

CONCERNS OF MOTHERS OF PRETERM  
LOW BIRTH WEIGHT INFANTS DURING  
THE FIRST WEEK OF THE  
INFANTS' DISCHARGE FROM HOSPITAL

CENTRE FOR NEWFOUNDLAND STUDIES

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MARGARET ELIZABETH NOWE









CONCERNS OF MOTHERS OF PRETERM LOW BIRTH  
WEIGHT INFANTS DURING THE FIRST WEEK OF  
THE INFANTS' DISCHARGE FROM HOSPITAL.

by

Margaret Elizabeth Nowe, BN,RN

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## ABSTRACT

In this qualitative study the purpose was to explore and describe the concerns of mothers of preterm Low Birth Weight (LBW) infants during the first week following the infants' discharge from hospital. Concepts from role theory formed the conceptual framework for the study.

Fourteen mothers of preterm LBW infants participated in the study. A structured diary and an audio-taped interview were used to collect data. Data were analyzed for themes and then categorized.

The analysis of the data revealed that mothers' major concerns were related both to the infants and to themselves. Over half of the concerns raised were related to the infants; the most frequent were infants' health, feeding, growth and development, and elimination. Mothers' concerns about themselves focused on feeling tired, their emotional state, and schedules. Mothers also had concerns about their partners and their families. The findings suggested that taking on the role of mother of a preterm LBW infant was facilitated by clear role expectations, positive learning experiences, and support from partners, family, and health professionals. These factors may have helped reduce mothers' concerns and therefore, role strain.

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## CHAPTER I

### Introduction

#### The Problem

The taking on of the parent role has been considered a form of crisis because of the physical and emotional adjustments the family must make, especially the mother (Broom, 1984; Hobbs & Cole, 1976; Miller & Sollie, 1980; Rossi, 1968; Russell, 1974). The mother must adjust to her new role, which includes learning to interpret the needs of her infant, take care of the infant, and relate to the infant. It is during the first week that she is home with the infant, when the mother has primary responsibilities for the care of her infant, that she judges how well she is able to take on this role. During this time the mother may experience difficulties with infant care or have concerns over the infants' health or physical progress.

When the course of pregnancy terminates in preterm labor and birth, the unanticipated birth ends the mother's perception of an ideal pregnancy (Rubin, 1984; Steele, 1987). The preterm birth may cause intense emotions and concerns. Mothers reported feelings of

helplessness and guilt about the preterm birth (Affonso et al., 1992). Steele (1987) emphasized that the weeks that follow a preterm birth are exhausting and confusing.

There may be an immediate separation of the infant and the mother because of the infant's need for intensive medical and nursing care attention. Furthermore, the mother is often discharged home without the infant, and therefore, adaptation to the mother role has to be postponed until the infant is discharged from the hospital. The prolonged separation may cause a delay in the mother-infant attachment process. The delay in attachment may in turn leave the mother with feelings of inadequacy to care for her infant. It is possible that feelings of affection towards the infant may be delayed. Goodman and Sauve (1985) and Jeffcoate, Humphrey and Lloyd (1979) reported that some mothers did not feel that the infant was really their own until the infant came home from hospital.

The birth of a preterm infant is stressful and can produce a crisis situation for the mother. According to Caplan (1964), a crisis occurs when a person is

confronted with an imbalance between the difficulty perceived and the usual method of problem-solving. A period of disequilibrium occurs if alternative ways cannot be found to solve the problem. Tension increases and feelings of anxiety and helplessness result. Parents of preterm LBW infants have a more difficult time adapting to parenthood. This may be due to the crisis of preterm birth, coupled with the adjustment of adding a new member to the family. When parents bring their infants home from hospital they no longer have the continued presence and support of hospital staff. They have to make day-to-day decisions regarding the infants' needs. Parents may feel that they have been abandoned (Censullo, 1986). The mothers lack confidence and feel insecure when they first take their infants home from hospital (Jeffcoate et al., 1979; Kenner & Lott, 1990; McHaffie, 1990). Mothers of preterm Very Low Birth Weight (VLBW) infants experienced more anxiety and depression from the time of delivery until the infant was two months corrected age (Gennaro, York & Brooten, 1990).

Despite the technological advances available to manage pregnancy, the birth rate of preterm LBW infants

in Canada has remained stable over the past 10 years (Yawn, 1990). Yawn (1990) reported that LBW infants are 40 times more likely to die within the first four weeks of life and they are three times more susceptible to neurological handicaps. Johnson, Cox, and McKim (1987) found that of 143 live born VLBW infants (infants weighing 1500 grams or less) delivered in Newfoundland in 1980-1981, 61 died during their first year. Eight of those who survived past their first year showed evidence of severe neurological abnormality. Nine were found to have various other problems, which included seizures and developmental delay.

The Department of Health, Health Research and Statistics Division reported 7685 live births in Newfoundland in 1990. The proportion of LBW infants (infants weighing 2500 grams or less) born in Newfoundland in the same year was 5.64% of the live births. Included in these statistics are preterm infants as well as full-term infants who had low birth weights. Therefore, the number of LBW infants born in Newfoundland in 1990 approximated 433.

Two recent studies revealed that the largest

category of concerns for mothers of preterm LBW infants was related to the infants' health (Butts et al., 1988; Gennaro, Zukowsky, Brooten, Lowell & Visco, 1990). Gennaro, Zukowsky, et al. (1990) reported that at one week following the preterm LBW infants' hospital discharge the most frequently articulated health related concerns were breathing patterns and medications, followed by care for infants on an apnea monitor, and lastly the infants' weight gain or loss.

McKim (in press-a) found that 48% of the 56 mothers in her study reported that the first week at home with their preterm infant was difficult. It was a time when mothers needed guidance and support from nurses. The factors associated with the difficult first week at home were related to the degree of the infant's prematurity, the degree of the infant's illness, whether the infant had apnea in hospital, and whether the Public Health Nurse visited during the first week after the infant was d'scharged from the hospital.

#### Rationale for the Study

The first week at home with preterm infants has

been identified as a stressful time for parents (Kenner & Lott, 1990; McHaffie, 1989). None of the research discussed here focused solely on the concerns of mothers of preterm LBW or VLBW infants in the first week following the infants' discharge from hospital. Currently there are limited data on concerns of mothers of preterm LBW infants in the early post hospital discharge period, especially during the first week the infants are home from hospital. More information is still needed on the concerns of mothers of preterm infants.

The nurse is in a prime position to help ease the factors contributing to the mother's stress during the preterm LBW infant's first week at home. It is important that nurses who work with these mothers of preterm LBW infants have a greater understanding of the mothers' concerns during the infants' first week at home from hospital. The mothers' perceptions of concerns may differ from what the nurses perceive as the mothers' concerns. Knowledge of the mothers' concerns will facilitate the discharge planning process. This information will be useful in meeting the needs of mothers of preterm LBW infants prior to

and following the infants' discharge from hospital. Therefore, this study is designed to explore and describe the concerns of mothers of preterm LBW infants during the first week following the infants' discharge from hospital.

### Definition of Terms

Concern A concern is a feeling of anxiety or apprehension, a worry, or something seen as a problem (Goodman & Sauve, 1985). A concern may relate to the infant, the mother, her partner, and the family. Family includes relatives and older children.

Mother. A primipara or multipara who has delivered a preterm LBW infant.

Primipara. A woman who has given birth to her first viable infant whether alive or stillborn.

Multipara. A woman who has borne one or more viable infants.

Low Birth Weight (LBW) Infant. A preterm infant whose birth weight was recorded at birth as 2500 grams or less and born at 37 weeks or less gestation.

Very Low Birth Weight (VLBW) Infant. A preterm infant whose birth weight was recorded at birth as 1500 grams or less.



## CHAPTER II

### Literature Review

The objective of this literature review is to identify those factors relating to the concerns of mothers of preterm infants after the infants go home from hospital. Studies which addressed the concerns of mothers of preterm LBW and VLBW infants were reviewed. The literature relating to the impact of taking on the role of mother and factors which influence the taking on the role of mother were also reviewed.

The review is organized in the following sequence which relates to the conceptual framework: the impact of taking on the role of mother (role taking, role strain), factors which influence the taking on the role of mother of a preterm LBW infant (role expectations, role learning), and the concerns of mothers of preterm LBW infants (role-set).

#### The Impact of Taking on the Role of Mother

Becoming parents is viewed as a critical point in the development of a couple's life together. The assumption of a parenting role is one of the demands and challenges faced by parents. Taking on a new role

involves a change in expectations of self and others, a change in relationships, and the learning or updating of skills (Meleis, 1975). Duvall and Miller (1985) emphasized that becoming a parent brings other responsibilities such as settling down to family life, stimulating and directing the infants' development, and endeavoring to meet individual and family developmental tasks.

There were two schools of thought relating to the impact of becoming a parent. Some researchers viewed taking on the parent role as a crisis (Broom, 1984; Hobbs & Cole, 1976; Russell, 1974). In fact these researchers viewed the whole area of family and marriage as a crisis. Russell (1974) defined crisis "as a change in self, spouse, or relationships with significant others which the respondent defines as 'bothersome'" (p. 295). Hobbs and Cole (1976) and Russell (1974) found significant association between the quality of spousal relationships and the ease or difficulty parents experienced in becoming parents. Hobbs and Cole (1976) stated that mothers reported significantly greater amounts of difficulty than did fathers. However, none of the variables studied were

found to be significant in identifying degrees of difficulty mothers experienced in taking on the role of mother. The authors suggested that further research is needed to explore the variables that impact on becoming a mother. Other researchers viewed parenthood as a normal crisis or a developmental event (Miller & Sollie, 1980; Rossi, 1968). Rossi pointed out that the paucity of educational programs for parenthood may explain why parents experience difficulty in taking on parental roles.

When the child is born, parents are forced to adapt from an adult centered dyad to a child focused triad (Broom, 1984). The parents must learn to balance their own and family needs with the child's requirements. It may be more difficult for some parents to move from a dyadic to a triadic relationship. Therefore, tension may occur in relationships. These parents may be the ones who need support.

Caplan (1960) and Kaplan and Mason (1960) were pioneers in research related to preterm infants. They found that the birth of a preterm infant precipitated stress and produced a potential crisis situation, and

when the infant was preterm and critically ill, the stress event caused a crisis situation for parents. Kaplan and Mason found that mothers were anxious when their infants came home. They worried about the smallness and fragility of the infants.

Goodman and Sauve (1985) emphasized that the birth of a preterm infant involved "a double adjustment for some parents - becoming a parent and having to cope with a crisis situation" (p. 239). They suggested that the stresses continued after the infants' discharge when the mothers took on the demanding task of full-time care of the infants. Jeffcoate et al. (1979) suggested that preterm birth could provide sufficient stimulus to develop into a crisis because the mothers' self esteem is threatened. Mothers viewed their role as a "giver" of love and essential care. Mothers were delayed in performing role expectations because of immediate separation from their infants.

Affonso et al. (1992) identified stressors as reported by mothers of hospitalized preterm infants. The infants weighed 1800 grams or less. Mothers were interviewed on four occasions while the infants were still in hospital. The first interview occurred within

96 hours of the delivery and the last interview took place one week prior to discharge. The sample size decreased over the interview period as shown: 36, 25, 16, 8. The mothers reported emotional issues as negative stressors (an event seen as undesirable) across all four interviews. They expressed feelings of guilt about having a preterm birth and felt a sense of helplessness. The infants' health status was considered a negative stressor during the first three interviews. The stress was related to the uncertainty of the infants' survival, the possibility of complications, and the infants' long term prognosis. Separation of the infants from the mothers was the most frequently cited negative stressor during the first interview and remained a stressor during the second interview. The stressors included not being able to hold the infants, being discharged without the infants, and having to leave the infants in the nursery after they visited. Also, mothering concerns were reported as negative stressors during the last two interviews. During the last interview mothers experienced stress associated with anticipating home responsibilities following the infants' discharge. Positive stressors

(an event which the mothers perceived as stressful but viewed as positive) included communication with nurses about the infants' health status. Mothers were unsure of how the nurses would react to their questions and concerns. Positive stressors related to the infants' health status included positive thinking about their infants' survival even though their infants' health was precarious.

