The Communicative Opportunities Afforded Parents of Premature Infants who had Graduated from a Neonatal Intensive Care Unit (NICU)

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A Research Report presented to the Faculty of Speech Pathology and Audiology, School of Humanities and Community Development, University of the Witwatersrand, Johannesburg, South Africa, in partial fulfillment of the requirements for the Degree in M.A. Speech Pathology by Coursework.

Johannesburg, 2004
DECLARATION

I hereby declare that this research report is my own original work and that the assistance which I have received is detailed in the Acknowledgement of this report, and that I am responsible for the text of the study and the conclusions reached.

No part of this report has been submitted in the past, or is to be submitted, for a degree at any other university.

__________________      __________________
Lynzi Ann Crisp        Date
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This study endeavored to explore the opportunities afforded parents to develop optimal communication with their infants during their experience of the NICU in a private-sectored hospital. Six sets of parents participated in a semi-structured interview and completed a short questionnaire. They were interviewed one year after their infants were discharged from the NICU. The interview and questionnaire probed the three main components that are known to influence the development of optimal communication between parents and their infants in the Neonatal Intensive Care Unit (NICU): the infant’s prematurity and medical condition; the nature of the NICU; and the parents’ ability to adjust and adapt to the challenges faced during the NICU experience. The data obtained was analysed qualitatively using a constant comparative method. Six main themes emerged: preparedness; contact with the infant; bonding; information; support; and previous parenting experience. The findings reflected that the parents were afforded limited opportunities for the development of adequate infant-parent interaction. The implications of this study highlight the need for appropriate developmental and family-centred care to be implemented within NICUs in private-sector hospitals, the role of the speech-language therapist in the NICU team to be defined, and future research into the nature of the care provided within NICUs in South Africa.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>DECLARATION</td>
<td>i</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>ii</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>iii</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>iv</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>vii</td>
</tr>
<tr>
<td>LIST OF APPENDICES</td>
<td>ix</td>
</tr>
<tr>
<td>CHAPTER ONE - LITERATURE REVIEW AND RATIONALE FOR THE STUDY</td>
<td>1</td>
</tr>
<tr>
<td>CHAPTER TWO - METHODOLOGY</td>
<td>18</td>
</tr>
<tr>
<td>2.1. Aims of the study</td>
<td>18</td>
</tr>
<tr>
<td>2.1.1. Sub-Aims</td>
<td>18</td>
</tr>
<tr>
<td>2.2. Research Design</td>
<td>18</td>
</tr>
<tr>
<td>2.3. Subjects</td>
<td>20</td>
</tr>
<tr>
<td>2.3.1. Sampling method</td>
<td>20</td>
</tr>
<tr>
<td>2.3.2. Subject selection criteria</td>
<td>21</td>
</tr>
<tr>
<td>2.3.3. Description of participants</td>
<td>23</td>
</tr>
<tr>
<td>2.3.3.1. Biological risk factors of the infants</td>
<td>25</td>
</tr>
</tbody>
</table>
2.4. Procedure

2.4.1. The preparation phase

2.4.1.1. Observation within the NICU

2.4.1.2. The focus group

2.4.2. The data collection phase

2.4.2.1. The questionnaire

2.4.2.2. The interview

2.5. Pilot Study

2.6. Data Analysis

2.6.1. Analysis of the data yielded from the interview

CHAPTER THREE - RESULTS AND DISCUSSION

Section 1: The infants’ medical condition

Section 2: Themes

Theme 1: Preparedness

• Preparedness for the NICU environment

• Preparedness for their initial contact with their infants

• Preparedness for parenthood

• Preparedness for communicative development

• Preparedness for the infant’s discharge from the NICU

Theme 2: Contact with the infant

• Touching and holding the infant

• Kangaroo Mother Care (KMC)

• Feeding

• Infant-parent separation
• Time spent in the NICU
• Parental involvement in the NICU

Theme 3: Bonding

Theme 4: Information
• The prenatal phase
• The acute phase of hospitalisation
• The convalescent and post-discharge phase

Theme 5: Support
• Support received from the spouse
• Support received from family members, friends and other parents of premature infants
• Support received from the NICU staff

Theme 6: Previous parenting experience

Summary of findings

CHAPTER FOUR – CONCLUSION AND IMPLICATIONS OF THE STUDY

REFERENCES

APPENDICES
LIST OF TABLES

CHAPTER TWO
Table 2.1. Description of the Parents
Table 2.2. Description of the Infants
Table 2.3. Key words and topics comprising the interview guide

CHAPTER THREE
Table 3.1. The infants’ medical condition
Table 3.2. The themes and sub-themes that emerged from the data
Table 3.3. The parents’ degree of preparedness for the premature delivery of their infants
Table 3.4. Examples of the responses made by the parents after their infant’s birth before they were able to enter the NICU
Table 3.5. Examples of the parents’ responses to their initial contact with their infants
Table 3.6. Examples of the parents’ responses regarding their preparation for their infants’ discharge from the NICU
Table 3.7. Examples of comments made by the parents regarding inability to initially hold their infants
Table 3.8. Examples of the parents’ attitudes towards the implementation of Kangaroo Mother Care
Table 3.9. Reported feeding difficulties experienced by the infants during the NICU experience
| Table 3.10. | Examples of comments made by the parents reflecting their attitudes to their time spent in the NICU |
| Table 3.11. | Examples of the comments made by the parents regarding the encouragement that they received from the nursing staff |
| Table 3.12. | Examples of the parents’ perception of their autonomy as caregivers |
| Table 3.13. | The parents’ sense of ownership of the infant |
| Table 3.14. | The parents’ perception of their infant’s responsiveness |
| Table 3.15. | The parents’ perception of their infant’s medical condition |
| Table 3.16. | The influence of infant-parent separation in the development of bonding |
| Table 3.17. | Comments made by the mothers reflecting their bond with their infants |
| Table 3.18. | The parents’ perceptions of the degree of information provided by the NICU staff |
| Table 3.19. | The parents’ responses to the NICU experience that influenced their ability to acquire information |
| Table 3.20. | The support received by the parents from their family and friends |
**LIST OF APPENDICES**

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix A</td>
<td>Questionnaire</td>
<td>126</td>
</tr>
<tr>
<td>Appendix B</td>
<td>Cover letter and consent form for participation in the study</td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>Cover letter to the hospital manager</td>
<td>143</td>
</tr>
<tr>
<td></td>
<td>Cover letters to the paediatricians</td>
<td>144</td>
</tr>
<tr>
<td></td>
<td>Cover letter to the matron of the NICU</td>
<td>145</td>
</tr>
<tr>
<td>Appendix C</td>
<td>Research clearance certificate</td>
<td>148</td>
</tr>
</tbody>
</table>
CHAPTER ONE

INTRODUCTION

The area of neonatology and the care provided within the Neonatal Intensive Care Unit (NICU) has evolved significantly in the past 40 years with the advent of technological advances and increased medical knowledge (Wyly, 1995a:3-4; Thurman, Gottwald, Cornwell & Korteland, 1997:114-115; Siegal, Gardner & Merenstein, 1998:647; Vergara & Bigsby, 2004a:2). A philosophy of family-centered care in the NICU evolved during this time due to an increased awareness of the stress experienced by both premature infants and their families in this environment (Jacobsen & Shubat, 1991:28; Allen, 1995:171; Klaus, Kennell & Klaus, 1995:115; Siegal et al., 1998:647; Rossetti, 2001:61; Vergara & Bigsby, 2004a:2). As a result, the NICU is no longer viewed as being merely a medical environment but is rather perceived as being an integrated organism influenced by numerous inter-related components that contribute to the care of infants and their families (Avery, 1994:4 in Thurman et al., 1997:115).

According to Thurman, (1997:6), the care provided in the NICU fits within a delicate ecological system, which strives to balance the reciprocal effects that the characteristics of both the individuals and the environment have on the overall outcome of the premature infant. It is widely accepted that there are three main components that influence optimal patterns of parent-infant interaction: the infant’s medical condition, the NICU environment, and the parents’ ability to adapt and adjust to the challenges faced during the NICU experience (Gottwald & Thurman, 1990:2; Jacobsen & Shubat, 1991:28; Wyly, 1995e:150-151; Rossetti, 2001:191-192). These three factors form a dynamic and ever-changing system and contribute substantially and interdependently to the developmental outcome of the infant (Vergara & Bigsby, 2004c:37). The influence that the infants, parents and NICU environment have on the outcome of parent-infant interaction is fluid, as
each component moves through a continuum of either acting as a stressor or a stabilizer during the NICU experience.

According to Vergara & Bigsby (2004a:1), infants are born with the skills to be active participants in their own development from birth and to make sense of their environment. Rossetti (1990:52), however, states that in spite of this innate capability infants need adequate opportunities to engage in activities. Anything that interferes with these factors, according to Rossetti, places the infant at increased risk for developmental delay. In other words, the infant may be unable to effectively engage with the environment due to compromised ability and/or limited exposure to optimal opportunities. Prematurity and low birth weight are two of the most significant of the primary risk factors associated with developmental delay and socio-communicative pathology (Rossetti, 1997:13). Premature infants are placed at further biological risk for developmental delay due to the maternal complications that resulted in their premature delivery. Maternal complications associated with premature delivery include multiple gestation, maternal age, inadequate prenatal care, substance abuse, maternal illness, hypertensive diseases, antepartum haemorrhage, preterm labour and preterm prelabour rupture of membranes (Rossetti, 2001:19; Odendaal, Steyn & Odendaal, 2003:61).

The technological and medical advances within the NICU have resulted in an increased survival of infants of lower birth weights and smaller gestational ages (Wyly, 1995a:3; Als, 1997: 47; Rossetti, 2001:20; Ritchie, 2002:76). As a result, there is a greater population of infants that are at-risk for future developmental delay. ASHA, (1989:32-24), states that this increase in number is of concern as a delay in the infant’s communicative development is likely to have a significant effect on the child’s academic, social and emotional outcome. As a result, a need for Early Communicative Intervention has been highlighted in order to act as a preventative strategy through reducing the occurrence and/or the severity of conditions affecting the development of communication in infants and toddlers (Louw, 1994 in Louw, 1997:1). Thurman, at al., (1997:113), propose that the NICU is a critical
site for intervention as the earlier intervention is implemented, the more efficacious it is likely to be in the prevention or reduction of developmental delay. The nature of the NICU environment, however, may have an adverse effect on both the abilities and opportunities afforded premature infants and their families to develop infant-parent interaction.

Premature infants enter a world for which they are neurologically, physiologically and anatomically unprepared (Wyly, 1995b:15). These infants as a result are at significant risk for numerous health-related problems due to the mismatch of organ maturity and care available outside of the womb (Als, 1997:47; Robison & Gonzalez, 1999:373). The implementation of this life-saving machinery and medical intervention may result in an increased survival rate in premature infants but the care provided in the NICU remains clumsy and crude in comparison to that provided in the mother’s womb (Als, 1997:47). As a result, the chronic medical conditions faced by premature infants may be exacerbated by the care provided in the NICU.

Premature infants with lower birth weights and smaller gestational ages are the populations at greatest risk for medical complications due to the degree of immaturity of their organs and central nervous systems. Medical conditions that premature infants may present with include Respiratory Distress Syndrome, Bronchopulmonary Dysplasia, Patent Ductus Arteriosus, Apnea and Bradycardia, Intercranial Haemorrhage, Necrotizing Enterocolitis and Retinopathy of Prematurity. The advanced care received in the NICU may control the severity and prevalence of these illnesses but prolonged intensive intervention may place the infant at further risk for acquiring subsequent medical complications and developmental delay (Als, 1997:47; Rossetti, 2001:21; Vergara & Bigsby, 2004f:78). Examples of the life-saving medical interventions provided to the infant in the NICU are Continuous Positive Airway Pressure, various techniques of mechanical ventilation and Extracorporeal Membrane Oxygenation.
Gardner & Lubchenco (1998:208) state that all infants experience their birth as being a disorientating and disruptive event, as they are required to adjust from being physiologically dependent on the mother during the pregnancy to acquiring physiological independence after birth. As the infant’s ability to establish an internal biorhythmic balance is affected by the infant’s maturity at birth, premature infants may experience difficulty in acquiring stable and organised physiological states and levels of arousal (Wyly, Pfalzer & Speth, 1995:62-67; Gardner & Lubchenco, 1998:197-205; Rossetti, 2001:109-111; Vergara & Bigsby, 2004h:138-141; 145-147). The infant’s ability to optimally function and engage within the environment may thus be affected.

Gorski, Davidson & Brazelton (1979, in Rossetti, 2001:109-111) and Vergara & Bigsby (2004h:147), describe three physiological states experienced by premature infants in obtaining internal biorhythmic balance. Premature infants that are in a chronic medical condition are initially described as being in an in-turned state during which the infant directs his or her physiological energy into maintaining life support. The infant as a result has limited internal resources to engage in interaction. As the infant becomes more medically stable and has better control of its physiological systems, its innate desire to interact with the environment becomes evident. This state, known as ‘coming out’, is a transitional phase between overcoming an acute illness and actively participating within the environment. The infant may continue to experience difficulty in regulating his or her autonomic responses and physiological state and thus the infant is at-risk of reverting back into the in-turned state in the presence of overwhelming stimuli. The final state, reciprocity, represents an optimal period for the development of infant-parent interaction, as the infant is healthy and able to respond in a specific and predictable manner within the environment. These physiological states are fluid and dynamic, as they are influenced by the infant’s medical condition, physiological maturity and responses to environmental stimuli. The infant’s ability to effectively engage with the environment may thus be affected as the infant progresses or regresses through these states.
The infant’s behavioural state or level of awareness influences his or her ability to interact effectively within the environment as this impacts on the infant’s readiness to engage in interaction or participate in caregiving activities (Wyly, et al., 1995:64-65; Gardner & Lubchenco, 1998:202-203; Vergara & Bigsby, 2004h:145-147). As cyclic patterns of activity and quiet become defined after 36 weeks gestation age, premature infants frequently exhibit disorganised behavioural states (Vergara & Bigsby, 2004h:145). According to Wyly (1995e:151) the premature infant’s behavioural states may be difficult to clearly identify, as the cues provided by the infant may be weak, delayed or disorganised. The development of infant-parent interaction may be further hindered as premature infants are considered to sleep for longer periods of time and to experience difficulty in sustaining a state of alertness needed for engaging in prolonged interaction (Vergara & Bigsby, 2004h:145).

According to Rossetti (2001:194) the premature infant’s limited ability to successfully engage in the environment significantly influences the development of synchronous infant-parent communication. Their parents thus need to take the first step in facilitating interaction through adapting their behaviour to that of their infant’s physiological rhythms, and assisting their infant’s ability to maintain prolonged attention and control of their regulatory systems (Brazelton & Cramer, 1990:121). The disruption in the development of infant-parent interaction is widely acknowledged as being further influenced by the parents’ response to the premature delivery of their infant and the limited opportunities afforded them to interact with their infants whilst in the NICU (Wyly, 1995e: 153-155; Rossetti, 2001:62-63; Nyström & Axelsson, 2002:275).

All parents expect to deliver a normal, full-term infant and have expectations and dreams for the arrival of their child (Allen, 1995:180; Klaus et al., 1995:103; Gardner et al., 1998:673; Rossetti, 2001:62). They also naturally anticipate their role as a parent and the manner to which they will care for their infant. The premature delivery of an infant is often sudden and unexpected resulting in parents being potentially psychologically unprepared for the event (Allen, 1995:171; Berns & Brown, 1998:64; Gardner, Merenstein
& Costello, 1998:673; Rossetti, 2001:61). They may experience a sense of loss for their anticipated ‘perfect’ child and may need to grieve and mourn this loss (Allen, 1995:180; Klaus et al., 1995:118; Gardner, et al., 1998:673). In addition, they may need to overcome their feelings of failure at not being able to produce their ‘ideal’ infant (Rossetti, 2001:63). It is commonly found that parents of premature infants travel through dynamic emotional states in adjusting and adapting their expectations to accept the reality of the situation (Allen, 1995:183; Gardner, et al., 1998:673). These emotional states may impact on the manner in which parents perceive their infants and thus influence their desire and ability to initiate infant-parent interaction.

It is natural for mothers of newborn infants to anticipate the arrival of a robust and responsive child whom they are able to hold and engage with (Allen, 1995:180; Klaus et al., 1995:118; Rossetti, 2001:62). Premature infants, however, are medically fragile and require medical intervention in the NICU, resulting in their parents being denied the opportunity to hold their infants in an en face position after the birth. This early contact between the mother and the infant is widely acknowledged as being an important stage in the development of infant-parent interaction and bonding as the infant is traditionally alert and responsive and the mother is psychologically prepared to interact with the infant (Klaus et al., 1995:69-70; Wyly, 1995e:146; Siegal et al., 1998:647; Rossetti, 2001:51-52). This is not the case in interactions with premature infants.

Most parents anticipate that after their infant’s birth they will be able to fulfil the role of being the infant’s primary caregiver (Allen, 1995:180; Klaus et al., 1995:118; Rossetti, 2001:62). The premature delivery of an infant results in his or her parents having to relinquish this role to the NICU staff. Rossetti (2001:53) states that limited opportunities afforded parents of premature infants to care for their infants may influence the development of infant-parent interaction. He describes that during caregiving activities, parents and their infants are provided with the opportunity to become acquainted with each other’s style of interaction and establish a synchronous relationship. As infants acquire a
sense of trust in the reliability and responsiveness of their parents in meeting their needs, and the parents experience satisfaction in their ability to interpret and correctly respond to the infant’s cues (Brazelton & Cramer, 1990:121; Hess, Dohrman & Huneck, 1997:113; Rossetti, 2001:53). In this way, in traditional infant-parent interaction, the bond between infants and their parents deepens. The limited opportunities afforded parents to care for their infants during the initial stages of the NICU experience, however, may influence their willingness to engage in future caregiving activities (Berns & Brown, 1998:67; Gardner & Lubchenco, 1998:215; vandenBerg, 1999:57; Rossetti, 2001:53).

Rossetti (2001:71) provides an insightful description of the reactions of these parents regarding the limited caregiving opportunities afforded them. He states that parents may perceive themselves as being “dumb” due to poor parent-professional communication and a lack of information regarding the equipment and medical care procedures within the NICU. According to Rossetti, the parents’ willingness to provide care to their infants may be further hindered as they may feel incompetent and ignorant in comparison to the perceived competence of care provided by the NICU staff. Furthermore, Rossetti (2001:72) states that parents of premature infants may feel “dangerous” as a result of their restricted early contact with their infant and having frequently been reminded of their infant’s fragile medical condition. Parents may thus feel that they are capable of causing their infant additional harm and may consequently become wary to actively participate in caregiving routines. The third response described by Rossetti (2001:72) is that of feeling “disenfranchised” due to the need of parents to initially surrender their role of primary caregiver. He states that as a result parents of premature infants may become passive observers within the NICU as they feel that they are not involved in the care provided to their infants. These parents may experience difficulty in the transfer of caregiving roles once the infant is in a stable medical condition and prior to the infant’s discharge from the NICU.
The time spent feeding the infant in particular is viewed as being an opportune moment for infant-parent interaction (Brazelton & Cramer, 1990:52; Klaus et al., 1995:86; Rossetti, 2001:53). Winnicott (1987:61) and Klaus et al., (1995:86), emphasise that feeding the infant is not just an act of providing nutrients but rather the beginning of the relationship between the mother and the infant. This ideal model of interaction involves the mother instinctively responding to the sight, sound, smell and feel of her infant and the infant being able to observe the mother, feel her touch and listen to her interaction whilst in a secure and comforting position. Winnicott (1987:78) describes this silent dialogue between the infant and the mother as “a song without words”.

Mothers of premature infants may not initially be afforded the opportunity to engage in this valuable time of interaction and bonding due to their infants’ feeding and swallowing difficulties. The oral musculature and co-ordinated suck, swallow breathe pattern needed for effective feeding are not adequately developed in infants until approximately 36 weeks gestational age (Wall, 1996:66; Comrie & Helm, 1997:240; Arvedson & Brodsky, 2002:30). Premature infants thus initially receive nutrients through gavage feeding. The medical condition of infants further exacerbates their difficulties, as the presence of respiratory and/ or cardiological problems results in infants not having the stamina and endurance needed for effective feeding (Comrie & Helm, 1997:242; Arvedson & Brodsky, 2002:305; Wilson-Jones, Morgan & Shelton, 2002:53). Furthermore, the intensive medical treatment received by premature infants may influence their orientation to feeding due to previous experiences of painful or invasive sensation in the oral area (Comrie & Helm, 1997:242; Arvedson & Brodsky, 2002:305; Wilson-Jones, Morgan & Shelton, 2002:53). Not only are parents of premature infants initially provided with minimal opportunities to engage with their infant, they may experience later difficulty in successfully feeding their infants due to their infant’s immature anatomical and neurological systems, medical condition and negative orientation to care (vandenBerg, 1999:58).
The nature of the care provided to premature infants in the NICU may impact on their ability to develop synchronous relationships and form symbiotic attachment with their parents during caregiving activities. Touch is one of the primary means of communication for infants. Through being touched, they receive information in the manner in which they are held and handled (Siegal et al., 1998:652). Through contact, infants become familiar with the parent’s patterns of interaction and adjust their responses to the stimuli in order to engage with the parent (Brazelton & Cramer, 1990:61-62). Premature infants are exposed to numerous caregivers in the NICU who handle them in various manners. Gardner & Lubchenco (1998:213) state that multiple caregiving may confuse the infant and cause irritability as the infant receives inconsistent and disorganised sensory information. The intensive and often invasive medical care that infants receive within the NICU may further influence their orientation towards interaction, as caregiving activities may be associated with painful medical procedures and excessive handling (Rossetti, 2001:187-189).

