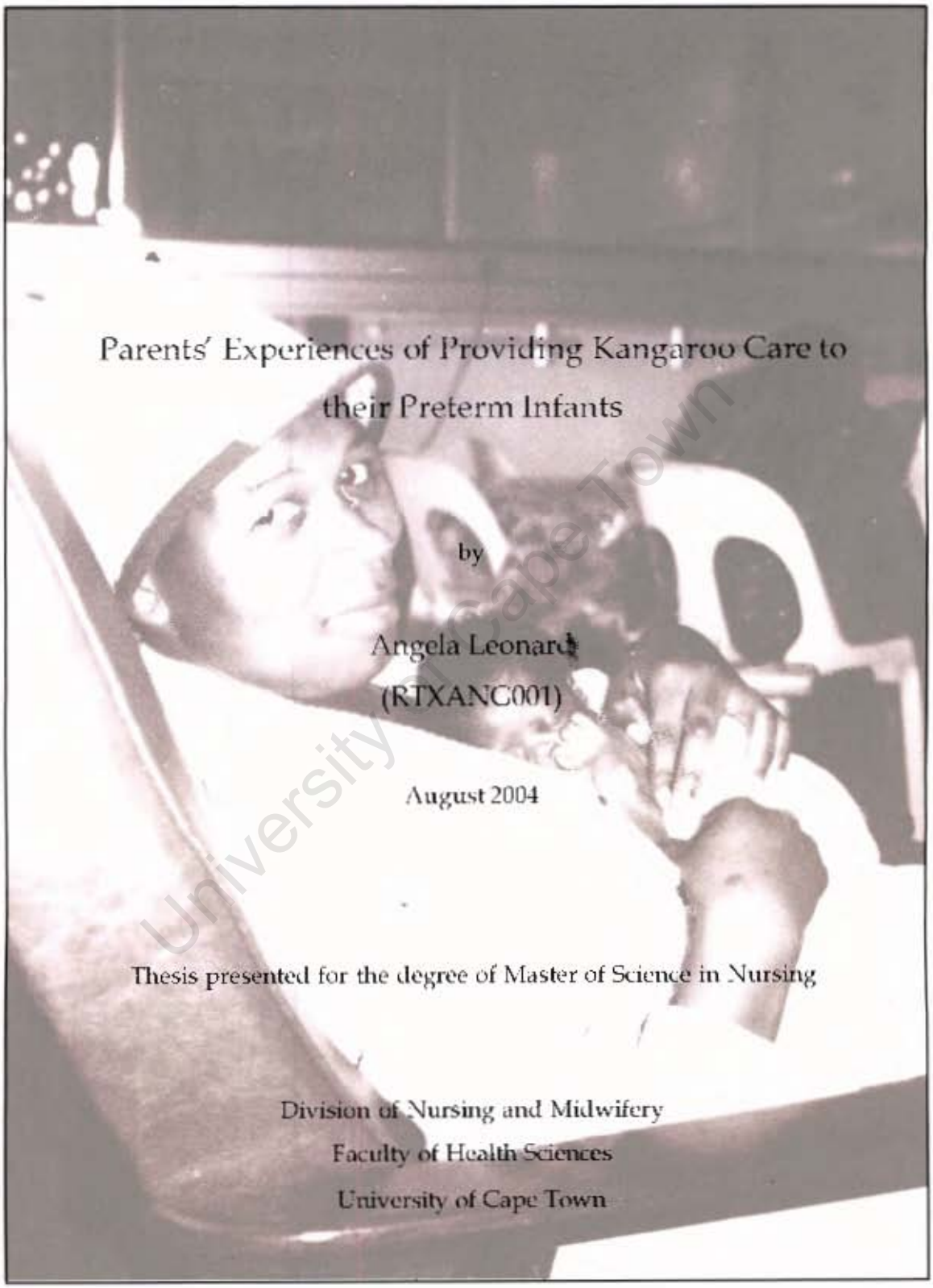

# Parents' Experiences of Providing Kangaroo Care to their Preterm Infants

by

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# TABLE OF CONTENTS

**TABLES:**



**GRAPHS:**

# DECLARATION

I, **Angela Louise Leonard**, hereby declare that the work on which this thesis 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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Leonard

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Date

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"*I can do all things through Christ who strengthens me*". Philippians 4:13.

# ABSTRACT

This phenomenological study explores the lived experience of parents who provided kangaroo care to their preterm infants. Six parents (four mothers and two fathers) participated in the study. In-depth 'free attitude' interviews were conducted and analysed using a combination of Colaizzi's, Giorgi's and Hycner's methods. Eight central themes emerged: (i) *"not his time"* - delivering a preterm infant; (ii) anxiety and barriers; (iii) intimate connection; (iv) adjustments/roles and responsibilities; (v) measurement of success; (vi) support network - *"standing by us"*; (vii) living without *"their infant"* and living within *"the hospital"*; and (viii) living with *"their infant"* outside *"the hospital"*.

The findings indicate that parents found the experience to be positive, and through kangaroo care were able to bridge the gap created by the infant's unexpected preterm birth and form a secure attachment. The support that the parents received from their partner/spouse, family, staff in the hospital and other mothers during this critical time was important for their well-being. A concern raised by parents was that information regarding preterm birth and kangaroo care should be made available to all pregnant women and future parents during the antenatal period.

The findings of this study provide information which will enable health care personnel to understand the lived experience of parents who provide kangaroo care. In supporting parents who provide kangaroo care, nurse-midwives assist these parents to regain confidence and enhance their willingness to participate. It is proposed that kangaroo care be extended into neonatal intensive care units and that additional kangaroo care wards be established in order to facilitate the involvement and competence of parents of preterm infants. All nurse-midwives should gain experience in this aspect of maternal-child care as part of their training.

# DEFINITIONS

**Attachment:**

An interactive process between partners resulting in a satisfying experience and an emotional bond that motivates parental commitment in caring for the infant (Mercer & Ferketich 1990, p. 268). (In this study, attachment is defined by the mother and fathers interaction and relationship with their preterm infant)

**Chorioamnionitis:**

An inflammatory reaction in the amniotic membranes caused by organisms in the amniotic fluid. The membranes become infiltrated with polymorphonuclear leukocytes (Glanze, Anderson &Anderson 1990, p. 250).

**Experience:**

Knowledge derived from one's own action, practice, perception, enjoyment or suffering (Markwardt, Cassidy & McMillan 1992, p. 447).

**Expressed Breast Milk (EMB):**

The pressing or squeezing of milk from the breast after pregnancy (Glanze *et al.* 1990, p. 452).

**Gestation:**

The period of time from fertilization of the ovum until birth, the average gestation is 266 days or approximately 280 days from the onset of the last menstrual period (Glanze *et al.* 1990, p. 517).

**Kangaroo Mother Care (KMC)/ Kangaroo care (skin to skin) care (KC):**

The practice of holding a preterm infant naked (except for a nappy and a hat) between the mother's breasts (Whitelaw 1990, p. 604).

**Lactation:**

The process of producing and supplying breast milk (Ladewig *et al.* 1994, p. 869).

**Low Birth Weight Infant (LBW):**

An infant whose weight at birth is less than 2500g, regardless of gestational age (Glanze *et al.* 1990, p. 705).

**Low Birth Weight Rate (LBWR):**

$$\frac{\text{Total number of births} < 2500\text{grams} \times 100}{\text{Total number of births}}$$

(MRC publication 2001, p. 4)

**Midwife:**

In South Africa, after 1980, midwifery became part of the general training of a nurse. General nurses thus have midwifery as a speciality, midwives are also nurses. The term midwife and nurse has therefore been used interchangeably.

**Midwife Obstetric Unit (MOU):**

A midwife run active birthing unit based in communities, which is staffed 24 hours a day by midwives, with a doctor on call if required. The units provide antenatal, perinatal and postnatal care in less affluent communities. Complicated cases are referred to secondary or tertiary care centres. Midwife Obstetric Units are unique to the health system in the Western Cape (Van Coeverden, De Groot, Davey & Howland 1978).

**Milieu:**

The environment, surroundings or setting (Glanze *et al.* 1990, p. 759).

**Nasogastric Tube:**

Any tube that is passed into the stomach through the nose to instil medication, food or fluids (Glanze *et al.* 1990, p. 794).

**Neonatal Intensive Care Unit (NICU):**

A hospital unit containing a variety of sophisticated mechanic devices and special equipment for the management and care of premature and seriously ill newborn infants (Glanze *et al.* 1990, p. 800).

**Nosocomial Infection:**

An infection acquired during hospitalisation (Glanze *et al.* 1990, p. 821).

**Parent - Infant Attachment:**

Close affectional ties that develop between parent and child (Ladewig *et al.* 1994, p. 871).

**Perinatal Mortality Rate (PNMR):**

$$\frac{\text{Total number of perinatal deaths} \times 100}{\text{Total number of births}}$$

(MRC publication 2001, p. 4)

**Perinatal Period:**

The perinatal period starts at the beginning of foetal viability (28 weeks gestation or 100grams in South Africa) and ends at the end of the 7th day after delivery (MRC publication 2001, p. 4).

**Preterm Infant:**

An infant born at less than 37 completed weeks (less than 259 days) of gestation (World Health Organisation 1998).

**Preterm Premature Rupture of Membranes (PPROM):**

The spontaneous rupture of the amniotic sac before the onset of labour (Glanze *et al.* 1990, p. 956).

**Term Infant:**

Any neonate, regardless of birth weight, born after the end of the thirty-seventh and before the beginning of the fortieth week of gestation. Infants delivered at term usually weigh between 2700 and 4000 grams (Glanze *et al.* 1990, p. 1156).

# ABBREVIATIONS

| | |
|---|---|
| **KMC** | **Kangaroo Mother Care** |
| **LBW** | **Low Birth Weight** |
| **LBWR** | **Low Birth Weight Rate** |
| **MOU** | **Midwife Obstetric Unit** |
| **NICU** | **Neonatal Intensive Care Unit** |
| **NND** | **Neonatal Deaths** |
| **NNDR** | **Neonatal Death Rate** |
| **PMNS** | **Peninsula Maternal and Neonatal Services** |
| **PNMR** | **Perinatal Mortality Rate** |
| **PROM** | **Preterm Premature Rupture of Membranes** |
| **VLBW** | **Very Low Birth Weight** |

# Chapter 1

# INTRODUCTION AND REVIEW OF THE LITERATURE

## 1.1 INTRODUCTION

The birth of a preterm infant is a crisis for any family. The mother is denied the last few weeks of pregnancy that help to prepare her psychologically for the stress of birth and the attachment process. The usual process of becoming a parent has been disrupted, and parents are in many ways as "premature" as their infants. According to Bowlby (1969), parents look forward to becoming attached to their infants even before their birth, by expecting to spend time with their newborn (cited in Goulet, Bell, St-Cyr Tribble, Paul & Lang 1998):

> *"Parents restrict space between themselves and their infant to favour interaction and the development of their parental roles. Early and extensive contact enables the parents to become acquainted with their infant" (Bowlby 1969, cited in Goulet et al. 1998, p. 1074).*

However, for parents of the preterm infant, their infant's unexpected birth challenges the previously held notions they may have held. They expect to deliver a healthy full term infant, but instead are faced with a small infant whose life is often supported by technological devices, is cared for by highly specialised health professionals, and seems very distant from their anticipated normal healthy infant.



## 1.2 RISKS ASSOCIATED WITH PREMATURITY

A preterm infant has been defined by the World Health Organisation (1998) as an infant born at less than 37 completed weeks (less than 259 days) of gestation

In South Africa in 2001, spontaneous preterm labour was second to unexplained uterine death as the most common cause of deaths in the perinatal period (Pattinson 2001). There are many reasons why an infant may be born

prematurely. The infant is born due to either prematurely induced labour ("an obstetric procedure in which labour is initiated artificially by means of amniotomy or the administration of oxytocics, performed for foetal or maternal indications" (Glanze, Anderson & Anderson 1990, p. 616)) or spontaneous preterm labour ("a birth occurring without the mechanical assistance of obstetric forceps or vacuum aspirator" (Glanze *et al* 1990, p. 1108)).

Causes of spontaneous preterm labour include:

- Idiopathic preterm labour
- Preterm premature rupture of membranes (PPROM)
- PPROM with chorioamnionitis
- Cervical incompetence
- Preterm labour with chorioamnionitis with intact membranes.

(Pattinson 2001)

The number of premature births decreases when complications during pregnancy are identified early and the pregnant women receive proper management of these complications. Premature infants are prone to infections and lung problems. These infants require special care in well-managed health facilities; a lack of access to such facilities results in the death of many of these premature infants (Pattinson 2000).

Dwindling health resources, loss of highly skilled nursing staff and lack of equipment/replacement of equipment are commonplace in numerous secondary and tertiary health care centres in South Africa (Baleta 1998). Parents are therefore being encouraged to take on additional responsibility for routine care of their infant.

One of the current options for management of preterm infants is kangaroo care. Kangaroo care[1] involves holding a preterm infant that is dressed only in a nappy and hat in an upright position between the parent's bare breasts (Whitelaw 1990). It is a form of skin-to-skin contact between the parent as the

[1]In the international literature kangaroo care may also be known as kangaroo mother care (KMC) or skin to skin care. For this study the term 'kangaroo care' will be utilised.

primary caregiver and his/her infant. The parent encloses the infant in his/her clothing to ensure that the infant's body temperature is maintained.

## 1.3 GUIDELINES FOR KANGAROO CARE

Kangaroo care is practised in both developing and developed countries. Broad guidelines were designed for the positioning of infants while receiving kangaroo care (Charpak & Figueroa 1998). Locally these guidelines have been adapted and the researcher's observations of implementation in the local hospital setting are described in detail below.

### 1.3.1 Immediate Post-Delivery

Once a mother has delivered a preterm infant, the infant is taken to the neonatal nursery for assessment, and if necessary placed on oxygen or a ventilator.

### 1.3.2 Neonatal Nursery

The preterm infant remains in an incubator in the neonatal nursery until s/he is stable and weighs 1700 g. At the first parental visit to the nursery, a neonatal nurse explains the concept of kangaroo care and demonstrates this to the parents. The explanations and demonstrations continue at each subsequent visit until the parents feel confident in placing their infant in the kangaroo care position themselves.

### 1.3.3 Kangaroo Care Position

As soon as the infant is in a stable condition and in 40% (or less) head box oxygen, irrespective of gestational age or weight, the mother and father are encouraged to keep their infant in the kangaroo care position throughout their visits. As the parents become more confident in handling their infants, they remove them from the incubator, even if the infant is still being tube-fed and/or receiving facemask oxygen, and the infant is held in the kangaroo care position. Mothers are invited to place their infants in the kangaroo care position and

participate in the educational talks on infant and child health topics and the discussion groups held in the kangaroo care ward.

### 1.3.4 Kangaroo Care Ward

When the infant reaches 1700 g and is partially breast-feeding s/he is removed from the incubator into 24-hour continuous kangaroo care. If already discharged, the mother returns to the kangaroo care ward. Parents are encouraged to keep their infants in the kangaroo care position 24 hours a day from the time that the infant leaves the incubator until s/he weighs at least 2 kg.

The kangaroo care ward is a separate ward where the mother stays with her infant for several days before the infant's discharge home. The kangaroo care ward is able to accommodate 10 mother-infant pairs under the supervision of a registered nurse who provides a supportive and domestic (rather than hospital) environment and atmosphere.

The mothers practise kangaroo care 24 hours a day, during which time they are mobile with their infants in the kangaroo care position. This is in preparation for doing light household chores or activities when they return home. Mothers sleep on their backs with the infants in the kangaroo care position, with the head of the bed slightly raised. Bassinets are only necessary while the mother sees to her own personal hygiene and ablution needs.

### 1.3.5 Discharge Home

The infant is discharged when his/her weight reaches 1.8 kg and he/she is breast-feeding adequately. The mother needs to be comfortable handling the infant, and able to cope at home. Once discharged from the hospital, infants are taken for weight checks at their nearest clinic within three days. An appointment with the paediatrician at the clinic is scheduled within 10 days of discharge (Hann, Malan, Kronson, Bergman & Huskisson 1999).

Kangaroo care is a cost-effective method of care since it reduces hospital expenses (Lima, Quintero-Romero & Cattaneo 2000, Tessier, Cristo, Velez *et al.* 1998) and the length of time (Hann *et al.* 1999) that the preterm infant spends in

hospital, thus making it one of the most affordable and well-accepted options in caring for stable preterm infants. Ninety-six per cent of premature infants born worldwide do not have access to any technology. They do, however, have access to a parent's body (habitat), which they require to survive (Bergman 1998).

The length of time a preterm infant spends in the kangaroo care position has been adapted to suit the requirements of different communities. In developed countries that have access to unlimited resources and incubators, kangaroo care has been defined as a "period of 60 to 75 minutes per day of skin-to-skin contact added to modern intensive and prolonged hospital care" (Diaz-Rosello 1996, p. 108). This study is set in a South African hospital; the definition of kangaroo care that was applicable in that hospital was continuous kangaroo care.



## 1.4 BACKGROUND TO THE STUDY/RESEARCH QUESTION

I became interested in the topic of kangaroo care during my third year as a student nurse, while working in a neonatal nursery at a tertiary hospital in Cape Town. A mother had given up her preterm infant for adoption. The preterm infant was crying uncontrollably and nothing would pacify her until a staff member suggested I try the kangaroo method. I was instructed how to hold and position the infant. Once in the kangaroo care position, the infant stopped crying and fell asleep immediately. As I witnessed the calming and comforting effect that kangaroo care had on the infant, I became aware of the awe I felt at how such a simple act of touch could evoke feelings of compassion towards an infant with whom I had had no prior contact. This experience of kangaroo care prompted me to conduct a small undergraduate research study on mothers' experiences of providing skin-to-skin care to their preterm infants.

In the neonatal nursery the focus of nursing attention is directed towards the preterm infant. Health professionals may be so occupied with the physical care of the infant that it is possible to forget about the parents who sit alongside the

incubator. For this study fathers' experiences along with those of the mothers, and the interactions between preterm infants and their parents were explored.

## 1.5 OVERVIEW OF THE LITERATURE

A literature review was undertaken, which was crucial in stimulating my desire to enable parents to express their feelings and perceptions, since the parents' perspective of kangaroo care was glaringly absent from the majority of the literature consulted.

This is a broad overview of the present literature related to premature birth and kangaroo care. A further in-depth literature review will be presented in Chapter 4, when discussing the findings of the study.

### 1.5.1 Premature Birth

Preterm delivery often means early physical separation of the mother from her newborn infant. The standard care of preterm infants involves extended maternal-infant separation and incubator care (Bergman, Linley & Fawcus 2004). Parents experience a range of emotions, ranging from fear regarding the survival of their infant, to disappointment about not delivering a full-term infant, and anxiety related to the separation from and decreased interaction with their infant (Miles, Funk & Kasper 1992).

The high rates of morbidity and mortality arising from preterm birth and low birth weight impose an immense burden on the health, education and social services, and on families (Petrou, Sach & Davidson 2001). It has been estimated that 95% of low-birthweight infants are born in developing countries. However, most of the globally available resources are invested in developed countries, both for advanced, costly technological care (Ruiz, Charpak & Figuero 2002).

There are often practical worries or financial burdens for parents of preterm infants. A study by Gennaro (1996) found that families had increased expenses while the infant was still hospitalised, while the mother herself was still

recuperating. Costs of having a preterm infant included non-reimbursed health costs, extra transportation costs, parking costs, child care for siblings, additional food costs, phone costs and the cost of equipment such as breast pumps or apnoea monitors. The greatest out-of-pocket expense was transportation costs, which were a barrier to a family's ability to visit their infant.

### 1.5.2 Kangaroo Care

Gorski, Huntington & Lewkowitcz (1990, p. 103) found that "inside a well functioning uterine environment, preterm infants continue to thrive towards a normal outcome at term". A duplicate uterine environment is essential to facilitate a smooth transition between uterine and extra-uterine life for the preterm infant. Although the hospital incubators can provide warmth, they are subject to equipment failure and human error. "The mother's body and her breast milk cannot become too hot or cold, but instead provide a steady ideal warmth" (Anderson, Marks & Wahlberg 1986, p. 807).

Kangaroo care involves "holding a preterm infant dressed only in a nappy and hat in an upright position between the parent's bare breasts" (Whitelaw 1990, p. 604). The name was chosen due to the method's similarity to the care which kangaroos provide to their young, who are always born prematurely and are guided into the maternal pouch for warmth and unlimited feeding opportunities until maturation (Ludington-Hoe, Thompson, Swinth, Hadeed & Anderson 1994).

### 1.5.3 Historical Context of Kangaroo Care

Prior to the early 1960s it was the accepted view that preterm infants were fragile and could not tolerate any stimulation. In the 1960s and early 1970s parents were only permitted into the neonatal nursery for the first time a day or two prior to their infant's discharge, if at all (Klaus & Kennell 1976). Handling of infants was identified as a source of stress and resulted in minimal handling protocols; affectionate and nurturing handling was kept to a minimum (Korner 1990). The main human contact for these preterm infants was through invasive

medical procedures. The high cost of equipment and small proportion of preterm births forced Neonatal Intensive Care Units (NICUs) to be situated in regional medical centres rather than at local hospitals, which further separated parents from their infants (Davis, Mohay & Edwards 2003).

In the 1970s sensory stimulation studies were carried out, and the results showed that infants were far from being sensorially deprived. They were exposed to high levels of monotonous noise and illumination, and intensive medical care disrupted their sleep and oxygen saturation (Korner 1990). (These findings were the basis for the introduction of minimal handling protocols.)

The pendulum then swung in the opposite direction, as researchers began to conduct studies about sensory deprivation. It was realised that depriving a preterm infant of stimulation had harmful effects by "causing dramatic changes in the brain's efficiency and lowering IQ" (Dooman 1984, p. 1). Sensory stimulation was again was considered essential practice for preterm infants. The touch and contact provided by kangaroo care was not stressful to infants, and in fact reduced the amount of stress under intensive care. In addition to the soothing effect kangaroo care had on infants, mothers also responded positively to the skin-to-skin contact experience. The kangaroo care position provides psychological as well as physical closeness (Ludington-Hoe *et al.* 1994). Browne (2004) confirms this view by stating that the early, intimate, and physiologically stabilizing benefits of kangaroo care provide the optimal environment for preterm infants in intensive care.

In Bogotá, Colombia prior to 1979 premature infants were separated from their mothers due to the threat of nosocomial infection, and cared for in shared incubators in the NICU. Mothers did not see their infants until the infants were discharged. Despite this isolation, infections persisted and mortality was high. Parents commonly abandoned their infants (Anderson *et al.* 1986).

The separation policy changed after the experience at the Hospital Materno Infantil in Bogota, Colombia, from September 1979. The Ambulatory Programme for Premature Infants - now commonly known as kangaroo care -

designed by physicians Rey and Martinez was implemented. Infants in a satisfactory clinical condition, no matter how small, went directly to their mothers as early as two to three hours after birth.

Morbidity and mortality dropped when infants were given breast milk expressed from either their own or another mother, and dropped further when they were directly breast-fed by their own mothers. "It was then realised that the maternal milieu of warmth, nourishment and love, provided the ideal environment for preterm infants. " (Anderson *et al.* 1986, p. 807).

Mothers were taught to breast-feed and to carry their preterm infants in the skin-to-skin upright position. Preterm infants who no longer required other interventions went home with their mothers as soon as 12 hours after birth, and were seen the next day at a follow-up clinic (Anderson et al. 1986).

The study by Anderson et al. (1986) found that discharging a stable preterm infant, irrespective of weight, was beneficial to the infant. Before the kangaroo care method was introduced all infants weighing less than one kilogram died. After the implementation of kangaroo care, 75% of those infants survived (Whitelaw & Sleath 1985). However, the early discharge of preterm infants and the kangaroo care method were initially viewed with scepticism. Diaz-Rosello (1996) stated that discharging an infant regardless of its weight and gestational age was inappropriate, and that no evidence existed to support the kangaroo care proposal of discharging infants below 1800 g. Once research had been published (Bergman & Jurisoo (1994); Whitelaw & Sleath (1985); Anderson et al. (1986). Ludington-Hoe et al. (1994)) showing its benefits, kangaroo care became widely accepted in the international health arena: "Kangaroo Mother Care is rapidly becoming an integral part of the care of the newborn infants worldwide" (Bergman, Malan & Hann 2003, p. 311).

Kangaroo care was associated with the following reduced risks: nosocomial infection at 41 weeks' corrected gestational age (relative risk 0.49, 95% confidence interval 0.25 to 0.93), severe illness (relative risk 0.30, 95% confidence interval 0.14 to 0.67), lower respiratory tract disease at 6 months

follow-up (relative risk 0.37, 95% confidence interval 0.15 to 0.89) (Conde-Agudelo, Diaz-Rossello & Belizan 2003).

Kangaroo care results in better physiological outcomes and stability than the equivalent care provided in closed temperature regulated incubators. The cardio-respiratory instability seen in separated infants in the first 6 hours is consistent with "protest-despair" and "hyper-arousal and dissociation" response patterns described in human infants. This shows that newborns should not be separated from their mothers (Bergman *et al.* 2004).

### 1.5.4 Establishment of the International Kangaroo Foundation

After the implementation of kangaroo care in Colombia in 1979, the *Fundación Canguro* or Kangaroo Foundation was established. The purpose was to promote the delivery of high-quality care to the high-risk newborn infant that was scientifically sound, humane and cost-effective, making it available even in situations of scarce resources. One of the Kangaroo Foundation's goals was to facilitate the dissemination and transference of knowledge and technology associated with the kangaroo care method through publications and training on kangaroo care offered to health professionals.

In 1996 the First International Meeting on Kangaroo Care was held in Trieste, Italy. Recommendations emanating from this conference were that kangaroo care did not need expensive and sophisticated equipment, that because of its simplicity it could be applied everywhere, including peripheral maternity units in very low income countries. Kangaroo care contributed to the humanisation of neonatal care and to better bonding between mother and infant in both poor and rich countries (Charpak, Figueroa de Calume & Ruiz 2000).

The Second International Meeting on Kangaroo Care was held in 1998 in Bogota, Colombia (Charpak *et al.* 2000). Recommendations from the first meeting were discussed and kangaroo care was viewed in its broader context. At this meeting the Declaration of the Kangaroo Infant was signed by delegates representing 30 countries:

*"We note that the major component of infant mortality in countries represented at the workshop and worldwide is perinatal and neonatal mortality. In many of these countries, there is a high incidence of low-birth-weight infants, which contributes significantly to the mortality rates observed.*

*"These neonates often suffer from neurological sequelae and poor growth and development because their care and maintenance is expensive and sometimes impossible to provide. Kangaroo care is an affordable, alternative method, which has yielded good results. Its safety has been documented to provide the basic requirements for the survival of the newborn : mother's warmth, mother's breast milk, and mother's love and protection.*

*"We recommend therefore that all governments, through their health ministries, incorporate this method into their national health programmes for newborns, that all international organizations concerned with the welfare of children and their mothers provide support and consider adopting Kangaroo care as part of their worldwide programmes.*

*"We declare that Kangaroo care should be a basic right of the newborn, and that it should be an integral part of the management of low-birth-weight and full-term newborns, in all settings and levels of care in all countries".*

(Charpak *et al.* 2000, p. 1140.)

The Third International Meeting on Kangaroo Care was held in 2000 in Yogyakarta, Indonesia. At this workshop the delegates focused on the implementation of kangaroo care and the necessity for kangaroo care to be acknowledged and understood by the general population. The Fourth International Workshop on Kangaroo Care took place in Cape Town, South Africa, in 2002. Following this workshop a regional South African Kangaroo

Care Foundation was instituted; it aims to encourage kangaroo care in sub-Saharan Africa (Bergman *et al.* 2003).

### 1.5.5 Perinatality in South Africa

In 2001 the low birthweight (LBW) rate for births in developed countries ranged between 6% and 7%, whereas in developing countries it was much higher at around 15% (Pattinson 2001; Kirsten 2000).

Infant mortality rate is a key indicator of the economic status of a country. In South Africa this measure remains a crude estimate since mortality data are of poor quality. Perinatal deaths and infant mortality rates reflect the quality of the health services as well as of environmental factors such as access to water, sanitation and fuel.

***Table 1: Perinatal care indices for 2000 for the Western Cape and estimated for South Africa***

| Province | Births >1000 g | NND >1000 g | PNMR >1000 g | NNDR >1000 g | LBWR (%) |
|---|---|---|---|---|---|
| Western Cape | 71 524 | 301 | 19 | 4 | 17.5 |
| South Africa | 387 957 | 4651 | 35 | 12 | 17.8 |

(Pattinson 2001, p. 41)

NND = Neonatal deaths; PNMR = perinatal mortality rate; NNDR = Neonatal death rate; LBWR = low birthweight rate.

In the 2000 calendar year there were 28 284 deliveries in the Peninsula Maternal and Neonatal Services (PMNS) in the Western Cape:

- the perinatal mortality rate was 33 per 1000 livebirths;
- the LBW rate was 16%; and
- the primary obstetric cause was spontaneous preterm labour (27, 3%).

The top three avoidable factors for the above in the PMNS were that:

- patients had never initiated antenatal care;

- there was a delay in seeking medical care during labour; and
- patients booked late in pregnancy.

(Pattinson 2001)

*Table 2. Proportion (%) of the primary obstetric causes of perinatal deaths between 999 g and 2000 g per area for 2001*

| Primary obstetric cause | Metropolitan | City and Town | Rural |
|---|---|---|---|
| Spontaneous preterm labour | 22.2 | 29.4 | 49.7 |
| Unexplained intrauterine death | 29.5 | 22.6 | 21.1 |
| Hypertension | 18.0 | 16.7 | 7.5 |
| Antepartum haemorrhage | 17.6 | 16.8 | 9.5 |
| Idiopathic intrauterine growth restriction | 1.2 | 1.3 | 2.0 |
| Intrapartum asphyxia and birth trauma | 1.6 | 3.8 | 3.4 |
| Infections | 1.8 | 5.3 | 1.4 |
| Congenital abnormalities | 4.8 | 2.1 | 2.0 |
| Pre-existing maternal disease | 2.0 | 0.6 | - |
| Other | 1.0 | 0.2 | 2.7 |

(Pattinson 2001, p. 34.)



In 2001 the perinatal mortality rate for the Western Cape was reported as 18.4 per 1000 births. "The perinatal mortality rate for South Africa in 2001 was estimated at 40 per 1000 births" (Pattinson 2001, p. 31).

"In South Africa in 2001 spontaneous preterm labour was the primary cause of perinatal death in both rural (49.7%) and city and town (29.4%) areas, and the second cause of perinatal death in metropolitan areas (22.2%)" (Pattinson 2001, p. 34). In 2001 the major causes of perinatal mortality and related avoidable factors included:

- lack of antenatal care;

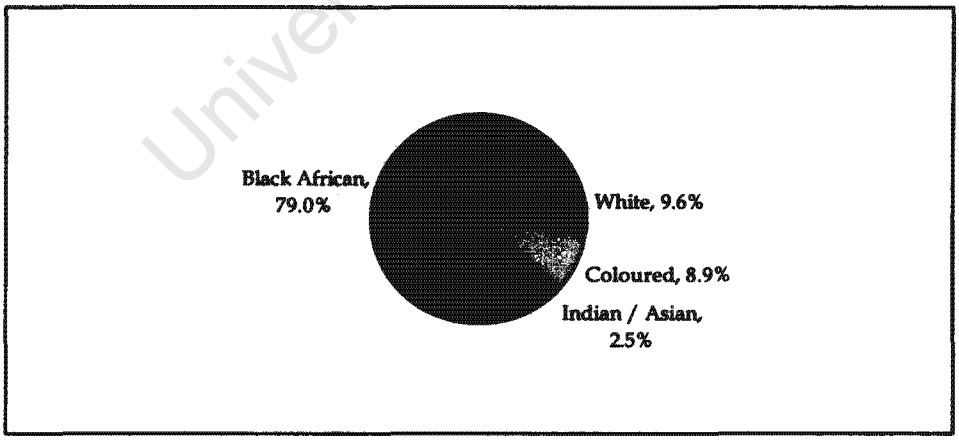
- management of labour;
- resuscitation of the asphyxiated neonate; and
- care of the premature infant.

It was recommended that equipment, protocols and trained health workers be available and specifically that kangaroo care be introduced for the care of preterm infants, thus making the reduction of perinatal mortality in South Africa feasible and inexpensive (Pattinson 2001).

The Western Cape has the highest number of LBW infants. In the Western Cape Province, from January 2000 - December 2000 there were 1477 infants born weighing between 500 - 999 grams. 12703 infants were born that weighed between 1000 – 2499 grams (MRC publication 2001). In 2000 the LBW rate in the PMNS in the Western Cape was 16% (Pattinson 2001). It thus follows that the kangaroo care for low birth weight infants is vital as NICU beds are limited. In the Western Cape the majority of the population is coloured, that is a contributing factor to the high number of LBW infants in the Western Cape.

The socio-economic and health status of South Africa is "colour-coded" (Cummins 2002, p. 49).






(International Expert Group Seminar on Population Census Data Dissemination and Use 2003)

**Graph 1: Distribution of population in South Africa by population group, October 2001**

The basis for the population/ethnic group classification in South Africa was The Population Registration Act (No. 30) of 1950. Under this Act all South Africans were to register their 'race' at 'birth with the government and were classified into four main 'racial' groups:

- 'Whites' (denoting those of indigenous European background);
- 'Bantu/Blacks' (denoting those of indigenous African background);
- 'Coloureds' (denoting those of mixed 'race', usually of 'black' and 'white'); and
- 'Indians' (denoting those of indigenous Asian background).

As a result of his/her classification, an individual was only allowed to find accommodation in an area designated for the use of the particular racial category which the State determined he or she belonged to. During 1991 the South African Parliament repealed the basic apartheid laws including the Population Registration Act.

'Coloured' infants are genetically much smaller than white or black infants and are often born below 'normal' birthweight. However, smoking, alcohol use and hypertension, all problems in South Africa and especially the Western Cape also influence foetal growth (Kirsten 2000).



## 1.6 KANGAROO CARE IN THE WESTERN CAPE

In 1997 kangaroo care was formally adopted as routine practice for the care of LBW infants in the tertiary hospital in which the study was conducted. In 1998 a kangaroo care protocol was designed for use in the neonatal nursery and kangaroo care ward. This protocol has three components, outlined below.

### 1.6.1 Kangaroo Care Position

The infant, dressed only in a hat and nappy, is placed on the mother's bare chest, in an upright position between the breasts. The infant's head is turned to the side so that the infant's ear is against the parent's heart. The infant is

secured in position by wrapping the mother's blouse, towel or blanket around the mother and her infant. The infant is able to remain in this position at all times except while the mother is performing personal hygiene tasks.

### 1.6.2 Kangaroo Nutrition

While the infant is in the kangaroo care position lactation is stimulated and he/she is able to breast-feed on demand.

### 1.6.3 Kangaroo Discharge

Infants are discharged from the neonatal nursery once they weigh 1800 g, are gaining weight and are mostly breast-fed; the mother must also be committed to providing kangaroo care at home.

## 1.7 BENEFITS OF KANGAROO CARE

There are benefits of kangaroo care for the infant, the parent and the health care services.

### 1.7.1 The Infant

**Infant Survival**

Bergman & Jurisoo (1994) reported on the introduction of kangaroo care at a rural mission hospital in Zimbabwe as the exclusive means of treating LBW preterm infants. The country had a lack of incubators for the care of preterm infants. Within minutes after delivery all infants were placed in the kangaroo care position. Mothers continued kangaroo care until the infant weighed 2000 g. "The survival of infants born weighing under 1500 g improved from 10% to 50%, and infants born weighing between 1500 g and 1999 g improved from 70% to 90%" (Bergman & Jurisoo 1994, p. 57). Preterm infants were once regarded as too small to survive and received only palliative care. After the initiation of kangaroo care there was a dramatic change in staff attitude towards preterm infants: "The nurses were no longer afraid to handle the infants and were confident of positive results" (Bergman & Jurisoo 1994, p. 60).

A study by Ludington-Hoe, Anderson, Swinth, Thompson & Hadeed (2004) showed that apnea, bradycardia, and periodic breathing were absent during kangaroo care. Regular breathing increased for infants receiving kangaroo care compared to infants receiving standard NICU care.

Clinical trial results revealed that the neonates in the KMC group demonstrated better weight gain after the first week of life (15.9 +/- 4.5 gm/day vs. 10.6 +/- 4.5 gm/day in the KC group and control group respectively $p < 0.05$) and earlier hospital discharge (27.2 +/- 7 vs. 34.6 +/- 7 days in KMC and control group respectively, $p < 0.05$) (Ramanathan, Paul, Deorari, Taneja & George 2001).

**Infants' Heads**

A noticeable advantage of the kangaroo care positioning was that preterm infants nursed in this position had well-shaped heads, in sharp contrast to the flat-sided heads that were accepted as inevitable in preterm infants. The swift return of infants to their mothers, who placed them in the kangaroo care position, eliminated the long time preterm infants spent lying on firm mattresses (Anderson *et al.* 1986).

**Infant Temperature Regulation**

Whitelaw & Sleath (1985) conducted a study which showed that during kangaroo care the infant was in contact with warm maternal skin on three sides, and that temperature regulation was excellent in very low birth weight (VLBW) infants held in the kangaroo care position. A study by Ludington-Hoe *et al.* (1994) confirmed the findings on temperature regulation. This randomised study, conducted at the Kadlec Medical Center in Washington, USA, comprised 25 premature (32-36 weeks' gestational age) infants and a pilot study of 6 premature infants. The effects that kangaroo care on a once-off basis for 2-3 hours had on each infant were observed. It was reported that the heart rate and abdominal temperature rose, there were no signs of heat loss, and instances of apnoea also declined. "Simultaneous measurements of maternal and infant temperatures during kangaroo care showed that the mothers appeared to be in

thermal synchrony with their infants. When an infant's temperature changed by 0.2°C, the maternal temperature response was a 1°- 2°C change in the opposite direction within one to two minutes " (Ludington-Hoe *et al.* 1994, p. 19).

Cattaneo, Davanzo, Uxa & Tamburlini (1998) summarised the recommendation of groups of health professionals for the implementation of kangaroo care in various settings, finding that kangaroo care prevented hypothermia and decreased morbidity. A study by Karlsson (1996) showed that for preterm infants cared for in the kangaroo care position there was an increase of 0.7°C in mean rectal temperature, and heat loss from areas in contact with the mother was reduced.

A randomized clinical trial conducted by Ludington-Hoe, Nguyen, Swinth & Satyshur (2000) found that toe temperatures were significantly higher during periods of kangaroo care, and maternal breast temperature met each infant's neutral thermal zone requirements within 5 minutes of onset of kangaroo care. In a subsequent randomized controlled trial infants receiving kangaroo care compared to control infants had higher mean tympanic temperature (37.3 degrees C vs. 37.0 degrees C), more quiet sleep (62% vs. 22%), and less crying (2% vs. 6%). (Chwo, Anderson, Good, Dowling, Shiau & Chu 2002). Mean cardiorespiratory and temperature outcomes remained within clinically acceptable ranges during kangaroo care compared to infants receiving standard NICU care (Ludington-Hoe *et al.* 2004).The LBW infants in a study by Ibe, Austin, Sullivan, Fabanwo, Disu & Costello (2004) had fewer episodes of hypothermia while receiving kangaroo care than during standard care.

Kangaroo care is an effective means of keeping premature infants warm, and has reduced the risk of serious infection by colonising infants with their mother's skin flora (bacteria and fungi) (Woods 1998). Kangaroo care is an affordable and available method to prevent neonatal hypothermia in most developing countries. (Tunell 2004).

## 1.7.2 The Parents

**Relaxation for Parents**

Relaxation of mothers and fathers due to the close contact of kangaroo care appeared to be very beneficial in families who came through a stressful period of neonatal intensive care. A quote by Whitelaw & Sleath (1985, p. 1208) states that "Colombia has nothing to teach developed countries about improving survival rates of VLBW babies but may yet heal some of the psychological problems incurred by modern neonatal care".

Randomized trials were conducted in developing countries, comparing kangaroo care and standard incubator care in LBW infants. Scores on mother's sense of competence according to infant stay in hospital and admission to NICU were better in kangaroo care than in control group (weighted mean differences 0.31 [95% confidence interval 0.13 to 0.50] and 0.28 [95% confidence interval 0.11 to 0.46], respectively) (Conde-Agudelo *et al.* 2003).

