feels helpless and may have reduced confidence in interacting with her baby, hence delaying the attachment process (Fegran, Helseth & Fagermoen, 2008).
The preterm babies’ physical appearance was not expected by the participants, and the presumed vulnerability coupled with the baby’s behaviour hampered the initial interaction of participants with their preterm baby. The literature presented illustrates how the preterm infants’ physical appearance and behaviour does not stimulate positive feelings in the mother towards the baby. According to Franklin (2006:81, cited in Kearvell & Grant, 2008:76), attachment is defined as “the formation of a relationship between a mother and her infant through a process of physical and emotional interactions”. The researcher will utilise the word ‘attachment’ interchangeably with ‘bonding’, since the words do not differ markedly in meaning.

Klaus and Kennell (1982:2) define bonding as “a unique relationship between two people that is specific and endures through time”, and as an emotional tie from the parent to infant, whereas attachment refers to the tie from infant to parent. Whitlow (2003) states that the terms acquaintance, bonding, attachment and interaction have been analysed and defined to mean the relationship between parent and infant. The formation of a relationship may be delayed when there is no immediate stimulation of positive feelings in the parents by the infants. Factors in the infant which could delay attachment in the parents are often due to the unexpected appearance of the infant (Schenk, Kelley & Schenk, 2005). Bowlby (1980:39) stated that attachment behaviours are needed to initiate attachment, these being described as “any form of behaviour that results in a person attaining or maintaining proximity to some other differentiated and preferred individual, so long as the attachment figure remains accessible and responsive, the behaviour may consist of little more than checking by eye or ear on the whereabouts of the figure and exchanging occasional glances and greetings.”

The preterm babies in this study were less active because they were sick and physically immature. The ability to communicate is needed by both the parent and the child to build a relationship. Infants show attachment behaviours such as crying, smiling, grasping, reaching out and establishing visual contact to maintain proximity with their parents and also communicate their needs (Bell, St-Cyr Tribble, Paul, Lang & Goulet, 1998). Consequently preterm babies are reported to be passive; they do not cry or smile and do not respond to touch because they are less alert and less active. The infants are also less able to provide clear signals when they are in distress compared to full-term infants (Bell et al., 1998; Poehlmann & Fiese, 2001). Parents have to be very committed to their preterm infants in order to develop a bond with them (Bell et al., 1998).

The fear of touching the preterm infant - one of the overwhelming experiences of the participants in this study - prevented them from interacting with their preterm baby initially. This has been reported in other studies. Proximity through touch is reported to be the most powerful
communication tool parents utilise in interacting with the baby (Bell et al., 1998; Fegran, Helseth & Fagermoen, 2008). The participants’ intense concern that their actions could harm the vulnerable preterm baby initially led to less contact between them and their babies. Martinez, Fonseca and Scochi (2007) and Tiloskulchai et al. (2002) found that mothers reported the desire to take care of their preterm baby, but were afraid of hurting the baby who was small and seemed fragile. Fegran, Helseth and Fagermoen (2008) reported that when mothers are deprived of contact with their infants, the inhibited physical stimulation delays the attachment process.

The participants in this study feared for the survival of their preterm baby, who was small and seemed vulnerable. Other researchers had similar findings, such as Schenk and Kelly (2010), who found that mothers reported being worried and scared because they had doubts about their infant’s chance of survival. Their study reported that mothers were worried because their babies had tubes inserted and were receiving intravenous fluids. Jackson et al. (2003) and Reid (2000) found that the mothers’ first sight of their preterm baby filled them with fear, worry and concern. The separation of their preterm babies from the mothers in this study generated anxiety and concern for the safety of their babies. Bowlby (1979) reported that threat of loss leads to anxiety. The participants felt threatened as a result of the separation and became anxious. Their anxiety was increased when the baby was sick and when the baby’s condition deteriorated. A number of studies have investigated the numerous challenges that mothers of preterm babies face, by examining the psychological adjustment of such mothers compared to those who delivered a full-term baby. Feldman, Weller, Leckman, Kuint and Eidelman (1999) interviewed three groups of mothers. The first group had delivered full-term infants, were not separated from their infants, and were able to hold, feed and take care of their baby. The mothers reported medium-high levels of preoccupations with thoughts and worries of infant safety and well-being. The second group of mothers had LBW infants and had a chance to hold their infant in their arms outside the bassinet with or without monitoring devices following initial separation. This group of mothers reported high levels of preoccupation. In contrast, mothers who had very LBW infants and were separated from their infants for periods reported low levels of preoccupation. Feldman et al. (1999) also reported that when mothers were asked about their distress caused by thoughts and worry, those with full-term infants reported a moderate level of distress, whereas those with LBW infants reported the highest level of distress. This demonstrates how the child’s illness and separation from the mother affects the process of maternal attachment.

The infant’s illness leads to maternal anxiety and depression, which may affect maternal-infant bonding. The findings also indicated that anxious mothers tended to experience higher levels of
“worrisome aspect of bonding” or bonding with worry (Feldman et al., 1999), which can easily be challenged or disrupted (Klaus & Kennell, 1982). Although separated from their infants, participants in this study were involved in the care of their babies, and this helped to moderate their distress as they interacted with their preterm baby.

Studies by Hall (2005) and Holditch-Davis et al. (2009) found that parents of a newborn child, including preterm infants, reported increased anxiety when the baby’s condition worsened, such as at admission of the baby to the NICU. Holditch-Davis et al. (2009) conducted a randomised study in which 177 African-American mothers of preterm infants from the rural and small towns of the South-Eastern state were recruited from the NICUs of two hospitals. The study was conducted over a period of 24 months and mothers were divided into four groups. The groups differed in relation to their psychological distress when they responded to a questionnaire about their infant appearance stress, parental role stress, depressive symptoms, state of anxiety, post-traumatic stress symptoms and daily problems. One group reported low distress; another high stress; one group had high depressive symptoms; and the other group reported extreme distress. It was reported that there was a decline in the percentages when symptoms of state of anxiety and depression were checked at 2, 6, 12 and 24 months for all the groups except the low distress group.

Hurst (2001a) and Rowe and Gardner and Gardner (2005) found that when mothers were involved in the care of their preterm baby, they were constantly watching over what was unsafe for the baby and were vigilant of changes of the infant’s condition. In their studies, Jackson, Ternestedt and Schollin (2003) and Nystrom and Axelsson (2002) found that when mothers were separated from their baby they expressed concern, worry and fear for their baby. The mothers had difficulty in leaving the baby because they were worried that something might happen to the baby. Mothers were reported to be insecure about whether their babies were exposed to blood tests that were not needed as well as about whether their children were left alone and cried.

5.1.2 An unfamiliar and intimidating environment

The preterm babies in this study were nursed in a technological environment which was stressful for the participants, to the point that they initially felt afraid when they visited the neonatal unit. The participants were overwhelmed at the sight of so many babies attached to numerous monitors and unfamiliar technologies. Several studies have demonstrated how the technological environment of the neonatal unit overwhelms parents and how it may affect the attachment process. Franklin (2006), Redshaw (1997) and Shin and White-Traut (2007) found that mothers of
premature babies reported having emotions of sorrow, fear and shock when seeing the neonatal unit.

Jackson, Ternestedt and Schollin (2003), in a phenomenological study involving seven mothers of preterm babies who were interviewed four times, found that mothers reported having been adversely affected by the very sick infants being cared for in the neonatal unit. The mothers stated that they were unable to handle the situation, although they wanted to participate in their infants’ care. They also reported that they wished that they could be with their baby in a private area. Shin and White-Traut (2007) stated that feelings and fears about the unfamiliar NICU environment may cause difficulty in establishing mother-infant attachment. Delayed or problematic processes of attachment may result, affecting the way the mother perceives her own well-being (Shin & White-Traut, 2007).

The participants’ preterm babies were nursed in incubators for provision of warmth and were initially on intravenous fluid therapy and oxygen to stabilise their condition. Participants were afraid of the equipment at first and could not initiate physical contact with their preterm babies through touch. These environmental factors together with other previously related fears hampered the initial contact between the participants and their preterm babies. Other research studies report how the unfamiliar environment of the neonatal unit with technology affects physical contact of the mother and her baby and poses a threat to interaction between them.

Bell et al. (1998) argue that under normal circumstances parents feel responsible for the growth and development of their baby. They have realistic expectations and feel competent in caring for their infant in an environment that is favourable for the development of attachment links. The family is the context within which an intimate link between parents and infant is made, but when mothers are in the neonatal unit the technology required for treatment of a preterm baby poses a barrier to the initial interaction of parents with their infants (Walker, 1998; Whitlow, 2003). Jamsa and Jamsa (1998) and Redshaw (1997) found that mothers reported that they were worried by the equipment in the unit, such as endotracheal tubes, chest drains, cannulae and feeding tubes. The parents reported that they were afraid of the equipment, and it took a long time before they were able to participate in the care of their child.

The participants in this study were separated from their preterm babies who were admitted to the neonatal unit; however, since they were generally recovering well post-delivery they were actively involved in the care of their preterm baby. The participants were able to interact with their preterm baby on a daily basis, and this helped to moderate their psychological distress of
separation from their baby. The literature reviewed showed how involvement of parents in the
care of their preterm baby moderated their distress and helped in building a relationship
between mother and preterm baby.

Physical separation of mother and baby when the baby requires care in the NICU affects
maternal-infant attachment. This occurs because babies who are born ill or very premature are
immediately taken to the neonatal unit to be stabilised, and mothers do not have a chance to
hold or see them (Franck & Spencer, 2003; Franklin, 2006). Active parent involvement in the care
of their preterm baby in the neonatal unit is thought to moderate psychological stress and lead to
parent-infant attachment (Franck & Spencer, 2003). This is confirmed by Orapiriyakul et al. (2007),
as cited in Kearvell and Grant (2008), stating that the process of attachment is complicated since
it is influenced by a number of factors, including environmental circumstances and the infant’s
and mother’s health status. In the present study participants began to build relationships with
their infants as they spent more time in the units with them.

Participants in the current study felt that they should have been orientated to the neonatal unit
on arrival since the environment of the unit was unfamiliar to them and the technology
frightened them. The participants were fearful and wondered how they were going to cope
within the environment as they had to fulfil their parental role. Walker (1998) conducted a
descriptive study at national level to identify neonatal nurses’ views on the barriers to parenting
in the neonatal nursery. One set of barriers identified by the nurse was environmental factors.
Nurses reported that they believed that orientating parents to the nursery would facilitate
parenting in the neonatal unit. Turan, Basbakkal and Ozbek (2008) conducted a study entitled
‘The effect of nursing interventions on stressors of parents of premature infants in the neonatal
intensive care unit’ and found that knowing about sources of environmental-related stress can
help to decrease parents’ anxiety. Parents can be informed about the use of monitors, reasons for
using them and the procedures that are followed when an alarm sounds. This knowledge can
reduce the mothers’ fears and help them cope with their parental role.

One finding of this study which was not reported in the literature reviewed is that participants’
fear was exacerbated if they witnessed the deterioration and death of another premature infant.
The participants felt very threatened by the deterioration and death of infants in the unit, and
this increased their fear about the prognosis of their own infant. This seemed to have contributed
to delay in the development of a relationship between participants and their preterm babies. The
other finding of this study not reported in the literature reviewed is that although participants
initially had fear when they arrived in the neonatal unit, they were reassured that somehow their
preterm babies were safe from infection since the neonatal unit was clean and utensils for feeding the babies were sterilised.

5.1.3 Experiences of interaction with medical and nursing staff
Generally the participants in this study felt that there was good interaction between them and the staff members who communicated with them as they expected. However, three participants felt that there was poor interaction between them and the staff members. Other related studies show how poor interaction between staff members and parents of preterm babies affect staff communication with parents. A phenomenological study conducted by Padden and Glenn (1997) on maternal experiences of preterm birth and neonatal intensive care involved 36 mothers of infants admitted to three NICUs. The study found that the overall communication with both doctors and nurses was regarded by mothers as good, although three mothers reported that nurses did not interact with them as expected.

A phenomenological hermeneutic study by Wigert, Johansson, Berg and Hellstrom (2006), who interviewed 10 mothers, found that mothers needed continuous information about the baby’s care; because sometimes there was no information from staff, mothers felt that their interaction with staff was not good and tended to have a lack of trust in them. Fegran and Helseth (2009) carried out a study with a hermeneutic approach to explore parents’ and nurses’ experiences of the close parent-nurse relationship when a premature baby is hospitalised. The study found that nurses experience the interaction with parents as the most challenging part of their job, and that the quality of nurses’ interaction depends more on their personal abilities than on their professional role. In a study entitled ‘Families’ views on ward rounds in neonatal units’, Bramwell and Weindling (2005) found that even though some parents appreciated the interactions they had with the professionals when they were involved in ward rounds in the neonatal unit, some did not. Some mothers reported that their interaction with the medical and nursing staff was not good and that staff did not communicate well with them. One parent reported that it would be good if the doctors made an effort to talk to the parents. These findings provide evidence of the need for good interaction between mothers and the staff while involved in the care of their preterm babies.

Nurses in the SCBU should aim to build good relationships with mothers while their preterm babies are admitted to the neonatal unit in order to promote communication. Kearvell and Grant (2008) conducted a study which demonstrated the importance of good interaction between nurses and mothers of preterm infants. This is important when the preterm baby is hospitalised, since the nurse supports the mother in establishing a connection with the baby. Nurses who are
sensitive to the needs of mothers are helpful in guiding and strengthening maternal responses to their infants, hence assisting them to attach to their preterm baby (Kearvell & Grant, 2008).

A strategy called ‘chat’ can be practised by staff in the SCBU where this study was conducted. ‘Chat’ is described as a social talk with mothers (Aagaard & Hall, 2008). Staff can utilise this strategy in building a rapport with the mothers in the unit, and get to know what the mothers expect from them. This could enhance the development of good relationships between staff and the mothers in the neonatal unit.

A study by Fenwick, Barclay and Schmied (2001) entitled “‘Chatting’: an important clinical tool in facilitating mothering in neonatal units”, found that mothers reported valuing nurses who chatted with them not only about the baby but about life outside the nursery. With these nurses, mothers stated that they felt relaxed, familiar and confident in caring for their baby. Nurses reported that chatting was an important strategy to develop a rapport with the parents. They shared part of their own lives and exchanged life experiences with mothers, as they believed that this form of interaction assisted mothers to feel comfortable and confident in providing care to their infant. Nurses were able to engage at a deeper level with mothers and were able to provide care according to the needs of the mother and the family. Nurses introduced themselves to mothers, went through the routine of the unit with them, and gave them an opportunity to ask questions about their baby. Nurses involved mothers in planning the care of the baby for the day, since this helped mothers in taking care of the baby. It is reported that ‘chatting’ helped mothers to relate to the nurse, and to feel equal and connected to them. The mothers in turn felt safe to express their concerns, which also helped them to participate actively in providing care to the infant. The nursery staff’s acknowledgement of a woman’s status as a mother helped mothers to have self-confidence and their self-esteem was not affected. Mothers experienced ‘chatting’ as establishing, maintaining and enhancing their confidence and self-image as mothers (Fenwick, Barclay & Schmied, 2001).