The hospitalisation of infants within the NICU is viewed as being a traumatic time for parents. Parents are faced with the challenge of adjusting and adapting their expectations of parenthood in accordance with the reality of the situation (Siegal et al., 1998:555; Meyer & Bigsby, 2004:172). Furthermore, the parents need to maintain the everyday demands of the family unit, that may included attending work, paying accounts and collecting other children from school. According to Able-Boone, Sandall, Stevens & Fredrick (1992:94) the support that parents receive during a crisis event, such as the NICU experience, influences the emotional responses of the parents, the manner in which they perceive their infant and their ability to engage in infant-parent interaction. As a result, parents that receive adequate support are considered to be more able to meet these demands and remain available to their infant, both physically and emotionally.

Various individuals may be involved in assisting the parents to cope with the NICU experience. The support received from family members and friends is valuable as they may assist in fulfilling everyday demands or providing words of encouragement or
sympathy (Berns & Brown, 1998:67). The access that family members and friends of the parents have to the NICU influences the type of support provided as if it is limited, they may be unable to comprehend the complexities of the NICU experience and may have difficulty fully appreciating the challenges the parents face (Allen, 1995:76; 79). Parents of premature infants may receive support from other parents within the NICU, which may assist them in adapting to the challenges faced. The support received from these parents, according to Plaas (1994:34) is based on a shared experience of the NICU and may reflect a deeper understanding and level of empathy. In addition, support received from parents of premature infants that have previously graduated from the NICU may provide other parents with a sense of hope regarding their infant’s outcome. A study conducted by Lindsay, Roman, DeWys, Eager, Levick & Quinn (1993) describes the value of parent-to-parent programs in the NICU. They state that these programs offer a unique support and informational system that contributes to that provided by the NICU team and facilitates the parents’ adjustment to the NICU experience.

The staff within the NICU play a significant role in the parents’ experience of the NICU, as they are actively involved in the care of the infant and have frequent contact with the parents. The degree of staff interaction with the parents is important to consider as they can encourage the involvement of parents in caring for their infants and empower the parents by providing them with information regarding their infant’s medical condition, caregiving routines and the NICU environment (Able-Boone et al., 1992:98; Wereszczak, Miles & Holditch-Davis, 1997:37; Berns & Brown, 1998:67). In addition, the staff within the NICU have insightful knowledge of the emotional reactions of parents in coping with the NICU experience (Miles, Carlson & Funk, 1996:50, Beal & Quinn, 2002:187). The support received by the staff is of importance in the development of infant-parent interaction as the staff of the NICU can determine the role that the parents play in the NICU (Holditch-Davis & Miles, 2000:20; Ritchie, 2002:78).
According to Louw & Weber (1997:17) the professionals in the NICU, and particularly the nursing staff, are influential in the infant’s communicative development as they share the primary caregiving role with parents and have frequent opportunities to interact with the infant. Staff members are often knowledgeable in identifying and interpreting the infant’s behavioural states and are thus able to encourage parents to engage with their infants during the most opportune moments for interaction (vandenBerg, 1999:57). Siegal et al. (1998:657) state that staff members serve as role models for parents in the NICU due to their knowledge of prematurity and the NICU environment and thus their attitude towards the parents can influence the time spent by the parents with their infants and the degree of parental involvement in caregiving activities.

The NICU staff are widely acknowledged as being instrumental in defining the philosophy of care implemented within the NICU and thus influence the nature of the environment (Harrison, 1993:644; Wyly, 1995a:4; Bruns & Steeples, 2001:238; Rossetti, 2001:178; Vergara & Bigsby, 2004b:22). The NICU environment is acknowledged as being a source of stress to the premature infant and thus a philosophy of appropriate developmental care has emerged to support the infant’s unstable internal biorhythmic balance and enhance the infant’s development and overall outcome (Als & Gilkerson, 1995:2; Wyly, 1995a:7; Gardner & Lubchenco, 1998:212; Rossetti, 2001:180; Vergara & Bigsby, 2004b:24). The principles of appropriate developmental care, however, do not solely focus on the infant’s well being, as according Als (1997:57) parents of premature infants need to be involved and invested in their infant’s development and care in order for their infant to survive and thrive. As a result, appropriate developmental care within the NICU therefore strives to address the needs of both infants and their parents. Practices of appropriate developmental care include modifying the nature of the NICU environment, controlling the levels of sensory stimuli, providing the infant with individualised developmentally supportive care, encouraging parental participation in the care of their infants and promoting infant-parent interaction and bonding (Wilson, 1995:116; Als & Gilkerson, 1995:3-5; Gardner & Lubchenco, 1998:212; Rossetti, 2001:181; Vergara & Bigsby, 2004b:24).
The implementation of appropriate developmental care in the NICU is supported by the principles of family-centred care as both strive towards an optimal outcome for the premature infant. Family-centred care, however, differs as it endeavors to empower parents through providing information, establishing, adequate support networks and forging parent-professional alliances that support the parents’ participation and preparation for ongoing care of their infant (Stonestreet, Johnston & Acton, 1991:42-45; Harrison, 1993:644; Bruns & Steeples, 2001:238-239). In addition, Johnson, (1995:11) states that family-centered care in the NICU focuses on promoting practices that nurture the bonds that develop between infants and their families before birth and support these attachments throughout the intensive care experience.

A team of specialists from varied disciplines has been called for to address the specific needs of infants and their families within the NICU. The role of the speech-language therapist within the NICU has evolved during the past 20 years due to the increased survival rate of premature infants and their associated risk for developmental delay (Dunn, van Kleek & Rossetti, 1993:52). Speech-language therapists are required to fulfil the multifaceted role of addressing the communicative, feeding and swallowing difficulties prevalent in premature infants and in acting as both consultant and educator to the parents and NICU staff (Billeaud, 1993:47).

In 1993, Dunn, Van Kleek, & Rossetti stated that the development of the role of the speech-language therapist within North American NICUs was in its infancy stage. They reported that few professionals of this nature were involved in providing service within the NICU in the USA. Furthermore, they emphasised the necessity for speech-language therapists to receive additional training in order to effectively address the diverse needs of premature infants, their families, and the NICU staff. This assertion was not surprising due to the limited training that therapists receive at an undergraduate level and, according to vandenBerg (1993:52), speech-language therapists thus need to obtain an additional base of primary and specialised knowledge relating to care within the NICU. The American
Speech-Language-Hearing Association (ASHA, 2003:2) has acknowledged vandenBerg’s (1993) findings and are in the process of constructing a policy statement. This document strives to address the needs of speech-language therapists working in NICUs through defining the role of the speech-language therapist within this environment and by providing an outline of the necessary skills and knowledge that are required in order to provide effective intervention.

Neonatal intervention services provided within developing countries such as South Africa, are in the initial stages of being implemented and are less developed in comparison to developed countries such as the USA (Kritzinger, Louw & Hugo, 1995:7). There has been a shift in the emphasis of health care in South Africa towards the provision of services that focus on prevention and primary health care. According to Louw (1997:1) there is a need for Early Communicative Intervention in South Africa. She constructed a guideline for the South African Speech-Language-Hearing Association (SASLHA) (Louw, 1997) delineating the role of speech-language therapists and audiologists and the skills needed to provide suitable intervention. As a result, speech-language therapists and audiologists have become increasingly aware of the necessity to implement practices that strive to prevent or reduce factors contributing towards communication disorders by providing earlier intervention. Early Communicative Intervention in South Africa, however, is still in the process of being established and developed.

Speech-language therapists and audiologists in South Africa have acknowledged the need for earlier intervention and as a result have become integral members of multidisciplinary teams in the NICU. A limited percentage of therapists, however, are involved in providing intervention within NICUs. Haasbroek (1999) indicated that only 19 speech-language therapists and audiologists were actively involved within NICUs at the time of her study. This figure may be somewhat higher at present due to increased awareness of the necessity for intervention within the NICU since her study was conducted. The role of speech-language therapists working within NICUs in South Africa was explored in a study by
deBeer (2003). She concluded that their role needs to be further developed and defined. deBeer’s study yielded similar results to those noted in Dunn et al.’s, (1993) American study, as she emphasised the need for speech-language therapists to receive adequate knowledge and training in order for practices of Early Communicative Intervention within the NICU to be successfully implemented.

There is a large variation in the resources available to provide health care to the South African population. Cooper (1999:1160) described three broad categories of care available to premature infants in South Africa. According to Cooper, infants born in private sector hospitals usually have access to all levels of neonatal care regardless of their birth weight. Infants born in public sector institutions are afforded access to all levels of care in hospitals where intensive care facilities exist. The limited financial and physical resources available for health care in these hospitals, however, has resulted in “rationing” of treatment provided to infants weighing less than 1000 g or being of a gestational age of less than 28 weeks. The third category described by Cooper includes the care provided to premature infants in areas in that there are limited or no intensive care facilities.

According to Pattinson, (2003b:445), South Africa has the ingredients for decreasing the mortality of premature infants as the necessary scientific knowledge is available, the teaching systems are in place, and a health care system exists in which a vast majority of the population can receive medical intervention. The National Institute of Child Health and Human Development (NICHD) (cited in Odendaal, Steyn, & Odendaal, 2003:61) reported that the survival rate of infants with very low birth weights has increased over the past few decades but that there still remain a high percentage of severely handicapped infants as a result of their prematurity. According to Cooper (1999:1160), fewer than 20% of infants are born in private sector hospitals, and a majority of infants born in South Africa do not have access to intensive care facilities. The results obtained from the NICHD, however, may be somewhat skewed as they depict the morbidity rate of
premature infants in South Africa without taking into consideration the quality and the nature of the care provided within the NICU.

The treatment provided to premature infants in the various hospital settings in South Africa further varies in relation to the philosophy of care implemented within the NICU and the availability of professionals to provide suitable intervention. There is a marked difference in the care provided in NICUs in private sector and state sector institutions, which may be as a result of the absence of national guidelines for neonatal care, separate registers for the training of paediatric and neonatal nurses in South Africa and models that prioritise family-centred care within the NICU (Irlam & Bruce, 2002:33; Pattinson, 2003a:435).

As the care provided in the NICU fits within a delicate ecological system (Thurman, 1997:6), each setting is considered to be unique due to the nature of the environment, the staff, and the degree to which developmental and family-centered care has been implemented. Research conducted in developed counties has yielded a tremendous amount of information regarding an ideal philosophy of neonatal care within NICUs, which is valuable in establishing suitable practices of care within South Africa. The South African context, however, differs significantly to that of developed countries, as there is a diverse range in available health care resources and professionals involved in service delivery. As a result, a unique definition of family-centred care needs to be established according to the characteristics of the South African health care system (Irlam & Bruce, 2002:30).

There is a varied range in the availability of professionals suited to provide intervention in NICUs in South Africa. In most large academic hospitals, professionals from various disciplines are involved in the care provided in the NICU. These professionals are often situated on the hospital premises and as a result are able to create and co-ordinate multidisciplinary teams with greater ease than those working at private sector institutions do. The NICU teams in larger academic hospitals have reportedly been involved in establishing programs that promote appropriate developmental and family-centred care
(Hann, Malan, Kronson, Bergman & Huskisson, 1999; van Rooyen, Pullen, Pattinson & Delport, 2002). The nature of intervention provided within NICUs in private institutions in South Africa, however, has not yet been documented in the literature. The medical care provided in these hospitals is considered to be of a superior standard due to the availability of medical professionals and the fairly unlimited provision of advanced technology. The active involvement of multidisciplinary teams in NICUs in private sector institutions, however, is considered to be more difficult to establish as a majority of the necessary professionals are not based on the hospital premises and are self-employed.

The characteristics of parents of premature infants vary greatly within South Africa. Individuals that receive care at private sector hospitals are generally considered to be better educated and of a higher socio-economic status. These factors are known to influence the risk faced by premature infants in overcoming the effects of the NICU experience in order to achieve an optimal developmental outcome (Rossetti, 2001:6). The involvement of speech-language therapists and the services provided within private sector hospitals in South Africa remains unknown and thus further exploration is necessary.

There is a paucity of information pertaining to the opportunities provided to parents of premature infants to establish optimal patterns of interaction within the South African context. It is widely acknowledged that a disruption in infant-parent interaction and attachment may result in later developmental delay and thus speech-language therapists need to be familiar with all factors that may contribute to these difficulties in order to provided appropriate intervention. As a result, there is a need for exploration in this area in order to provide guidelines for the improvement of services provided by speech-language therapists within the NICU.

This study aimed to obtain information pertaining to the experiences of parents of premature infants that were hospitalised in the private sector hospital in South Africa and to explore the opportunities that were afforded these parents to develop infant-parent
interaction. In addition, this research sought to yield information that may contribute to the service provided by speech-language therapists within the context of appropriate developmental and family-centred care within NICUs in private sector institutions. In this way, the study served to generate practical implications for the improvement of family-centred care in the NICU and make recommendations regarding optimal infant-parent interaction.
CHAPTER TWO

METHODOLOGY

2.1 AIMS OF THE STUDY

This study endeavoured to explore the experiences of parents of infants that had graduated from the Neonatal Intensive Care Unit (NICU) with regard to the opportunities that were afforded to them in order to communicate with their infants.

2.1.1 Sub-Aims

The sub-aims of this study were to identify variables that could affect the communication and interaction between the parents and infants with regard to:

1. Factors affecting and affected by parental variables
2. Factors affecting and affected by environmental variables
3. Factors affecting and affected by infant variables

2.2 RESEARCH DESIGN

An exploratory, cross-sectional multiple case study design was employed in order to investigate the aim and sub-aims of the study.

The nature of this study falls within a qualitative paradigm. Qualitative research has been described as an umbrella concept that covers several forms of inquiry that assist the researcher in studying phenomena in their natural settings and in understanding and
interpreting these in terms of the meanings people bring to them (Merriam, 1998:5; Denzin & Lincoln, 2000:3). The results obtained from studies of this nature have been previously thought of as being weak and immaterial but through the presentation of systematic and rigorous results, the researcher is able to overcome this poor perception and provide a rich description of people and events (Neuman, 1997:328; 418). The researcher therefore aimed to portray the diverse and unique experiences of the participants whilst acknowledging any possible methodological limitations that would influence the strength of the study.

An exploratory study design was selected as it allows the researcher to examine a relatively new subject (Babbie & Mouton, 2001:79). In addition, this design offers insight and a deeper understanding of the area being investigated to pave the way for future research. (Neuman, 1997:20). A criticism of an exploratory design, however, is the limited ability offered to generalise the results obtained, as the sample is not representative of the population (Rubin & Babbie, 2001:124). The value in the exploratory design, however, lies in its ability to generate hypotheses and directions for future research. It does not purport to offer conclusions that would be generalised to the broader population. The experiences of parents of premature infants have been thoroughly described in the literature. The area of family-centred care within the NICU is, however, in the infancy stage of being developed within the South African context. The researcher thus aimed to explore the experiences of South African parents of premature infants.

The use of a cross-sectional, survey research design allowed the researcher to gather a large amount of information and to provide a description of the experiences of parents of premature infants at a specific period in time (Robson, 1995:49; Rubin & Babbie, 2001:361). This method, however, does not offer the measure of reliability over time that may be achieved through a repeated-measure design (Neuman, 1997:138). For the purposes of the present research, however, it was appropriate to employ a cross-sectional
design in the interests of examining a discreet event, rather than the development of a variable over time.

A multiple case study design was utilised within the study as it is described as being “a means of investigating complex social units consisting of multiple variables” (Merriam, 1998:41) whilst retaining the holistic and meaningful characteristics of real-life events (Yin, 1984:14). Case studies are criticised as lacking rigour due to the influence of subject and research biases and the limited generalisability of the results (Yin, 1984:21; Merriam, 1998:43). This research design however is not chosen to optimise the generalisability of the findings but rather to become familiar with the unique characteristics of each case (Stake, 1995:8).

2.3. SUBJECTS

2.3.1. Sampling method

Non-probability sampling was used in the form of a purposive sample, which allowed for the researcher to target individuals that were likely to be able to provide useful information for the purposes for which the study was conducted (Babbie & Mouton, 2001:166). In addition, this method of sampling enabled the researcher to conduct an in-depth investigation in order to gain a deeper understanding of the characteristics of the participants (Neuman, 1997:206).

The nature of care provided and the resources available within the NICU vary in each hospital. Furthermore, there is a large discrepancy between the personal, cultural and socio-economic characteristics of individuals that receive care at the various hospitals within South Africa. As a result, there are numerous extraneous variables influencing the generalisability of the results. In an attempt to reduce the effect of this limitation, the
researcher selected participants of similar cultural and socio-economic backgrounds whose infants had been hospitalised at the same NICU. The researcher thus explored and gained a thorough understanding of the experiences of six sets of parents from one, private-care hospital within the South African setting.

### 2.3.2. Subject selection criteria

The following inclusionary and exclusionary variables were considered in the selection of parents suitable for the study:

**Inclusionary factors**

- Parents of premature infants that have spent a minimum of 28 days within the NICU.
- Parents of infants that have graduated from the NICU in the past year and have survived.
- Parents of premature infants that are the biological parents and have legal custody of the infant
- Parents of NICU graduates that have the ability to speak, read and understand English

**Exclusionary factor**

- Parents of premature infants that have genetic or congenital abnormalities.

The researcher proposed these criteria in order to eliminate any extraneous variables that could have impacted on the results obtained.

The birth and hospitalisation of a premature infant is a highly stressful event for parents that results in a roller coaster of emotions. Individuals cope with challenging situations uniquely as their reactions are influenced by previous experiences, background, education, religion, family and friends (Allen, 1995:172). The researcher thus aimed to obtain a diverse range of responses by including both parents within the study.
The researcher interviewed the parents a year after their premature infant had graduated from the NICU in order to reduce the influence that the immediate stressors, associated with the premature delivery and hospitalisation of an infant, may have had on their recall of the situation. An individual’s ability to recall information regarding an emotional event is reportedly restricted in the range of information and the detail in which the event unfolded and that additional memories are often based on a reconstruction of the event (Reisberg & Heuer, 1992:154). In light of this limitation, the researcher interviewed both parents together to facilitate their recall of the event, to reduce the risk of conflicting information and to allow for a thorough exploration of their experience (Fontana & Frey, 2000: 651).

The development of parent-infant attachment begins during the pregnancy as parents develop fears, expectations and dreams for the infant and their role in caregiving (Siegal, et al., 1998:648). Parents of premature infants thus grieve the loss of the fantasised perfect infant and are faced with numerous challenges in adjusting to the unexpected event (Allen, 1995:173). As a result, the researcher needed to explore the experiences of the biological parents of the infants.

The researcher limited the study to include infants that had spent a minimum duration of 28 days within the NICU to ensure that they were significantly exposed to the environment.

Families of infants that had not survived in the NICU or post-discharge and families of infants with genetic or congenital abnormalities were excluded from the study because the experiences of these families would differ significantly and thus impact on the interpretation of the results (Gardner, et al., 1998:676-677).

The researcher further limited the study to individuals who were able to write, speak and understand English competently. This criterion was included as the data obtained from the
interview was analysed through the use of content analysis and thus the researcher needed to have a thorough understanding of the language and of associated cultural factors (Rubin & Babbie, 2001:232). In addition, the reliability of the data obtained from individuals from varied linguistic backgrounds would have been affected by the use of a translator or an interviewer with the required language skills due to differing interpretations of the data and manners of conducting the interview (Babbie & Mouton, 2001:251).

2.3.3 Description of Participants

The participants were recruited from a private hospital based in Gauteng. The researcher telephonically contacted the parents of the premature infants who were suitable for the study. The participants were informed of the research project and were invited to participate in the study. Nine sets of parents were suitable to participate in the study. However, three families reported that they had time constraints and thus would not be able to be involved in the study. A description of the six families that participated in the study is presented in Table 2.1. Fictitious names have been given to each family for the sake of clarity and to ensure the information obtained remains confidential and that their identities are not disclosed.

a) Age of the parents

The participants ranged from between 25 and 38 years of age, with a majority of the parents being between 33 and 38 years. The age of the mother is an important factor to consider as infants that are born to adolescent mothers and mothers that are 35 years and older are at an increased risk of mortality and developmental delay (Rossetti, 1997:13-15).
Table 2.1. Description of the Parents (n = 12).