**Breast-feeding**

Routine separation shortly after hospital birth is a uniquely Western cultural phenomenon that may be associated with harmful effects including discouragement of successful breastfeeding (Anderson, Moore, Hepworth & Bergman 2003). Kangaroo care has promoted the establishment and maintenance of breast-feeding, and is a powerful way of enhancing bonding between the infant and parents (Woods 1998; Cattaneo *et al.* 1998). Infants in the kangaroo care position cannot feed independently without help, but the infant's closeness to the mother's skin means that the mother becomes aware of her infant's stirring from hunger, and she can then position the infant's mouth on the nipple, and self-regulatory breast-feeding is established (Gale & Vandenberg 1998). Kangaroo care stimulates prolactin and oxytocin production (essential in milk production and the let-down reflex). A mother who provides kangaroo care is more likely to breast-feed, produce more milk and breast-feed for longer (Gale, Franck & Lund 1993). A study by Thompson (1996) confirmed this view; mothers in this study were able to provide an adequate supply of

breast milk at the infant's discharge after initiating breast-feeding 27 days after the infant's birth. Ramanathan *et al* (2001) further confirmed this view by stating that in their study the number of mothers exclusively breastfeeding their babies at 6 week follow-up was double in the kangaroo care group than in the control group (12/14 vs. 6/14) ($p < 0.05$).

Among the many physiologic and psychobehavioral benefits to mothers and infants, one of the most important benefits is the promotion of successful breastfeeding (Kirsten, Bergman & Hann 2001). Anderson *et al* (2003) found statistically significant and positive effects of early skin-to-skin contact on breastfeeding at one to three months postbirth, breastfeeding duration, during an observed breastfeeding within the first few days postbirth.

**Emotional Satisfaction for Mothers**

A study in Sweden involved 66 mothers of preterm infants (800 g to 2300 g), with 33 providing kangaroo care and 33 providing standard forms of contact. The mothers who provided kangaroo care expressed confidence in breast-feeding and in monitoring their infants, and eagerness to be discharged. In contrast, the mothers in the control group expressed hesitation over discharge, reported a dependence on technological monitoring, and frequently abandoned breast-feeding (Affonso, Wahlberg & Perssons, 1989).

Kangaroo care has been valuable to mothers because it was one of very few things that they could do for their infants. Kangaroo care seemed to empower mothers and enabled them to realise the unique contribution that they were able to make during the intensive care phase of their infant's life (Ludington-Hoe *et al.* 1994).

In 1998 a study was conducted in Cape Town to identify parent's feelings towards kangaroo care, and to measure how frequently parents carried out kangaroo care. Interviews were held with 30 mothers who were providing kangaroo care (infants 1700 g - 2000 g at time of interview). It appeared that the majority of mothers saw themselves and their infants as a single unit. The researcher recommended that further studies be undertaken to prove or

disprove their assumption (Lippert, Kirkwood, Suberg, Mc Glenadolf & Jacobs 1998).

An experimental study with a crossover design with observational and qualitative data collected on temperature patterns and mothers attitudes to skin-to-skin care was conducted in the neonatal wards of three hospitals in Lagos, Nigeria. In this study despite the fact that kangaroo care was new, all the mothers, regardless of age or educational background felt that kangaroo care was safe, and preferred it to having their infants nursed in an incubator. The mothers expressed delight about kangaroo care because it did not separate them from their infants (Ibe *et al.* 2004).

**Cost to Parents**

Kangaroo care provides economic savings to families and health care facilities (Kirsten *et al.* 2001). With the involvement of mothers in the care of their infants, the workload of health care workers is reduced. Mothers form part of the team caring for the child (Stein 2000). "Before it was the nurse's child, now, it's the mother's child, which is how it should be" (Desai 2000, in Stein 2000, p.1).

Due to the limited number of postnatal beds, mothers were previously transferred back to referring hospitals very quickly after delivery, and breast-feeding seldom took place. Key elements of implementing kangaroo care have been to:

- motivate all mothers to breast-feed;
- commence skin-to-skin nursing and breast-feeding as soon as possible after delivery;
- encourage local mothers to spend each day with their infants;
- postpone transfer of rural mothers;
- obtain rooming-in accommodation in the hospital;
- motivate and educate staff on the importance of breast-feeding; and
- extend this programme to rural hospitals.

Developing countries have a high incidence of LBW infants, and this requires a high ratio of nurses to patients due to the intensive nature of care required. Maternal involvement in caring for their infants where appropriate is a partial solution to the nursing shortages in State hospitals in South Africa. Breast-feeding and intermittent skin-to-skin nursing increase the survival rate of LBW infants (Kirsten 2000).

### 1.7.3 The Health Care Services

Kangaroo care has cost benefits for hospitals. In 1996 a controlled clinical trial was conducted on 28 VLBW infants (below 1500 g) at Groote Schuur Hospital in Cape Town to determine the effects of kangaroo care on growth, length of hospital stay and breast-feeding. The 14 infants in the study group received a minimum of 12 hours of kangaroo care per week. In the study group there was a statistically significant gain of 3.42 g per day more than infants in the control group. Also, the infants in the study group were discharged 2.5 days earlier than those in the control group (Hann et al. 1999). Ramanathan *et al* (2001) showed that infants who received kangaroo care had better weight gain and were discharged from hospital earlier than their counterparts (Ramanathan, Paul, Deorari, Taneja & George 2001).

The neonatal care of a LBW infant is costly. In 1999 the average cost of hospitalisation (incubator care) per day was R300 ($42.80), exchange rate calculated as at January 2004 (Hann *et al.* 1999).

In 2000 The Western Cape Department of Health introduced kangaroo care as the preferred method of treating premature and other LBW infants. Kangaroo care shortened infants' stay in Tygerberg Hospital (a tertiary level facility) by 5 days, from 23 to 18 days, "Saving R1 million a year, just at our hospital, at the very least" (Kirsten, in Stein 2000). A number of provinces and countries have adopted kangaroo care as formal government policy (Bergman *et al.* 2003).

## 1.8 PARENTAL ISSUES

While most mothers of full-term infants experience close contact and interaction immediately and in the days following delivery, mothers who experience a preterm birth are quickly separated from their infants. Mothers attempt to forge relationships with their fragile infants while coping with the crisis of preterm delivery in a stressful environment with lack of privacy. Facilitation of healthy parent-preterm infant relationships is an investment in the infant's social, emotional and physical development.

Parents of preterm infants are under enormous strain after the birth of their infant. Attachment at this time is fragile, and interruption of the process by separation can affect the future parent-infant relationship. "The removal of once mandatory gowns, aprons and rigorous hand-washing practices in hospital neonatal units have eliminated some of the physical barriers between mothers and infants, thereby fostering an environment in which active maternal participation is encouraged" (Carter & Watson 1987, p. 25). Strategies aimed at increasing parental involvement and contact, such as open visiting for parents and the provision of information booklets, are also beneficial. By allowing close parent-infant contact, even when the infant is attached to monitors and intravenous therapy, the parent and infant have a chance to get to know each other. The time and attention spent in this way helps a premature infant to grow and to thrive physically and mentally (Carter & Watson 1987).

Although parental reactions and steps of attachment are altered by the birth of a preterm infant, a healthy parent-infant relationship can occur (Ladewig, London & Olds 1994). "Kangaroo care offers a way to help mothers and fathers to overcome their feelings of separation and inadequacy that frequently accompanies preterm deliveries" (Whitelaw 1990, p. 604).

Parents' perceptions of their competence in the parenting role reflect their confidence in their skill and ability to care for their infant. This confidence affects their interactions with their infant (Blenke Bullock & Pridham 1988).

Kaplan & Mason (1974, cited in Ladewig *et al.* 1994) identified four psychological tasks for coping with the stress of an at-risk or preterm infant, and for providing a basis for the mother-infant relationship:

- Anticipatory grief as a psychological preparation for possible loss of the infant while still hoping for his or her survival.
- Acknowledgment of maternal failure to produce a full-term infant expressed as anticipatory grief and depression.
- Resumption of the process of relating to the infant, which was interrupted by the threat of non-survival.
- Understanding the special needs and growth patterns of the preterm infant, which are temporary and yield to normal patterns.

Klaus & Kennell, writing in 1982, stated that the medical care of the preterm infant had advanced over the last 20 years, resulting in reduced neonatal morbidity and mortality; however, some 20 years on, infant survival has continued to increase. More preterm infants are discharged home to parents who have missed the opportunity for the early postnatal contact and interaction experienced by most parents of healthy full-term infants. The quality of attachment and subsequent maternal-infant relationship has an impact on the physical and psychological well-being of infants and their mothers.

### 1.8.1 Role of Parents in Care of their Preterm Infants

Parents play a major role in the care of their preterm infants, as they are required to take additional responsibility here. Research studies have reported that parents of physiologically stable premature infants described generally feeling positive about their experiences of providing kangaroo care (Ludington-Hoe *et al.* 1994; Lippert *et al.* 1998; Neu 1999, Kambarami, Mutambirwa & Maramba 2002).

**Mothers' Role**

The role of mother has remained constant over time. The mother has been portrayed as the one primarily involved with child care. The mother nurtures and provides sustenance for her infant through breast-feeding. The mother's

milk is the infant's first immunisation, providing antibodies which protect the infant from many common respiratory and intestinal diseases. In developing countries where water supplies are unsafe or food supplies are erratic, breast-feeding is essential in promoting and maintaining the health of the infant population. In addition, there are many direct health benefits to breast-feeding mothers. Immediately after birth, repeated bursts of oxytocin released in response to the infant's sucking cause contraction of the uterus. This protects mothers from postpartum haemorrhage (Dermer & Montgomery 1997).

In a study of healthy preterm infants, mothers indicated that they felt empowered by the skin-to-skin experience because it was their unique contribution to their infants' well-being (Ludington-Hoe *et al.* 1994). A study of mothers who were providing kangaroo care to their infants at Groote Schuur Hospital in Cape Town showed that "kangaroo care was acceptable to mothers and it provided them with a satisfying role in the care of their infants" (Hann *et al.* 1999, p. 39).

**Fathers' Role**

Traditionally fathers have been portrayed as uninvolved with child care but holding the role of family breadwinner, and being a distant role model to his children and providing assistance to his wife. In South Africa industrial urbanisation has had a significant effect on social structure, with the movement of rural populations to urban centres. A study by Edwards, Borsten, Nene & Kunene *et al.* (2001) examined the effects of urbanisation on South African fathers' perceptions of their paternal responsibilities. Perceptions were rank-ordered into three categories: breadwinner, governor and family. Results indicated that rural fathers, transitional fathers (migrant labourers who moved to the urban areas and were forced to send money home to families in rural areas) and urban fathers all viewed breadwinner responsibilities as most important. However, urban fathers stressed family responsibility more than the other two groups, thus moving away from the strict tribal authority and

conforming to the Westernised values where responsibilities of husband and parent are emphasised (Edwards *et al.* 2001).

The historical role of the father varies across culture, society and time periods. In Western society in the nineteenth century a father chose to either wait in the house or go about his work until his infant's arrival was announced. In the twentieth century the father's role in the birthing process has changed as the setting for childbirth began to move from home into hospitals, but in the early years fathers were left at home. As a result of denying men permission to become emotionally committed to childbearing, fathers grew to believe that they were unnecessary participants in pregnancy and birth (Bedford & Johnson 1988).

The mother controls the father's access to the unborn infant. This control and the lack of intimacy from the bodily experience may affect the man's attachment to his infant during pregnancy (Ferketich & Mercer 1995b). Information for fathers during pregnancy is obtained second-hand, either through their partners or from health professionals. This adds to the uncertainty in their role transition to fatherhood (Marks & Lovestone 1995). In an attempt to persuade men to become involved in their partners' pregnancies, a 'Men and Maternity' programme was launched in 2001 in KwaZulu-Natal, South Africa. Men attend three classes, two before the infant is born and one afterwards (Cullinan 2001). The programme has encouraged men to accompany their pregnant partners to classes and learn about pregnancy and child care. It has also improved the relationships between men and women and between fathers and their children, leading to paternal bonding.

Data were collected from interviews conducted with 584 male partners attending the 'Men and Maternity' programme from June 2001 to February 2002. Men admitted their lack of knowledge on reproductive health, and felt that it was important to be informed. Although most were hesitant about being present during labour and delivery, they wanted to attend counselling at times

convenient to their working hours (Kunene, Beksinska, Mullick, Zondi & Mthembu 2003).

*Table 3: Benefits of involving men in 'Men and Maternity' programme (N = 2082)*

| **Benefits** | **%** |
|---|---|
| Provide comfort and support | 57 |
| Assist in dealing with medical personnel | 18 |
| Better understanding of pregnancy | 46 |
| Men learn more about reproductive health | 4 |
| Other | 14 |

(Kunene *et al.* 2003).

The 'Men and Maternity' programme has been rolled-out into a second area in KwaZulu-Natal, with an improvement in the antenatal services and antenatal counselling as a result. Men were encouraged to assume more active roles during their partner's pregnancy and delivery, and in infant and child care. Post-intervention interviewing will be completed in 2003 and the results from this project will inform other districts and provinces of successful and unsuccessful interventions (Reproductive Health Research Unit of the University of the Witwatersrand, n.d.).

The special role of fathers in families with preterm infants has only recently been explored. The birth of a preterm infant evokes greater father involvement in caregiving, perhaps because of the additional time, energy and skill required to care for preterm infants (Yogman, Kindlon & Earls 1995). Kangaroo care has provided an opportunity for fathers to actively participate in all aspects of childbearing. This is not only important for the father's fulfilment, but is also beneficial to the family unit (Bedford & Johnson 1988).

Anner (1994) wrote positively about kangaroo care from a father's perspective. He stated that, after participating in this method of holding his premature

daughter, he experienced joy, love and a special closeness with her (cited in Neu 1999). In Neu's (1999) study, one father described kangaroo care as involvement in his child's life. He had never had a child before and he felt that kangaroo care helped him learn about his son.

In summary, the literature demonstrates that where there is a high incidence of premature births, the most cost-effective and beneficial manner of caring for a stable preterm infant is kangaroo care. The lived experience of parents who provide kangaroo care is sparse in the current literature. The studies by Kambarami *et al.* (2002) and Lippert *et al* (1998) are to date the only published studies describing this experience in a developing country. Two studies from developed countries are those of Neu (1999) and Affonso *et al.* (1989)

## 1.9 AIM OF THE STUDY

### 1.9.1 Problem Statement

Currently there is a lack of information about parents' lived experience of providing kangaroo care to their preterm infants. There is a gap in research relating parents involvement in their infants kangaroo care.

### 1.9.2 Aim of the Study

The aim of this study was to gain insight into and an understanding of parents' lived experience of providing kangaroo care to their preterm infants in a tertiary hospital setting in Cape Town.

## 1.10 OVERVIEW OF THE RESEARCH PROCESS

The enquiry paradigm chosen for this study was the qualitative paradigm. This was the most appropriate since there was little documented in the literature on the phenomenon of parents' experiences of kangaroo care (Field & Morse 1985). The qualitative paradigm enabled the researcher to examine the experiences, feelings and perceptions of the participants, and to uncover the meanings they

gave to their experiences. According to Morse (1994, p. 224), phenomenology assists in research where the research question aims to extract the "meaning or essence of an experience". The research methodology is discussed in Chapter 2.

## 1.11 CONCLUSION

The intention was to gain an in-depth understanding of both mothers' and fathers' experiences in providing kangaroo care. Understanding the experience of parents will facilitate the ability of health professionals to provide relevant education and emotional support to midwives, nurses, students and future parents.

These aims and purposes led to the formulation of the research question:

*"What is the lived experience of parents who provide kangaroo care to their preterm son/daughter"?*

# Chapter 2

# RESEARCH METHODOLOGY

## 2.1 INTRODUCTION

This chapter describes the research methodology, method of data generation, form of data sought, and how it was 'transformed' into knowledge. A qualitative research design was chosen since it was most appropriate to gaining an understanding of parents' lived experience of providing kangaroo care.

## 2.2 CHOICE OF QUALITATIVE RESEARCH DESIGN

"Qualitative research is a systematic, subjective approach used to describe life experiences and give them meaning" (Lackey 1992, p. 119). Despite the evidence regarding the physiological benefits of kangaroo care in the current literature, little is known about the parents' experiences. A qualitative methodology was therefore applicable to the study since it aimed to uncover the lived experience of parents who provided kangaroo care to their preterm infants.

The qualitative research paradigm has three major types of research approaches: grounded theory, ethnography and phenomenology:

> *Grounded theory* research is used when analysing qualitative data with the aim of developing theories and theoretical propositions that are grounded in real world observations (Polit & Hungler 1993).
>
> *Ethnography* is a branch of human enquiry associated with the field of anthropology that focuses on a culture (or subculture) of a group of people, in an effort to understand the world view of those under study (Polit & Hungler 1993).

*Phenomenology* is an approach to human enquiry that emphasises the complexity of human experience and the need to study the experience holistically as it is actually lived (Polit & Hungler 1993).

### 2.2.1 Phenomenology

The phenomenological research approach was most appropriate to the aim of the study, which was to 'explore and understand the lived experience of the parent who provides kangaroo care to their infant'. Phenomenology aims to "gain a deeper understanding of the nature or meaning of our everyday experiences" (Van Manen 1990, p. 9). The phenomenological approach allowed participants during in-depth interviews to elicit their own meaning of their experience of providing kangaroo care. "Phenomenology aims to describe a person's lived experience (phenomena) in an attempt to enrich lived experience by drawing out its meaning" (Van Manen 1990, p. 38).

Phenomenology reveals how people live in the world, the meanings and understanding they create for themselves. "It is the study of human experiences" (Lackey 1991, p. 291). An experience includes both the occurrence and its meaning (Polkinghorne 1989). "Uncovering meaning and 'essences' in experience facilitates understanding" (Munhall & Boyd 1993, p. 136). This leads to further knowledge of human beings, not only to know who they are but also "to understand them in order to know how to act" (Lynch-Sauer 1985, p. 105). The phenomenological research method examines and explores people's perceptions and understandings of an experience - the participants' experience of providing kangaroo care to their preterm infants.

If one paraphrased Munhall's description of the phenomenological methodology and applied it to kangaroo care, it would state that phenomenology as a method seeks to describe and uncover the phenomenon of providing kangaroo care, so that the essence of what it means to be a parent who provides kangaroo care to a preterm infant can be experienced and understood (Munhall 1994).

Phenomenology is rooted in the belief that everyday experiences are worthy of examination. Relying on theory to aid in understanding such experiences is not beneficial, since it places human experience in conceptual boxes, isolating people's experiences into component parts. The key purpose of the phenomenological approach is to uncover the "meaning of the human experience through the analysis of participant's descriptions of his/her own lived experience and perceptions" (Habermann-Little 1991, p. 188).

Heidegger (1962) stated that phenomenology was derived from the Greek word phenomenon, which means "to show itself", to put into the light or manifest something that can became visible in itself (cited in Ray 1994, p. 118). The phenomenological research study illuminates some of the fundamental ways in which we make sense of everyday life, to "... see what is normally hidden and forgotten ..." (Spiegelberg 1982, p. 382), to recollect and then recognise the value of the hidden, concealed and forgotten. Another component of the term "phenomenology" means in its literal sense "... a method of taking the hidden out of its hiding, and of detecting it as unhidden, i.e., as truth" (Spiegelberg 1982, p. 383).

### 2.2.2 Historical Overview of Phenomenology

Phenomenology has been described as a philosophy, method and approach (Ray 1994). There is no single school of phenomenology with one firm view; rather, it has been described as a movement since there are different approaches which have been adapted over time (Spiegelberg 1982; Taylor 1993). The phenomenological research method aims to 'borrow' the experience from 'others'/participants (Van Manen 1990) in order to provide a description and/or interpretation of that experience.

The early development of phenomenology as a research method was through the works of Edmund Husserl (1859-1938); Martin Heidegger (1889-1976); Gabriel Marcel (1889-1973); Jean-Paul Sartre (1905-1980); Maurice Merleau-Ponty (1907-1961) and Paul Ricoeur (1913- ). The researchers of note in the phenomenological field are Giorgi, van Kaan, Spiegelberg, Hycner and

Colaizzi. Although there are many researchers in this field, there is no definite structure to phenomenological analysis (Munhall 1994).

**Schools of Phenomenology**

Different philosophical traditions have informed the method of phenomenological research. The roots of phenomenology can be traced through Merleau Ponty (1962); Heidegger (1962) and Husserl (1969).

Phenomenology as discussed by Husserl introduces the concept of the 'life-world', or 'lived experience'; this constitutes what is taken for granted or those things which are common sense. He advocated a return to 'things themselves' and emphasised the importance of 'bracketing', a tool used to suspend preconceived ideas and prejudices. "Central to Husserl's approach was the fundamental recognition of experience as the ultimate ground and meaning of knowledge" (Koch 1995, p. 828).

Heidegger, a student of Husserl, stressed the importance of discovering how the participant came to experience the phenomenon in the manner that they did. This approach values the importance of past experience as well as future concerns and plans. Heidegger and Merleau Ponty differ from Husserl, since they considered that 'bracketing' was impossible to achieve (Koch 1995).

Merleau Ponty suggests that phenomenology is the rigorous science of the search for essences, and sees people in a world that already exists before any reflection (Koch 1995).

### 2.2.3 Van Manen's Phenomenology

The framework for this research was Van Manen's (1990) approach to researching lived experiences (phenomenology). Van Manen offered a furthering of the phenomenological approach which combines aspects of Husserl's, Heidegger's and Merlau-Ponty's approaches for his representation of human experience. Van Manen is an educational psychologist; however, his approach to phenomenological research is not specific to a pedagogical process, but can be adapted to this study. Focusing on immediate experience without

being obstructed by pre-conceptions or theoretical notions drives the researcher to an understanding of the essential nature of the phenomena, through the pursuit of the research question.

Through phenomenological research and writing a "possible interpretation of the nature of a certain human experience" (Van Manen 1990, p. 41) was constructed. "Lived experience is the starting and end point of phenomenological research, as a lived experience has a 'quality' that one recognizes in retrospect" (Van Manen 1990, p. 36).

Van Manen's approach aims to allow the lived experience to "speak for itself", while recognising that the phenomenon needs to be interpreted (through language) in order to be communicated to others. The aim of phenomenology as described by Van Manen (1990) is to transform the lived experience into a textual expression of its essence, so that a good description will allow one to grasp the nature and significance of this experience in a previously unseen way. "The text will be a reflective re-living and reflective appropriation of something meaningful" (Van Manen 1990, p. 36). According to Van Manen, real understanding of phenomenology can only be accomplished by doing it.

Van Manen (1990, pp. 8-31) states that the nature of phenomenological research has been conceptualised as:

- "The study of lived experience" - creating a deeper understanding of everyday experiences.
- "The study of essences" - discovering and describing the essences that constitute a lived experience.
- "The attentive practice of thoughtfulness" – the meaning of living a life.
- "The search for what it means to be human" – meaning to be in the world as a human being.
- "A poetising activity" – returning to where the result emanated from.

### 2.2.3.1 Van Manen's Six Procedural Research Activities

While there is no recipe of sequential steps in phenomenological research, Van Manen (1990, p. 31) identified six procedural research activities which give phenomenological research its methodological structure/rigour, and have formed the basis for the approach taken in this study:

- Turning to a phenomenon which seriously interests us and commits us to the world
- Investigating experience as we live it rather than as we conceptualise it
- Reflecting on the essential themes which characterise the phenomenon
- Describing the phenomenon through the art of writing and rewriting
- Maintaining a strong and oriented pedagogical relation to the phenomenon
- Balancing the research context by considering parts and whole.

***Turning to a phenomenon which seriously interests us and commits us to the world:*** In choosing to focus on the lived experience of parents who provided kangaroo care to their preterm infants, I selected a research area that interested me for the reasons detailed in Chapter 1.

***Investigating experience as we live it rather than as we conceptualise it:*** Parents' experiences were gathered through free attitude interviews, and the keeping of a research journal. An in-depth portrayal of the phenomenon of parents' lived experience of providing kangaroo care was created.

***Reflecting on the essential themes which characterise the phenomenon:*** At the end of the process eight main themes were uncovered, which described the experiences of parents that provided kangaroo care to their preterm infants. The analysis protocol was based on the work of Hycner

(1985); Giorgi (1975) and Colaizzi (1978), and is described later in this chapter.

***Describing the phenomenon through the art of writing and rewriting:*** Van Manen (1990, p.36) described the aim of phenomenology as: "transforming lived experience into a textual expression of its essence". Eight themes emerged from the analysis of the participants' transcripts. Phenomenological descriptions of the parents' experiences were recorded. The participants' own words provided evidence for the researcher's interpretations, and understanding of the emerging themes.

***Maintaining a strong and oriented pedagogical relation to the phenomenon:*** Analysis which consistently remained close to the research question throughout the study prevented side-tracking (Van Manen 1990, p. 33). Constant referral to the research question during all phases of the research process provided a deeper understanding of the lived experience of parents.

***Balancing the research context by considering parts and whole:*** These issues were considered throughout the study; they are discussed more fully under 'Ethical Considerations' (2.4) and 'Trustworthiness / Credibility' (2.6.1).



## 2.3 THE RESEARCH PROCESS

### 2.3.1 Study Population

The study population was parents who were actively involved in providing kangaroo care to their preterm infants at a tertiary hospital in Cape Town, South Africa. Both primary caregivers (mothers and fathers) were included in the study, since fathers have historically been under-represented in research relating to their children (Phares 1995). The researcher believes that both parents have a role to play in the parenting process, and therefore chose to include mothers and fathers in the research.

### 2.3.2 The Context

The context chosen for this research was the Neonatal Nursery and Kangaroo Care Ward at a tertiary hospital in Cape Town. This tertiary hospital is the referral hospital for two secondary Cape Town hospitals and for the Midwife Obstetric Units (MOUs) in the Cape Peninsula.

At the time of the fieldwork the Neonatal Nursery at the hospital had facilities to accommodate 60 preterm or ill infants, including 12 Intensive Care Unit beds, and 10 kangaroo mother care beds. There were 32 incubators for infants who weighed less than 1700 g, and infants above this weight were cared for in bassinets.

### 2.3.3 Sampling

Qualitative studies use small samples because the in-depth nature of the interviews yields rich data in relation to the relatively small number of research participants. In qualitative research theoretical richness is not dependent on the number of participants included in the sample, but rather on the describing the participants' experiences as richly and accurately as possible (Morse 1991).

The sample size was selected according to the requirements of the study, since the number of parents providing kangaroo care to their preterm infants is limited and not widely dispersed throughout the general population (Brink 1991). Sample selection has a powerful effect on the quality of the study (Coyne 1997). To obtain richly varied descriptions, participants who provided a variety of specific experiences of the phenomenon were chosen. This strategic sample selection was vital; selecting 'critical cases' or cases that would shed light on the lived experience of parents is known as purposive sampling (Patton 1990), and is discussed in detail below. Interviews with new participants were conducted until 'data saturation' (Polit & Hungler 1999, p. 299) occurred. Data saturation occurs when no new information is generated, participants are echoing each other, and redundancy is achieved.

Six parents - four mothers and two fathers - of preterm infants who were providing kangaroo care participated in the study. Participation was voluntary, with no monetary or other incentives offered.

**Purposive sampling**

The sampling approach was that of purposive sampling, where the researcher's knowledge about the population and its elements allows him/her to handpick the cases to be included in the sample (Polit & Hungler 1993). Information-rich cases are selected for in-depth study, since this allows the central issues of the phenomenon (providing kangaroo care) to be uncovered (Patton 1990). It was essential that each participant was a 'good informant'. A good informant is knowledgeable about the research area and an expert by virtue of his/her involvement in specific life events. He/she must be willing and able to critically examine his/her experience and be prepared to share the experience with the interviewer. He/she should have enough time to devote to the interview and sufficient patience to answer the questions (Morse 1991).

Participants who had undergone the experience of providing kangaroo care and had the capacity to provide full and sensitive descriptions of their experience were purposefully selected. Participants whose experience of kangaroo care was considered typical by the nursing staff were initially interviewed. As the study progressed, participants with particular knowledge of the kangaroo care experience were sought. Finally, participants with atypical, bad experiences or in some way 'different' experiences were sought. The entire range of parents' experiences ensured that distortion of the analysis toward one perspective did not occur (Morse 1991). It was important to show the breadth of parents' experiences of providing kangaroo care.

### 2.3.4 Participant Criteria

The criteria for selection of participants were adapted from a study by Ludington-Hoe *et al.* (1994) on kangaroo care. Each participant met all of the seven criteria listed below:

**Mother or father of a preterm infant** – whose preterm infant was receiving kangaroo care at the hospital, at the time of the interview.

**Participants able to converse in English.** The researcher's home language is English and therefore to facilitate effective communication only parents who were able to converse in English were approached for the study. Interviews were conducted without the use of a translator.

**Infant's neonatal age more than seven days.** Kaplan & Mason (1974) indicated that during the first seven days maternal failure to produce a full-term infant was expressed as anticipatory grief for loss and depression (cited in Ladewig *et al.* 1994). These feelings of depression and grief may not have been a true reflection of the parents' experiences of providing kangaroo care.

**Infant's neonatal weight above 1000 g at the time of the interview.** Kaplan & Mason (1974, cited in Ladewig *et al.* 1994) stressed that parents may have been experiencing anticipatory grief as a psychological preparation for possible loss of the infant while still hoping for his or her survival, and therefore may not have been able to respond to the interview.

**Infants not receiving critical care (intubation and/or life support).** Kangaroo care was commenced once the infant was stable and in 40% (or less) head box oxygen (Neonatal Unit Staff 1998). At this point there was still a significant threat that the infant may not survive and therefore an interview would not have been appropriate.

**Singleton birth.** Parents who had given birth to multiple infants may have viewed the experience differently to parents who had only given birth to one infant.

In addition to the criteria mentioned above, participants were chosen because they were articulate, reflective, and willing to share their experiences.

### 2.3.5 Interview Setting

All interviews were conducted in a room adjacent to the Neonatal Nursery and Kangaroo Care Ward. The room was quiet, free from interruptions and warm. The interview room was convenient and accessible, and familiar to all participants. All the infants accompanied their parents for the interviews but caused minimal distractions. During each interview a comfortable, secure environment was created in which the participants could have the freedom to share their experiences without hindrance.

The length of each interview ranged from forty minutes to an hour and a half. Termination of the interview occurred when the participant had come to a point of closure and had nothing further to share. The length of the interview was therefore dependent on the participant.

### 2.3.6 Gaining Access

The researcher was not employed as a staff member nor affiliated to the hospital or the staff of the unit in any way. Permission to conduct the study was obtained from the Deputy Director of Nursing, and the respective medical and nursing heads of the Neonatal Nursery and Kangaroo Care Ward at the hospital.

Ethical approval was obtained from the Research Ethics Committee of the Health Sciences Faculty of the University of Cape Town (Appendix A).

Once permission was obtained, the Neonatal Nursery and Kangaroo Care Ward were visited and were informed of the study. The researcher, although a registered nurse who had worked in those units as a student, was currently in the capacity of a researcher and therefore chose not to wear her uniform.

Access to the Neonatal Nursery was denied for a 2-month period as another researcher had been given access to parents. This was a frustrating interruption, but it was turned into an opportunity to observe parents' interactions with their preterm infants in the setting, before conducting any interviews. After the 2-

month period the other researcher had not commenced her interviews, and permission was given to commence data collection on this study.

Parents who met the participant criteria and who had indicated their willingness to participate in the study were identified. The researcher approached the parent, introduced herself, gave a brief description of the study, and asked them to consider participation in the study. Once the participant had agreed to the interview an appointment was made at a suitable date and time to carry out the interview.

### 2.3.7 Preparation of the Researcher

The researcher herself was the data collection instrument as she conducted the interviews with participants. Researcher preparation enhanced sensitivity and skill around the interpersonal aspects of the interview.

Oskowitz & Meulenberg-Buskens (1997) discuss the main areas in which the researcher prepares for a qualitative investigation:

***Creating an environment for introspection and reflection.*** Preconceived ideas of kangaroo care were noted.

***Personal preparation through diaries and memos.*** A research journal was kept throughout the research process; this documented and reflected issues pertaining to the study.

***Developing empathy for participants.*** Through the exercise of participant observation the researcher placed herself in the role of a parent who was providing kangaroo care. She examined her own feelings and attitudes as a potential parent of a preterm infant in order to empathise with participants in the study.

Preparation for the fieldwork included attendance of training courses in qualitative research.

## 2.4 ETHICAL CONSIDERATIONS

Ethical considerations are particularly important in a qualitative research study, since the research has implications in terms of individual human rights. Informed consent, confidentiality and anonymity, and avoidance of harm are discussed and their application to this study outlined in detail below.

### 2.4.1 Informed Consent

Written informed consent for the research was obtained from all participants before each interview. This included consent for the audio-taping of the interview. With the permission of the participants the interviews were recorded onto audiocassettes and then transcribed. The hospital also required a consent form to be signed (Appendix D*). A consent form (Appendix C) adapted from an example consent form provided by Polit & Hungler (1993) was designed for the study.

Informed written consent from participants was requested only after the following had been disclosed:

- the nature and purpose of the study;
- the structure of the interview;
- assurance of confidentiality and anonymity;
- implications of signing the consent form for both the participant and the researcher; and
- the right to discontinue or postpone the interview at any point.
- an opportunity was given to ask questions pertaining to the study.

These steps were achieved by explaining to the participants that they were included in the study because they were a parent of a preterm infant and were currently providing kangaroo care. The interview purpose was to obtain



* The hospital name on the consent form has been blacked out for anonymity; the original may be viewed on request.

information regarding their thoughts, feelings and experiences of providing kangaroo care.

Participants were told that the interviews were private and confidential, that interviews were voluntary and that they were free to discontinue or postpone the interview at any point. Interviews were granted freely. They were also told that participation or non-participation would not affect the care or services that they or any member of their family may receive from the Neonatal Nursery. The results of the research study would be given to participants on request.

Adequate information was given on which to base their decision regarding participation. The participants understood the extent and implications of their participation before the commencement of the interview process.

### 2.4.2 Confidentiality and Anonymity

All transcripts remained confidential and anonymous. To protect the identity of the participants in this study, each was assigned a number from one to six and for the duration of the study they were referred to by this number, as participant one to six.

All interview data were labelled accordingly when referring to the participants and when quotes were used from the interviews in the research report. This labelling protected the anonymity of participants.

The researcher was the only person with access to the participants' real names and access to the data to prevent any possibility of breaches in confidentiality. All audiotapes, hard copies and computer disks and their back-up copies were stored in a locked cupboard. Once all work pertaining to the study (i.e. publications) is complete, the audiotapes will be destroyed.

### 2.4.3 Benefit versus Risk

Participants were informed that their involvement in the study was voluntary and that there would be no direct benefit as a result of their participation. No benefits in kind or monetary value were offered to the participants. Since all of

the participants were interviewed in a hospital setting, no transport costs were incurred.

### 2.4.4 Researcher-Participant Relationships

***Researcher Biases, Assumptions and Pre-understandings***

A process of self-reflection enabled the recording of preconceptions, biases, past experiences and theories before interviewing the participants (Polkinghorne 1989). To contribute to the credibility of the research, all biases were made known for the reader to view as to whether they have affected the interpretation of the interview data, as suggested by Hycner (1985).

The researcher believes that family ties, parent-infant attachment and bonding are important aspects in the lives of parents, and especially for preterm infants. During the seven or eight months that a mother carried her infant in her womb, a special bond was likely to have formed between them. The father's bond with his infant may have been different, since the mother controls the access of the father to the unborn child (Ferketich & Mercer 1995a).

### 2.4.5 Researching Sensitive Issues

The nature of the interview may have been emotive for participants, and sharing their experiences may have triggered an emotional response or stimulated self-reflection. The free attitude, in-depth style of the interviews provided a means of getting beyond surface appearances, and permitted greater sensitivity to the meaning contexts surrounding the participants' statements. This was often in itself a cathartic experience for the participant (Lee 1993). Prior to each interview each participant was informed of the potential impact that the interview might have. One participant began to cry during the first ten minutes of the interview when she spoke about the miracle of her son's life, as she had been rushed into hospital and on waking after a caesarean section had been told that she had a son. The participant cried for a minute, then recovered once she moved onto another topic, and did not appear to be upset. The other

participants were grateful to have the opportunity to share their experiences freely and found the interviews cathartic.

The need to intervene appropriately and assess how the participant was responding to the interview was important. Each participant was encouraged to express his/her opinions. The free attitude interview technique was well suited to the research question as it encouraged empathy. Recognising that a participant may have required emotional counselling as a result of the interview, arrangements had been made for the provision of emotional support if necessary.

No parent's life or experiences were exactly like another's. Each parent is an individual, and the interaction with his or her preterm infant was unique to him/her. The protection of participants' rights was paramount, and participants' experiences were described as richly and accurately as possible.

## 2.5 DATA COLLECTION

Qualitative research interviews were the tool used to gather descriptions of the life-world of the participants with respect to interpretation of the described phenomena (Kvale 1983). In-depth free attitude qualitative interviews were held with six participants.

The 'raw data' of a phenomenological study are participants' personal experiences. Data were gathered through interviewing, observing, and writing (Perl 1996, p. 1). Two data collection methods were used in this study: free attitude interviews, and a research journal. In order to portray accurately the phenomenon of parents' lived experience of providing kangaroo care, more than one method of data collection was required. The use of two methods of data collection provided 'method triangulation', which broadened the understanding of information obtained during the study, providing conclusions and a basis for convergence about what constitutes the truth. Triangulation

characteristically depends on the convergence of data gathered by different methods (Ely 1991; Polit & Hungler 1993).

### 2.5.1 Phenomenological Interviews

The phenomenological interview seeks to "describe and understand the meaning of the phenomenon, by drawing from the participant a vivid picture of the experience, complete with the richness of detail and context" (Sorell & Redmond 1995, p. 1120). The goal of the phenomenological interview was not only to examine the participants' experiences, but also to create a situation in which reciprocal learning could occur. Perl (1996) confirms this view by stating that the one aspect of the transformative nature of phenomenology is the learning about self which often occurs for participants in such a study.

The phenomenological interview may have assisted the participants in "experiencing a healing or catharsis from the 'storytelling', as they are empowered through the awareness of new meanings in their experiences" (Sorell & Redmond 1995, p. 1120). The interview provided for a unique relationship between participant and researcher, providing participants with an opportunity to share information that they may not have disclosed in a questionnaire.

### 2.5.2 The Research Question

The aim of the study was to research the lived experiences of parents who provided kangaroo care to their preterm infants. The quality/essence of this experience was sought. Each participant was asked the same central question formulated by the researcher. The central research question was:

> *"What is the lived experiences of parents who provide kangaroo care to their preterm son/daughter"?*

This was translated for the participants as:

> *"Please would you describe your experience of providing kangaroo care to your preterm son/daughter; what is it like for you?"*

Phenomenological methodology requires that the researcher remains open to the presence of unexpected descriptions, and does not shape the reflections to test ready-made categories or schemes of interpretation. This evoked responses that were natural aspects of the individual participants' experiences.

### 2.5.3 The Researcher as the Instrument

In qualitative studies the researcher serves as the instrument through which the data are collected (Boyd 1993). These qualities enable the art of attentive listening and genuine unconditional positive regard towards participants to develop. The free attitude interview encouraged empathy.

Listening skills were essential; an accurate interpretation of the meaning of words and phrases led to appropriate responses (Sorrell & Redmond 1995). "The participant brought the researcher into his or her world. The quality of the information obtained during the interviews was largely dependent on the researcher" (Patton 1990, p. 279).

This form of interviewing required practice. This skill was practiced and gained during the psychiatric nursing course in the undergraduate programme, as well lectures on interviewing and practical in-depth, free attitude interviewing workshops. These all contributed to the researcher's individual style and ability to conduct an interview, which enabled the participants to feel at ease and comfortable to freely share their experiences.

Brink (1991) suggests that the researcher spends a period in the situation to become sensitised to the situation, before the data collection phase of the research. In preparation for interviewing, the neonatal nursery and the kangaroo care unit at a tertiary hospital in Cape Town were visited during the two months prior to conducting interviews. The role of participant observer was chosen throughout the visits, in order to become familiar with the hospital context and setting. Spradley (1980) listed nine major dimensions of social situations that were used to guide observations, and facilitate understanding of the context in which the participants found themselves. Patton (1990, p. 71) suggests that the following question be asked: "What is my experience of this

phenomenon and the essential experience of others who also experience this phenomenon intensely?". For the researcher, placing herself in the role of a mother of a preterm infant was required in order to understand her own responses and feelings in response to the situation.

The following guidelines from **Schurink's four-phase interview process** (1988) were used to establish a trusting and honest relationship with each participant:

**1. Preparing for an interview:** Mentally and emotionally preparing for the interviews by entering into the world of the participants. The researcher recorded preconceived ideas and biases and familiarised herself with the theoretical aspects of kangaroo care and spent time as a participant observer.

**2. Becoming acquainted:** A sound relationship of trust was established during this initial meeting phase. The aim and purpose of the study was clearly set out and the practicalities of the research discussed in detail. The participants felt secure and confident to speak freely during the interviews. If a participant refused the interview, as one father did, they were thanked for their time and none were pressed to grant an interview.

