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Maternal Adjustment to Premature Birth: Utilizing the Roy Adaptation Model as a Theoretical Framework

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MATERNAL ADJUSTMENT TO PREMATURE BIRTH: UTILIZING THE ROY ADAPTATION MODEL AS A THEORETICAL FRAMEWORK

By
Ivy Razmus

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ABSTRACT

MATERNAL ADJUSTMENT TO PREMATURE BIRTH: UTILIZING THE ROY ADAPTATION MODEL AS A THEORETICAL FRAMEWORK

By

Ivy Razmus

The purpose of this study was to ascertain whether the adjustment for primiparous mothers of preterm infants was less positive than for primiparous mothers of term infants utilizing the Roy Adaptation Model as a conceptual framework. This secondary analysis utilized data from a larger longitudinal study. The data was collected at three months post birth in the homes of the mothers. The sample consisted of 55 preterm and 46 full term mothers. The Affects Balance Scale (Derogatis, 1983) was used to measure adjustment. A significant difference was found between preterm and full term mothers on the Positive Affects Scale and the subscales: joy, contentment and vigor. No significant differences were found between preterm and fullterm mothers on the Negative Affects Scale.
Table of Contents

List of Tables. ................................................................. .v
List of Appendices. ........................................................... .vi

CHAPTER

1 INTRODUCTION ........................................................ 1

2 CONCEPTUAL FRAMEWORK ................................. 4

   Literature Review ..................................................... 7
   Fullterm Birth Research ........................................... 7
   Research Comparing Primiparous 
   and Multiparous ....................................................... 8
   Research Comparing Term and Preterm Birth .......... 9
   Preterm Birth research .............................................. 10
   Summary ................................................................. 12
   The Roy Adaption Model and The Birth 
   Experience ............................................................. 12
   Summary ................................................................. 14

3 METHODS ............................................................... 17

   Design ................................................................. 17
   Sample ................................................................. 17
   Instruments ........................................................... 18
   Procedure ............................................................ 19

4 RESULTS ............................................................... 22

   Preterm Mothers .................................................... 23
   Fullterm Mothers .................................................... 23
   Hypothesis ............................................................ 24

5 DISCUSSION .......................................................... 27
List of Tables

TABLE

1  Father’s Social Economic Status (SES) ................................................. 23

2  Positive Mean Affects Balance Scales Scores. .................................... 25

3  Negative Mean Affects Balance Scores. ............................................. 25
List of Appendices

APPENDIX

A  Affects Balance Scale
B  Computation of Affect Scores
C  Preterm Mother's - Consent to Release Information
D  Letter Recruiting Preterm Mothers
E  Verbatim Explanation for Families with High Risk Infant Project
F  Fullterm Mothers Telephone Contact- Sample Verbatim
G  Letter Recruiting Fullterm Mothers
H  Consent Form for Families with Premature Infants Project
For most families the birth of their infant is a positive experience. However, what begins as a natural process for many mothers becomes a disappointing experience when it culminates in an infant who is born early or at less than optimal weight. Preterm and low birth weight infants have needs that require intensive neonatal care. This care causes a physical and psychological separation from their mother. Each year approximately four million infants are born in the United States. Of those, 6.9% are born prematurely (U.S. Census, 1990). Billions of dollars are spent annually on health care for this high risk population. These infants not only require intensive care immediately after birth, but also have a higher morbidity rate. This results in a higher readmission rate to the hospital after discharge from the intensive care unit.

Mothers of these infants are at risk for maladjustment. There is research to suggest that mothers of preterm infants have more difficulty than mothers of term infants in adjusting to the maternal role (Mercer, 1975). In the case of preterm birth, the process of adjusting to the developmental crisis of having a new infant and the situational crisis of having a preterm infant provides a variety of stressors for the new mother. The multiple situational stimuli occurring with the birth of the preterm infant
include: 1) the maternal feelings associated with the loss of a normal birth experience; 2) the subsequent separation between mother and preterm infant due to the intensive care needs of the infant; and 3) inability of premature infants to respond positively to their mothers due to neurological immaturity. All of these create a variety of stressors for the new mother.

A mother’s ability to adjust to the stressors is related to the nature of the stimuli and to the mother’s existing mode of adaptation (Roy, 1981). In other words, the more preterm the infant, the more intense the stressors that affect the mother’s existing mode of adaptation. The mother’s existing mode of adaptation is dependent upon her previous experiences and her perception of the crisis event. Godson (1979) stipulates that mothers of preterm infants experience the same psychological stages in the adjustment process: shock, denial, sadness, anger, adaptation and reorganization, that Drotar (1975) identified as being manifested by parents following the birth of a malformed child. Fraley (1986) observed that mothers of preterm infants did not resolve the complexity of feelings and perceptions of loss of normal birth experience. In the mother, feelings of loss, grief, and fear not only follow the preterm birth experience, but they recur when other children surpass their child developmentally or when the child becomes ill. This could be indicative of a chronic adjustment problem for mothers of preterm infants.

The significant impact of the infant’s premature birth and the subsequent intensive care experience upon maternal adjustment was the focus of this study. The purpose of this study was to compare maternal adjustment at three months post-birth between mothers of term and preterm infants. Roy’s Adaptation Model was be used
as a theoretical framework. This information is significant to nursing since the rapid
growth in technology and knowledge in health care has increased the incidence of
surviving preterm infants. Empirical knowledge will assist nurses in their care of this
client population.

This research should yield a better understanding of the maternal adjustment
process. Characterization of the differences between full term and preterm adjustment
could change the scope of current discharge education practices. Nurses could
improve parent education by providing anticipatory guidance regarding the adjustment
process that can be anticipated after discharge from the hospital.
CHAPTER 2
CONCEPTUAL FRAMEWORK

Nursing is a science that is concerned with the responses of individuals to states of illness and to situational or developmental transitions or crises. Theoretical frameworks have been developed in nursing to organize the main concepts in nursing science. This study utilized the Roy Adaptation Model as a theoretical framework.

Roy views man as an organism in constant interaction with his changing environment (Roy, 1971). He has innate and acquired mechanisms which help him cope physiologically and psychologically with his constantly changing environment. The ways in which man adapts are labeled "adaptive modes" (Roy, 1976). Adaptation is a process involving the holistic functioning of the person using his potential to affect health positively (Roy, 1983). Roy also refers to adaptation as an act or response (Roy, 1970) as well as "a process of coping with stressors" (Roy & Roberts, 1981, p.57).

There are two mechanisms for adapting to various stimuli: the biological response known as the regulator subsystem; and the cognator subsystem that involves the higher brain functions of memory, information processing and judgement. These subsystems are divided into four adaptive modes (Roy, 1983). The four adaptive modes include: the physiologic mode, role function mode, interdependence mode and the self concept mode. The physiologic mode encompasses oxygenation, nutrition, elimination, activity and rest, skin integrity, the senses, fluid and electrolytes, neurological function and endocrine function (Roy, 1971). The role function mode
serves to alert the person when external demands fall outside the range of roles the person can adapt to, while the interdependence mode is described as a person’s drive for relative balance in relationships, friendliness, dominance and competitiveness (Roy, 1971). Finally, the self concept mode has been defined by Roy (1971) as the adaptive psychological and social behaviors that promote psychic integrity.