Brooten et al. (1988), Gennaro (1988), and Gennaro, York and Brooten (1990) investigated the emotional responses of mothers of preterm infants. Gennaro (1988) examined the differences of anxiety and depression in mothers of preterm LBW infants and full-term infants one week postpartum and each week for six weeks thereafter. Mailed questionnaires were completed by 16 mothers of LBW infants and ten mothers of term infants. Qualitative data were also collected on what each week was like for the mothers. Gennaro reported that the mothers of preterm LBW infants had heightened anxiety and depression in the first postpartum week. For the next six weeks there was no difference in anxiety and depression experienced by either group of mothers. Although not statistically significant, there

was a rise in anxiety scores on the fifth week for mothers of preterm infants as opposed to week four for mothers of full-term infants. Mothers reported sleepless nights were impacting on their adjustment in their roles. Family members who had come to help had now left. Gennaro (1988) commented that at about one month postpartum " the honeymoon was over and reality had set in" (p. 84).

Brooten et al. (1988) measured anxiety, depression, and hostility in 47 mothers of preterm VLBW infants. The infants were free from serious health problems. The data were collected at the time of the infants' discharge and again when the infants were nine months of age. Brooten et al. found that the mothers were more depressed and anxious prior to the infants' discharge than they were at nine months. Multiparas were more depressed than primiparas prior to the infants' discharge. However, there were no differences in anxiety and hostility experienced by primiparas and multiparas at the time of the infants' discharge or when the infants were nine months old. The multiparous women had previous child care experience and were possibly overwhelmed with the demands of caring for

another child especially one who may be vulnerable. Another finding was that mothers whose infants had long hospital stays, that is a mean of 51 days, were significantly less depressed at discharge than mothers of infants with shorter hospital stays. Brooten et al. (1988) suggested that this may be due to the mothers having time to gain emotional and physical equilibrium before the infants went home. Maternal age, education, and marital status had no effect on the amount of anxiety, depression, and hostility experienced by the mothers.

Gennaro et al. (1990) compared anxiety and depression responses of 27 mothers of VLBW preterm infants and 35 mothers of LBW infants. Data were collected from the time of delivery until the infants were five months adjusted age. Mothers of VLBW infants experienced higher levels of anxiety and depression from birth up to the first two months. The VLBW infants were considerably sicker than the LBW infants and this might explain the mothers higher levels of anxiety and depression. The highest levels of anxiety and depression for all mothers was the week following delivery.



Gennaro, Griseamer and Musci (1992) examined expected versus actual life-style changes of 60 mothers of preterm LBW infants. The mothers were interviewed eight times, one in person, and subsequently by telephone. The interviews occurred one week following delivery, at infant's discharge, and each month until the infants were six months adjusted age. Forty-six percent of the infants went home on an apnea monitor. Mothers reported that they got less sleep and were more tired than they expected to be following the infants' discharge from hospital. Fifty percent of the mothers reported experiencing less time for themselves, being more tired, and having more responsibility following the infants' discharge from hospital than they did following the infants' delivery. There were no differences in expectations of lifestyle changes between primiparas and multiparas. However, they stated that the mothers seemed to accept these changes as part of being a mother of a preterm infant.

McKim (in press-a, in press-b) studied the information and support needs of 56 mothers of high-risk preterm infants. These infants were followed by the Newfoundland and Labrador Perinatal Follow-up

Clinic after the infants' discharge from hospital. The data were collected during the mothers' first visit to the clinic. She reported that 48% of the 56 mothers in her sample found that the first week at home with their preterm infants was difficult. When questioned about what they found difficult about the week the mothers' responses centered around the infants being born preterm. How preterm the infant was, the seriousness of the illness, and a prompt visit from the Public Health Nurse were factors in whether the mothers found the first week difficult. McKim found a relationship between the infants' apnea episodes when in hospital and the reported difficulty mothers had during the first week of the infants' discharge from hospital. Some mothers expressed anxiety because now they and their partners were on their own without help of the hospital nurses. Some mothers feared that their infants might die.

The studies reviewed here seem to indicate that the birth of a preterm infant can have a positive and/or a negative influence on the mothers. However, most of the researcher's have not mentioned whether the mothers had professional or lay support and whether

they had participated in discharge teaching. Also, the mother-infant interaction process has not been discussed. These factors may have a positive or negative influence on the taking on of the role of mother of a preterm LBW infant.

**Factors Which Influence The Taking on the  
Role of Mother of a Preterm LBW Infant**

The ease with which mothers of preterm LBW infants assume the mother role depends on several factors. These factors include: mother-infant interaction, the mothers' teaching and learning needs, and the mothers' support needs.

The literature review, pertaining to mother-infant interaction, includes the effects of early delivery and infant behavior on the taking on of the mother role. Mothers of preterm infants have unique learning needs, therefore, the literature relating to the impact of pre-discharge and post-discharge teaching on the taking on of the mother role was examined. Also, the informal and formal support needs of mothers of preterm infants were explored.

### Mother-Infant Interaction

Klaus and Kennell (1982) stated that the bond formed between a child and parents is the strongest of all human ties and is crucial for the child's survival and development. The birth of infants who required intensive care overwhelmed the mothers with emotions and grief as they dealt with the loss of an ideal pregnancy (Steele, 1987). The fragility of the preterm infant, and the need for expert medical and nursing care caused immediate separation, and delayed attachment to the infant as well as taking on the mother role (Klaus & Kennell, 1982).

Rubin (1984) determined that one of the tasks of pregnancy is "binding in" to the child. Rubin affirmed that "it is the fetal movements that begin to transform the theoretical child to a real, living child" (p. 62). Rubin stated that it was at this time the mother began to fantasize about the idealized child. This was the beginning of the attachment process, which increased over the next months of pregnancy, and intensified following the birth of a full-term infant. When the birth was preterm, Rubin emphasized that the mother had "a very incomplete delivery with an incomplete infant"

(p.104). The mother became a parent before she was ready to take on the mother role. The preterm infant did not meet with her image or expectations of a newborn. The preterm infant's behavior and appearance are not what the mother usually expects, and thus interferes with the mother assuming her role.

Jeffcoate et al. (1979) interviewed two groups of families - parents of preterm LBW infants and a control group of parents of full-term infants, about role perception and response to stress. The parents of the preterm LBW group consisted of 17 mothers and 13 fathers. The control group consisted of 17 mothers and 12 fathers. The parents were interviewed in their homes, and separately where possible, when the infants were between six and twenty months of age. Whereas, the time of birth for the control group was a joyful event, the preterm group of parents expressed several emotions. Fifteen parents of preterm infants expressed being upset and shocked about the preterm delivery. Many parents felt a sense of failure, shame, or guilt at producing a preterm baby. Some parents were shocked by the appearance of their baby, describing them "as looking like a rat" or "skinned monkey". When the

infant was hospitalized, the mothers felt helpless and frustrated with their role. Eight of the mothers of preterm LBW infants reported delay in feelings of love and "real warmth" for two months or longer. These mothers reported that they felt numb or as though they were caring for someone else's baby. The demands of the baby and delay in attachment "caused some mothers to feel totally inadequate in their mother role; several reported at times they felt violent towards the child" (p. 142). Nine of the seventeen mothers of preterm LBW infants stated that they did not feel that the infant belonged to them until after the infant was discharged home. Only 50% of the primiparous mothers of preterm infants felt confident in taking on their mother role when they took them home, whereas experienced mothers expressed confidence in their role.

Bidder, Crowe and Gray (1974) examined 20 multiparas' attitudes to their preterm LBW infants as compared to their attitudes towards their previously born full-term infants. They found significant differences between the mothers' perception of the preterm and term infants and the idealized child of their pregnancy. The mothers described the ideal child

as more calm and contented than either of their children who were born full-term or preterm. Mothers were anxious following delivery and again after the infant was home. This anxiety impacted on the mother role; the mothers viewed their preterm infants as weak, and they were anxious handling their infants.

McHaffie (1990) studied 21 mothers' perceptions of their adjustment following their preterm births. The day prior to discharge two mothers said that they did not feel ready to take their infants home. Many factors emerged which related negatively to their feeling of readiness. The two mothers who expressed that they were not feeling ready to take on the mother role at home showed "difficulty establishing and maintaining relationships and held very inappropriate perceptions of their baby" (p. 10). These two mothers had concealed their feelings of not feeling ready to take their infants home from the staff. When the infants came home the mothers were elated but expressed feelings of insecurity and lacking confidence in their mother role. Many mothers reported how amazed they were at how much the infants cried. The mothers noted that "they had not gained a true picture of this aspect

of the infants' behaviour in a sheltered environment of the hospital" (p. 8). At first the mothers interpreted the infants' crying as a result of their inability to understand their infant. However, if the infants persistently cried, the mothers viewed the infants as demanding. McHaffie suggested that the interaction between mothers and infants, as well as the mothers' perception of readiness to take on the mother role at home, should be taken into consideration prior to the infants' discharge from hospital.

Using the Infant Temperament Questionnaire (ITQ), Medoff-Cooper and Schraeder (1982) found significant difference between the temperaments of 26 VLBW infants and the standard population in the areas of distractibility, adaptability, approach, withdrawal, and mood. Medoff-Cooper and Schraeder found that VLBW infants "were difficult to soothe (low distractibility), less adaptable, negative in mood, and withdrawing" (p. 71). They concluded that "VLBW seems to be associated with difficult temperament in infancy" (p. 71). They found that infants with low soothability and negative moods were more likely to be responded to in a negative manner by the mother. These findings



illustrate the need to enhance the mother-infant relationship. Mothers can be assisted to recognize the preterm infants' behavioral responses and learn to identify activities to soothe the infants.

Zahr (1991) investigated the relationship of 49 mothers' feelings of confidence, maternal behaviors and skills, and infant temperament. Maternal confidence was defined "as the perception mothers have of their ability to care for and understand their infants" (p. 280). The mothers were from low socioeconomic backgrounds, and had a mean of 10.5 years education. Maternal behaviors were evaluated while the infants were in hospital. The remaining data were collected when the infants were four and eight months adjusted age, during follow-up visits, using standardized instruments. The study revealed that the mothers' education, social support, previous infant care experience, and family income correlated positively with the mothers' confidence. Subjects who were confident in the mother role perceived their infants as more predictable, less difficult, and more adaptable at both testing periods. There was no relationship found between the infants' risk status and perceived

confidence scores, with the exception of the presence and severity of intraventricular bleed at four months. Zahr (1991) suggested that these infants were probably sicker and less alert than their full-term cohorts which could have affected the mothers' perception of confidence. There was also no correlation of maternal confidence with observed maternal behaviors in that mothers who appeared to be comfortable with the care of their infants did not necessarily perceive themselves as confident when asked.

#### The Mothers' Teaching and Learning Needs

Sammons and Lewis (1985) emphasized that upon discharge from hospital, parents of preterm infants often experience "the same feelings of failure and incompetence that they encountered when the infant was first born" (p. 181). These feelings may be alleviated if the teaching and learning needs of mothers of LBW infants are met.

McKim (in press-b) surveyed the information needs of 56 mothers of preterm infants. Although more than 80% of the mothers received information on infant feeding and bathing, more than 50% of the mothers would have liked information on infant colic, noisy

breathing, spitting up, and fussy periods prior to the infants' discharge from hospital. Fifty percent of the mothers wanted information on how to recognize signs that the infant was not well. Other information they wanted but had not received included: taking infant outdoors, infant behavior, diaper rashes, breathing patterns, and how to give medications. McKim found that 25 of the 42 mothers who had specific information needs, described that the first week at home with the infant was difficult.