The findings of the current study demonstrated that when the participants were provided with information on how to care and were also shown how to provide the caring activities, they developed confidence in taking care of their preterm baby. The participants were reassured when nurses and doctors were helpful while they were in the neonatal unit. Helpful nurses and doctors enabled the participants to fulfil their parental role, whereas mothers became anxious when they felt that nurses were not helpful. The importance of providing mothers with information on how to care for a preterm baby and their need for assistance with anything relating to the preterm baby’s care, have been highlighted in other studies. Aagaard and Hall
(2008) suggest that facilitative actions are important in helping mothers to develop care-giving actions for the baby. The facilitative actions include giving empowering and consistent information to the mother on how to provide care and help in minimising the separation between mother and baby throughout hospitalisation.

In order to facilitate attachment, mothers need to be taught how to interact with the baby. The information given to the mother boosts her confidence while providing care to the baby (Johnson, 2008). Nurses need to be aware that they are the ones who can facilitate mother-infant attachment positively or negatively, because if the mother does not receive information on arrival in the neonatal unit she will not be confident in providing care to her preterm baby, and this can affect the mother-infant attachment (Rowe, Gardner & Gardner, 2005). This was the case with one participant in this study, who stated that she was not given any information by the nursing staff on how to take care of her baby. However, the participant managed to bond with the baby since she was supported by her family, other mothers in the neonatal unit and some staff members during subsequent days while in the neonatal unit.

In Walker’s study (1998), when nurses’ views were established on what could facilitate parenting of mothers in the neonatal unit, they mentioned involving them in the care and decision-making as much as possible; ensuring that they are well informed; development of good staff relationships, including understanding of cultural needs; having open visiting hours; helping mothers with breastfeeding; encouraging parents to touch and hold their infant; and making sure that they are informed about what they need to know concerning the baby’s condition. Guided participation of the mother in caring for her preterm baby while in the neonatal unit is advocated, and the mother may be supervised in everything that she does in caring for the baby. This guidance enables the mother to gain competence in caring for her baby. According to Gove (1986), as cited in Pridham, Limbo, Schroeder, Thoyre and Van Riper (1998:948), “the competencies consist of knowledge, judgement, skill, resolve and actions that are sufficient for the challenges and necessities of living”. Guided participation includes sharing of information needed to determine what is going on or to come up with solutions. It also assists the mother in the search for information and helps the parent to become responsible (Pridham et al., 1998).

Previous studies have identified nurses’ ability to either positively influence the parent-infant relationship or negatively influence it (Flacking, Ewald, Nyqvist & Starin, 2006; Holditch-Davis & Miles, 2000; Hurst, 2001a; Lupton & Fenwick, 2001). It is reported that the development of maternal competence in caring for her baby facilitates the attachment between mother and baby (Flacking et al., 2006; Heemann, Wilson & Wilhelm, 2005; Lupton & Fenwick, 2001; Roller, 2005).
The participants in this study seemed to experience less anxiety when their baby’s condition was explained to them, when there was an explanation of procedures done to the baby and of the baby’s treatment. The converse was evident, in that their anxiety seemed to increase when there was no explanation provided about the baby’s condition and treatment. A number of studies demonstrate how the giving of information to parents about the preterm baby’s care and health status helps parents to cope with their anxieties and promotes interaction between the parents and their preterm baby. A phenomenological study by Hall (2005) found that parents reported that lack of communication about the baby’s condition, procedures performed on the baby and treatment of the baby increased their anxiety. The parents reported that they became anxious as they requested accurate information concerning the baby’s condition, and were always wondered what was happening concerning the baby’s progress while on treatment (Hall, 2005). The parents also reported that they wanted to know what was going on when their baby was sick and admitted to the intensive care unit. They wanted to understand and felt that it was important for them to know exactly what was happening concerning their baby’s condition. When the doctors and nurses told them what was going on, parents felt as if they were part of the team (Hall, 2005).

In his study on family-centred care in the NICU Griffin (2006) stated that ongoing communication with parents about their infants is necessary for them to be partners in care-giving and decision-making. Griffin (2006) further stated that communication of the infants’ condition and treatment plan helps to empower mothers in their role. Communication between the mother and the nurse in the neonatal unit influences the mothers’ self-confidence, sense of control and feeling of being connected to her infant. Parents need explanations about treatment plans and procedures. They want their questions answered in an honest manner and may experience stress when little or conflicting information is provided (Griffin, 2006).

Harrison (1993) stated that family-centred neonatal care should be based on open and honest communication between parents and professionals on medical and ethical issues. Communication in the NICU has been found to be frustrating for both parents and professionals. Harrison (1993) also mentioned that parents had previously reported that they were not always accurately told about the consequences of medical conditions and intensive care treatments or about medical and ethical controversies regarding care of their babies. This was possibly an attempt to shield parents from information about uncertainties or controversies concerning their babies’ NICU treatment.
Appropriate, timely and sensitive provision of information is a fundamental need for parents of preterm infants. Despite the overwhelming nature of such information, parents find it more stressful when information is withheld. Information has the potential to empower parents, and is viewed as a right (Herbst & Maree, 2006). Herbst and Maree (2006) reported that parents in their study wished to be informed about everything that could possibly be relevant to their child’s condition, such as causes, progress, outcomes, treatments, their infant’s behaviour, and all that happened while they were not present. This study also found that parents felt they should have access to their children’s medical records. A phenomenological study by Schenk and Kelley (2010) they found that mothers requested information about their infants’ health on a continuous basis by visiting and phoning the neonatal unit throughout the day. Mothers reported that they loved the nurses and were happy with the care when they received information about their infants, as they wanted to know about their infants’ diagnosis.

Family-centred care is advocated for in neonatal units. Although the need for the involvement of other family members is not reflected in the findings of the current study, family-centred care is not adequately practiced in the unit in which this study was conducted. The participants were the only family members allowed into the SCBU and thereby acted as representative of the family, but were not able to enjoy in-unit support from their family. Saunders, Abraham, Crosby, Thomas and Edwards (2003) state that family-centred care is a philosophy aimed at improving communication with families, and its possible benefits include improved satisfaction with care, decreased stress of parents, increased parental comfort and competence in post-discharge care, improved success with breastfeeding, shortened hospital stay, decreased readmissions post-discharge and increased staff satisfaction. Gooding et al. (2011:20) are of the opinion that “family centred care is an approach to medical care rooted in the belief that optimal health outcomes are achieved when patients’ family members play an active role in providing emotional, social and developmental support”. The inclusion of other family members in the care of a preterm baby is essential in neonatal units, because having a sick preterm baby is stressful for the family. If other family members like the father are equally involved in the care of a preterm baby, they will be actively involved in the decision-making concerning the baby’s care and will effectively support the mother during hospitalisation of the preterm baby, and even after discharge.

The exclusion of fathers from having contact with their preterm baby was not reflected in the findings of this current study. The researcher, who is a Motswana, knows about the cultural aspect of not involving fathers in the care of a newborn until after the mother’s confinement. It is worth noting that this cultural aspect may affect the attachment between the father and his
preterm infant. Increasingly, the trend worldwide is for parents to interact with their preterm baby in order to have increased connection. Studies conducted in other countries reveal the problems faced by fathers of preterm infants. The presence of fathers during the delivery of their preterm baby and their being involved in their care enhances the attachment between the two. Fathers of preterm infants reported that they did not feel like fathers and felt distant after the birth of their preterm infants (Lindberg, Axelsson & Ohrling, 2008; Lundqvist, Westas & Hallstrom, 2007). When fathers were involved in the care of their preterm infants they reported that they felt that they knew their infants better than fathers whose partners delivered full-term infants (Lindberg, Axelsson & Ohrling, 2008). In a study by Lundqvist, Westas and Hallstrom (2007) on fathers’ experiences of caring for their preterm infants, it was found that fathers experienced a feeling of “realness” after holding and having eye contact with their infant.

Another study conducted by Bowen and Miller (1980) found that fathers who were present at the delivery of their infant demonstrated more social attachment behaviour than fathers who were not present. The results of the study support the theory of a sensitive period shortly after birth for the development of the parent-infant bond. Klaus and Kennell (1982) in a book entitled 'Parent-infant bonding' reported that studies about rooming-in have demonstrated the importance of early contact between parents and their infants. The events taking place during the first hours after birth are important for the parents. There is strong evidence that at least 30-60 minutes of early contact in privacy should be provided for every parent and infant to promote their bonding experience. During the sensitive period parental interactions help to unite infants with their parents (Klaus & Kennell, 1982).

5.1.4 Overcoming fear: Emotional connections

Touch, one of our basic needs in communication, is one of the most fear-inducing responses in the connection between mothers and their preterm infants. The participants’ overwhelming fear of touch hindered their attempts to make physical contact with the preterm baby. With the encouragement of the nurses they were able to overcome their fear, and able to hold their preterm baby with confidence. The difficulties that mothers of preterm infants face before they are able to initiate contact with their baby can delay the building of a relationship between mother and baby. Support from staff may assist in establishing the mother-infant relationship.

Fenwick, Barclay and Schmied (2008) interviewed 28 mothers in hospital after the admission of their preterm baby in the nursery. Twenty-three of the mothers were re-interviewed 8 - 12 weeks after the discharge of their babies. Mothers reported that they wanted to touch and hold their baby while in the nursery, but were initially afraid to do so due to fear of harming the baby and
environmental barriers. Rowe, Gardner and Gardner (2005) explored the experiences of parents of preterm newborns during hospitalisation and their transition to home. They found that mothers reported that they felt as if they knew their infants as time went on, since they were competent in caring for their baby and were reassured. The mothers reported that the support from staff also helped them to hold their baby, and were reported to have described their babies as “theirs” after having an opportunity to hold them.

When they were able to hold their infants, the participants in the current study were thrilled. They developed a relationship with their preterm baby. The love that the participants experienced after holding their preterm baby helped them to develop an emotional connection with them. Studies have been conducted which demonstrate how the mother has to develop positive feelings and love towards her baby in order to bond with the baby. Karen (1994), as cited in Bell et al. (1998:1074), stated that “seeking and maintaining proximity arouses feelings of love, security and joy. The pleasurable feelings of intimacy in the relationship with the infant are essential for attaining higher states of affiliation. To feel affection for this particular infant and to be fulfilled by the attainment of this new parenting creates an emotional climate conducive to attachment.”

Bell et al. (1998) argued that parents experience connecting to their infant in an individualistic way. When parents are in contact with their infants they are able to recognise their infants’ cues, and this enables them to be emotionally connected with them. They further stated that “early and extensive contact enables parents to become acquainted with their infant. Feeding, embracing, rocking, maintaining prolonged visual contact, and actively seeking these opportunities for interaction with the intent all foster the development of an affective tie” (Bell et al., 1998: 1074). This was evident in the current study since the participants did not develop a relationship with their babies during the first few days of interaction, but managed to bond with them and maintain the bond because of the constant contact that they had with them. This is also confirmed by Klaus and Kennell (1982:2), who described “the formation of a bond as falling in love and maintaining a bond as loving someone”. Klaus and Kennell (1982) argued that the first feelings of love are not essentially attributed to the initial contact between the mother and the baby. Figueiredo, Costa, Pacheo and Pais (2009) affirm this by stating that maternal bonding does not occur after birth but occurs with time as the mother maintains contact and interacts with the baby. When mothers interact with their baby, the interaction affects the baby (Klaus & Kennell, 1982) and there are certain behaviours that infants show towards their parents which are
essential in promoting maternal attachment, such as crying, eye contact and facial expression (Figueiredo et al., 2009).

The mother who is interested in touching her baby enables the baby to recognise her as she communicates with the baby. The mother is sensitive to the voice of her infant, which may cause her to secrete milk (Klaus & Kennell, 1982). The increased levels of oestrogen, oxytocin and prolactin coupled with other maternal behaviours after delivery, such as touching and breastfeeding the baby, enable the mother to bond with the baby (Figueiredo et al., 2009; Klaus & Kennell, 1982).

The participants in the current study bonded with their baby after some time as they experienced difficulty in initiating contact. Early contact between the mother and her baby can be accomplished in the SCBU where this study was conducted by utilising KMC, as this has been proven to be very effective in promoting bonding between the mother and her preterm baby (Johnson, 2007; Tessier et al., 1998). KMC facilities are limited in the institution in which this study was conducted, since there are only three KMC beds for mothers which are situated in the postnatal ward. Since mothers are involved in the care of their preterm babies, they can be encouraged to kangaroo care their preterm babies in the SCBU as soon as the baby’s condition is stabilised.

Charpak et al. (2005) recommend that KMC is started after resuscitating the baby and ensuring that the baby is adapting well to extra-uterine life. The main objective of starting KMC after stabilising the baby is to control stress in both mother and baby. It is also done to help the baby cope physiologically, and to promote early bonding and future breastfeeding (Charpak et al., 2005). According to Johnson (2007) and Kearvell and Grant (2008), kangaroo holding has been shown to help mothers feel close to their infants, develop confidence in them, promote breastfeeding, decrease stress for both mother and baby, and enhance early development of the baby. Since KMC promotes breastfeeding, mothers are reported to feel confident after feeding their infants and this also assist mothers to become attached to their infants (Kearvell & Grant, 2008).

Tessier et al. (1998) conducted a randomised controlled trial involving 488 infants weighing below 2001g, with 246 in the KMC group and 242 in the traditional care group. Infants were enrolled in the KMC group if they were adapting well to extra-uterine life, gaining weight and feeding well from the breast. Mothers in the KMC group who carried their infants in the skin-to-skin position reported that they felt more competent than did their counterparts, although the
infants’ well-being determined the mothers’ attachment behaviour. In order to assess bonding of the mother and her infant, the mother’s attachment behaviour was shown by two outcomes. The first was the mother’s feelings and perceptions of her premature birth experience, including her sense of competence, feelings of worry and stress, and perception of social support. The second outcome was obtained from the observations of the mother and child’s response to each other during breastfeeding at 41 weeks of gestation. Based on the mother’s perception reported on a premature birth questionnaire, a sense of competence was found to be higher in the KMC group, while social support was perceived as lower for mothers in the KMC than in the traditional group. Mothers in the traditional group reported more stress when separated from their infants for a long time. The study also indicated that kangaroo carrying practised earlier (1 - 2 days) after birth helped improve the mothers’ sense of competence to a greater degree. Mothers’ sensitivity to their baby was reported to be higher in the KMC group when the babies spend more time at the NICU. It was also reported that infants in the KMC group showed clear signals and were more responsive to their mothers.

Another study conducted by Ramanathan, Paul, Deorari, Taneja and George (2001) found that when two groups of 14 mothers apiece, those who provided KMC to their LBW infants and those who provided a standard form of care, were observed and interviewed, 70% of those who provided KMC felt that they could touch and lightly stroke their infants’ entire bodies when using the method. Mothers who provided KMC to their infants also reported that they preferred KMC rather than incubator care, and eight mothers said they would continue KMC even after discharge. Other reported effects besides promotion of bonding on the KMC group were better weight gain after one week of life, shorter duration of hospital stay, and success in breastfeeding. The success in breastfeeding attributed to KMC has demonstrated benefits in neurological development, intelligence quotient (IQ), and the enhancement of mental development of preterm babies (Charpak et al., 2005).