Roy has also identified three types of stimuli that occur in each of the adaptive modes: focal, contextual or residual. Focal stimuli are defined by Roy (1981) as those immediately confronting the person. Contextual stimuli are all other stimuli present that affect the person’s behavior or the context of the situation. Roy (1981) describes the residual stimuli as nonspecific stimuli that influence the person’s response to the focal stimulus such as attitudes, beliefs, experiences and expectations.

Roy’s Adaptation Model provides a framework for explaining maternal adjustment following the birth of an infant. The birth experience provides a first time mother with multiple stimuli to which she must respond. The focal stimuli in this situation is the birth of a new infant. The contextual stimuli presenting to the mother is the preterm birth. Preterm birth stimuli are different than term birth stimuli requiring unusual adaptive responses. Stimuli confronting the first time mother of a preterm infant include: 1) lengthy stay of the infant in the intensive care unit which denies the mother a close relationship with her infant; 2) perceptions of the infant as fragile and different; 3) lack of extended visitation in the neonatal intensive care unit; and 4) the inability to deliver a healthy term infant.

The preterm birth presents significantly different stressors to a new mother than a full term birth. This creates a situation that can potentiate maladaptive
responses. For this study, psychological adjustment will be explained with the Roy Adaptation Model self concept mode.

Pregnancy and motherhood require adjustment within the self concept mode. Self concept is composed of perceptions of physical self and the personal self. Each individual perceives himself in a different and unique way. These perceptions become a point of reference or a starting point for everything one does. Total appraisal of oneself is self concept.

"The feelings and cognitive processes of self concept involve appearance, background abilities, attitude and feeling" (Roy, 1976, p.76). A threat to self concept is illustrated in the situation of a woman who is experiencing pregnancy and motherhood for the first time. The new mother needs to adjust to changes in social relationships with other personal systems and new feelings brought on by the birth of her infant. "As a young mother develops in her mothering role, one of the primary residual factors influencing the situation is how she feels about her self concept" (Roy, 1976, p.17). It is assumed that how she feels about herself will be reflected in her psychological well being.

Humans have innate and acquired mechanisms which help them cope physiologically and psychologically with their constantly changing environment. The environment for the mother of a preterm infant has changed due to the birth of the new infant (focal stimuli) and the adjustment will be more difficult with a premature infant (contextual stimuli). Therefore, a mother experiencing the focal stimuli of birth and the attendant contextual stimuli associated with the premature birth is more likely to demonstrate more severe changes in affect and psychological well being.
Review of the Literature

Maternal adjustment is defined as a state of well being and adaptation socially, physically and emotionally after the birth experience. Preterm and low birth weight infants have needs that provide a variety of stressors for the new mother. Maternal adjustment is physically more difficult due to the birth experience and emotionally due to the separation from the immature infant. It is not known when mothers of preterm infants resolve the complexity of feelings associated with the experience.

The review of literature will present research findings related to maternal adjustment to term and preterm infants as well as research studies completed using the Roy Adaptation Model as a theoretical framework.

Full Term Birth Research

Studies of maternal adjustment vary widely in variables, relationships and outcomes. Numerous studies have followed maternal adjustment variables over time. Tulman and Fawcett (1991) focused their research on the woman’s perception regarding recovery from childbirth. They interviewed 96 mothers six months after delivery. Twenty five percent had not recovered physically, twelve percent did not consider their emotional recovery to be complete and seven percent reported lower levels of energy and feelings of fatigue.

Another longitudinal study of full term mothers utilized income, everyday stressors and depressive symptoms as variables. Hall, Gurley, Sachs, and Kryscio (1991) studied two hundred and twenty five low income mothers who had children between one and four years of age. They found high depressive symptoms among fifty-nine percent of the sample population. It was also noted that the greater the
stressors, the greater the incidence of depressive symptoms.

Flagler (1990) proposes that lack of control over bodily functions may be viewed as a loss of self control, and may exert a negative impact on the woman’s self esteem after the birth of her infant. Flager studied twenty women who had term pregnancies and birth. Data was collected in the hospital and between four and six weeks after the birth. Forty-five percent of the sample used at least one negative descriptor during the first interview. At the second interview, eighty percent used one or more negative descriptors. Seventy-five percent of those descriptors were "tired, exhausted or fatigued". None of the respondents listed a positive descriptor the first week and only one did at the four to six week visit. Greater anxiety was also noted at the second visit. Negative emotional feelings were related to scores indicating less mothering. A limitation of this study was its small sample size.

Although Culp and Osofsky (1989) focused on family adjustment in their research, knowledge regarding maternal adjustment can be gleaned from the study. Self report measurements of maternal depression and maternal adjustment data were obtained from mothers during a prenatal interview, on the second postpartum day and at three months postpartum. As a group, there were no differences in maternal depression, maternal adjustment or maternal interaction at two days and three months postpartum. The study was limited, however, due to the small sample size. This focus on cesarean delivery as opposed to preterm delivery makes its findings less applicable here.

Research Comparing Primiparas and Multiparas

Research has also compared multiparas and primiparas longitudinally over
Crain and Thompson (1986) compared multiparous and primiparous women at one and two days and then again at four to six weeks. Primiparas showed more negative attitudes towards themselves than multiparas, and demonstrated more negative attitudes toward their infants. This finding is important to the proposed study since it focuses on primiparas' adjustment beyond the immediate hospitalization.

Primiparas and multiparas rated themselves differently in their perception of confidence at two months but not at four months in a study conducted by Pridham and Chang (1991). The perceptions of competence of multiparas were lower at four months, compared to perceptions at two months. Perceived maternal confidence did not improve for primiparas as much as for multiparas between two and four months.

Research Comparing Term and Preterm Birth

A few longitudinal studies have compared preterm versus term birth adjustment with varied results. In a sample of 36 fullterm and 41 preterm mothers only minor differences in available support were found when comparing high risk versus low risk infant mothers. (Coffman, Levitt, & Deets, 1990). An important finding from this study was that the three to five week time period was perceived as a stressful time.

Gennaro (1988) examined differences in anxiety and depression in mothers of term and preterm infants in the first weeks postpartum and over the next six weeks. Sixteen mothers of preterm infants were found to be significantly more anxious and depressed than ten mothers of term infants. The study was limited in its findings due to the small sample size.
Preterm Birth Research

Studies have also focused exclusively on the mother of the preterm infant and her adjustment over time. McHaffie (1990) found mothers who were not prepared for discharge hid it from the NICU staff. During this study of twenty-one mothers of infants less than 1500 grams at birth, six in-depth interviews were utilized and stages were identified in the adjustment process. Phase I was identified as anticipatory grief which was dominated by fear both of the death of the infant and of other sequelae related to the premature birth. The second phase occurred once the infant’s survival was no longer an issue. Maternal concerns changed to the quality of life the child could expect. The third phase was identified as positive anticipation, in this stage the mother is actively and positively preparing for discharge home. A period of anxious adjustment follows immediately after discharge, which is followed by a stage of exhausted accommodation. Finally, when the rewards of mothering exceeded the tiredness and anxiety, subjects moved into the last phase of confident caring.

A study by Gennaro, York and Brooten (1990) compared mothers of very low birth weight infants (defined as less than 1500 grams) with mothers of low birth weight infants weighing between 1501-2500 grams. The focus of their research was stress responses of anxiety and depression at eight time intervals up to five months. There was increased anxiety and depression until two months for the very low birth weight group, while the low birth weight group had increased anxiety and depression at three and four months.