**3. The contractual relationship:** It was explained to the participants that their role involved sharing their experiences with future parents of preterm infants and nursing staff in hospitals and clinics. A contractual relationship was established when the consent forms were signed by the participants.

**4. The trust relationship:** The mutual trust between the participants and researcher ensured both co-operation of the participants and improved the quality of the data collected. At each interview an environment was created in which the participants felt free to share their own lived experience without fear of reproach. The establishment of mutual trust began when an interview date and time was established, and these principles and skills were carried throughout the interview.

### 2.5.4 Bracketing

Bracketing can occur at different stages in the research process. Phenomenological research emphasises approaching the phenomenon without preconceived notions about what will emerge during the study. Munhall (1994, p. 60) describes bracketing as "laying down for the reader all self assumptions about the experience, or the phenomenon being researched in the study". Before conducting the interviews, preconceived ideas, thoughts and beliefs about parents' experiences of providing kangaroo care to their preterm infants were laid aside. The researcher recorded her thoughts and beliefs in a research journal and discussed these with her research supervisor. The researcher became more 'in touch with' and aware of her own beliefs surrounding parenting and kangaroo care. The bracketing process allowed each participant's interview to emerge as a meaningful whole, without the researcher having to validate her own beliefs or impose her 'knowledge' on the participant. Listening with 'openness' (Oiler Boyd 1989; Van Manen 1990) allowed the researcher to hear what the participant was saying, rather than what she expected the participant to say. This allowed the full expression of the reality of the participant's experience to be understood (Leininger 1985).

### 2.5.5 The Free Attitude/In-depth Interview

The qualitative phenomenological method utilised in this study required that in-depth interviews be undertaken. The free attitude interview was the tool employed during this study. It is a controlled, non-directive, in-depth interview (Meulenberg-Buskens 1996). The free attitude interview developed its characteristic form during an industrial psychological research study, the so-called Hawthorne Research, in the United States in 1929. The researchers discovered that when they gave the interviewees the freedom to speak, the information they received was more relevant than when they used a structured questionnaire. In 1941 Carl Rodgers, a psychologist, affirmed the method when he stressed the importance of the interview technique as a means of reflecting the participant's feelings in a therapeutic situation (Meulenberg-Buskens 1996).

The free attitude interview is a verbal technique to obtain information. It is non-directive, and opens the space for the participant to intervene and for the researcher to respond flexibly and sensitively (Meulenberg-Buskens 1996). It is classified as a person-to-person method of obtaining information concerning an opinion or experience, in a non-directive approach. During the interview the task of the researcher is to ask only one question and thereafter to remain an active listener, interrupting only to clarify, reflect and summarise at regular intervals. This interview technique has been described in detail below. Excerpts from the interviews have been included to illustrate how each step was performed*.

**Information**

The interview began with the researcher sharing information about herself as a researcher and about the context of the study. Providing information about the study at the beginning ensured that this did not have to be given later in the interview, thereby interrupting the participant's train of thought and the overall structure of the interview (Meulenberg-Buskens 1996).

**The Exploring Question**

This was the research question formulated so that it did not contain any suggestions or the researcher's opinion. The single exploring question was asked at the beginning of each interview:

> *"What were your experiences of providing kangaroo care to your preterm son/daughter; what was it like for you?"*

**Reflective Summary**

The participant's words, opinions and feelings were paraphrased in the researcher's own words, reflecting both the nature and the intensity of the participant's feelings (Meulenberg-Buskens 1996). This ensured that the

*In the transcript excerpts, the bold text has been used to denote the researcher and a series of dots have been used to denote pauses.

researcher had heard and understood what participants intended her to hear and understand, allowed the participant to structure his/her own thoughts, and invited the participant to share more information.

> ...but it's the same as the African ladies with the babies on their back, they also put the babies on their back to break the winds also.
>
> **So if I understand you, you are saying it is opposite to the African mothers?**
>
> It's the opposite, yes! Except with this one it is body heat as well. It is just the exact opposite, exactly.
>
> (Excerpt from interview with Participant 1)

### The Clarifying Question

At appropriate stages in the interview, clarification on ambiguous issues or words that also had commonsense meaning was sought. This was to check that a true understanding of what the participant was saying was gained, while a holistic understanding of the participant's experience was also obtained.

> It's fun ... it's an experience you have never felt before ... like bonding with your child all over again. It's nice.
>
> **When you say bonding, what do you mean? ...**
>
> It's like ... skin to skin, to feel her skin to skin, and even when I put her down she wants to cry, when I pick her up and put her against my skin, she is calm ...
>
> (Excerpt from interview with Participant 3)

### Pause or Silence

Silences were allowed to continue so that the participant had time to think and reflect. In 80% of cases the interviewee will resolve the silence within 10 seconds (Meulenberg-Buskens 1996).

I went immediately to the sister and they ... suctioned her and she was back to normal again ... so it has been great being here.

**Pause**

On the other hand ... being here is also quite demanding, because ... because she is not my only child.

(Excerpt from interview with Participant 2)

**The Final Summary**

All the information given by the participant was reflected upon, and the most important parts of the interview were reiterated.

The free attitude interview provided space for the participant to incorporate his/her own significant personal ideas and opinions, within the framework of the opening question. This facilitated the collection of rich illustrative data from participants. The main qualities of a free attitude interviewer encompass a feeling of respect for the participant and an interest in hearing his/her opinion.

**Audio-taping**

All the interviews were audio-taped, as an accurate recording of the entire interview was essential to facilitate the transcription process that occurred after the interview. It also reduced the potential for researcher error or cheating, and validated the accuracy of the data (Barriball & While 1994).

### 2.5.6 Research Journal

Personal thoughts, assumptions and emotions as well as methodological and theoretical issues throughout the research process were recorded in the research journal (Ely *et al.* 1991). Track was kept of insights, guidelines and questions that emerged during the research process. Preconceived ideas recorded before each interview enlightened the researcher of her prejudices. Notes recorded after the interviews were used to evaluate the decisions taken during each interview. This facilitated an awareness of decisions taken during the interview and enhanced objectivity.

## 2.6 ISSUES OF RELIABILITY AND VALIDITY

### 2.6.1 Trustworthiness/Credibility

Qualitative research has been criticised for not meeting the same criteria of rigour as are applied to quantitative research. In qualitative research the researcher is one of the most important instruments. Training the human instrument enables the research to be trustworthy (Guba & Lincoln 1985). Trustworthiness was vital to make this study credible, to produce results that can be trusted, and to establish results that were "worth paying attention to" (Guba & Lincoln 1985, p. 290).

Being trustworthy meant that the process of research was carried out fairly, and that the data represented as closely as possible the experiences of the parents who were interviewed. The entire process was grounded in ethical principles about how data were collected and analysed, checking of assumptions and conclusions, how participants were involved, and finally how the results from the study were communicated. Ely (1991) states that trustworthiness is more than a set of procedures, it is a personal belief system that shapes the procedure in process.

Guba & Lincoln (1989) refer to the rigour of qualitative research as **trustworthiness** and outlined qualitative analogues, which are more appropriate to qualitative research. These are **credibility** for truth value, **transferability** for applicability, **dependability** for consistency and **confirmability** for neutrality.

#### 2.6.1.1 Credibility

Credibility refers to gaining knowledge and understanding of the true nature, essence, meanings, attributes and characteristics of the particular phenomenon under study. Measurement was not the goal; rather, knowing and understanding the lived experience of parents who provided kangaroo care was the goal (Leininger 1985). To achieve credibility the research was conducted in

such a manner as to ensure that the phenomenon (the lived experience of providing kangaroo care to their preterm infant) was accurately identified and faithfully described.

In qualitative research credibility is subject-orientated, and in this study it was obtained from the discovery of parents' experiences of providing kangaroo care as they were lived and perceived by the participants. Confidence in the findings (participants' experiences and the context in which the study was undertaken) was established. Throughout the research process the findings were submitted to and discussed with the experienced research supervisor, thereby assisting with the creditability of the study. The research supervisor provided guidance and assisted in generating deeper insight into and interpretations of the research data.

#### 2.6.1.2 Transferability

Transferability involves presenting an accurate description of the interpretation of the lived experience of parents who provided kangaroo care, with the view that future parents of preterm infants and parents who have had a similar experience may recognise the description.

Qualitative studies aim to describe and explain phenomena. Van Manen (1990, p. 7) states that "phenomenology is a theory of the unique, it is interested in what is essentially not replaceable". Generalisability was not the aim of this study, therefore external validity was not the object (Brink 1991).

Van Manen (1990) refers to the "phenomenological nod", that implies that the experience is one that a person can relate to and understand, and that they actually contribute to the verification of data. In this case it refers to the parents' experiences of providing kangaroo care to their preterm infants.

#### 2.6.1.3 Dependability

The monitoring of personal responses and mapping an audit trail contributed to dependability. Verbatim transcriptions, detailed field notes and a record of analytical decisions provided an audit trail that contributed to dependability, in

addition to providing a rich description. An audit trail is an essential component of any qualitative research study (Guba & Lincoln 1989; Rodger & Cowles 1993). The audit trail provided explanations and justifications for decisions and changes that were made at each stage of the research process. This was essential since the researcher was responsible for all the analysis of data and documentation related to the research.

A comprehensive audit trail consists of four types of documentation (Rodgers & Cowles 1993), which are pivotal to the dependability of this study:

*1. Contextual documentation (field notes):*

"Contextual documentation or field notes were a description of the context and actual data collection process, providing a clearer understanding of the context in which the interviews took place" (Rodgers & Cowles 1993, p. 220).

In this study, interviews were the primary source of data collection. During the interviews key phrases were noted, which served as a rough guide for elaboration when the interview was completed. Note-taking during the interview could become a form of non-verbal feedback to the participant, and therefore only short non-verbal responses were recorded on paper. All the parents gave verbal permission for the recording of field notes.

Immediately after the completion of each interview a detailed record of the interview was written using the key words recorded during the interview. The detailed record included a description of the setting, any additional persons present for the interview, the participants' non-verbal behaviour, and any distractions, interruptions or other events that may have been significant to the research. All preconceived ideas that had surfaced before, during or after the interview, reactions to the interview, questions that emerged and insights gained, were noted.

*2. Methodological Documentation:*

Methodological documentation recorded and provided the rationale for all ongoing methodological decisions made regarding the study. "Identification,

explanation and reporting of all decisions made during the study made visible an accurate assessment of the dependability of the study" (Rodgers & Cowles 1993, pp. 220-221). Methodological decisions, thoughts and feelings about the research were recorded in a book. Reminders of things to do in relation to the study were also recorded. All the methodological decisions that were made were dated and synchronised with the interview data/transcript.

*3. Analytical Documentation:*

"Analytical documentation is a demonstration that reasonable procedures and lines of enquiry were followed during analysis" (Rodgers & Cowles 1993, p. 221). Ability to retrace the actual analytical paths and to demonstrate each line of enquiry that was followed was relevant. "The analysis of qualitative data is dependent on the thought processes in sorting, categorizing and comparing data and in conceptualising patterns that emerge as the data is examined and coded" (Rodgers & Cowles 1993, p. 221). Consistent and clear records of all phases of the analysis, including theoretical insight and outcomes regarding the analysis process, were maintained in order to ensure rigorous analysis.

*4. Personal Response Documentation:*

"Personal response documentation involved keeping honest personal, descriptive notes about thoughts and feelings in response to each interview and the research as a whole" (Rodgers & Cowles 1993, p. 223). These enhanced the rigour of the study and assisted in alleviating the psychological and emotional strain of research interviews. The experiences of the interviews, data and the research process were also documented.

Before discussing each interview experience or ideas surrounding the interview, a detailed record was written. "Discussing thoughts, feelings or experiences before writing about them may have diluted their importance or may have caused distortion and confusion about exactly what the participant had said" (Rodgers & Cowles 1995, p. 225).

#### 2.6.1.4 Confirmability

Records of preconceived ideas regarding the study were noted in the researcher's journal. The research journal was a record of ongoing thoughts and feelings, and enabled the researcher to minimise bias. During the interview process and analysis phase the capturing of participants' experiences was a priority. Holding in check experiences, knowledge and future anticipations of the phenomenon enabled the data to show itself 'as meant' (Ray 1994, p. 129).

## 2.7 DATA ANALYSIS

### 2.7.1 Introduction

Analysis in qualitative research refers to the "categorisation and ordering of information in such a way as to make sense of the data and to write a final report that is true and accurate" (Brink 1991, p. 178). The intention of qualitative data analysis is to clarify the research topic (i.e. parents' experiences of providing kangaroo care to their preterm infants) by organising, interpreting and categorising the data in such a way as to gain meaning and understanding of the parents' experiences (Lackey 1991).

Phenomenological analysis was chosen as the method of data analysis. Probing, in-depth analysis (Meulenberg-Buskens 1996) also complemented and enhanced the phenomenological analysis.



### 2.7.2 Bracketing

Bracketing can occur at various stages, as outlined in section 2.5.4. It is part of the intent of the researcher to ensure that the analysis is (as much as possible) free from any bias. Prior to the process of data analysis, thoughts and beliefs were set aside; they were listed and discussed with the supervisor. Hycner (1985, p. 281) describes the process of bracketing as "suspending as much as possible the researcher's meaning and interpretations and entering into the

unique world of the individual who was interviewed". Bracketing assists the researcher in focusing on the participant's whole experience without bias.

### 2.7.3 Transcription of Data

All interviews were transcribed verbatim in their entirety by the researcher, which allowed her to become familiarised with the data (Appendix E). This was an important initial phase in becoming acquainted with the data. Verbatim transcripts were essential for the arrangement of all data into text and analysis of it since the researcher could not rely on her memory or notes to capture all that had occurred during the interview. The transcriptions of the interviews included pauses, laughter, tears, distractions and occurrences of verbal and non-verbal communications (e.g. participant shifting in seat) during the interview. Patton (1990, p. 347) states that "the research would have little meaning if the researcher fails to capture the actual words of the participant, as there is no substitute for the actual quotations spoken by the participants".

Before the transcription process began, all interviews were taped onto a back-up audiocassette to reduce the risk of losing valuable data. Transcriptions were in turn also backed-up.

### 2.7.4 Stages of Analysis

Van Manen's (1990) fourth procedural research activity, which involves describing the phenomenon through the art of writing and rewriting, was rather challenging to apply. A more structured outline was required to assist in seeing the 'meaning' within the data that had been gathered. Therefore a combination of Colaizzi's (1978); Giorgi's (1975) and Hycner's (1985) stages recommended for analysis were adopted, as they provided guidance for the research analysis.

Colaizzi (1978) does suggest that the framework is not definitive and that there is a tendency for the stages to overlap. This was encountered, but every attempt has been made to describe the process of analysis as clearly as possible. It was of significance that I was a registered nurse and was not a parent, but was

attempting to analyse the thoughts and feelings of parents. There was a danger that I could interpret the meaning of the data through my own interpretation; the parents' own words have therefore been utilised whenever possible.

A detailed account of the process of data analysis is provided below, which followed the stages recommended by Hycner (1985, pp. 280-294); Giorgi (1975, pp. 87-95) and Colaizzi (1978, pp. 48-71).

**Stage 1: Interview Transcripts**

The first stage in the analysis process was listening to the tape recordings of the interviews and re-reading the typed transcriptions. This helped the researcher acquire a feeling for the data. The process of re-reading the transcriptions several times enabled her to 'make sense of them', and to gain a sense of the essence of the interviews as a whole. The nuances of language use and emotions were captured. Initial understandings, thoughts, feelings and general impressions in relation to the interviews were recorded against the interview transcripts.

**Stage 2: Extracting Units of General Meaning**

This stage involved returning to each transcript and extracting phrases or sentences that directly pertained to the phenomenon (the parents' lived experience of providing kangaroo care to their preterm infant), capturing the essence of the participant's experience, as described by Hycner (1985, p. 282) as the units of general meaning, "those words, phrases, non-verbal or paralinguistic communications which expressed a unique and coherent meaning, clearly differentiated from that which preceded and followed".

The units of general meaning were recorded alongside the transcriptions (Appendix F). Units of general meaning from the text were changed as little as possible, in order to retain the participant's meaning. All general meanings were included, even though some seemed redundant and vague.

**Stage 3: Formulating Categories**

Once the units of general meaning were identified and documented, categories were identified. Categories are "units of meaning that naturally clustered together" (Hycner 1985, p. 287). Any common essence that united the categories was noted, and each individual category was rigorously examined to elicit the essence of each unit of meaning in its individual context. The categories "responded to and illuminated the research question/specific purpose of the study" (Hycner 1985, p. 284).

Categories which were clearly redundant in terms of those previously listed were diminated, as suggested by Hycner (1985). However, an awareness of how many times a meaning was mentioned and how it was mentioned was recorded.

Colaizzi (1978) describes the process as one of spelling out the meaning of each unit of general meaning - going beyond the transcript, but not severing the meaning totally from the transcript. Thus the researcher aimed to stay close to the information offered by the participants and not add her own interpretation.

**Stage 4: Central Themes**

On completion of stage 3 with each transcript, a total of 47 categories had been identified. Eight 'central' themes emerged from the categories (Appendix H).

Once all the interviews were analysed, it was possible to determine themes: "one or more central theme which expressed the essence of the categories that occurred across the interviews" (Hycner 1985, p. 290). All the categories were listed and interrogated to determine if there were central themes that expressed the essence of the categories. This process included going back and forth among the various categories until the final eight central themes emerged:

Central Themes:

- *"Not his time"*, delivering a preterm infant
- Anxiety and barriers
- Intimate connection

- Adjustments/roles and responsibilities
- Measurement of success
- Support network *"standing by us"*
- Living without *"my infant"* and living within *"the hospital"*
- Living with *"my infant"* outside *"the hospital"*

The central themes were validated by returning to the transcripts. Where applicable, words that the parents had spoken were used as a title for the central themes.

**Stage 5: Exhaustive Descriptions**

An exhaustive description of the lived experience of the parent who provides kangaroo care to their preterm infant was formulated, based upon the eight main themes. An example of one of the themes is provided in Appendix G.

Once the themes were final, a literature review was undertaken in relation to the themes in order to link the findings to published literature. This assisted in providing a wider perspective, and enabled a richer dialogue around the themes to emerge.

**Stage 6: Return to Participants**

Colaizzi (1978) recommends validating the findings by returning to the participants, however, as the analysis was completed long after the infants had been discharged from hospital, this option was not possible. If the timing had been more appropriate, it would have been useful to return to the parents to discuss the analysis.

Reflecting on the data analysis phase, analysis of the data and the desire to be true to the parents' perceptions of their experience were perhaps the biggest challenges of the research study. The combination of Colaizzi's (1978); Giorgi's (1975) and Hycner's (1985) stages provided a reasonable framework for analysis of the data.

## 2.8 THE RESEARCH REPORT

Through the process of writing and re-writing, a greater insight into the themes and greater depth in writing was gained. The final product is a description of an experience, presented from the researcher's perspective as she engaged with the data (Oiler Boyd 1989).

A phenomenological study produces findings that are descriptions of real situations, rather than statistical measures or diagrams that are beyond people's experiences. The researcher aimed to create a phenomenological text that one would immediately recognise as meaningful, and which would portray a deeper understanding of parents' lived experience of providing kangaroo care. Verbatim statements from the participants are included in the phenomenological research report in order to provide evidence for interpretations, and to allow the reader to judge the validity of the interpretations.

# Chapter 3

# PRESENTATION OF FINDINGS

"Prematurity is a world you never know exists unless life takes you there."

(Shahan 2000, p. 1)

## 3.1 INTRODUCTION

This chapter presents the eight central themes that emerged during the process of data analysis, and describes parents' experience of providing kangaroo care to their preterm infants.

The research question: *"What have you experienced while providing kangaroo care to your premature son/daughter?"* generated the recollection of the experience, and the stories of parents of premature infants, who shared their emotional struggles. Direct quotations from the participants have been included to "allow the participants voices to be heard and to make their feelings explicit" (Sandelowski 1994, p. 480; Habermann-Little 1991).

Six participants (four mothers and two fathers) who had provided kangaroo care to their preterm infants consented to participate in this study. Five interviews occurred while infants were still receiving care at the hospital and one of interviews took place after the infant had been discharged home, but was still receiving kangaroo care. Three participants were not married but were living with their partners, two were married, and one was not in a current relationship with the infant's father at the time of the study.

The setting was the Neonatal Nursery and Kangaroo Care Ward in a tertiary hospital in Cape Town, where all the infants had been nursed. The Neonatal Nursery had facilities to accommodate 60 preterm or ill infants. Preterm infants were admitted here and nursed in incubators until they were stable and no longer required oxygen. A kangaroo care programme was initiated as part of

the routine care of healthy LBW infants before discharge, in which all parents were encouraged to participate.

For parents, their experience of kangaroo care can be viewed as a journey which begins when the mother unexpectedly delivers a preterm infant. Immediately after birth the preterm infant is taken to the NICU to be assessed and stabilised. The infant is cared for in an incubator while the mother regains her strength. The mother is discharged from hospital once she no longer requires 24-hour nursing care, and her infant is left in the care of the medical staff at the hospital. This is the first of many hurdles that the mother and infant will face.

Once the infant is stable, a staff member invites the mother to move into the 24-hour Kangaroo Care Ward at the hospital. Here she receives instruction and is prepared for her infant's discharge home. The final goal for all these parents is moving back home with their infants. When the infant has gained sufficient weight and the mother displays confidence in handling her infant, she is discharged home and followed-up on an outpatient basis. This signals the beginning of a new family life, and occurs weeks or even months after the infant is born. This eventually brings a 'sense of normality' to the preterm birth and kangaroo care experience.

The eight central themes that emerged are described in chronological order, although there is some overlap. Kangaroo care is a phased process, each phase brings a unique set of experiences, as will be seen from the descriptions below.



## 3.2 EMERGENCE OF THEMES

### 3.2.1 *"Not his time"*, Delivering a Preterm Infant

**Prior to Delivery**

Preterm birth is a dramatic, life-threatening event, filling parents with intense disappointment and overwhelming fear. It occurs with little or no warning. The birth of a premature infant is a time of stress and crisis for parents. Among the

stressors that parents face are losses and grief from the early and abrupt termination of pregnancy, feelings of emptiness, uncertainty regarding the infant's prognosis, and fear related to touch.

All participants had to discard their prenatal expectations when their infant was born prematurely. Every preconception of childbirth was shattered. Parents were disappointed after delivering a preterm infant because they felt 'cheated' out of a full-term 'normal' birth. The labour occurs unexpectedly, *"too soon"* and at *"not his time"*. The women were occupied with their daily activities, and not prepared for their infant's arrival.

> *"I was 4 cm dilated already ... and I was seven months..."(Participant 3)*

The anticipation of becoming a parent nine months after falling pregnant is replaced with the sudden reality of a preterm birth. The opportunity to prepare themselves psychologically, especially in the last few weeks, is lost. The preterm birth brings excitement together with a sense of loss of what might have been.

> *"The birth was the fifth of this month...August, and umm quite soon because the date would have been the end of September" (Participant 4)*

Feelings of urgency and of being rushed were common among parents' recollections of their preterm birth experience. The arrival of the new infant is unexpected. Parents are unprepared and disorganised; they are shocked at the suddenness of it all.

> *"I was also so busy working, and end of August would have been my finish of working. So it was, that weekend, it was, like chaos" (Participant 4)*

**Empty Arms**

Parents of preterm infants are denied so much. They are denied the 'normal' pregnancy. They are denied the joy of holding their infant in the first few seconds after birth. They are denied the joy of being discharged home with their infant. Mothers leave the hospital with *"empty arms"*.

The mothers expected to hold their infants after birth and were unprepared for the immediate separation as the medical team instituted treatment and life support. For these participants their anticipation of a healthy infant with whom they could engage and that they could touch has all been lost. Parents of preterm infants are deprived of those first few moments of getting to know their infant - their introduction to parenting is a strained quick glance, before being whisked away for medical attention. Mothers yearned to hold their infants, but were prevented from doing so because of the infant's small size. One mother was excited when she first saw her infant and wanted to connect with her, but was prevented from doing so. She was excited and yet disappointed:

> *"I went into the nursery and saw ... this small baby and thought is it really my baby and ... I was really not sure how to act towards her and that lasted for only a split second because then I was very excited and wanted to touch her and then I couldn't touch her because she was too small" (Participant 2)*

Mothers expected to give birth normally, to develop intimacy and to breast-feed their infant. In reality these mothers were separated from their infants, their arms were empty, and they were not able to accomplish what they had anticipated.

**Loss in Preterm Birth**

At a time when parents want to connect with their infant, they feel shocked, numb, detached and terrified. Parents' expectations are disrupted as they come to terms with multiple losses. Parents miss out on the last days of anticipation and preparation, the opportunity to go through a healthy delivery, to celebrate a new birth, and to bond immediately with their newborn infant. Parents are disappointed after a preterm birth because they 'missed out' on having their hopes fulfilled. One mother's birth experience was a complete surprise - she awoke from an emergency caesarean section *"surrounded by professor and students telling me 'It's a boy'"*.

**Prognosis for Infants – Life versus Death**

The parents' experience was a tug of war, a conflict of death versus life. After the birth of their infants, three participants had been told that their infants were dead, but were even more shocked to hear later that their infants had miraculously survived. Parents shared their conflicting feelings. They were told that their infant was dead and commenced the grieving process, only to be told that their infant was alive:

> *"Her birth was ... very traumatic for me, she was born at 24 weeks and declared dead at birth ... and then an hour later the sister came to the ward to tell me that my baby is alive and in the nursery" (Participant 2)*

> *"She came out and the nurses looked at her, and they said 'she is too small. She won't make it'. They said 'guys do you want a footprint or anything', then they gave her to us just to hold, we prayed for her soul and then they took her away... So the following morning I was busy around ten and the phone call came, 'I am phoning from the hospital, here is your wife, she said the baby's alive'" (Participant 6)*

Unbelief and mistrust of the medical staff caused distress. The parents were not able to trust the staff because they didn't know what to believe as the truth. The mother felt compelled to see for herself that her infant was actually alive. She knew that she would be able to sense her own infant:

> *"In the beginning it was really difficult for me ... because I had to ask is it really my baby because of the fact that she was declared dead at birth ... when I saw her and I wanted to touch her and then I felt that I will sense whether this is my baby or not ... "(Participant 2)*

**Fear of Being Blamed**

Because two of the mothers had previously suffered a miscarriage, they were very scared. One participant bled from 16 weeks onwards - *"we didn't know if we were even going to have a baby"*. They had experienced the pain of losing an infant before and were scared of being blamed for doing something wrong again. For

one couple this preterm infant was their second live child in seven pregnancies, and to them the infant was a miracle and a gift.

> *"I was 4 cm dilated already, it could have led to a miscarriage ... and that was a frightening thought ... Because I had a miscarriage already ... and it is hard because you can't tell anybody that you had a miscarriage because you don't know what they will say, will they blame you?"(Participant 3)*

**Fear – Touch; Smaller than Expected**

The adjustments and challenges of their preterm birth experience were unique for each parent, and for those who had experienced a full-term birth before, it was difficult and different - *"you don't know what to do, they're so tiny and the only one in the home"*.

Parents stared in disbelief at their tiny, fragile infant, who they were eager to touch but feared harming. Fathers, who expected to welcome a full-size term infant, were overwhelmed at the tiny size of their newborn infants. For the fathers the preparation was also lost; the infant was not as big as expected and there was not enough time to prepare for his son's arrival.

> *"I was like happy okay nine months, let's go through this nine months and him being big ... and I can get used to him. Being two months preterm and seeing that small thing, uh, it was quite scary" (Participant 5)*

The birth of a preterm infant is the beginning of the kangaroo care experience. Once an infant has survived a preterm birth experience, parents commence the journey of providing kangaroo care. The hurdles that parents faced included their own anxiety and the barriers of an unfamiliar Neonatal Nursery.

### 3.2.2 Anxiety and Barriers

After the shock of the preterm birth has subsided and realisation has sunk in that their infant is alive, parents' own anxieties surface. They erect barriers to protect themselves and their emotions when dealing with their infant.

Parents' anxiety and barriers were both emotional and physical. The first time that parents walk into the NICU and Neonatal Nursery, they feel incompetent.

It is initially a strange and unfamiliar environment, which is intimidating to parents. They feel overwhelmed by a health care system that is unfamiliar and concentrates on getting the infant well and may 'neglect' parents unintentionally. Parents believe they are less skilled than the nurses who care for their infant. They have to ask permission every time they wish to do something. The medical staff and other parents watch their every action.

Parents are overwhelmed by the amount of complex medical equipment, the invasive lines, nasogastric tubes and intravenous therapy lines attached to their preterm infant's tiny body, and the constant activity of the nurses and doctors. The main physical barrier that separates parents from their preterm infants is the high-tech equipment used in sustaining the life of a preterm infant. This is very daunting and unfamiliar to a parent.

> *"Unlike a ... term child ... that you take home and wash and handle immediately, with these little ones they are in incubators, you have to wash your hands, put on ... some disinfectant and then touch the baby and you can't touch the baby for too long. So there is minimal physical contact and I think ... that sometimes makes you feel a bit deprived as a mother because you want to pick up your baby, you want to touch them maybe rub them out [massage them] which you can't do" (Participant 2)*

The incubator restricts the parents' ability to initiate physical touch and to provide kangaroo care. One mother felt inadequate and frustrated at not being able to fulfil her role of mother, as her preterm infant spent his time *"locked away in an incubator"* surrounded by tubes and wires and not experiencing her touch. Parents wanted to hold their infants earlier, but the infants' poor health and small size resulted in a delay. Parents devised ways to overcome the physical barriers in order to show their infants that they cared.

> *"Those first few days ... that I couldn't have physical contact with her, sort of created a barrier between the two of us, but I tried to communicate somehow with her, by talking and humming to her" (Participant 2)*

**Small Size of their Infant**

Mothers experienced in child rearing were shocked at the *"tiny"* size of the preterm infant and were unsure how to hold their own infants: *"... you don't know how to pick them up and how to handle them properly"*. Parents are disappointed that the infant does not resemble the picture they had envisioned during pregnancy. They have to work through their own insecurities and fears that they will harm their infant if they hold them incorrectly. Their previous experience had not prepared them to trust their maternal abilities and confidently handle their preterm infant.

**Distancing - Fear of Non-survival**

The medical staff constantly told the participants in this study that their infant might not survive, describing it as *"a fifty/fifty chance that your child will survive ... or not"*.

The parents erected emotional walls to separate themselves from their infants, to distance themselves from their infant and create a temporary barrier. Participants *"feared getting attached"*, so refused to establish an emotional connection as their fears surfaced: *"I don't want to get attached to someone who might not make it"*. Parents prepared for the worst and insulated themselves from further loss and pain. Parents would adjust easier to their infant's death if they were not attached to their infant. When their infant survived for a few days, parents felt they were *"missing out"*, and took additional risks and connected intimately with their infant through kangaroo care. This enabled them to overcome the barriers they had erected. One father's breaking point was when he realised that he was *"getting attached"*.

> *"One then struggles to ... actually connect with your child because you, you are torn between ... becoming so attached to the child and the child dies the next day or the next minute for that matter and between not giving that child that warmth and affection for that short time that you might have with child, for the child's lifetime" (Participant 2)*

**Fear of Hurting the Infant**

Parents desperately wanted to hold their infants but feared hurting them. Their infant was someone *"delicate and precious"*. One father feared that he would drop his daughter and rhetorically asked the question *"What would happen if she falls?"* All parents felt clumsy and anxious when they first held their infant in the kangaroo care position; however, their confidence increased as they spent time with their infant.

> *"The first two days I didn't want to touch him because I was afraid of hurting him ... but ... umm I think that it [kangaroo care] provides you with that bonding experience" (Participant 5)*

***"Not Knowing"***

There is usually little, if any, preparation for a preterm birth. Parents are not prepared for nor educated on what occurs during a preterm birth - an unexpected birth, unknown terms (e.g. nasogastric tube, intravenous wires), and an unprepared outcome. They lacked the knowledge and education to equip them for an experience that might last up to several months. Their lack of understanding and sparse information at the beginning of their journey led to feelings of powerlessness and fear.

Most parents had never heard about kangaroo care before the birth of their infant: *"There is a lot of people out there that don't know about kangaroo ... I never knew"*. They had not received any preparation from the hospital or clinics they had attended for antenatal care. Parents' first exposure to kangaroo care was when they read either the informational posters on the hospital walls or the pamphlets from hospital staff while their infants were fighting for their lives in the NICU:

> *"I mean you go to the clinic and even so I attended this hospital and okay there is posters and that but no one like told you about it [kangaroo care]"(Participant 1)*

Fathers are strangers in the hospital environment. They were scared and intimidated by their lack of knowledge about even the simplest tasks such as opening the incubator. However, they did not want to feel inadequate in their role as father:

> *"I didn't know what to expect. I didn't know how I will react to baby, I definitely wanted a baby but, you know, I was scared of managing baby" (Participant 5)*

In response to the barrier created by their own unpreparedness, parents felt that clinics and health professionals should be informed of kangaroo care: *"I'm sure the clinics also don't know about this kangaroo"*. Mothers felt that the antenatal clinics should prepare pregnant women for the possibility of a preterm birth and the opportunity to provide kangaroo care:

> *"I think that people at the clinics and places like that should be informed about the kangaroo, so that they can also encourage mothers on their own" (Participant 1)*

Parents received education pertaining to kangaroo care from the nursing staff. The kangaroo care education and demonstrations for mothers and fathers were held at separate times. The mother, who visited the infant daily, received the kangaroo care information earlier than the father. The fathers returned to work soon after the birth and visited their infants either in the evening or during the weekend. The fathers would have preferred their partners or spouses to explain kangaroo care to them *"not somebody else"*, as it was a private issue relating to their family unit:

> *"Who are you going to listen to? I would appreciate it [kangaroo care education and demonstrations] more if it came from my spouse, if she told me, you have got to try this. I would probably listen more to my spouse than to the nurse staff" (Participant 5)*

Fathers faced additional barriers to those facing mothers. The judgements and criticisms directed at fathers while they provided kangaroo care was an issue that one father confronted:

*"Another lady said, 'I hope that you are not suffocating the child', because her head was lying at the side. The question I had in my mind was … it's a man, he comes with this kangaroo pouch…" (Participant 6)*

Because a male's anatomical build is different to a female's, they had to adjust the positioning of their infant to fit comfortably:

*"It feels like he is bunched up, because your chest goes inwards, you can let him lie at an angle … but now with him lying on the one side it gives his body a chance to space out more … with me being a bit of a slender person it just feels comfortable, for both of us. It is better to get his chest as close to my chest as possible, so when I lie him sideways [that] has sorted that one out" (Participant 5)*

Anxiety and barriers were major hurdles for all parents. When they overcame the barriers they had erected and dealt with their fear and anxiety, they began to form a connection with their infant that would last a lifetime.

### 3.2.3 Intimate Connection

Despite the initial anxiety and barriers created by the environment, all parents felt a special connection with their infant during kangaroo care: *"It's just the little moments you share"*.

There is an intimate connection that a parent and preterm infant develop throughout pregnancy. It starts before conception, when the parents imagine holding their infant in their arms. The process continues throughout the pregnancy and into infancy, and is flexible enough to overcome the many hurdles of anxiety, illness, Neonatal Nursery and separation. The close relationship that develops between the infant and his/her parent is a special commitment of a parent to an infant. The parent will look after, nurture and care for the infant until s/he can care for him/herself.

Touch and kangaroo care are intimate forms of communication. Kangaroo care satisfied the need to feel like a mother or father, and gave the participants a chance to make a positive impact in their infants' lives. None of the parents held

their infants immediately after birth and none felt like 'real' parents until they had held them. The first experience of holding their preterm infants in the kangaroo care position was one that all parents treasured as cathartic. The moment that the mother held her infant against her skin, the connection formed:

> *"My first experience with kangaroo caring [for] her... when I took her out and put her against my skin, it was just ... a great sense of relief for the first time really I felt bonded with her, that it was my daughter. So I think that kangaroo care helps to bridge that initial ... gap that is between a mother and her preterm baby" (Participant 2)*

Parents comfort and transfer strength, courage and hope to their infant through their touch, *"like two bodies in one"*. Mothers shared the intimacy that took place between the parent and infant: *"Your child gets to know you ... **to feel you, to touch you, to smell you**"*.

The physical closeness of their infant while in the kangaroo care position enhanced the parents' awareness of their infants' cues and signals. One mother could *"feel her breathing"*. Another mother knew when her infant had a wind: *"you can hear the breathing is different"*. The closeness allowed parents to constantly monitor their infants' condition. This heightened their perceptions of their infants' needs.

The preterm infant experience is a special time for parents; they have the unique opportunity to watch their infant develop, as s/he would have in the womb. Parents felt at ease, fulfilled and satisfied with the closeness of their infant: *"I can touch her, hold her, stroke her"*. Despite the initial fear, an intimate connection between parents and their infants occurred during kangaroo care. The feelings of joy that providing kangaroo care evoked in the parents were very real: *"It's a nice feeling'... It feels like I am bonded to my child"*.

**Intimate Connection for Fathers**

Fathers providing kangaroo care connected intimately with their infants. For one participant kangaroo care helped him to *"be part of"* his daughter's life.

Another participant said that kangaroo care *"helped me feel closer to him, we got used to each other much more quicker"*. Although the fathers were totally overwhelmed by the preterm birth, that became insignificant once they were able to become involved in providing kangaroo care, and their confidence increased:

> *"Kangaroo care has become so much part of me now. I am now owning this thing. I was thinking what was kangaroo care. It was nothing up in the sky, it was nothing other than what I was doing, all the other ideas, the breathing and the posture were part of it, and I developed it for myself so that it became more meaningful" (Participant 6)*

The initial shock and surprise of delivering a preterm infant was overwhelming, but was contained once the parents were able to initiate kangaroo care. Kangaroo care restored parents' confidence and created an intimate and close parent-child tie.

### 3.2.4 Adjustments/Roles and Responsibilities

It is not only the preterm infant that is affected by the preterm birth. The parents' lives and the lives of their family are also transformed. The family members have to decide whether they will allow the preterm birth to affect them in a negative or positive way.

The roles of individual family members adjust after the birth of a preterm infant, as would have occurred with a term infant. However, these parents are expected to assume additional roles and responsibilities in the care of their infant earlier than expected, for which some of the participants were unprepared. Individual parents coped with the birth of their infant in different ways, especially during different stages of the hospitalisation. The mothers in the study spent the majority of their time with their infants, since they were on maternity leave or had planned to stay at home when the infant arrived. Fathers (who were not entitled to leave or could not take it due to financial reasons) resumed work, in addition to visiting their infant. The fathers assumed the

majority of the household responsibilities and the sibling care, while the mother spent most of her time at the hospital.

The parents took on different roles that suited their particular lifestyles at the time. These roles were individual to each parent couple and their preterm infant. Individuals lost their once clearly defined roles, they no longer knew what was expected of them, as parents of a preterm infant. Parents focused on coping with their preterm infant as well as trying to manage two or three other roles, including partner or spouse, parent of another child, and employee.

**The mother's role**

One of the pivotal events in a woman's life is the occasion of becoming a mother. After a preterm birth, the woman's role as mother and caregiver is delayed. She is denied time to prepare for her infant's birth and deprived of immediate contact with her infant. The mother only has the opportunity to assume her role as primary caregiver when she moves into the Kangaroo Care Ward to accompany her infant. The 24-hour kangaroo care created new roles and responsibilities. The demands of these responsibilities have to be met in addition to the demanding roles and responsibilities the mother held before the birth of her infant:

> *"Well obviously I've got a husband and another one child at home, I mean most people have more than one child still at home and obviously have to cook ... you have to clean and do a lot of other things, besides looking after yourself and the baby" (Participant 1)*

For one mother just the sight of her infant triggered her maternal instinct, and made her feel like a mother:

> *"Baby laying there and on the first time I was thinking to myself gee whiz, am I really a mother now? I am starting to feel this closeness" (Participant 4)*

The mother plays two main roles, the first being the provision of breast milk, the source of nourishment for her infant that causes him/her to physically grow and gain weight. Mothers initially have to express milk and feed their infant

through a nasogastric tube or cup, because the infant's sucking reflexes are not adequately developed. Providing breast milk reassures the mother that this essential role benefits her infants' growth and development:

> *"About the third week there was less milk, the sisters encouraged me, by then she hadn't yet started breast-feeding ... but they encouraged me to keep putting her in the kangaroo care position and that really helped to stimulate the milk flow and when she eventually ... breast-fed I had more than enough milk" (Participant 2)*

The second main role is that of *"human incubator"*, the warmth from the skin-to-skin contact of the mothers' skin provided comfort and allowed their infants to grow. The mothers played their *"part"* - this required no additional assistance from the staff: *"It's your body temperature you give to the baby"*.