These studies demonstrate the benefits of KMC when mothers kangaroo their preterm infants. KMC promotes contact between the mother and the preterm infant and may enable mothers to develop confidence in touching and caring for their infant. The participants in the current study encountered difficulties in touching and holding their infants initially, which could have been minimised by KMC of their preterm infants.
5.1.5 Enabling support network

Taking care of a fragile baby in an unfamiliar environment was distressing for the participants in the current study. The participants needed some form of support in order to assist them to cope. The study findings revealed that the staff supported the participants in different ways, such as explanation of the baby’s condition. The staff also encouraged the participants to interact with their preterm baby, and this facilitated the attachment between participants and their preterm baby. Support that parents receive from staff is helpful in developing competence and attachment relationships with the baby.

Schenk and Kelley (2010) found that mothers reported their need to be supported individually in order to help them build a relationship with the baby. Cleveland (2008) conducted a systematic review of both qualitative and quantitative research to identify what is known about the needs of parents having a baby in the NICU and which behaviours support them. The review reported that mothers needed correct information which they could easily understand, and that they wanted to be involved in decision-making concerning their infants’ care. Mothers also mentioned that they were stressed if they did not receive the correct information about the condition of their baby.

In a study entitled ‘Nurses as providers of support for mothers of premature infants’, Mok and Leung (2006) found that mothers reported that they needed information about their infant’s care. They expected the information to be given at an appropriate time and to be given in an honest and clear manner. The parents reported that the information they received helped them to know what was planned for their infants. Mothers reported that they needed emotional support since they were disappointed, and had feelings of guilt and anxiety. They felt that nurses were caring when they listened and showed concern towards them. The study also found that mothers reported that they were strengthened and felt like mothers when staff encouraged them to participate in their infants’ care. They also reported that they needed to be encouraged in order to strengthen their relationship with their baby (Mok & Leung, 2006).

Participants in this study appreciated the support they received from other mothers, since they felt that it was very helpful. Encouragement of the participants by other mothers to touch and hold their preterm baby emerged from the findings. The encouragement and comfort that the mothers afforded each other assisted the participants to overcome obstacles in providing care and in building a relationship with their preterm baby. The support from other mothers for the mothers with sick preterm infants is helpful since it enables them to overcome their difficulties. In a study in which a supportive telephonic intervention was compared with standard care, Preyde and Ardal (2003) found that mothers in the intervention group, who received telephonic support
from trained mothers who had previously had a preterm baby, reported less stress at four weeks. At 16 weeks mothers in the intervention group reported less of a state of anxiety, less depression and greater perceived support than the control group.

The findings of the current study revealed that although mothers supported each other, most of them supported those mothers who had a baby in the same cubicle as theirs, and did not experience much interaction with others in other cubicles of the neonatal unit. The establishment of a support group in the SCBU by a professional who can empower mothers with information and coordinate the group functioning should therefore be considered. If there is a support group that is recognised by everybody, mothers can support each other effectively by sharing their experiences, thus helping other mothers in similar situations to cope. There can also be a parent support coordinator who is paid and mainly focuses on supporting parents in the neonatal unit.

The importance of support groups for parents of babies admitted to the neonatal unit is recognised in the literature. Jarrett (1996) reported that mothers were in support of such a programme since they felt that it would improve the quality of services provided. They also felt that the implementation of a support programme would increase the institution’s ability to attract more patients in a competitive market. Hurst (2006) found that parent support programmes are beneficial to mothers and professionals working in neonatal units due to relieving some of the stress experienced by mothers whose preterm babies are admitted to the neonatal unit. They feel isolated because they are separated from their preterm baby and family members, and the support group can provide a vital connection and an opportunity to engage with mothers with similar experiences.

The separation from their families and their preterm baby that the participants in this study experienced increased their need for support, since they were admitted in a separate unit from their preterm baby. The participants needed to be supported both emotionally and socially. They were supported by their families in different ways, such as visiting and comforting them by phone, which helped them to cope with their challenges and bond with their preterm baby. Studies have been conducted where parents of a preterm baby needed emotional and social support from their family members in order to cope with their stress and difficulties. In a study entitled ‘The relationship between maternal needs and priorities in a neonatal intensive care environment’, Bialoskurski, Cox and Wiggins (2002) found that mothers expressed their need to be supported by their family through reassurance, since this made them realise that the person was concerned about their comfort and health. Mothers need to be assisted and encouraged in order to bond with their infants (Bialoskurski, Cox & Wiggins, 2002).
Lee, Miles and Holditch-Davis (2005) recruited 64 mothers to their study on fathers’ support to mothers of medically fragile infants during hospitalisation of the baby. Mothers were interviewed at enrolment, at 1 month after discharge of the baby, and after the baby was 12 months old. The study found that mothers felt that the support they received from the fathers during the babies’ hospitalisation was more than after the discharge of the baby. Mothers felt that support from the father was high during the baby’s hospitalisation since they provided for the needs of the baby, which was also supportive to the mother.

5.2 THE NEED FOR KNOWLEDGE

Information about the possibility of preterm labour and delivery is seldom provided to pregnant women. In the current study three first-time mothers had never seen a preterm infant, and had had no previous exposure to an incubator or the neonatal unit. Pregnant women need to be sensitively informed about the possible complications of pregnancy and the available interventions that are provided. This provides them with knowledge which might assist them in dealing with the stress of preterm labour and delivery.

Although a number of topics are covered in the form of brochures for mothers from the Sexual Reproductive Health Unit in the Ministry of Health, information on preterm birth and care of a preterm baby is not freely available. Mothers should be informed about these and should be aware of the possibility of prolonged hospitalisation after the delivery of a preterm baby. Harrison (1993) advised that information regarding adverse pregnancy outcomes should be provided to expectant mothers, and suggested that parents should be given the opportunity to state their treatment preferences in advance in case their baby is born extremely premature or critically ill. Herbst and Maree (2006) found that parents need to be provided with information before admission of their baby to the neonatal unit, even though most infants would not need specialised care. This is the responsibility of nurses providing maternal and infant care.

Parents reported the need to be provided with the same information regardless of whether their child was critically ill or admitted for observation. Bialoskurski, Cox and Wiggins (2002) found that mothers reported the need for orientation to the neonatal environment, which was unfamiliar to them, and that mothers reported the need to be informed that they could visit the unit anytime. Taking the parents on a tour of the neonatal unit offers them the opportunity to see preterm infants and to observe the care provided for the infants (Perehudoff, 1987).
5.3 IMPLICATIONS OF THE STUDY

The findings of this study are of importance to mothers who deliver a preterm baby, and the medical and nursing staff providing care to neonates in the neonatal units.

5.3.1 Implications for mothers of a preterm baby

Mothers should be encouraged to provide KMC or skin-to-skin contact between them and their preterm baby as this will promote bonding. The participants in this study experienced less contact with their preterm babies during the first few days because of infant, maternal and environmental factors, which led to delayed attachment. If mothers could provide KMC to their preterm babies every time they go for feeds (after stabilising the baby’s condition), this will be helpful in promoting bonding (refer objective 1). Charpak et al. (2005), Feldman et al. (1999) and Kennell and McGrath (2009) argue that KMC promotes contact between mothers and their preterm infants who are initially separated from their mothers when they are admitted to the neonatal unit.

5.3.2 Implications for staff working in neonatal units

Nurses in are in a position to exhibit facilitative actions geared towards promoting maternal-infant attachment. Nurses who are new to the neonatal unit should go through an orientation programme in order for them to be competent in guiding and supporting mothers, especially those whose infants have just been admitted to the neonatal unit. One participant in this study felt that she was not provided with information on arrival to the neonatal unit. Studies on mothers’ experiences of having a baby in the neonatal unit showed that when nurses provided explanations to mothers on how to care and offered them emotional support, mothers were able to fulfil their parental role (Lee, Long & Boore, 2009; Trombini, Surcinelli, Piccioni, Alessandroni & Faldella, 2008). If the mother is provided with information on care of the baby, she will be in a position to make decisions concerning her infant’s care and her interaction with the baby will be promoted (Cone, 2007; Van Rooyen, Nomqokwana, Kotze & Carlson, 2006)(refer objective 2).

Although nurses in the SCBU are busy, it can be assumed that they are aware that giving accurate information to mothers plays a very important role in helping mothers cope with their anxieties while providing care to their babies. Failure to do so can have a detrimental effect on the attachment process of the mother and her sick preterm baby. Cone (2007) stated that use of medical terms while speaking to a parent may be frightening and should be avoided as much as possible.
Nurses and doctors have a responsibility to communicate with mothers about their infants’ condition, treatment and procedures which are done. With respect to the above issues, three participants in this study felt that staff members had not met their needs for information (refer objective 3). Mothers of preterm babies require considerable support. Mothers who receive reassurance on their infant’s condition are able to interact with the infant in a positive manner throughout their hospitalisation period (Mok & Leung, 2006).

When mothers deliver a preterm baby their self-esteem is affected (Reid, 2000). Self-esteem is defined as one’s self-worth or personal value (Amankwa, Pickler & Boonmee, 2007). For most women preterm birth is unexpected, their psychological preparation is interrupted, and their anticipated role as a mother is different. Mothers experience psychological difficulty as they try to look for reasons for the preterm birth, and need to have their self-esteem restored (Reid, 2000; Sydor-Greenberg & Dokken, 2000). They feel that they have lost out on the experience of giving birth to a full-term ‘ideal’ infant, and become worried or even grieve because they did not meet the societal expectation of delivering a full-term baby. Parents who did not give birth to a term ‘normal infant’ may experience grief and loss of self-esteem which may hinder the attachment between the mother and her infant (Franklin, 2006; Sydor-Greenberg & Dokken, 2000). Mothers need to find new ways of dealing with the situation (Reid, 2000).

The findings of this study have identified there were instance in which staff members shifted responsibility to others when confronted with questions from the participants. If parents are not provided with information they tend to ask a lot of questions, because they become anxious. Nurses and doctors should understand their responsibility to provide answers to questions that mothers ask in order to allay their anxiety, and if a nurse is not able to provide answers to the mother, she/he should enquire from the doctor on behalf of the mother during the doctor’s rounds. Since doctors are not always in the neonatal unit, the nurse should ensure that the mother who previously asked a question, such as the cause of the baby’s condition, is provided with an answer (Cone, 2007).

5.4 LIMITATIONS OF THE STUDY

This limited study and data were confined to mothers whose preterm babies were admitted to one neonatal unit. Although the findings of this qualitative study are not generalisable, they are transferable to other neonatal units in which specialised care of preterm babies is provided. The
findings may assist health professionals in gaining understanding about the needs of mothers who are not rooming-in but are involved in the care of their preterm babies.

Eight participants whose infants were cared for in the same neonatal unit were interviewed twice. All the participants were interviewed within the hospital setting and the researcher did not return to the participants to verify the study results after data analysis, as recommended by Colaizzi (1978). Once discharged it was not possible to follow-up the participants in their home environments. Verifying the findings of the study with the participants could have assisted the researcher to confirm whether the findings represented the participants’ feelings.

The interviews were conducted in Setswana and translated into English. Translation may have influenced the interpretation of the lived experiences and the participants’ feelings concerning care of their preterm baby.

This study explored and described the lived experiences of mothers only and not both parents of preterm babies. Particularly in the Setswana culture, in which the father has a limited role in the early days of a newborn’s life, an understanding of the experiences and role of the father with regard to a preterm infant would have enhanced the richness of the findings.

5.5 RECOMMENDATIONS

The recommendations are subdivided into those for the need for future research, mothers of preterm babies, managers and health professionals providing neonatal care, health training institutions, and the health system.

5.5.1 Need for future research

This qualitative study on the lived experience of mothers regarding care of their hospitalised preterm babies could be replicated in other neonatal units in the country. This could inform practice, since recommendations would be made based on the findings of a more than one study.

A study that involves fathers or that explores the experiences of both parents would give more meaning and would assist in improving the quality of care in neonatal units.
5.5.2 Mothers of preterm babies

Women should be encouraged to learn as much as possible about the birth process in order to raise awareness of the possibility of preterm birth and how this is managed in maternal care settings. This will help mothers understand the reason why they have to be separated from their preterm babies and hence reduce their anxiety (refer objective 1). Expectant mothers should be aware of the learning opportunities that they can utilise in order to get information. Where available, good-quality information should be provided through libraries and trustworthy online resources. Participants who were first time mothers expressed their lack of knowledge about the care of a baby (refer objective 1). Good quality, timeous and appropriate information about pregnancy and delivery, including preterm infants, is important. Nursing and other health care providers can then provide specific information as needed, thus facilitating the mother-infant interaction and care of the preterm infant in the NICU.

Mothers who are computer-literate should be encouraged to utilise Internet facilities in the national libraries of the country where possible in order to search for trustworthy information about pregnancy and motherhood. High quality sources can be recommended by health care professionals to prevent the accessing of erroneous and unnecessarily alarming information.

5.5.3 Managers and health professionals providing neonatal care

Mothers should have open access to the neonatal unit so that separation is minimised, thus reducing the mothers’ stress and enhancing mother-baby interaction (Franklin, 2006). The participants in the current study felt that the restrictive policy with regard to visiting hindered their interaction with their infants (refer objectives 1 and 2). The participants expressed concern for the safety of their preterm babies and felt that it would be safer for their babies if they were allowed into the neonatal unit more often.

Participants in this study felt that they needed counselling, and at least should have been told reasons why they had delivered a preterm baby, where such information was available. On arrival at the neonatal unit all mothers should be orientated to the unit, counselled, and informed about the reasons for admitting the baby and the treatment options and plan as appropriate. One participant in this study expressed fear and anxiety because when she arrived in the neonatal unit no one provided her with information on how to care for the baby and she relied on the assistance of other mothers (refer objective 2). Each neonatal unit should have an orientation package for parents, stipulating what they are expected to do and informing them of what they should expect while in the neonatal unit (Herbst & Maree, 2006).
The quality of care provided in the SCBU could be enhanced with the establishment of parent support groups or implementation of support programmes. The findings of this study revealed that mothers’ support of each other enabled them to overcome their anxieties. The support group should have a coordinator who is a professional, either a midwife or a social worker, who would empower mothers on how to support each other while their baby is admitted to the neonatal unit (Hurst, 2006). Mothers of preterm babies should be encouraged to attend support groups since this would assist the new mothers in learning from others with similar experiences.

Nurses should offer mothers emotional support by encouraging and helping them when they need assistance in the infant’s care. This can promote acceptance of the unexpected situation, and improve the mother’s self-worth and active participation in her infant’s care. In the current study participants had negative and positive experiences with regard to the perceived helpfulness of nurses. In order to prevent negative experiences, nurses in the SCBU should be aware of the unique needs of mothers. Fowlie and McHaffie (2004) stated that staff should be able to recognise and cater for the unique needs of different families whose infants are in the neonatal unit. Although all mothers experience stress when in the neonatal unit, they should be treated as unique individuals with unique needs. Meeting the individual needs of mothers while involved in the care of their preterm baby will improve the quality of nursing care provided and promote patient satisfaction.