Gennaro, Zukowsky, Brooten, Lowell and Visco (1990) interviewed a sample of 65 mothers over a six month time, they found that maternal concerns peaked at
three months adjusted age. The adjusted age is the age based upon the proposed term due date instead of the actual birth date. However, McCain (1980) found that mothers continued to have concerns about their preterm infants two to four years after the birth. The twenty-four mothers reported that their unhappiness was related to child care and marital issues.

Fraley (1986) studied the relationship between a preterm child's experience of a stressor event and chronic sorrow on the part of parents. Forty-three parents were in the initial study and thirty-six parents were in the replication. Parents reported feelings of helplessness, frustration, depression, anger and irritability when their preterm child experience a stressor event such as illness, surgery, day care, the discovery of a medical problem, being surpassed developmentally by other children, behavioral problems and chronic illness. The positive responses that were reported by the preterm mothers were related to the baby being alive or that the baby was alright.

Godson (1979) believes that mothers of preterm infants experience the same psychological stages as parents following the birth of a malformed child. The stages identified as being observed in the parents include: shock, denial, sadness, anger, adaptation and reorganization (Drotar, 1975). These occurred immediately after the preterm birth experience, but also when they perceive other children to surpass theirs developmentally. The grief process seems to be prolonged and occurs during stressful events such as when the child becomes ill.

Recently Zahr (1991) attempted to measure and determine maternal characteristics and preterm infant temperaments. Forty-eight low socioeconomic
mother-infant pairs were followed for eight months while their infants remained in the neonatal intensive care unit. At four months and eight months the study revealed that maternal confidence was related to education, income and parity. There was no relationship between observed behavior skill and maternal perception of confidence.

Summary

Maternal adjustment has been studied with term and preterm mothers. Adjustment was different for preterm mothers. They were significantly more anxious and depressed than term mothers. Primiparas and multiparas have also been compared. They too were different in the adjustment process. Adjustment can differ not only positively or negatively, but also over time. Limitations of the research has been the small sample sizes and the limited number of actual studies done comparing preterm and term maternal adjustment.

The Roy Adaptation Model and The Birth Experience

The most extensive research of the birth and parenting experience utilizing Roy’s Adaptation Model as a framework has been conducted by Fawcett and colleagues. Kehoe (1981) and Fawcett (1981a) utilized Roy’s Model to focus on the cesarean birth experience, an experience pertinent to this study because all cesarean births are high risk deliveries and result in loss of the normal birth experience which affects adaptation. Kehoe utilized unstructured interviews during subjects’ first five postpartum days to describe maternal feelings. The purpose was to obtain a qualitative nature in client responses and to provide information to guide the formulation of more research questions. Although the Roy Adaptation Model was found to be a rational and systematic approach in assessing a mother’s response
following an unexpected cesarean section, responses were difficult to sort according to the modes. Fawcett (1981b) attempted to measure parental reactions to caesarean birth. Twenty-four couples were given a retrospective survey after an unplanned caesarean birth. Ineffective responses were reported in each of the four adaptive modes. Fatigue and pain were the most frequently reported responses. Disappointment, anger, sense of loss of control were the most common self concept mode responses.

Fawcett used findings from Kehoe (1981) and Fawcett (1981a, 1981b) to develop and test a nursing intervention. The nursing intervention was nursing education regarding caesarean section in the form of a pamphlet and a follow up home visit or telephone call. Of the eighty-one pregnant women, eighteen had unplanned caesarean sections and of those, fifteen responded to the mailed questionnaires with open ended questions. More adaptive responses were noted than in the first study.

A second clinical test was conducted to compare responses of vaginally-delivered and caesarean-delivered mothers to the nursing intervention of a pamphlet and a focused class discussion in caesarean childbirth education classes. Reactions to the intervention were not significantly different for the 44 women, including 12 who had a cesarean section.

The findings from these two clinical field tests led to the development of an experimental study to determine the difference in response to cesarean birth of women who received the intervention versus those who did not. The contextual stimulus is the nursing intervention of a revised cesarean pamphlet and focused discussion in the childbirth education classes. The control treatment consists of the standard
curriculum for childbirth preparation courses. All four modes of adaptation are being measured, data collection is presently underway.

Summary

Review of the literature has provided a wide range of maternal variables associated with adjustment. Studies that focused exclusively on term mother adjustment have been conducted longitudinally up to four years after the birth. Descriptions of lower levels of energy and fatigue (Tulman & Fawcett, 1991), as well as a high level of depressive symptoms (Hall, Gurley, Sacks, & Kryscio, 1991) were used to describe term adjustment. These negative descriptions did not improve significantly over time (Flager, 1990; Hall et. al., 1991).

Some researchers looked at parity as a variable and measured differences between primiparas and multiparas. Primiparas were found to have a more negative attitude toward their infants (Walker, Crain, & Thompson, 1986) and their confidence did not improve significantly between two and four months (Pridham & Chang, 1991).

Studies have also focused solely on preterm mothers’ adjustment over time. Fraley, (1986) reported unresolved psychologic responses of helplessness, frustration, anger and irritability. Gennaro, Zukowsky, Brooten, Lowell and Visco (1990) identified three months as a critical time for maternal adjustment. McCain’s (1980) study of mothers two years to four years after a preterm birth described negative responses. Together, these longitudinal studies describe unique psychological responses from preterm mothers that have not been identified in research of term mothers.
The studies comparing the preterm and term birth are limited in number. More studies were reported that described separately the maternal adjustment to a term birth or maternal adjustment to a preterm birth. Of those studies documented, preterm adjustment appears to be less positive. Preterm mothers found the adjustment more difficult (Mercer, 1975). Although term mothers were reportedly fatigued and had depressive symptoms over time, preterm mothers described more psychological responses of anxiety and depression than term mothers (Gennaro, 1988).

Fawcett’s (1981a, 1981b) research is the most closely related research thus far that focuses on maternal adjustment to the birth experience. The results of preliminary studies indicated that mothers who experienced unplanned caesarean sections had ineffective emotional reactions prior to the implementation of specific nursing interventions. The nursing interventions were educational pamphlets and changes in childbirth education curriculum. Reactions to vaginal versus the unplanned caesarean birth were not significantly different after the educational strategies were implemented. Limitations of this research has been the initial small sample sizes and retrospective nature of the initial study.

The Roy Model has been successfully utilized as a framework in studies of adjustment to full term birth experiences, especially in regard to psychological and emotional responses within the self concept mode. However, research utilizing the Roy Adaptation Model in describing adjustment to the premature birth has not been documented.

This study utilized the Roy Adaptation Model as a framework for describing maternal adjustment for primiparous preterm and term mothers at three months post
birth. The focus was on maternal psychological well being within the area of the self concept mode. It was proposed that first time mothers who experience a preterm birth are less likely to have a positive adjustment than mothers who experience a term birth. The concept of preterm birth is defined as a birth of less than thirty-seven weeks gestation. A term birth is one that occurs between 37 and 42 weeks gestation. The primiparous woman in this study is one who has experienced her first birth of a live infant.

The research question in this study asked if birth adjustment for primiparous mothers of preterm infants was less positive than for primiparous mothers of term infants.
CHAPTER 3

METHODS

This study utilized available data from the High Risk Infant Project (Loveland-Cherry & Horan, 1990). This study was part of a larger longitudinal study of parental reactions in families of premature and term infants.