**The father's role**

For the male participants, their role in parenting was one of procreation followed by financial provision:

> *"I think most fathers, myself included, tended in most cases to say our parenting starts and ends with the act, and then the next one is just providing material" (Participant 6)*

Fathers feel useless on initially entering the Neonatal Nursery. They usually only sit and watch as the mother provides all the care: *"We as fathers tend to feel like not really part of it"*. Although fathers are also dealing with the overwhelming shock of the preterm birth, they are able to physically distance themselves from their infant by returning to work and carrying on with a normal semblance of their life. Work offered them a sense of regaining control, since they were able to 'participate' at work - which they could not do at the Neonatal Nursery.

Fathers who were unsure of their parenting skills were further intimidated by the Neonatal Nursery because their skills and actions were under constant scrutiny from the staff. Fathers felt incompetent and not *"good enough"* to care for their infants: *"I know nothing about fatherhood"*. Fathers feared that their

gender would be a hindrance to their infant, and that they would not thrive as they would when cared for by the mother:

> *"I was slightly nervous, but not as to say that I would crush her, but just that I would disturb her. I had this idea in my head that she still needed to be there ... with her mother. Though I am here, but maybe I might not be giving all that the mother does... the smells of the milk and everything, and me I am just ... a man" (Participant 6)*

Once they had participated in kangaroo care, both fathers in the study altered their personal views. *"Parenting is very much a part of me"*, said one. Parenting was no longer predominantly the mother's role; these fathers became involved with and enjoyed caring for their infants. Kangaroo care enabled fathers to feel part of the parenting role – a role they thought was held exclusively by mothers: *"Kangaroo care made me feel, I am doing the right thing, that's what I like about it"*.

**The siblings' role**

Siblings of a preterm infant were confused when their mother gave birth prematurely and spent a lot of time at the hospital. One participant's child felt jealous, forgotten and abandoned while his mother concentrated on his preterm sibling who desperately needed attention:

> *"I used to take her out and spend time with her ... he didn't like that and his face used to show that I was spending more time with her than with him ... He would tell me: 'Mommy put ... **that child** ... back ... in the incubator' " (Participant 2)*

> *"It has changed now ... it is no longer 'that child' ... **it's 'my sister'**... and he is so proud now" (Participant 2)*

The siblings seemed to be intuitive of their mothers' needs and were interested in the birth and kangaroo care process. The above participant's two-year-old infant was included in the preterm care of his sister. This facilitated the development of family relationships, since the sibling then felt part of the experience and that he contributed in a positive way:

*"Each time I left the home to come to the hospital and visit her he asked 'Mummy did you express?'" (Participant 2)*

The birth of a preterm infant leaves the parent unprepared. Only one of the participants had ever been in contact with a preterm infant. All the other parents had to adjust their perceptions, mindsets, hopes and ideals from those surrounding a term-size infant to suit their preterm infant.

### 3.2.5 Measurement of Success

**Weight Gain**

Successful care of a preterm infant is determined primarily by weight gain, that leads to the infant being discharged home. Parents perceive weight gain as a measure of success and of the status of their infant's progress and development. The infant has to grow bigger and weigh more for them to be succeeding. When parents suffer a setback, especially related to their infant's weight, they are disappointed. They are disheartened and depressed, knowing that the setback is another hurdle to overcome before their infant can join them at home.

How do parents deal with failure? Their measure of success is weight gain, so when an infant loses weight or the weight stays static, it impacts on the mother intellectually and emotionally since she knows that all infants suffer setbacks, and at a feeding level she feels frustrated. All that the mothers are able to do is just hold and feed their infant. There is a sense of helplessness. They can only do so much - and they want to do more. The mothers could not force their infants to grow any faster than they were going to grow:

*"Weight gain for them is crucial ... that is the only way really, that one can see whether they are ... developing. Especially as a parent ... the doctors might be able to see through other things, but as a parent your only measure of how your child is doing is, is the influence of weight gain" (Participant 2)*

Parents related in precise detail their infant's birth weight, and were able to recollect the exact weight that their infants had gained or lost each day. *"Once he picked up 50 grams and one day he picked up 10* [grams] *and 20* [grams]". Parents

were optimistic that their infant would gain weight, but knew that weight gain was unpredictable. Weight gain symbolised a step closer to being discharged and life as a family outside the hospital. Mothers become focused on their infants' weight gain. One participant, when speaking about the other mothers, said: *"They just want their babies weight to gain"*. Another mother hoped that her infant would pick up *"another 40* [grams] *today'*, which would enable her infant to be discharged.

Breast-feeding and expressing milk is an opportunity for the mother to feel successful and to play a beneficial role in her infant's care. She becomes an active participant in mothering, even if she cannot yet hold or care for her infant. Many emotions and feelings surround the breast-feeding struggle. Combined with the mothers' joy is fear - fear that she will be unable to produce enough milk for her infant, or that it will unexpectedly stop at any given time. At a time when she already feels like a failure because her infant was born *"too soon"*, a lack of success in expressing can be the final blow to a mother's self esteem:

> *"Because that's my problem! It's like, I have hardly any milk for this baby and I have to express and then my breasts are sore" (Participant 1)*

Mothers who persevere breast-feed successfully, which helps resolve the feelings of failure that surround a preterm birth.

Mothers feed their infant every three hours and then wait helplessly and watch to see whether the infant will gain weight. Their emotions are reliant upon whether on not their infants gain weight. When an infant gains weight the parents rejoice, but in contrast when the infant loses weight the parents view it as a personal failure:

> *"I was always very elated when she had, had gained. But in the course of time ... the child also has to lose some weight ... I would often accept it when she had lost weight, but other times ... I sort of didn't feel too good about it ... and I wished that her weight would just go up ..." (Participant 2)*

**Handling their Infants**

Parents wished to interact with their infants, especially when the infant was crying. They yearned to provide comfort and touch beyond the boundaries of the incubator. Kangaroo care provided an avenue for parents to contribute to the care of their infant and actively respond to their needs: *"When he was crying ... I could take him and put him on my chest and he would stop crying"*. The close contact with their parents pacified the infants.

Parents felt a sense of accomplishment, as their infant responded contentedly to the physical closeness and the warmth of their skin:

> *"She gained 50 grams. I think it was because I was here. I noticed every time when I am with her and doing kangaroo she gains weight" (Participant 3)*

Parents' initial fear of holding their infants subsided when their infants' condition improved. They allowed themselves to connect with their infant and surrendered their fear that the infant would not survive. Parents measured their own success by the ability to handle their infant confidently, but even this success was not enough for the infant to be discharged home. Parents and especially fathers, who initially felt helpless and lacked knowledge, shared their personal success stories. Through kangaroo care they had *"overcome that fear"* of handling their *"tiny"* infants. The skills and confidence they had gained erased the fear of their infants' tiny size, which moved them past their own inadequacies and clumsiness. They emerged as confident parents who were *"comfortable"* holding their infants. As one participant exclaimed: *"I also feel confident staying with her ... but as you can see it is a challenge"*.

One of the main nurturing activities involved in kangaroo care is the way the mother comforts her infant. She does everything right - and yet weight gain is the only measure of true success.

Success was visible to parents when they translated their infants' accomplishments into other aspects. Parents began to rejoice over small daily achievements and triumphs. They celebrated when their infant responded to their touch, and their confidence in breast-feeding and the new parenting skills

they had learnt were regarded as a major success. Parents learnt to adjust their expectations for their infant. They accepted that their infant's growth and development would be different from other full-term infants, as was the start of their infant's life.

There were moments of joy for the parents when their infants gained weight or responded to kangaroo care by opening his/her eyes. This contrasted with panic at the slightest sign of weight loss or hint of danger. Parents went through the daily process of coping with setbacks. The dream of a perfect birth was gone, but once parents began to experience the pleasure of their preterm infant, they recognised that life was no longer only a series of hurdles, but an incredible journey.

### 3.2.6 Support Network - *"Standing by Us"*

Childrearing for most parents is enhanced by support from family and friends. However, for these parents there was a significant expressed need for support. 'Support' is knowing what you need, being able to access it, and being able to depend on that support which gives you the confidence to succeed. The different support structures identified by parents included their immediate partner or spouse, the staff within the institution, and other mothers.

> *"One needs a lot of support ... and I have found that in my family, immediate family, the greater family, as well as the medical and ... nursing staff ... and I think they have helped ... tremendously" (Participant 2)*

**Father of the Infant/Immediate Partner or Spouse**

Mothers received support from the infant's fathers while pregnant. Fathers continued their involvement and support after their infant was born, by playing a role in their infant's care and assisting with the care of other siblings. Fathers were often the only ones present during the terrifying times when mothers feared losing their infants. The fathers were the stability in their lives and the shoulder on which they could cry. One father suppressed his own emotions and

fears in order to provide comfort and *"as much support as I possibly could"* to his partner during her difficult pregnancy:

> *"I needed to be strong for her, because I knew that she was going through a hell of a lot. I was too ... but ... I think to balance all ... the emotions ... that I had to suppress it" (Participant 5)*

**Staff within the Institution**

During the parents' moments of fear and depression, the empathy and understanding from staff and their words of support enabled them to cope. One mother expressed her understanding of the type of support that she had received from the hospital staff as *"standing by us"*. Mothers described the staff's desire to help as authentic: *"They were very helpful"*. Mothers relied upon the staff, they felt protected by them and no longer alone. Mothers appreciated the staff *"sharing the journey"* with them. The staff became companions to parents on their journey from inadequacy and fear to confidence. Parents were grateful that the staff informed them of their infants' progress and included them in their infants' care:

> *"They do inform you every day, and things like that ... they keep you up to date.*
>
> *Inform you ... Inform you of the progress of the infant, if there is something wrong with him or things like that, the Sisters are quite clued up so they keep you clued up as well" (Participant 1)*

Because of the parents' lack of knowledge, the support they received from the staff was vital. Parents were assisted in overcoming their initial fears and doubts about handling their infant. They were encouraged to develop the new skills and abilities essential for parents of preterm infants.

The parents and staff within the kangaroo care unit formed a community where the staff supported parents during their emotional struggles and rejoiced at every milestone attained by the infants. This positively influenced the participants' experience. One participant was comforted to know that there were people who cared about her, and to whom she could turn before she

became overwhelmed by the burden of coping alone with the pressures of kangaroo care. Parents did not expect the health professionals to have all the answers, but were grateful that they were willing to listen to their questions and concerns: *"I knew that they would listen to me."*

There were issues surrounding safety and security - both emotional safety and physical safety. For one mother (Participant 4) it was her need to feel emotionally and physically safe. The staff provided the emotional support; the emotional safety was provided partially by the partner or spouse, and yet physical safety was also important:

> *"Security played a big role, and at night they come round a do a check up, it is nice to see that they care about the children and the moms also. Things happen over the TV, like you hear all over babies is being kidnapped" (Participant 4)*

**Family Support Network**

Each participant's support network was different. Their support network affected how they viewed the kangaroo care experience. Some mothers felt challenged and grew stronger through the journey of looking after their preterm infant. Others withdrew and needed to be supported by their family until the crisis had passed. The participants' families became their *"strength and support"*.

For two participants in the study support in the hospital was experienced differently to that which they experienced outside. There was a shift in the support that parents received, some of which they found beneficial and some not. This participant usually had support from her family, but in hospital she did not have that support base to rely upon:

> *"It has been different, a very big difference, I must say ... because you can't tell your husband keep her a little ... do kangaroo ... nobody is there to do kangaroo for you, you have to do it yourself. It's just tiring, because there is no help for you ... at home there are quite a few hands there that can help" (Participant 3)*

For another participant the support she received while in hospital was unexpected. She was estranged from her own family and the father of her infant. The preterm birth experience reconciled family members, brought them closer, and actively involved them in the infant's care:

> *"They heard that I was in an emergency ward and baby, like for seven months they didn't expect that... and I'm very sick. The family, I mean there was such a lot of family and I didn't expect that. The baby's ...umm ... the father also, boyfriend and his mother contacting me every day and that didn't happen before" (Participant 4)*

The parents' support network provided them with instrumental assistance by helping them with practical issues like transport to the hospital: *"My brothers and sisters, giving me a hand, taking me, bringing me to hospital"*. Parents found this type of support immensely valuable as it provided solutions to practical problems.

**Other Mothers**

Parents from this study realised that it was comforting and validating to be surrounded by health professionals and other mothers while in the Neonatal Nursery and Kangaroo Care Ward. Participants had the opportunity to interact with other mothers, *"to share our joys, our frustrations ... our pain"*.

The other mothers provided an excellent source of encouragement. They became trusted listeners who understood their good days as well as their bad days, *"When I felt that I can't survive this day"*. Participants benefited from the opportunity to share their feelings, fears and emotions with other mothers who were going through the same experience. Mothers could identify with each other's feelings and fears. They provided each other with reassurance that their feelings and actions were normal and to be expected. Mothers compared their perceptions of their infants' success and failures:

> *"Often we would meet either one coming to the nursery and the other one leaving, in the bus sometimes, coming down in the taxi, we could enquire*

*about each others' children and that ... has also helped strengthen us as mothers..."(Participant 2)*

Participants received unconditional support from other mothers of preterm infants. They welcomed support when they felt despondent. There were many opportunities to eagerly reciprocate on days when other mothers felt depressed:

*"One day you will support another mother who is feeling very low ... or the child has not been umm ... gaining ... and the next day I would be in that position of needing ... and you knew that you could count on the next mom to be there for you" (Participant 2)*

Parents had two choices, either to view their infant's preterm birth as a tragedy and become bitter and unforgiving, or they could view it as a growth experience from which they could develop character and benefit others. Parents eagerly shared their experience of kangaroo care. As one mother exclaimed: *"It made my life richer. I always share it with other moms, they can take out what they want to. It might help them in some way"*. The extract below is from a father, who chose to turn the traumatic experience of his daughter's preterm birth into something positive. He made a difference to the lives of other parents by imparting hope, and presented his daughter as a visual demonstration of the success of kangaroo care:

*"We came here for a developmental here in the hospital, and then I just felt that I just had to approach this other woman and say 'Ladies, don't worry, you see this little one - she was just like your babies and she is doing well'" (Participant 6)*

Parents turned to a spiritual source for support. Two parents reported that their faith in God was a powerful source of support. They were grateful that He had carried their infants through their preterm birth experience and that they were *"born without any defects"*.

*"My son is about two weeks old and it is quite a miracle and I thank God that he is alive ..." (Participant 4)*

Parents are isolated after the birth of their preterm infant. While there is nothing that eliminates the parents' fear, loss of control and hopelessness, the value of a support network is not to be underestimated. The support that parents received from their families, the staff within the institution and their children enabled them to cope with the experience, rather than to be overwhelmed by it.

### 3.2.7 Living Without *"the Infant"* and Living Within *"the Hospital"*

Kangaroo care displays uniqueness in the type of care that the preterm infant receives. 'living without' occurs when the mother is discharged from hospital without her infant; her infant stays in an incubator in the NICU and the mother comes to visit her infant every day. The advantage of 'living without' is that the mother is able to stay in her own home, surrounded by her partner or spouse and family who provide her with support. The disadvantage is that her infant is being cared for in an incubator by unfamiliar nursing staff. The 'living within' is when the infant is stable enough to be moved to the Kangaroo Care Ward. The mother is then asked to join her infant, and she is required to stay continuously for days/weeks, until her infant has gained sufficient weight to be discharged home. The advantage of 'living within' is that the mother can care for her own infant and has the opportunity to provide for all his/her needs. She also receives support from the hospital staff and the other mothers that are "living in". The disadvantage is that the mother is separated from her partner or spouse, her other children and trusted support systems. The mother is required to abide by the rules of the Kangaroo Care Ward while she "lives within". There is real tension for these mothers, since they live in two worlds. While the mother "lives without", part of her longs to be inside the hospital with her infant, but when she "lives within", she longs to be outside at home with her partner or spouse, other children and family. The mother is pulled in two directions.



**Living Without *"their Infant"***

Mothers are discharged from hospital as soon as they no longer require nursing care, leaving their infants in the care of the medical staff: *"After her birth, she*

*went to ICU ... and I went home".* Parents felt distressed and sad at the separation of their newly experienced connection with their newborn, despite the fact that they knew that the infant was receiving good care.

Parents are instructed by hospital staff to visit their infant daily: *"I was discharged and I came in every two days".* They spend a major portion of each day at the Neonatal Nursery intimately connecting with their infant. Daily visits proved to one parent that she was assuming responsibility for her infant. The staff's attitude towards parents had a significant influence on whether they continued to visit the hospital and provide kangaroo care. A parent recalled that she had received a *"warm welcome"* from the staff, which encouraged her to return. Parents' daily visits involved dedication and a sacrifice of their time:

> *"When the baby was still here, coming here every morning, standing up about something to six, you don't mind. Coming here, it is being part of your baby, and you don't care what else is happening outside and then thinking when you go out of here ... I will be back tomorrow again" (Participant 4)*

For one father, the time that he and his partner spent with his infant was divided into shifts, to fit around his work schedule:

> *"We have shifts now ... she gets the morning shift and when I get home from work, umm, then we meet at the hospital and that whole session is mine!" (Participant 5)*

Parents constantly feared that something unpredictable might happen to their infant while they were not at the hospital. To counteract this fear, one parent couple stayed with their infant during her life-threatening times: *"If she doesn't make it ... we want to be there... so we were always there".* However, this practice was met with opposition from some of the nursing staff:

> *"A lot of nurses, not all, but some felt that 'these people are too much', but we felt that we had a right to be here" (Participant 6)*

**Living Within *"the Hospital"***

Mothers returned back into the hospital environment to live with their infant, but without the support of their family. Once the mothers entered the Kangaroo Care Ward, her world was restricted to the one room that was shared with eight other mother-infant couples, to the bed that she occupied, which was permanently raised at a 45-degree angle. Her days included conversations with staff and other mothers with whom she had had no prior contact. With her infant securely attached to her for 24 hours a day, she is no longer able to move about freely, and she sacrifices her own needs, placing her infant's wellbeing and safety above her own. Her family move in and out during the short daily visiting hours.

The 'living within' dominated the mothers' lives: *"all the time you have your baby with you ... sleep with you, eat with you, walk with you"*. It impacted on their relationships with their partners or spouses, family, friends, social support, their employment and leisure. They were confined to the hospital until their infant was deemed fit enough to be discharged home.

There was a tension between the mother's desire to stay in and care for her infant, and her desire to be at home. When in hospital they felt close to their infants, but isolated from family support. Yet staying at home was also difficult, as it meant less time with their infant. Two of the mothers could not cope with being in hospital, and returned home to sort out personal stressors:

> *"I have been here for two weeks and I had to actually go ... take off two days and attend to the boy and attend to other things that had to be done at home" (Participant 2)*

The mothers faced major adjustments when they came to live in the Kangaroo Care Ward. Mothers who lived in the ward fell into two categories: those who saw the living-in period as a privilege and a culmination of the infant's time spent in hospital, and others who felt it was a delay of the discharge process and a major inconvenience. The following passage illustrates a mother's joy at spending 24 hours a day with her infant:

*"When she eventually came over to be with me ... 24 hours in the kangaroo care unit, I was very excited about that... I just didn't expect that I would be that elated to have her with me" (Participant 2)*

Living in the Kangaroo Care Ward was an emotionally charged experience, and also a physically exhausting one for the mothers. The reality of living within the hospital environment restricted the mothers' freedom as they were only allowed to do certain activities and experienced a loss of contact with family and friends. The negative aspects of living in the Kangaroo Care Ward were backache, boredom, loneliness, tiredness and anxiety. The physical elements were linked to the prolonged nature of the living-in experience, and the mothers' adjustment to constantly caring for their infant in the kangaroo care position.

**Backache** was a fairly common complaint from the mothers: *"My back is sore from that bed"*. They had to adjust to sleeping on a hospital bed, at a 45-degree angle with their infant on their chest:

*"The first few days it's okay, it's very nice, you find it quite an experience ... but then a few days passes and then you feel the backache, then it starts, then you get tired, just after a few days ..."(Participant 3)*

Mothers were annoyed about having to adjust to sleeping on their backs, something to which they were unaccustomed and they struggled to fall asleep. The living-in process was tiring for one mother, having to tend to all of her infant's needs: *"It is tiring doing everything ... you have to feed them every three hours"*.

**Boredom** was another grievance. The mothers were used to being independent and now felt restrained:

*"Sometimes you get bored here, you don't know what to do, they only have a TV and a radio, you have to sit down the whole day ... doing nothing" (Participant 3)*

Adjustment to the physical boundaries and the confined space of the Kangaroo Care Ward frustrated some of the mothers: *"We can only walk from there to there ... from the Nursery to the KC room".*

Living in the hospital isolated the mothers from their friends and family. The mother went through the living-in process alone, leaving behind familiar support systems, and leaving their partners or spouses and other children to cope at home on their own. For mothers who had other children there was a sense of not being able to fulfil the parental role. This increased anxiety about not being able to be there to physically care for other children:

> *"Being here is also quite demanding, because ... because she is not my only child. I have also to worry about my little boy, about how he is doing ... and whether the two of them are coping" (Participant 2)*

Mothers who were separated from their partners or spouses and families felt isolated: *"You get very lonely here ... because of the aloneness ... I have felt it".* One participant's deep loneliness surfaced when her husband and family member left after visiting hours, at a time when she needed emotional support: *"when they go home I want to burst out and cry".*

Fathers were excluded from the living-in experience since regulations in the Kangaroo Care Ward restricted their involvement in kangaroo care. The *"control"* was frustrating and fathers felt helpless and unable to interact with their infants. One father witnessed a fellow father's exclusion from the Kangaroo Care Ward:

> *"I was inside sitting there and there was another father, he had his daughter and he was kangaroo caring. I felt 'yes', it's happening, but what was so very disturbing was just at that point in time the nurse said "No, men are not allowed" and they had to ask him to go out. I understood it at one point but I also felt that the approach was rather harsh" (Participant 6)*

The participant felt that the nurses judged fathers unfairly. The nurse had assumed that he had an ulterior motive because he was a man:

*"Fathers, I mean we are not here to ogle other people. We are here for our babies and whatever mothers are feeding, we are just happy for her, so I felt unease about that, but in any case I thought, it won't be long until we are home" (Participant 6)*

Mothers discharged home from hospital without their infants established a routine of sleeping through the night. They did not need to wake up every three hours to feed their infant. When these mothers came into the 24-hour kangaroo care unit there was a sudden transition to becoming the full-time mother and having to provide 24-hour care. Mothers were excited about spending uninterrupted time alone with their infants, but the reality of being 'a real mother' and having to wake up and feed the infant every two or three hours was challenging:

*"The first day... I was excited, but became a bit worried during the day as to whether I would manage to feed her 2-hourly during the night, because I love my sleep ... I thought how will I manage, but luckily ... she wakes up, exactly when it is her feeding time ... and she wakes me in the process. So I didn't miss one of her feeds. But the next day I could hardly open my eyes ... I was so tired" (Participant 2)*

While living in the hospital, the mothers cared for their own infants. They reclaimed their roles as primary caregiver, *"human incubator"* and sole provider of nutritional support. The balance of responsibility was redressed, and mothers were allowed to assume a more pivotal role in their infants' lives. Mothers enjoyed the supportive environment where they could ask the staff questions, as they were *"a few steps away"* and provided assistance in emergencies:

*"One night I got quite a fright because I had given her 20 ml of expressed breast milk ... and then she vomited about 15 ml. I went immediately to the sister and they ... suctioned her and she was back to normal again" (Participant 2)*

The living-in period is a stepping-stone to discharge. During this time the mothers received *"preparation for when you go home"*. They gained vital knowledge and gained confidence in their own ability to care for their infants. All participants were eager to be discharged - *"anxious to go home with the baby"*.

The staff decided upon discharge from the Kangaroo Care Ward, which was granted when the infant had met all the discharge criteria, including adequate weight gain and ability to breast-feed successfully. Mothers had to be competent enough to care for their infant at home, without the 24-hour support from the staff. One mother was annoyed that her infant's discharge criteria were altered and the discharge date was postponed: *"when that day comes ... they tell me 'no, you can't go home'"*. She blamed the doctors for *"dragging it"*, which meant that she and her infant had to spend additional days in the ward.

The length of time a mother stayed in hospital was dependent on her infant's success and their accomplishment as a team. The living-in phase of kangaroo care reduced the stress of the infants' transition from hospital to home. Participants were empowered, they gained knowledge and were better prepared for discharge, which influenced their practice. While living in the hospital the mothers were surrounded by caring professionals and fellow mothers of preterm infants, who understood what it meant to be the parent of a preterm infant.

### 3.2.8 Living With *"the Infant"* Outside *"the Hospital"*

The mothers moved outside the parameters of the hospital, to live at home with their infants and their support structures, but without the hospital support.

This was the last phase of the cycle, and occurred when parents took their preterm infants home to begin a "normal/regular" life outside the hospital. All mothers anticipated going home: *"I am also looking forward to going home ... everybody is waiting for me there"*. They were able to spend time with their infants in the comfort and privacy of their own homes, in a space that was safe, provided protection and felt familiar. It was a time of rejoicing and reuniting of the family unit.

Parents had to incorporate the principles/skills that they had learnt from kangaroo care into their daily lives. One father felt uncomfortable in the hospital and therefore did not provide kangaroo care. He commenced it after his infant's discharge home. *"At home I didn't have kind of spectators ... I felt at peace and I could hold her and put her on me and it was beautiful"*. Kangaroo care made such a strong impact on him and his partner that they continued to provide it ten months after their preterm infant's birth.

The participants' main reason for discontinuing kangaroo care was either that the infant became too heavy, or the parent had to leave the infant in the care of someone else and return to work. Participant 1 applied what she knew about kangaroo care to her own situation:

> *"I will continue until I can't anymore, until the weight is too much. Most probably until 4 months or so – 'cause I'm going to go work" (Participant 1)*

Parents roles and responsibilities once their infant is discharged are different from those while in the hospital. One of the biggest transitions that occurred was the realisation that they were fully responsible for their infant. Parents learnt to interact and treat their infant "normally" once they came home, as they took full responsibility for their infants' care. Once discharged home, no one checked up on whether or not the parents continued with kangaroo care. Each parent had to make his or her own decision whether to continue at home:

> *"When I go home I have still got to do the kangaroo, until she is 2 kilos ... and I intend to do it for my baby's sake ... not for me." (Participant 3)*

One participant had been providing kangaroo care and decided to postpone his return to work:

> *"I am at the point where I am only starting much later at work now, I work part-time. Why is this parenting thing taking a hold of me? Because I just feel I am spending a lot of time with them ... getting to know them" (Participant 6)*

One mother experienced a new outlook on life after her son's preterm birth. She attributed this to the *"trauma"* of the birth that brought her face to face with the fact that a person's lifespan was governed by nature's time limits, which could be imposed suddenly and with little warning. *"... Not to take advantage of people, and everyday routine..."*. The reassessment of her own life made her stronger and more appreciative of life, which had a positive impact on her relationship with her son.

Mothers highlighted the positive aspects of kangaroo care: *"it's just a nice experience"*. Providing kangaroo care had made their lives *"richer"*. All would recommend and eagerly share their experience of kangaroo care with other mothers

The parents' role of providing kangaroo care created an avenue for them to work alongside health professionals in the care of their preterm infants. These parents became more acutely aware of the vulnerability of their infants due to their size and gestational age. This awareness increased their desire to go beyond the boundaries of the preterm infant's needs, not only to provide for their survival, but also to enable them to prosper.

Moving between these phases is both positive and negative, as parents were eager to spend time with their infants, yet were prevented from doing so because of the small size and instability of the infant. Conversely, when mothers had the opportunity to spend 24 hours with their infants in the Kangaroo Care Ward, they were unable to cope with the additional demands this required.

## 3.3 CONCLUDING COMMENTS

In this chapter the lived experience of parents have been illustrated through reflection on the in-depth descriptions from the interview transcripts. Providing kangaroo care to a preterm infant has an appreciable impact on the lives of the parents, portrayed as a chronological and linear process that parents follow,

with a circular dynamic, affecting the parents' life from the moment the infant enters the world. The parents have the choice to become focused on the barriers that prevent attachment, growth and "healing", or to adjust to the birth of their preterm infant and engage with the challenges and opportunities to form an intimate connection with their infant.

# Chapter 4

# DISCUSSION AND RECOMMENDATIONS

## 4.1 INTRODUCTION

In Chapter 3 the lived experience of the parents interviewed in this study was described. Providing kangaroo care to a preterm infant was found to be a dynamic, linear and cyclical experience that shifts the equilibrium of the parents' world. It was evident that there is a particular chronological process which is set in motion when a mother delivers a preterm infant and commences on the journey of providing kangaroo care.

The findings indicate that each parent's experiences of kangaroo care differed in intensity and were influenced by gender. This difference in intensity was evident during the preterm birth and initial separation period. Two significant events that parents described were: firstly, when the mother was discharged and the preterm infant was left in the hospital to be cared for by the neonatal staff, and secondly, when the mother moved into the kangaroo care ward of the hospital and spent twenty four hours a day with her infant.

The significant themes that emerged in this study related to the shock of the preterm birth experience, the parents' efforts to form an attachment with their infant, and their reliance upon a secure support network. This chapter provides a discussion of the themes in the light of the available literature on kangaroo care and the broader fields of attachment and support.

## 4.2 DISCUSSION OF FINDINGS

The eight main themes that emerged from the transcribed data are presented below:

### *a "Not his Time" - Delivering a Preterm Infant*

This theme described the parents' thoughts, emotions and fears during the time immediately prior to and including the delivery of their preterm infant. Parents were unprepared, disorganised, and shocked at the suddenness of the birth. Parents felt that they had 'missed out' on a normal birth experience. The mothers were often discharged home alone leaving their infant in the NICU, which exacerbated their sense of loss. Life and death issues were foremost in their minds, since the prognosis for some of the preterm infants was uncertain.

### *b Anxiety and Barriers*

Parents erected emotional and physical barriers to protect their emotions when coping with their infants' condition and the unfamiliar NICU. The lack of parental preparation for the preterm birth, the complex medical equipment and constant activity of the health personnel intensified parents' sense of inadequacy and created barriers between them and their infant. Fear that their infant may not survive united all the parents. Parents were eager to touch their infants but feared harming them, and therefore distanced themselves from their infants. Kangaroo care provided a simple, effective tool that enabled parents to overcome these barriers. Parents felt that clinics and health professionals should prepare pregnant women for the possibility of a preterm birth and the opportunity to provide kangaroo care. The fathers' anatomical build created a physical barrier, and they had to adjust the positioning of their infant to allow them to fit comfortably.

### *c Intimate Connection*

Despite the initial anxiety and barriers created by the environment, parents felt a special connection with their infant during kangaroo care. Kangaroo care satisfied the parents' need to feel like a 'parent', and an intimate connection

formed. Parents felt at ease and fulfilled by the closeness of their infants. The physical intimacy enhanced the parents' awareness of their infants' cues and signals, allowing them to constantly monitor their infants' condition. Initially the fathers in the study were overwhelmed by the shock and surprise of their infants' preterm delivery. Providing kangaroo care helped fathers to share in the lives of their preterm infants and restored their confidence.

*d Adjustments/Roles and Responsibilities*

The lives of both the parents and their family were transformed through this experience. Parents received roles and responsibilities far earlier than they expected and assumed additional tasks in the care of their infant. Fathers shouldered the majority of the household responsibilities and the care of siblings. The mothers spent most of their time at the hospital. Mothers juggled vital roles, providing breast milk and acting as a 'human incubator' to assist the infant's growth and weight gain. Since the mothers spent lengthy periods of time at the hospital, the preterm infants' siblings were encouraged to visit. Inclusion of siblings in the NICU facilitated the development of family relationships. Initially fathers chose the role of observer, watching while the mother provided kangaroo care, since they were intimidated by the environment and constant scrutiny of the staff. Fathers were very aware of their "maleness", felt incompetent, and feared that their infants would not thrive as they would when cared for by the mothers. Kangaroo care enabled fathers to feel part of the parenting role – a role they thought was held exclusively by the mothers. Each parental couple responded to their roles in a unique way.

*e Measurement of Success*

Parents perceived weight gain as a measure of success of their infants' progress and development. Weight gain was linked to discharge – and a successful outcome. Through breast-feeding and expressing milk, mothers had the opportunity to feel successful in their infants' care. Kangaroo care allowed parents to hold their infants and satisfied their yearning to provide comfort and touch beyond the boundaries of the incubator. Parents measured their own

success by the ability to handle their infant confidently. They learnt to adjust their expectations for their infant and accepted that their infant's growth and development would be different from that of other, full- term, healthy infants.

*f* ***Support Network*** **- "Standing by Us"**

The parents expressed a significant need for support. The main support structures identified by parents included: the immediate partner or spouse, their family support network, the staff within the institution, and other mothers. Parents also turned to a spiritual source for support. While there was nothing that eliminated the parents' fear, loss of control and hopelessness, the value of a support network cannot be underestimated. The support that parents received enabled them to cope with the experience rather than be overwhelmed by it.

*g* ***Living Without "their Infant" and Living Within "the Hospital"***

The challenge for the mother providing kangaroo care is that she moves between two worlds: 'living without' occurs when the mother is discharged from hospital. The infant stays in an incubator in the NICU and the mother comes to visit her infant every day. This separation is a stressful time for the parents, despite the fact that their infant is receiving optimum care. The 'living within' commences when the infant is stable enough to be moved to the kangaroo care ward. The mother moves back into the hospital and cares for her infant in the kangaroo care position 24 hours a day. The mother may stay continuously for days/weeks, until her infant has gained sufficient weight to be discharged home, and this experience dominated the mothers' lives. This impacted on their relationships with their partners or spouses, family, friends and social support, as well as their employment and leisure time. Fathers were excluded from the 'living within' experience since regulations in the kangaroo care ward restricted their involvement.

The major adjustments that the mothers faced included sharing a small living space and sleeping in a hospital bed with their infant on their chest. The negative aspects of living within the kangaroo care ward were backache,

boredom, loneliness, tiredness and anxiety. On the positive side, mothers assumed a more pivotal role in their infants' lives and reclaimed their role as primary caregiver. Mothers enjoyed the supportive environment in which staff were available for consultation and to provide assistance in emergencies. The 'living within' phase of kangaroo care reduced the stress of the infants' transition from hospital to home.

*h "Living With" Outside*

Once the infants attained the desired weight, the mothers went home with them. They relinquished the hospital support, but regained their family support network. Mothers anticipated going home and spending time with their infants in the comfort and privacy of their own homes. Kangaroo care principles and skills were incorporated into their daily lives. All parents recommended kangaroo care and eagerly shared their experience with others. Kangaroo care instilled in parents a sense of worth and created an avenue for parents to work alongside health professionals in the care of their preterm infants. Parents altered their priorities and their outlook on life as a result of their infants' preterm birth and the provision of kangaroo care.

### 4.2.1 Parental Attachment/Parent-infant Attachment

The themes of *'Intimate Connection'*, *'Adjustments'* and the subtheme *'handling their infant'* within the main theme of *'A Measurement of Success'* related to the attempt by parents to establish some attachment (physical and emotional) with their infant. The origins of the term 'attachment' date back to the 13th century (Goulet, Bell, St-Cyr Tribble, Paul & Lang 1998). The term refers to the relationships between an infant and his/her primary caregiver, which develops gradually (Scroufe & Waters 1977). Attachment theory was rooted in concepts developed by Bowlby (1969) and expanded by Ainsworth Slater, Blehar, Waters & Wall (1978) and Klaus & Kennell (1976).

**John Bowlby** (1907-1990) was a British psychoanalyst and child psychiatrist who drew upon ideas within several disciplines, including biological theories about preservation of species, theories about cognitive development,

psychoanalytic theories and control systems theories. Bowlby was particularly interested in the connection between poor social relationships and psychopathology and the experience of neglect or traumatic separation in early life. Bowlby emphasised the influence of early family environment on development, and the adverse effects of maternal deprivation and early separation, advising mothers to visit their young children in hospitals.

Bowlby introduced an ethological theory of attachment in the late 1950s. In the subsequent decades numerous other researchers have elaborated upon this theory, which integrates viewpoints from psychoanalysis and cognitive psychology. In 1969 (p. 194) Bowlby defined attachment as the "lasting psychological connectedness between human beings". It specifically describes the affective bond that develops between an infant and a primary caregiver (usually the mother), and later towards meaningful others. This bond is a necessity for mammalian newborns, which are all born immature and thus unable to immediately survive by themselves.

However, Bowlby only described the attachment process as being from the infant to the parent. Researchers (Ainsworth 1989; Waters, Posoda, Crowell & Kay 1994) who followed this theoretical understanding concluded that a secure infant to parent attachment promotes the development of an infant's healthy self-image and influences relationships later in life.

Attachment theory is, first of all, a theory about the nature of all human beings. It touches on several critical elements of an individual's emotional life: the tendency to form attachment bonds; the role of the caregiver; the anxiety and anger which separation and loss provoke; and the nature of grieving for the loss of an attachment. Secondly, this theory categorises the nature of a child's first attachment as either secure or anxious, and attempts to describe the impact of these patterns on subsequent behaviour and relationships.

Attachment is an enduring emotional bond characterised by a tendency to seek and maintain closeness to a specific figure, particularly during stressful situations. The infant uses the caregiver as a haven of safety or a secure base

while exploring the environment; when the infant feels threatened he/she will turn to the caregiver for protection and comfort. A pattern of interaction develops over time as the infant and caregiver interact, particularly in the context of the infant's needs and search for attention and comfort. Closeness to the attachment figure provides protection and a psychological sense of security. Early attachments should lay a good foundation for one's capacity to form other secure relationships, to seek support when needed, and to draw strength from the support which is given. A caregiver who is reliable, available and responsive to an infant's needs helps mould the attachment relationship into a pattern of interaction that develops over the first year of life and forms the basis for secure attachment, for competence in exploring the environment and forming other relationships, and for developing self-esteem.

Bowlby (1969/1982) referred to attachment bonds as a specific type of a larger class of bonds, that he and Ainsworth (1989) described as "affectional" bonds.

Ainsworth (1989) established five criteria for affectional bonds between individuals. First, an affectional bond is persistent, not transitory. Second, it involves a particular person who is not interchangeable with anyone else. Third, it involves a relationship that is emotionally significant. Fourth, an individual wishes to maintain proximity or contact with the person with whom he or she has an affectional tie. Fifth, he feels sadness or distress at involuntary separation from the person. A true attachment bond, however, has additional criteria: the person seeks security and comfort in the relationship.

Ainsworth *et al.* (1978) defined sensitivity as a parent's ability to perceive and interpret accurately the signals and communications implicit in the infant's behaviour, and given this understanding to respond to the signals appropriately and promptly. Based on detailed observations, Ainsworth found sensitive and responsive care to be a critical element in the development of a secure attachment. This finding has been replicated in other studies (De Wolff & van IJzendoorn 1997) and has provided the rationale for a number of attachment interventions. Interventions designed specifically to improve a

mother's sensitivity to her infant's communication have been somewhat successful, particularly with low-risk samples (van den Boom 1995).

Ainsworth described three major categories of attachment: secure, anxious/avoidant, and anxious/ambivalent. After years of additional research by many investigators, Main and Solomon in 1986 identified a fourth pattern: anxious/disorganised/disoriented.

**Klaus and Kennell** (1976) were the first researchers to focus on the mother's perspective of attachment, and described it as "a unique relationship between two people that is specific and endures through time" (Klaus & Kennell 1976, p. 2). They hypothesised that prolonged contact between a mother and her infant was crucial to the formation of an attachment. Klaus & Kennell (1976) used the terms attachment and bonding interchangeably. Their theory of the formation of maternal attachment hypothesises that maternal attachment is facilitated by the interaction of several factors between mother and infant during a "sensitive period" in the hours and days following delivery. This hypothesis has been challenged, and studies by Gottlieb (1978); Rubin (1984) and Schroeder (1977), cited in Goulet *et al.* (1998) have shown that attachment occurs over time. In 1982 Klaus & Kennell modified the notion of a 'sensitive period' to encompass the long-term process of parents establishing an emotional tie with their infant. Growing understanding of the importance of early contact stimulated acceptance of the 'bonding theory' and the practice of 'rooming in', which allows an infant to stay with his/her mother in hospital (Davis *et al.* 2003).

#### 4.2.1.1 Attachment as an Interactional Process

Certain definitions of attachment apply solely to the parent rather than to the interaction between the parent and infant (Rutter 1995). Mercer & Ferketich (1990, p. 268) described attachment as an "interactive process between partners resulting in a satisfying experience and an emotional bond that motivates parental commitment in caring for the infant". Attachment develops through the "interactions between parent and infant" (Schroeder 1977, cited in Goulet *et al.* 1998, p. 1073). Taking into account these definitions, interactional feedback

between a parent and an infant plays a role in the development of the attachment process. Proximity to the infant and opportunities for pleasurable satisfying experiences are an important part of the attachment process (Mercer 1977, cited in Mercer, Ferketich, May, DeJoseph & Sollid 1988).