It should be considered that other family members, especially the fathers, be allowed in the neonatal unit as long as they adhere to the preventive measures of infection control. Preterm birth is distressing for parents, not only to the mother of the baby but also to other family members, so allowing them access to the neonatal unit will help them cope and they will offer the necessary support to the mother when they have seen the condition of the baby when admitted.

Guidelines on the rationale for and implementation of KMC will facilitate this intervention. There is a need for training nurses in the neonatal unit about the basic concepts of KMC, such as how it is implemented, and its advantages for both mother and baby. Adequate staff members should be allocated to the SCBU and doctors and management should support nurses and midwives working in the unit as they educate mothers on how to safely provide kangaroo care to their preterm infants. Information sharing can be done through seminars and/or workshops (Engler et al., 2002; Johnson, 2007). The participants in this study felt that the staff did not make time to support them while in the kangaroo room, and they experienced delayed attachment with their
preterm babies. If staff members can encourage mothers to provide KMC to their preterm babies between feeding times, that will assist mothers to bond with their preterm babies.

The counselling skills of nurses should be improved through workshops, or alternatively there should be a social worker allocated to the neonatal unit with an office within the unit if possible in order to address the psychological needs of mothers. The participants expressed the need for counselling after the trauma of preterm birth, and because sometimes nurses are busy with other nursing duties, the social worker can counsel the mothers. The social worker should not come to the SCBU only when the need arises but should rather be within reach of all mothers who have delivered a preterm baby.

5.5.4 Health training institutions
Student midwives in training institutions should be taught about strategies that have been developed worldwide, such as BFHI and KMC, in order for them to be knowledgeable about their implementation guidelines and advantages. These strategies promote rooming in and if midwives understand the need for the mother and her preterm baby to be together, they will promote rooming-in, in different ways and prevent the separation of the mother and her preterm baby. (refer objective 1) The midwives will be in a position to assist parents in neonatal units and even to share information with other nurses who are not informed about the strategies. An assessment report by the Ministry of Health (2011) reported that out of the 34 hospitals assessed in Botswana in the year 2010, none qualified to be declared as ‘baby-friendly’ based on global and national criteria. This could be attributed to a lack of information by staff members, who cannot implement the strategy in hospitals. One of the gaps identified on the assessment report is that there is inadequate ownership of the strategy by staff members, and BFHI has not been incorporated in the post-basic training curricula of nurses.

5.5.5 The health system
BFHI and KMC should be promoted in SCBUs. This can be ensured by utilising the global and national criteria to monitor compliance of neonatal units; if the criteria are not met then strategies should be implemented in order to promote BFHI and KMC. A rooming-in policy should be developed since mothers are separated from their preterm babies in the SCBU, and families should be allowed access in neonatal units. (Addresses obj 1) According to Bennett and Sheridan (2005) in their study entitled ‘Mothers’ perceptions of rooming-in’, mothers reported that rooming-in enhances breastfeeding, helps them to bond with their baby, and helps mothers to develop ownership and gain confidence when taking the baby home.
Mothers would benefit from the provision of a comfortable space as close as possible to the neonatal unit in which they could relax, interact with other mothers in similar situations or be supported by family members. This would help the mothers to feel less isolated and better able to cope with the baby’s hospitalisation period. This may reduce homesickness and promote interaction with and care of their sick preterm baby (refer objective 3). Social support to mothers of a preterm baby who is separated from them and sometimes from the family is of significant value (Bialoskurski, Cox & Wiggins, 2002).

5.6 CONCLUSION

The health of the mother, preterm infant and family is a critical aspect of maternal and child health care. This study contributes to the body of knowledge, specifically with regard to Botswana. The lived experiences of mothers of preterm babies who were involved in the care of their preterm babies in SCBU in Princess Marina Hospital was the focus of this qualitative study. Descriptive phenomenology was utilised to explore and describe the participants’ experiences. Five themes emerged from the data, which provide a rich description of the experience: a life uncertain - my baby’s vulnerability; an unfamiliar and intimidating environment; experiences of interaction with medical and nursing staff; overcoming fear: emotional connections; and an enabling support network.

The study found that the involvement of participants in the care of their preterm baby in SCBU was very helpful. Even though they experienced fear in interacting with their baby initially due to different barriers such as fear of hurting the preterm baby and fear of the equipment in the neonatal unit, the participants managed to overcome their fears as they interacted with their preterm baby on a daily basis. Other contributory factors which led to the mothers’ anxiety in and fear in this setting were negative interactions that participants experienced, such as non-explanation of the baby’s condition and the procedures performed on the baby. Support from staff, other mothers in the neonatal unit and the participants’ families assisted them to cope and promoted bonding.

The findings of this study alert professionals providing neonatal care to observe certain important aspects of providing care which are important in improving the quality of care provided. The professionals should try to provide ongoing communication with parents while in the neonatal unit about the condition of the baby, procedures performed on the baby and the baby’s treatment in order to allay their anxiety, which can affect maternal-infant bonding. The findings
also suggest that the planning of neonatal care should include meeting individual maternal needs in the form of counselling and orientation of mothers to the neonatal unit on arrival. In order to promote early contact between mothers and their preterm babies while admitted in SCBU, so as to promote bonding, mothers should be encouraged to provide KMC to their preterm infants.

The study findings also call for the recommendation of rooming-in, which promotes bonding, as has been advocated for by the international strategies of KMC, BFHI and the Humane Neonatal Care Initiative. The use of support groups in SCBU may have a positive influence in helping mothers cope with their difficulties by learning from other mothers’ past experiences. Family-centred care advocates for involvement of parents in the care of their sick babies, and it is recommended that fathers be involved in the care of their preterm baby in the SCBU where the study was conducted, and in order to promote infant-father attachment.
REFERENCES


Finlay, L., & Ballinger, C. 2006. *Qualitative Research for Allied Health Professionals: Challenging Choices*. Chichester: John Wiley and Sons Ltd.


Leonard, A. 2004. *Parents’ experiences of providing Kangaroo Care to their preterm infants*. Thesis presented for the degree of Master of Science in Nursing, Division of Nursing and Midwifery, Faculty of Health Sciences, University of Cape Town.


http://journals.cambridge.org/action/displayFulltext?type=1&pdftype=1&fid=67566&jid=DPP&volume [27 July 2011].


http://www.springerlink.com/content/yg10tw84w712685/fulltext.pdf [8 August 2011].


APPENDICES

APPENDIX A: INFORMATION SHEET FOR PARTICIPANTS

Research Ethics Committee
E52 Room 24
Old Main Building
Groote Schuur Hospital
Observatory
Tel: 27 21 406 6338
Fax: 27 21 406 6411

Thank you for volunteering to participate in this research study that seeks to explore your personal stories regarding care of your hospitalised preterm baby. I realise that you are feeding your baby almost every three hours and this means that half the night you did not sleep. I would like to thank you for the time that you are going to spend in this interview.

Kindly read this sheet together with the information on the consent form that follows and sign to consent for participating.

Yours sincerely

Rosinah Ncube [Researcher]

Cell No: 0026771729395
APPENDIX B: CONSENT FORM FOR CONDUCTING THE STUDY

Research Ethics committee  
Supervisor: Hilary Barlow  
E52 Room 24, Old Main Road  
Contact details: 021 658 7723  
Groote Schuur Hospital  
Co-Supervisor: Pat Mayers  
Observatory  
Contact details: 021 406 6464  
Telephone: 27 21 406 6338  
Fax: 27 21 406 6411

TITLE: 
THE EXPERIENCE OF MOTHERS REGARDING CARE OF THEIR HOSPITALISED 
PRETERM BABY

RESEARCHER: ROSINAH K. NCUBE [Masters Student at the University of Cape Town]

This study aims to explore the experience of mothers who are admitted in Princess Marina Hospital whose babies are admitted in Special Care Baby Unit after being delivered prematurely. The baby can either be sick or awaiting weight gain.

The researcher will observe you while in the Special Care Baby Unit feeding and interacting with your baby and will be taking some notes. You will also be interviewed individually in a quiet room in the postnatal ward. You will be required to tell the researcher your experience of having your baby cared for in the neonatal unit. Other follow-up questions will be asked by the researcher to clarify that which you will say about your experience. The interview is expected to take one hour to one and a half hours, a second interview will be conducted just before or after discharge to clarify some information. A tape recorder will be used to record what you will be saying. This saves time as the researcher will not have to write everything that you will be saying.

The study may not benefit you directly but recommendations will be made to the relevant people and the findings may influence future nursing practice which will benefit you and other clients. The study will contribute towards the completion of the researcher’s degree. The risk that may be involved is emotional distress and you may need counselling. Should you be emotionally affected, you will be offered counselling by the social workers.
You are not forced to participate in the study but you can volunteer to participate. Even if you
volunteer to participate in the study, you are free to withdraw from the study any time you wish
to do so without any penalty.

You will not be required to disclose your names and your identity will remain anonymous even
during the publishing of study findings. No confidential information will be shared with anyone
unless permitted by you.

If you have questions about the study or about participating in the study, please feel free to
phone this number 0026771729395 and you will be answered by the researcher. You can also
contact Mrs Mary Kasule, The Principal Research Officer at the Health Research and Development
Unit on this number: 3632466/3632018 or email her at mkasule@gov.bw.

The study has been approved by the Human Research Ethics Committee of the Faculty of Health
Sciences, University of Cape Town. Permission has been sought from the Ministry of Health of
Botswana to conduct the study.

I have discussed the above information with the participant and believe that she understands the
benefits, risks and expectations in participating in this research.

________________                                                                                              ________
Researcher                                                   Name of participant          Date

I understand that my participation is voluntary and that I may refuse to participate or withdraw
from the study any time without penalty.

I hereby consent to participate in this research.

________________                                                                                              ________
Signature of participant                                   Name of participant          Date

________________                                                                                              ________
Signature of witness                                      Name of witness          Date
APPENDIX C: ETHICS APPROVAL LETTER

UNIVERSITY OF CAPE TOWN
Health Sciences Faculty
Research Ethics Committee
Room 652-654 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone (021) 466 5528 Fax (021) 466 6411
Email: research.ethics@uct.ac.za

09 July 2018

HRREC REF: 332/2018

Ms B Ncube
U/Ms H Baskin & Dr P Meyu
Nursing & Midwifery

Dear Ms Ncube,

PROJECT TITLE: THE LIVED EXPERIENCE OF MOTHERS REGARDING CARE OF THEIR HOSPITALISED PRETERM BABY.

Thank you for submitting your study to the Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has formally approved the aforementioned study.

Approval is granted for one year until the 30th July 2018.

Please submit an annual progress report if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approved period so that we can note out this.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HRREC REF in all your correspondence.

Yours sincerely,

[Signature]

[PROFESSOR M BLOOMAN]
[CHAIRPERSON HSP HUMAN ETHICS]
[Federalwide Assurance No. 00001307.]
[Observatory 7925]
Institutional Review Board (IRB) number: HR097B/11

This study has been approved by the University of Cape Town Research Ethics Committee compliant with the International Council for Harmonisation (ICH) Good Clinical Practice (GCP), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH), and Declaration of Helsinki guidelines.

The Research Ethics Committee granting the approval is in compliance with the ICH, Good Clinical Practice (GCP) Guideline E6, Rules for Guidance on Good Clinical Practice (ICH E6), and PHARMA Good Clinical Practice (GCP) Regulation Part 50, 56 and 512.
APPENDIX D: INTERVIEW SCHEDULE

TITLE: The lived experience of mothers regarding care of their hospitalised preterm baby.

RESEARCHER: Rosinah K. Ncube

Time of interview:

Date:

Place:

Interviewer:

Interviewee:

Brief description of the study:

QUESTION

“Tell me your experience of having your baby cared for in the neonatal unit.”

The following questions will be asked as ‘prompts’ if necessary as adopted from Padden & Glenn (1997):

- Can you describe your feelings when you first saw your son/daughter?
- Since you first held him/her, how have your feelings changed?
- Describe anything in the neonatal unit that strongly affected you, for example: made you feel happy or sad, frightened or reassured?
- Tell me about your interaction with the medical and nursing staff in the neonatal unit.
- If you would have anything to make this time easier for you and your family what would it be?
SECOND INTERVIEW WITH PARTICIPANT SEVEN

I would like to thank you for participating in this study. The first question that I am going to ask you is the main one which says: Tell me about your experience of having your baby cared for in the neonatal unit.

*Pause*

Are we not having the same questions? Ehe! Are we continuing already? What did the first question say?

*(Interviewer repeats the question)* Tell me about your experience of having your baby cared for in the neonatal unit.

*Pause*

Heishi! Ehe how do I start?

*Silence*

No. All I can say is that the care is okay now that the baby is grown. I used to be scared at first, babies dying and doing what, I wondered if my baby will ever survive or what. The baby had ... his grams were lower than everyone else’s. You would hear one mother saying my baby is weighing ... because at first I delivered him weighing 1.4 and his weight dropped, dropped and dropped until he weighed ten something. I wondered if he would end up weighing 500g as his weight dropped *(participant laughs and interviewer smiles)* or not? This is because I heard that some babies were weighing 650g and these are the babies that were going, even that of 1.1. I also wondered aa if my baby is also going, but now I am proud because he has gone a mile *(participant laughs and interviewer smiles)*. It does ... I am not scared nor ...

I can see that he is now a person because at first he did not show whether he would be a person or not. Now he is gaining and I think it is okay, it is not affecting me *(participant laughs and interviewer smiles)*. What scared me at the beginning is no longer there. It is only that sometimes I wonder if... like it was said that he has breathing problems, he is having what, I think ... I sometimes think that he was born asthmatic and that they have not yet diagnosed it. I have been
telling myself that aa the problem that he can face is a breathing problem or something of that sort, but the rest aa because I think he is just okay.

Silence

It sounds as if you are saying that you are happy and that you have hope because the baby is gaining weight, he is growing and is not like before. Could you elaborate more on that?

(Participant laughs) Aa! I do not know what I can say because I am excited. All these other things ... mmm because nowadays I am able to sleep. It is not like before when I used to think and at three when arriving there I would even get a fright. This time I am free when I get there. Initially whenever the time of feeding was ticking like 3 o’clock, 9 o’clock and 12 o’clock I was disturbed, every three hours I was not eating wondering if I will find him having changed because there is one time that they told me that with premature babies it is 50/50, you might lose you might win. The doctor said that to me and ever since he said that it has always stayed in my mind, so much that every time, I found the baby shifted with his things, I would immediately wonder ooh! ‘Is it not my baby who is gone or what?’ Sometimes the baby is shifted to another place and his position changed, all that will be in your mind will be that the baby is gone. I used to be frightened. Getting a fright, but now I am okay.

Silence

I heard you say that there is one time that the baby stopped breathing and the doctor said to you that with premature babies it is 50/50. The baby might live and the baby might not live. How were your feelings at that time?

Hei! It was a shock because I was frustrated. Yes, because firstly it is me who realised that he has lost ... I thought he has lost his life because I shook him when I saw him quiet and not moving and looking pale. So I called the doctor and when they came, I saw them running with those things (participant laughs and interviewer smiles) that are used for pumping. After that ... when they were doing it, he was having some foam from his mouth. There was an orange stuff coming from his nostrils. I wiped him ... wiped him and wiped him. The doctor and the nurse called me and the nurse was told to talk to me. The nurse then told me that if it is like this, it is 50/50.