Kenner and Lott (1990) reported that parents of preterm infants expressed a need for more information and teaching when their infants went home from hospital. They found that, at the time of discharge and when the infants went home, mothers were experiencing grief and they worried if their infants would survive. Thus, they questioned whether the mothers were able to assimilate all the information prior to the infants' discharge from hospital. The mothers viewed their infants as different and sicker than term infants and still worried about their breathing patterns. Kenner and Lott (1990) stated that the move of the infants from a controlled environment

to a less controlled environment, and lack of positive reinforcement from their infants, may have caused the mothers to have doubts about their caretaking skills. They emphasized that nurses need to provide a flexible and individualized educational program in order to reduce mothers' stress, enabling them to cope when their infants are discharged. Censullo (1986) suggested that counselling, teaching, and follow-up after the preterm infants' discharge can assist parents in gaining a sense of mastery and thus, increase their self confidence and enhance their parenting skills.

Broton, Gennaro, Knapp, Brown and York (1989) examined the pre-discharge and post-discharge learning needs of parents of preterm VLBW infants. The sample included 36 mothers and 39 infants (three sets of twins). The mothers were predominately black, unmarried, and of lower socioeconomic status. Infants requiring complex care were eliminated from the study. Teaching and home follow-up were conducted by Clinical Nurse Specialists. Follow-up visits were made at one week, one month, nine, twelve, and eighteen months. Post-discharge teaching needs included the need for information about infant feeding and current infant

health problems. Breastfeeding mothers needed intense teaching. Twenty-six percent of the infants were re-hospitalized during the eighteen months of the study. Other major areas of teaching included infant growth and development, and administering and monitoring medications. Teaching regarding the home environment included the need to maintain adequate home temperatures and to obtain a flashlight in case of power failure. Parents needed constant reinforcement that their infants' growth and development should be assessed using the corrected age and not as a term infant. Parents worried constantly about their infants' weight and need to "catch up". Post-discharge teaching related to infant feeding involved a mean of eight sessions per family, while the usual teaching protocol for VLBW infants provided only one session. The study findings emphasized the need for continuity of care and follow up teaching for these families.

Harrison and Twardosz (1986) studied the effects of a structured teaching program on mothers' perceptions of and interaction with their preterm LBW infants. Thirty mothers whose preterm infants were in intensive care were randomly assigned to one of three

groups: control, instruction, and attention. The interventions occurred when infants were 14.6 days old. Mothers in the control group received support and routine care from the nursing staff. The mothers in the instruction group received routine care as well as an one hour teaching session on the preterm infants' physical and behavioral characteristics. The researchers gave the mothers in the attention group the opportunity to discuss non-medical concerns. This intervention lasted one hour. No significant differences were found amongst the three groups when maternal perceptions of their infants were measured when the infant was in hospital and again when the infant was home approximately one month. A Neonatal Perception Inventory was administered prior to intervention for the instruction and attention groups. Also, no significant differences were found in maternal behaviors when measured during three home visits. This finding did not support Harrison and Twardosz's hypotheses that mothers of preterm LBW infants who received structured teaching about their infants' physical and behavioral characteristics would demonstrate a more positive perception of their

infants, and more positive maternal behaviors than those mothers who did not receive structured teaching. The outcome of this experimental study is inconclusive. The findings suggest that either a one time teaching intervention may not be adequate or that the neonatal nurses were already providing adequate teaching and support. Other things to consider would be the timing of the teaching, and the amount of time spent on the intervention.

Cagan and Meier (1983) evaluated the discharge planning tool they had developed and piloted in 1979. There were two study groups: 35 high-risk infants for whom discharge planning was not systematic and structured, 40 high-risk infants whose discharge planning was coordinated using the discharge planning tool. A questionnaire was administered two to four days following discharge. The discharge planning tool facilitated the transition from hospital to home and proved to be an effective tool for standardizing and documenting the discharge planning process. The most valuable finding was that parents felt that they were a vital part of the discharge planning process and this helped relieve the anxiety which accompanied discharge.

Cagan and Meier (1979 and 1983) did not define the term "high-risk infants" but did describe them as previously ill infants who were cared for in the special care nursery and for whom survival was no longer a threat.

Cagan (1988) stressed that standard discharge planning tools are only one method of smoothing the transition from hospital to home. Nurses should strive to wean parents from the intensive care unit prior to the infant's discharge by fostering parent-nurse interdependence. The parents can learn to depend on themselves and make decisions while using nursing staff as a resource. The parents will take their infants home feeling more secure about their abilities.

#### The Support Needs of Mothers of Preterm LBW Infants

It is a policy in Newfoundland that a Public Health Nurse visit new mothers within the first week of the infants' discharge from hospital to assess the family needs and to provide support. McKim (in press-b) in describing the support needs of the 56 mothers in her study found that although 93% of the mothers received a visit from the Public Health Nurse, only 61% of these mothers were visited during the first week of the infants' discharge from hospital. McKim found that



there was a delay in the Public Health Nurses' visits if the infants had been very ill in hospital. The mothers who were not visited during the first week by the Public Health Nurse described the first week as difficult. McKim reported that 93% of the mothers had at least one source of lay support. The partner was named as the primary source of support by 75% of the mothers, followed by the mothers' own mother (21%).

McHaffie (1989) studied the informal and formal support systems of 21 mothers of VLBW infants. The mothers were interviewed on six occasions; three times during the infants' hospitalization, and one week, one month, and three months following the infants' discharge from hospital. Following the infants' discharge 16 of the 18 mothers who had partners found them the most supportive. The partners were especially helpful in the areas of sharing in decision making, household chores, and decreasing anxiety during the first week. Initially, when their partners expressed fear of caring for the infants the mothers stated that they appreciated the help with other tasks. This gave them more time to spend with the infants. A few mothers noted that they preferred to tend to the infant

themselves. Following the initial adjustment to being home with the infants, most of the mothers said that they felt depressed and tired. They appreciated assistance from their partners with feeding the infants' and in caring for the infants when their crying persisted. Most of the mothers stated that they did not have as much time to spend with their partners as they would have liked. They reported that the partners' support prevented the deterioration in their relationships. Ten of the mothers found their own mothers supportive following delivery because they expressed concern for their daughters and not just concern for the infants. Eleven of the mothers had some assistance from their own mothers during the infant's first days at home. Relatives were supportive initially following the infant's birth and again following the discharge of the infant. Support from relatives waned during the months that followed, when the mother was tired, anxious and depressed from continued demands of the infant. McHaffie stated that the relatives appeared to have difficulty in knowing how to be supportive. McHaffie reported that five of the mothers had not been visited during the first week

by the health visitor and they expressed anger. Many of the mothers who were visited found the visit was short. These mothers were not satisfied with the information and support given by the nurse. They indicated that they would have liked more support from the nurse such as listening and the giving of accurate information.

In summary, the literature supports that factors such as mother-infant interaction, teaching and discharge planning, and social support can impact on the mother's ability to care for her infant and the anxieties she experiences post discharge as she assumes the role as caretaker for a preterm LBW infant. Preterm delivery and subsequent separation of the mother and infant results in different expectations than the mother anticipates and delays the attachment process. This delays the taking on of the mother role, causing the mother to feel inadequate in her role. Also, the preterm infant's temperament has been shown to affect mother-infant interaction negatively. Flexible and individualized discharge teaching plans may help reduce the mother's anxiety upon the infant's discharge from hospital. The taking on of the mother

role when the infant is home, can be facilitated by support from partners, family, and health professionals.

#### Concerns of Mothers of Preterm LBW Infants

Adams (1963) surveyed the concerns of 20 first time mothers of preterm LBW infants and 20 first time mothers of full-term infants. Adams did not make reference to the mean gestational age of the infants although she did define preterm infant as weighing under 2500 grams. The mean hospital stay for all infants was four days. The range of hospital stay was three to twenty-one days. Therefore, one would assume that these LBW infants were a low-risk group. The mothers were interviewed prior to the mothers' discharge, at one week, and four weeks following the infants' discharge. The mothers of LBW infants in this study had a higher level of education than mothers of full-term infants. Adams was one of the first researchers who defined concerns and she referred to a concern as an area of "special interest or worry to mothers as indicated by questions pertaining to particular areas of care" (p. 72). These mothers

seemed to have access to more information and sought the nurses' assistance regarding the care of their infants at home. Both groups of mothers had similar kinds of concerns. Feeding, bathing, and crying were the major concerns during the first week. At the end of four weeks, feeding and crying were again cited as the major concerns, however, bathing was of minor concern. Other categories of concerns for both groups of mothers included rashes, sleeping, hiccups, weight, and taking the infant out of doors. Hiccups caused the mothers of LBW infants anxiety when the infants were home for one week.

Goodman and Sauve (1985) reported that 30 mothers of high-risk infants had similar concerns to 30 mothers of full-term infants, two and six weeks following the infants' discharge from hospital. The high-risk infant referred to any newborn who required hospitalization in the Neonatal Intensive Care Unit. Twenty-six of the thirty high-risk infants were preterm infants. A concern was defined by Goodman and Sauve (1985) "as a feeling of anxiety or apprehension, a worry, or something seen as a problem" (p. 236). The mothers rated concerns related to infant care and behavior, the

mother, her spouse, and other children. Both groups of mothers expressed concerns regarding feeding, sleeping, attachment, gastro-intestinal problems, rashes, husband, and self. Only the mothers of high-risk infants cited the infants' appearance as a concern. The difference in the concerns of both groups was statistically significant in four areas: feeding, sleeping, appearance, and attachment. Feeding concerns of the high-risk mothers centered around the amount of feeding and the infants' weight gain. More mothers of high-risk infants than mothers of full-term infants expressed concern regarding the infants' sleeping patterns. Two of the mothers were concerned that their infants would cease to breath while sleeping. Forty percent of the mothers of high-risk infants felt that their infants did not know them 28 days after the infants' discharge from hospital, as compared to 17% of the mothers of full-term infants. Goodman and Sauve reported that it usually wasn't until the high-risk infant came home that the mother felt the infant was really hers. The concerns of both groups of mothers decreased at six weeks. However, mothers of high-risk infants tended to express more concerns than mothers of

full-term infants at the six week interview.

Gennaro, Zukowsky, et al. (1990) interviewed 65 mothers of LBW infants in hospital, one week following discharge from hospital, when the infant was 40 weeks gestational age, and again each month until the infant reached six months adjusted gestational age. Mothers were asked at the time of each interview "what are your concerns right now"? (p. 460). Most of the concerns were raised the week following birth and one week following the infants' discharge. The infants' health remained the major concern for the duration of the study. Breathing patterns and medications were the most frequently voiced concerns related to the infants' health one week following discharge. The next most frequent category of concerns at one week post discharge was using apnea monitors, then the weight of the infants, followed by the infants' development. Infant development was the second most frequent concern when the infants were three months adjusted age. At this time the mothers were starting to expect their infants to achieve a developmental milestone of a five to six month old full-term infant. Concerns about maternal career and child care did not surface until

later in the study when the mother began to worry about her plans for the future. There was not a significant difference in the number of overall concerns voiced by primiparas and multiparas or when concerns were grouped according to the infants' sex. When grouped according to the level of education, mothers with more than a high school education voiced more concerns than those mothers with less than high school education.

Butts et al. (1988) monitored the number of telephone calls made to the perinatal clinical nurse specialist by 36 parents of VLBW infants following the infants' hospital discharge, over an 18 month time span. Seventy-seven percent of the mothers were multiparas. The majority of calls were made by mothers during the first three months. Only two fathers and one grandmother initiated telephone calls. The reasons for the calls were ranked according to frequency. The major concern during the first four months was infant health problems followed by normal infant concerns. Health concerns included respiratory problems, medications, skin rashes, infections, and feeding problems. Very few mothers had concerns about themselves. Butts et al. did not compare the data for



parity. They did suggest that the high number of mother-initiated calls during the first months following discharge may be due to the mothers' readiness to learn. Also, the mothers' interest may have been stimulated by the nurse-initiated phone calls during the first two months. Although the title of this study was concerns of parents of LBW infants, the sample studied were mothers of VLBW infants (weight 1500 grams or less).