Design

A descriptive research design was utilized to describe maternal adjustment at three months postpartum. This secondary analysis compared responses of first time mothers of preterm infants with first time mothers of term infants at one specific point in time. The data was obtained from the larger study at the time of the first home visit which took place at three months of age. The larger study obtained data at five time intervals over an eighteen month time period. The variables for this study focused on the psychosocial variables within the context of the Roy Adaptation Model self concept mode, whereas the larger study was multidimensional in scope. The sample for this study consisted of all primiparas enrolled in the larger study. There were fifty-five mothers of preterm infants and forty-six mothers of term infants.

Sample

Preterm mothers were recruited from two level III neonatal intensive care units (NICUs). Each hospital was located in a large city, serving urban and rural populations. Recruitment of the mothers occurred over a two year time period. Criteria for inclusion in the larger study were that mothers were living with a male partner acting as a father and that infants were less than 37 weeks gestation, size
appropriate for gestational age, hospitalized in the NICU for more than one week but less than three months and free of congenital anomalies that would severely impair developmental progress.

The term mothers in the study were contacted by a trained interviewer who had obtained information about the birth from the community newspaper. These mothers were from the same geographic area as the preterm mothers. All subject criteria were the same as for the preterm sample with the exception that the term infants were born between 37 and 42 weeks gestation and were free of congenital anomalies. For both groups, only primiparous mothers who experienced single births were included in the sample for this study.

Instruments

The mother's adjustment to the preterm and term birth experience in the Self Concept Mode was measured with the Affects Balance Scale (ABS) (See Appendix A). The Affects Balance Scale (Derogatis, 1983) is a 40 item self report adjective checklist that measures affective status (See Appendix B).

The ABS is a reflection of the balance between positive and negative affect (Derogatis, Meyer & Bolas, 1981). The scale measures eight affect states, four positive: 1) joy, 2) contentment, 3) vigor, and 4) affection; and four negative: 1) anxiety, 2) depression, 3) guilt and 4) hostility. There are five emotions for each state.

The subject is asked which of the feelings she had experienced in the past two weeks and to what degree she felt each emotion. Responses are assigned a score of zero (for "never") to four (for "always"). Each affect state can be scored separately.
with a range of 0-20, or collectively (e.g., the negative dimension score is a sum of the four negative affect scores with a range of 0-80). The sum of the negative scores is subtracted from the sum of the positive scores to determine the balance "score".

Derogatis (1983) reported Cronbach's alpha coefficients for the Affects Balance Scale from .78 (anxiety) to .94 (joy) in a sample of 355 heterogenous male psychiatric inpatients. It has been utilized in other studies (Derogatis, 1978 & 1979; Derogatis, Meyer & Boland, 1981). Horan, (1983) utilized the Affects Balance Scale in studying parental adjustment to an infant with a defect. The reliability for the subscales ranged from .68 (affection) to .88 (joy). The alpha for the negative affects reached 0.80 and for the positive affects .73.

Procedure

A neonatologist in each NICU evaluated families in the high risk population to determine eligibility for the study. If the mother met the criteria, she was approached and asked if she would consider participation in the study and asked if she would be willing to receive a phone call from a person connected with the study. When permission was granted, the mother's name and phone number along with any other information necessary for contact was provided to one of the interviewers (See Appendix C). At the same time, a letter bearing the name of the interviewer, signed by the neonatologist and by the principal investigators was sent to the mother (See Appendix D). It restated the purpose of the study and reminded the mother of the impending telephone contact from the interviewer.

After sufficient time from the receipt of the letter, the interviewer telephoned the mother and, after explaining the study in more detail, made an appointment for a
home visit. During the telephone conversation, the mother was apprised of the time involvement and assured of confidentiality and the right to refuse to participate. She was told that the study was being done to learn more about how families respond to the birth of an infant and how their babies develop during the first months of life (See Appendix E).

The term subjects were contacted by phone by a research assistant after the birth was announced in the local paper. A description of the research project was given (See Appendix F). If the families were interested, the infant’s sex would be matched with that of the preterm infant and the family was entered into the study. Subsequently, a letter describing the study was sent to the families (See Appendix G).

Actual consent was signed at the three month visit prior to any data collection (See Appendix H). The same procedure was used to obtain consent in both groups. Mothers were again given a description of the study, time involved, and the voluntary nature of the study was reinforced. Anonymity and confidentiality were also reinforced. Each family was assigned a number, with which the subjects would be identified throughout the study.

The first home visit was conducted when the infants were three months chronological age. It was the first interview of a longitudinal study that collected data up to eighteen months at three month intervals. During the interview the mothers were asked to complete other self report items as well as some interviewer report items. The infant was assessed using the Bayley Infant Development Scale during this visit. The average length of time for the interview was approximately two hours. The
Affects Balance Scale comprised a very small portion of the interview.

Limitations to design and methodology for this study were that the type of sampling was nonprobability sampling and accidental. Homogeneity of groups was attempted by using primiparas from the same geographical areas. Threats to internal validity may include selection bias, since the mothers were not from a random sample from the population of new mothers.

A possible threat to external validity may include the Hawthorne effect, since it is an uncommon experience to have a researcher collecting data in the home. Experimenter effects were controlled for by consistent training and evaluating of interviewers. Each interviewer was trained approximately 30 hours, audiotapes were obtained and evaluated prior to initial data collection. Interrater reliability was evaluated at three months by the interviewers at both sites as well and for both study groups.
CHAPTER 4

RESULTS

A descriptive research design was used to examine birth adjustment in primiparous mothers of preterm and fullterm infants. An independent samples t-test was used to evaluate differences in means of the Affects Balance Scale for the two groups.

The sample consisted of 55 preterm mothers recruited from two level III neonatal intensive care units (NICUs), and 46 full term mothers recruited through an advertisement in the newspaper. Equivalency of groups was established through use of t-test and chi-square on a number of demographic variables. There were no significant differences in age, employment status, maternal SES, family income, ethnicity, baby's gender, and number of infant illnesses. There was no difference in level of maternal SES as calculated by the Hollingshead scale, the majority of both groups were in the skilled clerical or minor professional categories. For the father’s SES, however, the two groups differed significantly $X^2(4, N = 101) = 11.20282, p < .024$. Table 1 shows the percentage of preterm and fullterm fathers in each SES category.
Table 1

**Father's Social Economic Status (SES)**

<table>
<thead>
<tr>
<th>SES Category</th>
<th>Preterm</th>
<th></th>
<th>Fullterm</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Unskilled, menial</td>
<td>2</td>
<td>3.6</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Machine operators</td>
<td>10</td>
<td>18.2</td>
<td>5</td>
<td>10.9</td>
</tr>
<tr>
<td>Skilled clerical</td>
<td>21</td>
<td>38.2</td>
<td>11</td>
<td>23.9</td>
</tr>
<tr>
<td>Med. bus., minor prof.</td>
<td>11</td>
<td>20.0</td>
<td>23</td>
<td>50.0</td>
</tr>
<tr>
<td>Maj. bus., professional</td>
<td>11</td>
<td>20.0</td>
<td>7</td>
<td>15.2</td>
</tr>
</tbody>
</table>

Preterm Mothers

The sample of preterm mothers consisted of first time birth mothers of which thirty-eight (69.1%) had no previous pregnancies; 14 (25.5%) had one abortion; 2 (3.6%) had two; and 1 (1.8%) had three abortions. Thirty-five (63.6%) of the infants were female, and 20 (36.4%) were male.