I was scared and asked her: aa ‘you mean there is no hope?’ She then told me that if it can happen that he removes oxygen then she does not want to lie to me. It might just happen like that. Aa I did not ... I cried seriously and left. I did not finish feeding him. I left him and I ... I felt that I could not manage at all. I came here, stayed for some time and slept. I was not sleeping as
such, I thought of why I should lose my baby when I have seen his face. It could be better if he
died before I could see him with my eyes since I would accept it. I had labour pains but I am
leaving empty handed. So ai it was painful the past two days until I met one nurse whom I asked if
there is change and she said that there was a lot of change and I should not worry.

So what this nurse said to me was something to me because she saw that I was losing hope, so
she said I should not lose hope. She said yes it is like ... premature babies live like this and yours is
just fine. The baby is a person but you are worried, so that word meant a lot to me (participant
laughs).

Can you describe your feelings when you first saw your son?

Hei! At first I was scared (participant laughs) because when I arrived in the delivery unit I was told
that I am going to deliver though in Block 9 where I went before I went to the delivery unit, I was
told that my labour pains will be stopped. It was my first time to hear that somebody’s labour
pains can be stopped. At first I was saying aa since I am seven months, it has happened because it
is said that a person can be menstruating while pregnant, this means that I am going to deliver a
premature. I knew that there are premature babies, who are small. The premature babies I have
seen ... were already grown. So even when I was told that he is a premature, I thought since I
delivered my first baby weighing 4.6 and the second one weighing 4 kg, I will deliver him
weighing 2 or something to 3kg. In fact I thought of 3kg. After delivery, when the nurse brought a
small baby of my phone’s size aa! I was scared you know though I was ... I think you know that the
baby is put on your chest and the nurse said to me: ‘here is your baby, what sex is he?’, then I said
a boy. As she put him on me, in fact I did not expect that she will put him on my chest so when
she put him on my chest I was so scared, wondering if such a small baby is ever seen. I was
scared. I was so scared at first, at first, at first because it was my first time to see such a small
baby.

Even when I was told that the baby is taken to the bottle, I thought the baby was going to be put
in the bottle. I was told that the baby will be observed while in the bottle until he reaches his
months. When I was told that he is going in a bottle, I thought what was meant was the real
mayonnaise bottle. I thought he was going to be put in there with some water or something. You
see! That is what I thought because when the baby is in the womb is like is in blood or what so
that is what I was thinking. I did not think that I will always go and see him. I thought I was going
to stay in the ward until this baby reaches his months. I did not know that they are weighed, they
are fed because I thought when he was inside me, he fed from me. I did not think that he is being
fed, being sponged. I thought he just stays like that not wearing anything (participant laughs). That is what ... I was thinking like when the baby is still in the womb. I thought his life was like that. He is not in the womb anymore but surprisingly it was not like that.

Since you first held him, how have your feelings changed?

Pause

I think I was afraid of him the first day when I found him put somewhere in the neonatal unit because he was wrapped in that receiver of theirs. When I saw him where he was with drips and other things, very thin and I was wondering aa if ... if I was not going to break him when I touched him until some mothers who were there were saying, touch him, and kiss him. At least kiss his leg or the hand aa I cried while looking at him wondering whether mmm thinking that he is not a baby even if people can say what. When I looked at the other babies, they were just the same and I was wondering if they will survive or what? Until I ended up touching his leg, I did not touch his whole body the first day. I touched his leg and I wanted to see if he is a real person. But today aa (participant laughs) I find him okay because at first after touching him, I saw him ... isn’t it you know what the baby does ... smiling like this. Then I was ... hee I became happy. I said hee this means that he is a baby who is alive and is able to feel that his mother is touching him. So when I saw him show some sign of life, that smile with some movements told me something. You see!

Tell me more

Aa! There is nothing I can say.

Describe anything in the neonatal unit that strongly affected you. For example: made you feel happy or sad, frightened or reassured.

Pause

Heishi! No that which affects ... that which affected me the most was on my first day. When I arrived in the neonatal unit there was no, what is it ..? We were not told anything about care of those babies. I went there without being told ... I arrived there with other mothers because I was told that every three hours ... when I arrived here, nurses here told me that I have to go to the baby every three hours. It was something past 2 yes, and at 3 I saw other mothers going to the babies. I asked the one that was next to me if she was going to her baby so that we could go together. I told her that I was also told to go to the baby and so I went with those other mothers. When I got there, I stood there not knowing what to do until one mother asked me my name. I then told her my name and she said okay, let me ask the nurse where your baby is. She told the
nurse that I was looking for my baby since I was just arriving. She asked her my name and I said I am so and so and then she said okay, there is your baby on desk number this. I then went to the baby. I was not told ... she did not come to me and tell me how the baby is and how the baby is being treated because it was the first time that this happened to me. When I arrived there I found people having cotton wool, having ... what you call it, having sweet oil, others having Vaseline and others baby oil. They were applying different things to their babies. My baby had no ... They told me to put a nappy on the baby. I did not know if the baby was going to be dressed or not until ... one nurse came to me and said may you please put a nappy on him. I told him/her that I did not bring anything since I came as a patient and knowing that I am far from delivery. The nurse then went to collect a nappy for me to put on him. I was told nothing. That is what annoyed me the most since it was my first time ... at least if they could have asked me something or told me how the baby was treated ... but it is not like that.

Silence

Other things which were frightening are babies who were dying. You will find a baby who has long died kept for a long time. It is you who will tell yourself that the baby is dead because ... isn’t it that the baby has to breathe. You will see that this baby is not breathing well. The baby will be put there until you eventually see the baby being covered with a sheet. Then you will obviously know that the baby has passed away. This is one of the things that I think are not okay. If you are a mother you become emotionally disturbed wondering if you will find your baby like that the following day. You can even see your baby on your own because some mothers found their babies like that and said ao ‘nurse do you mean that this baby is breathing?’ . Such mothers were asked why they were saying that though when the nurse came to the baby and realised that the baby was dead, she would tell the mother to wait somewhere far from the baby. Which means that ... I thought that if the baby is dead ... it is only that we are not told how often the babies are checked and maybe it would even be better if mothers were going there every 30 minutes but it is 3 hours which I think is too long.

Mmm! Go on

Yes. Like reassuring ... I was never reassured by anyone. I mean yes ... the nurse who reassured me said to me that it is okay though ... most of the time I was reassured by other mothers. They told me not to cry since it will be okay. They were saying that the more I cry is the more the baby feels pain. I feel that other mothers were there for others. They used to put themselves in other mother’s situations. As for the nurses, they were totally out. I have never ... seen a nurse who
comes and say this and this and this unless you ask. If a person has time that is when they can explain to you but if you do not ask, it will be just like that. I was reassured by other mothers and my family. They used to tell me that I should not worry since it will be alright.

Tell me about your interaction with the medical and nursing staff in the neonatal unit.

Pause

Hei! Myself I don’t think there is any interaction ... well this one and that one because we are from different families. Some would go ... and would come with their moods from home. When you ask her she asks you: ‘why are you saying that, what makes you think like that?’, if I see something different on my baby, something that I am not used to. When I told her that my baby seems to be having eye discharges, she said: ‘yes, it is normal’. I asked her if it is really normal and also asked her why she could not come to me and ... at least if she came and asked me to show her because sometimes they would say it is normal ... like there are babies who are said to be having jaundice isn’t it? That light which is said to be for jaundice can end up affecting another baby ... like mine. Last time I asked the nurse about the fact that my baby experienced eye discharges every time the light was put on and whether that does not affect him. He/she then said that it has never happened that it affects the baby. I told him/her that I am wondering why the baby presented with eye discharges when the light was put on.

It does not happen when there is no light. He/she said to me that may be it is my psychological thinking. I then asked other mothers, ‘does this happen to your babies’. Two of the mothers told me that their babies also present with eye discharges when the light is on. He/she ended up refusing and I got cross with him/her. I told him/her that aa there is no cooperation between us. I told her not to talk to me since she was not in the mood to do so and since she did not talk to me with love. I then drifted away from her. This is poor interaction. Doctors ... doctors are the ones who could be nurses who are always there because when you ask the doctor to explain to you, he/she would come and explain wholeheartedly and even ask if you understand. The funny thing about doctors is that there is a communication problem. We are not able to communicate with them since they are not able to explain some of the words to us in Setswana and I think it is because some of the words are the doctor’s language. If the doctor is not a Motswana it is difficult for him/her to explain more. So if they ... if nurses were able to translate all the time, it could be better, or having a translator who is always next to the doctors because I think that we are having a problem of communication.
The other thing is that our educational background is not the same. Some mothers have never been to school completely. They are not able to talk to the doctor and tell them, for instance, if the baby’s cord is bleeding or whatever could be happening. That mother waits to tell the nurse in order for the nurse to tell the doctor and sometimes that nurse would even ‘crash’ her when she talks to her. These are the things that, I do not give credit to nurses for but I think doctors are the best. The problem is communication because one would even try to talk to ... using signs while communicating ... you do not know anything about sign language and this becomes difficult because he/she is also just trying as he/she communicates. When he asks you something you answer it in a different way. The doctor might be asking you if the baby is well or not, then you would say, the baby is okay yet the baby is not okay since you did not understand what the doctor was saying. So this is the main problem.

It sounds as if you are saying doctors are the ones who are explaining a lot of things, the problem is communication breakdown. Could you elaborate more on that?

Aa! There is nothing more, I stop there.

The last question says: If you would have anything to make this time easier for you and your family, what would it be?

Pause

What would make ... aa I think that at this point in time I am fine. I do not need anything (participant laughs) because ... the very first day my family accepted what has happened and they said aa ‘it is a baby xxxxxx, so and so’s child is a grown up man who was born as a premature baby’ but you think your baby will not live. ‘God has a plan for everyone’s life, even if the baby can go or do what it would still be according to the will of God’, you see. So I think that they were supporting me though some were saying aa a premature, a premature baby never survive. My close parents never said that to me. They said to me that the baby will grow and I will be surprised when I see that the baby has grown. Even when the baby was sick and feverish, if I told them that the baby was feverish, they told me that he is a baby and he is changing. It is not that the baby is sick. Their main concern would be whether the baby is active, ‘yes he is active’ and then they would say it shows that the baby is okay. ‘Fever is fever and later on it will go down’. I think my parents were there for me.

Silence
Thank you for this interview. I am so grateful especially because I can see a smile on your face. It is wonderful to be blessed when you have hope. So I am grateful. It was wonderful talking to you. I would like to thank you for volunteering to participate in this study. Go home well.

Yes, Ma. Thank you.
## APPENDIX F: EXAMPLE OF ANALYSIS

### INTERVIEW TRANSCRIPT: SECOND INTERVIEW WITH PARTICIPANT 7

<table>
<thead>
<tr>
<th>Interview Transcript-Original</th>
<th>Units of general meaning</th>
<th>Units of relevant meaning</th>
<th>Direct quote</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like to thank you for participating in this study. The first question that I am going to ask you is the main one which says: Tell me about your experience of having your baby cared for in the neonatal unit. <strong>Pause</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Are we not having the same questions? Ehe! Are we continuing already? What did the first question say? <em>(Interviewer repeats the question)</em> Tell me about your</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
**experience of having your baby cared for in the neonatal unit.**

*Pause*

Heishi! Ehe how do I start?

*Silence*

No. All I can say is that the care is okay now that the baby has grown. I used to be scared at first, babies dying and doing what, I wondered if my baby will ever survive or what. The baby had ... his grams were lower than everyone else’s.

You would hear one mother saying my baby is weighing ... because at first I delivered him weighing 1.4 and his weight dropped, dropped and dropped until I delivered him weighing 1.4. His weight dropped until he weighed ten something

<table>
<thead>
<tr>
<th>Care is okay</th>
<th>The care of P7’s baby was okay now that her baby grew. P7 used to be scared wondering if her baby will survive since the baby had a lower weight than all other babies.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Now that the baby has grown</td>
<td>No. All I can say is that the care is okay now that the baby has grown. I used to be scared at first, babies dying and doing what, I wondered if my baby will ever survive or what. The baby had ... his grams were lower than everyone else’s.</td>
</tr>
<tr>
<td>I used to be scared at first, babies dying</td>
<td>baby had a weight of 1400g at birth but his weight dropped until he weighed ten something and P7</td>
</tr>
<tr>
<td>I wondered if my baby will survive</td>
<td>You would hear one mother saying my baby is weighing ... because at first I delivered him weighing 1.4</td>
</tr>
<tr>
<td>Baby’s grams were lower than everyone else’s</td>
<td>Fear for the survival of the baby - small</td>
</tr>
</tbody>
</table>

Hope for baby’s future

Fear for the survival of the baby - others die
| He weighed ten something. I wondered if he would end up weighing 500g as his weight dropped (participant laughs and interviewer smiles) or not? This is because I heard that some babies were weighing 650g and these are the babies that were going, even that of 1.1. I also wondered if my baby is also going, but now I am proud because he has gone a mile (participant laughs and interviewer smiles). It does ... I am not scared nor ... |
|---|---|---|
| Wondered if he will end up weighing 500g. I heard that some babies were weighing 650g. These are babies that were going. Now I am proud because he has gone a mile. |
| Wondered if he will end up weighing 500g since babies of that weight were dying. P7 was now proud that her baby had gone a mile. |
| his weight dropped, dropped and dropped until he weighed ten something. I wondered if he would end up weighing 500g as his weight dropped or not? This is because I heard that some babies were weighing 650g and these are the babies that were going, even that of 1.1. I also wondered if my baby is also going, but now I am proud because he has gone a mile. |
| Reassured by baby’s condition |

| I can see that he is now a person because at first he did not show whether he would be a person or not. |
|---|---|---|
| I can see that he is now a person. Did not show he would be a person |
| P7 could see that her baby was now a person since he was gaining weight. P7 was no longer |
| I can see that he is now a person because at first he did not show whether he would be a person or |
| Reassured by baby’s condition |
Now he is gaining and I think it is okay, it is not affecting me *(participant laughs and interviewer smiles)*. What scared me at the beginning is no longer there. It is only that sometimes I wonder if ... like it was said that he has breathing problems, he is having what, I think ... I sometimes think that he was born asthmatic and that they have not yet diagnosed it.

I have been telling myself that aa the problem that he can face is a breathing problem or something of that sort, but the rest aa because I think he is just okay.

Telling myself that the problem which her baby could face was a breathing problem and she thought that he was just okay.

P7 told herself that the problem that he can face is a breathing problem or something of that sort, but the rest aa because I think he is just okay.

Anxiety about baby’s condition

Anxiety about baby’s condition

Anxiety about baby’s condition

Anxiety about baby’s condition

Anxiety about baby’s condition

Anxiety about baby’s condition

Anxiety about baby’s condition
Silence

It sounds as if you are saying that you are happy and that you have hope because the baby is gaining weight, he is growing and is not like before. Could you elaborate more on that?