Kenner and Lott (1990) conducted a qualitative descriptive study to determine parents' concerns regarding discharge of their infants from the Neonatal Intensive Care Unit. Parents of four preterm infants and 6 full-term infants were interviewed in their homes at one and four weeks following the infants' discharge. The parents were also requested to keep diaries in which they were asked to record concerns or problems they had about themselves or their infant. Five categories emerged: information needs, anticipatory grief, parent-child development, stress and coping, and social support. Kenner and Lott did not cite the number of parent responses in their study. Parents expressed concerns regarding the infants' health and

would have liked information regarding the infants' behavioral and physical characteristics. They still worried about the infant dying, about the infant's breathing patterns, and the possibility of illness. The parents had concerns about feeding their infant and worried about weight loss. A major finding was the gap between what parents perceived as concerns and what nurses perceived as parents' concerns. Parents expressed concern about the lack of clarity of their role in the Neonatal Intensive Care Unit. Parents had concerns about their competency to care for their infants and perceived that their infants belonged to the nurses more than to them. In their view, nurses in the hospital were not supportive to them as parents and did not involve them in decision making, which compounded the stress they felt when they took their infants home. They felt that if the neonatal staff had been more supportive they would have coped in a more positive manner with their role responsibilities. At one month the parents expressed more confidence in their ability to recognize the infants' needs. The researchers did not include a description of the demographic variables of the sample. They referred to

parents but did not state whether the mother and father were interviewed together or separately.

#### Summary of Literature Review

Traditionally there are two approaches used in viewing the taking on of the parent role. The first approach uses the concept of crisis in viewing the transition to parenthood. The second approach, however, uses the developmental perspective and sees the assumption of the parent role as a normal crisis. It has been well documented that parenting a preterm infant is stressful and presents a potential crisis event for parents. The stress of a preterm birth may be compounded by prolonged separation and hospitalization because of the infants' special care needs.

Mothers of preterm infants have many concerns related to the demands within their role-set throughout their infants' hospitalization and following their infants' discharge from hospital. Most of these concerns are related to the infants' health, feeding, sleep patterns, and attachment.

Several researchers have focused on factors that influence the taking on of the role of mother of a

preterm LBW infant. Factors which were reported to affect the mothers' adjustment to the mother role included: maternal-infant interaction, support of the mothers, and the mothers' learning needs.

It is evident that mothers of preterm infants have concerns following the infants' discharge from hospital. Although there are studies which had examined the concerns of mothers of preterm LBW infants, no studies have concentrated solely on the concerns of mothers of preterm LBW infants during the first week following the infants' discharge from hospital. Also, the week following the infants' discharge from hospital has been identified as difficult and raises the most concern for mothers. Mothers of preterm LBW infants may encounter difficulties in assuming the mother role while the infants are in hospital because of the abruptness of the preterm birth, because of prolonged separation from their infants, and because the appearance and behavior of the infants are not congruent with their expectations of an ideal infant. When mothers take their preterm LBW infants home they must now take on the role of mother without the continuous support and

presence of hospital staff. Mothers feel insecure, lack confidence, are depressed and anxious when the infants are discharged from hospital. Factors found to be associated with the difficult first week were: the degree of prematurity, the infants' health status, prompt Public Health Nurse visits, and whether the infant had apnea in hospital.

The research that has been carried out on mothers of preterm LBW infants has been done largely in the United States where the culture and health care set-up differ from Canada. Only one Canadian study has been located which deals with the above topic. Therefore, more studies are needed, using qualitative methods, to find out how mothers perceive the first week at home with their preterm LBW infants.

The studies reviewed here show that taking on the mother role of a preterm infant presents the role incumbent with many difficulties, such as, anxiety, uncertainty, adaptation of learning needs, and different expectations. All these call for modification of expectations, consistent support, and teaching by others.

In conclusion, further investigation is needed to

focus on the concerns of mothers of preterm LBW infants during the first week following the infants' discharge from hospital. Also, more information is needed on the impact on the mother when she takes on the mother role and factors which influence the taking on the role of mother during the first week of the infants' discharge from hospital.

## CHAPTER III

### Conceptual Framework

The birth of a first child forces a woman to take on the mother role. In order to enact the role effectively the new mother needs to continue to learn all about the role and the skills that are necessary for role performance. The skills are perfected over time. Mothers of healthy full-term infants take on the duties and obligations of their role after birth, thus role learning and role performance occur immediately following birth.

The literature review shows that when a preterm LBW infant is born the infant is usually in a poor state of health and requires prolonged periods of hospitalization in an intensive care unit. With the separation of mother and infant, the mother is unable to enact the mother role, and role learning is delayed.

Concepts from role theory are used to provide the conceptual framework of this study. The concepts used are role taking, role-set, role expectations, role learning, and role strain. Sarbin and Allen (1968) defined a role as "an organized set of behaviors that belongs to an identifiable position, and these

behaviors are activated when the position is occupied" (p. 56).

When an incumbent of a position puts into action the rights and obligations of the role, she enacts her role. Sarbin and Allen (1968) pointed out that to enable the role incumbent to enact her role convincingly she needs aptitude, appropriate experience, and specific skills. Mothers vary in their experiences of enacting the mother role. Some mothers may have taken on the role more than twice, while for others it may be the first time they have taken on the role.

A mother may have enacted the mother role several times and may have acquired experience and skills, but may have never given birth to a preterm LBW infant. Her past experience may not be adequate to interpret the specific needs of a preterm LBW infant and she would need to adjust to an infant whose needs differ from her other children. Therefore, she may need to learn new specific skills to help her carry out the duties and obligations of her mother role.

In the case of a primiparous woman, taking on the mother role of a preterm LBW infant may be more



problematic than her counterpart because of lack of experience, delay in role learning, and delay in role performance.

Every role is a way of relating to other roles in a situation. This refers to role-set. A role cannot exist without one or more relevant others towards which it is oriented (Merton, 1968). Thus a role of a wife makes no sense without a husband, equally a role of a mother makes no sense without a child. In the case of a preterm LBW infant the mother has to relate to an infant who is fragile and at best may have health problems. Thus within the mother-infant role-set the mother may experience tension, anxiety, and concerns over the health of the infant.

When a woman takes on a mother role, she plays not only the role of mother to her infant but an array of other roles as a mother. In her role as a mother she relates to her partner, her family, and health professionals. Merton stressed that role-set differs from that of multiple roles. Multiple roles refer to various social positions such as wife, daughter, and career woman. Each social position has its own role-set. The mother may have concerns related to demands

within her role-set as a mother or her other multiple roles (Goodman & Sauve, 1985; McHaffie, 1990).

Role expectations refers to the rights and obligations of the occupant of a position (Sarbin & Allen, 1968). Role expectations define the range of acceptable behaviors. People may have different expectations about a particular role. Burr, Leigh, Day and Constantine (1979) proposed that the clearer the role expectations, the easier it is to move into a new role. Sarbin and Allen (1968) stated that the degree of abruptness in the transition from one role to another will affect the clarity of a person's role expectations. The birth of a preterm infant for both a primipara and multipara is an abrupt and unexpected occurrence. This may result in different expectations than the mother anticipated, and may delay the readiness to take on the mother role (Jeffcoate et al., 1979; Rubin, 1984). When the infant arrives home from the hospital, the mother may expect the partner to take on added responsibilities in the home activities and care of the other children while she is adjusting to the care of the infant. If the partner's expectations are contradictory to what the mother expects, concerns

may result.

Sarbin and Allen (1968) stated that role learning are the performances that make up a role and are the products of learning experiences. The mother defines and learns her mother role, in part, through frequent interaction with her infant. The mother may have previously had a full-term infant. While her knowledge of infant care can be considered adequate, she however, may not have the knowledge and skills necessary to look after a preterm infant. Therefore, role learning is also essential in this situation to decrease the mother's concerns. The mother of a preterm infant may have concerns regarding her knowledge, infant care skills, and responsibilities when she brings the infant home (Brooten et al., 1988). The characteristics of the preterm infant, as well as the prolonged separation, may present barriers to the mother's role learning. It is not possible to learn all there is to know about a given role, thus a role incumbent may need to refer to others for clarification and sometimes for support. Thus, in most Intensive Care Units teaching plans are instituted for the benefit of mothers. Professional support is also available following the

infant's discharge from hospital.

Role strain is defined by Goode (1960) as "the felt difficulty in fulfilling role obligations" (p. 101). Goode suggested that a person cannot fully satisfy all the demands of role obligations and must make attempts to adjust role demands. Sarbin and Allen (1968) proposed that when a person is unable to reduce role strain, then the person is impeded in carrying out the duties of the role, and the quality of role performance is affected. Mothers' concerns may result in role strain. Role strain may be influenced by multiple demands of her roles, unclear role expectations (Burr et al., 1979), as well as inadequate role learning experiences and an inadequate social support system. Role strain in turn influences the ease with which the mother enacts her role (Burr et al., 1979). If the role demands are excessive, the mother may be forced to eliminate or delegate some of the duties of her role, or remove herself from the untenable situation.

In summary, the events surrounding the first week following the preterm LBW infants' discharge from hospital will be perceived uniquely by each mother.

How the mother interprets these events will influence her interactions with her infant, partner, family, and health care workers as she actively takes on her mother role. Clear role expectations, role learning, and support of partners, family, and health care professionals are essential factors needed to reduce the concerns of mothers of LBW infants as they relate to the infant, self, partner, and family during the infants' first week at home. In turn, the presence of these factors will help reduce role strain. Consequently, this will influence the ease with which the mother takes on her role during the first week following the preterm LBW infants' discharge from hospital in a positive direction.

#### **Statement of Purpose**

The purpose of this study is to explore and describe the concerns of mothers of preterm LBW infants during the first week following the infants' discharge from hospital.

#### **Research Questions**

This study is designed to examine the following

questions:

1. What are the areas of concern as perceived by mothers of preterm LBW infants during the first week following the infants' discharge from hospital?
2. What factors influence the taking on the role of mother during the first week following the preterm LBW infants' discharge from hospital?
3. Do the mothers experience role strain during the first week following the preterm LBW infants' discharge from hospital?

## CHAPTER IV

### Method

The literature review revealed that mothers of preterm LBW infants have concerns. However, studies that were reviewed did not focus solely on the concerns of the mothers of preterm LBW infants during the first week following the infants' discharge from hospital.

The present study examined the concerns of mothers, the factors which influence the taking on of the mother role, and role strain experienced by mothers during this time.

An exploratory design was chosen to carry out this research study. A qualitative exploratory design is an inductive method of research and is a preliminary study designed to explore and describe new information (Polit & Hungler, 1991). This is a design in which few or any of the variables are under the control of the researcher. Therefore, no inferences can be drawn from the data. However, conclusions drawn from the data may subsequently be used to develop hypotheses for further research (Field & Morse, 1985). Although every design has its advantages and disadvantages, the qualitative exploratory design is considered appropriate when

little is known about the topic under study (Field & Morse, 1985). The flexibility of the design gave the researcher the opportunity to explore and describe several aspects of the topic. In this study the qualitative approach permitted the mothers to describe their concerns using their own words and from their own perspective. This approach provided a way for the researcher to construct meaning from the mothers' experiences.

However, there is an inherent weakness in the design in that it cannot be replicated and there is always the problem of validity (Brink, 1989). Brink stated that researchers are selective in what they observe and what they report and therefore, the same results would not be achieved. Samples in exploratory studies are typically small in size, for example, 10 to 20 subjects. Researchers using this design often continue to interview new subjects until no new information is being added to the data base (Brink, 1989).

#### Sample Selection

A sample of convenience was used for this study



which entailed the use of the most conveniently available subjects from two city hospitals. The sample in this study included mothers whose preterm LBW infants were ready for discharge from two local hospitals and who met the criteria for selection. This nonprobability approach to selecting a sample might result in a sampling bias. Sampling bias refers to the possibility that some characteristic relevant to the research questions may be under presented (Polit & Hungler, 1991).