Fullterm Mothers

The sample consisted of first time birth mothers of which thirty-three (71.7%) had no previous pregnancies; 10 (21.75%) had one previous abortion; 2 (4.3%) had two; and 1 (2.2%) had three previous abortions. Twenty-three (50.0%) of the fullterm infants were male, and 23 (50.0%) were female.
Hypothesis

The hypothesis which stated that birth adjustment is less positive for mothers of preterm infants than for mothers of term infants was supported. An independent samples t-test, was used to determine significant differences between the scores on the Affects Balance Scale for the mothers of preterm and fullterm infants. Although no significant differences were found between the preterm and fullterm mothers on the total Affects Balance Scale, significant differences were found between preterm and fullterm mothers on the Positive Affect Scale and the subscales of joy, contentment and vigor. No significant differences were found between the preterm mothers and fullterm mothers on the Negative Affect Scale. Tables 2 and 3 displays the means, and the standard deviations for both the preterm and fullterm mothers on the Affects Balance Scale.
### Table 2

**Mean Positive Affects Balance Scores for Preterm and Term Mothers**

<table>
<thead>
<tr>
<th>Affect</th>
<th>n</th>
<th>Preterm</th>
<th>Term</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joy</td>
<td>101</td>
<td>13.8</td>
<td>14.9</td>
<td>-2.38</td>
<td>0.019*</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>13.8</td>
<td>14.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>2.5</td>
<td>2.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contentment</td>
<td>101</td>
<td>13.05</td>
<td>14.67</td>
<td>-2.91</td>
<td>0.004**</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>13.05</td>
<td>14.67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>2.96</td>
<td>2.57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vigor</td>
<td>100</td>
<td>11.87</td>
<td>13.28</td>
<td>-2.21</td>
<td>0.030*</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>11.87</td>
<td>13.28</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>3.19</td>
<td>3.19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affection</td>
<td>101</td>
<td>14.89</td>
<td>14.82</td>
<td>0.12</td>
<td>0.901</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>14.89</td>
<td>14.82</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>2.84</td>
<td>2.29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>100</td>
<td>53.57</td>
<td>57.70</td>
<td>-2.25</td>
<td>0.027*</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>53.57</td>
<td>57.70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>9.34</td>
<td>8.86</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>97</td>
<td>1.67</td>
<td>1.97</td>
<td>-1.78</td>
<td>0.078</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>1.67</td>
<td>1.97</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>.89</td>
<td>.75</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05; **p < .001*

### Table 3

**Mean Negative Affects Balance Scores for Preterm and Term Mothers**

<table>
<thead>
<tr>
<th>Affect</th>
<th>n</th>
<th>Preterm</th>
<th>Term</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>100</td>
<td>7.38</td>
<td>7.07</td>
<td>0.52</td>
<td>0.606</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>7.38</td>
<td>7.07</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>3.23</td>
<td>2.77</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>100</td>
<td>4.46</td>
<td>3.85</td>
<td>1.03</td>
<td>0.307</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>4.46</td>
<td>3.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>3.05</td>
<td>2.91</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guilt</td>
<td>100</td>
<td>3.11</td>
<td>2.53</td>
<td>1.06</td>
<td>0.293</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>3.11</td>
<td>2.53</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>2.97</td>
<td>2.35</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hostility</td>
<td>100</td>
<td>5.26</td>
<td>4.56</td>
<td>1.23</td>
<td>0.221</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>5.26</td>
<td>4.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>3.10</td>
<td>2.42</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>98</td>
<td>20.24</td>
<td>18.02</td>
<td>1.12</td>
<td>0.266</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>20.24</td>
<td>18.02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>10.45</td>
<td>8.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>97</td>
<td>1.67</td>
<td>1.97</td>
<td>0.178</td>
<td>0.078</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td>1.67</td>
<td>1.97</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>.89</td>
<td>.75</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05; **p < .001*

25
Preterm mothers experienced lower levels of joy, contentment, and vigor than did mothers of full term infants. The preterm mothers average scores were below the mean of the fullterm mothers for the positive affect states of joy, contentment and vigor and the total positive affect score. This indicates a less positive adjustment for preterm mothers than for fullterm mothers.
CHAPTER 5
DISCUSSION

The premise that the mother of a preterm infant has a more difficult adjustment because of the contextual stimuli associated with a preterm infant is supported in this study. In this study, the preterm mothers reported experiencing less positive affects than did the fullterm mothers. The self concept mode of the Roy Adaptation Model allows for evaluation of emotional well being, which influences the other adaptive modes of physiologic, role function, and the interdependence mode. The degree of the changes in affect and psychological well being were not as severe as anticipated. Possible reasons for these findings will be discussed in this chapter.

The Roy Model has been used as a theoretical framework in evaluating maternal adjustment when comparing cesarean and vaginal birth experiences (Kehoe, 1981; Fawcett (1981 a, 1981b ). These studies demonstrate applicability of the model to maternal adjustment.

Even mothers experiencing the focal stimulation of the birth of a healthy infant have difficulty adjusting emotionally (Tulman & Fawcett, 1991). High depressive symptoms were found in mothers one to four years after delivering a healthy infant, and there was a greater incidence of depressive symptoms in women who experienced more everyday stressors (Hall, Gurley, Sachs, & Kryscio, 1991). None of the respondents in Flager’s (1990) study listed a positive descriptor the first week and only one did at the four to six week visit.

A study that evaluated maternal adjustment between type of delivery, cesarean
or vaginal, found no differences in maternal adjustment (Culp & Ososfsky, 1989).

The research compared primiparas and multiparas showing primiparas as having more negative attitudes towards themselves and their infants (Crain & Thompson, 1986) and a difference in their confidence at two months (Pridham & Chang, 1991).

Investigators that compared preterm and term mothers found the three to five week time period after birth to be a perceived stressful time (Coffman, Levitt, & Deets, 1990). Gennaro (1988) found preterm mothers to be more anxious and depressed than fullterm mothers during the first six weeks. The means for the negative affects were very low for the preterm mothers in this study, reflecting limited negative feelings. It’s possible that the preterm mothers in this study had resolved some of these negative feelings at three months.

Other studies that focused only on preterm mothers found that mothers had increased anxiety and depression until two months for the very low birth weight group, while the low birth weight group had increased anxiety and depression at three and four months (Gennaro, York, & Brooten, 1990). Gennaro, Zukowksy, Brooten, Lowell, and Visco (1990) found that maternal concerns peaked at three months which supports the idea that the adjustment process for preterm mothers is not complete at three months. Another study by McCain (1980) found concerns two to four years after delivering a preterm infant. The process of adjustment does not resolve for a long time after the preterm birth.

Preterm parent’s in Fraley’s (1986) study reported numerous negative emotions related to stressor events. However, when positive responses were reported they
were related to the baby being alive or alright. The differences in positive affect states of joy, contentment and vigor between the fullterm and preterm mothers in this study may be related to the differences in the stressor to which they are adjusting. Preterm mothers may be focusing more on the survival of their infant, while the full term mother's may not be since their infant's health was not as threatened. Term mothers may not be dealing with the same issues at three months, because their infant's health was not as threatened.

McCaffie (1990) found some preterm mothers were not ready for hospital discharge even though the baby was of adequate weight and reasonably healthy. It was difficult for them to enjoy being with and caring for their baby. The hospital staff expects mothers to look forward to the discharge, already loving their baby. Some women did not perceive their infant in this way and had difficulty with establishing and maintaining relationships with their infants according to this study. These women may not be sharing this information with the staff. Although the time period was not well defined in this study, the possible maladjustment may not be apparent to the staff in the NICU and therefore needs follow-up after the discharge from the hospital.