<table>
<thead>
<tr>
<th>FAMILY</th>
<th>AGE GROUP</th>
<th>HIGHEST LEVEL OF EDUCATION</th>
<th>EMPLOYMENT STATUS</th>
<th>APPROXIMATE FAMILY INCOME PER YEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td>PENNY</td>
<td>Father</td>
<td>25-32</td>
<td>Diploma</td>
<td>Full-time</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>25-32</td>
<td>Grd 11–Grd 12</td>
<td>Full-time</td>
</tr>
<tr>
<td>GAVIN</td>
<td>Father</td>
<td>33-38</td>
<td>Grd 11–Grd 12</td>
<td>Full-time</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>33-38</td>
<td>Grd 11–Grd 12</td>
<td>Part-time</td>
</tr>
<tr>
<td>MICHAEL</td>
<td>Father</td>
<td>33-38</td>
<td>Diploma</td>
<td>Full-time</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>33-38</td>
<td>Honours Degree</td>
<td>Full-time</td>
</tr>
<tr>
<td>VICTORIA &amp;</td>
<td>Father</td>
<td>25-32</td>
<td>Honours Degree</td>
<td>Full-time</td>
</tr>
<tr>
<td>VINCENT</td>
<td>Mother</td>
<td>25-32</td>
<td>Honours Degree</td>
<td>Full-time</td>
</tr>
<tr>
<td>EMILY &amp;</td>
<td>Father</td>
<td>33-38</td>
<td>Grd 11–Grd 12</td>
<td>Full-time</td>
</tr>
<tr>
<td>ERICA</td>
<td>Mother</td>
<td>25-32</td>
<td>Grd 11–Grd 12</td>
<td>Full-time</td>
</tr>
<tr>
<td>LISA &amp;</td>
<td>Father</td>
<td>33-38</td>
<td>Masters Degree</td>
<td>Full-time</td>
</tr>
<tr>
<td>LUKE</td>
<td>Mother</td>
<td>33-38</td>
<td>Honours Degree</td>
<td>Full-time</td>
</tr>
</tbody>
</table>

b)  Level of education

Approximately half of the parents had tertiary education qualifications, with the remaining participants having obtained a Grade 11 or 12. The education level of parents is a relevant area to explore as infant mortality rates decline with an increase in maternal education. Furthermore, infants of parents that have an educational level of less than Grade 9 are considered to be at-risk for developmental delay (Rossetti, 1997:13).

c)  Status of employment and approximate family income

Ten of the parents were either employed on a full-time or part-time basis, with two of the mothers not being currently employed. The approximate family income of a majority of
the participants was above R240 000 per year, which places them in a relatively high socio-economic bracket. Gavin’s family did not provide information pertaining to their approximate yearly income. However, both parents were employed, were on a medical aid and owned their own home. The employment status and approximate family income are important factors to consider, as infants are viewed as being environmentally at-risk for developmental delay in the event that both parent are unemployed, there is a lack of stable residence and/or there is inadequate medical insurance (Rossetti, 1997:13).

d) **Family structure**

All of the participants reported that they lived at home with the infants that participated in the study. Three sets of twins took part in the study and the other infants were singletons. One set of parents stated that they were parents for the second time as they had another infant. The environmental risk factors associated with the challenges faced by both first time parents and parents of infants of multiple births may have a profound impact on the developmental outcome of the infant (Klaus et al., 1995:93; Berns & Brown, 1998:62). The structure of the family is thus an imperative issue for exploration.

### 2.3.3.1 Biological risk factors of the infants

The premature infant is faced with various medical, environmental and biological factors that place the infant at-risk for developmental delay. In addition, the underlying cause for the premature delivery of the infant may have a negative influence on the infant’s overall outcome. The biological risk factors of the infants that had graduated from the NICU are presented in Table 2.2.
a) Age and gender of the infants

At the time of the study, the infants ranged in chronological age from 11 months 4 days to 14 months 23 days, with a mean age of 12 months 12 days. There were five female and four male infants that participated in the study.

Table 2.2. Description of the Infants (n = 9).

<table>
<thead>
<tr>
<th>Name</th>
<th>Current Chronological Age</th>
<th>Gender</th>
<th>Birth Weight (grams)</th>
<th>Weeks premature</th>
<th>Weeks in NICU</th>
<th>Multiple birth</th>
<th>Number of siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>PENNY</td>
<td>14 months 2 days</td>
<td>F</td>
<td>1800</td>
<td>9</td>
<td>4</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>GAVIN</td>
<td>14 months 23 days</td>
<td>M</td>
<td>1650</td>
<td>9</td>
<td>4</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>MICHAEL</td>
<td>11 months 4 days</td>
<td>M</td>
<td>1650</td>
<td>8</td>
<td>6</td>
<td>No</td>
<td>None</td>
</tr>
<tr>
<td>VICTORIA</td>
<td>12 months 7 days</td>
<td>F</td>
<td>840</td>
<td>13</td>
<td>12</td>
<td>Yes</td>
<td>One</td>
</tr>
<tr>
<td>VINCENT</td>
<td>12 months 7 days</td>
<td>M</td>
<td>900</td>
<td>13</td>
<td>14</td>
<td>Yes</td>
<td>One</td>
</tr>
<tr>
<td>EMILY</td>
<td>12 months 22 days</td>
<td>F</td>
<td>1700</td>
<td>8</td>
<td>4</td>
<td>Yes</td>
<td>One</td>
</tr>
<tr>
<td>ERICA</td>
<td>12 months 22 days</td>
<td>F</td>
<td>1600</td>
<td>8</td>
<td>4</td>
<td>Yes</td>
<td>One</td>
</tr>
<tr>
<td>LISA</td>
<td>11 months 9 days</td>
<td>F</td>
<td>1500</td>
<td>5</td>
<td>5</td>
<td>Yes</td>
<td>Two</td>
</tr>
<tr>
<td>LUKE</td>
<td>11 months 9 days</td>
<td>M</td>
<td>2300</td>
<td>5</td>
<td>2</td>
<td>Yes</td>
<td>Two</td>
</tr>
</tbody>
</table>
b) Birth weight

The birth weight of the infants ranged from 840 grams to 2300 grams, with a mean weight of 1549 grams. Premature infants are categorised as being either low birth weight (less than 2500 grams), very low birth weight (less than 1500 grams) or extremely low birth weight (less than 1000 grams) (Vergara & Bigsby, 2004g:108). Therefore, six of the infants had low birth weights, with one having a very low birth weight and two infants having extremely low birth weights.

The birth weight of the premature infant is an important factor to consider, as this is influential on the infant’s medical and developmental outcome. Infants with smaller gestational ages and lower birth weights are at a greater risk for complications as they are exposed to numerous biological, environmental and medical insults associated with medical intervention and long hospitalisation (Wyly, 1995a:8-10).

c) Number of weeks premature

The number of weeks that the infants were born prematurely ranged from 5 to 13 weeks, with a mean duration of 8.7 weeks.

The infant’s gestational age at the time of birth is an important aspect to consider because the premature infant is neurologically and anatomically unprepared to cope with the challenges faced outside the womb. Infants with smaller gestational ages are considered to be at greater risk for poor developmental outcomes as they require aggressive medical intervention and extended hospitalisation to ensure their survival (Rossetti, 2001:13).
d) **Number of weeks spent in the NICU**

The number of weeks spent by the infants in the NICU ranged from 2 to 14 weeks, with a mean duration of 6.1 weeks. A criterion of a minimum duration of 28 days spent by the infant in the NICU had been established in selecting the participants. One of twins, however, had been discharged from the NICU after 2 weeks whilst his sister had remained in the NICU for an additional 3 weeks.

The infant and families’ exposure to the NICU is an important factor to consider as the NICU has been identified as being a site for early intervention due to the stress experienced by both the infant and its parents (Thurman et al., 1997:119). The premature infant is neurologically and physiologically unprepared for adapting to life outside the womb is faced with excessive stimulation within the NICU. As a result, the infant’s ability to self-regulate and develop organised behavioural states is affected which is influential in early social, emotional and cognitive interactions (Wyly, 1995c: 38).

The parents of premature infants also perceive the NICU as being a stressful and overwhelming environment. The NICU milieu, the infant’s medical state and the family’s ability to adapt to the environment are all factors, which are influential the development of optimal parent-infant interaction (Wyly, 1995e:150).

e) **Additional considerations**

The gestational age and the birth weight of premature infant are important predictors of an infant’s health and survival and serve as rough indicators of the infant’s anticipated perinatal and postnatal needs (Vergara & Bigsby, 2004g:109). There is a diverse range in the birth weight and gestational age of the infants that participated in the study. The researcher did not control these factors in order to establish a homogenous group, as the focus of the study was to explore the experiences of the participants within the NICU. The
factors, however, are important to consider as they influence the medical condition of the infant, the duration spent by the infant in the NICU, the reactions of the parents to the premature birth of their infant and the effect that the NICU environment has on the infant (Wyly, 1995e:151-155). As a result, the possible influence of the gestational age and birth weight of the infants will be discussed in the interpretation of the data.

2.4 PROCEDURE

There were two phases involved in conducting the study: 1) the preparation phase and 2) the data collection phase.

Before the preparatory and data collection phases were conducted, the following procedures were carried out:

A submission was made to the University of the Witwatersrand Committee for Research on Human Subjects for permission to conduct the research project. The Committee approved the study. The Research Clearance Certificate Number is H03-02-02 and is included in Appendix C.

The proposal was submitted to the Graduate Studies Committee of the Faculty of Humanities at the University of the Witwatersrand. The Committee approved the proposal.

The manager of the hospital, the matron in charge of the NICU and the relevant pediatricians were contacted and informed of the proposed study in order to obtain permission to conduct the study. The letters requesting permission to conduct the study are set out in Appendix B. A letter granting permission to access the hospital files and to contact suitable parents for the study was obtained and is included in Appendix B. In order
to preserve confidentiality, the researcher erased the names of both the hospital and the professionals from all correspondence.

2.4.1 The Preparation phase

The preparation phase comprised of two parts: 1) observation of the NICU environment and 2) the implementation of a focus group.

The aim of the preparation phase was to familiarise the researcher with the NICU and the experiences of South African parents in South African contexts, so as to guide the research process.

2.4.1.1 Observation within the NICU

The aim of this observation period was to acquaint the researcher with the NICU from which the premature infants had graduated as each unit functions in a unique manner. The NICU is considered to be a potentially stressful environment for both the infant and the parents, which may contribute to difficulties in establishing optimal infant-parent interaction (Wyly, 1995c:38). As a result, the researcher aimed to become familiar with the structure, social environment, and everyday functioning of the index NICU in order to have an understanding of the environment that the participants experienced. This institutional knowledge would ensure that the researcher could place the participants’ experiences, have a shared reference and to allow the researcher to probe for additional information during the interview when necessary (Collins & Noblit, 1978 in Merriam, 1998:41).

The researcher gained insight of the NICU through non-participatory observation over an accumulative period of 15 hours. The observation was undertaken in five shifts, each lasting three hours, at various times during the day and early evening. After the end of the
observation period, the researcher was familiar with the NICU environment, the staff members involved in caring for the infants, the routines of caregiving and staff-parent interaction.

2.4.1.2 The focus group

Focus groups are described as being a purposeful method in exploring the diverse experiences of a small number of people with shared interests through a free-flowing discussion within an open and non-threatening environment (Schurink, Schurink & Poggenpoel, 1998:314).

The objective of the focus group was to supplement the researcher’s knowledge through gaining insight of the experiences of South African parents of premature infants with regard to their NICU experience. The birth of a premature infant is considered to be a life event that needs to be experienced before it can be truly understood. Few professionals have personal knowledge regarding the thoughts, feelings and behaviours of parents of premature infants (Stonestreet, et al., 1991:38) and thus the researcher considered the information obtained from the focus group to be valuable in providing guidance in the construction of the questionnaire and interview schedule (Carey, 1994:227).

a) Procedure in conducting the focus group

The participants of the focus group were recruited from a private speech therapy practice in Gauteng. The group consisted of three sets of parents of infants that had been born prematurely and hospitalised in a NICU for approximately one month. The researcher contacted each family telephonically and informed them of the research project. The parents were invited to participate in the focus group, which would be conducted from the speech therapy practice from which they had been recruited. A time for the focus group was made at a time that was convenient to both the researcher and the families.
The focus group was conducted as a free-flowing discussion. The researcher initiated the conversation by asking each family to describe their experience. Parents respond differently to the challenges faced with the premature birth of their infant and thus the objective of using a focus group was to allow for the similarities of the participants within the group to emerge while emphasising their differences (Morgan, 1998:59).

b) Outcome of the focus group

Each participant of the focus group provided an in-depth account of their unique experiences whilst their infant was in the NICU and challenges that they faced once their infant was discharged from the hospital. The researcher noted the following themes that emerged from the focus group:

- The need for more emotional support from professionals
- A need for information
- Difficulty in bonding with the infant
- An initial fear of caregiving activities
- A lack of awareness of the developmental difficulties that an infant may experience

The researcher acknowledged the importance of these themes and incorporated them within the structure of the interview guide.

2.4.2 The data collection phase

The data for the study was collected through two means: 1) a questionnaire and 2) an interview.
The use of this multi-modal method, termed triangulation aimed to allow the researcher to thoroughly explore the experiences of the parents of premature infants (Neuman, 1997:151). In addition, the researcher aspired, through the initial administration of the questionnaire, to yield responses that could be probed further within the interview.

2.4.2.1 The questionnaire

a) **Cover letter**

The cover letter (Appendix B) served to introduce the participants to the researcher and the research topic. The letter aimed to highlight the importance of the study, to reduce any doubt that respondents might have and to motivate them to participate in the study through informing them of the potential benefits of the research (Robson, 1995:251). In addition, the researcher aspired to assure the participants that their responses would remain anonymous and that they may withdraw from the study at any time (Strydom, 1998a:26).

The cover letter also included a consent form in order to obtain the respondents’ permission to participate in the study, to tape record the interview, and to use their responses in the write up of the study and any future publications or presentations (Merriam, 1998:216-219).

b) **The questionnaire**

The aim of the questionnaire was to introduce the participants to the research topic, to yield responses that could be further explored within the interview and to supplement the information obtained from the interview.

A survey of the existing literature did not reveal a questionnaire appropriate to the needs of this particular study. Therefore, through a review of the literature and the focus group, the
researcher developed an original research instrument to elicit the necessary information (Berg, 1995:22). Efforts were made to enhance face validity and content validity by including a wide range of items from aspects and issues highlighted in the literature and mentioned in the focus group (Babbie & Mouton, 2001:122-123). In addition, an expert in the area of Early Intervention was consulted and was asked to review the questionnaire to ensure that all aspects had been considered. The questionnaire is set out in Appendix A.

In order to ensure the effectiveness of the administration of the questionnaire, the questions were kept relevant to the study while ambiguous, double-barrelled, and leading questions were avoided (Neuman, 1997:233-236). Social desirability effects, where participants seek to give more socially acceptable responses, were considered and efforts were made to reduce them by using non-threatening, indirect question forms and by stressing the scientific importance of the research (Rubin & Babbie, 2001:179).

The questionnaire consisted of a majority of closed-ended questions, which allows for a quicker completion of the questionnaire (Fouché, 1998:161). The length of a questionnaire is often of concern with regards to the validity of the answers received, as respondents are likely to tire during the completion of a lengthy questionnaire (Rubin & Babbie, 2001:216).

The closed-response items chosen for the questionnaire included that of dichotomous items and rank-order questions. The option of a middle position was provided in the ranking to allow for more accurate responses as it reduces the possibility of the respondents leaving blanks when completing the questionnaire (Neuman, 1997:242). The fixed responses obtained from closed-ended questions are however limited in portraying the participant’s opinions, attitudes, and feelings (Neuman, 1997:240).

The researcher included open-response format questions within the questionnaire, as they are valuable in obtaining unlimited and detailed responses to complex issues that are
reflective of the unique characteristics of the participants (Neuman, 1997:241). Furthermore, open-ended questions may yield responses that had not been anticipated by the researcher (Fouché, 1998:160).

The questionnaire comprised of the following sections:

Section A – Background information regarding the family member and the infant

Singleton, Straits & Straits (1993:293) recommend that the first questions be easy to answer to encourage further participation in the questionnaire. For this reason, questions relating to the participants’ background were asked first as they tend to be of a less sensitive nature (Berg, 1995:42). This section aimed to elicit background information regarding the parent and the infant, the family structure and the professionals involved in the treatment of the infant whilst in the NICU. Items requiring the following biographical information were included:

- Age of the parent and of the infant
- Gender of the parent and of the infant
- Parent’s marital status
- Parent’s employment status
- Level of education of the parent
- Individuals that are presently living within the home
- Infant’s birth weight
- Number of weeks that the infant was born prematurely
- Number of weeks that the infant spent in the NICU
- Number of infants born prematurely in a multiple birth
- Professionals that were involved in the infant’s care whilst in the NICU
Section B – Information and support received by the families of NICU graduates

This section aimed to explore the information and support received by parents of NICU graduates during the four phases as proposed by Brazy, Anderson, Becker & Becker, (2001):

i) the prenatal phase
ii) the acute phase of illness
iii) the convalescent phase
iv) the post-discharge phase

These items targeted issues related to the information provided, the manner in which information was obtained, useful resources in obtaining information, sources of support and the parent’s concerns during each phase.

Section C – Information regarding adjusting to and coping with the demands of the premature infant

This section aimed to investigate which individuals were involved in assisting the parents in adjusting to the demands of the premature infant. In addition, this section explored the factors that the parents perceived as positively or negatively influencing the manner in which they cope with the experience.

Section D – Additional remarks

As suggested by Robson (1995:233), the respondents were provided with several open-ended questions at the end of the questionnaire which allowed for views to be expressed that were not anticipated by the researcher. These items probed the parents’ suggestions for better service delivery and explored advice that the participants would provide to other
families that are faced with a similar experience. In addition, the parents were provided with an opportunity to write down some of their experiences of whilst their infant was in the NICU.

**Procedure used in administrating the questionnaire**

The researcher delivered the questionnaires to the parents’ home a few days before the interview was conducted. Both parents were requested to complete a questionnaire.

A self-administered questionnaire was considered to be useful, as the participants were able to complete the answers in a non-threatening environment, in their own time and to have the opportunity to clarify information relating to the questions (Babbie & Mouton, 2001:258).

In an attempt to reduce the possibility of biased answers, the researcher verbally instructed each parent to complete the questionnaire separately and requested that the participants did not discuss their responses with each other (Neuman, 1997:251). The parents were encouraged to contact the researcher in the event that they experienced difficulty in understanding the meaning of any of the questions in an attempt to ensure that the participants completed the questionnaire (Fouché, 1998:155).

Two sets of participants phoned the researcher to ask for clarity regarding the question, which aimed at determining whether the parents had been aware that their infant was going to be born prematurely. The researcher provided the parents with an explanation of the aim of question and the participants were able to complete the remainder of the questionnaire with little difficulty. Due to the confusion experienced, the researcher telephoned the remaining parents to ensure that they had understood the question and provided them with an explanation if this was deemed necessary. However, the participants had not considered the question to be ambiguously worded.
2.4.2.2 The interview

a) Face-to-face interview

A face-to-face, semi-structured interview allowed the researcher to unveil the unique, personal feelings and experiences of the participants. The use of a flexible interview guide consisting of very open-ended questions allowed the participants to direct the interview and to illuminate their perspectives on the topic (Hutchinson & Wilson, 1994:309). The researcher is thus provided with the basis to elicit more specific responses through appropriate follow-up questions in order to gain a deeper understanding (Shaw & Gould, 2001:144). In addition, the use of a face-to-face interview allows the researcher to provide explanations and reword questions to ensure that a true reflection of the views of the participants is obtained (Robson, 1995:229).

b) The interview guide

An interview guide of relevant questions and themes was established through information obtained from a review of the literature, the observation of the NICU, the focus group and the questionnaire. The use of a guide within the interview creates a comfortable framework for discussion that provides a logical progression through the issues in focus and ensure that all topics relevant to the study are explored (Gaskell, 2000:40).

The researcher began the interview by asking the parents to provide a description of their experiences of the NICU and then used the interview guide to facilitate the direction of the conversation. The following themes were included in the interview guide:

- The parents’ degree of preparedness for the NICU experience
- Opportunities afforded the parents in having early contact with their infants
- Information received by the parents during the NICU
• Support received by the parents whilst their infants were in the NICU
• Advice that parents would provide to future parents of premature infants within the NICU

The specific key words and topics that comprised the interview guide are presented in Table 2.3.

**Table 2.3. Key words and topics comprising the interview guide**

<table>
<thead>
<tr>
<th>The parents’ preparedness for the premature delivery of their infants</th>
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</thead>
<tbody>
<tr>
<td>The parents’ initial perceptions of the NICU</td>
</tr>
<tr>
<td>The parents’ initial perceptions of their infant</td>
</tr>
<tr>
<td>The parents’ perception of the NICU staff</td>
</tr>
<tr>
<td>The parents’ perceptions of their role of caregiver during the NICU experience</td>
</tr>
<tr>
<td>The opportunities afforded the parents to have early contact with their infants</td>
</tr>
<tr>
<td>The types of information received by the parents during the NICU experience</td>
</tr>
<tr>
<td>The support received by the parents during the NICU experience</td>
</tr>
<tr>
<td>The parents’ perception of their ability to bond with their infants whilst in the NICU</td>
</tr>
<tr>
<td>The parents’ ability to communicate with their infants during the NICU experience</td>
</tr>
<tr>
<td>Kangaroo Mother Care</td>
</tr>
<tr>
<td>Feeding difficulties</td>
</tr>
<tr>
<td>Factors that the parents perceived as assisting them in coping with the NICU experience</td>
</tr>
<tr>
<td>Factors that the parents perceived as causing additional stress during the NICU experience</td>
</tr>
<tr>
<td>Advice for future parents of premature infants</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>
The researcher aimed to get structured information from the interviews through the use of the interview guide but realised that each individual would emphasise different factors relating to their NICU experience, which would result in a range in the quality and quantity of the information obtained pertaining to each theme. The researcher therefore used the interview guide in order to ensure that all aspects relating to the study were discussed but allowed the participants to discuss in detail their unique experiences of the NICU.

c) Procedure used in conducting the interview

The researcher interviewed the participants a few days after delivering the questionnaires. The participants were provided with two options of where the interviews could be conducted. All six families chose to have the interview at their homes, rather than at a private speech therapy practice in the area. The researcher considered the distractions that may arise when conducting the interview at the participants’ homes. Thus, the researcher scheduled the interviews at times at which the infants are usually sleeping or when a caregiver would be available to look after the infant.