The criteria for selection of participants were:

1. Mothers of preterm infants of 2500 grams or less and of 37 weeks gestation or less at birth.
2. Infants had no neural tube or chromosomal defects.
3. Mothers who were married or living with a common-law partner.
4. Mothers had to reside within a 60 mile radius of the city's outer boundaries.
5. Mothers were able to read and write in English.

It was assumed that the inclusion of mothers

without partners, and of infants with neural defects, or chromosomal defects would cause and affect the mothers' ability to cope with the infants' needs, thus giving a different picture of concerns of mothers in the first week. A 60 mile radius of the city was chosen in order to facilitate travelling to the mothers' place of residence for interviewing.

The week prior to the infants' discharge from hospital, mothers who met the criteria for selection were approached by the nursing supervisors of the neonatal intensive care units for verbal permission to participate in the study. Following verbal permission, the supervisors gave the mother the letter of explanation (Appendix A). The names of those mothers who were interested in participating in the study were submitted to the researcher. The mothers were then seen by the researcher prior to the infants' discharge from hospital for further explanation of the study. One mother was seen in her home the day of the infants' discharge because the infant was discharged before the researcher could meet with her. After informed consent was obtained (Appendix B), the mothers were given an envelope containing the seven day diary (Appendix C),

instructions for the use of the diary (Appendix D), and a pen. The instructions for use of the diary were reviewed with the mother.

### Sample Size

Fourteen subjects participated in the study which was carried out over a nine month period. Initially, it was hoped that the sample size would be larger when 18 mothers agreed to participate. However, three mothers withdrew from the study; one the day of the interview, and two mothers the day before the scheduled interview. The reasons for withdrawal from the study included death in the family, and two mothers deciding not to participate. One other mother agreed to participate but was not considered suitable because although the infant was classified as LBW, the infant had a gestational age of 38 weeks and was considered a full-term infant. Therefore, the mother was not interviewed.

The sample of infants included 13 single births and one set of twins. One of the 13 single births had a congenital anomaly involving the lower limb. One infant had been hospitalized for a year because of a

chronic lung problem and was interviewed eight days following the infant's discharge from hospital. It was decided to include mothers of these infants in the study because they met the criteria of the study and they experienced similar concerns to mothers in the study yet had some unique concerns. Also, they were enacting the role of mothers to preterm LBW infants following their discharge from hospital.

#### The Setting

All mothers were interviewed in their own homes which provided a naturalistic setting for the interviews. The environment was considered part of the phenomena under study and all environmental factors such as interruptions and noise and other influences were considered (Lincoln & Guba, 1985). It was also assumed that to interview the mother in her own home would be more convenient for the mother because of her busy schedule and would increase the response rate.

#### Data Collection Instruments

A search of the literature failed to uncover a suitable instrument for collecting data on the concerns

of mothers of preterm LBW infants during the first week following the infants' discharge from hospital. Therefore, a demographic data (infant) form, a diary sheet, and a guide to interview topics were developed by the researcher.

#### Demographic Data (Infant)

The demographic data infant form was designed in order to obtain essential information regarding the infant (Appendix E). The data were obtained from the infant's file prior to discharge from hospital. The information obtained included the sex of the infant, gestational age, corrected age on discharge, birth and discharge weight, length of hospital stay, the discharging hospital, and the discharge date. The data were deemed as minimal data which needed to be considered when analyzing data obtained from the diaries and interviews.

#### The Diary

The development of the diary format was suggested in an article by Freer (1980). The questions included in the diary were formulated from knowledge gained from the literature review. The diary sheets were designed

with the mothers' busy schedule in mind. The mothers were able to complete the diary in approximately five to ten minutes each day. The purpose of personal diaries was to gather prospective data on a day to day basis for seven days and to act as a control for accuracy of information gathered in the interview.

The diary consisted of eight sheets. The first sheet contained guidelines for the use of the diary (Appendix E). The remainder of the diary consisted of seven identical diary sheets; one for each day of seven days (Appendix D for sample diary sheet). On the left side of each diary sheet was a space for the mothers to indicate the date of recording. Also, the left side of each diary sheet contained the days of the week (1-7). The mothers were asked to indicate the day of the week that they were recording, starting the day following the infant's discharge from hospital. The remainder of the diary sheet contained eight open ended questions. The mothers were informed that they could write on the back of the diary sheet if more space was needed. The telephone number of the researcher was given to the mothers if they wished to make contact regarding the diary. The mothers were told that the diary would be

collected on the day of the interview.

### Interview Topic Guide

The interview topic guide consisted of two sections (Appendix F). Section I consisted of 23 open-ended questions designed to obtain the mother's perceptions of concerns related to her infant, herself, her partner, and other family members. The development of this section was based on relevant literature of mothers' concerns (Gennaro, Zukowsky, et al., 1990; Goodman & Sauve, 1985, McHaffie, 1990). The remaining questions numbers 1-5, 7-12, and 22, were developed to incorporate selected concepts from role theory which formed the framework for this study. Section II was designed to obtain specific demographic characteristics pertaining to the family. Section II consisted of nine closed-ended questions to gather demographic data pertaining to mother's age and marital status, number and ages of her children, the mother's and partner's occupations, and level of education. These were variables that were identified in the literature as impacting on the concerns and mother's role adjustment.

### Reliability and Validity

Two major criteria for assuming the quality and adequacy of any research instruments are reliability and validity (Polit & Hungler, 1991). No attempt was made to test the reliability of the instruments. Validity refers to the degree to which the tool measures what it is supposed to measure (Polit & Hungler, 1991). The level of face validity was established when the researcher deemed that the tool seemed to be an appropriate way to collect the information needed. It is the lowest level of validation and is appropriate when little is known about the variables (Brink & Wood, 1983). "Content validity is concerned with the sampling adequacy of the content area being measured" (Polit & Hungler, 1991). Content validity was estimated through a literature review, and through consultation with two thesis supervisors who had extensive experience in the field of study.

To further test the tools for validity, clarity, and freedom from bias, the first three informants were included in a pilot study. The three informants possessed the same characteristics as those who



comprised the main sample. The informants kept a diary for seven days following the preterm LBW infants' discharge from hospital. The informants were interviewed eight to ten days following the infants' discharge from hospital.

Following the completion of audio-taped interviews the tapes were transcribed verbatim and questions on the interview guide were examined. The tapes were reviewed by the researcher and thesis supervisor. As a result, only one question was revised. Question number two "did you feel confident in taking your baby home?" was revised. It was reworded to ask "did you feel ready to take your baby home"? The revised question was clearer and was designed to reveal more information on role learning prior to discharge. Question number 16 which asked the informant to "please explain why these have caused you concern" was eliminated. It was determined that this question was not necessary as informants had included the rationale in their responses to other questions or the information could be obtained through probing.

The informants confirmed that the questions on the diary sheet were clear and easy to complete. As a

result no revisions were made in the diary sheet.

To increase the validity of the findings of this study the triangulation principle was used. Four types of triangulation were identified by Denzin (1989): data triangulation, investigator triangulation, theory triangulation, and methodological triangulation. Methodological triangulation was chosen for this study. Methods triangulation refers to the use of two or more research approaches in one study to assess the same phenomena (Kimchi, Polivka & Stevenson, 1991). Two qualitative approaches were used to measure the concerns of mothers; a diary and an open-ended interview. The diary data and the interview data were analyzed separately and then compared to validate the findings.

#### Data Collection Procedures

The mothers began the seven day diaries the day following the preterm LBW infants' discharge from hospital. Following the completion of the diaries the mothers were interviewed in their own homes. Interviews took place between two to three days following the completion of the diaries with one

exception. The researcher was not informed of one infants' discharge, therefore the interview took place on the ninth day following the completion of the diary. Initially it was hoped that all of the mothers would be interviewed on the eighth day following the infants' discharge to minimize the effects of forgetting information and chronological confusion (Gorden, 1975). The interview topic guide was used to interview the mothers. It allowed the researcher to ask mothers the same questions, therefore, data categorization and analysis were facilitated. However, the questions were not necessarily asked in the same sequence which allowed the interview to proceed according to the particular mother's needs and responses (Gorden, 1975). The face-to-face interviews provided the opportunity for the researcher to clarify questions and to elicit further information by the use of probing. Probing helped the mother provide more relevant data without restricting, distorting or suggesting responses (Gorden, 1975). The researcher encouraged the mother to expand upon a topic by using neutral non-directive probes as was suggested by Gorden. These included encouragement probes such as a nod of the head or

responding with such remarks as "hmmm", "I see". These probes indicated to the mother that the researcher accepted the responses and wanted the mother to continue. Also, elaboration probes were used, for example "then what happened"? and "would you like to tell me a little more about that"? The elaboration probes encouraged the mother to elaborate upon the topic but did not alter the mother's own frame of reference on the topic. To get immediate clarification on the topic being discussed, the clarification probe was also used. Gordon suggested the use of the clarification probe when a specific kind of additional information is needed. An example of a clarification probe used was "when did that happen"?

The interviews were audiotaped eliminating the need to hand record responses. Also, by tape recording the responses, the researcher could devote her full attention to the mother. The tape recorder was checked prior to each interview to ensure it was in good working condition. As recommended by Ives (1974), the tape recorder was equipped with an extension cord and fresh batteries were always available in case electrical outlets were inaccessible. However,

batteries were used in all cases because the electrical outlets were not conveniently placed. Following an explanation of the use of the tape recorder to the mother, the machine was placed so as not to distract the mother during the interview.

Each interview lasted from 45 to 60 minutes. Prior to the interview the purpose of the study was reviewed with the informant. The informant was given the opportunity to ask questions or have any part of the study clarified. None of the informants had questions about the study.

The researcher took precaution to avoid bias and to maintain objectivity during the interviews. Polit and Hungler (1991) defined bias as "any influence that produces a distortion in the results of the study" (p. 640). During the collection of interview data the researcher may have biased views of what the responses to the questions should be. Therefore, the results would be swayed in a particular direction. A concerted effort was made by the researcher to present questions clearly and objectively, and to avoid asking questions that suggested a particular response. Following each interview, the tape was checked for possible

interviewer bias and steps were taken to minimize the introduction of that bias in subsequent interviews. This was a continuous process. McCall and Simmons (1969) stated that if all precautions are taken in discovering one's biases "another look may still uncover something that up until then has not been seen" (p. 103).

It was agreed before the interview that if the mothers sought information or advice about their infants during the interview, the advice would be given immediately after the interview was completed because it might have influenced the mothers' responses (Smith, 1992). Following the interview, this researcher took the opportunity to reinforce their decisions or to suggest available resources. Advice was given on two occasions only. One informant was concerned about her infant's respiratory status and one other about lack of follow-up.

There were interruptions during the interviews. Six of the mothers responded to their infants' crying and at times during the interview held their infants. Five of the mothers' partners came in during the interview and two mothers had unscheduled visitors.

This often necessitated the turning off of the tape recorder. It usually took a few minutes trying to recall the conversation when the tape recorder was restarted.

Despite the inherent disadvantages of face-to-face interviews and the use of audiotaped interviewing technique such as the possibility of introducing interviewer bias, the cost of interviewers, time spent in travelling and in interviewing, loss of information, and time spent listening and transcribing each tape (12 hours), the advantages outweighed the disadvantages (Polit & Hungler, 1991). The response rate was (82.35%). There was some security against ambiguous questions because they could be clarified by the interviewer. The semi-structured questions permitted the gathering of a rich source of data.

The major purpose of using diaries in this study was that the information recorded could be compared with the interview data to check for consistency of information. A major disadvantage of diaries is the time they take to complete. Consideration was given to this factor when designing the diary. The mothers stated that they completed each diary sheet in five to

ten minutes. The diaries were completed but the researcher had no way of knowing with certainty that they were completed daily and who really did the recording.