Gennaro, Zukowsky, Brooten, Lowell & Visco (1990) discovered that preterm mothers have concerns that continue past the preterm birth experience. They studied mothers every month up to six months. The most prevalent concern was the health of the baby even at six months. They also found different concerns based on educational level, with the more educated group having more concerns. The sample in this study
was of a higher SES level as calculated by the Hollingshead scale for both fullterm and preterm mothers. The Hollingshead scale is a reflection of income and education. It is important for nurses to include these parents in discharge follow-up programs so that these concerns can be discussed as they arise. This population group may be more neglected in the follow-up process because of their higher SES and educational level, and there may be greater concerns by health professionals for the lower SES group. An understanding of the feelings surrounding a preterm birth would allow nurses to provide teaching, guidance, and encouragement to aid the new mother in positive adjustment. By initiating nursing interventions such as prenatal preparation for high risk mothers, provision of emotional support during the post partum period; and assistance in utilization of needed social support systems a more positive adjustment may be an outcome for these mothers.

Application to Practice/Administration/Education

Information about preterm maternal adjustment is significant to nursing because of the increasing number of surviving preterm infants. Research and success in saving premature infants have resulted in a rapidly expanding field of nursing. Hospital administrators and community nursing services must consider looking at maternal adjustment from a quality assurance and risk management perspective in providing educational and support services after discharge from the Intensive Care Nursery.

Providing resources that would facilitate adjustment after discharge could prevent readmission to the hospital at a later date. Although Neonatal Intensive Care
Nurseries (NICU) have educational programs to help prepare parents for infant discharge, they can modify their educational programs to include anticipatory guidance for the complex feelings involved in the adjustment process for preterm mothers. They could also provide anticipatory guidance through social support groups and networking.

Anticipating the degree of maternal adjustment will provide NICU and public health nurses with a beginning data base with which to diagnose and plan the nursing needs for the family unit. The results of this study indicate a need for educational information through hospital and community based education programs that describe emotional as well as physical aspects of the preterm adjustment process. Most education has been on caring for the infant and physical care of the mother, with limited attention to the emotional aspects involved after a preterm birth. Assessing maternal feelings before the discharge of the infant from the NICU could assist nurses to facilitate and individualize teaching.

Limitations

Other variables that would impact adjustment that have not been addressed in this study include: 1) degree of paternal involvement; 2) quantity and quality of support systems; 3) general adjustment of the infant to extrauterine environment regarding sleep patterns and temperament; 4) the physical environment in which adjustment takes place, such as housing and material resources; and 5) maternal complications that may have occurred with this birth, e.g., infection, or prolonged hospitalization.
The degree of paternal involvement would influence general adjustment both physically and psychosocially. If the father was more involved with direct care activities which Cronenwett, Sampselle, and Wilson, (1985) identified as feeding a child, bathing a child, dressing a child, attending to the child when awakens at night, there could be more physical rest and this could positively influence maternal adjustment. If the father was also supportive of the mother's emotional needs and psychological needs, the adjustment could be more positive as well. If the father was supportive of mother's emotional needs and psychological needs, she could adjust more positively to her role as a mother.

Women's roles have evolved significantly over the past thirty years, with an increase in young mothers staying in the work force. Fathers' participation in child care or housework activities did not change significantly between 1965 and 1975 (Coverman & Sheley, 1986), while women's responsibilities have increased significantly. This has placed a greater burden on the mother, failure of the father to fulfill his role as father influences the well being of the family (Brown, Rustia, & Schappert, 1991). The researchers discovered that fathers of infants with health problems spent more time in infant care than fathers of healthy infants. The fathers in this study were not evaluated according to their participation in child care or housework activities, which could impact the degree of maternal adjustment.

In assessing the mother's support system, nurses should consider not only the mother's family members and friends, but also church members and any available social service programs. In times of situational and developmental crisis, these
people tend to support the person through the crisis. Without an adequate social support system, the adjustment would be less positive. This study did not explore the relationship between support systems and adjustment.

Infant temperaments are unique to each individual baby. If an infant is irritable and has difficulty eating or sleeping, maternal adjustment could be less positive. Likewise, a happy and contented baby could impact the maternal adjustment more positively. Infant characteristics of temperament may also influence paternal involvement in family work (Jones & Heerman, 1992).

A planned pregnancy may facilitate a positive adjustment to the birth experience. However, it could influence adjustment negatively if the experience did not turn out as planned. What one may anticipate the birth experience to be and what actually occurs may cause some conflict for the new mother.

Housing conditions varied widely within the study. Some homes had inadequate plumbing, electricity and multiple safety hazards. This could have a negative impact on adjustment. However, the subjects who lived in these conditions did not appear concerned about their conditions. Therefore, it is difficult to ascertain whether this could positively or negatively affect the outcome of this study.

Resources for parenting was another variable that has not been addressed. Examples of resources would include such items as furniture, food, clothing, toys, washer and dryer. It is assumed that those mothers with greater resources for the baby will have a more positive adjustment. A lack of resources may have a negative effect on the adjustment.
Complications during the birth experience such as an infection or bleeding could prolong hospitalization and impact the maternal adjustment process. It would be difficult for the mother to assume care of an infant when she may not have the physical strength to do so. This may have a negative impact on the adjustment process.

Overall, both groups in this study were of a higher SES. The majority of the mothers who worked were skilled clerical and middle management, or minor professional. Many preterm births occur in a higher risk, lower socioeconomic population than the preterm group of this study. This difference in SES, could be a result of selecting only mothers who were living with the father of the baby, as single mothers are more likely to be of a lower socioeconomic status. The fathers' SES was different between the groups with the preterm fathers having a greater number employed in unskilled, skilled clerical or machine operators, whereas the term fathers were predominantly minor professionals or professional. This is to be expected as the higher risk preterm families tend to come from a lower socioeconomic group. The sample population is representative of a higher SES than is generally observed in the neonatal intensive care units. This makes a stronger argument for the adjustment process being different. It is expected that there would be even greater differences in the adjustment process for the lower socioeconomic group than for the population studied. A major limitation in design was the nonprobability and accidental sampling.
Suggestions for Future Research

The paternal role has not been sufficiently studied, the father's involvement in the care of the infant and its effect upon maternal adjustment would provide valuable information regarding the adjustment process. In addition, single parent, divorced or adoptive parents could be targeted to detect differences in preterm adjustment. This study could be replicated using different cultural groups or lower socioeconomic groups. Further, subjects could be compared at three months and every three months thereafter to describe the progression of the adjustment process.

To further evaluate maternal adjustment, future research should evaluate environmental variables both psychological and physical. These variables would include support systems and housing conditions and their effects upon maternal adjustment.

It would also be useful to explore the relationship between maternal complications and maternal adjustment. A more difficult adjustment would be anticipated if the mother experienced health problems during the post partum time. This could also be studied over time and could compare term mothers who experienced complications with preterm mothers who experienced complications. The preterm infant's adjustment as it pertains to sleep patterns and temperament could be described and correlated with maternal adjustment at three months and longitudinally as well.

Other variables that could be evaluated would be the degree of maternal adjustment as it relates to amount of prenatal care received. The larger study
followed these families up to eighteen months, the adjustment could be evaluated at three month intervals up to eighteen months utilizing secondary analysis. Another suggestion would be to replicate this study in other countries with lower infant mortality rates.