Both parents of the NICU graduate were interviewed simultaneously, as the researcher felt that this would yield a diverse range of responses to enhance the richness of the information obtained. The researcher, however, needed to be aware of dynamics or power hierarchies that may potentially affect who speaks and what is said and ensure equal contribution by making an overt appeal for other comments (Shaw & Gould, 2001:147).

The interviews were recorded on an audiocassette and later transcribed verbatim into written form to allow the context of the conversation to provide as much meaning as possible for future analysis (Unrau & Coleman, 1997:79).

The responses made by the participant in the pilot study emphasised the concerns that parents of premature infants may have with regard to their infant’s development. The
researcher recognised that her primary role in this study was that of a researcher but acknowledged the increased risk of premature infants for developmental delay and the need for early intervention. As a result, the researcher was prepared to advise the parents during the interview about their concerns regarding their infant’s development and was able to provide them with a referral list of suitable professionals.

\[ d) \text{ Inter-rater reliability} \]

Face-to-face interviews have been criticised as being vulnerable to subject and interview biases (Babbie & Mouton, 2001:253). In an attempt to reduce socially desirable responses, the researcher emphasised the scientific importance of the study and informed the participants that she was not acting as a representative of the hospital at which their infants had been hospitalised (Neuman, 1997:258).

Another threat to reliability is generated by the interview structure. The lack of specific structure of a semi-structured interview could lead to the researcher guiding and influencing both the flow of the interview and the content of the ideas generated by those being interviewed. The researcher used an interview guide to ensure that all areas relevant to the study were explored. The use of this guide thus aided in the reliability of the interview but at the same time could have placed the researcher at risk for interviewer bias.

To enhance the reliability of the data captured in the interviews, two raters were chosen to rate both the interviews and the results obtained. The selection criteria for the raters were that they had experience in interviewing and had a clear understanding of the variables that can affect reliability. Two qualified psychologists agreed to rate the data. They were both female, had completed research at a Masters level at South African universities and were registered with the South African Health Professions Council.

The raters needed to be familiar with the aims of the study and the role that they were expected to perform. Once this had been explained to them, the raters randomly selected
extracts from the transcripts and evaluated them to ensure that the comments made by the interviewer in response to the participants’ responses were non-judgemental, objective and relevant to the study. In addition, the questions used within the interview were examined to ensure that they were relevant to the study and that ambiguous, double-barrelled and leading questions had been avoided. The raters, furthermore, assessed the use of the interview guide and probes within the interview in order to ensure that all areas relevant to the study had been thoroughly explored (Robson, 1995:128; Neuman, 1997:258-259; Babbie & Mouton, 2001:253).

Once both of the raters had perused the data, a meeting was held with the researcher in which areas of concern were discussed. Each example of possible bias was thoroughly explored and a resolution was obtained conditional on the agreement of two out of the three individuals. There were no instances in which agreement could not be obtained through discussion.

2.5. PILOT STUDY

A pre-test of the questionnaire and interview was conducted before the data was collected in order to identify any flaws and to make any changes necessary to reduce misinterpretations of questions (Strydom, 1998b:182-183). In addition, the researcher was provided with an opportunity to gain experience in the skills needed in interviewing (Neuman, 1997:257). It is generally recommended that the people involved in the pilot studies are from similar socio-economic status and race, to the participants and who have the same experiences as the members of the research (Singleton, et al., 1993:290). Furthermore, the individuals who take part in the pre-test should not be included in the final study as their responses would be influenced by their recognition of the questions and the interview procedure, thereby posing a threat to the internal validity of the research instrument (Rosenthal and Rosnow, 1996:112).
A parent of a premature infant who had graduated from the NICU contacted and asked to complete the questionnaire and to be interviewed.

The participant appeared flustered and self-conscious when completing the questionnaire in front of the researcher. In addition, she did not complete the open-ended items on the questionnaire as she stated that she would talk about those aspects during the interview. In light of the participant’s response to the completion of the questionnaire, the researcher decided that it would be of benefit for future participants to receive the questionnaire before the interview was conducted. The parents would thus be provided with time to complete the questions at their own pace and without the researcher being present.

The researcher realised the flow of the interview was poor resulting in the researcher asking the participant numerous questions in order to initiate the conversation. In addition, the researcher noticed that there were many factors that were recalled in relaying the event, which resulted in the interview losing focus. The researcher felt, in light of these observations, that the conversational flow and the focus within the interview could be improved by initially asking the parents to recall their experience as this would allow for the researcher to guide the conversation with relevant questions.

2.7 DATA ANALYSIS

Two research tools were used to obtain data in the present study. The primary tool was the interview, with the information being supplemented by the short questionnaire.

Analysis of the data yielded from the interview

The interviews yielded a quantity of data that required the researcher’s careful analysis and meaningful reconstruction (Stake, 1995:75). The analysis of the information obtained thus
needed to be an interactive process that allowed the researcher to make sense of the complex multifaceted nature of the cases (Merriam, 1998:152). The researcher used a constant comparative method of data analysis in order to construct categories or themes that are representative of recurring patterns that are evident in a majority of the data (Merriam, 1998:179). This type of analysis was valuable and relevant to the study as it allowed for deeper insight, identification of commonalities between participants, an exploration of uniqueness characteristics and in the interpretation of the meaning of the discovered patterns (Boyle, 1994:180).

a) Procedure used in analysing the data

In accordance to the constant comparative method of data analysis, the researcher read each transcript and made comments and notes of the units of data that were detected. Through the repeated perusal and analysis of the transcripts, the researcher identified units of data that were meaningful and relevant to the study (Lincoln & Guba, 1985:345). The units of data were then compared with one another in order to find re-occurring regularities in the data, which were then placed into categories. These categories were further divided into more abstract categories (Merriam, 1998:180). The data was deconstructed into units until all relevant information had been categorised in a manner that was reflective of the aim and sub-aims of the research.

The data were organised and presented in a descriptive narrative of the concrete and abstracts themes that had emerged. The researcher established linkages between categories, compared the findings to literature relating to the same phenomenon and inferred meaning to data in order to build a general explanation that fits each of the individual cases, in spite of the varied nature of the cases (Yin, 1984: 112). Furthermore, the researcher incorporated direct quotes from the transcripts within the discussion in order to portray the unique nature of each participant’s experience of the NICU and to provide a rich description of each theme.
b) **Reliability considerations**

Qualitative research is by nature a subjective phenomenon (Neuman, 1997:328), which opens itself to bias due to the influence that the researcher may place upon the meaning of each response. In order to enhance the reliability of the analyses in terms of the units of data, themes identified and interpretative value, the two raters who evaluated the reliability of the interview were employed to evaluate the data. They were asked to determine whether the categories created were sensitive and exact with regard to the units of data and exact in capturing the meaning of the phenomenon. The raters were requested to randomly select extracts from the transcripts that had been analysed and placed within the relevant category in order to ensure that they were in agreement with the conclusions made by the researcher. A meeting was held with the researcher once the raters had reviewed the transcripts in order to obtain intrapersonal reliability through gaining agreement regarding the analysis of the data (Bauer, 2001:143). Agreement was defined as conditional upon two of the three individuals. At the conclusion of the meeting, there were no instances of disagreement that could not be resolved by discussion.
CHAPTER THREE

RESULTS & DISCUSSION

The main aim of the study was to identify the variables that affected communication and interaction between parents and their premature infants in the NICU. The sub-aims were developed following the ideas expressed by Jacobson & Shubat (1991), Harrison (1993) and Bruns & Steeples (2001) from which the researcher extrapolated a simple model of three interacting constructs as depicted in Figure 1. In this model, the infant, the parents and the environment interact in a dynamic and fluid manner, not necessarily cohesively at all times.

Figure 1. The three interacting constructs

Key:

I = Infant variables
P = Parental variables
E = Environmental variables
C = Optimal infant-parent interaction
It would be simplistic to present the results of the study as a list of the variables identified in each group, as set out in the sub-aims. In the interest of flow, clarity and meaningfulness, they are presented in two sections.

The first section explores the infant’s medical condition and the parents’ perception of their infant’s medical status. This section is presented first because it should be viewed as the most critical information as it dictates, to a large extent, the development of infant-parent communication. Furthermore, the medical status of the infant forms the background against which the rest of the data can be viewed. The second section describes the themes that were identified from the analysis of the units of data generated by the interviews and questionnaire.

SECTION 1: THE INFANTS’ MEDICAL CONDITION

This section aims to explore the infant’s medical condition and the parents’ perception of their infant’s medical status during the NICU experience.

The premature infant’s neurological and organ immaturity at birth is widely acknowledged as placing the infant in a medically fragile condition, which influences his or her ability to effectively interact within the environment (Billeaud, 1993:53; Wyly, 1995b:21; Rossetti, 2001:21; Vergara & Bigsby, 2004f:78). In addition, the medical intervention that premature infants receive whilst in the NICU might further impact on both the infant’s medical status and the development of infant-parent interaction.

The premature infant’s medical condition has been identified in numerous studies as being the most powerful variable associated with parental stress during the NICU experience (Scharer & Brooks, 1994:44; Catlett, Miles & Holditch-Davis, 1994:47; Moehn & Rossetti, 1996:242; Shields-Poë & Pinelli, 1997:35; Wereszczak et al., 1997:36; Holditch-
The parents in this study reported that their infants presented with various medical conditions that ranged in degree of severity. The comments made by the parent’s regarding the information that they received pertaining to their infant’s medical condition and their perception of their infant’s medical condition whilst in the NICU are laid out in Table 3.1.

A majority of the parents reported that the paediatricians had informed them during the initial phases of the NICU that their infants were in a stable medical condition and that the doctors did not foresee any additional complications. These parents did not appear to express concerned regarding their infant’s medical condition, as their comments suggested that they perceived the time spent by their infants in the NICU as being related to the infant’s weight and size.

Michael’s parents stated that the staff had not expressed concern regarding his medical condition and reportedly had expressed that they were content with his progress. His parents did not comment on his medical condition during the acute phase of his hospitalisation and the possible medical intervention that he received. Michael’s parents, however, stated that he had an eye operation prior to his discharge from the NICU, which suggests that he may have had Retinopathy of Prematurity. According to Vergara & Bigsby (2004f:95), there are numerous factors that may result in this condition but Retinopathy of Prematurity is most commonly found in premature infants that have been
**Table 3.1. The infants’ medical condition**

<table>
<thead>
<tr>
<th>PENNY</th>
<th>VICTORIA &amp; VINCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>They made it very clear that there were still a lot of dangers and</td>
<td>The doctor came to us and said that the first 72 hours were the most critical and</td>
</tr>
<tr>
<td>that the next 24 hours were really important to see if she copes with</td>
<td>then if we can get through the first 10 days</td>
</tr>
<tr>
<td>keeping herself warm ...they quickly put her on a respirator because</td>
<td>She didn’t cope well on the ventilator so she was oscillated</td>
</tr>
<tr>
<td>she really battled to breathe.</td>
<td>The first major crisis hit when they were 10 days old</td>
</tr>
<tr>
<td>She battled to breathe on her own, to stay warm and she got jaundice</td>
<td>He had a puncture in his small intestine so the paediatric surgeon came to</td>
</tr>
<tr>
<td>as well. So I reckon for the first three weeks, she was quite ill.</td>
<td>perform the operation</td>
</tr>
<tr>
<td>The main things that we worried about were her lungs</td>
<td>We thought that we were not going to pull through this</td>
</tr>
<tr>
<td></td>
<td>They were on the ventilators and oscillators for six weeks</td>
</tr>
<tr>
<td></td>
<td>I was concerned that she may get brain damage because her head was twice the</td>
</tr>
<tr>
<td></td>
<td>size that it was supposed to be</td>
</tr>
<tr>
<td></td>
<td>He got every possible germ and thing that anyone can get</td>
</tr>
<tr>
<td></td>
<td>He would get the infection and then a day or two later, Victoria would get it as</td>
</tr>
<tr>
<td></td>
<td>well. Those were really critical times</td>
</tr>
<tr>
<td></td>
<td>They wanted to transfer him but he was too critical</td>
</tr>
<tr>
<td></td>
<td>They got peptic ulcers because of the stress</td>
</tr>
<tr>
<td></td>
<td>He couldn’t get off the CPAP machine</td>
</tr>
<tr>
<td></td>
<td>If felt like it was 1 step forwards and 4 steps backwards</td>
</tr>
<tr>
<td></td>
<td>You have no control over the situation. They get sick. They get better. They get</td>
</tr>
<tr>
<td></td>
<td>sick again</td>
</tr>
<tr>
<td></td>
<td>He was eventually discharged with us still giving him oxygen at home</td>
</tr>
<tr>
<td></td>
<td>He finally came home but he was readmitted three months later</td>
</tr>
<tr>
<td></td>
<td>They said to me that there wasn’t going to be a problem</td>
</tr>
<tr>
<td></td>
<td>There was never a disaster</td>
</tr>
<tr>
<td></td>
<td>We never walked in and there was something going wrong or them saying that he</td>
</tr>
<tr>
<td></td>
<td>was regressing</td>
</tr>
<tr>
<td></td>
<td>He had to have a lazer operation</td>
</tr>
<tr>
<td></td>
<td>They said to me that they are doing fine</td>
</tr>
<tr>
<td></td>
<td>They had oxygen for three days</td>
</tr>
<tr>
<td></td>
<td>They were there for four weeks because they needed to put on weight.</td>
</tr>
<tr>
<td></td>
<td>They had oxygen starvation pre-birth so they had to give him some oxygen for a</td>
</tr>
<tr>
<td></td>
<td>day</td>
</tr>
<tr>
<td></td>
<td>She was the tiniest but she didn’t need oxygen</td>
</tr>
<tr>
<td></td>
<td>They said that they were fine and that there was nothing major</td>
</tr>
</tbody>
</table>
exposed to high concentrations of oxygen. The researcher cannot make assumptions regarding his medical condition and the intervention that he may have received during his hospitalisation in the NICU. These factors, however, will be taken into consideration in section 3, as the researcher will explore the influence that the infants’ medical condition may have had on the opportunities afforded their parents to develop infant-parent interaction during the NICU experience.

Penny’s parents and Vincent & Victoria’s parents reported that their infants were in a critical medical condition after their births. Penny’s parents had not received prior warning of the possibility that she may be born prematurely. As a result, her mother had not received medication to enhance the development of Penny’s lungs prior to her delivery, unlike a majority of the mothers in this study. Penny’s parents reported that they had been concerned about her medical condition throughout her hospitalisation as her mother stated that she had perceived Penny as a “tiny, little baby that was fighting”. Her parents commented that they had not seen significant progress in her medical condition and stated that after her discharge from the hospital she needed to be looked after like a “little puppy”. Their response to her medical status and progress in the NICU may be explained by the findings of Catlett et al. (1994:46). The results of their study indicated that the mothers perceived their premature infant’s medical condition as being worse than what they actually were, which they discussed as being related to the level of the mother’s anxiety.

Vincent & Victoria were born at 27 weeks gestational age. Their parents were informed after the twins’ births that the first 10 days of the NICU experience were the most critical. Vincent & Victoria’s mother reported that she felt that she had been ignorant during this time in spite of receiving information pertaining to risks that her infants faced. She stated that she had felt that her infants would not experience any difficulties, as they were on ventilators. Vincent & Victoria reportedly experienced serious medical complications that
required intensive and prolonged invasive intervention during their hospitalisation in the NICU. The parents commented that they had been concerned at times regarding their infants’ survival and the possibility that their twins’ may present with major disabilities. Vincent’s & Victoria’s parents further stated that they had felt that they had no control over their twins’ medical status, as the infants’ medical status fluctuated significantly during the acute phase of the NICU experience.

Vincent’s medical condition was reportedly more severe during the twins’ hospitalisation in the NICU and as a result, he was discharged from the NICU two weeks after Victoria. After his discharge, he remained medically fragile as he required oxygen during feedings and he reportedly was readmitted to the NICU three months after his initial discharge.

The medical status of the infants was taken into account in the analysis of the themes, which are presented in the following section.

**SECTION 2: THEMES**

The interviews yielded a tremendous amount of data regarding the participants’ experiences of their infant’s hospitalisation in the NICU. The researcher analysed the information obtained in accordance with the aims of this study. The various themes and sub-themes that emerged through the use of the constant comparative method of analysis are set out in Table 3.2.
Table 3.2. The themes and sub-themes that emerged from the data

<table>
<thead>
<tr>
<th>THEMES</th>
<th>SUB-THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>PREPAREDNESS</td>
<td>Preparedness of the NICU environment</td>
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<tr>
<td></td>
<td>Preparedness for their initial contact with their infants</td>
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<tr>
<td></td>
<td>Preparedness for parenthood</td>
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<tr>
<td></td>
<td>Preparedness for communication development</td>
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<tr>
<td></td>
<td>Preparedness for the infant’s discharge</td>
</tr>
<tr>
<td>CONTACT WITH THE INFANT</td>
<td>Touching and holding the infant</td>
</tr>
<tr>
<td></td>
<td>Kangaroo Mother Care</td>
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<tr>
<td></td>
<td>Feeding</td>
</tr>
<tr>
<td></td>
<td>Separation</td>
</tr>
<tr>
<td></td>
<td>Time spent in the NICU</td>
</tr>
<tr>
<td></td>
<td>Parental involvement in the NICU</td>
</tr>
<tr>
<td>BONDING</td>
<td>The prenatal phase</td>
</tr>
<tr>
<td>INFORMATION</td>
<td>The acute phase of hospitalisation</td>
</tr>
<tr>
<td></td>
<td>The convalescent and post-discharge phase</td>
</tr>
<tr>
<td>SUPPORT</td>
<td>Support received from the spouse</td>
</tr>
<tr>
<td></td>
<td>Support received from family members, friends and other parents of premature infants</td>
</tr>
<tr>
<td></td>
<td>Support received from the NICU staff</td>
</tr>
<tr>
<td>PREVIOUS PARENTING EXPERIENCES</td>
<td></td>
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</tbody>
</table>

**Theme 1: Preparedness**

Preparedness emerged as a consistent theme in the data. This finding is not at all surprising given the fact that prematurity is most often unexpected with parents having little or no time to prepare for the event (Allen, 1995:171; Gardener et al., 1998:676; Rossetti, 2001:61). Some parents, however, do get time to prepare for prematurity. The parents’ degree of preparedness for the premature delivery of their infants is laid out in Table 3.3.
Table 3.3. The parents’ degree of preparedness for the premature delivery of their infants (N = 6).

<table>
<thead>
<tr>
<th>Degree of preparedness</th>
<th>Number of parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipated</td>
<td>1</td>
</tr>
<tr>
<td>Prepared in advance</td>
<td>1</td>
</tr>
<tr>
<td>Prepared a few days before</td>
<td>3</td>
</tr>
<tr>
<td>Not prepared at all</td>
<td>1</td>
</tr>
</tbody>
</table>

The degree of the parent’s preparedness for the situation may be influential in the manner in which they cope and react to the situation. Parents that have received prior warning regarding the possible premature delivery of their infant are considered to experience anticipatory grief, which serves to both prepare and protect the individual from the pain of the impending loss of their ‘ideal’ child (Gardner, et al., 1998:674). As a result, the parent begins to psychologically prepare for the anticipated traumatic event and thus may adapt more easily to the challenges that they may confront.

In the present study, Lisa & Luke’s mother had anticipated that they would be born prematurely as she was aware that prematurity is a common risk in multiple births (Wyly, 1995a:14; Pompa, 1996:130; Rossetti, 2001:19). She described how her “bags were packed” even before her gynaecologist had warned her that the babies may be born prematurely. The anticipation of the premature infant may not, however, truly prepare the parent for the event, as they do not have a previous point of reference on which they can base their experience. This sense of not being completely prepared for the situation was expressed by Luke & Lisa’s mother as she stated that she had cried when she realised that she was unable to hold her infants after their birth. Her response to the few opportunities afforded her in having early contact with her twins suggests that she may have anticipated the need for their hospitalisation in the NICU but had not necessarily been aware of the consequences of their premature delivery on her ability to engage with the infants.
The responses presented by the parents that had received a few days warning prior to the premature delivery of their infants reflected a sense of limited preparedness for event.

Victoria & Vincent’s father reported that he knew that they would be born prematurely but not at that particular point in time, which was also portrayed in the reactions of the other parents. The three families stated that in spite of being informed of the risks associated with the mother’s medical condition, the sudden delivery of their infants resulted in them feeling in a “flat spin” and overwhelmed by the situation. The reactions of these parents may be as a result of them not being prepared for the premature delivery of their infants as they had been unable to perceive and process the reality of the event at the time that they were informed of the risk for prematurity.