The routine care for preterm infants is usually in an incubator. However, parents view the incubator as a barrier and one of the main separators between them and their infants. Bowlby (1982) stated that infant behaviours such as crying and smiling bring the parent physically closer, and behaviours of sucking and clinging allow the infant to maintain close contact. Klaus & Kennell (1982) included touch, eye-to-eye contact, high-pitched speech, entrainment, time giving, immunity (via breast milk), bacterial flora, odour, heat and oxytocin and prolactin release (through nipple stimulation) as factors that facilitated attachment. Attachment theorists such as Bowlby based their attachment theories on key aspects such as feeding, looking, connecting and touch which, to be sustained, require participation from both parent and infant. A parent must be able and willing to notice an infant's cues, to interpret their meaning accurately, and to respond appropriately. A secure attachment is established through interactions between an infant and his/her parent.

#### 4.2.1.2 Responses in a Preterm Infant

"A passive infant who seldom cries, never smiles, or resists physical contact, will require a greater investment from the parents for attachment to develop" (Goulet *et al.* 1998, p. 1074). In comparison, preterm infants spend longer periods of the day sleeping than full-term infants. During kangaroo care, infants spend fourfold as much time in the quiet alert state, with longer episodes that persist after the period of contact (Furman & Kennell 2000). This in turn leads to fewer opportunities for parent-infant interaction, to rouse the infant and socially engage with the infant (Feldman, Eidelman, Sirota & Weller 2002). "Kangaroo contributes to the infants' efforts to regulate themselves in terms of sleep organization during the transition from the womb to the extrauterine environment" (Ferber & Makhoul 2004, p.861). Feldman, Weller, Sirota &

Eidelman (2002) studied the effect of kangaroo care on self-regulatory processes of premature infants. At term, kangaroo care infants showed more mature state distribution and more organized sleep-wake cyclicity. At 3 months, kangaroo care infants had higher thresholds to negative emotionality and more efficient arousal modulation while attending to increasingly complex stimuli. The results highlight the importance of maternal body contact for infants' physiological, emotional, and cognitive regulatory capacities.

Full-term infants provide cues for responses from parents, which result in attachment. Preterm infants initially lack the ability to provide cues/respond to the parent. The preterm infant may miss out on the close physical contact if an interaction with the parent does not occur. If the parent has a difficult time understanding the infant's cues, or the infant does not respond as expected, the interaction is interrupted and the synchrony between them can be broken (Maroney 2001).

Mothers of preterm infants tend to be overactive or intrusive and their premature infants less responsive when compared with interactions between mothers and term infants (Barnard, Bee & Hammond 1984, cited in Harrison 1990). The kangaroo care position, however, minimises over-stimulation of the infant, and is considered to be a significant advantage (Griffin 2000). In the theme *'intimate connection'* the physical closeness of their infant while in the kangaroo care position enhanced the parent's awareness of their infant's cues. The closeness allowed parents to constantly monitor their infant's condition and heightened their perceptions of their infant's needs. Through kangaroo care the infant has continual skin-to-skin contact with the parent without having to provide any unnecessary interactional feedback (e.g. crying or moving) to gain the parent's attention. Infants will securely attach to parents who are sensitive while interacting with them. Sensitivity requires knowing and valuing the infant as an individual, reading the infant's cues effectively, and responding to the infant's needs for comfort and nurturing (Boris, Aoki & Zeanah 1999). Kangaroo care supports individualised interactions between the parents and the infant. These interactions help the parents to develop sensitivity and

responsiveness to the infant's behavioural signs (Ohgi, Fukuda, Moriuchi, Kusumoto *et al.* 2002).

The interactional process begins with the initial acquaintance stage and develops towards attachment (Gay 1981; Lobar & Phillipps 1992; Boulanger & Goulet 1994, cited in Goulet *et al.* 1998). For the parents in the study the initial acquaintance stage occurred later than they had expected, since they were separated immediately after delivery. The separation prevents the parents from "getting to know" their infant, which may threaten confidence and belief in their ability as parents. One mother described her separation from her infant as a *"barrier between the two of us"*. How does a parent who is physically separated from his/her infant for days experience attachment? The onus is upon the parent to establish a relationship since the infant is vulnerable and unable to interact/provide cues.

The participants in the study begin to interact and establish a relationship with their infants at their first introduction. They designed inventive ways to show their infants that they were loved, communicating with their infants by talking, humming and singing while the infant was in the incubator. The parents persevered with verbal communication even though they were not sure that the infant could hear them. They attempted to engage with and maintain close proximity to the infant through touch and ultimately kangaroo care. This relationship flourished as the parents spent additional time with their infants.



#### 4.2.1.3 Preterm Birth - its Effects on Attachment

The birth of an infant is a joyous time of celebrating new life, but for the parents of a preterm infant expectations about this event are abruptly altered. Additional stress and trauma and the inevitable admission of the infant to the NICU brings with it unique challenges, for which too often parents are not prepared. As discussed in the previous chapter, a preterm infant places additional time, financial, emotional and care demands on parents, especially during the first couple of weeks and months.

For the participants in this study preparation for parenthood was interrupted, they endured an unexpected preterm delivery, and the physical separation and anxiety caused by their infants' medical condition and admission to the NICU. The sterile, unfamiliar hospital environment and in particular the NICU fuelled their fears about their infants' uncertain future. A particular fear for parents during the early phase of their infants' life was that they did not want to *"get too close"* or establish a bond for fear that it may be irrevocably broken if their infants' condition deteriorated. Richards (1983) stated that these stressors interfere with the development of the parents' attachment to their infants.

Attachment is a complex, multifactorial, individualised process that requires physical contact and early interaction. Prematurity and separation at birth can affect the attachment process (Bialoskurski, Cox & Hayes 1999). If one considers the views of attachment (interactional and early, prolonged contact), then the process of attachment is severely compromised following a preterm birth. The lack of continuity, lack of touch and intimate physical contact prevent parents attaching to their infants. For a preterm infant who is fighting for survival, a reciprocal interactive relationship is too great a challenge, and if established may not be sustained for a prolonged period of time. Unlike the parents of full-term healthy infants, who have the opportunity to connect and attach to their infant immediately after birth, the parents of a preterm infant have fewer prospects for contact during this time. They spend time grieving the loss of their 'ideal' infant and considering their infants' immediate future.



#### 4.2.1.4 Factors Influencing Attachment

Premature birth has been shown to put the attachment process and maternal role/relationship at risk (Alfonso, Wahlberg, and Perrson 1989). Impaired maternal-infant attachment is a recognised difficulty in families of preterm infants (Wille 1991; Harrison 1990; Sims-Jones 1986). Factors that may influence attachment include the physical appearance of the infant, the premature infant's disorganised interaction behaviour, and the mother's coping mechanisms to prevent grief. Other factors may include the mother's poor maternal health at the time of and after delivery, lack of social support, presence of other

dependent children, drug dependency, financial issues, and break-up of the relationship with her partner (Bialoskurski *et al.* 1999).

*Delivering a 'Different' Infant*

The theme of being 'different' emerged in this study. The preterm birth experience was different for parents who had experienced delivering a 'normal' [healthy] full-term infant. To deliver an infant who weighs 1400 grams is something 'out of the ordinary'. The preterm birth is a new experience, particularly during the first few weeks until the infant gets to the point where they are perceived to be like other 'normal' infants, weighing 2 - 2.5 kilograms.

The preterm infant's birth was a unique experience, even for those parents who had experienced a healthy full-term birth. The preterm infant was born *'too soon'* and had to be handled in a special way. There were adjustments and challenges for all parents; even the experienced parents (those who had raised another child) needed to re-learn how to handle their fragile preterm infant. Parents were denied the freedom of access to their infant – to be free to walk into the NICU, pick up their infant, and intimately connect with him/her - since the infant was attached to machines, intravenous lines and monitors. Parents also had to follow a strict routine of hand washing when they wanted to touch their infant in order to prevent the spread of infection.

*"Seeing for Myself"*

*"Seeing that it was my child"*, were the words of one mother who wanted to "check" that it was her child, especially since her child had been declared dead for five minutes. The mother wanted to make sure that her infant was alive, turning the 'unknown' into the 'known'. Was this mother allowed to hold her infant? Do any of the mothers get to touch, hold or see their infants as soon as they are born, or are the infants all immediately rushed to the NICU to be checked out by the doctors and other health personnel? The introduction to parenting for these parents is a strained quick glance, before the infant is whisked away for medical attention. They know that they have missed out and have to reassure themselves that once they see the infant a bond will form, and

they will recognise that it is their child. A study on full-term infants and their parents by Zeanah, Zeanah & Stewart (1990, cited in Boris *et al.* 1999) reported that for most mothers, actually seeing their infant intensified their feelings of affection.

*Anxiety vs. Confidence Gained in Kangaroo Care*

"Anxiety during this period of crisis is pervasive and a manifestation of the perceived loss of control and the lack of predictability subject to the birth of a preterm infant" (Hawkins-Walsh 1980, p. 30). In the themes *'not his time'* and *'anxiety and barriers,'* participants in this study described the anxiety they faced after the birth of their preterm infants. The mother's failure to deliver a full-term infant may impact on her intimate relationship with her infant during the first few days and weeks after birth. Feelings of failure, anxiety, loss of self-esteem and grief were common among parents. Grieving may cause the parents to withdraw from the infant (Kaplan & Mason 1960) until his/her survival is ensured. If a mother feels like a failure at not having delivered a full-term infant and being unable to breast-feed, the additional disappointment of her infant not gaining weight may impact on her attachment with her infant. To counteract the feelings of inadequacy and failure, the staff and other mothers showered new mothers with constant support and encouragement. This helped the mothers to normalise their feelings and anxieties and put their fears into perspective.

How did parents overcome these barriers? The support of their partners/spouses, family structure and the medical staff played a significant role. Parents in this study instinctively developed coping mechanisms, which enabled them to resolve their feelings of guilt and failure and to construct meaning in their lives and look towards the future. Parents built confidence through the assistance from staff and their involvement in their infants' basic care (e.g. feeding, washing and changing nappies). Gender was found to influence the parents' coping strategies. The experience described by mothers

and fathers of preterm infants in this study confirm the findings of Lau & Morse (2001) that parents use varied coping strategies to deal with preterm birth.

Curry (1982), in her study of maternal attachment and the effect of early skin-to-skin contact, states that there are a number of variables that affect the development of attachment. These include the events of pregnancy, the availability and use of support systems, and the infant's characteristics. The study reported that each woman's developing maternal attachment should be assessed within the context of the many variables that may affect its development. Nurses need to evaluate and nurture each mother individually, in response to her individual needs. In the theme *'support network,'* a young primigravida mother with 24-hour family support at home, when moved into the kangaroo care ward was exhausted and felt alone. She was unable to cope with the demands of her preterm infant's routine and the separation from her family. This mother's exhaustion and loneliness adversely affected her attachment with her infant; therefore, to restore it, she was discharged home for a couple of days.

#### 4.2.1.5 Physical Separation – 'Deprivation vs. Attachment'

*'Loss in preterm birth'*, a sub theme in *'not his time'* highlighted the parents' feelings of loss after the preterm birth. Parents were shocked, numb, detached and terrified. They were denied time to prepare physically, emotionally or mentally for their preterm birth experience. Jackson, Ternestedt & Schollin (2003) similarly found that mothers of preterm infants described the actual birth as unexpected and talked of not feeling part of the event.

The unexpected birth timing created a loss of predictability, an upheaval in the anticipated cycle of events; the couple entered into a new world of prematurity which held further adjustments. They had expected to deliver a term infant that they would get to hold immediately. This is the first of a series of delays and disappointments for parents of preterm infants. According to Jackson *et al.* (2003), parents experienced feelings of alienation when the preterm infant was born because parenthood came sooner than they expected.

For the parent who delivers a full-term infant, there is an immediate attachment during the "critical time" (Klaus & Kennell 1960). Mothers of full-term [healthy] infants experience close contact and interaction with their infants immediately after birth, since the infant is either placed on the mother's bare chest or wrapped in a blanket and given to the parents to hold. There is an expectation of 'intimate moments' with their infant following his/her birth. For parents of preterm infants, there is a gap since their infant is immediately removed in order to be resuscitated or stabilised by the medical staff. The loss is experienced as deprivation: "*you feel deprived as a mother*". Parents were denied physical contact with their infants, were not allowed to touch or hold their infants during the early phases of their hospitalisation. Depending on the infant's medical condition, preterm infants may remain for weeks or months in the NICU. The preterm infant is physically unable to survive without the assistance of intensive medical care and is placed in an isolated environment in the incubator. The isolation and separation necessary for the infant's survival reduces the opportunities for parents to interact with their infants.

Early and extended contact and privacy are thought to be facilitative of, but not essential to the development of maternal attachment. Early contact cannot be judged as the tool by which parental attachment is measured, since parents of preterm infants are often denied immediate contact with their infant, as highlighted in the theme *'anxiety and barriers'*. As the medical care of the preterm infant has advanced, there has been an increase in the survival rates for preterm infants (Davis *et al.* 2003). One of the consequences of the improved survival rates is an increase in the number of parents who have missed the opportunity for early postnatal contact and interaction similar to that experienced by the majority of parents of healthy full-term infants.

Curry (1982), in a study involving 55 mothers, found that mothers who had extended skin-to–skin contact during the first hour after delivery did not demonstrate more attachment behaviours at 36 hours' post-delivery or at three months after delivery. However, only married, financially stable, well-educated, well-prepared mothers with full-term infants were used in his study.

The findings dispute that there is a maternal-sensitive period in the first few hours following birth as proposed by Klaus & Kennell (1972).

The theme *'intimate connection'* show that although in the immediate postpartum period parents were physically and emotionally detached, attachment still occurred between these parents and their infants. The parents were flexible and capable of forming attachments in 'suboptimal circumstances', such as the NICU of a hospital. For these parents more time and effort may be required to establish this attachment.

The parents attempted to forge relationships with their fragile infants while coping with the crisis of preterm delivery in a stressful environment which lacked privacy. The parents had sporadic and time-limited contact with their infant during the initial hospitalisation in the NICU. Their sensory contact was restricted during this time by the NICU regulations and equipment barriers.

The loss of 'normality of birth' impacts on the parents' attachment with their infant. The birth of a preterm infant forces the parents to attach in a different way. Once the parents were given the freedom to adjust to the physical differences of their infant without undue pressure from the health professionals, they were able to interact and an attachment occurred at their own individual pace.

Kangaroo care offers an alternative option for attachment since it encourages parents to spend time in close physical contact with their infant while in the NICU, and then on a full-time basis once their infant is discharged into the kangaroo care ward.

#### 4.2.1.6 Failure to Attach Because of Fear

Parents described two types of fears: firstly "distancing" due to the fear of non-survival of the infant, and secondly fear of hurting the infant.

*Fear of Non-survival - "Distancing"*

For all the parents the preterm birth of their infant was unexpected. Although they had planned for a birth, this had not occurred according to plan, so

expectations had to change (expectations versus reality). The nature of such expectation is fraught with uncertainty. For one parent couple, to be informed that their infant was dead, only to be later told that she was indeed alive, was an overwhelming experience. Medical staff had expressed extreme caution with respect to the outcome of the delivery, and parents had developed a significant fear that their infant would not survive. The contrast in birth experience for these parents is evident - birth is meant to be a time of rejoicing, when someone "comes into the world", yet for these parents their infants' birth is counterbalanced by the threat of possible death.

The subtheme of *'distancing'* in the theme *'anxiety and barriers'* describes the parents' constant fear that something unpredictable might happen to their infant while they were away from the hospital. The fear impacted on the attachment process – since parents delayed engaging with their newborn, they emotionally and physically distanced themselves from their infant. One participant described the formation of a relationship with her child as a "struggle". The parents' emotions and feelings were consistent with the findings of other studies. Bell *et al.* (1996) found that parents of preterm infants were initially preoccupied with their infant's physical well-being and felt distant from their infant (cited in Goulet *et al.* 1998). Jackson *et al.* (2003) also reported that parents experienced considerable fear and were afraid to leave the infant because they were worried that s/he may die. In a study by Sullivan (1999), fathers were hesitant about physically and emotionally caring for an infant whose survival was uncertain.

When does the fear of becoming attached change? Does attachment happen anyway? In their study, Jackson *et al.* (2003) found that the point at which fear changed to attachment varied between mothers and fathers. Fathers described difficulty in becoming attached to their infants, but an important turning-point in their experience was when they felt confident enough to hold the infant and have physical contact. For the mothers the turning-point came when the infant could be taken out of the incubator for increasing lengths of time. This made the situation more real, and positive feelings for the infant became stronger. The

theme *'intimate connection'*, describes how parents overcame the barriers they had erected due to the fear of losing their infant. After the first few days, when it was evident that survival was possible, they began to establish a relationship through touch and kangaroo care. In her study Sullivan (1999) found that the times at which fathers felt that their infants were going to survive were significant in the development of feelings of warmth and love for their infant.

Touch and kangaroo care were experienced as intimate communication by the participant parents. It satisfied their need to *feel* like a mother or father. The first experience of holding their preterm infants in the kangaroo care position was one that all parents treasured, since it made them feel like a "real" parent and attachment was formed. Several of the fathers in Sullivan's (1999) study reported that the first time they held their infants in their arms was of special importance to their feelings of attachment.

*Fear of Hurting the Infant*

Parents in this study desperately wanted to hold their infants, as described in the theme *'empty arms'*, yet the fear that they may unintentionally hurt their infant created a sense of clumsiness which increased their anxiety. Affonso, Bosque, Wahlberg & Brady (1993) described similar findings in their study. Mothers in their study expressed concern that they might hurt their infant while holding them. Lima, Quintero-Romero & Cattaneo (2000, p. 25), reporting on a study of 244 participants, also identified this pattern, reporting that "13% of the mothers admitted fear when they began kangaroo care". Initially the parents (theme: *'anxiety and barriers')* were not allowed to touch their infants due to their fragile medical condition, which hindered attachment. When they were allowed to touch their infants they did not know how to do so and lacked confidence, and some parents were too scared. These parents faced an adjustment to their expectations of the parental role.

#### 4.2.1.7 Kangaroo Care and Attachment

Drawing on the recognised importance of *early social interactions* (Tessier *et al* . 1998) with the caregiver, such as holding, touching, and eye contact, kangaroo

care facilitates the emotional care response. Kangaroo care is an attempt to improve care given during the period in the NICU and to enhance both communication and attachment between parent and infant. Anecdotal evidence and findings of maternal interviews suggest that skin-to-skin contact [kangaroo care] enhances maternal attachment (Affonso *et al.* 1993; Nyqvist, Sjoden & Ewald 1994). Kangaroo care should be seen as a means to ensure the successful discharge of a frail infant from hospital by enhancing active parent participation during the NICU and kangaroo care ward periods.

***Parental involvement in care of their infant – allowing parents to regain control***

For parents, the NICU is an intimidating and alien environment in which they have little control over or participation in the care that their infant receives. A parent's lack of involvement in his/her infant's care is a major source of stress and contributes to feelings of disempowerment and lack of confidence in their parenting abilities (Zhar 1991; May 1997). A study conducted by Holditch-Davis & Miles (2000) found that mothers of preterm infants had a higher degree of stress than mothers of full-term infants. The mother's task while her infant is hospitalised is to prepare to care for her infant, until the infant becomes stable enough for her to assume care. The nurse's task is to care for the infant, teach the mother the required care, and then relinquish that care. Active parental involvement in caring for their infant in the NICU is thought to improve parent-infant attachment and to reduce the psychological stress for parents (Affleck & Tennen 1991). A study of 146 three-month-old preterm infants and their parents, showed that following kangaroo care, mothers and fathers were more sensitive and less intrusive, infants showed less negative affect, and family style was more cohesive (Feldman, Weller, Sirota & Eidelman 2003).

In the themes *'empty arms'* and *'anxiety and barriers'* mothers spoke of a loss of control related to their infant's care, which was most pronounced during the infant's first few days in the NICU. Fenwick, Barclay & Schmied (2002) discussed the issue of control, stating that parents in the NICU were in a situation where establishing a sense of attachment to their infant required 'visiting' their own child on the staff's terms and in an environment that could

not be their own. To minimise stress and anxiety, parents' feelings should be recognised. In a study by Jackson *et al.* (2003) mothers felt that they had a need for control and participated more in the care of their infants. Parents can be informed, given choices, and involved in the infant's care. The more informed parents feel, the more they feel "in control". Parents should feel they are part of the team which cares for their infant and that their contribution and feelings matter. Encouraging parents to spend time with their infants and to actively participate in their care by touch and holding is believed to facilitate parental role development (Gale & Franck 1998).

Parents feel a sense of responsibility for their infant's safety, growth and development (Goulet *et al.* 1998). Pridham & Chang (1985) stated that it is essential that parents place the infant at the centre of their lives and their family. Kangaroo care enables parents to have an interactive relationship with their premature infant and promotes the parent-infant attachment process (Clifford & Barnsteiner 2001). Attachment is strengthened when physical contact occurs between mother and infant (Bialoskurski *et al.* 1999). While most attachment theories relate to full-term, healthy weight infants, the findings from this research show that for preterm infants and their parents, kangaroo care facilitates attachment during this time of adjustment and challenges.

Kangaroo care equipped parents to form an intimate relationship with their infant, and offered the contact which is vital in the development of the relationship. All the participants said that it enabled them to get to know their infants more rapidly than they would have with standard incubator care. Kangaroo care promotes physical and emotional relationships between parents and their infants. The necessary medico-technical procedures are kept to a minimum while still promoting the survival of the preterm infant. Kangaroo care has been shown to have a positive impact on the mothers' sense of competence and on the mother-infant attachment process (Tessier *et al.* 1998; Ohgi *et al.* 2002). Affonso *et al.* (1993); Neu (1999) described it as reconciliation or a healing process for mothers. Kangaroo care provides maternal proximity during a period when maternal separation is common and serves to increase

infant attention and alertness (Feldman *et al.* 2002). Mothers who provided kangaroo care were less depressed, perceived their infant as more normal and provided increased maternal affiliative behaviour (e.g. touch, gaze, positive affective display) during the hospitalisation period (Feldman *et al.* 2002, p. 23). Skin-to-skin contact in the form of kangaroo care may contribute to the preterm infant's cognitive development, since kangaroo care integrates rhythmic, sensory and tactile components into the mother-infant context (Feldman *et al.* 2002).

Mothers who provide kangaroo care report a more positive feeling towards their infant (Affonso *et al.* 1993; Anderson 1991). The active care of the preterm infant and the physical bonding may reduce maternal depression and increase her familiarity with the infant and his/her interactive signals. Kangaroo care may improve alertness during mother-infant interaction, resulting in increased maternal involvement (Feldman *et al.* 2002). Several studies (Charpak, Ruiz-Pelaez, Charpak & Martinez 1994; Bier, Ferfuson, Morales, Liebling, Oh & Vohr 1997; Whitelaw, Heisterkamp, Sleath, Acolet & Richards 1998) have shown that mothers providing kangaroo care produce larger volumes of breast milk and lactate for a longer period than mothers who did not have this experience. Furman & Kennell (2000) refer to the practice of combining kangaroo care and breast-feeding, which enables mothers to appreciate that they are making an important contribution to their infant's care so they will intimately connect with their infant earlier than expected.

Kangaroo care, while not designed to promote attachment, has demonstrated the advantage of promoting and facilitating a number of aspects of infant behaviours that aid attachment, as described by Bowlby (1982) and Klaus & Kennell (1982). These include crying and smiling, which bring the parent physically closer. The behaviours of sucking and clinging allow the infant to maintain close contact, touch, and eye-to-eye contact. High-pitched speech, time giving, immunity (via breast milk), bacterial flora, odour, heat and oxytocin and prolactin release (through nipple stimulation) also aid attachment.

Kangaroo care as a means of caring for preterm infants was predominately introduced for cost- effective reasons, not for humanitarianism. Attachment was not one of its goals, and yet attachment has proved to be of vital importance, with kangaroo care aiding earlier attachment of parents with preterm infants.

#### 4.2.1.8 'Forced' Attachment

"Prolonged contact between a mother and her infant is crucial to the formation of an attachment" (Klaus & Kennell 1976, p. 2) Mothers should be encouraged from the earliest contact to be involved in the care of their infant. In a study by Anderson (1999), parents reported increased closeness to their infants and improved feelings of competence. Lima *et al.* (2000) confirmed this view in their descriptive study involving 244 LBW infants. They reported that the advantages of kangaroo care included increased self-confidence and empowerment of mothers, and increased bonding and stimulation of breast-feeding. Kangaroo care was considered comfortable and convenient, and 100% of the mothers were confident in their capacity to care for their infants at home.

What is it that kangaroo care does in promoting parent-infant attachment? Kangaroo care *forces* the parent to spend time with their infant. While the mothers are 'living within' the kangaroo care unit they have their infants in the kangaroo care position for 24 hours a day. They are not allowed to walk around outside the kangaroo care ward. Kangaroo care is a tool for parents to form a relationship with their infant through their interactions with him/her. One father described it as *"...not go anywhere, just be here and be present with your child..."*

As a consequence of kangaroo care it was no longer painful for parents to interact with their infants, as they could touch them. They worked through their grief and disappointment at not delivering a full-term infant, and were now committed to providing care that would enable the infant to thrive. Although parents in the study felt that touching and holding their infants was an important means by which they could interact with their infant, they still felt that they were not doing enough. Kangaroo care provided them with the

assurance that they were doing everything possible to allow their infants to gain weight and grow. For one mother it was *"a greater way in which to nurture her [her infant] and to build up this relationship for the child's growth"*. For these mothers the feeling of closeness to their infants was one of the valuable outcomes of kangaroo care. Furman & Kennell (2000) described similar findings in their study.

Kangaroo care is an example of attachment (relationship-building behaviour) that has important effects on both the present and future health of the preterm infant, and those involved in his/her care, including the parents and the family unit. Kangaroo care provides the opportunity for intimate interaction between the parents and their infant. It is more effective than incubator care or standard contact (where the infant is wrapped in a blanket to maintain temperature regulation and cared for in a bassinet) in providing many of the influencing factors for maternal attachment as identified by Klaus & Kennell (1982).

Kangaroo care provides for contact between a parent and his/her preterm infant. The psychological, emotional, social and physiological benefits enable the preterm infant to thrive in all spheres of health. Active participation in kangaroo care by parents demonstrates an interest in their infant's well-being.

Kangaroo care enhances parental involvement in the care of their preterm infants and may eliminate an often overwhelming sense of guilt and failure at not having delivered a term infant. With kangaroo care parents are given the rare opportunity to continue what began *in utero*, by providing a similar environment to that of the uterus. In the theme *'measurement of success'*, all parents preferred kangaroo care to the traditional incubator care since they felt that they could participate in the care and monitoring of their infants.

Kangaroo care positively influences parental adaptation to the impact of preterm delivery, and the establishment and development of healthy parent-infant relationships. Parents, grandparents and the infant's siblings are all included and encouraged to visit the infant - the entire family unit is involved in kangaroo care. This has a profound influence on the growth and

development of the premature infant (Rice 1989) as well as on the family as a whole. Facilitation of healthy parent-preterm infant relationships is an investment in the infant's social, emotional and physical development.

The theme *'intimate connection'* described the special quality of the parent-infant interaction, and the intense connectedness of parents with their infant that occurred through kangaroo care.

**4.2.1.9 Lifestyle Changes - The Transition of 'Living Without' and 'Living Within'**

***'Living Without'***

Parents in this study learnt to adapt to the impact of the preterm birth of their infants and its implication for their own lives. A unique aspect of kangaroo care is the progression of the parents (especially mothers) through the phases of *'living without'*, *'living within'* and finally *'living with outside'*. Once discharged from hospital the mother lives at home - *'living without'* - and visits the NICU daily, until the preterm infant is medically stable and the mother moves into the kangaroo care ward - *'living within'*.

In 1982, Klaus & Kennell described the term 'nesting', in their book on parent-infant bonding. They suggested that "early discharge of preterm infants, preceded by period of isolation of the mother-infant dyad, may help to normalise mothering behaviour in the intensive care nursery" (1982 p. 179). Once the mother is confident in her provision of care and the infant's weight is at an acceptable level, the mother and infant are finally discharged home together.

Mothers of preterm infants do not meet the expected social 'norms' of motherhood and are perceived as incompetent since they have not brought their newborn home when they themselves are discharged. A preterm infant needs to remain under supervised medical care in hospital for an extended period, while a healthy full-term infant usually leaves the birthing centre with his/her mother. Leaving their infant in the care of 'more competent caregivers' - the health personnel - was one of the most difficult experiences for the study

participants. This has been reported in studies from the 1960s to the present date: Kaplan & Mason (1960); Affonso, Hurst, Mayberry *et al.* (1992); Fenwick *et al.* (2002). Separation from their preterm infant was reported as the mother's greatest negative stress in a study by Affonso *et al.* (1992). The separation of parents and their infant following a premature birth may interfere with the parent-infant relationship and may give rise to poor outcomes such as dysfunctional parenting and delayed physical and/or intellectual development (Lau & Morse 2001). To rectify the stress caused by the separation, as indicated in the theme *'living without'*, parents returned to the hospital on a daily basis to spend time 'intimately connecting' with their infants. They were introduced to kangaroo care and given demonstrations on caring for a preterm infant, and they were encouraged to actively participate in the infant's care during their visits. Prior to kangaroo care as an option, preterm infants were cared for in incubators, isolated from their parents except for occasional human touch and comfort. Touch, verbal conversation, reassurance and kangaroo care enabled the parents to re-establish a connection with their infant.

During the *'living without'* phase the mother moves back home and is required to adopt a daily visiting schedule until her infant has gained sufficient weight to move into the *'living within'* phase of kangaroo care. Parents visit their infants daily while they are cared for in the NICU. One father had to return to work but divided the time he and his partner spent with their infant into shifts, so each could have an equal opportunity to provide kangaroo care. Findings from a study by Ohgi *et al.* (2002) suggest that kangaroo care increased visiting rates of parents.

***'Living Within'***

All the mothers in this study had to make a temporary lifestyle change in order to return to the hospital to begin the *'living within'* phase. The mother is admitted for several days or weeks before the infant is discharged so that she can become acquainted with her infant, his/her routine, and take over complete charge of her infant under the supervision of health personnel. The kangaroo

care ward provides a transition from the specialised care of the NICU to home, and aids the parents in viewing their preterm infants as 'normal' and safe to take home. The lifestyle change involves the mother moving from *'living without'* in her home surroundings into the kangaroo care ward, where she is required to room-in with eight other mother-infant pairs. This is a major adjustment for the mother as she loses contact with her "outside world". Her spouse, family and friends only visit for an hour a day. She has to rely upon the newly acquired relationship with her infant and the "internal" support network of the staff and other mothers to support her during the difficult times. The mothers described feeling a deep sense of "aloneness" while isolated from their support networks. Particularly difficult for the mothers in this phase was the loss of connection with the familiarity of their own homes and the support of family and friends.

The views of the participants in the study were that the *'living within'* period of kangaroo care was a 'privilege' and a time for equipping the mothers for home care of their infant. The first weeks are an important time in the development of the parent-infant attachment, and when hospitalisation occurs during this time the process of attachment may be disturbed (Lampe, Trause & Kennel 1977). These authors recommend that facilities be provided for parents to live in the hospital during their infant's hospitalisation. 'Normalising' for parents of preterm infants while in the NICU is not possible; however, kangaroo care and *'living within'* the kangaroo care ward offers some aspects of this, by attempting to normalise the interaction between parents and their preterm infants.

Providing kangaroo care becomes part of the mother's every day existence, it permeates everything she does and she has little control in the kangaroo care ward. The woman's decisions and actions are all controlled by her commitment to continuous kangaroo care. For the mothers in this study, movements were restricted to the designated area of the kangaroo care ward and NICU, had access only to a television and radio in a communal room. In a country such as South Africa with its diverse cultures and languages this presents a challenge, since there is little for the women to occupy themselves with while providing

kangaroo care. The loss of control extends to the submission to the hospital routine, with limited options for individual choices with respect to eating and the other activities of daily living. The parents in this study were required to adapt to the unfamiliar environment and learnt to abide by the stipulated rules and regulations. Fenwick *et al.* (2002) described similar findings.

Although the duration of the *'living within'* phase was different for each parent-infant team, most mothers spent an average of 1-2 weeks in the kangaroo care ward. The extended hospital stay was seen as the most negative aspect of the experience. In their study Lima *et al.* (2000) found that 43% of mothers complained about the long stay in hospital (but considered that it was necessary), and 25% felt homesick.

A study by Affonso *et al.* (1993) interviewed eight mothers of preterm infants who were providing kangaroo care for a period of four hours a day, for three continuous weeks. Mothers were interviewed weekly, and when interviewed during their second week, they expressed fear for their infants' well-being, intensive fatigue due to events at home, and an overall apprehension about their ability to manage. All the mothers expressed a desire to be relieved from kangaroo care because they felt tired and stressed, and took a day out to spend at home with their families. The second week appears to be a stressful time for mothers, since the tension between the desire to stay in the hospital and care for her infant and the desire to be at home becomes unbearable. When the mothers returned after the break they were once again committed and enthusiastic about providing kangaroo care. As discussed in Chapter 3, two mothers in this study voluntarily took days off in the second week of kangaroo care to sort out personal stresses.

In the theme *'measurement of success'* the mothers compared their infant's weight and success to that of other infants, and felt demotivated when they saw other infants gaining weight faster and being discharged earlier. Who else can the mother blame but herself? Breast-feeding is one of the keys to weight gain. It has been shown that "breast milk supports growth rates approximating

intrauterine rates" (Furman & Kennell 2000 p. 1280). The mother has to continue to breast-feed and express milk even though she may feel like a "failure" and has too little milk for her infant to gain weight and prosper.

The theme *'living within'* highlights the mothers' confidence as providers of kangaroo care and their competence as caregivers. They displayed competence and were eager to be discharged with their infants as early as possible. They were confident in handling their infants since they had played a vital role in their infants' care during his/her hospitalisation. This increased their confidence, self-esteem and sense of efficacy. These findings concur with those of Furman & Kennell (2000).

Jackson *et al.* (2003), in their study of seven sets of parents of preterm infants who had no experience of kangaroo care, found that the mothers did not feel prepared for the infants' discharge from hospital and for their new responsibility. They felt insecure about caring for their infants and felt that the decision to discharge was made too quickly. In contrast, the theme *'living within'* highlighted that mothers who had spent time living in the kangaroo care ward were eager and well prepared to be discharged with their infants. Denson, Consolvo & Adcock (1984) in their study found that parents are anxious at two particular points in their infant's neonatal course: the time of the birth and the time of discharge. In the theme *'not his time'* parents felt anxious after the birth, but through kangaroo care and the *'living within'* process they gained confidence in their own abilities. The days/weeks that mothers spent growing accustomed their infants' behaviour and routine increased their feelings of confidence in handling their infants. Affonso *et al.* (1992) in a study on skin-to-skin contact in an American tertiary level intensive care nursery found similar findings of increased maternal confidence and mothers ready to take their infants home sooner then mothers who had received standard care.

There is no doubt that kangaroo care is acceptable to parents, providing them with a satisfying role in the care of their small infants, and enabling them to re-

establish a bond with their infant that may have been broken by the initial separation of incubator care and isolation.

#### 4.2.1.10 A Cultural Perspective on Attachment

Although the issue of cultural views and customs did not emerge as strongly as the other issues in this study, there was, for one of the participants, a strong sense of cultural custom which influenced the father's involvement with the preterm infant. It altered his provision of kangaroo care and thus attachment with his infant.

The Xhosa speaking father in this study held strong "cultural views". One such view was that he would not hold his infant at night as it was considered inappropriate in his culture. To the medical/nursing staff this "cultural view" was seen as an impediment in the attachment process while his daughter was in hospital, since he used to come to visit her at night. *"I used to come at night or late to visit her, so I mean, especially with us African people to walk at night and then you come in and take the child is usually not considered right or good, anything out there, dark forces or whatever, and then the child, there was also that aspect" (Participant 6).* A misinterpretation of parenting behaviour is possible when the nurse and parent are from different cultural backgrounds (Kussano & Maehara 1998). However, once the infant was discharged home the father described how the attachment process commenced.

In the Xhosa cultural tradition it is customary for the mother to carry her infant on her back. This enables her to have both hands free to continue with her household and work duties. The infant is kept close to the mother and is secure and comfortable. Thus kangaroo care was seen as an adaptation of this practice. The fathers made a few adjustments with regards to positioning the infant in the front rather than at the back. Positioning the infant in the front allows the mother to make eye contact and form an attachment with her infant. In the African culture the continuous carrying of an infant on the mother's back is seen as acceptable. This is contrary to the Western culture, in which parents

who carry their child around for an extended period of time are considered to be spoiling them.

> *"There is a Xhosa idiom or saying that translates to: a child that doesn't cry, on the mother's back, dies. I think that I like the kangaroo position, because it's here [points to against his chest] and you can constantly monitor the child". (Participant 6)*

It is necessary for hospital staff to be aware of the cultural views and customs of parents and to consider cultural differences, since they can significantly influence the parent-infant relationship and the process of attachment.

#### 4.2.1.11 A Father's Perspective of Attachment – "The Time Factor"

Research on attachment has demonstrated that although mothers and fathers attach to their infant through a similar process, the pace at which they attach may be different (Anderson 1986).

Jackson *et al.* (2003) in their study found that fathers felt unprepared for the sudden delivery and as a result a number of the fathers felt like outsiders. The father's role in the NICU is equally important as the mother's, and his involvement is especially important in the NICU during the first few hours and days following the birth, when the mother may initially be absent after a traumatic delivery experience (Vine 1995).

"Health professionals have a strong tendency to forget the father after the birth and to confine him to the role of spectator" (De Courval & Goulet 1985). The number of mothers visiting the NICU and providing kangaroo care contrasted with the smaller number or the lack of fathers who participated in the care of their infant. In the NICU it is more common to witness fathers holding their infants wrapped in a blanket than see those infants lying on their father's chest in the kangaroo care position. In the theme *'living within'* the fathers shared their eagerness to participate in kangaroo care, although the 'exclusion' of fathers from the kangaroo care ward was an emotive issue. They felt controlled and frustrated by the hospital rules and regulations, since they left them helpless to interact with their infant. Goulet & De Courvel (1989), cited in

Goulet *et al.* (1998) reported similar findings. They found that fathers were dissatisfied with the amount of contact they were allowed with their infant during the hospitalisation, because of the control exercised by the health care professionals. The fathers therefore returned to the familiar environment of work where they could regain a sense of order and control. However, when they returned to work they were further excluded from their infant's care since the formal education given by the hospital staff with respect to kangaroo care was offered during the day when fathers were at work, and the information they then received was second-hand (from their partners/spouses). In general, education programmes are offered during daytime work shifts, and thus exclude working parents (fathers) from accessing this information (De Courval & Goulet 1985).

Two fathers in the study had difficulty in getting paternity leave from work, which resulted in fewer visits to see the infant. They were forced to make alternative arrangements, and began to visit their infants in their lunch breaks or before and/or after work. The hospital, a State facility, provides services for predominantly the lower socio-economic patients. The fathers in the study were reliant on public transport, and would catch taxis or buses to the hospital after work. Public transport services do not service the hospital after the normal visiting hours, and this restricted the time they spent forming a relationship with their infant. One father found that if he stayed at the hospital for more than half an hour after work he would miss the last available taxi home.

Fathers play an important and direct role in the development of preterm infants. In a study by Yogman, Kindlon, & Earls (1995) the fathers' involvement enhanced cognitive development in African-American, LBW preterm infants. Sullivan (1999) demonstrated the importance of participation of fathers in the care of the preterm infant in order to form an attachment with the infant. Yet one of the major differences that exists between mothers and fathers is the amount of time that each spends with their infant.

The stress of the preterm delivery and the NICU environment triggered a greater determination and effort in the fathers to attach to their infants. Similar findings were noted in a study by Mercer & Ferketich (1990). The fathers' persistent attempts to establish a relationship and attachment with their infants was described in the theme *'intimate connection.'* The fathers were grateful for the option of kangaroo care, which facilitated their achievement of this goal. It had a positive impact on their lives and their relationship with their infant. This confirms the findings of Gloppestad (1998), cited in Engler, Ludington-Hoe, Cusson *et al.* (2002) that fathers experienced feelings of closeness during kangaroo care.

The responsiveness of the infant to the father was seen as important in a study by Sullivan (1999). Fathers identified smiling and other responses by the infants as significant catalysts to their feelings of attachment. Sullivan (1999) investigated the perceptions and feelings of fathers of preterm infants, and reported that the fathers felt pleasure when they were with their infants. This was relevant considering how difficult it is to interact with a preterm infant in the hospital environment. This view is contradictory to the views of the fathers in this study, who found the environment restrictive and "controlling" as outlined in the theme *'living within'*.