### Data Analysis

An approach to data analysis as suggested by Polit and Hungler (1991) was used as a guide in analysing the interview and diary data.

The first step was to transcribe the taped interview. The data were transcribed following each interview. An hour interview resulted in approximately 60 pages of handwritten text. The data were transcribed word for word by the researcher to ensure accuracy. The transcribed data were then typed by a typist with instructions to leave a margin on the left and right side of each page to permit the insertion of codes and the researcher's comments. A code is a conceptual scheme which aids in the identification of themes by topic (Polit & Hungler, 1991). The pages were numbered and the informant's code number was entered on each page. Two copies were made. The original copy was placed in a locked filing cabinet in



the researcher's office to ensure against loss.

To increase the validity of the data, methodological triangulation was used. Diaries and open-ended interviews were used to collect data about the concerns of mothers. The data from the interviews and the data from the diaries were analyzed and coded separately and then compared to validate the findings. The data contained in the diaries were consistent with the interview data, for example, one mother stated in her diary, "I suppose she's getting bigger" and then in the interview stated that the infants' weight was a concern.

The data from the diaries and interviews were analyzed for themes. A theme included a word, a phrase, a sentence, or a paragraph which embodied ideas. For example, eleven mothers made statements regarding their emotional reactions during the first week the infant was home from hospital. This theme was categorized under the subcategory of 'emotional state'.

The themes kept recurring as data were collected (Polit & Hungler, 1991). Major categories were developed, for example, 'Concerns of mothers about themselves', and then each category was assigned a code

number. Categories were compared to find out the differences as more data were collected. The data were subsequently divided into subcategories, for example, 'feeling tired'. Code letters were assigned to the subcategories. New categories were added as subsequent interview data revealed new themes.

The major categories are as follows: demographic characteristics, concerns of mothers of preterm LBW infants, factors influencing the taking on the role of mother of a preterm LBW infants, and role strain. Each major category has subcategories, for example, concerns of mothers about the family has five subcategories. These include: handling of infant by relatives, opinions/advice, phone interruptions, older children seeking attention, and a subcategory of 'other' to include single responses made by mothers which could not be categorized under one of the other subcategories. Data analysis of themes ceased when no new categories and subcategories emerged.

Role strain was measured by an adaptation of the Burr et al. (1979) scale on a continuum ranging from 1 = none, 2 = low, 3 = moderate, 4 = high, to 5 = very high role strain. The scale was adapted to include the

core concepts of the study. The amount of role strain experienced by mothers was measured by using the role strain scale and criteria (Appendix G). The rating by the researcher of the amount of role strain experienced by mothers of preterm LBW infants during the week following the infants' discharge from hospital was based on the assessment of all the interview and diary content during analysis of the data as suggested by Mercer, (1985).

#### Ethical Considerations

Ethical issues were considered throughout this research study to ensure anonymity and confidentiality.

Consent for this study was approved by the Human Investigation Committee of Memorial University at the Health Science Complex. Then letters requesting permission to carry out this study were forwarded to the three Assistant Executive Directors of Patient Care Services of the three neonatal referral centres in St. John's (Appendix H). One hospital committee did not respond to the request, possibly because the obstetrical services were in the process of relocation at that time.

Following approval from the Human Investigations' Committees from two hospitals, the researcher approached the Nursing Supervisors to explain the study and to obtain their consent to act as intermediaries in obtaining verbal consent from the mothers prior to being approached by the researcher. The Supervisors provided the researcher with the names of the mothers who were willing to participate in the study. The researcher met with each mother prior to the infant's discharge from hospital to further explain the study, to obtain informed consent, and to arrange a date and time for the interview.

The mothers were assured that their decision to participate was voluntary, and that if they agreed to participate they reserved the right to withdraw at any time. Also, they were assured that there were no health risks involved. The mothers were informed that their anonymity would be protected by using codes instead of names on the data sheets and on tape labels. They were also informed that the original audiotapes used to record the interview would be erased following the completion of the study.

When collecting qualitative data, it is not

unusual for the researcher to be confronted with a situation which demands intervention (Archbold, 1986). The researcher took the opportunity to intervene, when necessary, after the interview was completed.

## CHAPTER V

### The Results

In this chapter the results of the study are presented in the following sequence: demographic characteristics of the sample, concerns of mothers of preterm LBW infants following the infants' discharge from hospital, factors influencing the taking on of the role of mother of preterm LBW infants, and role strain.

#### Demographic Characteristics of the Sample

##### Demographic Characteristics of the Mothers

Table I shows the demographic characteristics of the mothers in the study sample. The ages of the mothers ranged from 23-38 years. The mean age of the mothers was 30.29 years. Three of the mothers had older children. One had a toddler and a young school age child. Another had an older school-age child and the third had a preschooler. Most of the mothers had continued their education beyond highschool. Seven of the mothers were employed prior to the infants' birth. Two mothers were working up to the time of the infants' discharge. Seven of the employed mothers were on maternity leave at the time of the interview. One mother was to begin work in one month and another

mother worked on a contractual basis.

TABLE 1

Demographic Characteristics of the Mothers

CHARACTERISTICS	FREQUENCY (n=14)
Age	
< 30 years	7
> 30 years	7
Marital status	
Married	12
Common-law	2
Parity	
Primiparas	11
Multiparas	3
Education	
University degrees	4
1-5 year post secondary	9
Grade 10	1
Employment status	
Employed	9
Housewife	5

Demographic Characteristics of the Infants

Table 2 outlines the demographic characteristics of the preterm LBW infants in the sample.

TABLE 2

Demographic Characteristics of the Infants


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CHARACTERISTICS	FREQUENCY
<hr/>	
Sex	
Male	6
Female	9
Birth weight in grams	
< <u>1500</u>	11
1501-2500	4
Gestational age in weeks	
< 30	10
> 30	5
Discharge weight in grams	
< 2500	10
> <u>2500</u>	5
Corrected age at discharge	
40 weeks or less	12
1 - 2 months	2
9 months	1
Length of hospital stay in weeks	
< 10	8
10 - 15	5
26	1
52	1

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Note.     There was one set of twins and thirteen single births included in the infant sample.

The infants' birth weight ranged from 625 to 2315 grams. The mean birth weight of the sample was 1189.33 grams.



Eleven infants weighed 1500 grams or less at birth which would place them in the category of VLBW infants. The gestational age of 10 of these VLBW infants was less than thirty weeks. The mean hospital stay for the 11 VLBW infants was 15.86 weeks as compared to a 12.43 weeks hospital stay for the entire sample. The length of hospital stay ranged from 2-52 weeks. The two infants who had the longest hospital stay, 26 and 52 weeks because of chronic lung problems, were also the most immature at birth, with gestational ages of 24 and 25 weeks respectively. One other infant with a gestational age of 25 weeks was hospitalized for 15 weeks. The gestational age of the infant sample ranged from 24-34 weeks with a mean gestational age of 28.63 weeks.

The discharge weights of the infants ranged from 2040-5910 grams. The weight of nine of the infants with a corrected age of 34-39.5 weeks at the time of discharge, was in the range of 2040-2380 grams. The corrected ages of seven infants were below 38 weeks. The mean discharge weight of the 11 infants weighing less than 2500 grams was 2230.50 grams as compared to a mean discharge weight of 2668.33 grams for the sample.

The trend of discharging the infants with weights below 2500 grams and gestational age of less than 40 weeks continued throughout the study period. Two of the infants with the lowest discharge weights were included towards the end of the study. The birth of a preterm infant was a first-time experience for all mothers in this study.

#### Demographic Characteristics of Partners

Table 3 depicts the demographic characteristics of the mothers' partners.

**TABLE 3**

#### Demographic Characteristics of Partners

CHARACTERISTICS	FREQUENCY (n=14)
Employment status	
Employed	11
Unemployed	3
Education	
University degrees	2
7 years post secondary	1
1 - 2 years post secondary	6
High school	3
Grade 7 - 9	2

Twelve of the partners had completed high school

and nine of these partners had continued their education beyond high school. Three of the eleven employed partners were self-employed. Two partners who were unemployed at the time of the study were employed on a seasonal basis.

Concerns of Mothers of Preterm LBW Infants Following  
the Infants' Discharge From the Hospital

Diary entries were concise, often consisting of single words. In the interviews, the same concerns were raised with the mothers elaborating more freely.

Concerns of Mothers About Their Preterm LBW Infants

In order to ascertain the concerns of the mothers about the infants now that the infants were home the following question was asked: "What concerns did you have about your baby during the past week"?

The mothers of preterm LBW infants expressed a total of 131 infant related concerns that they had experienced during the first week at home with their infants.

Table 4 shows the concerns expressed by mothers about their preterm LBW infants. The concerns are presented in order of frequency for each category.

Single responses which could not be placed into a subcategory were totalled and placed under 'other'.

TABLE 4

Concerns of Mothers About Their Preterm LBW Infants

Concerns	Frequency
Health	
Infections/illness	10
Apnea/SIDS	9
Taking infant outdoors/keeping warm	9
Fussy periods	7
Medications	5
Respiratory symptoms	4
Detecting illness	3
Grunting sounds	3
Skin rashes	3
Responding to an emergency	2
Concern for infants survival	2
Other	5
Total concerns	62
Feeding	
Amount of milk intake	10
Spitting up	8
Weight gain	7
Feeding schedule	7
Gas	2
Different feeding nipple on the bottle	2
Other	8
Total concerns	42

Table 4 (continued)

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Concerns	Frequency
Growth and Development	
Sleep/awake patterns	10
Developmental outcome	3
Infant size	3
Weak cry	2
Bowel Elimination	7
Car seat	2
Total of all concerns	131

---

Note.       Some mothers expressed several concerns within a category of concerns.

Infant Health.   The infant's health was the major category of concerns for the mothers, accounting for 47.33% of all infant concerns.

Infections and illness were the major health concerns for 10 mothers. For one mother of a VLBW infant who had been hospitalized for a lengthy period of time because of a chronic respiration problem, infections meant setbacks and the possibility of her infant becoming critically ill again with an infection.

I think I can never quite shake the feeling that something might go wrong. Where she was so ill before.... I'll be adamant about people not coming in with colds and flu's or even if they have a bit of a sniffle.... You know I'm scared to death about it.

Four mothers expressed concern about respiratory

symptoms ranging from a runny nose, raspy breathing, being "stuffed up", to administration of oxygen at home. Detecting signs of illness was a concern for three mothers. They worried about missing the signs of infection in their infants and something happening to them because of an infection.

Apnea was also mentioned as a major source of concern. Three mothers made the connection of prematurity and Sudden Infant Death Syndrome (SIDS). The mothers stated that their infants had not had apneic attacks for at least a week prior to discharge, but they still continued to worry that the infants might stop breathing. The mothers referred to the apneic attacks as "bradys". They had observed their hospitalized infants' heart rate decreasing on the cardiac monitors followed by an alarm which alerted the nurses to the falling heart rate. The mothers made the connection between the falling heart rate and subsequent cessation of breathing. Eight of these mothers kept constant vigilance over their infants especially when the infants first came home, even though six of these mothers had purchased monitoring devices to monitor their infants' breathing and crying.

The use of monitoring devices gave the mothers reassurance that the infants were still breathing and alerted them to any change in infants' breathing or sounds. The mothers felt that it gave them more freedom to move around the house during the day while the infant slept. One mother who was concerned about her infant's breathing patterns intended to purchase a monitor within the next week. Ten of the infants slept in the parents bedroom so that they could be heard at all times. Initially, worry about something happening to the infant such as apnea interrupted the mothers' sleep at night. They were tired due to lack of sleep.

Two mothers were concerned about how they would react to an emergency situation. One mother who was concerned about "bradys" said:

Like, what would I do if she had a bad one.  
Because I know you have to bag them or  
something ... what would I do at home if it  
happened to her? Would I be able to make it to the  
hospital?