The information that parents receive prior to delivery of their premature infants may influence their reactions and manner of coping with the situation. In the present study, Erica & Emily’s mother stated that she had gone into labour 5 weeks before their delivery and had been informed by her gynaecologist that her twins would present with fewer complications if the pregnancy could be maintained until after 30 weeks. Emily & Erica were born in the 32nd week of the pregnancy, which their mother reported assisted her in feeling at ease on the morning that they were delivered as she believed that “everything would be okay” with her infants.

The information that parents receive prior to the delivery of their infants is viewed as being valuable in providing them with a sense of mastery during a time in which they are feeling out of control and emotionally vulnerable (Siegal et al., 1998:656). The degree of preparedness of parents for the NICU environment is an important factor to consider as this environment has been described as being a source of stress (Wereszczak, et al., 1997:36) as parents of premature infants are presented with unfamiliar technology, a new medical language and a need to adapt their anticipated parenting role in the NICU (Siegal et al, 1998:662). Their reactions to the situation need to be considered as they may
influence their patterns of interaction with their infants and the desire to be involved in caregiving routines (Loo, Espinosa, Tyler & Howard, 2003:33).

**Preparedness for the NICU environment**

All of the participants in this study reported that they had to wait for the necessary medical procedures to be conducted on their infants before they were granted access to the NICU. During this delay, a majority of the participants reported that they felt overwhelmed by the rapid progression of events after their infant’s birth and uncertainty regarding their infant’s medical condition. A comment made by Michael’s father highlights these initial reactions: “You’re in a flat spin because you don’t know where he is going, what they are going to do to him and if he is going to be okay”. Additional responses provided by the parents after the birth of their infants portrayed emotions of uncertainty and concern are presented in Table 3.4.

**Table 3.4. Examples of the responses made by the parents after their infant’s birth before they were able to enter the NICU**

<table>
<thead>
<tr>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are so many things that go through your mind</td>
</tr>
<tr>
<td>It’s very daunting knowing that your child is going to the NICU</td>
</tr>
<tr>
<td>You don’t know what’s happening and if she will be okay</td>
</tr>
<tr>
<td>…uncertain of what lies ahead</td>
</tr>
<tr>
<td>…didn’t know what to expect</td>
</tr>
<tr>
<td>…didn’t have the slightest idea of what was waiting for me behind those doors</td>
</tr>
<tr>
<td>You don’t have a clue about what’s next, what to do and what you should do to prepare yourself</td>
</tr>
<tr>
<td>Half the battle is won if I know what the war is that I am going to fight</td>
</tr>
</tbody>
</table>

The sudden and unexpected delivery of the infant may result in parents being thrust into parenthood with an overwhelming sense of a loss in control (Siegal et al., 1998:658). A study conducted Wereszcak and her colleagues (1997:36) reported that parents identified the uncertainty of the infant’s outcome and concern about the severity of the infant’s
illness after the delivery as being one of the most stressful experiences. Information has been noted as being important during the prenatal and acute phases of the NICU experience as it provides parents with a locus of control that reduces stress (Wereszczak et al., 1998:36). In addition, the provision of information assists parents in appreciating the reality of the situation, begin the grief process and mobilise support (Gardner et al., 1998:691).

A majority of the parents reported that they experienced their initial visit to the NICU as being overwhelming due to the unfamiliar technology and the alarms on the monitors. The initial reactions of the parents are clearly highlighted by a comment made by Gavin's mother who described her initial visit to the NICU as being a “shock to the system”. The reactions of the parents to the NICU environment and the appearance of their infants may result in parents experiencing a state of shock (Allen, 1995:183; Klaus et al., 1995:119; Gardner et al, 1998:689; Meyer & Bigsby, 2004:171), which may impact on their ability to obtain and retain information (Brazy et al., 2001:41). This reaction to the NICU experience was identified in Penny’s mother. She stated that Penny was in a glass room away from the other infants, which she perceived as indicating that her infant was in a chronic medical condition and thus may die. Penny’s mother reported that she subsequently was in a state of shock resulting in her being unable to listen to the information provided by the paediatrician regarding Penny’s medical condition. Her response to the situation appeared to be heightened in comparison to those reported by the other participants, which may be as a result of Penny’s family having received no prior warning of the possibility for her premature delivery.

Gardener et al. (1998:689) state that previous orientation to the physical environment and technical equipment in the NICU eases the parent’s adjustment to the situation, which was identified in Gavin’s father’s responses to the NICU. Gavin’s father was noted, as being the only parent that was able to view the NICU prior to the delivery of his son. He stated that he had been shown the incubator where Gavin would be situated in the NICU and had
been informed of the necessary medical procedures that would occur after his son’s birth. He commented that he had felt at ease knowing that his son would be in “good hands” and stated that his first visit to the NICU after Gavin’s birth had not been stressful, as he knew what to expect. Gavin’s father, however, had been shocked at the size of his son, which is not surprising as Wereszczak and her colleagues (1997:35) had found that parents were distressed by the appearance of their premature infants in spite of receiving information in the prenatal stage.

Victoria & Vincent’s mother reported that she had previous experience of the appearance of a NICU setting, as she had worked as a dietician in this environment. She stated that she perceived that her knowledge and understanding of the nature of a NICU had resulted in her coping better than that of her husband during their initial visit, as she “knew what lay behind the doors”. Victoria & Vincent’s mother, however, reported that she was in a state of disbelief when seeing her infants for the first time as she commented that she had never seen premature infants like hers before. Her response regarding their appearance might be related to maternal investment in her infants rather than an unfamiliarity with the appearance of premature infants. However, as Victoria & Vincent were delivered at 27 weeks gestational age, their mother may not have previously been exposed to infants of such small gestational age in the NICU in which she had previously worked.

Parents are often faced with an additional stressor during their initial visit to the NICU, as this time may be the first occasion that they are able to see their infants. As identified in a study conducted by Shields-Poë & Pinelli (1997:34), parents perceive their initial contact with their infant within the NICU environment as being more stressful than if seen immediately after the birth. Parents thus need to be prepared for what they will see, hear and feel during their initial visit to the NICU (Gardner et al., 1998:695).
Preparedness for their initial contact with their infants

Klaus et al., (1995: 118), indicate that the initial visit to the NICU is important for both the infant and the mother as the infant requires contact with the caregiver and the mother needs to overcome her feelings of guilt in delivering an ‘imperfect’ child. Parents, however, need to be prepared for the appearance of their infant and the infant’s medical condition as the initial perceptions of the parents regarding their premature infants may be influential in the development of bonds of attachment and their desire to engage in interaction with their infants (Wyly, 1995e:153).

All of the mothers in this study reported that they had to wait a few hours before they were able to see their infants, whereas the fathers of the infants were provided access to their infants once the necessary medical procedures had been performed and thus were able to inform their wives of their infant’s medical condition. Penny’s mother, however, stated that in spite of her husband’s account of the situation, she remained uncertain of her daughter’s medical condition and the procedures that were being conducted. Her response may suggest the need for information provided by a more knowledgeable source, such as a health professional as obtained by two mothers in this study. Erica & Emily, and Lisa & Luke’s mothers reported that a representative from the NICU had informed them, prior to their initial visit to the NICU, that their infants were in a stable medical condition and that their infants “would be okay”. These mothers stated that as a result, they were provided with a sense of comfort before entering the NICU.

The time delay experienced by the mother before seeing her infant may result in the mother developing fantasies regarding her infant’s medical condition and the worst possible scenario of her infant’s outcome (Gardner et al., 1998:695). The information that is provided by professionals prior to the mother’s initial visit might assist her degree of preparedness for the situation but as Klaus et al., (1995:120) describe mothers need to see
their infants in order to reconcile their images of their infants with their true physical condition.

A majority of the parents reported that they were in a state of shock and disbelief during their initial visit to the NICU due to the size of their infants and the numerous pipes and monitors that were attached to their infants. These reactions to the infant’s appearance were highlighted by a comment made by Michael’s father. He stated that he had been terrified by the appearance of his son as he felt that Michael did not look human due to the pipes that were attached to him and the pads that were placed over Michael’s eyes. Additional examples of the responses that were reported by the participants regarding their initial reactions to the appearance of their infants are laid out in Table 3.5.

<table>
<thead>
<tr>
<th>Table 3.5. Examples of the parents’ responses to the initial contact with their infants</th>
</tr>
</thead>
<tbody>
<tr>
<td>I couldn’t believe that this was my baby</td>
</tr>
<tr>
<td>I had seen prem babies in the NICU but never like this</td>
</tr>
<tr>
<td>You stand there in total disbelief</td>
</tr>
</tbody>
</table>

All parents of newborn infants expect to be met with a robust and responsive infant. Premature infants, however, are often unresponsive and medically fragile resulting in their parents having to adjust their expectations of the anticipated ‘perfect’ infant (Rossetti, 2001:X). Gardner et al., (1998:674-676), emphasise the need for parents to receive support during this time as the parent’s ability to effectively engage with the infant is affected by the time taken by the parent to grieve the loss of their ideal child (Gardner et al., 1998:674-676).

The emotional reactions of the parents during their initial visit to the NICU may hinder their ability to gather and process information as was identified in Penny’s mother. The acquisition of information at this stage of the NICU experience is considered to be of importance, as informed parents are equipped with tools that enable them to discuss the
situation between themselves and to engage in interaction with staff members and thus receive support to assist them in overcoming the challenges faced in the NICU (Allen, 1995:182; Siegal et al., 1998:656). In addition, the provision of information aids the parent in intellectually understanding the traumatic event and thus facilitates the parent in adjusting to the challenges faced in interacting with their infants in the NICU (Gardner et al., 1998:691).

**Preparedness for parenthood**

The birth of a premature infant may result in a disruption in the parent’s anticipated role as a parent as they may be afforded limited opportunities to have early contact with their infants and to be actively involved caregiving activities (Gardner et al, 1998:676; Rossetti, 2001:52-53). The loss of this role was identified in comments made by Gavin and Lisa & Luke’s mothers as both mothers reported being tearful when they realised that they would be unable to hold their infants. Lisa & Luke’s mother’s response to this situation may have been exacerbated by her previous parenting knowledge as she was familiar with the opportunities that are afforded parents of full-term infants, unlike Michael’s mother that reported that she did have any expectation regarding her role as a parent as she had no previous experiences on which to base her situation.

Emily & Erica’s mother reported that she had had no expectations of parenthood and as a result did not perceive the limited opportunities afforded her to have early contact with her infants as being an anti-climax. Gavin’s mother, however, stated that she had been disappointed when she had realised that she would be unable to have unrestricted contact with him as she had “expected more”. Her response to the situation may be related to greater expectations of parenthood, as she and her husband had experienced difficulty in falling pregnant.
Parents of newborn infants expect to fulfil the role of being the infant’s primary caregiver and thus parents of premature infants need to adjust to the nature of the care provided in the NICU. Vincent and Victoria’s mother expressed the loss of this parenting role as she stated that had “mixed emotions” during her initial visit to the NICU as she felt that she was not involved in the care of the infants in spite of their mother. Penny’s mother further highlighted this sense of parental exclusion in the care provided to the infant in the NICU. She reported frustration in the limited opportunities afforded her to be actively involved in the care of Penny during the initial stages of Penny’s hospitalisation, as she felt that she would have been able to perform the necessary caregiving routines with a similar degree of competence as provided by the NICU nurses.

*Preparedness for communicative development*

The literature widely acknowledges that premature infants may initially experience difficulty in effectively engaging with the environment due to their immature neurological and physiological systems and effects of their fragile medical condition (Klein & Briggs, 1987; Brown & Ruder, 1995:71; Robison & Gonzalez, 1999; Rossetti, 2001; Vergara & Bigsby, 2004a:9). As the development of synchronous infant-parent interaction may be impaired, parents of premature infants need to be provided with the necessary knowledge and guidance to overcome the difficulties that may arise.

A majority of the parents reported that they had been encouraged to talk to their infants during their visits to the NICU, which is encouraging, given recommendations made by Brown & Ruder (1995). Their study concluded that parents of premature infants engage less with their infants and their infants are less responsive in comparison to the synchronous infant-parent interaction including full-term infants. As a result, Brown & Ruder (1995:89) encouraged practices that assisted parents of premature infants in spending more time talking to their infants in order to improve the quality of interaction.
Premature infants, however, may present with disorganised behavioural states due to the immaturity of their neurological and physiological systems and the adverse effect of excessive stimulation within the environment (Wyly, Pfälzer & Speth, 1995:57-58; Rossetti, 2001:109-111; Vergara & Bigsby, 2004h:138-141). The development of infant-parent interaction is interrupted by the infant’s difficulties in effectively engaging with the parent as the parent may experience difficulty in reading the social cues provided by the infant as they may be weak or delayed in response to those provided by the parent (Rossetti, 2001:53). Parents of premature infants, thus need to be informed of opportune moments to engage with their infants in accordance with their behavioural states and to be assisted in adapting their interactional style to the infant’s own rhythms (Brazelton & Cramer, 1990:121).

All of the parents that were involved in this study reported that they had not been informed of their infant’s behavioural states and stated that they had been unaware of suitable times to engage with their infants. The impact that the infant’s behavioural state may have on the development of infant-parent interaction and the need for parents to be informed of the infant’s communicative limitations were highlighted by comments made by Michael’s parents. They reported that they had been initially encouraged by the NICU staff to talk to Michael during their visits. Michael’s parents, however, stated that they thought that their time with him was of little use, as they perceived their interaction with him as being similar to “talking to a person that’s sleeping”. Michael’s mother reported that she had been reluctant to talk to him, as she perceived that he was unable to hear her voice, as he was unresponsive.

Vincent & Victoria mother reported that she spent a majority of their time in the NICU talking to their infants as she had felt a strong need for her twins to learn to recognise her voice due to the presence of numerous caregivers within the NICU. She stated that during the initial stages of her infants’ hospitalisation, she felt that her twins would be oblivious to her absence as they appeared to be unresponsive to her presence. Vincent & Victoria’s
mother, however, commented that the time that she spent engaging with the infants was important in helping her to cope with their prematurity. Her attitude to the time spent interacting with her infants was similarly noted in a study conducted by Oehler, Hannan & Catlett (1993:71). Their results reflected that parents of premature infants viewed the time that they spent talking to their infants in the NICU as being beneficial regardless of the responses obtained from their infants. Furthermore, the results of the study indicated that these parents were encouraged by the knowledge that their infants were aware of their presence and valued the time provided to them in being able to tell their infants that they were loved and in becoming familiar with their infants’ behaviours.

Preparedness for the infant’s discharge

The role of parents of premature infants may evolve during the NICU experience from initially being passive observers to becoming actively involved in the care of their infants. As the NICU nursing staff often fulfil the primary caregiving role during the acute phase of the infant’s hospitalisation, parents need to be provided with the necessary skills and knowledge to feel adequately prepared for the responsibility of caring for the infant once at home (Siegal et al., 1998:668). Rossetti, (2001:183) suggests that after their infant’s discharge from the NICU, parents are expected to care for their infants as though the infant is similar to that of a full-term infant. The transition home for parents and their infants, however, poses a unique set of concerns (Barker, 1991:50) and thus the NICU staff need to assist parents into their role of active parenting (vandenBerg, 1999:57).

All of the parents in the study reported that the NICU nursing staff had encouraged them to become actively involved in the caregiving routines during the convalescent phase and prior to their infant’s discharge. Examples of the preparation received by the parents for their infant’s discharge from the NICU is presented in Table 3.6.
Table 3.6. Examples of the parents’ responses regarding their preparation for the infants’ discharge from the NICU

|__________________________________________________________________________|
|...I have to feel comfortable in taking her home                           |
|...you must know everything about her                                     |
|I went in closer to the time that she came home so they could show me everything |
|They told us what to expect there and in all possible situations          |
|They were pushing you to do it because you have to care for them afterwards|
|They would say “right, it’s your responsibility”                          |

A majority of the parents reported that they felt that they were adequately prepared for their infant’s discharge from the NICU and stated that they benefited from the professional assistance that they received in learning to care for their infants. Parents of premature infants need to feel a sense of competence in relating to their infants and in being able to meet their needs in order to continue the development of attachment and infant-parent interaction (Siegal et al., 1998:668).

Emily & Erica’s mother reported that she had “mixed emotions” at the time to which her twins were discharged from the NICU. She stated that she had been elated to be able to take her twins home but had later felt deflated as she realised that she was primarily responsible for the care of her infants. Emily & Erica’s mother commented that she found the first few days after their discharge to be the most stressful time of her NICU experience as she felt alone and was wary of her capabilities as a caregiver. She reported that she had wished that one of the NICU nursing staff had visited her at home after Emily & Erica’s discharge in order to reassure her that her abilities as a mother and that of her home environment were suitable to provide care for her infants. These feelings of ambivalence regarding the infant’s discharge from the NICU and concern of parental competence are not uncommon according to the themes that emerged through an investigation conducted by Barker (1991:50) regarding the experiences of parents during the discharge phase of the NICU experience. Furthermore, a study performed by Bruns, McCollum & Cohen-Addad, (1999:282) described the series of caregiving roles identified in mothers of premature
infants during the NICU experience. They noted that the mother’s initial role as a worrier during the acute stage of the infant’s hospitalisation turns full circle in reoccurring during the pre-discharge stage. The anxiety identified in mothers at this stage is described as relating to apprehension regarding her role as primary caregiver and concern about the limited time provided to prepare their homes as well as themselves for the infant’s discharge.

Previous parenting knowledge and experience may assist the parent’s reaction to the infant’s discharge. Lisa & Luke’s parents reported minimal difficulty in being able to meet their infant’s caregiving needs after their discharge, whereas all of the remaining parents reported various degrees of concern regarding their parenting abilities. A comment made by Penny’s father emphasises the stress that that first time parents may experience during the NICU experience and after the infant’s discharge “...for first time parents it is difficult and then the ICU and then the baby. It all becomes too much”.

The support that parents receive at the time of their infant’s discharge from the NICU is considered to influence their degree of preparedness and the manner of coping with the event (Scharer & Brooks, 1994:44). Brazy et al. (2001) describe that the parents’ primary sources of support evolve during the NICU experience in a circular manner as the support received from family members is deemed of importance during the prenatal and post-discharge phases. A majority of the participants stated that they received support from family members and friends after their infants’ discharge pertaining to concerns regarding suitable caregiving. Erica & Emily’s mother, however, reported that she felt that perceived the support that her mother could provide was of little value as she stated that her mother’s experiences were different to hers as her mother had not brought up twins that had received care in the NICU. This mother regarded the care that her infants needed as being unique and thus had desired the support from the NICU nursing staff.
The support received from the NICU staff members, in particular that of the nursing staff, is viewed as being of importance after the infant’s discharge as identified in the responses made by all of the participants. They reported that they had felt a sense of comfort in knowing that they were able to contact the NICU at anytime in the event that they required assistance.

**Theme 2: Contact with the infant**

A second theme to emerge from the analysis of the data was contact with the infant. The literature widely describes the negative effect that the infant’s medical condition, the NICU environment and the challenges faced by the parents during the NICU experience have on the development of bonds of attachment and infant-parent interaction (Klaus et al., 1995:114; Wyly, 1995e:150-159; Als, 1997:52-53; Siegal et al., 1998:567; Rossetti, 2001:62; Meyer & Bigsby, 2004:171-172; Vergara & Bigsby, 2004e:72). The following sub-themes were identified within this theme:

- Touching and holding the infant
- Kangaroo Mother Care
- Feeding
- Separation from the infant
- Time spent in the NICU
- Involvement in the NICU

**Touching and holding the infant**

Most parents anticipate their parenting role after the birth of their infants and expect to be able to hold their infants in an en face position immediately after the delivery. Klaus et al., (1995:58) describe this time spent between the mother and the infant as being an important
moment in the development of attachment, in addition to marking the beginning of synchronous infant-parent interaction. Parents of premature infants, however, are usually not afforded the opportunity for this early contact due to the infant’s fragile medical condition and need to receive intervention within the NICU.

A majority of the parents reported that they were able to touch their infants on his or her hands and feet during their initial visit to the NICU. Penny’s parents and Vincent & Victoria’s parents stated that they were unable to touch their infants during the initial stages of the acute phase of the NICU experience due to the infants’ unstable medical condition. Penny’s mother expressed that her early contact with her daughter was controlled by the NICU staff’s orientation to her restricted contact as she stated that a few of the nursing staff would encourage her to touch Penny by saying “nobody’s looking, you can touch her hand or something”.

Siegal et al., (1998:651) report that parents of premature infants may experience “empty arms” due to their inability to hold and cuddle their infants. They state that the contact that parents have in touching and exploring their infants does not completely satisfy the species-specific behaviour of touch until being able to hold their infants. All of the parents in the study reported that they were unable to hold their infants until their infant’s medical condition had stabilised within the NICU. The time waited by the parents before being able to hold and cuddle their infants varied from a few days to more than a month.