(Participant laughs) Aa! I do not know what I can say because I am excited. All these other things... mmm because nowadays I am able to sleep, it is not like before when I used to think and at three when arriving there I would even get a fright. This time I am free when I get there.

Nowadays I am able to sleep and able to sleep unlike before because I was not like before when she used to think and get a fright while in the neonatal unit. P7 was excited and able to sleep unlike before when she was in the neonatal unit. P7 was free when she was in the neonatal unit. P7 was not free when she was there.

This time I am free when I get there. I am excited

I am excited

Aa! I do not know what I can say because I am excited. All these other things... mmm because nowadays I am able to sleep. It is not like before when I used to think when arriving there. This time I am free when I get there.

Hope for baby's future

Relief from difficulty
Initially whenever the time of feeding was ticking like 3 o’clock, 9 o’clock and 12 o’clock I was disturbed, every three hours I was not eating wondering if I will find him having changed because there is one time that they told me that with premature babies it is 50/50, you might lose you might win. The doctor said that to me and ever since he said that it has always stayed in my mind, so much that every time, I found the baby shifted with his things, I would immediately wonder ooh! ’Is it not my baby who is gone or what?’.

<table>
<thead>
<tr>
<th>Anxiety about baby’s condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>P7 was disturbed every three hours, not eating wondering if she would find her baby’s condition changed. P7 was worried about her baby’s condition because the doctor once told her that with premature babies it is 50/50, you might win or lose and P7 remembered this all the time. Every time P7 went to the neonatal unit and found a baby shifted with his things she would wonder if it was her baby who was dead</td>
</tr>
<tr>
<td>Fear for the survival of the baby - thought baby not alive</td>
</tr>
</tbody>
</table>

Initially whenever the time of feeding was ticking like 3 o’clock, 9 o’clock and 12 o’clock I was disturbed, every three hours I was not eating wondering if I will find him having changed because there is one time that they told me that with premature babies it is 50/50, you might lose you might win. The doctor said that to me and ever since he said that it has always stayed in my mind, so much that every time, I found the baby shifted with his things, I would immediately wonder ooh! ’Is it not my baby who is gone or what?’.
| Sometimes the baby is shifted to another place and his position changed, all that will be in your mind will be that the baby is gone. I used to be frightened. Getting a fright but now I am okay. | Baby is shifted to another place  His position changed  All will be in your mind is that baby is gone  I used to be frightened  Now I am okay | P7 was now okay unlike before because she used to be frightened when her baby’s position was changed or shifted to another place as she thought that her baby was dead | Sometimes the baby is shifted to another place and his position changed, all that will be in your mind is that the baby is gone. I used to be frightened. Getting a fright but now I am okay. | Relief from difficulty |

Silence

I heard you say that there is one time that the baby stopped breathing and the doctor said to you that with premature babies it is 50/50. The baby might live and the baby might not live. How were your feelings at that time?

Hei! It was a shock, I

P7 was shocked and frustrated

Hei! It was a shock because I

Fear for the
because I was frustrated. Yes, because firstly it is me who realised that he has lost ... I thought he has lost his life because I shook him when I saw him quiet and not moving and looking pale. So I called the doctor and when they came, I saw them running with those things (*participant laughs and interviewer smiles*) that are used for pumping.

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<tr>
<th>was frustrated. Yes, because firstly it is me who realised that he has lost</th>
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</thead>
<tbody>
<tr>
<td>It is me who realised that he has lost</td>
<td>P7 shook the baby when she saw him quiet, not moving and pale. After calling the doctor P7 saw them running with those things that are used for pumping.</td>
</tr>
<tr>
<td>I thought he lost his life</td>
<td>I called the doctor</td>
</tr>
<tr>
<td>I shook him when I saw him quiet, not moving and pale</td>
<td>I saw them running with those things that are used for pumping.</td>
</tr>
<tr>
<td>I called the doctor</td>
<td></td>
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After that ... when they were doing it, he was having some foam from his mouth. There was an orange stuff coming from his nostrils. I wiped him ... wiped him and wiped him. The doctor and the nurse called me and the nurse was

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</tr>
</thead>
<tbody>
<tr>
<td>When they were doing it</td>
<td>Secretions from mouth and nostrils</td>
</tr>
<tr>
<td>Had some foam from his mouth</td>
<td>Possible survival or death</td>
</tr>
<tr>
<td>Had some orange stuff coming from his nostrils</td>
<td></td>
</tr>
<tr>
<td>Nurse told me that if it is like that it is 50/50</td>
<td></td>
</tr>
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</table>

When P7’s baby was resuscitated, he had some foam from his mouth and some orange stuff coming from his nostrils. The nurse told P7 that if it is like that it is 50/50 and P7 was scared and asked

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</tbody>
</table>

Survival of baby - thought baby not alive
<table>
<thead>
<tr>
<th>I left him and I ... I felt that I could not manage at all. I came here, stayed for some time and slept. I was not sleeping as such, I thought of why I should lose my baby when I have seen his face. It could be better if</th>
<th>I got scared and asked if there is no hope. Told me that if it can happen again. She does not want to lie to me. It might just happen like that. I cried seriously and left. I did not finish feeding him.</th>
<th>Possibility of losing the baby</th>
</tr>
</thead>
<tbody>
<tr>
<td>Told the nurse if there is no hope. The nurse then told P7 that if it can happen again, she does not want to lie to her since it might just happen like that. P7 cried seriously and left and did not finish feeding the baby.</td>
<td>and the nurse was told to talk to me. The nurse then told me that if it is like this, it is 50/50. I was scared and asked her: aa ‘you mean there is no hope?’ She then told me that if it can happen again, she does not want to lie to me. It might just happen like that. Aa I did not ... I cried seriously and left. I did not finish feeding him.</td>
<td>Unable to cope</td>
</tr>
<tr>
<td>I left him and I ... I felt that I could not manage at all. I came here, stayed for some time and slept. I was not sleeping as such, I thought of why I should lose my baby when I have seen his face. It could be better if</td>
<td>P7 left her baby since she felt that she could not manage at all. She went to the postnatal ward and slept though she was not sleeping as much as she thought of why she had to lose</td>
<td>Fear for the survival of the baby - too ill</td>
</tr>
<tr>
<td></td>
<td>I left him and I ... I felt that I could not manage at all. I came here, stayed for some time and slept. I was not sleeping as such, I thought of why I should lose my baby when I have seen his face. It could be better if</td>
<td>Unable to cope</td>
</tr>
</tbody>
</table>
he died before I could see him with my eyes since I would accept it. I had labour pains but I am leaving empty handed. So ai it was painful the past two days until I met one nurse whom I asked if there is change and she said that there was a lot of change and I should not worry.

<table>
<thead>
<tr>
<th>what this nurse said to me was something to me because she saw that I was losing hope, so she said I should not lose hope. She said yes it is like ... premature babies live like this and yours is just fine. The baby is a</th>
<th>What this nurse said to me was something</th>
<th>What the nurse said to P7 encouraged her since she saw that she was losing hope. The nurse told P7 that premature babies live like this and yours is just fine. Said baby is a person and you</th>
<th>be better if he died before I could see him with my eyes since I would accept it. I had labour pains but I am leaving empty handed. So ai it was painful the past two days until I met one nurse whom I asked if there is change and she said that there was a lot of change and I should not worry.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support by staff – reassure</td>
<td>Support by staff – encourage</td>
<td>Support by nurse - reassure</td>
<td>Support by staff</td>
</tr>
</tbody>
</table>
person but you are worried, so that word meant a lot to me (participant laughs).

Can you describe your feelings when you first saw your son?

Hei! At first I was scared (participant laughs) because when I arrived in the delivery unit I was told that I am going to deliver though in Block 9 where I went before I went to the delivery unit, I was told that my labour pains will be stopped. It was my first time to hear that somebody’s labour pains can be stopped.

At first I was saying aa ‘since I am seven months’, it are worried

that her baby was a person yet she was worried, that meant a lot to P7

person but you are worried, so that word meant a lot to me.

- reassure

Afraid of baby - did not know what to expect
has happened because it is said that a person can be menstruating while pregnant, this means that I am going to deliver a premature. I knew that there are premature babies, who are small. The premature babies I have seen ... were already grown. So even when I was told that he is a premature, I thought since I delivered my first baby weighing 4.6 and the second one weighing 4 kg, I will deliver him weighing 2 or something to 3 kg. In fact I thought of 3 kg.

<table>
<thead>
<tr>
<th>After delivery, when the nurse brought a small baby of my phone’s size aal I was scared you</th>
<th>When the nurse brought a small baby of my phone’s size I was scared</th>
<th>When she was told that her baby is premature P7 thought that she would deliver him weighing 3 kg because her first two babies were born with a weight of more than 4 kg</th>
<th>Expected a bigger baby</th>
</tr>
</thead>
<tbody>
<tr>
<td>When I was told that he is premature I thought since I delivered my first baby weighing 4.6 kg and second one weighing 4 kg, that I will deliver him weighing 3 kg</td>
<td>When she was told that her baby is premature P7 thought that she would deliver him weighing 3 kg</td>
<td>So even when I was told that he is a premature, I thought since I delivered my first baby weighing 4.6 kg and the second one weighing 4 kg, I will deliver him weighing 2 or something to 3 kg. In fact I thought of 3 kg.</td>
<td></td>
</tr>
</tbody>
</table>
know though I was ... I think you know that the baby is put on your chest and the nurse said to me: ‘here is your baby, what sex is he?’, then I said a boy. As she put him on me, in fact I did not expect that she will put him on my chest so when she put him on my chest I was so scared, wondering if such a small baby is ever seen. I was scared. I was so scared at first, at first because it was my first time to see such a small baby. The baby was put on her chest. I did not expect that she will put him on my chest. I was so scared. Wondering if such a small baby is ever seen. I was so scared at first because it was my first time to see such a small baby.

Even when I was told that the baby is taken to the bottle, I thought the baby was going to be put in the bottle. I was told that the baby

<table>
<thead>
<tr>
<th>The baby was put on her chest</th>
<th>her chest and since she did not expect that the baby will be put on her chest she was scared. P7 wondered if such a small baby is ever seen and was so scared at first because it was her first time to see such a small baby</th>
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</table>

<table>
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<tr>
<th>I was so scared</th>
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Even when I was told that the baby was going to be put in the bottle

<table>
<thead>
<tr>
<th>When told that the baby was going to be put in the bottle</th>
<th>When P7 was told that her baby was going to be put in a bottle until he reached his months, she thought that</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>I thought the baby was</th>
<th>Uninformed about the incubator</th>
</tr>
</thead>
</table>
will be observed while in the bottle until he reaches his months. When I was told that he is going in a bottle, I thought what was meant was the real mayonnaise bottle. I thought he was going to be put in there with some water or something. You see! That is what I thought because when the baby is in the womb is like is in blood or what so that is what I was thinking.

I did not think that I will always go and see him. I thought I was going to stay in the ward until this baby reaches his months. I did not know that they are weighed, they are fed because I

I did not think that I will always go and see him. I thought I was going to stay in the ward until this baby reaches his months. Did not know that they are fed because I

P7 did not think that she would always go and see her baby but thought she would be in the ward until the baby reached his months. P7 did not know that babies are

I did not think that I will always go and see him. I thought I was going to stay in the ward until this baby reaches his months. I did not know that they are weighed, they are fed because I

Not provided with information
| Thought when he was inside me, he fed from me. I did not think that he is being fed, being sponged. I thought he just stays like that not wearing anything (participant laughs). That is what ... I was thinking like when the baby is still in the womb. I thought his life was like that. He is not in the womb anymore but surprisingly it was not like that. | Weighed and fed. Thought when he was inside me he fed from me. Did not think that he is fed and sponged. I was thinking like when he was inside the womb. | Weighed, fed and sponged while they are nursed in an incubator since the baby fed from her while in the womb. | Thought when he was inside me, he fed from me. I did not think that he is being fed, being sponged. I thought he just stays like that not wearing anything. That is what ... I was thinking like when the baby is still in the womb. I thought his life was like that. He is not in the womb anymore but surprisingly it was not like that. |

| Since you first held him, how have your feelings changed? Pause | I think I was afraid of him the first day when I found him put somewhere in the neonatal unit | P7 thought she was afraid of her baby the first day when she found him put somewhere in |

<p>| I think I was afraid of him the first day I found him put somewhere in | I think I was afraid of him the first day I found him put somewhere in | I think I was afraid of him the first day when I found him put somewhere in the | Afraid of the baby - wrapped in a receiver of theirs |</p>
<table>
<thead>
<tr>
<th>because he was wrapped in that receiver of theirs. When I saw him where he was with drips and other things, very thin and I was wondering aa if ... if I was not going to break him when I touched him until some mothers who were there were saying, touch him, and kiss him. At least kiss his leg or the hand aa I cried while looking at him wondering whether mmm thinking that he is not a baby even if people can say what.</th>
<th>the neonatal unit I saw him with drips and other things, very thin. Wondered if I was not going to break him when I touch him. Some mothers who were there were saying touch him and kiss him. I cried while looking at him. Thinking that he is not a baby even if people can say what.</th>
<th>somewhere in the neonatal unit wrapped with a dressing towel. P7 saw her baby with drips and other things, very thin and wondered if she was not going to break him when she touched him. Mothers who were there encouraged P7 to touch her baby and kiss him. P7 cried while looking at her baby thinking that he was not a baby even if people were saying what.</th>
<th>neonatal unit because he was wrapped in that receiver of theirs. When I saw him where he was with drips and other things, very thin and I was wondering aa if ... if I was not going to break him when I touched him until some mothers who were there were saying, touch him, and kiss him. At least kiss his leg or the hand aa I cried while looking at him wondering whether mmm thinking that he is not a baby even if people can say what.</th>
<th>Afraid of hurting the baby</th>
<th>Support by other mothers - encouragement</th>
<th>Difficulty in accepting the baby</th>
<th>Overcoming fear</th>
</tr>
</thead>
<tbody>
<tr>
<td>When I looked at the other babies, they were just the same and I was wondering if they will survive or</td>
<td>I ended up</td>
<td>P7 ended up</td>
<td>When I looked at</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Touching his leg</td>
<td>Touched his leg and wanted to see if he is a real person</td>
<td>Touching her son’s leg and she did not touch his whole body the first day. P7 touched her son’s leg and wanted to see if he was a real person. After touching him P7 saw her son smiling and she became happy. P7 felt that it meant that her baby was alive and able to feel that his mother touched him.</td>
<td>The other babies, they were just the same and I was wondering if they will survive or what? until I ended up touching his leg, I did not touch his whole body the first day.</td>
<td>Through encouragement, checked his humanity, happy to see her baby’s response, hope for the survival of baby.</td>
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<tr>
<td>Did not touch his whole body the first day.</td>
<td>After touching him I saw him smiling and I became happy.</td>
<td>This means that he is a baby who is alive and able to feel that his mother is touching him.</td>
<td>So when I saw him, I felt that it meant that he is a baby who is alive and is able to feel that his mother is touching him.</td>
<td>So when I saw him show some sign of hope for survival.</td>
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</tbody>
</table>
life, that smile with some movements told me something. You see!