Two mothers were concerned for their infants' survival and it was only after the infant was home for a few days that they believed their infants would make it. These mothers were still afraid that something was going to happen to their infants.

Six mothers expressed concern about taking their infants outdoors in damp and cold weather. For three of the mothers, providing the right environmental temperature and clothing to keep their infants warm was a concern. One mother articulated her experience as follows:

I was afraid about him on the first couple of nights. We were like Goldilocks and the three bears because we had him probably too cold the first night. And then the next day it was really hot, it was really humid and we had the heat on in the house and we had him bundled up. And he was so warm.

One half of the mothers were concerned about their infants' fussy periods. One of these mothers was concerned that her infant might have colic. The infant had long periods of crying after he was brought home from hospital. She had difficulty settling him down and wondered if he'd experienced colic in hospital. She said that she wished that she had been told he was colicky while in hospital.

The infants' medications were a cause for concern for some mothers. Ferrous Sulphate (an iron supplement) was of particular concern for three mothers. They believed it caused symptoms such as constipation, and emesis. One mother had difficulty



getting her infant to take the Ferrous Sulphate because she said that it was bitter. This mother was advised by her physician to add a pinch of sugar to the iron supplement and she believed this advice worked. Two of the mothers had stopped giving their infants the iron supplement. One of these mothers had consulted the Public Health Nurse and was considering starting the iron supplement again.

While mothers knew the infants' grunting sounds were normal, they were still a cause of concern. One mother stated:

Her grunting always seems to confuse me.  
Instinctively they don't sound right....  
For some reason she has these scrunchy sounds....  
She'll bunch up sometimes looking in pain.... I  
don't know if it's gas or whatever.

There were concerns regarding rashes. Two mothers stated that their infants had a rash on their buttocks, while one mother was concerned about a rash on her infant's face. One mother had tried several ointments. She had purchased ointments from the drug store such as Zincofax, Peneten, and Desitin. She had experimented with each one. Desitin finally worked.

Other single concerns expressed by mothers about the infants' health included immunization reaction, a

congenital anomaly, fear that the infant would aspirate his feeding, and use of a device which was required to prevent gastro-esophageal reflux. Follow up care was a major concern for one primipara. This mother felt that she and her infant had "been abandoned by those in the health care system." She was apprehensive about this and stated:

I felt that she was discharged and that is it, it was over. We weren't given any sort of like little meetings with the doctor. I never met the doctor who discharged her - never met him. Never met the perinatal group.... I felt we were a little bit - I was abandoned.

Infant Feeding. Infant feeding was the second major category of concerns for the mothers. Although the mothers were not asked if they were or had been breastfeeding, several mothers discussed it. Three mothers were feeding their infants breast milk. One of these mothers was still expressing her milk after 12 months and was giving the milk by naso-gastric tube. Three others had expressed breast milk for one to two months but stated their milk dried up while the infants were in hospital and then the infants were fed formula. One mother, who was requested to consider breastfeeding, refused because she perceived that the quality of her milk was connected somehow to the pre-

term delivery. She felt considerable guilt about the preterm birth and wondered whether she had been the cause. She explained her fears this way:

I wasn't going to breastfeed because I was afraid my milk would do more harm than good. Like they were saying to me, well it's better for her. But there was no way I would do it. I really thought that it would probably kill her even. I was afraid she would die if she took my milk.

Over one-half of the mothers in the study mentioned spitting up (regurgitation) and the amount of milk intake as concerns. One mother was watching her infant's intake carefully and totalling up the intake at the end of the day.

When she came home from the hospital they said feed her every three hours - two ounces every three hours. And since she's been home she doesn't want two ounces every three hours. So it's kind of touch and go.

Weight gain was a concern for seven of the mothers. Weight gain to these mothers was an indication that their infants were obtaining sufficient nutrition. They were relieved when the physician weighed the infants during their initial post discharge visit and that their infants had gained weight. It was confirmation that they had not failed in that aspect of their performance of the mother role.

Feeding schedules were cited as a concern by seven

mothers. When the infants were discharged from the hospital they were feeding every three to four hours. However, much to the amazement of the mothers, the infants did not maintain the schedules they had in hospital and some were feeding as frequently as every two hours, while other infants were feeding every three to four hours as in hospital. The mothers were not informed that this might happen.

Two mothers were concerned about gas. One mother stated that she spent hours trying to rid the infant of gas. She stated that her infant had a lot of gas and even after the infant had burped she still seemed to have gas.

Changing the infant to new nipples was a source of concern for two mothers. One mother had been given a supply of "premature" nipples.

I'm trying her on the regular ones but its like she gets really tired. So how long will it take her to get up to being able to take any.... If I runs out of them what am I going to do if she can't take the other nipple?

Concerns categorized under 'other' included: being nervous about feeding, starting solid foods, and the milk not looking as concentrated as the milk in hospital. One breastfeeding mother was concerned about

her infant not latching on to the breast but this was later resolved during the week. Another breastfeeding mother was concerned about supplementing breastfeeding with formula. For one mother it was a concern that her infant would not take milk from a bottle and continued to be tube fed. Despite continued efforts in hospital to encourage this infant to take milk orally, the infant refused to take the milk by mouth.

Growth and development. The majority of mothers viewed their preterm LBW infants' physical and social developmental milestones according to their corrected age. When comparing their infants to other children the same age, the mothers responded that the size difference was a concern. Three of the mothers expressed concern regarding their infants' size and the precautions they had to take because of their size. The mothers who were concerned about their infants' development expressed concerns regarding their infants' future social and cognitive functioning. Two mothers stated that they worried about their infants' long term development and the disadvantages the infants might have because of their preterm births. They admitted that the infants' future functioning was a concern, but

for the present time they tried to put it out of their minds. Two of these mothers were educators and had experience working with children who had a history of a preterm birth.

Nine primiparas were concerned about their infants' sleep and awake patterns. They were concerned that their infants were either not getting enough rest or that they were sleeping longer than they should between feedings. Three infants had periods of staying awake at night following their feedings. This caused the mothers concern as it interrupted their nights' sleep more than they had anticipated. One mother thought that once you fed the infant in the nighttime, he'd go right back to sleep. She was surprised that he stayed awake for an hour after feeding when she wanted to sleep. The mother found this frustrating.

Two mothers who were concerned about their infants' weak cry were afraid that they would not hear them when they cried.

Bowel Elimination. Seven of the mothers were concerned about their formula fed infants being constipated. They indicated that they were unsure of the normal bowel patterns of infants, the frequency of

a newborn's bowel action, and stool consistency. As one mother who was bottle feeding her infant said:

I thought he should have at least one or two a day. He's only had about three in seven days since he's been home.... It's a soft stool but it's not much to it. Like one stool was really seedy. I don't know if that's normal. I'm not really sure you know.

Indications that their infants were constipated included straining, absence of a daily stool, and signs of abdominal pain. The mothers used various remedies to help the infant overcome constipation. Five mothers added various amounts of sugar to water or formula. Two of these mothers had received advice on adding sugar from a nurse in the nursery and one from a Public Health Nurse. One mother acted upon the advice of her sister and the other, who was a multipara, acted upon her own decision. Responses varied from "a bit of sugar in milk" to "one teaspoon of sugar to four ounces of milk." One mother, on the advice of a relative, gave her infant "soap stimulation." She responded that it was "a suppository.... it's ivory soap ... it's just a little stimulation and it worked but its only a small amount."

Car seat. There were concerns regarding the

infants' car seats. The infants were too small for the car seats. The mothers stated that when they took their infants home from the hospital they sat in the back seat of the car with their infants because they were concerned about their safety. One of the mothers who had contacted the nurse in hospital regarding her concern about the car seat, was told that a "bucket car seat" would probably be more suitable for small infants.

These findings show that when a woman enacts the mother role of preterm LBW infant she has concerns about her own performance in the interpretation of the infants' needs regardless of her past experience.

#### Concerns of Mothers About Themselves

The mothers of preterm LBW infants expressed a total of 51 concerns which were related to themselves during the first week the infant was home. Table 5 shows the concerns which mothers articulated about themselves. The concerns are displayed in order of frequency for each category. The major categories were feeling tired, emotional state, and schedules.



TABLE 5

Concerns of Mothers About Themselves


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Concerns	Frequency
Feeling tired	14
Emotional state	11
Schedules	11
Nutrition	5
Doing everything right	4
Medical Problems	4
Returning to work	2
Total of all concerns	51

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Feeling tired. All of the mothers stated that they were tired. Lack of sleep and night feedings were major reasons that the mothers were tired. As one mother said, the feedings in the night caused so much interruption because she was used to sleeping through the night.

The majority of mothers were making efforts to take "naps" during the day when their infants were sleeping and said that they were surprised by how little rest they needed in order to function during the

day. As one mother said:

Like when the baby is resting I have to rest too.  
And I've gotten into a time and taking a nap.  
Even if it's just an hour nap it is enough to give  
me a boost and I am okay.

Emotional state. The mothers stated that they experienced various emotional reactions during the first week that the infant was home. Eleven of the mothers expressed concern about their emotions and attributed their emotions to lack of sleep and feeling tired. Seven of the mothers stated that they were irritable. Their irritability was expressed in various ways. One mother stated that she tended to "over react". One multipara and one primipara stated that they were not pleasant persons when they were tired. One multipara who lacked support from her partner felt that she might "explode." One mother who had difficulty expressing how she felt stated:

Just the tired feeling.... I feel sometimes it's just a little bit ... I don't know - remorseful.... I guess I'm not used to having him home. And I just, I almost feel a little bit ashamed to feel this way.... I don't think I should feel this way.

Schedules. The majority of mothers made statements that directly indicated that their days'

schedules and routines revolved around their infants. For example, one mother indicated that the baby was number one in everything. The infant came first above anything else that had to be done at the time.

For the majority of mothers, having the infants home meant they were restricted in going out as they pleased. Only three mothers cited this as a concern and stated that they felt confined since the infant came home. It meant that they had to plan before they went out. Six of the mothers stated that it was a pleasure or more relaxing having the infant home. For four of these mothers it meant not having to travel to and from the hospital. One mother referred to having her infant home as a relief compared to visiting the hospital everyday.

The mothers found that the daily routines kept them busy. There never seemed to be enough time to meet the demands of the infant, household activities, and have time for themselves, their partners and their families. Nine of the mothers were home alone with their infants during the day and had the sole responsibility of infant care during that time.

The mothers were tired at the end of the day at

home performing their various roles. One said: "by the time I get everything done its 11:30 at night. I'm dropping then."

Eight of the mothers stated that housework was the last thing to get done but this was not viewed as a concern. Three of the mothers fed their infants exclusively and viewed feeding the infant as part of their mother role. Two of the partners were reluctant to feed their infants but the mothers were not concerned. One of the mothers chose to feed the infant herself until she had the infant feeding well from the bottle. "No, no, no. Nobody feeds him. That's my choice. He would definitely feed him but not yet.... It's just that I'm a little bit nervous yet."

Twelve of the mothers felt that they themselves were the center of all activities and felt a responsibility to meet role expectations. As one mother articulated:

It's having to be everything to everyone I guess. Trying to keep myself up so I don't get rundown. Of course, trying to do my best for her, and still trying to be a companion to my husband.

Nutrition. The daily routines and demands of the infant caused some of the mothers to be concerned about

their own nutritional status. As one mother said:

Everything takes its toll. When you eat, your appetite is down in your boots because you feel like you're in such demand between housework and the other little girl and the baby.

Doing everything right. A concern for four primiparas was that they were doing the best for the baby. It seemed that they needed reassurance that they were giving their infants the care they required now that they did not have the support of the neonatal nurses. As one mother explained:

My main concern was I doing everything right. I almost felt like I wanted someone looking over me. Saying "that's right, that's good, that's right or you shouldn't do that". Little things like that.

This mother emphasized the need to have a support person available during the infants first week at home.