The fathers interacted with infants less than the mothers did and usually took a different role in relation to the infant. Their role involved returning to work and the care of other children. The factors which underlie secure attachment to the father may, therefore, differ from the factors which relate to secure attachment to the mother.



### 4.2.2 Support

Webster's *New World Dictionary* defines support as: to carry the weight of, to hold up; to encourage, help; to advocate, uphold; to maintain (person, institution, etc.) with money or subsistence; to help prove, vindicate; to bear, endure.

Parents of infants born prematurely and admitted to the NICU require extensive care and support. In a difficult situation a parent may feel that he/she is alone, that no one really understands or can identify his/her feelings or experience. The theme *'support network'* describes to whom parents turned for assistance in order to cope with the stress of their infant's premature birth and subsequent hospitalisation. During the different phases of kangaroo care the mother moves from hospital to home and then back to the hospital. The mother's support network alters during this time and she learns to rely on 'outside' support (family and friends) while living at home and then adjusts to the 'inside' support (hospital staff and other mothers) while staying in the kangaroo care ward. A study by the New South Wales Maternity Review 1989 (cited in Sullivan 1999) also reported this finding. Perceived and actual availability of social support may also influence the parents' attempt to cope with the events of the preterm birth (Lau & Morse 2001). Participants in this study found that their support networks were of immense value. Reliance upon their support structures was one of the coping mechanisms used by all the participants in this study.

The parents' need for support intensified when they provided continuous kangaroo care. Mothers experienced isolation during the extended period of hospitalisation. Tessier *et al.* (1998) stated that kangaroo care produced negative feelings in the mothers and feelings of isolation. This was especially true for those mothers whose infants spent a longer time in hospital, when the infant could not gain sufficient weight or suckle properly, had an infectious disease, or was sick. These mothers, burdened with the sole responsibility of taking care of their infant, felt overwhelmed, and felt that they were not getting sufficient help from the hospital staff and their family. This implies that adequate social support is an integral aspect of kangaroo care.

Support is essential in the NICU and kangaroo care ward, irrespective of from whom or from where it comes. For certain of the participants their 'outside' social support networks were sufficient. For other participants whose support structures were not sufficient, the support they received from 'inside' the

hospital enabled them to cope with their preterm birth and kangaroo care experience. The need for individualised support of mothers and fathers throughout their experience of parenting a preterm infant and providing kangaroo care is evident. An awareness of gender and cultural differences in this kangaroo care experience is also important when interacting with and providing support for parents.

In a study on kangaroo care and bonding, Tessier *et al.* (1998) identified the need for more **social support** for mothers engaged in kangaroo care. Neu (1999) in her study, that explored parents' perception of kangaroo care with their preterm infant receiving assisted ventilation, found that parents needed a supportive environment. Increased social support from family and health care providers decreased levels of parenting stress and anxiety. Parents also had a more positive attitude towards the infant. The **quality** of the support received during this time, rather than the amount, is important (Whitfield 2003).

Social support has been defined as the resources one obtains from one's interpersonal ties (Cohen & Hoberman 1983). Knowledge of accessibility of support as well as actually receiving support was important for parents who were providing kangaroo care. When participants lived in the kangaroo care ward they felt confident knowing that they had continual access to medical/nursing staff in the event of an emergency.

One participant's social support network was re-established following her hospitalisation and her infant's preterm birth. Family differences were laid aside and she was reunited her with her infant's grandmother. For other participants, their existing social support networks changed. These mothers learnt to rely upon other mothers in the kangaroo care unit for encouragement as members of their own 'external support' structure were only allowed to visit during the allocated visiting hours. As the parents provided kangaroo care and moved from *'living without'* to *'living within'*, there was a significant change in their views on support. The social support within the NICU and kangaroo care environment led to a sense of security which protected them against the effects

of the crisis situation that they unexpectedly faced. The crisis for these parents was delivering a preterm infant, spending the majority of their time in the NICU, and adjusting to the 24-hour kangaroo care ward.

Social support can be subdivided into four broad categories of supportive behaviour: material/instrumental, emotional, informational and comparison/appraisal (House 1981; Cronenwett 1985), which are briefly described below.

#### 4.2.2.1 Material/Instrumental Support

Material or instrumental support comprises access to behaviours/material aid, labour or another physical aid which directly help the person in need. This is important to parents who are providing kangaroo care because of the financial constraints that are placed on the family, such as time lost from work and time/costs of transport to the NICU. The instrumental support available to most new parents comes from female relatives and friends. In the preterm birth and kangaroo care situation these relatives and friends are of little practical help in providing relief, since parents and grandparents are the only visitors allowed into the NICU and kangaroo care ward. For participants with another child at home there was an increase in the need for material support.

#### 4.2.2.2 Emotional Support

This includes the provision of empathy, caring, love, trust, talking, listening, understanding and encouraging expression of feelings. This is relevant to parents of preterm infants because of the emotional rollercoaster that they have faced, through the risk of death, feelings of loss of control and helplessness. The parents' reactions to preterm birth are expressed in a range of emotions, as described in the themes *'not his time'* and *'anxiety and barriers'*. Parents felt shock, unbelief, uncertainty and a number of fears, including fear of death, fear of being blamed and fear relating to the tiny size of the infant. Preterm labour and delivery followed by hospitalisation of the infant are documented as stress-provoking events that increase a mother's vulnerability to emotional crisis

(Kaplan & Mason 1960). The participants shared how family members withdrew during this time, which weakened their social support structure.

The greater the amount of emotional support given to the parents, the less the stress in adjusting to the preterm birth and kangaroo care experience. The more sources of emotional support the parents have in addition to each other, the smoother their transition to preterm parenthood. According to NICU parents in a study by Lindsay, Roman, De Wys, Levick & Quinn (1993), understanding can come only from another parent who has lived through a similar experience.

#### 4.2.2.3 Informational Support

This includes the provision of information, advice, and suggestions which the person can use in coping with personal and environmental problems, information about their infant's condition and other aspects of the infant's care. Explaining and interpreting information that parents receive on the visits to the NICU and from the staff regarding kangaroo care is a valuable part of informational support. Informational support for these parents included learning about their role as the parents of a preterm infant and their role in providing kangaroo care.

In the theme *'not his time'* it is described how the parents became the primary caregivers earlier then they expected. Due to the unpredictable nature of preterm birth, the delivery of their preterm infant was a completely unexpected event for all the parents. Parents therefore had no time to prepare for their role of caregiver to a preterm infant and provider of kangaroo care. Their lack of preparedness created anxiety, fear and uncertainty in the parents. The study findings corroborate Kaplan & Mason's (1960) statement that a mother's emotional response to a premature birth encompasses a "shock reaction" for which she was unprepared.

#### 4.2.2.4 Comparison/Appraisal Support

This refers to the access to or receipt of affirmation and/or social comparison. For parents it was useful to know how parents in similar situations had coped. The participants compared their preterm birth experience with their previous

'normal' full-term birth experience. They continually compared their preterm infant's progress and weight gain against that of other infants in the NICU and kangaroo care ward. The greater the number of active parent role models with whom the parents have frequent contact, for example other parents who are practicing kangaroo care in the NICU and the kangaroo care ward, the greater a new parent's sources of appraisal support.

In this study the support that the parents received was primarily from the other mothers in the NICU or living within the kangaroo care unit, hospital staff and family.

#### 4.2.2.5 Other mothers in the NICU/Kangaroo Care Ward

As described in the themes *'support network'* and *'living within'*, the spontaneous/'spur of the moment' emotional support that mothers received from other preterm mothers was valuable. They could identify with each other's sense of failure, disappointments, frustrations, joys and triumphs.. "New" parents could talk to the experienced parents in an unguarded manner. One mother's empathic understanding from another mother provided her with the reassurance that her emotional reactions in the situation were "normal". A study by Lindsay *et al.* (1993) found that experienced parents of preterm infants were an important source of information and support for new mothers. They offer a unique, credible and important resource to new parents, but do not replicate or replace professional support.

The formalisation of this kind of support has been greeted with success in NICUs in America and Canada, where parent support groups and parent-buddy support programmes exist. This consists of individual parent-to-parent support, primarily telephone support given by a parent experienced with the NICU ('a buddy') to a parent of a preterm infant in the NICU (Preyde & Ardal 2003). Support from individual trained peers was found to be effective in helping mothers to deal with the stress of a preterm birth. Mothers who did not receive support from a peer reported anxiety and depression (Preyde & Ardal 2003). In the South African context there has not been adequate establishment of

parent support systems in hospitals. In addition to general social workers, some American hospitals have a paid position for a Parent Support Coordinator for their intensive care unit, devoted totally to parent support (Preyde & Ardal 2003).

#### 4.2.2.6 Spouses/Family and Friends

The NICU in the hospital in which this study was conducted had a visiting policy that only allowed parents, grandparents and siblings to visit the preterm infant. Grandparents play an important role within a family and need to have their own fears recognised. The participants described the reluctance of the grandparents to visit their grandchild while in the NICU, as they feared hurting or becoming too attached to the infant. Jackson *et al.* (2003) described influencing factors, such as family situation and health status of the child, which can support or weaken the coping ability of the parents of preterm infants.

A common problem for parents of preterm infants is the sense of social isolation as a consequence of their infant's hospitalisation and the critical need for human support (Lindsay *et al.* 1993). The themes of *'adjustment/roles and responsibilities'* and *'living within'* highlighted the isolation that the parents felt because their family and friends lacked understanding about preterm infants and what their care involved. The mothers' environmental support structures impact her experiences and her sense of purpose. The support structures of mothers who move into the 24-hour kangaroo care ward are altered; mothers feel abandoned by their 'outside' support network and have to adjust to the support offered in the hospital environment.

#### 4.2.2.7 Staff in the Hospital

Nurses in the NICU and Kangaroo Care Ward have a vital role to play in helping parents come to terms with the reality of having an infant in the NICU, cope with any setbacks that may occur, and prepare to care for their infant after discharge. During this process the neonatal nurses facilitate interaction and attachment between parents and their preterm infants. They are the most

appropriate and accessible health care professionals to provide the sensitive support, understanding and skilful care that the parents need at this time. To fill this role nurses need to have an understanding of the attachment process that develops between parents and their infants. Nurses can enable parents to cope with the overwhelming situation of the preterm birth and hospitalisation of their infant. Providing constant support at this time enhances the parents' feelings of personal control, thereby minimising stress. In her study Grieve (1990) found that a well-functioning nurse-parent relationship greatly facilitated the mothers' coping behaviour. Nurses should not underestimate the parents' need for knowledge and support and the value of providing it.

The NICU can be a frightening place for parents. In this study they described feelings of loss of control over an event which is of critical importance to them and their lives. The life of their infant is in the hands of the staff. What role do the staff play in facilitating kangaroo care? As pointed out by Holditch-Davis & Miles (2000), the behaviour displayed by the staff can negatively or positively affect parents of preterm infants. Staff need to be aware of the physical and psychological impact of the environment on parents. The *'support network'* theme depicted the support that the parents had received from the staff as a facilitating tool in their own attachment to the infants by boosting their confidence as caregivers.

Parents rely upon the staff for encouragement, reassurance and support during kangaroo care. The term midwife means *"to be with"*. This is more than a physical presence, it is being present in a moment of crisis and need. The nurses are fulfilling their roles not only in the antenatal and labour wards but also in the nursery and kangaroo care unit. Parents appreciate and are grateful to the staff for *"walking the road with them"*. The support from staff is essential to enable the parents of preterm infants to have confidence in their own abilities as parents and primary caregivers. The health professional as a carer is second best to the mother or father, and realising that parents have been given this creative gift it, should not be suppressed.

The support from the staff was crucial to all participants, since participants had no prior knowledge of kangaroo care, and this was therefore their first encounter with the NICU and kangaroo care ward.

## 4.3 IMPLICATIONS OF THE FINDINGS FOR NURSES / NURSING PRACTICE

### 4.3.1 "The Need for Knowledge" - What Information Should be Given to Parents?

Parents are required to cope with the turmoil of delivering a preterm infant, providing kangaroo care and adjusting to life within the NICU. Although mothers had obtained information about infant care from books and from other mothers in preparation for their anticipated role, all the books that they had read or conversations that they had had, related to full-term infants. The mothers had been preparing for a role that they would never fulfil, since they delivered earlier than expected. These mothers had to deal with the unknown - preterm infant care. The parents' preparation in the antenatal period was of no use, and they had to rely on the staff to provide them with information and literature that was relevant to the preterm infant.

Parents were desperate for appropriate/relevant knowledge that could assist them in understanding the unfamiliar environment of the NICU and in caring for their infant, whom they initially felt 'belonged' to the staff. Parents, thrust into the new world of the NICU, were afraid. Parents felt inadequate to face the challenges of prematurity that lay ahead of them. After the infants' first few days post-delivery parents began to accept their situation as parents of a preterm infant and were keen to get involved in their infants' care. Fathers especially did not want to feel inadequate and were therefore eager for any available literature on kangaroo care as a means of establishing a relationship with their infant. The findings of this study revealed that parents need and seek vital information during the initial period after their infants' birth, while s/he

was being cared for in the NICU. This is how one mother described her sense of inadequacy to care for her preterm infant: *"...you don't know what to do"*.

Coping with preterm birth and kangaroo care is easier for parents who are prepared and empowered with knowledge. For parents knowledge about what is happening to their infant in the NICU and an explanation and demonstration about kangaroo care are essential. Reducing the distance parents initially feel from their preterm infant can be facilitated by explaining the use of equipment, and decreasing the geographical distance between the parent and preterm infant in the NICU (having the maternal intensive care unit/postnatal wards and NICU on the same floor). A parent who is not equipped with relevant information will struggle to become an active participant in her/his infant's care and to form an attachment.

### 4.3.2 Do Health Workers in Antenatal Settings Provide Pregnant Woman with Adequate Information Surrounding Prematurity?

Participants described a lack of information available to pregnant women and expectant fathers on kangaroo care. Only one mother had previous NICU experience, had ever been in contact with a preterm infant, and had an awareness of kangaroo care. The others had had no previous experience of premature infants or kangaroo care. The participants felt that their own lack of information stemmed from the lack of information about prematurity that was available to them in the antenatal health setting.

Another possibility is that the lack of knowledge may have stemmed from the fact that the nurses in the health care centres expressed reservation and uncertainty regarding the benefits of kangaroo care. Engler *et al.* (2002) examined practice, knowledge, barriers and perceptions of kangaroo care from the nurse's perspective. The findings suggest that nurses need the knowledge and skills required to provide kangaroo care safely and effectively. The education should emphasise the value of kangaroo care to infants and parents, since nurses reported that one of the major barriers to kangaroo care was the nurses' concern for the infants' safety.

In order to share information with pregnant women and parents, clinics and hospitals need to be equipped with relevant information regarding kangaroo care. In 2003 the World Health Organisation published a document titled ***Kangaroo mother care – a practical guideline.*** This document, prepared for health workers in settings with scarce resources, describes the kangaroo care method for the care of stable preterm/LBW infants. A copy of this document should be available to staff working in antenatal clinics, NICUs and kangaroo care wards.

### 4.3.3 What Information on Preterm Birth and Kangaroo Care is Available to the Layperson?

The general health education that is available to the layperson relates to 'normal' births and full- term infants. Rightly, the emphasis is on preparing pregnant women for normality. However, the lack of information on and preparation for prematurity may possibly increase the mother's sense of failure if she does deliver a preterm infant. The mother expecting a full-term infant has no knowledge or support structure to assist her in this unexpected time. Occasionally articles highlighting premature birth and kangaroo care may appear in a lay magazine or newspaper – is this enough to prepare parents for the crisis of delivering a preterm infant?

### 4.3.4 When Should Information be Given to Pregnant Women?

Antenatal clinics should have an allocated slot during which information is made available. This can be in the form of talks, use of multimedia presentations and posters, and should be supplemented by information pamphlets. Opportunities should be provided for questions. Topics should include the early weeks in a premature infant's life, and the day to day routine of a mother of a preterm infant. Mothers of preterm infants who have experience in providing kangaroo care and have appeared to adjust to the experience and are willing to give support could be invited to share their own personal experience and views on preterm birth and kangaroo care to women at antenatal clinics.

Pregnant women identified by health professionals as being at high risk for a preterm birth should be given educational material at their antenatal visits. They should be encouraged to take them home, read and discuss the information with their partners/spouses and come to the next clinic visit or hospital appointment with any questions. Information packs could contain basic factual information regarding preterm birth, and pictures and quotes from parents who have provided kangaroo care.

At each subsequent clinic visit the pregnant women should receive the same basic information about prematurity and kangaroo care. The provision of information and the opportunity to engage with the issues may 'demystify' the fear surrounding prematurity and equip women with knowledge before they are faced with the reality of a premature, LBW baby and the unfamiliar NICU. While many preterm births cannot be prevented, there are risks that can be minimised, e.g. smoking. Information about risky behaviour and practices should also be explained to mothers in an attempt to reduce the incidence of preterm births.

### 4.3.5 Once a Parent has Delivered a Preterm Infant, How Should Information be Delivered?

The NICU is an intimidating place. Parents should be assisted to overcome intimidation so that they can be a part of their infants' life. As highlighted in this study, parents are unprepared for a preterm birth. They lack the information and the understanding to make informed decisions about their infants' care. The intense feelings of shock that parents of preterm infants feel after the birth of their infants needs to be addressed. Assisting parents to work through their feelings and provision of moral and emotional support in addition to the infants' physical care is crucial. Parents learn from both positive and negative experiences during their preterm infants NICU and hospitalisation journey. Nurses need to be aware how to deal with the emotional issues of parents in the NICU and kangaroo care ward. An understanding of the parents' initial feelings of helplessness and finally

closeness and intimacy will enable the nurse to better support and aid the parent to work through these feelings successfully. In this study all parents re-evaluated their situation, and readjusted their expectations and measurements of success. They began to include previously "insignificant" daily accomplishments that their infants had achieved.

Early interventions and assessment of parental needs can assist parents to adjust to parenting a preterm infant and can promote the concept and earlier use of kangaroo care. In order to be most effective, information should be provided at the time when parents are most receptive to it. For this information to be useful, it needs to be based on the parent's individual needs and expectations, assessed through conversations with parents.

Parents who have delivered a preterm infant need to know about the option of kangaroo care. Information about the emotional and health benefits of kangaroo care should be made available to the staff and parents. A notice board in the corridor of the NICU giving a visual account of kangaroo care would be beneficial, as well as easy-to-read information booklets for parents. Videos, magazine and journal articles should also be available.

Education aimed at increasing the parents' feelings of competence and confidence will aid parents during their transition to parenthood. Equipping parents has a direct impact on their competency and self-efficiency in the future handling of their preterm infants. Individual support of mothers and fathers in their experience of kangaroo care and an awareness of cultural and gender differences in experience is important in the nurses' interaction with parents.

### 4.3.6 Who Should Provide/Deliver this Information?

The neonatal nurses and medical staff who provide care to preterm infants hold key positions. They are the ones with whom parents have the most contact in the NICU during the time of their infants' hospitalisation. Nurses are influential in facilitating positive outcomes for preterm infants and their parents, through the promotion of parental attachment. Nurses who understand the emotional turmoil felt by parents of premature infants have the potential to positively

influence parental adaptation to the impact of preterm delivery, and establishment and development of healthy parent-infant relationships, and attachment.

Input from a parent who has provided kangaroo care to his/her infant should be included in midwifery curricula. An understanding of the parents' experience may assist nurses to enhance the interaction between parents and their fragile preterm infants. In understanding the parents' perspective and the powerful force driving behind their provision of care, they can appreciate why parents go beyond the boundaries and expectations set by the health care teams. They should be more open to accommodate this parenting instinct in the health care of the preterm infant within the nursery.

Parents' perceptions of the nursery environment and staff are crucial to the kangaroo care they provide. The staff should strive for an environment where parents feel comfortable and accepted, where they can provide their preterm infant with kangaroo care without feeling uncomfortable and out of place. In this study the parents felt deprived as parents while their infants were cared for in the NICU. The insight into parents' lived experience of providing kangaroo care and the perceptions of barriers they faced enables nurses to foster a 'parent-friendly' atmosphere in NICUs and neonatal nurseries. Nurses should recognise that the infant they are taking care of is the child of a parent or parents in a family with a distinct set of dynamics. Parents should have as much control as possible, since the infant is part of a family.

Findings from this study show that parental attachment occurs during kangaroo care. To promote attachment, nurses have a responsibility to impart knowledge and guide parents in the techniques of kangaroo care. A clear understanding of attachment, combined with the practicalities of kangaroo care, will assist the staff in their provision of support and care to both the preterm infant and his/her parents. Grieve (1990) states that neonatal nurses can assist in the facilitation of healthy maternal-infant relationships. Nurses should

evaluate their own role in empowering parents to provide kangaroo care and form an attachment to their preterm infants.

For health care professionals who have a theoretical knowledge base about kangaroo care, the findings of this study provide them with insight into the lived experience of parents who provided kangaroo care to their preterm infants. It encompasses parents' feelings, their understanding of the NICU and the preterm birth and kangaroo care experience. A partnership between the parent and the nurse needs to be established, so that the parents' practical experience of providing 'hands-on' kangaroo care can be combined with the nurses' theoretical knowledge to facilitate the establishment of guidelines for optimum care of both the infants and the parents.

Nurses should encourage and work alongside the parents, to enable that which is innate (i.e. to develop intimacy and an attachment with their infant) to be drawn out. Nurses therefore need to relinquish the 'dictator' role and work alongside the parents to advance the use of kangaroo care. Parents should have as much control as possible, since the infant is part of their family.

The information that the public receives from trustworthy sources regarding their health practices determines how they respond, and whether or not they will put into practice the advice that is shared with them. The teaching and empowering of parents in the unfamiliar environment of the NICU has a direct impact on the competency and self-efficiency of parents in the handling of their preterm infants. Teaching is only relevant once the nurse finds out what level of knowledge and understanding the parents have and then builds knowledge on that base. Finding out exactly what parents feel, understand and experience will promote the provision of more appropriate education and support - during both the postnatal and antenatal periods - that is parent-centred.

## 4.4 LIMITATIONS OF THE STUDY

The study findings are limited by the small participant sample. In addition, the participants were members of a naturally occurring group, chosen by non-random selection from one hospital. The lack of comparative studies in a variety of settings limits the ability to generalise the findings, since nursing practices may vary from one NICU to another. Although the findings cannot be generalised across the population, they do provoke new thinking regarding the potential of kangaroo care as a tool in promoting parental involvement in the care of preterm infants in the context of the current health care environment.

All the interviews were conducted in a hospital environment and only parents with surviving infants were interviewed. The researcher did not return to her participants with the research findings as a result of a long delay between the interviews and the completion of data analysis.

Since the interviews were conducted in English, there is a risk that participants may not have been capable of adequately expressing their thoughts and feelings in the English language. On the other hand, only participants who were fluent in English were interviewed.

Two different racial groups ('coloured' and 'black') formed part of this study. In such a vastly diverse cultural society as South Africa, the ideals and beliefs of other cultural groups would have added depth and enrichment to the data. Limitations of memory may also play a role in capturing the accuracy of data.

The truth of responses is a main concern when data are obtained through interviews. Parents with preterm infants in either the NICU or the kangaroo care ward who are interviewed may have indicated that the staff and care was wonderful because they feared reprisal of staff. The researcher clearly stated that she was in no way affiliated to the NICU or the kangaroo care ward and that all interview data received would be treated as anonymous and confidential.

## 4.5 RECOMMENDATIONS FOR FURTHER RESEARCH

Further qualitative research is required to provide a deeper understanding of the experience of parents. It seems critical to explore the experience of parents and parental attachment, and how the experience/attachment might differ by situation and cultural group.

Increasing the sample size and expanding the study to a multi-centre approach would provide a richer description of the experience. Studies should be conducted at various hospitals in each province to determine the information regarding the implementation of kangaroo care and its practices in the hospitals' NICUs and neonatal nurseries.

A further study may answer the question as to what impact kangaroo care has on attachment. Researchers could interview parents a week after the delivery of their preterm infant, after their infants' discharge from the NICU/on entering the kangaroo care ward, and then 6 weeks later. A comparison of the information obtained during these various phases of the parents' experiences of the kangaroo care could be compiled.

A long-term research study may provide evidence with regard to long-term effects of kangaroo care and attachment in later childhood. Parents may be followed up and interviewed at six- monthly intervals. Parents may be asked to spend time before each interview reflecting on their experience in the form of jottings or in a mini-reflective journal.

## 4.6 CONCLUSION

In South Africa in 2001, spontaneous preterm labour was second to unexplained uterine death as the most common cause of deaths in the perinatal period (Pattinson 2001). A preterm birth is not planned nor worked towards; all the parents in this study were shocked at their infant's, birth which occurred ahead of schedule. The second that a preterm infant is born, the parents' previous expectations are shattered. The parents of preterm infants face more difficulties

in forming a relationship with and feeling attached to their infants than parents of infants born healthy and at term.

An understanding of parents' experiences as they grappled to adapt to a preterm birth and cope with the unfamiliar kangaroo care has been described in this study. There are many inexplicable factors in the way that parents adapt to the events that unfold after the birth of their preterm infant and during his/her hospitalisation in the NICU. The parents' support structures, including the staff in the hospital, can make this transition into parenthood either a struggle or a success. Acknowledgement of parents' fears, struggles and success can assist the nurses in providing family-centred care while the infant is cared for in the NICU.

The birth of a preterm infant is the impetus of kangaroo care. Although there are guidelines for the implementation of kangaroo care, there is at present no uniform approach across hospitals in the provinces of South Africa. However, the implementation of kangaroo care in hospitals and MOUs in Cape Town has increased over the past couple of years. The practice of kangaroo care has been reported in isolated cases in the media in an attempt to boost awareness of this unique form of neonatal care. Renewed interest in kangaroo care through the experiences of parents may promote awareness of this issue. Information reaching the public regarding kangaroo care is sparse, and parents' first introduction to kangaroo care was at an overwhelmingly emotional time, on their infants' admittance to the NICU. Further information and support is essential to assist parents in their transition to parenthood, and specifically parents of preterm infants.

The preterm infant is not an isolated individual but is part of a family, and the family therefore has to be considered in the course of care of the preterm infant. There is very little published in the medical literature about the experiences of parents who provide kangaroo care to their preterm infants. Nurses and midwives are not adequately informed of parents' experiences, have also controlled access to the mother and infant (e.g. through visiting rules) and may

allow personal preferences to interfere with decisions regarding infant care. The introduction of kangaroo care is changing this principle – it is dependent on the parents to be successful, it hands the infant back to the parents since they are viewed as beneficial members of the infants' health care team.

Parents have thus become more involved in the care of their preterm infants, with kangaroo care becoming a more common and 'parent-friendly' way to care for a preterm infant. The valuable experiences shared by the parents mean that parents' views, opinions and feelings have a significant place in the NICU setting, and that their voices need to be heard. Kangaroo care promotes parent-infant attachment in the hospital setting, and continues in the context of the home after the infants' discharge.

Parents have needs. They experienced fear, they felt lonely, and they lacked support. They need to know that there is hope for their infants, since they felt that they struggled to form an attachment for fear that their infant may not survive. Information plays a role in easing the parents' anxiety. The 24-hour continuous provision of kangaroo care empowers parents and improves communication. Parents gain an awareness of the infants' condition and provide relevant health information on a daily basis to the health personnel.

The study demonstrates that parental support in both the NICU and kangaroo care ward is essential and needs to be effective. It is important to recognise the parents' multifaceted need for support. Some parents needed more that that usually provided by health professionals. Parents were resourceful, they sought out support from staff, partners and other mothers where necessary. The introduction of a counsellor working exclusively in the NICU and kangaroo care ward may provide the additional support that health personnel are unable to provide due to time constraints and excessive workloads. Parent support groups and individual parent-to-parent support may be another option when considering the improvement of parental support.

Parents who participated in this study shared their joys and frustrations regarding kangaroo care. There were noticeable similarities and differences in

the ways in which mothers and fathers described the kangaroo care experience. Gender-sensitive support and information is an aspect of kangaroo care which has not previously been described.

It is evident that kangaroo care is an essential tool that enhances parental-infant attachment through the positive relationships that are formed between the parents and their preterm infant. Although kangaroo care is a structured method of providing care, it is not a rigid set of 'step by step' rules and guidelines to be followed exactly; it is an evolving means of allowing parents to regain confidence in their own abilities at a pace at which they feel comfortable. Kangaroo care is unique, it was adapted to suit the infants' health needs in addition to the parents' emotional and physical circumstances. In the unfamiliar NICU, kangaroo care offers a glimmer of hope for parents, gives them a sense of purpose, and returns the parent to the role of primary care giver, equipping them to confidently celebrate their infants' discharge.

Parents, through their involvement in their infants' care, found meaning in their lives, that have been transformed since the birth of their preterm infant. Although the parents and especially fathers in this study were totally overwhelmed by the preterm birth, once involved in kangaroo care their fears became insignificant and their confidence increased. Kangaroo care has become a lifeline for these parents, securing a strong link to their preterm infants.

*Challenge for the future*

Perinatality mortality and morbidity in South Africa is a major concern. As a developing country, the LBW rate is higher than for developed countries. The high numbers of perinatal deaths and infant mortality rates reflect the inadequacy of the current health services to meet the needs of the expanding South African population. Individual hospitals and MOUs are adopting practices to encourage women to attend antenatal sessions to enable them to monitor women through pregnancy and delivery. A broader awareness of prematurity, information and the option of providing kangaroo care is required

to prepare women for this possible eventuality. Is it pessimistic - or just honest of health care professionals to provide women with this information?

The further economic and physical strain on hospital resources caused by diseases such as HIV/AIDS have forced hospitals to employ cost-saving strategies in all departments. One cost-saving strategy was the implementation of kangaroo care, which has reduced spending on incubators and the time that preterm infants spend in hospital. In 1997 kangaroo care was adopted as routine practice for the care of LBW infants in the tertiary hospital where the study was conducted. Seven years later, a well-equipped kangaroo care ward and 'wall of preterm graduates' bears witness to the success of the practice of kangaroo care.

This study has provided insight into another aspect of kangaroo care - it presents an understanding of parents' lived experience. The emerging themes have exposed parents' joys, fears, frustrations and needs while coping with their infants' preterm birth and adjusting to giving of kangaroo care. The parents who participated in the study were unanimous in their declaration that although they had to cope with what appeared at times to be insurmountable obstacles, they enjoyed the experience. They shared how they had 'grown' from insecure intruders in the NICU to competent caregivers of tiny preterm infants. A once hands-off/distant father boasted that the once unfamiliar concept of kangaroo care was now part of his daily existence: *"kangaroo care has become so much part of me now. I am now owning this thing"*.

There is hope for future parents of preterm infants. They can relax in the knowledge that they are not alone, that other parents have been through similar experiences, and have endured. As health professionals, the challenge is to realise the valuable contribution that parents can make in the lives of their very own, very precious, preterm infants.

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# APPENDICES

## APPENDIX A: PERMISSION TO CONDUCT STUDY

# UNIVERSITY OF CAPE TOWN

**FACULTY OF HEALTH SCIENCES**
**Marilyn de Vries**
Bernard Fuller Building, Anzio Road, Observatory 7925
Telephone: 406 6340
Fax: 4478696
eMail : mdevries@curie.uct.ac.za

25 October, 2000

Ms A L Rate
P O BOX 50538
BLOUBERGSANDS
7441

Dear Ms Rate

**MSC PROPOSAL**

| | |
|---|---|
| **Candidate:** | **Rate, AL (Ms) (RTXANG001)BSc(Nurs)1998** |
| **Degree:** | **M Sc in Nursing** |
| **Title:** | **"Parents' experience of providing kangaroo care to their preterm infants"** |
| **Supervisor:** | **Mrs P Mayers, Ms B Oskowitz** |

I am pleased to advise that Professor JP van Niekerk, chairperson of the Postgraduate Programmes Committee, has approved your candidature for the above degree on behalf of the Committee. Formal approval will be obtained by publication in the next Dean's Circular (MED04/00).

If you have any further queries, please do not hesitate to contact me.

With best wishes.

Sincerely

signature removed

**MARILYN DE VRIES**
**ADMINISTRATIVE OFFICER: POSTGRADUATE**

# UNIVERSITY OF CAPE TOWN

*Research Ethics Committee*
**Faculty of Medicine**
**Anzio Road, Observatory, 7925**
**Queries : Martha Jacobs**
**Tel : (021) 406-6492 Fax: (021) 406-6390**
**E-mail : Martha@medicine.uct.ac.za**

26 November 1999

**REC REF: 278/99**

Ms A Rate
Nursing

Dear Ms Rate

**PARENTS' EXPERIENCES OF PROVIDING KANGAROO CARE WITH THEIR PRETERM INFANTS**

Thank you for your application submitted to the Research Ethics Committee on 20 September 1999.

I have pleasure in informing you that the above study has been **formally approved** by the Research Ethics Committee on 24 November 1999.

Included is a list of Research Ethics Committee Members who have formally approved your protocol.

Please quote the above Reference number in all correspondence.

Yours sincerely,

signature removed

1.12.1999

**PROFESSOR FOLB**
**CHAIR: RESEARCH ETHICS COMMITTEE**

Queries: Martha Jacobs
Research Ethics Committee
Room 212 Werner and Beit
UCT Medical School
Anzio Road, Observatory, 7925
Tel: (021) 406-6492 Fax: (021) 406-6390
E-Mail: martha@medicine.uct.ac.za

## APPENDIX B: REQUEST TO CONDUCT THE STUDY

P.O.Box 50538
Bloubergsands
Table View
7441

14 February 2000

Head of Neonatal Nursery
Maternity Unit

Dear Mrs Ryan

**Application to Conduct Research in the Neonatal Nursery and the KMC Ward.**

I, Angela Rate am a full-time Masters student from the Nursing Department at the University of Cape Town. My research is a qualitative study that aims to investigate parents' own experiences of providing kangaroo care to their preterm infants.

I am writing to request permission to interview six parents who at the time of the interview, will be providing kangaroo care to their preterm infants. Parents who either are visiting parents to the Neonatal nursery or are residents in the Kangaroo Mother Care Ward would be viable for this study.

I will interview each participant separately and the entire interview will be recorded by means of a tape recorder. The In-depth, free-attitude interview technique will be used for all the interviews, this interview technique including only one formal exploratory question and then reflecting and summarising exactly what the person has said to ensure clarity of statements.

Each parent before an interview will be given an explanation of the aim of the interview and be requested to sign a consent form acknowledging the confidentiality of the interview, their voluntary participation, and the option to terminate the interview at any time. The proposed interview time schedule will be during the months of February and March 2000.

The research aims to understand the mothers and fathers' experiences of providing kangaroo care to their preterm infant and, in addition, what prompted the parents involvement in providing this kangaroo care. Finding out what parents feel, understand and experience will promote education that is more adequate and support that is client cantered. Knowledge gained from the research will be fed back to the Neonatal Nursery and KMC ward staff.

signature removed

Please find enclosed a copy of my research proposal and a copy of the letter of consent that each parent will be required to sign. I would appreciate your reply to this letter at your earliest convenience. You may contact me at either at the telephone number listed below or at the UCT Nursing Department.

Thank you

signature removed

**Angela Rate (Miss)**

(H) 554 4871
(Cell) 0829765887

UCT Nursing Department (Tel) 406 6911
(Fax) 406 6319

signature removed

## APPENDIX C: INTRODUCTORY LETTER AND CONSENT FORM

Dear .....

(participant)

Thank you for taking the time to participate in this research study. I am aware that as a parent of a preterm infant, your time is valuable and I therefore greatly appreciate you consenting to this interview. I would ask you to carefully read this letter and then sign the consent form on the next page.

Thank you for your participation in this study.

Angela Rate

(H) 554 4871

(Cell) 0829765887

I the participant, am signing this letter to give consent to be interviewed by a Masters student from the University of Cape Town's Department of Nursing, which is a non-profit based research organisation. I will be part of a study that will focus on parents' experiences of providing skin to skin or kangaroo care to their preterm infants in either the Neonatal Nursery or Kangaroo Mother Care Ward at xxxx Hospital [name withheld] in Cape Town. This study will give some guidance to health care workers and future parents of preterm infants by providing an understanding of the experiences of other parents who were in the same situation.

I understand that I will be interviewed in a private room within the maternity block at a place and time that is convenient to me. I will be asked to share my experiences of providing kangaroo care to my preterm son/daughter, and why I am doing it. The interview will be approximately 1 hour in length.

I understand that I was selected to participate in this study because I am a parent of a preterm infant and I am currently providing kangaroo care. I am recruited into this study with other participants by Angela Rate who is the researcher of this study. The interview will be granted freely. I have been informed that the interview is entirely voluntary, and that even after the interview begins I can refuse to answer any specific questions or decide to end or postpone the interview at any point. No reports of this study will ever identify me in anyway. I have also been informed that my participation or non-participation will not affect the care or services that any member of my family or I may receive from the Neonatal Nursery.

I am aware that the results of this research may be given to me if I ask for them and that Angela Rate is the person to contact if I have any questions about the study or about my rights as a study participant.

_____ _____

Participants Signature Date

## APPENDIX D: HOSPITAL CONSENT FORM

404 —

FAX (021) 47-6048
REPLY TO: MED. SUPERINTENDENT
SKRYF AAN:

CAPE/KAAP 7925
REP. SOUTH AFRICA/SUID-AFRIKA

SECTION/
SEKSIE P.R.

REF./VERW. PR/1

DATE/
DATUM

I ..... give permission to the Medical Superintendent of Hospital to be interviewed / televised/ photographed for the purpose of publication / broadcasting / telecasting.

Date : .....

Signature of Patient/Guardian : .....

1. Witness : .....

2. Witness : .....

## APPENDIX E: EXAMPLE OF ORIGINAL FULL TRANSCRIPT – PARTICIPANT TWO

Interview with participant 2, in a room at the hospital where the study was conducted.

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**I have written the question down in case you would like to refer back to it at any time during the interview. The question is: What have you experienced while providing kangaroo care to your premature daughter, what has it been like for you...**

**That is the only question that I am going to ask so you are welcome to say whatever you felt, how you thought. So now, it is up to you...**

**Pause**

I actually enjoyed Kangaroo care... quite a lot, because it helped me to bond with my daughter. Her birth was... very traumatic for me, she was born at 24 weeks and declared dead at birth... and then an hour later I was called from the ward, or the sister came to the ward to tell me that my baby is alive and in the nursery. At first... when she was born and I was told that she was dead at birth I had a lot of mixed feelings but I did not cry, I... sought of expected that maybe she wont, umm survive because I was so early in the pregnancy. When they came and told me, afterwards that she was alive... I began sobbing, I wasn't sure if it was tears of joy or anger and frustration, and I suppose it was a release too of all of that. I went into the nursery and saw... this small baby and thought is it really my baby and... I was really not sure how to act towards her and that lasted for only a split second because then I was very excited and wanted to touch her and then I couldn't touch her because she was too small.

**Mmm**

Those first few days... that I couldn't have contact, umm physical contact with her, sort of created a barrier between the two of us, but I tried to communicate somehow with her, by talking and humming to her, but I wasn't sure if she was hearing me, and on the fourth day... I felt much more at ease than I was before, I still wanted to touch her, which I couldn't do at that stage. On the second week she got very ill, about day... 11, she got very ill, she was put on a life support system... that was also a very difficult time to... to work through, but just the fact that I could touch her and be with her helped, her father and I stayed over several nights... to be with her and we prayed through with her... and when eventually she was out of the danger zone, I was very happy. Then I actually cried the first time that the sister... took her out and put her in my hands and I could touch her. I felt so clumsy... because she was still oxygen dependent and so I had to be sure to take the oxygen mask off, and then I wasn't sure whether she is breathing or not... and then she felt cold and I just had her for about 2 minutes and I called the sister 'please put her back in', and... it was a beautiful experience for myself, in fact, for both of us, for me and the nurse that was assisting me because she was also nervous she gave me the child but she wasn't sure of whether it was okay. That was my first experience with kangaroo caring her... when I took her out and put her against my skin, it was just... a great sense of relief for the first time really I felt bonded with her, that it was my daughter. So I think that kangaroo care helps to bridge that initial... pause... gap that is between a mother and her preterm baby, (participant clears her throat) because for me having a preterm child... it's not an easy thing, because you are always told by the sisters and the doctors that maybe your child... won't make it and ... they tell you that it is a fifty/fifty chance that your child will survive... or not, so one then struggles to... actually connect with your child because you, you are torn between... becoming so attached to the child and the child dies the next day or the next minute for that matter and between not giving that child that warmth and affection for that short time that you might have with child, for the child's lifetime. With kangaroo care, starting off, it helped me to make that decision that however little or long time I have with her I want it to be the best

time of her life and... just to make her feel that I am there for her and that the rest of the family is there for her. I also agree with the whole idea of kangaroo care... even though I'm not sure exactly when it was introduced as a unit here, because my... her brother was also preterm...