The infants in this study were not the most preterm infants. The infants in this study were healthy preterm infants who were in the hospital a minimum of one week and not more than three months, with the average length of stay being less than one month. This population of infants also required less mechanical instrumentation in the NICU environment than the more acutely ill neonate. This is not indicative of the more intensely ill premature infant population, and the threat to survival for the infant may not be as significant for this preterm population. This may account for the fact that, the preterm mothers responses were significantly less positive than the term mothers but not significantly more negative.

The results of this study suggest that nurses should allow mothers to identify their feelings associated with the birth experience. Thousands of dollars are spent keeping premature infants alive and well in the NICU, but not enough has been done for families after discharge. The process of adjustment does not end when the infant is discharged from the hospital, it is only the beginning. Nursing could be instrumental in facilitating a positive adjustment for the preterm mother by keeping open lines of communication between mothers, nurses and nurses from other services prior to, during and following the preterm birth experience.
LIST OF APPENDICES
APPENDIX A

AFFECTS BALANCE SCALE
PLEASE NOTE

Copyrighted materials in this document have not been filmed at the request of the author. They are available for consultation, however, in the author's university library.

Appendix A

University Microfilms International
APPENDIX B

COMPUTATION OF AFFECT SCORES
APPENDIX B

COMPUTATION OF AFFECT SCORES

---

POSITIVE

\[
\begin{array}{cccc}
J_y & C_k & V_g & A_f \\
5 & 6 & 7 & 8 \\
13 & 14 & 15 & 16 \\
21 & 22 & 23 & 24 \\
19 & 30 & 31 & 32 \\
37 & 38 & 39 & 40 \\
\end{array}
\]

NEGATIVE

\[
\begin{array}{cccc}
A_x & D_p & C_l & H_o \\
1 & 2 & 3 & 4 \\
9 & 10 & 11 & 12 \\
17 & 18 & 19 & 20 \\
25 & 26 & 27 & 28 \\
33 & 34 & 35 & 36 \\
\end{array}
\]

\[
\frac{\text{POSITIVE SCORE TOTAL}}{20} - \frac{\text{NEGATIVE SCORE TOTAL}}{20} = 0
\]
APPENDIX C

PRETERM MOTHERS - CONSENT TO RELEASE INFORMATION
APPENDIX C

PRETERM MOTHERS - CONSENT TO RELEASE INFORMATION

The research project has been explained briefly to me. I give my consent to Butterworth Hospital to release my name, address, and telephone number to the research team involved with this project. I understand that I will be contacted by mail with further details.

_________________________  ______________________
Participant's Signature        Date

_________________________  ______________________
Witness' Signature            Date
APPENDIX D

LETTER RECRUITING PRETERM MOTHERS
Dear Parents:

Your name was given to us by Dr. Jones, the neonatologist from Butterworth Hospital, as being willing to be contacted regarding a study we are currently conducting. We are interested in understanding how families adjust to the premature birth of an infant. We expect that the information you give us will help nurses to better guide and counsel other families who experience the early birth of an infant.

The study is under the direction of nurse faculty at the University of Michigan and Grand Valley State College and in no way is connected to your infant's care. The study involves separate, private interviews with each parent done in your home by nurses specially trained for this. Total time involved for each visit is about one and one half hours. Also included are infant assessments done at the developmental assessment clinic at Butterworth Hospital which will be paid for by the study. The study will continue until your baby is 18 months old. Interviews and assessments will be done at 3 months, 6 months, 9 months, 12 months, and 18 months.

Your interviewer, Martha Katt, will contact you soon to further explain the study and to answer questions you may have. You can decide at any time not to continue participating in the study, even after the study has begun. All information about you and your baby will be kept confidential. Thank you for your willingness to be contacted about this study.

Sincerely,

Dr. Mary Horan, Ph.D., R.N.
Grand Valley State College

Dr. Carol Loveland-Cherry, Ph.D., R.N.
University of Michigan

Dr. Alan Jones, M.D.
Butterworth Hospital
APPENDIX E

VERBATIM EXPLANATION FOR FAMILIES WITH
HIGH RISK INFANTS PROJECT
APPENDIX E

VERBATIM EXPLANATION FOR FAMILIES WITH
HIGH RISK INFANTS PROJECT

Loveland-Cherry, Carol J. 374-42-9821

VERBATIM EXPLANATION

Families with High Risk Infants Project

The parents will receive information about the study in three phases prior to signing the consent. They will have the opportunity to decline to participate at any point.

I. The first approach will be made by a staff member of the intensive care nursery, just prior to the infant's discharge. Parents will be asked if they would be willing to receive a phone call from a nurse who is conducting a study of parents and their infants. The study will be briefly explained:

"To gain more knowledge about the experience of having a high risk infant, the investigators are asking parents to participate in a study which involves interviews with the parents and assessments of the baby during the first 18 months. The interviews are being done by nurses and the assessments will be done here in our developmental assessment clinic. The study is under the direction of nurse faculty from the University of Michigan and Grand Valley State College and in no way is connected to your infant's care. However, we do encourage you to allow us to provide the researchers with your phone number so that they can contact you with more information which will help you make the decision to participate or not. It is necessary that both parents participate, therefore, you may want to discuss it between yourselves before the interviewer phones."

Parents who agree will receive a letter acknowledging their agreement to be contacted, indicating the name of the interviewer, and signed by the individual in the NICU who made the initial request and by the investigators.

II. During the phone call, parents will receive additional information and have an opportunity to ask questions. A more detailed description of the involvement will be provided:
APPENDIX E

VERBATIM EXPLANATION FOR FAMILIES WITH HIGH RISK INFANTS PROJECT

"The study consists of two parts. I will come to your home to do an assessment of your baby. The assessment involves measuring his/her progress and growth. While I am there, I will be asking you to complete a questionnaire and answer some questions. The questions involve how you feel about the experience of having a high risk infant and how it has affected you and your family. The home visit will take about one and one half hours and will be done five times during the next year and a half. The second part of the study involves bringing your baby to the clinic at Hospital for the developmental assessment. This will be scheduled five times at three month intervals. There will be no expense to you; the study will pay for all of your baby's assessments and the results will be made available to you. All information about you and your baby will be kept confidential. Even though you agree to allow me to come to your home for the first visit, you may change your mind and withdraw from the study at any time.

I realize that this will cause you some inconvenience, but I urge you to consider participation, as the knowledge gained will be of great benefit to parents who will have similar experiences in the future.

If you agree, I would like to make an appointment to come your home at a time which is convenient to both you and your spouse. At that time, I will review the study again and will ask you to sign a form indicating your agreement to participate."

III. At the first home visit, the study will be reviewed using the description provided over the telephone in Step II, and parents will be encouraged to ask further questions. Additional information to be provided by the interviewer at this time includes:

"For the parental interview part of this visit I will need to meet with each of you separately. The baby's assessment is best done with either or both of you present. The consent form specifies your rights and will need to be signed before we proceed. Before I leave, I want to make an appointment for the next visit - then I will contact you to verify the appointment before coming."
APPENDIX F

FULLTERM MOTHERS TELEPHONE CONTACT

SAMPLE VERBATIM
APPENDIX F

FULLTERM MOTHERS TELEPHONE CONTACT - SAMPLE VERBATIM

For the purposes of subject recruitment, interviewers will be telephoning families who have been identified from newspaper announcements, and whose addresses and telephone numbers will be obtained from the telephone book. As announcements do not indicate when the baby is born, if the baby is a fullterm infant, or if there are older siblings in the family, it will be necessary to screen the families by telephone to determine if they meet study criteria and if they have characteristics that match the preterm infant families already recruited. It is suggested, therefore, that the interviewer making initial telephone contact with these families use the following procedure for the telephone contact.