The researcher organised the responses obtained from the parents that reflected their reactions to the restricted contact that they had with their infants into 4 categories according to her own interpretation of the comments. These categories were disappointment, depression, injustice and desire. Examples of the comments made by the parents that highlight these categories are presented in Table 3.7.
Table 3.7. Examples of comments made by the parents regarding their inability to initially hold their infants

<table>
<thead>
<tr>
<th>Depression</th>
<th>You feel depressed as you can’t hold, can’t touch, can’t feed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disappointment</td>
<td>It was tough because you expect more</td>
</tr>
<tr>
<td></td>
<td>I couldn’t hold them the first time and I was very tearful</td>
</tr>
<tr>
<td>Desire</td>
<td>You just want to at least feel your baby</td>
</tr>
<tr>
<td></td>
<td>I would have liked to have picked her up earlier that what they allowed us to</td>
</tr>
<tr>
<td></td>
<td>In the beginning, it’s fine not to touch but after a week or so, it’s very hard</td>
</tr>
<tr>
<td>Injustice</td>
<td>Why were they allowed to touch her, bath her and all of that and I wasn’t allowed to from the beginning?</td>
</tr>
</tbody>
</table>

The limited opportunities afforded parents to hold their infants may impact on their ability to engage with the infant and their willingness to participate in caregiving activities as identified in comments made by Michael’s parents. His mother’s remarks suggest that she felt a sense of being dangerous during the initial stages of the NICU experience as she stated that she had taken it for granted that it was not safe for her to hold him. Her response to the situation is not uncommon, as according to Rossetti (2001:71) restricted contact with the infant, a sense of unfamiliarity of the NICU environment and a perceived sense of incompetence may result in parents of premature infants feeling dangerous. Michael’s father reflected a similar attitude as he reported that he had no ambition to hold Michael during the first two weeks as he feared that he would cause his son additional harm. His response suggested a fear to hold his son and to establish bonds of attachment. This fear appeared to be based on firstly uncertainty regarding his infant’s survival and secondly a perception of his own incompetence in an unfamiliar, medical environment.
Kangaroo Mother Care (KMC)

The limited opportunities afforded parents to have early contact with their infants may negatively impact on their ability to establish bonds of attachment and their desire to engage in interaction with their infants. A technique of care, Kangaroo Mother Care, has been documented as reducing the effects of these challenges faced by both infants and their parents in the NICU and in promoting positive infant-parent interaction (Affonso, Bosque, Wahlberg, Brady, 1993:31; Wyly, 1995d:98; Kirsten, Bergman & Hann, 2001:444; Rossetti, 2001:191; Vergara & Bigsby, 2004b:25). In light of the benefits of KMC, it was not surprising that this sub-theme emerged from the analysis of the data.

Kangaroo Mother Care (KMC) is defined as “skin-to-skin contact between the mother and the low birth weight infant in a hospital setting” (Kirsten, et al., 2001:443). This method of care is considered to facilitate the development of socio-communicative interaction as it improves the medical well being of the infant and assists in the infant’s ability to organise his or her behaviour states resulting in increased states of alertness (Rossetti, 2001:191). In addition, KMC is considered to enhance infant-mother bonding by increasing the mother’s self-esteem and sense of competence in being able to provide care for her infant (Affonso, et al., 1993:31).

All of the parents in this study reported that they were familiar with the term “Kangaroo Mother Care”. A majority of the parents stated that they had been informed of this technique whilst their infants were in the NICU by the nursing staff, whereas Michael’s mother reported that she had read about KMC in a book. In spite of the parents’ familiarity with this technique, only Victoria & Vincent’s family and Gavin’s family were involved in providing KMC to their infants.

Gavin’s mother reported that she had been provided with frequent opportunities to provide KMC in the week prior to his discharge. She stated that she had enjoyed the time in which
she was involved in providing KMC but did not feel that this opportunity had enhanced her
sense of attachment to Gavin and her ability to communicate with him as she felt that these
aspects had already been established.

Vincent and Victoria’s mother expressed disappointment in the opportunities afforded her
to provide KMC as she stated she had relied on the nursing staff to initiate the provision of
this care. She reported that she had hope that there would have been a time during the day
in which KMC was provided, as she felt awkward in asking the staff for their permission to
engage with her infants in this manner.

Many of the parents involved in this study reported that they felt that the NICU nursing
staff did not encourage KMC resulting in their inability to provide this method of care.
Penny’s mother, however, reported that one of the nurses had encouraged her to provide
KMC during the week prior to her daughter’s discharge. She stated that she had perceived
that her involvement in this care to be useless, as she felt that the practice KMC should
have been introduced earlier as she perceived that it was too late for her to bond with her
daughter.

A majority of the parents expressed enthusiasm about the concept of KMC and reported
disappointment in not been able to provide this method of care whilst their infants were in
the NICU. Examples of their responses regarding their attitudes to KMC are presented in
Table 3.8.

**Table 3.8. Examples of the parents’ attitudes towards the implementation of
Kangaroo Mother Care**

| I thought that it was a brilliant idea |
| …that would have been nice             |
| I would have liked more               |
| Maybe they could do a bit more of that in the NICU |
The varied availability of opportunities afforded parents to provide KMC could be related to numerous factors. One of the reasons may be the availability of the NICU nursing staff as Gavin’s mother had reported that at the time of his admission to the NICU, he was one of three infants receiving care. His parents stated that they considered this situation to advantageous, as they stated that the nursing staff were always available to be of assistance. Kirsten et al., (2001:446) state that the success of KMC relies on the availability of and support from the NICU staff, as the parents require assistance in successfully implementing KMC techniques and need encouragement to overcome their apprehension about harming their infants.

An additional reason for the discrepancy in the opportunities afforded the parents to practice KMC may be attributed to the degree of risk faced by the infant and his or her parents in developing poor attachment and interaction. Victoria & Vincent were delivered at 27 weeks gestational age thus requiring intensive intervention and prolonged hospitalisation in the NICU. As a result, their parents were at a greater risk for experiencing difficulty in bonding and successfully interacting with their infants in comparison to that of the other parents (Rossetti, 2001:6). The NICU staff may have acknowledged the additional challenges faced by this family and thus implemented the practice of KMC.

The practice of KMC originated in Bogota, Columbia in 1978 in response to limited resources available for neonatal care. The benefits of KMC on both the infant and mothers well-being have been widely acknowledged in literature and this method of caregiving has been implemented in numerous modern technological NICUs in developed countries (Affonso et al., 1993:25; Wyly, 1995d:98; Klaus et al., 1995:131-132; Siegal et al., 1998:664-665; Kirsten et al, 2001:444; Rossetti, 2001:191; Vergara & Bigsby, 2004b:25).

The limited opportunities afforded the parents in this study to practice KMC, however, may be related to the philosophy of care provided within NICUs in South Africa. Family-
centered care within NICUs in South Africa is in its infancy stage in being implemented and as there are no national guidelines describing appropriate neonatal care, there is little standardisation of the care provided in NICUs (Cooper, 1999:1160). In addition, Pattinson (2003a:435) states that there is a paucity of information and training courses available to professionals working within NICUs in South Africa in order to obtain the necessary skills to successfully implement practices of KMC within this environment. The success of two KMC programs implemented at state tendered hospitals in South Africa, however, has been documented (Hann et al., 1999:37-39; van Rooyen et al., 2002:6-10) and programs of a similar nature reportedly have been established at other large academic hospitals. There, however, is a paucity of literature regarding the practices of KMC in private sector institutions.

**Feeding**

A sub-theme of feeding arose through the analysis of the data, which was not unexpected as the time spent feeding the infant has been accepted as being an ideal opportunity for infant-parent interaction (Brazelton & Cramer, 1990:52; Klaus et al., 1995:86; Rossetti, 2001:53).

Parents of premature infants, however, may be denied this opportunity to establish a relationship with their infants, as the infant may be neurologically and developmentally immature resulting in the need for enteral feedings (Wall, 1996:66). Jones, et al. (2002:56) state that the feeding difficulties presented by premature infants may result in their parents feeling inept in their ability to nourish and nurture the infant and thus a further breakdown in interaction may occur as the mother withdraws from the care provided to the infant.

All of the infants in this study were reportedly fed via a naso-gastric tube until they were medically stable and at a developmentally appropriate age for feeding. Gavin, Lisa and Luke were described as experiencing minimal difficulty during the transfer to oral feeding,
whereas the remaining infants reportedly presented with various feeding problems that ranged in severity. These reported difficulties are laid out in Table 3.9.

**Table 3.9. Reported feeding difficulties experienced by the infants during the NICU experience (N=9).**

<table>
<thead>
<tr>
<th>REPORTED FEEDING DIFFICULTIES</th>
<th>NUMBER OF CHILDREN</th>
</tr>
</thead>
<tbody>
<tr>
<td>No difficulties</td>
<td>3</td>
</tr>
<tr>
<td>Lazy to suck</td>
<td>5</td>
</tr>
<tr>
<td>Couldn’t latch onto the nipple</td>
<td>3</td>
</tr>
<tr>
<td>Fell asleep during feeds</td>
<td>4</td>
</tr>
<tr>
<td>Peptic ulcers</td>
<td>2</td>
</tr>
<tr>
<td>Battled with textured food</td>
<td>2</td>
</tr>
</tbody>
</table>

*Note:* Numbers do not add up to 9, as some children reportedly presented with more than one feeding difficulty.

A majority of the parents reported that their infants’ feeding difficulties were related to their infant being “lazy to suck”, unable to effectively latch onto the nipple, and/or due to fatigue during feeds. The feeding problems described by the parents are not surprising as infants that are born less than 34 weeks and particularly those less than 28 weeks gestation frequently experience feeding difficulties due to their underdeveloped systems and the effects of their medical conditions (Comrie & Helm, 1997:242).

Victoria and Vincent’s parents reported that their twins were initially fed intravenously and that their infants developed peptic ulcers at the time in which milk was introduced during enteral feedings. As a result, Victoria & Vincent alternated between intravenous and enteral feedings on a weekly basis until their medical condition had stabilised. Victoria reportedly did not experience any difficulty in transferring from enteral to oral feeding. Vincent, however, was described as being chronically ill during the acute phase of his hospitalisation, including that of respiratory problems. As a result, he needed to receive oxygen during feedings until two months after his discharge from the NICU. Both infants
were introduced to solid food prior to their discharge and reportedly experienced difficulty in tolerating these feedings.

The feeding problems experienced by Vincent & Victoria are not unexpected as they are commonly identified in infants of extremely low birth weights and small gestational ages due to the degree of immaturity of their systems and their need for prolonged hospitalisation and intensive intervention in the NICU (Arvedson & Brodsky, 2003:303;416). The influence of the necessary invasive medical intervention that Vincent & Victoria received may have exacerbated their ability to tolerate solid feedings as discussed by Comrie & Helm, (1997:244), infants that have received aversive oral/ facial sensory input are at increased risk of developing tactile defensiveness and oral hypersensitivity.

Vincent required prolonged ventilation and highly concentrated oxygen during the acute phase of his hospitalisation in the NICU due to respiratory difficulties, which as documented in a study conducted by Oliver, Forcht & Lawrence, (1998:224), placed him at increased risk for feeding and swallowing difficulties. Vincent reportedly fatigued easily during feedings, which may be associated with the medical difficulties that he experienced as he may have not had the necessary sufficient stamina and endurance for effective feeding (Comrie & Helm, 1997:250).

A majority of the parents reported that they continued to experience difficulty in feeding their infants after their discharge from the NICU. Premature infants are frequently discharged earlier from the NICU in relation to their weight, gestational age and medical stability and as a result, may continue to present with difficulties, including that of feeding, that are related to their prematurity and their hospitalisation in the NICU after their discharge (Vergara & Bigsby, 2004i:247).
Parents of premature infants may feel a loss in their parenting role as a result of the feeding difficulties presented by their infants in the NICU. Shellbarger & Thompson (1993:39) promote activities that encourage the involvement of parents in feeding their infants during the NICU experience. They state that the active participation of parent in providing care to their infants may reduce their feelings of helplessness and frustration, facilitate their identification with their role as parents and thus encourage the development of infant-parent interaction.

Two mothers in this study expressed their attitudes towards their involvement in feeding their infants. Victoria & Vincent’s mother reported that she felt included during her twins’ enteral feedings, as she stated that she could put the milk in the tube and thus felt that she was making a contribution. Emily & Erica’s mother, however, reported that she perceived that her presence during their feeds was pointless. She stated that she felt excluded and perceived that she did not have a role to fulfil as the nursing staff would feed her infants from the bottle and then place the milk that was remaining into the naso-gastric tube. The involvement of parents of premature infants in caring for their infants is acknowledged as facilitating the development of interaction and attachment. Parents of premature infants, however, may feel disenfranchised in their role in parenting to the active involvement of the NICU staff and thus Rossetti, (2001:76), suggests that parents be “put to work” within the NICU in order to obtain a sense of accomplishment and franchiseimento in the infant’s care.

Thoyre (2001:41) states that prior to the infant’s discharge parents need to be proficient at feeding their infants and emotionally ready to take on the responsibility for this caregiving activity. The NICU nursing staff are considered to play an important role in preparing parents for the care that needs to be provided to their infants once at home. All of the parents in this study stated that they had been encouraged by the NICU nursing staff to be involved in feeding their infants prior to their infant’s discharge. Michael’s mother reported that the staff had been informative in explaining his feeding difficulties and had
provided her with techniques to facilitate his ability to effectively feed. Victoria & Vincent’s mother, however, expressed frustration in the limited information that she had received from the NICU staff regarding additional feeding difficulties that may arise, oral-sensory problems and knowledge regarding professionals that could be of assistance.

Parents of premature infants need to be informed of the challenges faced by premature infants in being able to feed orally and need to be provided with adequate information to assist their decision regarding whether the infant will be bottle or breast fed (Siegal et al., 1998:657). Mothers of premature infants may express their milk in order to provide their infants due to its highly nutritional value and ease in digestion or in preparation for later breast-feeding. The development of infant-parent attachment may be enhanced in mothers that express their milk. Mothers that are unable to feed their infants may feel that through providing the infant with expressed milk, she is able to contribute to the infant’s care in a unique manner and thus may feel a sense of control in the caregiving activity (Gardner, Snell & Lawrence, 1998:336).

All of the mothers in this study reported that they had expressed their milk during the initial stages of the NICU experience but that they had all bottle-feed their infants with formula when oral feeding was introduced. The mothers reportedly stopped expressing their milk for numerous reasons. The parents of the sets of twins stated that they had decided to bottle feed their infants during the pregnancy due to convenience. Michael’s mother reported that she had experienced difficulty in producing milk and thus had stopped expressing her milk after a few days.

Two of the mothers stated that they had expected to be able to breast-feed their infants. Gavin’s mother reported that she chose to stop expressing her milk and to bottle-feed her son when made aware of the duration that she would have to wait before being able to breast-feed him. She commented that she had been disappointed but stated that she felt that her role as a mother had been fulfilled during the time that she was pumping. Penny’s
mother reported that she had wanted to breast-feed her daughter but stated that she had been frustrated during the NICU experience. She reported that Penny had been fed with formula milk rather than expressed milk and thus stated that she had stopped expressing her milk, as she perceived her efforts as being pointless.

Separation

Mothers of newborn infants anticipate that they will be able to have unrestricted and unlimited access to their babies and be able to take their infants home with them at the time of their discharge (Rossetti, 2001:63). The premature delivery of an infant results in the infant being immediately admitted into the NICU and thus the close contact between the mother and the infant is interrupted and opportunities for interaction are reduced (Nyström & Axelsson, 2002:275).

Gavin’s mother expressed a sense of loss as she stated that her most difficulty time during the NICU experience was leaving the hospital without her son. She reported that she visited Gavin every day in the NICU but expressed that her need to take him home remained constant. Similar experiences of mothers of premature infants to the infant-parent separation were identified in a study conducted by Nyström & Axelsson (2002). They described that mothers of premature infants feel a sense of disappointment in separated from their infants, as they perceived that their anticipated role in motherhood and their symbiosis with their infants have been interrupted. Furthermore, Nyström & Axelsson, (2002:279), state that the mother experiences despair in repeatedly being separated from their infants and a sense of powerless in assuming her role of mother. Erica’s, Emily’s and Michaels’ mothers, however, stated that they had felt impartial to their separation from their infants as they reported they had no expectations of their role as parents and had no previous experiences to base theirs upon. Gavin’s mother’s reaction to her separation from her son may be associated to her increased anticipation of his birth and
her role in motherhood, as she and her husband had experienced difficulty in falling pregnant.

The development of infant-parent relationships may be influenced by the separation of the mother and infant during the NICU experience as Holmes (1993:51) describes that parents that are separated from their infants after their birth may feel less competent and confident in their role in mothering. Lisa’s mother expressed that she had been concerned that due to their separation, she and her daughter would experience difficulty in bonding with each other.

Nyström & Axelsson (2002:278) reported that all of the mothers expressed a desire for closeness with their infants, which was identified in comments made by Victoria & Vincent’s father regarding his time spent in the NICU. He stated that he had found the time that he spent with his infants in the NICU as being healing and comforting and a means of coping challenges faced during the NICU experience.

*Time spent in the NICU*

The time spend by parents within the NICU is the foundation for future parent-infant attachment, as they are provided with opportunities to become familiar with the infant through been involved in caregiving routines (Griffin, 1999:75). Furthermore, through spending time in the NICU, parents are able to receive support from NICU staff members and other parents of premature infants that may assists in the manner in which they cope with the situation (Brazy et al., 2001:46).

The parents in this study reportedly spent various amounts of time within the NICU. A majority of the mothers stated that they spent their days with their infants in the NICU and that they would later travel through to the hospital with their husbands in the evening.
The time that the parents spend in the NICU may be influenced by their perceived role within the environment. The researcher identified 7 attitudes from the comments made by the parents in this study regarding their time spent in the NICU. These attitudes were placed into categories according to the researcher’s interpretation of the data and they are presented in Table 3.10.

**Table 3.10. Examples of comments made by the parents reflecting their attitudes to their time spent in the NICU**

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helpful</td>
<td>It helped to bond with the babies</td>
</tr>
<tr>
<td>Comforting</td>
<td>…felt comfort in keeping close to the babies</td>
</tr>
<tr>
<td>Healing</td>
<td>It was part of the healing process</td>
</tr>
<tr>
<td>Supportive</td>
<td>…you talk to the staff and try and share some of your feelings</td>
</tr>
<tr>
<td>Pointless</td>
<td>It’s boring to just look at him sleeping</td>
</tr>
<tr>
<td>Useless</td>
<td>I just felt like I wasn’t making a contribution</td>
</tr>
<tr>
<td>Stressful</td>
<td>The longer you sit there, the more you stress out</td>
</tr>
</tbody>
</table>

Vincent & Victoria’s father described the amount of time that he spent in the NICU as being “almost 24 hours of the day”. He stated that the numerous hours that he spent in the NICU created expectations of his infants’ well being and thus he reported that he became “emotionally bruised” as a result of travelling through “emotional ups and downs” in response to his infants’ fluctuating medical condition. Vincent & Victoria’s father, however, reported that he perceived the time that he spent in the NICU as being supportive as he was provided with the opportunity to discuss his feelings with individuals that were able to empathise with his experiences.

Michael’s parents reported that they visited him each day in the NICU but that they spent little time in the NICU. They stated that they perceived the NICU as being a stressful environment due to the alarms on the machinery and their exposure to other infants in chronic medical conditions. Michael’s mother reported that she went back to work after
her discharge from the hospital as she felt that her time in the NICU during the acute phase was useless, as she perceived that she had no role to fulfil in caring for her son. In addition, Michael’s parents reported that they had found their time during the initial phase of his hospitalisation was pointless, as he was unresponsive and impervious to their presence. His parents, however, stated that they spent more time in the NICU prior to his discharge, as they became more involved in the caregiving routines.

A majority of the fathers in this study commented that they found the routine of working full-time and spending their evenings in the NICU to be tiring, as aptly stated by Lisa & Luke’s father in saying “they were very long weeks and very long days”. Furthermore, the parents stated that they were in a continual rush to get to the NICU at night, which resulted in them spending limited time together. All of the parents as a result reported that there were a few nights during the NICU experience in which they did not go through to the NICU as they felt that they needed to break the “mad rush” and stay at home to “recharge their batteries”.

Two families reported that they were faced with an additional stressor as one of their infants was discharged earlier than their sibling. Victoria & Vincent’s parents stated that their infants’ separation resulted in them being unable to spend the same quantity of time within the NICU, as they had to halve their available time between their infants. A comment made by their father emphasises the stress that the family occurred during this time: “there is only one thing worse than having your babies in hospital and that is having one in hospital and one at home. That’s absolutely traumatic because you now are spending half the time with each one and they are aware that you should be around and you are not there”.

Luke and Lisa’s mother reported that she had to “keep her head together”, as she stated that she had to focus her time on Luke and her older daughter at home, whilst trying to not worry about Lisa in the NICU. Their mother stated that she and her husband shared the
responsibility of looking after their children and thus was only able to see Lisa in the NICU every alternate night.

Penny’s father reported an additional stressor that influenced the amount of time that he spent in the NICU. He stated that he worked on a full-time basis and needed to complete the renovations on their home before Penny was discharged from the NICU. Penny’s father reported that the NICU nursing staff had encouraged him to participate in his daughters care towards the end of her hospitalisation but was not involved as he stated that he had felt that he was too busy.

_Parental involvement in the NICU_

The sub-theme of parental involvement in the NICU emerged through the analysis of the data. The importance of the active participation of parents in the care provided to their premature infants during their infant’s hospitalisation in the NICU has been widely acknowledged (Wyly, 1995d:88; Moehn & Rossetti, 1996:243; Burns & Brown, 1998:67; vandenBerg, 1999:58; Rossetti, 2001:76; Beal & Quinn, 2002:188; Ritchie, 2002:78; Meyer & Bigsby, 2004:168).