**Oh**

and although I was introduced, to kangaroo care they didn't have this unit and even at that time there wasn't much encouragement of siblings coming in to see the child. But now with this one now they encourage not just the parents, but the grandparents on both sides and the siblings to visit... and that has helped us, all of us, her brother is two and a half years old and he has been coming regularly to see her, everyday to visit and... I believe that both of them have become very attached to each other, and he definitely is very attached to attached to her. Each time I left the home to come to the hospital and visit her he asked 'Mummy did you express?' (participant laughs)

**(Interviewer laughs) It sounds as if he also knows what is going on...**

Yes, he makes sure that his sister has her milk (participant laughs). Just being with her... touching her... telling her that he loves her... and that in itself gave me all the love and strength lot of hope, that this little boy, knew that he had a sister and he was excited about her and wanted her to be with him, and he had all these great plans for his sister for example... riding his bicycle and playing karate with him. And then... she had a long time in the nursery and when she eventually came over to be with me... 24 hours in the kangaroo care unit, umm I was very excited about that, I really was, they had told me long ago about that possibility... but I just didn't expect that I would be that elated to have her with me, having had the opportunity of being with her whole day every day while she was in the incubator, coming here wasn't really new, but it was... just a

richer experience. The first day... I was excited, but became a bit worried during the day as to whether I would manage to feed her 2 hourly during the night, because I love my sleep (participant laughs).

**(Interviewer laughs)**

I thought how will I manage (participant laughs), but luckily, and I suppose it is because of her age, umm... she wakes up, exactly when it is her feeding time... and she wakes me in the process, so I didn't miss one of her feeds. But the next day I could hardly open my eyes... I was so tired, I just couldn't believe how fatigued I was, and then the sister in charge... she came in, she came in to greet me and I just said 'umm' (participant laughs) and she said I can see that you are not a morning person and it wasn't that after all... I was just too fatigued. But then... the next day went much better, I made sure that I got rest in between, during the day, when she rested, I rested and then from the second day it was plain sailing as it were. I was also much more alert in the morning. I think also for myself, umm... it has helped quite a bit being here and doing kangaroo care... I was able to be helped, with my milk, umm I didn't have problems with my milk in the beginning but about the third week their was less milk, the sisters encouraged me, by then she hadn't yet started breastfeeding... but they encouraged me to keep putting her in the kangaroo care position and that really helped to stimulate the milk flow and when she eventually... breastfed I had more than enough milk, ja, so about 2 weeks later it trickled down. I ... know it was because of other stresses... we were just in the process of moving into a new house and I was all worried about that, they had given us endless problems and so I was very stressed and I know it was because of that, that the milk dried up. They gave me tablets and I was allergic, in fact... I took one and I had a very severe reaction to it.

**When you say severe reaction...**

I had... they had given me Maxolon (Metoclorpramide), to help with the milk production, Maxolon (Metoclorpramide) and... vitamin B complex. Umm, they gave it to me the afternoon at about five... and I was just about to leave... her granny came to visit on that day, while I was sitting I suddenly felt very warm, my whole body was warm and I became very agitated and fidgety and I said to her come on lets go, I just wanted to leave, I had no patience, I just wanted to leave. As we got out the door I felt this great sense of fatigue... I could barely move my legs to get to the car. that was about 10 past... we went to Pick 'n Pay down the road to do some shopping... and I said that I felt that I was getting ill, I wanted to vomit, and we are staying in Observatory, just 5 minutes drive from the hospital, when we got home, laying on the bed I felt my jaws... becoming stiff, I called the boy and told him to get his daddy, and said please take me to the hospital now... He just drove very fast, less than 3 minutes he was at the hospital, by that time my... jaws were completely dislocated. My neck was... completely stiff, in a spasm and the muscles in both shoulders were quite tight... and I could actually feel that the... oxygen flow... to my brain was being cut off. Intermittently I was then having excruciating pain in my head, my jaws and in my shoulders. Ja... I went from doctor to doctor trying to find out what it was, they thought that it may have been lock jaw, they did X-rays, when I went to casualty the doctor on call didn't know what it was, and then while the doctors were all discussing one doctor finally recognized what it was asked me what tablets I had taken. In fact I had told them that it was a reaction to the tablets and they had said that it can't be, but I insisted that it is, because I hadn't had anything umm out of the ordinary... either in my diet or what I had done or where I had gone... and only then did they look at it and they discussed it as a group what these reactions could be to those tablets and only then did they realize that it was that and they gave me an antidote which helped immediately. It was a terrifying experience... I didn't know what to do, and I was just worried about my baby... how she would react. I then informed the nursery about it, and together we decided that I won't... be giving her, as it were

contaminated milk so I expressed and threw that milk away... and just gave her milk the following day.

**Silence**

**It sounds as if you have had a lot of traumatic events happen in the short space of the three months...**

Ja... ja. All in all it has helped me tremendously being here, being able to attend to her... like I'm here now in the kangaroo care unit washing her, feeding her, give her medication... under professional supervision and I knew, I was very secure...that I knew that if anything goes wrong, even if there was no sister with us I could just walk out the door and have a sister or the doctor attend to her. And it happened... about 2 weeks ago, that she vomited quite a bit... at first I just thought that it was just that she was struggling to burp... and I suppose it was that, it was just a little vomit. But one night I got quite a fright because it was quite a lot, I had given her 20 ml of expressed breast milk... and then she vomited about 15 ml. I went immediately to the sister and they... suctioned her and she was back to normal again... so it has been great being here.

**Pause**

On the other hand... being here is also quite demanding, because... because she is not my only child. I have also to worry about my little boy, about how he is doing... and whether the two of them are coping. They came to visit everyday and gave me a run down of what was happening and of course they left out what they didn't want me to know (Participant laughs). It put me quite a bit at ease... and... but I have been here for two weeks and I had to actually go... take off two days and attend to the boy and... to attend to other things that had to be done at home. I came back, umm in the meantime they had kept her in the

nursery... and... when I went there I was hardly five minutes there and I was already quick in a hospital gown (Participant laughs) and feeding the baby. But we were all very excited about that.

**Pause**

**Earlier on you mentioned the word bond... that you were able to bond with your child, can you tell me a bit more about that...**

Mmm, Mmm, Ja, to bond with her... for me... it's more on an... on an emotional level more than a physical level.. physically definitely just having her close to me, because unlike a... term child... that you take home and wash and handle immediately, with these little ones they are in incubators, you have to wash your hands, put on... some disinfectant and then touch the baby and you can't touch the baby for too long. So there is minimal physical contact and I think... that sometimes makes you feel a bit deprived as a mother because you want to pick up your baby, you want to touch them maybe rub them out which you can't do. And... being in kangaroo mother care unit now I can do that, so in terms of the physical part of bonding I can touch her, hold her, stroke her and she is not as it were... locked away in an incubator. On an emotional level, as I said in the beginning it was really difficult for me... in the beginning because I had to ask is it really my baby because of the fact that she was declared dead at birth... when I saw her and I wanted to touch her and then I felt that I will sense whether this is my baby or not... and ja... for me that is bonding... just sensing that... this is your child, you feel at ease with the child and you would also feel your baby at ease, she would cry... she doesn't cry much but when she cries, I know as soon as I speak to her or hum a little... she will immediately quieten down, and either fall asleep or just... stare at me with beautiful big eyes. Umm, as oppose to another baby. Mothers often, like, when they have to go to the bathroom or go out of the unit... ask one another to look after their baby. And I

have from time to time looked after other mother's babies, for a very short period, and... touching the baby sometimes... it will help, the baby will keep quiet, but not for long. Even if I had to hum to the baby, which I often just do spontaneously to babies, they keep quiet for a little while and then... they just start crying... afterwards because they just have to cry, for whatever reason. Whereas with her, when I do that... she becomes calmer and... settles down and I feel that even if she were to cry it is not an anxious cry... for me it is just a little, ag ' I have to cry, it is my work as a baby ', and it doesn't agitate me, really her crying... or... moaning.

**It sounds like you are saying that there is a difference between the bonding between your baby, and someone else's...**

Someone else's baby... Ja, and I think... I am not saying that, that couldn't be established with someone else's baby, but it would need some time, it would need time for the baby to get to know you and for you to get to know the baby's rhythm.

**Silence - Baby stirs**

**It also sounds like it is a family affair, like you said, with the grandparents on both sides and your son and husband participating, how have you found that?**

Umm, I accredit it a great success of this whole kangaroo mother care idea... because the child, not only her, but many other children, stay long in hospital. For at least a week..., which is a long, time... and... for siblings... for adults too for that matter they wonder really, you tell them that they have a baby sister or brother in hospital, but especially when they are really young they can't

comprehend what that means, because the baby is... far off. Like if I could take the example of my son, he used to know that he knew that he had a sister but... but she was far off and when he spoke of his family it would be me, himself and his father and that was the end of the family. With being able to come and see her, immediately for him that changed, he started including her... in his talks and... even at night when he says his prayers, he has to squeeze in her name somehow... and pray for her... umm, even with his cousins who are his peers, he would always... tell them I have a sister.. he was always very proud or... he is... always very proud. Yesterday I laughed at him, one of the sisters was teasing him and he said ' I am gonna tell my Daddy ', the sister said but your Daddy is not here... it just took him a few seconds and then ' I'm gonna tell my sister... there she is ' (participant laughs).

**Ah**

Yes, I think that, that has helped whereas in the beginning though... the first few days were very difficult for him... because... when he used to come here with me... I used to take her out and spend time with her...he didn't like that and his face used to show that I was spending more time with her than with me... then I used to bring him either... a muffin along or fruit, that he could have... and it would help be a pacifier for some time... and as soon as he has had it, he would tell me ' Mommy put... that child... back... in the incubator ' (participant laughs).

**That child?**

That child!!!... and it has changed now... it is no longer that child... it's xxxxx.[name withheld] or it's my sister... and he is so proud now. Whereas I think that if that wasn't the case, if that inclusion of the siblings wasn't there. I would have struggled quite a bit... now after 3 months, taking her home. For him to get... to know her, to get used to her... all of a sudden, and she is already so big... Even with her father and the rest of the family... I think that, that has

helped quite a bit. The grandfathers haven't come to visit her yet... they are too nervous... she is just... too small, they can't (participant laughs)... because they always ask how she is doing... how big she is, and they get the run down. But they are constantly asking about her and the grandmothers are very happy to visit. Umm, she has opened up a new world for her little cousins at home, about this child being very far off, so they always ask about her... It is beautiful the fact that the rest of the family can come and share in this experience... because for that matter, if the child were not to... live long at least the family has had a chance to... to meet her and then... she is not just a name... or for that matter if the child hadn't yet been named, not just one of the children... but there is a face to the child. Having the family too, has given me strength as a mother, because I can immediately feel and also see the support of my immediate family circle.

**Silence**

**It sound as if you need a lot of strength at a time like this...**

Oh, definitely

**When you said to be away from your husband and son for the two weeks...**

Yes, one really needs a lot of... strength, because... especially in terms of what she has gone through, umm, being on a life support several times, getting blood transfusions, she had been given.. when... my milk dried up for a little, being given formula feeds and she reacted to it and got ill and had to be put on antibiotics, so there has been a lot that has been happening to her... and there has been several times that were critical in terms of her surviving or not surviving...and... One needs a lot of support... and I have found that in my family, immediate family, the greater family, as well as the medical and... nursing staff... and I think they have helped... tremendously, not just the fact

that, that I know that they are professional and know what they are about, but the fact that they involved me in whatever she had gone through that they had discuss with me how she is doing everyday, give me reports about how she had done during the night... if I wasn't here. If they were to... either give blood or... draw blood for some reason, they would tell me before hand, explain to me why they have to do it... and... I think the nurses and the doctors too, have really helped... they have given more of, they have given a lot of themselves... more than what is asked of them as... umm... professional staff. I found that they don't just deal with the children as a case, they put in a lot of themselves... in dealing with the children, and here I am speaking particularly of her because that is my first connection. Ja, I find they always have an ear to listen when I have a question to ask... and... even when I felt a bit down, and I have had those times, they had been optimistic most of the time, but there have been times when I felt that I can't survive this day... and... I have felt free to speak to, to either the sister or the doctor and I knew that they would give me that time to listen to me... and when at times advising me, but not always advising me... just giving me an ear... and that has helped tremendously. And everybody... the doctors, the nurses, the matron, the ladies who are cleaning here... everybody has really been... very supportive.

**Pause**

As well as the other moms. Ja, that I mustn't leave out. We had... I have lost track really of who... her peers are really, those who have been born at the same time as her... many of them have left, the children are at home already, most of them...all of them...

**All of them?**

All of them, but while the times that they were here... we were able to share our joys, our frustrations... our pain and even when we met each other along the

way... often we would meet either one coming to the nursery and the other one leaving, in the bus sometimes, coming down in the taxi, we could inquire about each others children and that... has also helped strengthen us as mothers... because... the one day you will support another mother who is feeling very low... or the child has not been umm... gaining... and the next day that would be in that position of needing... and you knew that you could count on the next mom to be there for you.

**When you said there are joys and pains and you said gaining, what did you mean...**

Weight gain

**Oh, weight gain.**

Weight gain for them is crucial...that is the only way really, that one can see whether they are... developing. Especially as a parent... the doctors might be able to see through other things, but as a parent your only measure of how your child is doing is, is the influence of weight gain.

**So you found that a big issue, the weight gain?**

Umm... yes, to some extent... yes, it was a big thing for me... I was always very elated when she had, had gained. But in the course of time and after speaking to the doctors, they explained to me that...umm... the child also... has to lose... some weight... and I would often accept it when she had lost... weight, but other times if I look at her and then look at the fact that the graph was going down... I sort of didn't feel too good about it...and I wished that her weight would just go up... so much so, that after some time, I decided that I am not going to open her

file first and look at... the graph. I will first come and look at her, see how she looks, touch her and feel her and then make my own judgment as to whether she is improving or not... before I would actually go to the file... and that helped, especially those the days that she had lost weight, and I had looked at her and she seemed fine... and I saw that the graph was showing that she was going down, or that it is just static... I was quite at ease... I thought, ag... it is just one of those things, she is having a day off. You know, I was okay. But in the beginning... it was very difficult, because I tended to first look at the graph and see whether she has gained, and by the time looked at her I could just see... that she was not well.

**It sounds as if you devised coping mechanisms, to deal with things along the way...**

Ja, and I think... one develops that... and one has... to develop that... because irrespective of how much inner strength you've got, at some point or another it gets depleted if you don't charge it... from time to time, and it's those mechanisms that, those coping skills that have help, that have charged both energy and hope of, umm the child growing.

**Silence**

**I am just so overwhelmed, when I hear that... sharing your daughter's life with me and I feel so privileged to hear that what you have gone through these past three months and I am sure that it is an amazing testimony for other moms. I can't wait to go home and actually write down what I have heard. I just want to say thank you, to have heard what you have been through and where you are now, I think that you have the strength and hope for the future. I definitely wish you all the best.**

Thank you, ... yes, for us this really is a miracle child, not just the fact that she was born very prematurely and very small... but... she is our second child that's alive but one of 7 pregnancies... so just having her... is a great gift. Both her and her brother... umm, we never thought that we be able... to have... either of them. With both of the them I had the shirodca suture, which kept till the last, but with her my waters broke... despite the fact that I had the suture and they to... to almost rupture the suture because she just wanted to come out. So for me, she is a real miracle child.

And thank you... for asking, I... am always happy to share this experience, because it is an experience that has made my life... richer and it has brought us all very close together, because we had to be... each others strength and support. I always share it with other moms... and I always say, they can take out what they want to it might help them in some way, or some aspect of it might help them and it might not help them at all, either way... For me, it is such a great experience that I want to share with others. So, thank you Angela.

As for her name, xxxxx, which means in Xhosa 'beautiful story' and the very story of her life for us is beautiful...and in Zulu it means 'beautiful flower' and really for us, she been the flower that has opened as has blossomed and just keeps on blossoming. Thank you very much.

**Thank you Angela, I wish you all the best for your research and your future.**

## APPENDIX F: PARTICIPANT TWO

### Example of Analysis: Units of general meaning – Units of relevant meaning - Categories

| **I have written the question down in case you would like to refer back to it at any time during the interview. The question is: What have you experienced while providing kangaroo care to your premature daughter, What has it been like for you.....**<br><br>**That is the only question that I am gong to ask so you are welcome to say whatever you felt, how you thought. So now it is up to you.....** | **Units of General Meaning** | Units of relevant meaning (Passive) | *Direct Quote* | *Categories* |
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| I actually enjoyed Kangaroo care... quite a lot, because it helped me to bond with my daughter. | enjoyed Kangaroo care<br>helped bonding with daughter. | P2 enjoyed kangaroo care as it helped her to bond with her daughter. | *I actually enjoyed Kangaroo care... quite a lot, because it helped me to bond with my daughter.* | Bonding – physical level |
| Her birth was... very traumatic for me, she was born at 24 weeks and declared dead at birth... and then an hour later I was called from the ward, or the sister came to the ward to tell me that my baby is alive and in the nursery. | very traumatic birth<br>born at 24 weeks and declared dead at birth<br>my baby is alive | P2's daughters birth was traumatic.<br>P2's daughter was born at 24 weeks and declared dead at birth...<br>An hour later the sister told P2 that her baby was alive and in the nursery. | *Her birth was... very traumatic for me, she was born at 24 weeks and declared dead at birth... and then an hour later I was called from the ward, or the sister came to the ward to tell me that my baby is alive and in the nursery.* | Dead at birth<br>Alive |
| At first... when she was born and I was told that she was dead at birth I had a | expected that she wont survive | P2 expected her daughter not to survive because it was so early in the | *At first... when she was born and I was told that she was dead at birth I* | Dead |

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| lot of mixed feelings but I did not cry, I... sought of expected that maybe she wont, umm survive because I was so early in the pregnancy. When they came and told me, afterwards that she was alive... I began sobbing, I wasn't sure if it was tears of joy or anger and frustration, and I suppose it was a release too of all of that. | Early in the pregnancy.<br>saw this small baby and thought is it really my baby | pregnancy.<br>When the staff told P2 that she was alive, she began sobbing, P2 wasn't sure if it was tears of joy or anger and frustration,<br>It was a release of all P2 had been through. | *had a lot of mixed feelings but I did not cry, I... sought of expected that maybe she wont, umm survive because I was so early in the pregnancy. When they came and told me, afterwards that she was alive... I began sobbing, I wasn't sure if it was tears of joy or anger and frustration, and I suppose it was a release too.* | Threat of non survival<br>Alive<br>Relief |
| I went into the nursery and saw... this small baby and thought is it really my baby and... I was really not sure how to act towards her and that lasted for only a split second because then I was very excited and wanted to touch her and then I couldn't touch her because she was too small.<br>**Mmm** | not sure how to act towards her – lasted a second<br>I was very excited<br>wanted to touch her<br>I couldn't touch her because she was too small. | P2 went into the nursery and saw a small baby and wondered if it was really her baby<br>For a split second P2 was unsure how to act towards her daughter<br>P2 was excited and wanted to touch her, but she couldn't touch her daughter because she was too small. | *I went into the nursery and saw... this small baby and thought is it really my baby.*<br>*I was really not sure how to act towards her and that lasted for only a split second because then I was very excited and wanted to touch her.*<br>*I couldn't touch her because she was too small.* | Barriers<br>Size<br>Barriers<br>Size |
| Those first few days... that I couldn't have contact, umm physical contact with her, sort of created a barrier between the two of us, but I tried to communicate somehow with her, by talking and humming to her, but I wasn't sure if she was hearing me, and on the fourth day... I felt much more at ease than I was before, I still wanted to touch her, which I couldn't do at that stage. | first few days, no physical contact created a barrier between the two of us<br>communicate with her, by talking and humming to her<br>more at ease than before<br>wanted to touch her - couldn't | P2 was not allowed physical contact with her daughter for the first few days.<br>The lack of contact created a barrier between P2 and her daughter.<br>P2 communicated by talking and humming to her daughter, but was unsure if she was hearing her.<br>On the fourth day P2 felt more at ease, she still wanted to touch her daughter, but couldn't at that stage. | *Those first few days... that I couldn't have contact, umm physical contact with her, sort of created a barrier between the two of us, but I tried to communicate somehow with her, by talking and humming to her, but I wasn't sure if she was hearing me*<br>*On the fourth day... I felt much more at ease than I was before, I still wanted to touch her, which I couldn't do at that stage.* | Barrier<br>Coping skills<br>Infant responses<br>Barrier |

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| On the second week she got very ill, about day... 11, she got very ill, she was put on a life support system... that was also a very difficult time to... to work through, but just the fact that I could touch her and be with her helped, her father and I stayed over several nights... to be with her and we prayed through with her... and when eventually she was out of the danger zone, I was very happy. | very ill, day 11,<br>life support system<br>very difficult time<br>touch her and be with her, helped,<br>stayed over several nights | On the second week, day 11 her daughter was very ill, and was put on a life support system.<br>It was a very difficult time, but the fact that P2 could touch her and be with her helped<br>P2 stayed over at the hospital several nights | *On the second week she got very ill, about day... 11, she got very ill, she was put on a life support system... that was also a very difficult time to... to work through, but just the fact that I could touch her and be with her helped, her father and I stayed over several nights... to be with her and we prayed through with her... and when eventually she was out of the danger zone, I was very happy.* | Threat of non survival<br>Feelings - Joy |
| Then I actually cried the first time that the sister... took her out and put her in my hands and I could touch her. | Cried the first time that the sister took her out and put her in my hands and I could touch her. | P2 cried the first time that the sister took her daughter out of the incubator and put her in her hands for her to touch. | *I actually cried the first time that the sister... took her out and put her in my hands and I could touch her.* | Feelings - Joy |
| I felt so clumsy... because she was still oxygen dependent and so I had to be sure to take the oxygen mask off, and then I wasn't sure whether she is breathing or not... and then she felt cold and I just had her for about 2 minutes and I called the sister 'please put her back in', and... It was a beautiful experience for myself, in fact for both of us, for me and the nurse that was assisting me because she was also nervous she gave me the child but she wasn't sure of whether it was okay. | I felt so clumsy, oxygen dependent, oxygen mask<br>Unsure whether or she was breathing or not... she felt cold<br>I just had her for about 2 minutes and I called the sister 'please put her back in',<br>a beautiful experience for myself - for both of us, | P2 felt so clumsy when she first held her daughter because she was still oxygen dependent<br>P2 wasn't sure whether her daughter was breathing and she felt cold<br>P2 held her for only 2 minutes when she called the sister and asked her to put her back in the incubator – it was still a beautiful experience'<br>The nurse that was assisting was nervous as she wasn't sure if P2 should hold her daughter.<br><br>P2's first experience with kangaroo | *I felt so clumsy... because she was still oxygen dependent and so I had to be sure to take the oxygen mask off, and then I wasn't sure whether she is breathing or not... and then she felt cold and I just had her for about 2 minutes and I called the sister 'please put her back in', and... it was a beautiful experience for myself*<br>*The nurse that was assisting me because she was also nervous she gave me the child but she wasn't sure of whether it was okay.* | Fear<br>Feelings - Joy<br>Staff |

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| That was my first experience with kangaroo caring her... when I took her out and put her against my skin, it was just... a great sense of relief for the first time really I felt bonded with her, that it was my daughter. | first experience with kangaroo care - took her out and put her against my skin - a great sense of relief<br>I felt bonded with her, that it was my daughter. | care, when she took her out and put her against her skin<br>P2 experienced a great sense of relief<br>for the first time P2 really felt bonded with her, that it was her daughter. | *That was my first experience with kangaroo caring her... when I took her out and put her against my skin'*<br>*It was just... a great sense of relief for the first time really I felt bonded with her, that it was my daughter.* | Feelings - Joy<br>Relief<br>Bonding – physical level |
| So I think that kangaroo care helps to bridge that initial... [pause]... gap that is between a mother and her preterm baby, (participant clears her throat). | kangaroo care helps to bridge initial gap between mother and her preterm baby | P2 thought that kangaroo care helped to bridge that initial gap that is between a mother and her preterm baby | *I think that kangaroo care helps to bridge that initial... [pause]... gap that is between a mother and her preterm baby* | Bonding – emotional level |
| Because for me having a preterm child... it's not an easy thing, because you are always told by the sisters and the doctors that maybe your child... won't make it and ... they tell you that it is a fifty/fifty chance that your child will survive... or not, so one then struggles to... actually connect with your child because you, you are torn between... becoming so attached to the child and the child dies the next day or the next minute for that matter and between not giving that child that warmth and affection for that short time that you might have with child, for the child's lifetime. | Having a preterm child is not easy<br>told your child may not make it<br>fifty/fifty chance that your child will survive... or not<br>struggle to connect with your child<br>torn between becoming attached and the child dies and not giving that child that warmth and affection for the child's lifetime. | P2 did not find having a preterm child easy<br>P2 was always told by the sisters and the doctors that her child may not make it.<br>P2 was told that her daughter had a fifty/fifty chance of survival<br>P2 struggled to connect with her daughter because she was torn between becoming so attached and her child dying the next day or the next minute for that matter and between not giving her child that warmth and affection for that short time that you might have her child, for the child's lifetime. | *For me having a preterm child... it's not an easy thing, because you are always told by the sisters and the doctors that maybe your child... won't make it ... they tell you that it is a fifty/fifty chance that your child will survive... or not.*<br>*So one then struggles to... actually connect with your child because you, you are torn between... becoming so attached to the child and the child dies the next day or the next minute for that matter and between not giving that child that warmth and affection for that short time that you might have with child, for the child's lifetime.* | Staff<br>Threat of non survival<br>Barriers<br>Bonding – emotional level<br>Threat of non survival |
| With kangaroo care, starting off, it helped me to make that decision that however little or long time I have with her I want it to be the best time of her | kangaroo care helped me to make that decision<br>the best time of her life and... | Kangaroo care helped P2 make the decision that however little or long time she was to have with her daughter it would be the best time of | *With kangaroo care, starting off, it helped me to make that decision that however little or long time I have* | Bonding – emotional level |

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| life and... Just to make her feel that I am there for her and that the rest of the family is there for her. | just to make her feel that I am there for her | her life<br>P2 would make her daughter feel that she and the rest of the family is there for her. | *with her I want it to be the best time of her life and... just to make her feel that I am there for her and that the rest of the family is there for her.* | Support<br>Coping skills |
| I also agree with the whole idea of kangaroo care... even though I'm not sure exactly when it was introduced as a unit here, because my... her brother was also preterm... | agree with kangaroo care... | P2 agreed with the whole idea of kangaroo care | *I also agree with the whole idea of kangaroo care...* | 24 hour kangaroo care |
| **Oh** | | | | |
| And although I was introduced to kangaroo care they didn't have this unit and even at that time there wasn't much encouragement of siblings coming in to see the child. | I was introduced to kangaroo care<br>Didn't have this unit | Although P2 had been introduced to kangaroo care they didn't have the kangaroo care unit | *Although I was introduced to kangaroo care they didn't have this unit* | 24 hour kangaroo care |
| But now with this one now they encourage not just the parents, but the grandparents on both sides and the siblings to visit... and that has helped us. | encourage all family members to visit...<br>that has helped us, all of us | With P2's daughter they encourage not just the parents, but the grandparents on both sides and the siblings to visit, that has helped P2. | *Now they encourage not just the parents, but the grandparents on both sides and the siblings to visit... and that has helped us,* | Support<br>Siblings role |
| All of us, her brother is two and a half years old and he has been coming regularly to see her, everyday to visit and... I believe that both of them have become very attached to each other, and | brother is two and a half years old –everyday to visit<br>both of them, very attached to each other, | P2's son is two and a half years old and he has been coming to see his sister everyday<br>P2 believes that they have become attached to each other | *Her brother is two and a half years old and he has been coming regularly to see her, everyday to visit*<br>*I believe that both of them have become very attached to each other, and he definitely is very attached to* | Siblings role |

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| he definitely is very attached to her.<br><br>Each time I left the home to come to the hospital and visit her he asked 'Mummy did you express?' (participant laughs)<br><br>**(Interviewer laughs) It sounds as if he also knows what is going on...**<br><br>Yes, he makes sure that his sister has her milk (participant laughs). Just being with her... touching her... telling her that he loves her... and that in itself gave me all the love and strength lot of hope, that this little boy, knew that he had a sister and he was excited about her and wanted her to be with him, and he had all these great plans for his sister for example... riding his bicycle and playing karate with him.<br><br>Then... she had a long time in the nursery and when she eventually came over to be with me... 24 hours in the kangaroo care unit, umm I was very excited about that, I really was, they had told me long ago about that possibility... but I just didn't expect that I would be that elated to have her with me, having had the opportunity of being with her | 'Mummy did you express?'<br><br>makes sure that his sister has her milk<br><br>Just being with her... touching her... telling her that he loves her... and that in itself gave me all the love and strength<br><br>he was excited about her wanted her to be with him, had all great plans for her<br><br>long time in the nursery<br><br>kangaroo care unit - excited<br><br>elated to have her with me, | Each time P2 left the home to come to the hospital and visit her he asked 'Mummy did you express?'<br><br>P2's son makes sure that his sister has her milk.<br><br>Being with her, touching her and telling her that he loves her has given P2 love and strength and a lot of hope.<br><br>P2's son knew that he had a sister and he was excited about her and wanted her to be with him, and he had all these great plans for his sister<br><br>P2's daughter spent a long time in the nursery.<br><br>When she eventually came over to spend 24 hours in the kangaroo care unit with P2 she was excited and elated to have her with her.<br><br>P2 had the opportunity of being with her whole day every day while she | *attached to her.*<br><br>*Each time I left the home to come to the hospital and visit her he asked 'Mummy did you express?'*<br><br>*He makes sure that his sister has her milk*<br><br>*Just being with her... touching her... telling her that he loves her... and that in itself gave me all the love and strength lot of hope, that this little boy, knew that he had a sister and he was excited about her and wanted her to be with him, and he had all these great plans for his sister*<br><br>*And then... she had a long time in the nursery and when she eventually came over to be with me... 24 hours in the kangaroo care unit, umm I was very excited about that, I really was, they had told me long ago about that possibility... but I just didn't expect that I would be that elated to have* | Siblings role<br><br>Feeding<br><br>Siblings role<br><br>24 hour kangaroo care / living in |

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| whole day every day while she was in the incubator, coming here wasn't really new, but it was... just a richer experience. The first day... I was excited, but became a bit worried during the day as to whether I would manage to feed her 2 hourly during the night, because I love my sleep (participant laughs). | every day while in incubator,<br>Kangaroo care wasn't new just richer experience.<br>first day... I was excited,<br>worried - manage to feed her 2 hourly during the night, | was in the incubator.<br>Coming to the kangaroo care ward wasn't really new, but it was a richer experience.<br>The first day P2 was excited, but became a bit worried during the day whether would manage to feed her 2 hourly during the night, because P2 loved her sleep . | *her with me, having had the opportunity of being with her whole day every day while she was in the incubator, coming here wasn't really new, but it was... just a richer experience.*<br>*The first day... I was excited, but became a bit worried during the day as to whether I would manage to feed her 2 hourly during the night, because I love my sleep.* | Feelings - Joy<br>Feeding<br>24 hour kangaroo care ward - demanding |
| I thought how will I manage (participant laughs), but luckily, and I suppose it is because of her age, umm... she wakes up, exactly when it is her feeding time... and she wakes me in the process, so I didn't miss one of her feeds. | how will I manage<br>she wakes up, exactly at feeding time...wakes me<br>I didn't miss one of her feeds. | P2 wondered she would manage, but luckily, because of her age, her daughter woke up exactly when it was her feeding time, and she woke P2 in the process, so P2 didn't miss one of her feeds. | *I thought how will I manage but luckily, and I suppose it is because of her age, umm... she wakes up, exactly when it is her feeding time... and she wakes me in the process, so I didn't miss one of her feeds.* | Feeding |
| But the next day I could hardly open my eyes... I was so tired, I just couldn't believe how fatigued I was, and then the sister in charge... she came in, she came in to greet me and I just said 'mmm' (participant laughs) and she said I can see that you are not a morning person and it wasn't that after all... I was just too fatigued. | I could hardly open my eyes... I was so tired, just couldn't believe how fatigued I was<br>I was just too fatigued. | The next day P2 could hardly open her eyes... she was so tired and couldn't believe how fatigued she was<br>P2 was just too fatigued. | *The next day I could hardly open my eyes... I was so tired, I just couldn't believe how fatigued I was.*<br>*I was just too fatigued.* | 24 hour kangaroo care ward - demanding |
| But then... the next day went much better, I made sure that I got rest in between, during the day, when she rested, I rested and then from the second day it was plain sailing as it were. I was also much more alert in the | I made sure that I got rest in during the day,<br>second day, plain sailing | P2 made sure that she got rest in between, during the day, when her daughter rested<br>From the second day it was plain sailing. | *The next day went much better, I made sure that I got rest in between, during the day, when she rested, I rested and then from the second day* | 24 hour kangaroo |

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| morning.<br><br>I think also for myself, umm... it has helped quite a bit being here and doing kangaroo care... I was able to be helped, with my milk, umm I didn't have problems with my milk in the beginning but about the third week their was less milk, the sisters encouraged me, by then she hadn't yet started breastfeeding... but they encouraged me to keep putting her in the kangaroo care position and that really helped to stimulate the milk flow and when she eventually... breastfed I had more than enough milk, ja, so about 2 weeks later it trickled down. I ... know it was because of other stresses... we were just in the process of moving into a new house and I was all worried about that, they had given us endless problems and so I was very stressed and I know it was because of that, that the milk dried up. They gave me tablets and I was allergic, in fact... I took one and I had a very severe reaction to it.<br><br>**When you say severe reaction...**<br><br>I had... they had given me maxolon (Metoclorpramide), to help with the milk production, maxolon (Metoclorpramide), | helped quite a bit being here and doing kangaroo care..<br><br>helped, with my milk problem.<br><br>third week their was less milk, she hadn't yet started breastfeeding...<br><br>kangaroo care position helped to stimulate the milk flow<br><br>she eventually breastfed I had more than enough milk<br><br>other stresses... moving into a new house<br><br>I was very stressed - the milk dried up.<br><br>tablets and I was allergic, had severe reaction to it. | P2 thought that she herself had benefited being at in the kangaroo care ward and doing kangaroo care. P2 was assisted with her milk.<br><br>In the beginning P2 didn't have any problems with her milk, but the third week there was less milk.<br><br>P2's daughter hadn't yet started breastfeeding but they encouraged P2 to keep her in the kangaroo care position, this helped to stimulate the milk flow.<br><br>When P2 eventually breastfed she had more than enough milk<br><br>2 weeks later it trickled down, because P2 was worried about other stresses, they were moving into a new house, which had problems.<br><br>P2 was very stressed and because of that, her milk dried up.<br><br>The staff gave P2 tablets, however she was allergic to them, as she had a very severe reaction.. | *it was plain sailing.*<br><br>*I think also for myself, umm... it has helped quite a bit being here and doing kangaroo care...*<br><br>*I was able to be helped, with my milk,*<br><br>*I didn't have problems with my milk in the beginning but about the third week their was less milk, the sisters encouraged me, by then she hadn't yet started breastfeeding... but they encouraged me to keep putting her in the kangaroo care position and that really helped to stimulate the milk flow and when she eventually... breastfed I had more than enough milk,*<br><br>*About 2 weeks later it trickled down. I ... know it was because of other stresses... we were just in the process of moving into a new house and I was all worried about that, they had given us endless problems and so I was very stressed and I know it was because of that, that the milk dried up.*<br><br>*They gave me tablets and I was allergic, in fact... I took one and I had a very severe reaction to it.* | care / living in<br><br>24 hour kangaroo care / living in<br><br>Feeding<br><br>24 hour kangaroo care ward - demanding<br><br>24 hour kangaroo care ward - demanding |

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| and... vitamin B complex. Umm, they gave it to me the afternoon at about five... and I was just about to leave... her granny came to visit on that day, while I was sitting I suddenly felt very warm, my whole body was warm and I became very agitated and fidgety and I said to her come on lets go, I just wanted to leave, I had no patience, I just wanted to leave. As we got out the door I felt this great sense of fatigue... I could barely move my legs to get to the car. that was about 10 past... we went to Pick 'n Pay down the road to do some shopping... and I said that I felt that I was getting ill, I wanted to vomit, and we are saying in Observatory, just 5 minutes drive from the hospital, when we got home, laying on the bed I felt my jaws... becoming stiff, I called the boy and told him to get his daddy, and said please take me to the hospital now... He just drove very fast, less than 3 minutes he was at the hospital, by that time my... jaws were completely dislocated. My neck was... completely stiff, in a spasm and the muscles in both shoulders were quite tight... and I could actually feel that the... oxygen flow... to my brain was being cut off. Intermittently I was then having excruciating pain in my head, my jaws and in my shoulders. Ja... I went from doctor to doctor trying to find out what it was, they thought that it may have been lock jaw, they did Xrays, when I went to casualty the doctor on call didn't know what it was, and then while the doctors were all discussing one doctor finally recognized what it was | | | | |

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| asked me what tablets I had taken. In fact I had told them that it was a reaction to the tablets and they had said that it can't be, but I insisted that it is, because I hadn't had anything umm out of the ordinary... either in my diet or what I had done or where I had gone... and only then did they look at it and they discussed it as a group what these reactions could be to those tablets and only then did they realize that it was that and they gave me an antidote which helped immediately. It was a terrifying experience... I didn't know what to do, and I was just worried about my baby... how she would react. I then informed the nursery about it, and together we decided that I won't... be giving her, as it were contaminated milk so I expressed and threw that milk away... and just gave her milk the following day.<br><br>Silence<br><br>**It sounds as if you have had a lot of traumatic events happen in the short space of the three months...**<br><br>Ja... ja. All in all it has helped me tremendously being here, being able to attend to her... like I'm here now in the kangaroo care unit washing her, feeding | terrifying experience...<br><br>worried about my baby... how she would react.<br><br>together we decided that I won't... be giving her, as it were contaminated milk so I expressed and threw that milk away... and just gave her milk the following day.<br><br>helped me being here,<br><br>able to attend to her,. | P2 described her allergic reaction as a terrifying experience, she didn't know what to and was worried about how her baby would react.<br><br>P2 informed the nursery and together they decided that she would express the milk and throw it away.<br><br>P2 only gave her daughter milk the following day.<br><br>It has helped P2 tremendously being in the kangaroo care ward, being able to attend to her daughter. | *It was a terrifying experience... I didn't know what to do, and I was just worried about my baby... how she would react.*<br><br>*I then informed the nursery about it, and together we decided that I won't... be giving her, as it were contaminated milk so I expressed and threw that milk away... and just gave her milk the following day.*<br><br>*All in all it has helped me tremendously being here, being able to attend to her... like I'm here now* | Fear<br><br>Feeding<br><br>24 hour kangaroo |

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| her, give her medication... under professional supervision and I knew, I was very secure...that I knew that if anything goes wrong, even if there was no sister with us I could just walk out the door and have a sister or the doctor attend to her. And it happened... about 2 weeks ago, that she vomited quite a bit... at first I just thought that it was just that she was struggling to burp... and I suppose it was that, it was just a little vomit. But one night I got quite a fright because it was quite a lot, I had given her 20 ml of expressed breast milk... and then she vomited about 15 ml. I went immediately to the sister and they... suctioned her and she was back to normal again... so it has been great being here.<br><br>Pause<br><br>On the other hand... being here is also quite demanding, because... because she is not my only child. I have also to worry about my little boy, about how he is doing... and whether the two of them are coping. They came to visit everyday and gave me a run down of what was happening and of course they left out what they didn't want me to know (Participant laughs). It put me quite a bit at ease... and... but I have been here for two weeks and I had to actually go... | in the kangaroo care unit washing her, feeding her, give her medication<br><br>professional supervision<br><br>secure - if anything goes wrong, walk out the door and have a sister or the doctor attend to her.<br><br>she vomited, sister suctioned her – was back to normal<br><br>been great being here.<br><br>being here is demanding<br><br>she is not my only child.<br><br>worry about my little boy, about how he is doing... whether the two of them are coping.<br><br>visit everyday, give a run down of what was happening | In the kangaroo care unit P2 washed her daughter, fed her and gave her medication under professional supervision<br><br>P2 was secure in the knowledge that if anything went wrong, even if there was no sister with them, P2 could just walk out the door and have a sister or the doctor attend to her.<br><br>One night P2 got a fright because she had given her daughter 20 ml of expressed breast milk and she vomited about 15 ml.<br><br>P2 went immediately to the sister and they suctioned her and she was back to normal again<br><br>For P2 it has been great being here.<br><br>P2 felt that staying in the kangaroo care unit was demanding<br><br>P2 was also worried about her little boy, about how he was doing and whether her partner and son were coping.<br><br>P2's partner and her son came to visit everyday and gave a run down of what was happening, leaving out what they didn't want her to know. | *in the kangaroo care unit washing her, feeding her, give her medication... under professional supervision.*<br><br>*I knew, I was very secure...that I knew that if anything goes wrong, even if there was no sister with us I could just walk out the door and have a sister or the doctor attend to her.*<br><br>*But one night I got quite a fright because it was quite a lot, I had given her 20 ml of expressed breast milk... and then she vomited about 15 ml.*<br><br>*I went immediately to the sister and they... suctioned her and she was back to normal again... so it has been great being here.*<br><br>*On the other hand... being here is also quite demanding, because... because she is not my only child.*<br><br>*I have also to worry about my little boy, about how he is doing... and whether the two of them are coping.*<br><br>*They came to visit everyday and gave me a run down of what was happening and of course they left out what they didn't want me to know. It put me quite a bit at ease...* | care / living in<br><br>Staff<br><br>Support<br><br>Staff<br><br>Support<br><br>Staff<br><br>Relief<br><br>24 hour kangaroo care ward - demanding<br><br>Coping skills |