TELEPHONE CONTACT

"Hello, I'm ________________, a registered nurse, and an interviewer for the study conducted by Dr. Mary Horan at Grand Valley State University (Dr. Loveland-Cherry at the University of Michigan.) Within the past week, you should have received a letter that briefly described the study. Do you recall receiving that letter?"

(If not, proceed with a brief summary of the study, as described in the letter, including the administration of the Bayley test at each visit, the completion of questionnaires with interviewer and on own, and mailed questionnaire completion around the first birthday. Stress how important the information will be when obtained, and that it is necessary for a comparison with the families in the study who have a preterm infant.

If the parent does recall the letter, ask if there are any questions at that point, and then state that you will be explaining the study more fully after you ask some questions which are necessary to determine if the family is eligible to participate.)

"The letter was an overview of the study, and was to let you know ahead of time that I would be calling. Is the study of interest to you?" If yes, "Then let me ask a few questions to see if you can participate in the study."

We saw from the newspaper that your new baby was a girl (boy). Is this correct?

Can you please tell me your baby's birthdate? (must be on or after April 15, 1988)
FULLTERM MOTHERS TELEPHONE CONTACT - SAMPLE VERBATIM

Was your baby born earlier or later than he/she should have been? (If so, how long? Baby must have been at least 38 weeks, and less than 42 weeks gestation at birth.)

What was your baby's length and weight? (Birth weights should be between 5 and 10.5 lbs; birth lengths 17.75 to 22 inches. Birth weight is most important criteria, as weight is the measurement used to determine if infant is small or large for gestational age (Whaley & Wong, 1987, p. 371).

Did your baby go home with his/her mother (with you), or did he/she have to stay in the hospital? (must have gone home with mother.)

Does your baby have any medical problems you know about? (Infant should be free from serious congenital abnormalities.)

Are both the baby's father and mother living together? (If the biological parents are not living together, ask if there is any male partner living with the mother who acts as the baby's father.)

How many other children do you have? (Match to preterm infant families on list.)

At the end of the screening questions, tell the parent if the answers have indicated eligibility for the study. If the family is eligible proceed with the following:

"The main interest of the study is how families adjust to the birth of a premature infant. In order to do this, we need to know how parents react to the birth of a full term infant. If you agree, I will come to your home to do an assessment of your baby. The assessment involves measuring his/her progress and growth. While I am there, I will be asking you and the baby's father/mother to complete a questionnaire and answer some questions. The questions involve how you feel about the experience of having a full term infant, and how it has affected you and your family. The home visit will take about 1 1/2 hours and will be done five times during the next year and a half. All information about you and your baby will be kept confidential. Even though you agree to allow me to come to your home for the first visit, you may change your mind and withdraw from the study at any time."
I realize that this will cause you some inconvenience, but I urge you to consider participation, as the knowledge gained will be of great benefit to parents who will have similar experiences in the future.

If you agree, I would like to make an appointment to come to your home at a time which is convenient for both you and the baby's father/mother. At that time, I will review the study again, and will ask you to sign a form indicating your agreement to participate.

(If parent declines participation:

"Thank you for talking with me. If you change your mind before your baby is three months old, you can call the research project office at ______________.")

(If parent agrees to participate:

"As I indicated, I will need to talk with you and the baby's father/mother at the first visit, which should be around the baby's 3 month birthday. When can we schedule an appointment so that I could meet with the two of you and then do the assessment of your baby? It would be best to do so when the baby would be rested and fed. If you have other children, it would be important for them to be busy and supervised elsewhere, if possible. It is often difficult for children when new babies get so much attention. I will also need a table to do part of the assessment; one where I can sit opposite you and the baby. A kitchen or dining room table is fine. If this is a problem, I can bring a small card table with me.")

If the family does not meet the study criteria, or cannot be matched with current preterm infant families, close the call in the following manner:

"Thank you for your time and patience in answering the screening questions. Your family is not eligible to participate because ______________ (explain to them briefly why their family was not eligible to participate.)

"Congratulations, again, on the birth of your baby. I and the research project staff wish you good luck in the growth of your family."
APPENDIX G

LETTER RECRUITING FULLTERM MOTHERS
Dear Parents:

We see from the birth announcements in the newspaper that you have recently had a new baby. Congratulations! Dr. Carol Loveland-Cherry, The University of Michigan, and I, Dr. Mary Horan, Grand Valley State University, are registered nurses conducting a study about families with new babies. We are particularly interested in understanding how families adjust to the birth of a preterm infant. In order to do this, we need to know how parents react to the birth of a full term infant. We expect that the information you give us will help nurses to better guide and counsel other families who experience the birth of premature and full term infants.

The study is under the direction of Dr. Loveland-Cherry and myself, and in no way is connected to your infant's care. The study involves separate, private interviews with each parent, done in your home by nurses specially trained for the project. Total time involved for each visit is about one and one half hours. The study will continue until your baby is 18 months old. Interviews and assessments will be done at 3 months, 6 months, 9 months, 12 months, and 18 months. At this time we are looking for families with healthy, full term babies who are similar to the premature infants and their families in the study.

____________________, a nurse who is an interviewer for the project, will contact you soon by telephone to further explain the study, and to answer any questions you may have. It will be necessary for the interviewer to ask preliminary screening questions to determine if your family is eligible to participate. If your family is eligible, and you are willing to participate, the interviewer will schedule an appointment to meet with you in your home. You can decide at any time not to continue participating in the study, even after the study has begun. All information will be kept confidential. Thank you for your willingness to be contacted about this study.

Sincerely,

Dr. Mary Horan, Ph.D., R.N.
Grand Valley State University
APPENDIX H

CONSENT FORM FOR FAMILIES WITH THE PREMATURE INFANT PROJECT
APPENDIX H

CONSENT FORM FOR FAMILIES WITH PREMATURE INFANTS PROJECT

I, the undersigned, agree to participate in a study of family adjustment to the birth of a premature infant. The study is being conducted by Carol Loveland-Cherry, Ph.D., R.N., Assistant Professor, School of Nursing, University of Michigan and Mary Horan, Ph.D., R.N., Associate Professor/Director, Kirkhof School of Nursing, Grand Valley St. College. I understand that my participation is voluntary. I have been reassured that the care my baby receives will not be affected in any way and am free to withdraw my consent at any time during the study and have any information collected from me removed from the study.

I understand that I will not be identified by name at any time during or after the study and that any information obtained about me will be held in confidence. The questionnaires will have only code numbers on them.

The interviewer will answer any question I may have, or I may call the researchers at the numbers listed below. I may choose not to answer any question(s) (I decide not to) without explaining why.

My participation will involve interviews and assessments of my baby's development in my home at my convenience. My baby will be scheduled for appointments at the Developmental Assessment Clinic. I understand that I will not have to pay for the clinic visits. I also give permission for use of information from my baby's hospital and clinic records. If I request, the results of the study will be made available to me upon completion of the project.

I agree to participate in the study as outlined above.

Signature

Signature Date

If you have any concerns or questions, please feel free to contact either of us at:

Dr. Loveland-Cherry - (313) 936-3586
Dr. Horan - (616) 979-3558
LIST OF REFERENCES


Loveland-Cherry & Horan, 1990).