Tell me more

Aa! There is nothing i can say.

Describe anything in the neonatal unit that strongly affected you. For example: made you feel happy or sad, frightened or reassured.

Pause

Heishi! No that which affects ... that which affected me the most was on my first day. When I arrived in the neonatal unit there was no, what is it ..? we were not told anything about care of those babies. I went there without showing some sign of life by smiling and moving she learnt something.

Pause

Heishi! No that which affects ... that which affected me the most was on my first day. When I arrived in the neonatal unit there was no, what is it ..? we were not told anything about care of those babies. I went there without knowing anything. P7 was affected the most when she was not told anything about care of her baby on arrival to the neonatal unit. P7 was told by nurses in postnatal ward that she had to go to the baby every three

Life, that smile with some movements told me something. You see!

Not provided with information

Provided with information
<table>
<thead>
<tr>
<th>being told ...</th>
<th>three hours</th>
<th>there without</th>
<th>Helpless</th>
</tr>
</thead>
<tbody>
<tr>
<td>I arrived there with other mothers because I was told that every three hours ... when I arrived here, nurses here told me that I have to go to the baby every three hours. It was something past 2 yes, and at 3 I saw other mothers going to the babies.</td>
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<tr>
<td>I asked the one that was next to me if she was going to her baby so that we could go together. I told her that I was also told to go to the baby and so I went with those other mothers. When I got there, I stood there not knowing what to do until one mother asked me my name. I then told her my</td>
<td></td>
<td></td>
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<tr>
<td>I went with those other mothers. When I got there, I stood there not knowing what to do</td>
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<tr>
<td>P7 went with other mothers to the neonatal unit and when she arrived there she did not know what to do and just stood there.</td>
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</tbody>
</table>
I was not told ... she did not come to me and tell me how the baby is and how he is treated because it was the first time that this happened to me. When I arrived there I found people having cotton wool, having ... what you call it, having sweet oil, others. Support by other mothers - helped

Helpful nurse

Non-explanation of baby’s condition

Non-explanation of baby’s treatment

Brought nothing for baby
| having Vaseline and others baby oil. They were applying different things to their babies. My baby had no ... They told me to put a nappy on the baby. I did not know if the baby was going to be dressed or not until ... one nurse came to me and said may you please put a nappy on him. | different things to their babies. They told me to put a nappy on the baby. I did not know if the baby was going to be dressed or not. | different things to their babies’ bodies yet she did not have anything. P7 was told by the nurse to put a nappy on her baby, but she did not have it since she did not know that the baby was going to be dressed. | others having Vaseline and others baby oil. They were applying different things to their babies. My baby had no ... They told me to put a nappy on the baby. I did not know if the baby was going to be dressed or not until ... one nurse came to me and said may you please put a nappy on him. |

| I told him/her that I did not bring anything since I came as a patient and knowing that I am far from delivery. The nurse then went to collect a nappy for me to put on him. I was told nothing. That is what annoyed me the most since it was my first time ... at | Told him/her that I did not bring anything since I came as a patient and knowing that I am far from delivery. The nurse then went to collect a nappy to put on him. I was told | P7 told the nurse that she did not bring anything for the baby since she came as a patient and knew that she was far from delivering. The nurse then went to collect a nappy for P7 to put on the baby. P7 was not told anything about | I told him/her that I did not bring anything since I came as a patient and knowing that I am far from delivery. The nurse then went to collect a nappy for me to put on him. I was told nothing. That is what annoyed me the most since it was my first time ... at |

| Lack of information on care of a preterm baby | Unexpected delivery | Helpful nurse | Not provided |
least if they could have asked me something or told me how the baby was treated ... but it is not like that.

Silence

Other things which were frightening are babies who were dying. You will find a baby who has long died kept for a long time. It is you who will tell yourself that the baby is dead because ... isn’t it that the baby has to breathe.

You will see that this baby is not breathing well. The baby will be put there until you eventually see the baby being covered with a sheet. Then you will obviously

| least if they could have asked me something or told me how the baby was treated ... but it is not like that. |
| Things which were frightening are babies who were dying. A baby who has long died kept for a long time |
| You will see that this baby is not breathing well. The baby will be put there until you eventually see the baby being covered with a sheet. Then you will obviously |
| with information |
| Nothing |
| That is what annoyed me the most told me how baby is treated |
| Noth |
| That is what annoyed me the most told me how baby is treated |
| Care of her baby, how her baby was treated and that annoyed her. P7 was frightened by babies who were dying in the unit since they were kept for a long time |
| Care of her baby, how her baby was treated and that annoyed her. P7 was frightened by babies who were dying in the unit since they were kept for a long time |
| with information |
| Other things which were frightening are babies who were dying. You will find a baby who has long died kept for a long time. |
| Other things which were frightening are babies who were dying. You will find a baby who has long died kept for a long time. |
| with information |
| Fear of other babies who die |
| You will see that this baby is not breathing well. The baby will be put there until you eventually see the baby being covered with a sheet. Then you will obviously |
| You will see that this baby is not breathing well. The baby will be put there until you eventually see the baby being covered with a sheet. Then you will obviously |
| Fear of |
| You will see that this baby is not breathing well. The baby will be put there until you eventually see the baby being covered with a sheet. Then you will obviously |
| You will see that this baby is not breathing well. The baby will be put there until you eventually see the baby being covered with a sheet. Then you will obviously |
| Fear of |
know that the baby has passed away. This is one of the things that I think are not okay. If you are a mother you become emotionally disturbed wondering if you will find your baby like that the following day. You can even see your baby on your own because some mothers found their babies like that and said ao ’nurse do you mean that this baby is breathing?’

Things that I think are not okay
If you are a mother, you become emotionally disturbed
Wondering if you will find your baby like that the following day
Some mothers saw their babies like that
Nurse do you mean that this is my baby

was not okay for a mother to see that because she could become emotionally disturbed wondering if she will find her baby like that the following day.
P7 saw some mothers who found for themselves that their baby was not alive

know that the baby has passed away. This is one of the things that I think are not okay. If you are a mother you become emotionally disturbed wondering if you will find your baby like that the following day. You can even see your baby on your own because some mothers found their babies like that and said ao ’nurse do you mean that this baby is breathing?’

emotional disturbance

Mother witnessing death of own baby

Such mothers were asked why they were saying that though when the nurse came to the baby and realised that the baby was dead, would tell the mother to wait
somewhere far from the baby.

Which means that ... I thought that if the baby is dead ... it is only that we are not told how often the babies are checked and maybe it would even be better if mothers were going there every 30 minutes but it is 3 hours which I think is too long.

Mmm! Go on

<table>
<thead>
<tr>
<th>Yes. Like reassuring ... I was never reassured by anyone. I mean yes ... the nurse who reassured me said to me that it is okay though ... most of the time I was reassured by other mothers. They told me not to cry since it will be okay. They</th>
<th>I was never reassured by anyone. The nurse who reassured P7 told her that it was okay and most of the time she was reassured by other mothers. Other mothers told P7 not to cry since it will be</th>
<th>P7 was never reassured by anyone. The nurse who reassured me said it is okay</th>
<th>Yes. Like reassuring ... I was never reassured by anyone. I mean yes ... the nurse who reassured me said to me that it is okay though ... most of the time I was reassured by other mothers. They told me not to cry since it will be okay.</th>
</tr>
</thead>
<tbody>
<tr>
<td>No support by staff - no reassurance</td>
<td>Support by staff -reassurance</td>
<td>Support by other mothers -</td>
<td></td>
</tr>
</tbody>
</table>
were saying that the more I cry is the more the baby feels pain. I feel that other mothers were there for others. They used to put themselves in other mothers’ situations. As for the nurses, they were totally out. I have never seen a nurse who comes and say this and this unless you ask.

Said the more I cry, the more the baby feels pain. Felt that other mothers were there for others. Nurses were totally out. Never seen a nurse who comes and say this and this unless you ask.

okay and that the more she cried the more the baby felt pain. P7 felt that other mothers were there for her since they reassured her. P7 felt that nurses were totally out since she never saw a nurse who came to her and told her something unless she asked.

be okay. They were saying that the more I cry is the more the baby feels pain. I feel that other mothers were there for others. They used to put themselves in other mothers’ situations. As for the nurses, they were totally out. I have never seen a nurse who comes and say this and this unless you ask.

If a person has time that is when they can explain to you but if you do not ask, it will be just like that. I was reassured by other mothers and my family. They used to tell me that I should not worry since it will be alright.

If a person has time that is when they can explain to you. But if you do not ask, it will be just like that. I was reassured by other mothers and my family.

Nurses explained to P7 if they had time and if she asked them. P7 was reassured by other mothers and her family.

If a person has time that is when they can explain to you but if you do not ask, it will be just like that. I was reassured by other mothers and my family. They used to tell me that I should not worry since it will be alright.

Support by other mothers - reassure
No support from staff - no reassurance

Support by other mothers - reassure
Support by family - reassure
Tell me about your interaction with the medical and nursing staff in the neonatal unit.

**Pause**

Hei! Myself I don’t think there is any interaction ... well this one and that one because we are from different families. Some would go ... and would come with their moods from home. When you ask her she asks you: ‘why are you saying that, what makes you think like that?’ if I see something different on my baby, something that I am not used to. When I told her that my baby seems to be having eye discharges, she said: ‘yes, it is

<table>
<thead>
<tr>
<th>Poor interaction</th>
<th>Good interaction</th>
<th>Unhelpful nurse</th>
<th>Nurse lacks knowledge</th>
</tr>
</thead>
</table>
| Hei! Myself I don’t think there is any interaction ... well this one and that one because we are from different families. Some would go ... and would come with their moods from home. When you ask her she asks you: ‘why are you saying that, what makes you think like that?’ if I see something different on my baby, something that I am not used to. When I told her that my baby seems to be having eye discharges, she said: ‘yes, it is
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<th>Poor interaction</th>
<th>Good interaction</th>
<th>Unhelpful nurse</th>
<th>Nurse lacks knowledge</th>
</tr>
</thead>
</table>
| P7 did not think that there was any interaction between her and the medical and nursing staff though some staff members interacted well with her since they were different. Some staff members were moody when P7 asked them since one asked her what made her to think the way she did. When P7 told a nurse that her baby had eye discharges, the nurse said it was normal
<table>
<thead>
<tr>
<th>Poor interaction</th>
<th>Good interaction</th>
<th>Unhelpful nurse</th>
<th>Nurse lacks knowledge</th>
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</table>
I asked her if it is really normal and also asked her why she could not come to me and ... at least if she came and asked me to show her because sometimes they would say it is normal ... like there are babies who are said to be having jaundice isn’t it? That light which is said to be for jaundice can end up affecting another baby ... like mine. Last time I asked the nurse about my baby who has eye discharges when light is on. Whether that does not affect him. He/she then said that it has never happened.

| I asked her if it is really normal and also asked her why she could not come to me and ... at least if she came and asked me to show her because sometimes they would say it is normal ... like there are babies who are said to be having jaundice isn’t it? That light which is said to be for jaundice can end up affecting another baby ... like mine. Last time I asked the nurse about the fact that my baby experienced eye discharges every time the light was put on and whether that does not affect him. | Asked if it was really normal  
Asked why she could not come to me  
At least if she came and asked me to show her  
Light which is for jaundice can affect another baby like mine  
Asked the nurse about my baby who has eye discharges when light is on  
Whether that does not affect him. | P7 asked the nurse if it was really normal that the baby should have eye discharges. P7 asked the nurse why she could not come to me at least to see what she was talking about. P7 felt that a phototherapy light for jaundice affected her baby since he had eye discharges when the light was on. P7 asked the nurse if that did not affect her baby and the nurse said it never happened. | I asked her if it is really normal and also asked her why she could not come to me and ... at least if she came and asked me to show her because sometimes they would say it is normal ... like there are babies who are said to be having jaundice isn’t it? That light which is said to be for jaundice can end up affecting another baby ... like mine. Last time I asked the nurse about the fact that my baby experienced eye discharges every time the light was put on and whether that does not affect him. |

| He/she then said that it has never | He/she said it has never | P7 told the nurse that she was | He/she then said that it has never |

| | | | |

| | | | |
happened that it affects the baby. I told him/her that I am wondering why the baby presented with eye discharges when the light was put on.

It does not happen when there is no light. He/she said to me that maybe it is my psychological thinking. I then asked other mothers, ‘does this happen to your babies?’ Two of the mothers told me that their babies also present with eye discharges when the light is on. He/she ended up refusing and I got cross with him/her. I told him/her that there is no cooperation between us. I told

wondering why the baby presented with eye discharges when the light was on. The nurse told P7 that maybe it was her psychological thinking. P7 asked other mothers if it happened to their babies and two of them said that their babies presented with eye discharges when the light was on. The nurse ended up refusing and P7 told her that there was no cooperation between them and left her

No support from staff - no reassurance

Other babies having same problem

Voiced her concerns
her not to talk to me since she was not in the mood to do so and since she did not talk to me with love. I then drifted away from her.

This is poor interaction.
Doctors ... doctors are the ones who could be nurses who are always there because when you ask the doctor to explain to you, he/she would come and explain wholeheartedly and even ask if you understand. The funny thing about doctors is that there is a communication problem with doctors. We are not able to communicate with them since they are not able to explain some of the words to us in Setswana.

P7 felt that it was poor interaction. P7 felt that doctors were the ones who could be nurses and be in the unit always since they explained when she asked them. Doctors explained to P7 wholeheartedly and asked if she understood. There was a communication problem between P7 and the doctors since they were not able to explain some words to her in Setswana. P7 thought that

her not to talk to me since she was not in the mood to do so and since she did not talk to me with love. I then drifted away from her.

This is poor interaction.
Doctors ... doctors are the ones who could be nurses who are always there because when you ask the doctor to explain to you, he/she would come and explain wholeheartedly and even ask if you understand. The funny thing about doctors is that there is a communication problem. We are not able to communicate with them since they are not able to explain some of the words to us in Setswana.
Setswana and I think it is because some of the words are the doctor’s language. If the doctor is not a Motswana it is difficult for him/her to explain more.

It was because some of the words were doctor’s language. It was difficult for a doctor who was not a Motswana to explain more to P7.

So if they ... if nurses were able to translate all the time, it could be better, or having a translator who is always next to the doctors because I think that we are having a problem of communication.

The other thing is that our educational background is not the same. Some mothers have never been to school completely. They are not able to talk to the doctor and tell

P7 felt that if nurses were able to translate when doctors were talking to her, it would be better. P7 thought that it could be better if there was always a translator next to the doctors to translate to mothers, especially those who have never been to school. P7 thought that some mothers were not able to tell the doctors their problem and had to wait

So if they ... if nurses were able to translate all the time, it could be better, or having a translator who is always next to the doctors because I think that we are having a problem of communication.