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| take off two days and attend to the boy and... to attend to other things that had to be done at home. I came back, umm in the meantime they had kept her in the nursery... and... when I went there I was hardly five minutes there and I was already quick in a hospital gown (Participant laughs) and feeding the baby. But we were all very excited about that.<br><br>**Earlier on you mentioned the word bond, that you were able to bond with your child, can you tell me a bit more about that....**<br><br>Mmm, ja, to bond with her... for me... it's more on an... on an emotional level more than a physical level.. physically definitely just having her close to me, because unlike a... term child... that you take home and wash and handle immediately, with these little ones they are in incubators, you have to wash your hands, put on... some disinfectant and then touch the baby and you can't touch the baby for too long. So there is minimal physical contact and I think... that sometimes makes you feel a bit deprived as a mother because you want to pick up your baby, you want to touch them maybe rub them out which you can't do. And... being in kangaroo mother care unit now I can do that, so in | It put me quite a bit at ease...<br><br>I had to take off two days and attend to the boy<br><br>they had kept her in the nursery...<br><br>hardly five minutes there in a hospital gown and feeding the baby.<br><br>excited about that.<br><br>bond - emotional level more than physical level..<br><br>physically - having her close to me,<br><br>term child take home and wash and handle immediately,<br><br>these little ones they are in incubators,<br><br>you have to wash your hands, put on disinfectant and then touch the baby<br><br>can't touch the baby for too long. | The visits put P2 at ease<br><br>When P2 had spent 2 weeks in the kangaroo care unit she took 2 days off to attend to her son and other things that had to be done at home.<br><br>While P2 was at home they kept her daughter in the nursery.<br><br>P2 was only back in the kangaroo care unit five minutes when she was already in a hospital gown feeding her baby.<br><br>P2 was excited about that.<br><br>For P2 bonding with her daughter was more on an emotional level than a physical level.<br><br>Physically - just having her close,<br><br>P2's daughter was unlike a term child, her daughter was in an incubator<br><br>P2 had to wash her hands, put on... some disinfectant and then touch the baby and you can't touch the baby for too long.<br><br>There is minimal physical contact which made P2 feel deprived as a mother, because she wanted to pick up and touch her infant but she | *I have been here for two weeks and I had to actually go... take off two days and attend to the boy and... to attend to other things that had to be done at home.*<br><br>*I came back, umm in the meantime they had kept her in the nursery... and... when I went there I was hardly five minutes there and I was already quick in a hospital gown (Participant laughs) and feeding the baby. But we were all very excited about that.*<br><br>*To bond with her... for me... it's more on an... on an emotional level more than a physical level.*<br><br>*Physically definitely just having her close to me,*<br><br>*because unlike a... term child... that you take home and wash and handle immediately, with these little ones they are in incubators, you have to wash your hands, put on... some disinfectant and then touch the baby and you can't touch the baby for too long.*<br><br>*So there is minimal physical contact and I think... that sometimes makes you feel a bit deprived as a mother* | Feeding<br><br>Bonding – emotional level<br><br>Barriers<br><br>Bonding – physical level<br><br>Deprivation |

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| terms of the physical part of bonding I can touch her, hold her, stroke her and she is not as it were... locked away in an incubator. On an emotional level, as I said in the beginning it was really difficult for me... in the beginning because I had to ask is it really my baby because of the fact that she was declared dead at birth... when I saw her and I wanted to touch her and then I felt that I will sense whether this is my baby or not... and ja... for me that is bonding... just sensing that... this is your child, you feel at ease with the child and you would also feel your baby at ease, she would cry... she doesn't cry much but when she cries, I know as soon as I speak to her or hum a little... she will immediately quieten down, and either fall asleep or just... stare at me with beautiful big eyes. Umm, as oppose to another baby. Mothers often, like, when they have to go to the bathroom or go out of the unit... ask one another to look after their baby. And I have from time to time looked after other mothers babies, for a very short period, and... touching the baby sometimes... it will help, the baby will keep quiet, but not for long. Even if I had to hum to the baby, which I often just do spontaneously to babies, they keep quiet for a little while and then... they just start crying... afterwards because they just have to cry, for whatever reason. Whereas with her, when I do that... she becomes calmer and... settles down and I feel that even if she were to cry it is not an anxious cry... for me it is just a little, ag ' I have to cry, | minimal physical contact<br>feel a bit deprived as a mother - you want to pick up your baby,<br>you want to touch them maybe rub them out which you can't do.<br>kangaroo mother care unit now I can do that,<br>can touch, hold, stroke her<br>not locked away in an incubator.<br>On an emotional level,<br>beginning - difficult<br>is it really my baby - declared dead at birth<br>when I saw her and I wanted to touch her and then I<br>bonding... just sensing that... this is your child,<br>you feel at ease with the child<br>feel your baby at ease,<br>I speak to her or hum - quieten down, and falls asleep<br>with her, when I do that... she | couldn't<br>In the kangaroo mother care unit P2 can touch and pick up her infant.<br>In terms of the physical part of bonding P2 can touch her, hold her, stroke her and she is not as it were... locked away in an incubator.<br>On an emotional level, as P2 said in the beginning it was really difficult.<br>P2 questioned whether it was really her baby because of the fact that she was declared dead at birth.<br>when P2 saw her and wanted to touch her<br>P2 felt that she would sense whether it was her baby or not and this for her is bonding.<br>P2 felt at ease with her infant and could also feel her baby at ease<br>P2's daughter doesn't cry much but when she cries, P2 know as soon as she speak to her or hums a little she will immediately quieten down, and either fall asleep or just stare at P2.<br>When P2 hums her daughter becomes calmer and settles down | *because you want to pick up your baby, you want to touch them maybe rub them out which you can't do. And... being in kangaroo mother care unit now I can do that, so in terms of the physical part of bonding I can touch her, hold her, stroke her and she is not as it were... locked away in an incubator.*<br>*On an emotional level, as I said in the beginning it was really difficult for me... in the beginning because I had to ask is it really my baby because of the fact that she was declared dead at birth...*<br>*When I saw her and I wanted to touch her and then I felt that I will sense whether this is my baby or not... and ja... for me that is bonding... just sensing that... this is your child, you feel at ease with the child and you would also feel your baby at ease, she would cry... she doesn't cry much but when she cries, I know as soon as I speak to her or hum a little... she will immediately quieten down, and either fall asleep or just... stare at me with beautiful big eyes.*<br>*Whereas with her, when I do that (hum)... she becomes calmer and...* | Barriers<br>Bonding – physical level<br>Barriers<br>Deprivation<br>Dead<br>Bonding – emotional level<br>Dead<br>Bonding – emotional level<br>Infant responses<br>Infant responses<br>Infant responses |

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| it is my work as a baby ', and it doesn't agitate me, really her crying... or... moaning.<br><br>**It sounds like you are saying that there is a difference between the bonding between your baby, and someone else's...**<br><br>Someone else's baby... Ja, and I think... I am not saying that, that couldn't be established with someone else's baby, but it would need some time, it would need time for the baby to get to know you and for you to get to know the babies rhythm.<br><br>Silence - Baby stirs<br><br>**It also sounds like it is a family affair, like you said, with the grandparents on both sides and your son and husband participating, how have you found that?**<br><br>Umm, I accredit it a great success of this whole kangaroo mother care idea... because the child, not only her, but | becomes calmer and... settles down | P2 accredits the kangaroo care idea | *settles down and I feel that even if she were to cry it is not an anxious cry.*<br><br>*I accredit it a great success of this* | 24 hour kangaroo |

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| many other children, stay long in hospital. For at least a week... which is a long time... and... for siblings... for adults too for that matter they wonder really, you tell them that they have a baby sister or brother in hospital, but especially when they are really young they can't comprehend what that means, because the baby is... far off. Like if I could take the example of my son, he used to know that he knew that he had a sister but... but she was far off and when he spoke of his family it would be me, himself and his father and that was the end of the family. With being able to come and see her, immediately for him that changed, he started including her... in his talks and... even at night when he says his prayers, he has to squeeze in her name somehow... and pray for her... umm, even with his cousins who are his peers, he would always... tell them I have a sister.. he was always very proud or... he is... always very proud. Yesterday I laughed at him, one of the sisters was teasing him and he said ' I am gonna tell my Daddy ', the sister said but your Daddy is not here... it just took him a few seconds and then ' I'm gonna tell my sister... there she is ' (participant laughs).<br><br>**Ah** | great success - kangaroo mother care<br><br>being able to come and see<br>her, he started including her... tell them I have a sister..<br><br>he is/was always very proud | as a great success<br><br>P2's son knew he had a sister but she was far off and when he spoke of his family it would be P2, himself and his father and that was the end of the family.<br>Being able to come and see her, immediately for him that changed, he started including her... in his talks and... even at night when he says his prayers, he has to squeeze in her name somehow... and pray for her...<br><br>He is... always very proud. | *whole kangaroo mother care idea...*<br><br>*Like if I could take the example of my son, he used to know that he knew that he had a sister but... but she was far off and when he spoke of his family it would be me, himself and his father and that was the end of the family.*<br>*With being able to come and see her, immediately for him that changed, he started including her... in his talks and... even at night when he says his prayers, he has to squeeze in her name somehow... and pray for her... umm, even with his cousins who are his peers, he would always... tell them I have a sister.. he was always very proud or... he is... always very proud.* | care/living in<br><br>Siblings role<br><br>Siblings role |

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| Yes, I think that, that has helped whereas in the beginning though... the first few days were very difficult for him... because... when he used to come here with me... I used to take her out and spend time with her...he didn't like that and his face used to show that I was spending more time with her than with me... then I used to bring him either... a muffin along or fruit, that he could have... and it would help be a pacifier for some time... and as soon as he has had it, he would tell me ' Mommy put... that child... back... in the incubator ' (participant laughs). | first few days were very difficult for him...he used to come here with me...<br>I used to take her out and spend time with her...<br>he didn't like that I was spending more time with her than with him<br>I used to bring him a pacifier<br>'Mommy put... that child... back... in the incubator ' | P2 think that the involvement of her son has helped<br>The first few days were very difficult for him... because... when he used to come here P2 used to take her daughter out of the incubator and spend time with her...he didn't like that<br>His face used to show that P2 was spending more time with her than with P2 ... then P2 used to bring him either... a muffin along or fruit, that he could have... and it would help be a pacifier for some time... and as soon as he has had it, he would tell P2 ' Mommy put... that child... back... in the incubator ' . | *I think that, that has helped whereas in the beginning though... the first few days were very difficult for him... because... when he used to come here with me... I used to take her out and spend time with her...he didn't like that and his face used to show that I was spending more time with her than with me... then I used to bring him either... a muffin along or fruit, that he could have... and it would help be a pacifier for some time... and as soon as he has had it, he would tell me ' Mommy put... that child... back... in the incubator ' (participant laughs).* | Siblings role<br>Siblings role |
| **That child?**<br>That child!!!... and it has changed now... it is no longer that child... it's my sister... and he is so proud now. Whereas I think that if that wasn't the case, if that inclusion of the siblings wasn't there. I would have struggled quite a bit... now after 3 months, taking her home. For him to get... to know her, to get used to her... all of a sudden, and she is already so big... Even with her father and the rest of the family... I think that, that has helped quite a bit. The grandfathers haven't come to visit her yet... they are too nervous... she is just... too small, they can't (participant laughs)... but they always ask how she is doing... how big | That child!!!...<br>it has changed now it's my sister...<br>he is so proud now.<br>if that inclusion of the siblings wasn't there.<br>I would have struggled quite a bit..., taking her home.<br>I think that, that has helped | That child!!!... and it has changed now... it is no longer that child... it's my sister... and he is so proud now.<br>P2 think that her son would have reacted differently if he was not included.<br>P2 would have struggled after 3 months, taking her daughter home. For P2's son to know her, to get used to her all of a sudden, and she is already so big<br>P2 think that, that including her | *That child!!!... and it has changed now... it is no longer that child... it's M... or it's my sister... and he is so proud now. Whereas I think that if that wasn't the case, if that inclusion of the siblings wasn't there. I would have struggled quite a bit... now after 3 months, taking her home. For him to get... to know her, to get used to her... all of a sudden, and she is already so big... Even with her father and the rest of the family... I think that, that has helped quite a bit. The* | Siblings role<br>24 hour kangaroo care<br>Support |

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| she is, and they get the run down. But they are constantly asking about her and the grandmothers are very happy to visit. Umm, she has opened up a new world for her little cousins at home, about this child being very far off, so they always ask about her... It is beautiful the fact that the rest of the family can come and share in this experience... because for that matter, if the child were not to... live long at least the family has had a chance to... to meet her and then... she is not just a name... or for that matter if the child hadn't yet been named, not just one of the children... but there is a face to the child. Having the family too, has given me strength as a mother, because I can immediately feel and also see the support of my immediate family circle.<br><br>Silence<br><br>**It sound as if you need a lot of strength at a time like this...**<br><br>Oh, definitely<br><br>**When you said to be away from your husband and son for the two** | quite a bit.<br>The grandfathers are too nervous... she is just.. too small, they can't grandmothers - happy to visit.<br>rest of the family can come and share the experience<br>family has had a chance to... to meet her and then...<br>she is not just a name..... but there is a face to the child.<br>family, given me strength as a mother,<br>feel and see the support of my immediate family circle. | family has helped. The grandfathers haven't come to visit her yet they are too nervous she is just too small, they can't ... but they always ask how she is doing... how big she is, and they get the run down.<br>The grandmothers are very happy to visit.<br>P2's family shared in the experience... If the child were not to... live long at least the family has had a chance to... to meet her and then... she is not just a name... or for that matter if the child hadn't yet been named, not just one of the children... but there is a face to the child.<br>Having the family around her gave P2 strength as a mother.<br>P2 could feel and also see the support of her immediate family circle. | *grandfathers haven't come to visit her yet... they are too nervous... she is just... too small, they can't (participant laughs)... but they always ask how she is doing... how big she is, and they get the run down.*<br>*The grandmothers are very happy to visit.*<br>*It is beautiful the fact that the rest of the family can come and share in this experience... because for that matter, if the child were not to... live long at least the family has had a chance to... to meet her and then... she is not just a name... or for that matter if the child hadn't yet been named, not just one of the children... but there is a face to the child. Having the family too, has given me strength as a mother, because I can immediately feel and also see the support of my immediate family circle.* | Size<br>Support<br>Threat of non survival<br>Support |

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| **weeks...**<br><br>Yes, one really needs a lot of... strength, because... especially in terms of what she has gone through, umm, being on a life support several times, getting blood transfusions, she had been given.. when... my milk dried up for a little, being given formula feeds and she reacted to it and got ill and had to be put on antibiotics, so there has been a lot that has been happening to her... and there has been several times that were critical in terms of her surviving or not surviving...and... One needs a lot of support... and I have found that in my family, immediate family, the greater family, as well as the medical and... nursing staff... and I think they have helped... tremendously, not just the fact that, that I know that they are professional and know what they are about, but the fact that they involved me in whatever she had gone through that they had discuss with me how she is doing everyday, give me reports about how she had done during the night... if I wasn't here. If they were to... either give blood or... draw blood for some reason, they would tell me before hand, explain to me why they have to do it... and... I think the nurses and the doctors too, have really helped... they have given more of, they have given a lot of themselves... more than what is asked of them as... umm... professional staff. I | need a lot of... strength,<br><br>life support several times,<br><br>milk dried up for a little,<br><br>given formula feeds and she reacted to it and got ill<br><br>a lot has happened to her...<br><br>critical in terms of her surviving or not surviving...<br><br>One needs a lot of support...<br><br>Found support in family and medical staff<br><br>Doctors involved me in decisions<br><br>discuss how she is doing<br><br>give reports about the night... if I wasn't here.<br><br>tell me before hand, explain to me why they have to do things | P2 needed a lot of strength, especially in terms of what her daughter had gone through. She was on a life support several times, getting blood transfusions, being given formula feeds and she reacted to it and got ill and had to be put on antibiotics<br><br>There has been several times that were critical in terms of her surviving or not surviving<br><br>P2 needed a lot of support<br><br>P2 found support in her family, immediate family, the greater family, as well as the medical and nursing staff.<br><br>P2 thinks the staff have helped tremendously,<br><br>P2 knows that they are professional, but they involved P2 in all her infant went through<br><br>They discussed with P2 her condition and gave her daily reports and informed her how she had done during the night if P2 wasn't here.<br><br>If they were to do a procedure, they would tell P2 before hand and explain why they have to do it | *One really needs a lot of... strength, because... especially in terms of what she has gone through, umm, being on a life support several times, getting blood transfusions, she had been given.. when... my milk dried up*<br><br>*There has been a lot that has been happening to her... and there has been several times that were critical in terms of her surviving or not surviving.*<br><br>*One needs a lot of support... and I have found that in my family, immediate family, the greater family, as well as the medical and... nursing staff... and I think they have helped... tremendously, not just the fact that, that I know that they are professional and know what they are about, but the fact that they involved me in whatever she had gone through that they had discuss with me how she is doing everyday, give me reports about how she had done during the night... if I wasn't here. If they were to... either give blood or... draw blood for some reason, they would tell me before hand, explain to me why they have to do it... and... I* | support<br><br>Threat of non survival<br><br>Threat of non survival<br><br>Support<br><br>Staff<br><br>Staff |

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| found that they don't just deal with the children as a case, they put in a lot of themselves... in dealing with the children, and here I am speaking particularly of her because that is my first connection. Ja, I find they always have an ear to listen when I have a question to ask... and... even when I felt a bit down, and I have had those times, they had been optimistic most of the time, but there have been times when I felt that I can't survive this day... and... I have felt free to speak to, to either the sister or the doctor and I knew that they would give me that time to listen to me... and when at times advising me, but not always advising me... just giving me an ear... and that has helped tremendously. And everybody... the doctors, the nurses, the matron, the ladies who are cleaning here... everybody has really been... very supportive.<br><br>Pause<br><br>As well as the other moms. Ja, that I mustn't leave out. We had... I have lost track really of who... her peers are really, those who have been born at the same time as her... many of them have left, the children are at home already, most of them...all of them... | nurses and the doctors - really helped...<br><br>given a lot of themselves... more than what is asked of them as... professional staff.<br><br>don't just deal with the children as a case, they put in a lot of themselves...<br><br>always have an ear to listen<br><br>even when I felt a bit down,<br><br>they had been optimistic most of the time,<br><br>I felt that I can't survive this day... advise from sisters / doctors<br><br>Not always advising me...<br><br>just giving me an ear... and that has helped tremendously.<br><br>everybody, really supportive.<br><br>the other moms.<br><br>Ja, that I mustn't leave out. | The nurses and the doctors helped<br><br>They gave more of themselves, more than what was asked of them as professional staff. P2 found that they don't just deal with the children as a case, they put in a lot of themselves<br><br>P2 found that they always had an ear to listen to questions<br><br>When P2 felt a bit down, they were optimistic<br><br>been times when P2 felt that she couldn't survive the day<br><br>P2 felt free to speak to, to either the sister or the doctor and knew that they would give her that time to listen<br><br>At times they advised her and other time just gave an ear that has helped tremendously.<br><br>The doctors, the nurses, the matron, the ladies who are cleaning here... everybody has really been very supportive.<br><br>The other moms were supportive.<br><br>P2 has lost track of her daughters peers, those who were born at the same time as her as those children were at home already | *think the nurses and the doctors too, have really helped... they have given more of, they have given a lot of themselves... more than what is asked of them as... umm... professional staff. I found that they don't just deal with the children as a case, they put in a lot of themselves... in dealing with the children, and here I am speaking particularly of her because that is my first connection. Ja, I find they always have an ear to listen when I have a question to ask... and... even when I felt a bit down, and I have had those times, they had been optimistic most of the time, but there have been times when I felt that I can't survive this day... and... I have felt free to speak to, to either the sister or the doctor and I knew that they would give me that time to listen to me... and when at times advising me, but not always advising me... just giving me an ear... and that has helped tremendously. And everybody... the doctors, the nurses, the matron, the ladies who are cleaning here... everybody has really been... very supportive.*<br><br>*As well as the other moms. Ja, that I mustn't leave out. We had... I have lost track really of who... her peers are really, those who have been born at the same time as her... many of them have left, the children are at* | Staff<br><br>Staff<br><br>Staff<br><br>Support<br><br>Other moms - sharing |

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| **All of them?**<br><br>All of them, but while the times that they were here... we were able to share our joys, our frustrations... our pain and even when we met each other along the way... often we would meet either one coming to the nursery and the other one leaving, in the bus sometimes, coming down in the taxi, we could inquire about each others children and that... has also helped strengthen us as mothers... because... the one day you will support another mother who is feeling very low... or the child has not been umm... gaining... and the next day that would be in that position of needing... and you knew that you could count on the next mom to be there for you.<br><br>**When you said there are joys and pains and you said gaining, what did you mean...**<br><br>Weight gain<br><br>**Oh, weight gain.** | many have left, the children are at home already,<br><br>most of them...all of them...<br><br>... we were able to share our joys, our frustrations... our pain<br><br>we could inquire about each others children<br><br>helped strengthen us as mothers...<br><br>support another mother who is feeling very low, the next day that would be in that position of needing..<br><br>you could count on the next mom to be there for you. | The times that they were here... we were able to share our joys, our frustrations... our pain<br><br>When they met each other along the way, often met either one coming to the nursery and the other one leaving, in the bus sometimes, coming down in the taxi, we could inquire about each others children that helped strengthen us as mothers.<br><br>The one day P2 would support another mother who was feeling very low, or her child had not been gaining<br><br>The next day P2 would be in that position of needing, and she knew she could count on the next mom to be there for her. | *home already, most of them...all of them...*<br><br>*While the times that they were here... we were able to share our joys, our frustrations... our pain and even when we met each other along the way... often we would meet either one coming to the nursery and the other one leaving, in the bus sometimes, coming down in the taxi, we could inquire about each others children and that... has also helped strengthen us as mothers... because... the one day you will support another mother who is feeling very low... or the child has not been umm... gaining... and the next day that would be in that position of needing... and you knew that you could count on the next mom to be there for you.* | Other moms - sharing<br><br>Other moms - sharing<br><br>Weight – as a measure<br><br>Support |

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| Weight gain for them is crucial...that is the only way really, that one can see whether they are... developing. Especially as a parent... the doctors might be able to see through other things, but as a parent your only measure of how your child is doing is, is the influence of weight gain.<br><br>**So have you found that a big issue, the weight gain?**<br><br>Umm... yes, to some extent... yes, it was a big thing for me... I was always very elated when she had, had gained. But in the course of time and after speaking to the doctors, they explained to me that...umm... the child also... has to lose... some weight... and I would often accept it when she had lost... weight, but other times if I look at her and then look at the fact that the graph was going down... I sort of didn't feel too good about it...and I wished that her weight would just go up... so much so, that after some time, I decided that I am not going to open her file first and look at... the graph. I will first come and look at her, see how she looks, touch her and feel her and then make my own judgment as to whether she is improving or not... before I would actually go to the file... | Weight gain for them is crucial...<br><br>Only way that one can see whether they are... developing.<br><br>Especially as a parent... the doctors might be able to see through other things,<br><br>as a parent your only measure of how your child is doing is, is the influence of weight gain.<br><br>Weight, a big thing for me...<br><br>Elated when she had gained.<br><br>Accept it when she had lost... weight,<br><br>I didn't feel too good about it...<br><br>wished that her weight would just go up...<br><br>I will first come and look at | P2 described weight gain for premature infants as being crucial.<br><br>P2 said that especially for parents weight gain was the only way that they could see whether their baby was developing.<br><br>P2 said the doctors might have been able to see through other things, but as a parent her only measure of how her child was doing was the weight gain.<br><br>To some extent weight gain was a large issue for P2.<br><br>P2 was elated when her daughter had gained weight.<br><br>A certain times P2's daughter lost some weight and she often accepted it when she had lost weight<br><br>At other times P2 looked at her daughter and then looked at the graph that was going down and didn't feel good about it<br><br>P2 wished that her daughter would gain weight.<br><br>After some time, P2 decided that she | *Weight gain for them is crucial...that is the only way really, that one can see whether they are... developing. Especially as a parent... the doctors might be able to see through other things, but as a parent your only measure of how your child is doing is, is the influence of weight gain.*<br><br>*Umm... yes, to some extent... yes, it was a big thing for me... I was always very elated when she had, had gained. But in the course of time and after speaking to the doctors, they explained to me that...umm... the child also... has to lose... some weight... and I would often accept it when she had lost... weight, but other times if I look at her and then look at the fact that the graph was going down... I sort of didn't feel too good about it...and I wished that her weight would just go up... so much so, that after some time, I decided that I am not going to open her file* | Weight – as a measure<br><br>Weight – as a measure |

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| and that helped, especially those the days that she had lost weight, and I had looked at her and she seemed fine... and I saw that the graph was showing that she was going down, or that it is just static... I was quite at ease... I thought, ag... it is just one of those things, she is having a day off. You know, I was okay. But in the beginning... it was very difficult, because I tended to first look at the graph and see whether she has gained, and by the time boked at her I could just see... that she was not well. | her, see how she looks make my own judgment as to whether she is improving or not...<br><br>before I would actually go to the file... and that helped, especially those the days that she had lost weight, and I had looked at her and she seemed fine...<br><br>I was quite at ease... I thought, ag... it is just one of those things,<br><br>she is having a day off.<br><br>You know, I was okay.<br><br>in the beginning... it was very difficult, I first looked at the graph and see whether she has gained, | was first going to look at her daughter, see how she looked, touch her and feel her and then make her own judgment about whether she was improving prior to looking at the weight graph.<br><br>P2 found that it helped her, especially on the days when she had lost weight,<br><br>On the days that P2 had looked at her and she seemed fine, but the graph showed that she was loosing weight or was static, P2 was at ease and classified it as her baby having a day off, which was okay for P2<br><br>In the beginning P2 found it very difficult, because she tended to first look at the graph and see whether she has gained, and by the time looked at her P2 could just see... that she was not well. | *first and look at... the graph. I will first come and look at her, see how she looks, touch her and feel her and then make my own judgment as to whether she is improving or not... before I would actually go to the file... and that helped, especially those the days that she had lost weight, and I had looked at her and she seemed fine... and I saw that the graph was showing that she was going down, or that it is just static... I was quite at ease... I thought, ag... it is just one of those things, she is having a day off. You know, I was okay. But in the beginning... it was very difficult, because I tended to first look at the graph and see whether she has gained, and by the time looked at her I could just see... that she was not well.* | Coping skills<br><br>Coping skills<br><br>Coping skills |
| **It sounds as if you devised coping mechanisms, to deal with things along the way...**<br><br>Ja, and I think... one develops that... and one has... to develop that... because irrespective of how much inner strength you've got, at some point or another it gets depleted if you don't charge it... from time to time, and it's those mechanisms that, those coping skills that have help, that have charged both energy and hope of, umm the child growing.<br><br>Silence | inner strength gets depleted<br><br>coping skills<br><br>hope of, the child growing. | P2 said that one developed coping skills<br><br>P2 said irrespective of how much inner strength one had, at some point it becomes depleted when it is not charged.<br><br>P2 found that her coping skills helped to charge both her energy and her hope of her child growing. | *Ja, and I think... one develops that... and one has... to develop that... because irrespective of how much inner strength you've got, at some point or another it gets depleted if you don't charge it... from time to time, and it's those mechanisms that, those coping skills that have help, that have charged both energy and hope of, umm the child growing.* | Coping skills |

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| **I am just so overwhelmed, when I hear that, sharing your daughters life with me and I feel so privileged to hear that what you have gone through these past three months and I am sure that it is an amazing testimony for other moms. I can't wait to go home and actually write down what I have heard. I just want to say thank you, to have heard what you have been through and where you are now, I think that you have the strength and hope for the future. I definitely wish you all the best.** | | | | |
| Thank you, ... yes, for us this really is a miracle child, not just the fact that she was born very prematurely and very small... but... she is our second child that's alive but one of 7 pregnancies... so just having her... is a great gift. Both her and her brother... umm, we never thought that we be able... to have... either of them. With both of the I had the shirodca suture, which kept till the last, but with her my waters broke... despite the fact that I had the suture and they to... to almost rupture the suture because she just wanted to come out. So for me, she is a real miracle child. | a miracle child,<br>born very prematurely<br>very small...<br>second child that's alive but one of 7 pregnancies.<br>a great gift.<br>we never thought that we be able... to have... either of them.<br>she just wanted to come out. | P2 described her daughter as a miracle child, she was born very prematurely and very small<br>This child was P2's second child that was alive out of 7 pregnancies<br>P2 said just having her was a great gift.<br>P2 never thought that she would be able to have either of her children.<br>P2 had a shirodca suture for both children, but with her daughter her waters broke despite the fact that she had the suture | *Thank you, ... yes, for us this really is a miracle child, not just the fact that she was born very prematurely and very small...*<br>*she is our second child that's alive but one of 7 pregnancies... so just having her... is a great gift.*<br>*we never thought that we be able... to have... either of them.*<br>*but with her my waters broke... despite the fact that I had the suture and they to... to almost rupture the suture because she just wanted to come out.*<br>*So for me, she is a real miracle child.* | Miracle child<br>Size<br>Alive<br>Miracle child |

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| And thank you... for asking, I... am always happy to share this experience, because it is an experience that has made my life... richer and it has brought us all very close together, because we had to be... each others strength and support. I always share it with other moms... and I always say, they can take out what they want to it might help them in some way, or some aspect of it might help them and it might not help them at all, either way... For me, it is such a great experience that I want to share with others. So, thank you Angela.<br><br>As for her name, M, which means in Xhosa 'beautiful story' and the very story of her life for us is beautiful...and in Zulu it means 'beautiful flower' and really for us, she been the flower that has opened as has blossomed and just keeps on blossoming. Thank you very much. | she is a real miracle child.<br><br>happy to share this experience,<br><br>it has made my life richer brought us all very close together<br><br>strength and support.<br><br>I share it with other moms...<br><br>A great experience that I want to share with others.<br><br>Her name, 'beautiful story' and 'beautiful flower' | The suture had to ruptured because she wanted to come out.<br><br>P2 sees her as a real miracle child.<br><br>P2 thanked the interviewer for asking her to share.<br><br>P2 was happy to share her experience because it was an experience that has made her life richer and brought them all close, because they had to be each others strength and support.<br><br>P2 shared her story with other moms and said they could take out what they wanted to. P2 felt some aspect of it might have helped them or it might not,<br><br>For P2 it was a great experience that she wanted to share with others.<br><br>Her name in Xhosa means 'beautiful story' and in Zulu it means 'beautiful flower' | *thank you... for asking,*<br>*I... am always happy to share this experience, because it is an experience that has made my life... richer and it has brought us all very close together, because we had to be... each others strength and support. I always share it with other moms... and I always say, they can take out what they want to it might help them in some way, or some aspect of it might help them and it might not help them at all, either way... For me, it is such a great experience that I want to share with others. So, thank you Angela.*<br><br>*As for her name, M, which means in Xhosa 'beautiful story' and the very story of her life for us is beautiful...and in Zulu it means 'beautiful flower' and really for us, she been the flower that has opened as has blossomed and just keeps on blossoming.* | Other moms - share<br><br>support<br><br>Miracle child |

## APPENDIX G - EXAMPLE OF CATEGORY OF SIZE (SMALL) AND THE RESEARCHER'S REFLECTIONS ON THIS THEME DURING THE PROCESS OF ANALYSIS, INTERVIEW TWO

Size (small)

Description: The small size of the infant

**Researcher's reflections:**

As nurses we have become so accustomed to the small size of premature infants that they almost become "normal", to us and we are not shocked or taken aback when we see one. It is in a sense as if our views on the size of infants have been skewed - we see infants as the size of a premature infant and not a full-term infant. On the other hand, parents have mostly never seen a premature-sized infant and the shock and unexpected surprise at their size is often evident. Parents may have read about prematurity in a magazine, but when it is so up close and real, and directly affects them, it has much more impact. Do we as nurses see this shock, or have we forgotten what it was like when we first saw a premature infant and registered the surprise of how tiny they were? I know I wasn't prepared for how tiny they would be, how fragile and vulnerable they were.

Tiny = vulnerable, exposed, helpless, dependent, fragile (handle with care), susceptible, defenceless

The small size of the infant is one of the categories that this participant shares. She describes her infant as 'small', a diminutitive word. We know that infants are normally 2500 – 3500 grams when they are born, but this mother's infant was born much smaller, further emphasising the small size of her infant. The small size of premature infants is often overwhelming. Even though you expect a baby to be born small, these premature infants are unbelievably small.

> *"I went into the nursery and saw ... this small baby and thought is it really my baby and ... I was really not sure how to act towards her and that lasted for only a split second because then I was very excited and wanted to touch her and then I couldn't touch her because she was too small" (Participant 2).*

*"The grandfathers haven't come to visit her yet ... they are too nervous ... she is just ... too small, they can't but they always ask how she is doing ... how big she is, and they get the run down, they are constantly asking about her and the grandmothers are very happy to visit" (Participant 2).*

*"For us this really is a miracle child, not just the fact that she was born very prematurely and very small ..."(Participant 2).*

This participant was not a first-time mother, so she was aware of how small babies are – but this infant was much smaller than her previous infant was. With the infant being so small, additional care needed to be taken when handling and caring for the infant. I know that when I first saw a premature infant I was shocked at its small size, and yes, even though in pictures premature infants do look adorable, when it comes to seeing them up close or picking them up, the fear of hurting them overwhelms the feeling of how adorable they look.

## APPENDIX H: CATEGORIES AND THEMES EMERGINIG FROM THE DATA

| | Categories | Participant | Description | Central Theme |
|---|---|---|---|---|
| 1 | African culture | P1, P6 | Description of the cultural views and comparisons to kangaroo care | |
| 2 | Alive | P2, P4, P6 | The participants infant was now alive after being dead | "*Not his time*", a preterm birth |
| 3 | Anxiety - baby | P1 | The anxiety of having a baby that is born early / premature and how to care and cope with the infant. | Anxiety and barriers |
| 4 | Anxiety - home | P1, P3 | The parent is anxious to go home/to be discharged | Living without and living within |
| 5 | Backache | P3 | The backache experienced by parents during kangaroo care | Living without and living within |
| 6 | Barriers | P2, P6 | Description of the barriers that prevented touch | Anxiety and barriers |
| 7 | Birth experience "chaos" | P3, P4, P5, P6 | Description of the premature birth experience and pregnancy | "*Not his time*", a preterm birth |
| 8 | Bonding – emotional level | P2, P5 | Bonding with infant because on an emotional level, knowing this was his/her child | Intimate connection |
| 9 | Bonding – physical level | P2, P5, P6 | The bonding/physical contact that the participant felt, occurred during kangaroo care | Intimate connection |
| 10 | Bored/Frustrated | P3 | Description of the negatives of kangaroo care | Living without and living within |
| 11 | Closeness | P1, P3, P4, P5, P6 | The feeling of closeness between the participant and his/her infant, continually aware of their presence. | Intimate connection |
| 12 | Continuation of kangaroo care | P1, P6 | The continuation of kangaroo care once the infant is discharged home | Living with outside |

## APPENDIX H: CATEGORIES AND THEMES EMERGINIG FROM THE DATA

| | Categories | Participant | Description | Central Theme |
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| | | | | |
| 13 | Coping skills | P2 | Description of ways in which the parent coped with her infants prematurity and hospitalisation | Living without and living within |
| 14 | Daily Practice | P1 | The daily practice of KC, how the parent deals with his/her day to day routine and activities | Living without and living within |
| 15 | Daily Visits | P4, P6 | The daily visits while their infant was in the incubator in the neonatal nursery | Living without and living within |
| 16 | Death/dead at birth | P2, P4, P6 | The participants infant was declared dead at birth | *"Not his time"*, a preterm birth |
| 17 | Deprivation | P2 | The feeling of deprivation as a mother, minimal physical contact in first couple of weeks. | Living without and living within |
| 18 | Different | P1 | The experience of having a premature infant is unlike that of having a full term infant. | *"Not his time"*, a preterm birth |
| 19 | Discharge | P3, P4 | Description of the discharge process from hospital | Living with outside |
| 20 | Discharge criteria | P3 | The criteria that the infant and mother had to reach in order to be discharged home | Living with outside |
| 21 | Fathers Involvement/a fathers perspective | P1, P5, P6 | The father's involvement in the life and care of the premature infant | Support Network *"standing by us"* |
| 22 | Fear | P2, P5, P6 | Fear of touching and holding the preterm infant | Anxiety and barriers |
| 23 | Feeding | P1, P2, P4 | The premature infants feeding pattern and food intake, which determines his/her weight. | Measurement of success |
| 24 | Feelings – Joy | P2 | The joyous feeling shared by this participant about her kangaroo care experience | Intimate connection |
| 25 | Gratitude - staff | P4, P6 | Gratitude towards staff/hospital for care infant received and saving his/her life | Support Network *"standing by us"* |

## APPENDIX H: CATEGORIES AND THEMES EMERGINIG FROM THE DATA

| | Categories | Participant | Description | Central Theme |
|---|---|---|---|---|
| | | | | |
| 26 | Infant responses | P1, P2, P3, P5 | Description of the infants responses to kangaroo care | Intimate connection |
| 27 | Informed/not knowing | P1, P4, P5 | The information parents received about kangaroo care | Anxiety and barriers |
| 28 | Life lessons | P4 | The participant has learnt lessons from her kangaroo care experience that will be with her for life | Living with outside |
| 29 | Loneliness | P3 | Descriptions of loneliness felt during the KC experience | Living without and living within |
| 30 | Male Anatomy | P5 | The father male anatomy was different to the females. | Anxiety and barriers |
| 31 | Miracle child | P2, P4 | The description of the miracle of the child being dead and now alive. | "*Not his time*", a preterm birth |
| 32 | Mothers role - human incubator | P1 | The role the mother takes to provide the warmth to her infant | Adjustments/Roles and responsibilities |
| 33 | Natural Instinct | P1 | The natural instinct of the parent towards his/her premature infant. | Intimate connection |
| 34 | Other moms - sharing | P2, P3, P4, P6 | Interactions, support and thoughts on the other moms in the kangaroo care unit | Support Network *"standing by us"* |
| 35 | Positive | P1, P3, P6 | Description of the experience of kangaroo care as a positive one. | Living without and living within |
| 36 | Relief | P2, P5 | A sense of relief at the fact that things could have turned out differently for this premature infant | "*Not his time*", a preterm birth |
| 37 | Responsibility | P1, P4 | The responsibility that parents have towards their premature infant | Adjustments/Roles and responsibilities |
| 38 | Safety | P1, P4 | Safe against the threat of kidnapping/baby snatching | Support Network *"standing by us"* |

## APPENDIX H: CATEGORIES AND THEMES EMERGINIG FROM THE DATA

| | Categories | Participant | Description | Central Theme |
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| | | | | |
| 39 | Siblings role | P2, P6 | The inclusion of the infants' sibling in the infants care. | Adjustments/Roles and responsibilities |
| 40 | Size | P1, P2, P3, P5, P6 | The small size of the infant | Anxiety and barriers |
| 41 | Staff | P1, P2, P5 | Experiences with the staff, the staff's role, advice, support, information and assistance from the hospital staff | Support Network *"standing by us"* |
| 42 | Support | P2, P3, P4, P5, P6 | The support received during the kangaroo care experience | Support Network *"standing by us"* |
| 43 | Tiring | P3 | Description of the negatives of kangaroo care | Living without and living within |
| 44 | Threat of non-survival | P2, P6 | The threat that the infant may die (a fifty/fifty chance of survival) | Anxiety and barriers |
| 45 | Weight - as a measure | P1, P2, P3, P4, P5 | The issue of weight gains and losses in a preterm infants life, a measure for parents as to the progress of their infant | Measurement of success |
| 46 | 24 hour kangaroo care ward –demanding | P2, P3 | The demanding strain that living in the kangaroo care unit 24 hours a days for weeks places on the participant. | Living without and living within |
| 47 | 24 hour kangaroo care/Living In | P2, P4 | The description of living in the KC unit | Living without and living within |