Daily caregiving affords the mother the opportunity to become familiar with her infant’s rhythms and interaction patterns and for the infant to identify and respond to the mother. As a result, the time spent by parents in caring for their infants is considered to be an opportune moment for the development of attachment and synchronous infant-parent interaction (Brazelton & Cramer, 1990:121; Hess et al., 1997:113; Siegal et al., 1998:651; Rossetti, 2001:53).

Parents of premature infants may be afforded limited opportunities to have early involvement in the care of their infants in the NICU resulting in a loss in the their anticipated parenting role, difficulty in becoming acquainted with their infants interactional

The parents in this study reported that their role as caregivers within the NICU evolved from being passive observers during the acute phase to active participants during the convalescent phase and prior to their infant’s discharge. These findings are not surprising as Bruns et al., (1999:288), identified that parents travel through a series of caregiving roles during the NICU experience in accordance with their infant’s medical condition and their degree of knowledge.

The NICU nursing staff are actively involved in caring for the premature infant throughout the NICU experience and may be viewed as fulfilling the mother’s anticipated role as primary caregiver. The loss of parental role in mothers of premature infants has been identified as being a traumatic stressor (Wereszczak et al., 1997:39; Peebles-Kleigher, 2000:268), which may result in the parent resenting the NICU staff and feeling a sense of disenfranchisement due to their limited involvement in the care of their infants (Berns & Brown, 1998:67; Rossetti, 2001:76). Parents of premature infants, however, may become dependent on the NICU staff to care for their infants during the initial stages of the NICU experience due to the gap in knowledge between parents and professionals (Ritchie, 2002:78). The NICU staff, thus, may be perceived as acting as the “gatekeeper” of their infant and thus controlling the parent’s access to their infant and the degree of their involvement in caregiving activities (Scharer & Brooks, 1994:41).
The literature widely acknowledges that parents of premature infants need to acquire the necessary skills and develop a sense of mastery and competence in order to feel adequately prepared to cope with the responsibilities of caring for their infants once at home (Siegal et al., 1998:669; Bruns et al., 1999:283; vandenBerg, 1999:58; Rossetti, 2001:53; Beal & Quinn, 2002:188; Vergara & Bigsby, 2004:245). The NICU nursing staff, thus, play an important role in providing parents with information, support and adequate opportunities to be actively involved in the care of their infants (Scharer & Brooks, 1994:46; Moehn & Rossetti, 1996:243; vandenBerg, 1999:58).

A majority of the parents reported that they had been encouraged by the nursing staff to become involved in the care of their infants during the convalescent phase of the NICU experience. Examples of the comments made by the parents reflecting the encouragement that they received are presented in Table 3.11.

**Table 3.11. Examples of the comments made by the parents regarding the encouragement that they received from the NICU nursing staff**

<table>
<thead>
<tr>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>When we were there, they would always say “you do it”</td>
</tr>
<tr>
<td>You were never an observer</td>
</tr>
<tr>
<td>They threw you in the deep end but you got their assistance</td>
</tr>
<tr>
<td>They showed us what to do and then it was up to us</td>
</tr>
<tr>
<td>They never said to me “you’re not allowed to do this or you’re not allowed to do that”</td>
</tr>
<tr>
<td>They would say that it was our responsibility but that if we needed them, we could call them</td>
</tr>
</tbody>
</table>

A majority of the fathers reported that they had been encouraged by the NICU nursing staff during the convalescent phase to become involved in caring for their infants during the convalescent phase. These findings are not surprising as Russell & Rodojevic (1992:309) identified fathers as being important participants in the care and nurture of their infants. Gardner et al. (1998:681) state that fathers of premature infants are often actively involved at the time of their infant’s birth and may be able to see, touch or hold the infant before the mother, accompany the infant to the NICU and receive the first information about the
infant’s medical condition. The involvement of the father during this phase is considered by Siegal et al., (1998:650), to enhance the development of infant-father attachment, which may increase their participation in caregiving activities.

Lisa & Luke’s mother reported that she appreciated the care provided by the nursing staff as she knew that she would have to fulfil these caregiving duties each day after their discharge. She commented that she did not feel a sense of loss in her parenting role as her infants’ primary caregiver as she reported that she had been a parent previously and was thus aware of the numerous opportunities that she would be afforded once her infants were at home. This mother’s response to her limited contact with her infants during the NICU experience can also be attributed to the time that she had to wait before becoming actively involved in their care. Lisa & Luke were born at 35 weeks gestation age and reportedly did not require any intensive intervention during the initial stages of their hospitalisation. After a few days, Luke’s mother was able to hold him and feed him orally and she stated that she had been able to spend a majority of her days with her infants in the NICU at this time, as her mother looked after her older daughter. Luke was discharged two weeks after his delivery and his mother reported that she had not experienced difficulty in caring for once at home. Lisa’s mother, however, was not afforded the same opportunities to interact with her daughter, which resulting in her fearing that they may experience difficulty in establishing a bond.

One mother reported that she had felt excluded in the care provided to her daughter in the NICU. Penny’s mother stated that she had not informed by the nursing staff of suitable times for her to return to the NICU and that she had felt excluded when they bathed her daughter for the first time without her being present. Klaus et al., (1995:134) state that parents of premature infants may view the change the care of the infant as being a major milestone in their infant’s progression, which alters the parent’s perception of the infant and desire to initiate interaction. They, thus, encourage the NICU staff to encourage parents to participate in these activities.
The involvement of the parents in actively participating in caregiving activities may be influenced by their perception of the degree of their autonomy in caring for their infants. Three of the parents reported that perceived that they perceived that the staff were “in-charge” of care provided in the NICU environment, which resulted in them feeling hesitant to initiate contact with their infants without the staff’s permission. Gavin’s mother, however, reported that she felt that the NICU nurses respected her role as a parent as she stated that they encouraged her involvement in Gavin’s care and gave her time to spend with him alone. Examples of comments made by these parents regarding their perceptions of their autonomy in providing care to their infants are presented in Table 3.12.

Table 3.12. Examples of the parents’ perception of their autonomy as caregivers

<table>
<thead>
<tr>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>You don’t want to step on any toes</td>
</tr>
<tr>
<td>You don’t want to overstep the mark</td>
</tr>
<tr>
<td>You just stand back and wait</td>
</tr>
<tr>
<td>I’d step back</td>
</tr>
<tr>
<td>I’d think “no, they’re the NICU nurses, they know what they are talking about. Let me just let them get on with it”</td>
</tr>
<tr>
<td>…they back off if the mother is there</td>
</tr>
</tbody>
</table>

Rossetti, (2001:71) stated that parents of premature infants may feel disempowered and disenfranchised due to their loss of role of primary caregiver and the limited opportunities that are afforded them in caring for their infants. The NICU staff may reduce the stress that parents may experience by establishing caring relationships and by treating parents as partners in the care of their infants (Wereshczak et al., 1997:39).
Theme 3: Bonding

Bonding was the third theme to emerge from the analysis of the data. The bond that develops between parent and their infants lays the foundation for the development of future language, cognitive and motor skills and the infant’s general health (Sullivan, 1999:33). According to Klaus et al. (1995:xiv), bonding refers to the unique ties between the parent and the infants that may be initiated from the time at which the pregnancy is planned and continues to develop throughout the infant’s life. The premature delivery of an infant is widely acknowledged as a disruption in the development of parent-infant bonding, as the parents are not physically and psychologically prepared for the arrival of the infant and the medically-fragile infant may initially experience difficulty in engaging with his or her parents (Klaus et al., 1995:118; Moehn & Rossetti, 1996:231; Gardner et al, 1998:676; Siegal et al., 1998:650; Vergara & Bigsby, 2004a:17).

There is no real critical period for the development of the bonds of attachment (Bruer, 2001:15) but the challenges faced by both infants and their parents during the NICU experience may delay the establishment of this relationship. There are numerous factors that influence the development of parent-infant bonds including contact with the infant, parental attitudes towards their infant and their parental role, the infant’s medical condition, parental involvement in the care provided in the NICU, Kangaroo Mother Care, the NICU environment and access to information and support. As the development of parent-infant bonds is closely related to interaction between infants and their parents, these factors have been explored in detail in the other themes that emerged through the analysis of the data.

A majority of the parents in this study reported that they had experienced difficulty in bonding with their infants during the NICU experience, which may be due to the numerous challenges faced by parents during their infant’s hospitalisation in the NICU. The
comments made by these parents suggested that there were various factors influencing their ability to establish bonds of attachment with their infants.

The first reason for the difficulties experienced by the parents in establishing parent-infant bonds is ownership of the infant. Taylor & Hall, 1979 (in Rossetti, 2001:62), describe that parents of premature infants have to adjust their expectations of their anticipated “perfect” infant. According to Gardner et al., (1998:674), parents of premature infants need to emotionally detach from their infants in order to mourn the loss of their ideal infant and to accept the situation. Furthermore, parents of premature infants may experience difficulty in developing a bond with their infants, as they are unable to initially provide care to their infants (Rossetti, 2001:53). The comments made by the parents as presented in Table 3.13, portray their difficulty in claiming ownership of their infants.

Table 3.13. The parents’ sense of ownership of the infant

| I would be visiting a little patient there |
| She didn’t really feel like my baby |
| She needed to be looked after like a little puppy |

The infant’s responsiveness to interaction is a second factor that may result in parents experiencing difficulty in establishing bonds of attachment with their infants. The parents’ perception of their infant may influence the ability to bond with their infants as indicated in a study conducted by Levy-Shiff, Sharir & Mogilner (1989, in Sullivan, 1999:34). Their results suggested that the parent’s degree of disappointment regarding their premature infants influenced their involvement in caregiving activities and thus the degree to which they attached with their infants. Three parents in this study described their perceptions of their infant’s responsiveness and their comments are presented in Table 3.14.
Table 3.14. The parents’ perception of their infant’s responsiveness

<table>
<thead>
<tr>
<th>Perception</th>
</tr>
</thead>
<tbody>
<tr>
<td>Their eyes looked dead</td>
</tr>
<tr>
<td>They just lie there and do nothing</td>
</tr>
<tr>
<td>It’s like looking at some child lying there with pipes in it</td>
</tr>
</tbody>
</table>

An addition factor that may have influenced the parents’ ability to bond with their infants was the parent’s perception of the infant’s medical status. Shields-Poë & Pinelli, (1997:35), identified similar findings in their study as they concluded that the parents’ perception of their infant’s medical condition was a major stressor during the NICU experience that resulted in poor interaction with their infants. Examples of the parents’ perception of their infant’s medical condition are laid out in Table 3.15.

Table 3.15. The parents’ perception of their infant’s medical condition

<table>
<thead>
<tr>
<th>Perception</th>
</tr>
</thead>
<tbody>
<tr>
<td>We saw him as being a medical problem</td>
</tr>
<tr>
<td>She was always this little baby that was fighting</td>
</tr>
</tbody>
</table>

The final factor that emerged through the analysis of the data pertaining to parent-infant bonding was separation. Parents are geographically and physically separated from their infants during the NICU experience due to the necessity of their infant’s hospitalisation and the limited opportunities afforded parents to have contact with their infants (Nyström & Axelsson, 2002:277-278). Although, Griffin (1999:75) stated that parental presence in the NICU might facilitate the development of parent-infant bonding, the infant’s behaviour state or medical condition may limit the parent’s ability to engage with the infant. The comments made by the parents in this study regarding the difficulty that they experienced in bonding with their infant’s as a result of infant-parent separation are presented in Table 3.16.
Table 3.16. The influence of infant-parent separation in the development of bonding

| It’s very hard to connect with something that you only seeing once a night |
| …you sit next to them and you know they are yours but you don’t feel close |

Three of the mothers in this study reported that they felt that they were able to bond with their infants, which may be due to various reasons. The possible factors that may have facilitated their ability to bond with their infants are that two of these mothers were actively involved in caregiving activities in the NICU, practiced Kangaroo Mother Care and frequently spoke to their infants. The other mother in comparison had been less involved in NICU but had previously been a parent, which may have been of assistance in helping her to bond with her infants. The remarks made by these mothers reflecting their bond with their infants are laid out in Table 3.17.

Table 3.17. Comments made by the mothers reflecting their bond with their infants

| I never once felt that he was someone that I didn’t know |
| I just knew that I would do anything for this baby |
| I thought that we would battle to bond but everything was fine |

The development of bonds of attachment between fathers and their infants is an important aspect to consider as fathers are acknowledged as being important participants in the care of their infants (Russell & Rodojevic; 1992:309). The fathers in this study reported that in comparison to their wives, they experienced more difficulty in bonding with their infants. This finding is not surprising as mother-infant bonds are developed during the pregnancy and mothers are often more involved in providing care to their infants (Moehn & Rossetti, 1996:242). A majority of the fathers, however, were actively involved in the birth of their infants, which is considered to facilitate father-infant bonding (Siegal, et al., 1998:650) and were provided with opportunities to develop bonds with their infants after the infant’s delivery. According to Gardner et al., (1998:681), fathers are often able to bond with their
infants before their wives as they have earlier contact with their infants and are often provided with the first information regarding their infant’s medical condition.

An additional factor that may have influenced the ease to which the parents bonded with their infants may be related to the amount of time spent by the fathers in the NICU. All of the fathers in this study worked on a full-time basis during their infant’s hospitalisation, whereas a majority of the mothers were able to spend their days in the NICU and thus were afforded more opportunities to have contact with her infant and to participate in caregiving activities. A study conducted by Sullivan (1999:37), however, concluded that there was no correlation between the frequency of paternal contact with the infant and bonds of attachment.

**Theme 4: Information**

A fourth theme to emerge through the analysis of the data is information. The literature widely documents the influence that information has on assisting parents to gain a sense of control over the NICU experience (Harrison, 1993:644; Berns & Brown, 1998:66; Gardner et al., 1998:691; Brazy et al., 2001:41; Beal & Quinn, 2002:188; Loo et al., 2003:31).

The parents in this study reported that the information and ease with which they obtained information during the phases of their NICU experience varied. For the purpose of clarity, the findings of this theme will be presented according to the 4 phases of the NICU experience proposed by Brazy and her colleagues (2001).

**The prenatal phase**

The prenatal phase is defined in Brazy et al., (2001:43) as being the time from the first indication that the infant may be delivered prematurely to the time of the birth.
Five of the families in this study reported that they had been aware of the possibility for their infant’s premature delivery. They stated that during this phase, they had been informed of the risks associated with the mother’s medical condition and the necessity for their infant’s premature delivery by the physicians and nursing staff. In addition, a majority of the parents reported that they had received information from books and the Internet. The comments made by the parents, however, suggested that medical professionals were their main source of information, as they did not mention the importance of the information that they received from these additional sources. Brazy et al., (2001:45) indicated that the parents in their study needed to have a positive perception of and confidence in the information obtained and identified the physicians and nurses as providing the best opportunities for learning.

All of the parents in this study reported that they had required information regarding the challenges that they were going to face after the infant’s delivery as they stated that they had not feel adequately prepared for the outcome of their infant’s prematurity. The parents’ need for additional information during this phase is not unexpected as parents of premature infants may initially experience unique and unfamiliar emotions, as they grapple with the loss of their anticipated “perfect” infant, fear of the infant’s survival and the beginning of a journey for which they may have no point of reference. As a result, Gardner et al., (1998:691) state that parents require information at this time in order to intellectually understand the crisis, organise their thoughts and mobilise sources of support.

The acute phase of hospitalisation

Brazy and her colleagues (2001:43) define this phase as being the time during the mother’s hospitalisation and the period in which the infant was in an unstable medical condition.

All of the parents in this study reported during this phase they had received information from the NICU staff regarding their infant’s medical condition, the technology in the
NICU and the medical procedures that were being conducted. The parents expressed that they had viewed the professionals in the NICU as being informative. Examples of the comments made by the parents reflecting their perception of the staff are presented in Table 3.18.

Table 3.18. The parents’ perceptions of the degree of information provided by the NICU staff

<table>
<thead>
<tr>
<th>Comment</th>
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<tbody>
<tr>
<td>The people in the ward were very informative</td>
</tr>
<tr>
<td>If I asked them something then they would answer me</td>
</tr>
<tr>
<td>At all times we got a run down</td>
</tr>
<tr>
<td>They explained to me everything that was going on medically with her, what the machines do and what treatment she is receiving</td>
</tr>
<tr>
<td>There was never a situation when we asked and they didn’t tell us what was happening</td>
</tr>
<tr>
<td>They explained everything to me</td>
</tr>
<tr>
<td>If you didn’t understand something then they would tell you</td>
</tr>
<tr>
<td>I think that most of the time they told us most of the things before we had to ask them</td>
</tr>
</tbody>
</table>

Parents of premature infants travel through states of emotions in coping with and adjusting to the challenges faced during the NICU experience, which may impact on their ability to obtain information (Allen, 1995:181; Gardner et al., 1998:679; Loo et al., 2003:31; Meyer & Bigsby, 2004:174). The influence of the parents’ response to the NICU experience on the ease to which they acquired information was identified in the remarks made by two mothers in this study. The researcher placed these responses into two categories based on her interpretation of the comments made by these mothers. These categories proposed by the researcher are laid out in Table 3.19.
Table 3.19. The parents’ responses to the NICU experience that influenced their ability to acquire information

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Shock</td>
<td>I don’t think I really listened to them. You’re still in a state of shock</td>
</tr>
<tr>
<td>Overwhelmed</td>
<td>I just wanted to hear a few things and then I would cut off</td>
</tr>
</tbody>
</table>

Penny’s mother reported that she had been in a state of shock during her initial visits to the NICU. She stated that the staff had informed her of her daughter’s medical condition and the technology within the NICU but that she had been unable to process the information as she was shocked by Penny’s appearance and the numerous pipes that were attached to her.

Michael’s mother reported that during this phase she had found the information that was provided by the staff as overwhelming as she was not familiar with the terminology. She, however, stated that she had no desire to understand the various procedures and the medical jargon used to discuss her son’s medical condition as she was only concerned about his well being. Her response to the information provided during this phase may be related to a sense of guilt as Michael’s mother reported that she believed that she had caused her son’s prematurity. Michael’s mother, therefore, may have focused her attention on obtaining information that would reduce her concerns but would not exacerbate her feelings of guilt by highlighting the medical difficulties that he was experiencing at the time.

The ease with which parents acquire information during this phase in the NICU may be influenced by their familiarity of the situation (Brazy et al., 2001:41). This factor was identified in a comment made by Victoria & Vincent’s mother, as she stated that she had “felt stupid” during this phase in the NICU as she had not known what questions to ask the staff. This finding was surprising as Vincent & Victoria’s mother had previously worked as a dietician in a NICU and one would thus expect that she would be familiar with the environment. She, however, had expressed that she had not been exposed to premature...
infants in a similar condition to hers and thus was unfamiliar with the complications that may occur as a result of extreme prematurity.

Harrison, (1993:644), outlines the principles of family-centred neonatal care states that “parents must have available to them the same facts and interpretation of this facts as the professionals”. Vincent & Victoria’s parents, however, reported that the paediatrician had informed them he was not going to describe all the possible risks associated with their infants’ prematurity, but rather that he would provide an explanation at the time in which a complication arose. Their father stated that he had appreciated the paediatrician’s decision to withhold information, as he expressed that he felt that he had been able to deal with the present situation rather than worrying about possible scenarios that may occur. His response to the restriction placed upon the amount of information that he received is surprising as Loo et al., (2003:31) report that the knowledge gap between parents and professionals is a source of stress for parents. Furthermore, the acquisition of information assists the parent in confronting the crisis and preparing for possibly stressful situations by mobilising sources of support (Gardner et al., 1998:691). Vincent & Victoria’s father, however, reported that he felt unprepared for the challenges that they were going to face during the NICU experience as reflected in the following comment: “we didn’t have a clue about what was next, what needed to be done and how to prepare ourselves”.

The convalescent and post-discharge phase

The convalescent phase is defined by Brazy et al., (2001:43) as being time from the baby’s transfer to the immediate care nursery to the time of the infant’s discharge. The infants in this study, however, remained in the NICU until their discharge and thus the researcher viewed this phase as being the period extending from the time in which the infant was medically stable to the time in which the infant was able to go home.
The parents in this study reported that during this phase they had obtained information from the NICU nursing staff regarding caregiving activities. Bruns et al., (1999:296), identified that need for parents to be provided with individualised opportunities for caregiving in an environment of open communication in order to become adequately prepared for their infant’s discharge. The parents in this study appeared to have been afforded these opportunities as they reported that the NICU staff had encouraged them to become actively involved in care of their infants and had provided the parents with the necessary knowledge. This remark made by Gavin’s mother reflects the knowledge that she gained through being actively involved in caring for him in the NICU “I spent so much time with him so I knew what to do and what to expect”.

The amount of information that parents need in order to feel confident about their knowledge is unique (Loo et al., 2003:33). Parents of premature infants, thus, need to facilitate the acquisition of information and according to Brazy et al., (2001:45), parents become active seekers of information in order to obtain the necessary knowledge. This symbiotic interaction in preparing parents for their infant’s discharge through the use of information was identified in a comment made by one family in this study. Gavin’s parents reported that they had perceived the NICU nursing staff as a means to obtain information. They stated that they had made use of this available information through asking the staff numerous questions.