The other thing is that our educational background is not the same. Some mothers have never been to school completely. They
them for instance if the baby’s cord is bleeding or whatever could be happening. That mother waits to tell the nurse in order for the nurse to tell the doctor and sometimes that nurse would even crash her when she talks to her.

| These are the things that I do not give credit to nurses for but I think doctors are the best. The problem is communication because one would even try to talk to … using signs while communicating … you do not know anything about sign language and this becomes | These are the things I do not give nurses credit for but think doctors are best. | P7 did not credit nurses for not explaining things to her but thought doctors were the best. P7 thought the problem was communication breakdown between her and the doctors. When the doctor asked P7 something there was a possibility of her giving a | These are the things that, I do not give credit to nurses for but I think doctors are the best. The problem is communication because one would even try to talk to … using signs while communicating … you do not know anything about sign language and this becomes |

Unhelpful nurses

| Language barrier | Language barrier |
difficult because he/she is also just trying as he/she communicates. When he asks you something you answer it in a different way. The doctor might be asking you if the baby is well or not, then you would say, the baby is okay yet the baby is not okay since you did not understand what the doctor was saying. So this is the main problem.

<table>
<thead>
<tr>
<th>Doctor might ask if baby is well or not</th>
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<tbody>
<tr>
<td>Would say baby is okay yet baby is not okay</td>
</tr>
<tr>
<td>Since you did not understand</td>
</tr>
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</table>

wrong answer since she would have not understood
difficult because he/she is also just trying as he/she communicates.
When he asks you something you answer it in a different way. The doctor might be asking you if the baby is well or not, then you would say, the baby is okay yet the baby is not okay since you did not understand what the doctor was saying. So this is the main problem.

It sounds as if you are saying doctors are the ones who are explaining a lot of things, the problem is communication breakdown. Could you elaborate more on that?

Aa! There is
nothing more, I stop there.

The last question says: If you would have anything to make this time easier for you and your family, what would it be?

Pause

What would make ... aa I think that at this point in time I am fine. I do not need anything (participant laughs) because ... the very first day my family accepted what has happened and they said aa ‘it is a baby xxxxxx, so and so’s child is a grown up man who was born as a premature baby’ but you think your baby will not live.

I think I am fine

I do not need anything

My family accepted what has happened

It is a baby

Told her about a grown up man who was born premature

P7 thought she did not need anything because her family accepted her baby. P7’s family told her of a grown up man who was born as a premature baby to encourage her to have hope that her baby will also live

What would make ... aa I think that at this point in time I am fine. I do not need anything because ...

... the very first day my family accepted what has happened and they said aa ‘it is a baby xxxxxx, so and so’s child is a grown up man who was born as a premature baby’ but you think your baby will not live.

Support by family - accepted her baby

Support by family - encouragement

‘God has a plan for everyone’s life, even if the baby

Told her that God has a plan for every one’s

P7’s family told her that God had a plan for her

‘God has a plan for everyone’s life, even if the baby

Support by family - comfort
can go or do what it would still be according to the will of God’, you see. So I think that they were supporting me though some were saying a premature, a premature baby never survive. My close parents never said that to me. They said to me that the baby will grow and I will be surprised when I see that the baby has grown. Even when the baby was sick and feverish, if I told them that the baby was feverish, they told me that he is a baby and he is changing. It is not that the baby is sick.

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<tr>
<th>can go or do what it would still be according to the will of God’, you see. So I think that they were supporting me though some were saying a premature, a premature baby never survive. My close parents never said that to me. They said to me that the baby will grow and I will be surprised when I see that the baby has grown. Even when the baby was sick and feverish, if I told them that the baby was feverish, they told me that he is a baby and he is changing. It is not that the baby is sick.</th>
<th>Their main concern would be whether the baby</th>
<th>Their main concern would be whether baby</th>
<th>Their main concern was whether P7’s</th>
<th>Support from family - comfort</th>
<th>Support by family - reassure</th>
</tr>
</thead>
<tbody>
<tr>
<td>life</td>
<td>baby’s life since he has a plan for everyone’s life. P7 thought that her family was supportive.</td>
<td>can go or do what it would still be according to the will of God’, you see. So I think that they were supporting me though some were saying a premature, a premature baby never survive. My close parents never said that to me. They said to me that the baby will grow and I will be surprised when I see that the baby has grown. Even when the baby was sick and feverish, if I told them that the baby was feverish, they told me that he is a baby and he is changing. It is not that the baby is sick.</td>
<td>Support by family - reassure</td>
<td>Support from family - comfort</td>
<td>Support by family - comfort</td>
</tr>
</tbody>
</table>
is active, ‘yes he is active’ and then they would say it shows that the baby is okay. ‘Fever is fever and later on it will go down’. I think my parents were there for me.

Silence

Thank you for this interview. I am so grateful especially because I can see a smile on your face. It is wonderful to be blessed when you have hope. So I am grateful. It was wonderful talking to you. I would like to thank you for volunteering to participate in this study. Go home well.

Yes, Ma. Thank you.
APPENDIX G: LETTER TO CONFIRM REPRESENTATION OF TRANSCRIPTIONS

Re: audio-tape interviews

Dear Prof Mayers,

Mrs Rosinah Ncube requested me to listen to the above-mentioned tapes for validating the content of Setswana audio-tapes and the English written information for her research study.

Two interviews were listened to over a period of two hours. Participant 1 was a shorter version while participant 7 was the longest.

My observation was that the Setswana version was accurately translated to English. I therefore without prejudice declare that the content of both versions are the same.

Sincerely,

Mrs Makhutsisa Martha Mothibe.

RN, RM, Bcur, Mcur & Neonatal Nursing Science.

School of Nursing Principal
# Appendix H: Categories and Themes Emerging from the Data

<table>
<thead>
<tr>
<th>Categories</th>
<th>Participants</th>
<th>Description</th>
<th>Central theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afraid of baby - small</td>
<td>P1, P2, P3, P4, P5, P6, P7, P8</td>
<td>Afraid of baby who is too small</td>
<td>A life uncertain - my baby’s vulnerability</td>
</tr>
<tr>
<td>Didn’t know how to handle - afraid</td>
<td>P1, P2</td>
<td>Afraid of handling the baby</td>
<td>A life uncertain - my baby’s vulnerability</td>
</tr>
<tr>
<td>Afraid of hurting baby</td>
<td>P1, P7</td>
<td>Afraid of touching baby as it might hurt</td>
<td>A life uncertain - my baby’s vulnerability</td>
</tr>
<tr>
<td>Anxiety about baby’s condition</td>
<td>P2, P3, P4, P5, P6, P7</td>
<td>Anxiety about the outcome of the condition of the baby</td>
<td>A life uncertain - my baby’s vulnerability</td>
</tr>
<tr>
<td>Fear for survival of baby - small</td>
<td>P2, P7</td>
<td>Fear for the survival of the baby who is born too small</td>
<td>A life uncertain - my baby’s vulnerability</td>
</tr>
<tr>
<td>Concerned about baby’s well-being</td>
<td>P2, P4, P7</td>
<td>Concern that the well-being of the baby may be or is affected in a way</td>
<td>A life uncertain - my baby’s vulnerability</td>
</tr>
<tr>
<td>Concerned about baby’s safety</td>
<td>P1, P2, P4, P5, P7, P8</td>
<td>Concern that baby may be in danger or unsafe</td>
<td>A life uncertain - my baby’s vulnerability</td>
</tr>
<tr>
<td>Shocked by baby - small</td>
<td>P2</td>
<td>Shocked by delivery of a small baby who was not expected</td>
<td>Overcoming fear: emotional connections</td>
</tr>
<tr>
<td>Shocked by a preterm baby - small</td>
<td>P7</td>
<td>Shocked to deliver an unexpected small preterm baby</td>
<td>Overcoming fear: emotional connections</td>
</tr>
<tr>
<td></td>
<td>Difficulty in accepting baby</td>
<td></td>
<td>Difficulty in accepting the baby who was small</td>
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<tr>
<td>10</td>
<td></td>
<td>P2, P7</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Happy to hold baby</td>
<td>P1, P6</td>
<td>Happy that she is able to hold the baby unlike before</td>
</tr>
<tr>
<td>12</td>
<td>Accepted baby</td>
<td>P2, P5</td>
<td>Accepted the baby after holding him</td>
</tr>
<tr>
<td>13</td>
<td>A loving relationship with baby</td>
<td>P3, P5, P7, P8</td>
<td>Mother feeling the love and expressing it to her baby</td>
</tr>
<tr>
<td>14</td>
<td>Bonded with baby</td>
<td>P1, P5, P8</td>
<td>Mother had an emotional connection with the baby as she got used to the baby</td>
</tr>
<tr>
<td>15</td>
<td>Provided with information</td>
<td>P1, P2, P5, P6, P7, P8</td>
<td>Mother informed and shown how to care for the baby</td>
</tr>
<tr>
<td>16</td>
<td>Satisfied with the care</td>
<td>P1, P2, P3, P4, P6, P8</td>
<td>Mother pleased with the way the baby was cared for by staff</td>
</tr>
<tr>
<td>17</td>
<td>Good staff communication</td>
<td>P1, P8</td>
<td>Staff communicating with the mother well while in the neonatal unit</td>
</tr>
<tr>
<td>18</td>
<td>Helpful nurses</td>
<td>P1, P2, P4, P7, P8</td>
<td>The nurse helping the mother when she needed</td>
</tr>
<tr>
<td></td>
<td>Experience Type</td>
<td>Participants</td>
<td>Description</td>
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<tr>
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</tr>
<tr>
<td>19</td>
<td>Good interaction</td>
<td>P1, P2, P3, P4, P5, P6, P8</td>
<td>Mother interacting well with doctors and nurses</td>
</tr>
<tr>
<td>20</td>
<td>Explanation of baby’s condition</td>
<td>P3, P4, P5, P7, P8</td>
<td>Explanation of the condition of the baby and its prognosis to the mother</td>
</tr>
<tr>
<td>21</td>
<td>Explanation of procedure</td>
<td>P3, P5, P8</td>
<td>Explanation of the procedure done on baby to the mother</td>
</tr>
<tr>
<td>22</td>
<td>Support by staff</td>
<td>P1, P2, P4, P5, P8</td>
<td>Support of the mother by encouraging her, reassuring, comforting and showing her that you care while in the neonatal unit</td>
</tr>
<tr>
<td>23</td>
<td>Helpful doctor</td>
<td>P1, P2, P4, P7</td>
<td>Doctors assisting the mother who needed help</td>
</tr>
<tr>
<td>24</td>
<td>Not provided with information</td>
<td>P7</td>
<td>Mother not informed and not shown how to care for the baby</td>
</tr>
<tr>
<td>25</td>
<td>Unhelpful nurse</td>
<td>P3, P4, P5, P6, P7</td>
<td>The nurse not willing and not able to help</td>
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</tr>
<tr>
<td>26</td>
<td>Delay in assistance</td>
<td>P5, P7</td>
<td>The delay of doctors and nurses in attending to the baby when called by mother</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Experiences of interaction with medical and nursing staff</td>
</tr>
<tr>
<td>27</td>
<td>Non-explanation of treatment</td>
<td>P5, P6, P7</td>
<td>Treatment given to the baby not explained to the mother</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Experiences of interaction with medical and nursing staff</td>
</tr>
<tr>
<td>28</td>
<td>Non-explanation of procedure</td>
<td>P5, P6, P7</td>
<td>Procedures done on the baby not explained to the mother</td>
</tr>
<tr>
<td></td>
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<td>Experiences of interaction with medical and nursing staff</td>
</tr>
<tr>
<td>29</td>
<td>Non-explanation of baby’s condition</td>
<td>P5, P6, P7</td>
<td>Condition of the baby and its prognosis not explained to the mother</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Experiences of interaction with medical and nursing staff</td>
</tr>
<tr>
<td>30</td>
<td>Unsatisfied with the care</td>
<td>P5, P6</td>
<td>Not pleased with the way the doctors and nurses were taking care of baby</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Experiences of interaction with medical and nursing staff</td>
</tr>
<tr>
<td>31</td>
<td>No support from staff</td>
<td>P4, P7, P8</td>
<td>Staff not counselling, comforting or reassuring the mother while in the unit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Experiences of interaction with medical and nursing staff</td>
</tr>
<tr>
<td>32</td>
<td>Shifting responsibility</td>
<td>P4, P5, P7</td>
<td>Not acting responsibly and transferring the responsibility to someone</td>
</tr>
<tr>
<td></td>
<td></td>
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</tr>
<tr>
<td>33</td>
<td>Poor interaction</td>
<td>P2, P4, P7</td>
<td>Mother not interacting well with doctors and nurses in the unit</td>
</tr>
<tr>
<td>34</td>
<td>Unhelpful doctor</td>
<td>P2, P5</td>
<td>Doctor not able to help the mother when she needed assistance</td>
</tr>
<tr>
<td>35</td>
<td>Afraid of equipment - new</td>
<td>P5, P7</td>
<td>Mother afraid of the strange equipment in the unit</td>
</tr>
<tr>
<td>36</td>
<td>Non-explanation of neonatal environment</td>
<td>P7</td>
<td>Non-explanation of the neonatal environment to the mother who does not know what to expect</td>
</tr>
<tr>
<td>37</td>
<td>Environment safe - clean room</td>
<td>P1, P5, P8</td>
<td>The environment was safe for the baby as room was clean</td>
</tr>
<tr>
<td>38</td>
<td>Environment safe - clean feeding utensils</td>
<td>P5, P8</td>
<td>The environment was safe for the baby as the feeding utensils were clean</td>
</tr>
<tr>
<td>39</td>
<td>Afraid of other babies who die</td>
<td>P7</td>
<td>Mother afraid of babies who were dying in the neonatal unit</td>
</tr>
<tr>
<td>40</td>
<td>Fear for survival of baby - other babies die</td>
<td>P7, P8</td>
<td>Fear for survival of baby as others were dying</td>
</tr>
</tbody>
</table>
|   | Description                                      | Participants     | Support provided by:                                                                 | Enabling support
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>41</td>
<td>Non-explanation of the equipment</td>
<td>P6</td>
<td>Non-explanation of equipment used on the baby to the mother</td>
<td>An unfamiliar and intimidating environment</td>
</tr>
<tr>
<td>42</td>
<td>Support by staff</td>
<td>P1, P2, P4, P5, P8</td>
<td>Support of the mother by encouraging her, reassuring, comforting and showing her that you care while in the neonatal unit</td>
<td>Enabling support network</td>
</tr>
<tr>
<td>43</td>
<td>Support by other mothers</td>
<td>P1, P2, P5, P7, P8</td>
<td>Mother reassured, comforted, encouraged, given information and helped by other mothers in the unit</td>
<td>Enabling support network</td>
</tr>
<tr>
<td>44</td>
<td>Support of other mothers</td>
<td>P1, P4, P7</td>
<td>Mother supporting another mother by encouraging her and offering assistance</td>
<td>Enabling support network</td>
</tr>
<tr>
<td>45</td>
<td>Support by family</td>
<td>P2, P4, P6, P7</td>
<td>Family supporting the mother by visiting, phoning, reassuring, encouraging and meeting other needs</td>
<td>Enabling support network</td>
</tr>
<tr>
<td>46</td>
<td>Belief in God</td>
<td>P3, P4, P6, P7</td>
<td>Believing God to intervene in difficult situations when one trusts in him and prays</td>
<td>Enabling support network</td>
</tr>
</tbody>
</table>
DECLARATION

I Rosinah K. Ncube, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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[05-12-11]

Date