This study aimed to explore the opportunities afforded parents to interact with their infants during their infant’s hospitalisation in the NICU and thus their experiences after their infant’s discharge should not be discussed. Vergara & Bigsby, (2004i:244), however, state that premature infants are being discharged earlier from the NICU and may continue to present with complications as a result of their prematurity. In light of this finding, the researcher aimed to gain a sense of the parents’ degree of preparation and information obtained through exploring the experiences of the parents in this study once their infants were at home.
A majority of the parents stated that they perceived that they had received sufficient information during this phase and reported that they had felt prepared to fulfil the role of primary caregiver after their infant’s discharge. Two parents, however, expressed that they perceived that they had received insufficient information regarding the developmental outcome of their infants. The parents in this study reported that they had not frequently required advice from the NICU staff but stated that they found comfort in knowing that this source of information and support was available.

**Theme 5: Support**

A fifth theme to emerge through the analysis of the data is support. Parents of premature infants have described the NICU experience as being a roller-coaster ride with peaks and troughs depending on their infant’s medical condition and their sense of comfort in the NICU (Allen, 1995:179; Bruns & Steeples, 2001:238). According to Able-Boone, et al. (1992:94) the support that parents receive during a crisis event, such as the NICU experience, influences their emotional responses, perception of their infant and ability to interact with the infant.

The parents in this study reported that they received support from various individuals during the NICU experience.

*Support received from the spouse*

The parents reported that they had found each other to be their primary means of support. This finding is not surprising as the comments made by a majority of the parents suggested that they both had been actively involved throughout the during the NICU experience. All of the fathers in this study had been present during the time that their infant was born, had been involved with the birth and had been able to inform the mother of the infant’s medical condition before her initial visit to the NICU. The involvement of both parents during this
stage is thought to be of support as Siegal et al, (1998:655), describe that parents of premature infants are psychologically vulnerable due to suddenly being thrown into the role of parents and having limited control of the situation.

A majority of the fathers reported that they had returned to work shortly after their infant’s birth, resulting in the staff playing a more important role in supporting the mothers during the day. All of the families, except for that of Penny’s reported that both parents had visited their infants in the NICU at night. The value of the support that the parents provided to each other in visiting the NICU together was identified in comments made by Penny’s mother. She stated that her husband had been unable to accompany her to the NICU and reported that he was often unfamiliar with the information that she relayed regarding Penny’s care in the NICU. As a result, Penny’s mother commented that she had felt alone and a sense of isolation during the time that she spent in the NICU. She further stated that she had felt excluded by the NICU staff in providing care to her daughter, which may have exacerbated her sense of being alone during the NICU experience.

Victoria & Vincent’s parents stated that at times their attitudes to their infants’ medical condition would differ and relied on each other for support during these moments. These parents reported that they perceived that one of the most stressful moments in the NICU experience was the time in which their infants were separated as Victoria had been discharged from the NICU prior to Vincent. They stated that they had found this time to be difficulty, as they had been unable to spend the same quantity of time with each other and with their infants. This comment made by Victoria & Vincent’s father emphasises the value that he placed upon the support that he received from his wife: “I couldn’t imagine how one could go through this journey alone. It is emotionally traumatising and you need a sound partner that you can share your deepest feelings with”.
Support received from family members, friends and other parents of premature infants

All of the parents in this study reported that their family members and friends had been of support during the NICU experience. The type of support provided by their family and friends varied from words of encouragement, assistance in maintaining the everyday routines of the parents, care of other children, transportation to the hospital and practical advice with regards to parenthood and caregiving. Examples of comments reflecting the support received by the parents from their family and friends are presented in Table 3.20.

### Table 3.20. The support received by the parents from their family and friends

<table>
<thead>
<tr>
<th>Comment</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Our families were very supportive</td>
<td></td>
</tr>
<tr>
<td>Our friends were wonderful</td>
<td></td>
</tr>
<tr>
<td>Even though they weren’t allowed to see the children, they were supportive</td>
<td></td>
</tr>
<tr>
<td>I must say that our saving grace was that we had friends</td>
<td></td>
</tr>
<tr>
<td>It’s not like hundreds of calls, it’s thousand of calls</td>
<td></td>
</tr>
<tr>
<td>It was a sense of comfort going to work and having people trying to understand</td>
<td></td>
</tr>
<tr>
<td>I would spend the day there and then my mom would pick me up</td>
<td></td>
</tr>
<tr>
<td>Most of our friends have had children so we got a lot of information from them</td>
<td></td>
</tr>
<tr>
<td>The phone calls and their concern was amazing</td>
<td></td>
</tr>
<tr>
<td>My mom came when they were born and they looked after our other daughter so we could go through everyday</td>
<td></td>
</tr>
</tbody>
</table>

Victoria & Vincent’s parents reported that they had appreciated the support that they received from their family and friends but stated that they felt that they were unable to truly understand the challenges that they faced in the NICU. This finding is not unexpected as Allen (1995:179) describes the emotional states that parents experience in adjusting to their infant’s prematurity and hospitalisation results in parents feeling disorganised and unable to convey their experiences.

A few families stated that they had received support from other parents in the NICU and friends that had premature infants. They reported that they found these parents to be more understanding and empathetic, which is not unexpected as Plaas (1994:32) states that the
only person that can truly appreciate a parent’s NICU experience is another NICU parent. The parents in this study further commented that they found comfort in knowing that their friends’ infants had survived the NICU experience.

Emily & Erica’s parents had a relatively unique source of support as they reported that they had a friend that worked as a nurse in the NICU. They stated that in being familiar with a staff member had influenced their perception of the NICU environment, as their friend had accompanied them to the NICU during their initial visit and had provided them with information and support. Emily & Erica’s parents reported that they believed that this friendship had resulted in them feeling less intimidated by the other staff members, having more trust in the information that they received and in feeling at ease about the competence of the care that their twins were going to receive.

Support received from the NICU staff

A majority of the parents reported that they had found the NICU staff to be supportive. Als, (1997:48), medical professionals have become increasingly aware of the influence that the parent’s emotional state has on their ability to be involved and invested in their infant’s development and care.

Peebles-Kleiger, (2000:262), states that NICU staff can serve as containers for the parent’s feelings during their infant’s hospitalisation. Her depiction of the emotional support provided by the NICU staff was identified in a comment made by Victoria & Vincent’s mother. She stated the nursing staff in the NICU were able to understand her responses to the situation and emotional limitations. This mother reported that they would sit with her and encourage her to cry and at times would cry with her. She later described her appreciation of the support that they reported that by stating that she felt that she “owed her life to them”.
Vincent & Victoria’s father described that he became “emotionally bruised” during the NICU experience. He reported that the NICU staff had assisted him in coping with the situation with words of encouragement and daily mantras in reminding him to ‘take each day at a time’ and to ‘focus on the short-term’.

Michael’s parents, however, reported that they had perceived the NICU as not being an environment where they could get moral support. They stated that they felt that the NICU staff were solely interested in the care of their infant and in providing information. Their perception of the support that they received from the NICU staff, however, may have been influenced by their attitude towards the time that they spent in the NICU. Michael’s mother stated that they had spent limited time in the NICU during the first three weeks of his hospitalisation and commented that they had visited Michael during this time to ensure that his medical condition was improving. His parent’s further reported that they were not seeking emotional support from the NICU nursing staff as they had perceived that they were not experiencing difficulty with the NICU experience.

Two mothers in this study reported that they had perceived the NICU nursing staff of being more supportive than the paediatricians were. Both mother’s stated that the paediatrician had “made no effort” to talk to them and commented that their interaction with them had focused on discussing the medical condition of their infants.

The parents in this study reported that the NICU staff were supportive, as they were instrumental in providing them with information regarding their infant’s medical condition, involving them in caregiving activities and in preparing them for their infant’s discharge from the NICU. Able-Boone et al., (1992:98) supports this finding as they noted that parents considered health professionals to be of support if they provided positive and useful information and assistance in the care of their infants.
Many of the parents stated that they found comfort in knowing that care that was provided by the NICU staff was professional and competent. A study conducted by Holditch-Davis & Miles, (2000:20), identified similar findings as their results indicated that the competent care provided by NICU nurses was perceived by mothers as being the most important source of support during the NICU experience. A majority of the parents in this study reported that they felt at ease knowing that the nursing staff would cope with an emergency if one arose and felt that they were able to ‘take a night off’ from visiting their children in the NICU.

Lisa & Luke’s mother stated that she had found the separation of her twins due to Luke’s earlier discharge from the NICU as being a stressful event. She reported that she had been unable to visit Lisa in the NICU during the day as she had two other children to care for at home. She stated that she believed that she had been able to cope with this situation, as she had known that she could rely on the nursing staff to care for her daughter.

Gavin’s mother described an additional type of support that she received from the NICU nurses that assisted her ability to cope with her separation from her son. She reported that she had perceived that the nursing staff were fond of Gavin, which she stated had provided her with comfort in knowing that her son was able to receive a sense of “parental love” during times that she was unable to be in the NICU. In addition, this support received by Gavin’s mother may have facilitated the ease to which she bonded with her son, as according to Siegal et al., (1998:657) the parent’s perception of their infant may be influenced by the staff’s attitude and manner in interacting with the infant.

**Theme 6: Previous parenting experience**

The final theme to emerge through the analysis is previous parenting experience. The birth of the first infant is a life-changing event in any family that requires adjustment in family
roles, lifestyles and relationships (Siegal et al., 1998:648). The premature delivery of an infant may exacerbate the stress that first-time parents may experience in accepting the change in family dynamics. Previous parenting experience may influence the manner in which the parents engage with their infant, as according to Holmes, (1993:51), parents are considered to be more relaxed and less apprehensive during caregiving activities with their second children.

Luke & Lisa’s parents reported that they had an older child. They stated that they perceived that their previous parenting knowledge that had assisted them in coping with the NICU experiences, as they were familiar with the caregiving routines. Lisa & Luke’s mother commented that she had felt at ease in interacting with her twins, as she stated that she knew that she could not cause them additional harm.

Lisa & Luke’s mother reported that she had not been concerned about their well being during the NICU experience as she stated that her previous parenting experiences had revealed that infants are resilient. Her response to Lisa & Luke’s medical condition, however, may be influenced by the fact that the paediatrician had informed her that there was minimal possibility that her twins would experience any medical complications during their hospitalisation in the NICU.

**SUMMARY OF THE FINDINGS**

The findings of this study revealed that the parents were provided with a range of both positive and negative opportunities to develop communication with their infants during the NICU experience.

The parents in this study spent more time in the NICU and became more actively involved in caregiving routines to their infants’ discharge resulting in the parents feeling adequately prepared to resume their role of primary caregiver once at home. The limited opportunities
afforded the parents to have early contact with their infants and to participate in the care provided during the initial stages, however, appeared to hinder their sense of empowerment over the situation and their ability to develop infant-parent interaction and attachment.

The findings revealed that the parents had received support during the NICU experience from various individuals and had felt a sense of comfort in their perception of the competent care that the NICU staff provided to their infants. The parents, however, were afforded limited opportunities to obtain support from other parents of premature infants, which is acknowledged as being of benefit in assisting parents to adjust to the NICU experience (Lindsay et al., 1993:42; Plaas, 1994:34).

The parents in this study described the NICU staff as being informative but the information that they received was limited as it pertained primarily to the infant’s medical condition and caregiving routines. The findings, however, suggested that the parents had been unaware of the adverse effects that the NICU may have on the infant’s medical condition, development and ability to engage effectively within the environment. This lack of information resulted in the parents experiencing difficulty in communicating and bonding with their infants.

The overall findings of this study indicated that the parents had been afforded limited opportunities to develop communication with their infants during the NICU experience. The care provided in this NICU was noted as being primarily focused on ensuring the infant’s survival through intervention of a team of physicians and nursing staff. As a result, principles of appropriate developmental care had not been implemented within the care provided within the NICU. Appropriate developmental care is widely acknowledged as being ‘best practice’ in reducing the adverse effects that the NICU has on both infants and their parents and strives towards enhancing the infant’s overall developmental outcome (Rossetti, 2001:187; Byers, 2003:176; Vergara & Bigsby, 2004b:24). Principles of appropriate developmental care include: modifying the NICU environment; controlling
levels of sensory stimuli; providing the infant with individualised developmentally supportive care; promoting active parent participation throughout the NICU experience and promoting practices that enhance infant-parent interaction and bonding.

Aspects of appropriate developmental care were noted within the NICU in this study as the NICU nursing staff attempted to introduce Kangaroo Mother Care and provide the infants with optimal positioning. However, the care provided was mainly medically orientated and appropriate developmental care had not been adequately implemented. The findings of this study advocate for a shift in the philosophy of care within the NICU and the involvement of multidisciplinary teams in order to address the unique and diverse needs of infants and their parents during the NICU experience.
CHAPTER FOUR

CONCLUSION AND IMPLICATIONS OF THE STUDY

Many writers have postulated that very early successful infant-parent communication lays the foundation for later successful communication skills (Brown & Ruder, 1995:83; Hess et al., 1997:112; Jacobsen, Starnes & Gasser, 1998 in Rossetti, 2001:196; Rossetti, 2001:215). This theory was promoted by many theorists from a wide array of professional fields, and led to a philosophy of care of the newborn infant. The advent of the NICU and the expansion of medical services into appropriate developmental care, has meant that the theory of very early communication development has had to be extrapolated to infant-parent communication in a non-optimal setting. This set the rationale for the present study, which set out to explore the experiences of a group of parents in a private NICU in South Africa. The results indicate that for this group of parents in this setting, opportunities for optimal communication were generally limited.

In 1995:7, Kritzinger et al. stated that neonatal intervention services provided within South Africa are in the initial stages of being implemented and developed. However, almost ten years later, the care provided within NICUs in South Africa remains primarily focused on ensuring the infant’s survival and thus in many hospitals minimal attention is directed towards enhancing the developmental outcome of premature infants. Pattinson (2003b:445) reported that as there has been a significant decrease in the mortality of premature infants in South Africa, and emphasised the need for professionals to shift to the next level of care and begin to address the high rate of disability noted in premature infants within South Africa.

The literature widely acknowledges that the principles of appropriate developmental and family-centred care are ‘best practice’ in addressing the diverse and unique needs of premature infants and their families in the NICU. The success of this intervention relies on
the involvement of numerous professionals from diverse disciplines, that work within a transdisciplinary framework to reduce the adverse effects that the NICU may have on the infants’ development and to enhance maximal parental involvement (Rossetti, 2001:174; Vergara & Bigsby, 2004d:57). As a result, Byers (2003:174) thus states that the philosophy of appropriate developmental care requires for the relationship between the infant, family, and health professionals to be rethought.

The findings of this study highlighted that the care provided within NICUs remains primarily within a medical model and emphasises the need for healthcare professionals to become involved in neonatal intervention within South Africa. There are no national guidelines that delineate practices of suitable neonatal care within South Africa. The tremendous amount of information obtained from studies conducted in developed counties pertaining to ideal NICU care are valuable in establishing practices of intervention within South Africa. The care provided within the South African context differs significantly to that of developed countries due to the diverse range in health care resources and professionals involved in service delivery. As a result, there is a need for professionals to establish a unique definition of appropriate developmental and family-centred care in accordance with the South African health care system.

The success of the implementation of principles appropriate developmental and family-centred care is known to rely on the commitment and active involvement of multidisciplinary teams within NICUs. As a result, healthcare professionals in South Africa need to adjust their perception of neonatal care and obtain the necessary knowledge and clinical skills to become integral members in implementing appropriate developmental and family-centred care in NICUs. However, the incorporation of multidisciplinary teams within the care provided in the NICU needs to be approached with sensitivity as the successful transition to appropriate developmental and family-centred care relies on active participation of all professionals working within the NICU.
The results of this study reflected that the parents were not provided with adequate opportunities to establish infant-parent interaction during the NICU experience. According to Rossetti (1990:52) any disruption in the infant’s ability to effectively engage within the environment, results in the infant being at increased risk for developmental delay. As a result, Rossetti (2001:191) emphasises the need for early intervention within the NICU in order to reduce the effects that this environment may have on the communicative outcome of the infant.

Early Communicative Intervention in South Africa is a reality, and has evolved due to an increased awareness of the need for the implementation of practices that strive to prevent or reduce factors that contribute towards communication disorders. Haasbroek (1999) and deBeer (2003) noted that speech-language therapists in South Africa have become increasingly aware of the need for their involvement in transdisciplinary teams working within NICUs. However, the role of speech-language therapists within the NICU needs to be defined and further established in order for speech-language therapists to become integral members in the care provided within NICUs.

The results of this study highlighted the need for speech-language therapists to become involved in facilitating the development of infant-parent interaction within the NICU. A study conducted by Louw & Weber (1997) emphasised the role that nurses working in paediatric and neonatal intensive care units play in the development of communication of infants. Their findings portrayed a need for speech-language therapists and nurses to work together in order to enhance the development of communication in infants during their hospitalisation.

The findings of this study also raised questions regarding the fundamental premise that Jacobsen et al. (1998 in Rossetti, 2001:196) propose. They emphasise the need for early communicative intervention within the NICU as they assume that a delay in infant-parent interaction places the infant at increased risk for subsequent socio-communicative delay.
and future academic difficulty. However, their conjecture needs to be critically evaluated as there is a paucity of literature that rigorously delineates the effect that the limited infant-parent interaction in the NICU has on the infant’s long-term communicative outcome in the absence of additional risk factors that may influence the infant’s developmental outcome. In addition, the long-term communication outcome of premature infants is difficult to ascertain due to the unique disposition of the NICU experience and the care provided to the infant after his or her discharge from the NICU. The effect that the NICU experience has on the development of infant-parent needs to be explored through numerous stringent investigations that are able to tease out and reduce the influence that additional variables may have on the infant’s long-term communicative ability.

The NICU has been identified as a site for Early Intervention due to the numerous risks associated with prematurity and the influence of the NICU experience. The efficacy of communication-based intervention within the NICU, however, has not been thoroughly investigated. A study conducted by Jacobsen et al. (1998 in Rossetti, 2001:196) examined the success of a program designed to increase mothers’ interaction with their infants and noted that a month after the program had been implemented, the mothers had maintained their acquired skills. Rossetti (2001:196) stated that in light of their findings, one could assume that communication-based intervention in the NICU has the potential to enhance the long-term outcome of the infant’s communication skills. However, there is a need for additional research that examines the long-term effects of this intervention and which considers the various factors influence the development of infant-parent interaction.

There are numerous questions that require answers with regard to the NICU. The present study was conducted on one small group of parents from one NICU, and the findings cannot be generalised widely; there is need then to explore both the private and public sectors to ascertain just how far appropriate developmental care is being practised.
The acquisition of infant-parent interaction during the NICU experience can be envisaged as being similar to a dangerous crossing over a raging river on a foot bridge.

The parent embarks on this journey with a sense of fear and uncertainty, as the bridge is unfamiliar and the crossing seems daunting. The wooden boards of the bridge are rickety and the bridge swings and moves resulting in the parent experiencing uncertainty during each step. There is a rope railing along the side of the bridge that provides the parent with limited support. Each parent’s journey across the bridge is unique as each crossing differs depending on the stability of the wooden boards, movement of the bridge and support provided by the rope railing. In light of the possible challenges that the parent may face in crossing the bridge and reaching the destination, some parents may need additional time to complete the journey.

Despite the somewhat poetic description, the analogy provides a model of the opportunities provided for the development of communication between infants and their parents during the NICU experience.

The journey begins at the time in which parents become aware of the possibility that their infants may be born prematurely. As a result, many parents may happen upon this bridge quite unexpectedly and have limited time to psychologically and physically prepare for the journey. The wooden boards of the foot bridge represent the opportunities afforded parent to interact with their infants and thus they facilitate the parents in reaching their final destination of optimal infant-parent communication at the time of the infant’s discharge from the NICU. The infant’s medical condition and the parent’s reactions to the NICU experience may cause the bridge to sway and move resulting in a sense of instability and the need for additional support.

Each family in this study had a unique journey filled with various challenges and means of support. Some of the parents crossed the bridge alone, whereas others had company along
the way. Each journey began with a bumpy start, as the parents felt inadequately prepared for the premature delivery of their infants and their initial visit to the NICU. Their few steps were unsteady as the parents became accustomed to the nature of the NICU and adjusted their expectations of parenthood. The parents traveled across the bridge together during this stage, holding onto each other, and relying on the information received from the NICU staff as a means of stability. The bridge swayed more ferociously for a few parents, as they initially feared for their infants’ survival. As a result, they stopped their journey as they waited for the momentum of the bridge to slow down.

The boards on the bridge were unstable and often absent during the initial part of the journey, as the parents were unable to have early contact with their infants and were passive observers of the care provided to their infants. The parents experienced difficulty in crossing the bridge during this time, as they relied on the information received from the NICU nurses and the time that they spent in the NICU to provide them with a sense of comfort as they crossed over the unsteady boards.

The journey became less hazardous as their infant’s medical condition stabilised and the parents prepared for their infant’s discharge from the NICU. The parents were provided with numerous boards that provided support as they were able to hold their infants, felt informed and were encouraged to become actively involved in the care provided to their infants. The boards on the bridge, however, were loose as the parents were afforded limited opportunities to practice Kangaroo Mother Care and many of the parents had not adequately bonded with their infants. The opportunity for the development of optimal communication between parents and their infants were indeed limited in the present study.

It is now incumbent on the Speech Language Pathologist to develop both the role of the speech therapist in order to enhance neonatal care and to advocate the implementation of appropriate developmental care within the NICU.
REFERENCES