Medical problems. Three mothers were coping with personal medical problems. The first mother was concerned about her diabetes. She was having difficulty controlling her blood sugars which she attributed to breastfeeding and nutrition. The second mother had developed Bell's Palsy during the infants' first week at home. The third mother, who had

delivered three weeks prior to the interview, expressed concern about soreness in the episiotomy site. One other mother was concerned that she might have been the cause of her infant's preterm birth and expressed guilt about the preterm birth.

Returning to work. Seven mothers were planning on returning to work when their maternity leave was over. Two mothers whose infants were hospitalized for six months and 12 months respectively, had returned to work following recovery from delivery in order to use their maternity leave when the infants were discharged from hospital. All seven mothers had babysitters in mind. Two of these mothers stated that their husbands' jobs were flexible and that they would stay home during the day with the infant. Relatives were going to look after the infant when they returned to work. Only two of the mothers had concerns regarding returning to work. These mothers were concerned about leaving their infant with a babysitter and felt that they needed to spend more time with the infant. One mother stated that she did not like the idea of leaving the infant home and going to work when the infant was so young.

Concerns of Mothers About Their Partners

The mothers of preterm LBW infants expressed a total of 21 concerns that they had regarding their partners during the first week the infant was home.

Table 6 shows the mothers concerns about their partners. The concerns are presented in order of frequency of each category of concerns.

**TABLE 6**

Concerns of Mothers About Their Partners

Concerns	Frequency
Partner feeling tired	6
Would like partner to do more	5
Partner caring for infant alone	4
Feeling that partner was left out	4
Partner not supportive	2
Total of all concerns	21

Five of the partners were at home during the first week of the infants' discharge from hospital. Two of these fathers had taken a week of vacation and three were not working at the time of the infants' discharge from hospital. Eight of the fourteen partners were

totally involved in the infants' care and household activities. The partners shared night time feedings especially on weekends when they did not have to get up in the morning to go to work. Two of the fourteen partners were involved in all aspects of infant care with the exception of feeding their infant. This was not a concern for these mothers as they preferred to feed the infants themselves. These two partners also assisted with the household activities and helped with the older children.

Partner feeling tired. Six primiparas were concerned that their partners might be tired. Their partners were actively involved in the infants' care and household activities. Five of these partners were working during the daytime. The partners often shared night time feedings and their sleep was interrupted.

Would like partner to do more. There were five primiparas who stated that they would like their partners to become more involved with infant care. Even though the mothers viewed their partners as supportive with infant care and other activities, they perceived that their partners could do more, especially



in helping with the infants' care. Four of the five partners had to go to work during the day time. These mothers were home alone with their infants during the day and they were tired at the end of the day. The one mother whose husband was not working said that she was doing most of the care for the infant by choice because her partner was nervous because the infant was so small.

Partner caring for infant alone. Four primiparas expressed concern regarding their partners caring for the infants when they were left alone with them. They said that they wanted their partners to have enough confidence to stay alone with the infants when the mothers left the house for short periods. One mother stated her partner was afraid to be by himself with the infant because he was afraid that something would happen to her.

Feeling that the partner was left out. The four mothers who were concerned that their partners were feeling left out had taken responsibility for most of the infants' care. Two of the partners were perceived as "nervous" around the infant.

Partner not supportive. When asked to name the person who was the most supportive during the first week, all but one of the mothers stated without hesitation that their partners were the most supportive. One multipara viewed her partner as not being supportive to her. He was unemployed and yet spent most of his time away from home. One primipara noted that she would like her partner to stay home more with her and their infant. This mother named her partner as being the most supportive to her during the infant's first week at home, yet made several comments regarding the inability to communicate their needs to each other. She said that "he's worried about her .... he's one of those people who don't speak about how he feels."

Concerns of Mothers About The Family - (Relatives and Older Children)

The mothers discussed a total of 16 concerns which related to their family during the infants first week at home.

Table 7 shows the concerns that mothers had about their relatives and older children. The concerns are presented in order of frequency of each category of

concerns. The category 'other' incorporates single concerns.

**TABLE 7**

Concerns of Mothers About the Family (Relatives and Older Children)

Concerns	Frequency
Handling of infant by relatives	3
Opinions/advice	3
Phone interruptions	3
Older children seeking attention	2
Other	5
Total of all concerns	16

Handling of infant by relatives. When relatives visited, three mothers were concerned about them picking the infant up or touching and handling them. These mothers noted that the infants were too small to be constantly picked up because the frequent handling could cause the infant to regurgitate

Opinions/advice. A concern of three mothers was

about opinions or advice given by relatives regarding the infants' care. One primipara indicated how she was dealing with the opinions and advice of a relative.

She's the kind of person who will come in and say. "No, you can't do that, that's not right, you've got to do it this way, and I've raised five children". And you know I have to be firm with her and say, "Well no this is the way I've got to do this and this is the way I have to do that". You know, like I've had to take a firm stand right away, right from the beginning because otherwise everything I do will be wrong.

Phone interruptions. Three mothers were concerned about relatives telephoning at inappropriate times. The mothers found that telephone calls were disruptive and relatives often called when they were feeding or bathing the infant. One mother indicated that she had three phone calls the previous night when she was bathing her infant. She stated that almost everyone knew she bathed her infant in the evening and yet they continued to call at inappropriate times.

The majority of mothers were delighted when relatives visited or telephoned. For the mothers it meant that relatives were concerned about their infants and their families.

Older children seeking attention. Two of the

three multiparas in the sample expressed concerns about their older children. They were seeking attention because of the shift of the mothers' attention to the infants. Initially, when one infant came home, a preschooler was demanding attention from her mother, was irritable and tired. However, towards the end of the week the mother stated that her child was coping well and assisting her with the infant's care. She said that her daughter was anxious for the infant to wake up for his feed because then she get a chance to hold him for awhile while the mother was getting the bottle. Another mother of a toddler noted that he seemed to be very jealous of the infant. He was waking up during the night, and wanting to spend the night in his parents' bed. Also, when she had the infant up in her arms he wanted to be up too. The toddler continued to exhibit this type of behavior throughout the week.

Other. Other concerns expressed regarding relatives included: relatives staying late, relatives not being supportive, neglecting family because of infant demands, a relative smoking, and not being able to celebrate her mother's birthday which had always been done in the past.

Summary of Findings Related to Mothers' Concerns

Mothers expressed a total of 219 concerns. Over one-half (59.82%) of the concerns articulated by mothers were infant related. The findings indicated that the infant's health was the major infant concern followed by infant feeding, infant growth and development, and elimination. The category of health accounted for 47.33% of the total infant concerns.

Parity and age may be variables in the number of concerns. The three multiparas expressed a mean of four infant concerns as compared to a mean of 10.8 infant concerns expressed by primiparas. Mothers 30 years and over expressed a mean of 7.4 infant concerns; whereas, mothers who were less than 30 years of age expressed a mean of 9.7 concerns. This data suggests that previous experience with children and/or age contributed to these mothers expressing fewer concerns. One primipara who was less than 30 years of age cited 17 infant concerns. However, this mother had minimum involvement in the care of her infant in hospital and voiced concern about lack of support from her partner. These factors could have contributed to her voicing of so many concerns. Multiparas articulated five of their

total of twelve infant concerns in the health category.

The mothers had concerns about themselves which accounted for 23.29% of all concerns. Feeling tired, their emotional state, and schedules were the mothers' major concerns about themselves, suggesting that taking on the role of mother when the infants comes home is demanding. They also had concerns about their partners (9.59%) and other family members (7.30%). The assumption of role responsibilities and role demands as well as concerns about their infants, themselves, their partners, and family indicated that the mothers were experiencing role strain.

**Factors Which Influence the Taking on the  
Role of Mother of a Preterm LBW Infant**

**Mothers' Readiness to Take Infant Home**

All fourteen mothers indicated that they had been looking forward to taking their preterm LBW infants home from hospital. For the majority of the mothers it was a relief that their infants were now well enough to be discharged. Also, many of the infants had been hospitalized for a long period of time and it meant that the long hours spent visiting their infants were

over. Two mothers continued employment while their infants were hospitalized. Up to the time of discharge, the majority of mothers visited their infants in hospital two to three times daily. As one mother stated:

About all together I'd say maybe six to seven hours a day. I used to go first thing in the morning, about eight o'clock. I used to leave about ten or eleven and then sometimes I used to go back, maybe I'd stay about one or two hours or so, maybe a little later. And then in the evening I used to go back until ten.

The many hours spent in visiting their infants in hospital was disruptive to the mothers' daily routines, and tiring. One mother noted that her infant was in the hospital for six months and that going back and forth to the hospital was exhausting.

Two of the fourteen mothers were taken by surprise when they were informed that their infants were ready to go home. They had one to three days notice. One multipara had expected that the infant would be discharged in about another month and was still engaged in full-time employment. She said that she was surprised when she was informed that she could take her infant home. She had three days to notify her employer and prepare for the infant's homecoming.



The mothers expressed various emotions when they were informed about the infants' discharge; these were happiness, excitement, joy, delight, and apprehension. Ten mothers said that they were apprehensive about taking their infants home. One mother who was excited that her infant was discharged after being hospitalized for four months said, "Oh my God I wanted to kiss the doctor, literally I did.... Oh I was so happy I couldn't wipe the smile off my face."

The majority of the mothers expressed that they felt ready to take the infant home as the hospital experiences had prepared them for taking care of their infants at home. One mother stated that she really felt like she had a good experience and that she felt like she had three and one half months "on the job training".

One primipara stated that she was afraid that she was going to do something wrong when the infant was discharged from hospital. When asked if there were any learning experiences that would have prepared her for the infant's discharge she responded that probably she could have visited her infant in the hospital more frequently. However, there was a transportation

problem which prevented this from occurring.

One primipara who had participated actively in her infant's care prior to discharge was not completely convinced that she was ready to take her infant home. When asked if she felt ready to take her infant home she responded:

Ah I suppose. It's hard to say you know with thinking about all the responsibility and where she was born so small. She was still only four pounds, ten ounces when I took her home.... Oh I was ready, I think.

One primipara whose infant was discharged from hospital weighing 2115 grams and 34 weeks corrected age was happy and delighted to bring her baby home from hospital. However, she indicated that she was somewhat apprehensive because the infant was so small and had required so much care in the beginning. Although she realized that the infant was ready for discharge, she was anxious about going home without the continuous support of the nursing staff.

#### Mothers and Discharge Teaching

All mothers had participated in infant care prior to the infants' discharge from hospital. Initially the mothers were dependent on the nurses when their infants were in critical condition and receiving intensive

nursing care. Two primiparas had limited experience with the giving of direct infant care until one to two weeks prior to the infants' discharge. One of these mothers had been re-hospitalized because of illness and the other mother stated that she did not spend much time with her infant because she had no way of travelling to the hospital.

Three of the fourteen mothers had older children at home and felt that they adjusted to giving infant care in hospital, for example bathing and changing diapers, without problems. They needed assistance adapting and learning aspects of infant care that were different from that for a full-term infant, for example, administration of medications. Three primiparas had experience with newborns and infants prior to the birth of their preterm infants and noted that the physical care of a newborn was not a new experience, however, the size of the infant was the cause for concern. The remaining eight primiparas were apprehensive when they first became involved in the care of their infants but with the guidance of the neonatal nurses the majority gained confidence. One mother said that the nurses were "remarkable" for

letting her get involved.

The majority of the mothers took gradual responsibility for their infants' care when they were in hospital and they viewed the nursing staff as supportive of their independence. They felt that the experiences had prepared them to care for the infant at home. One of the mothers expressed how she felt about her experience and the support she received from nursing staff:

Oh my yes, they were wonderful. I know being a new mother is trial and error for everybody, I would say, but they told me things you wouldn't ordinarily pick up on yourself and not only on a medical basis but on family, you know, a mother, the things to do.

One mother expressed discontent about the method of infant feeding used in hospital. Prior to the infant's discharge the nurses were feeding the infant by bottle and then supplementing by naso-gastric tube. When the infant was discharged his oral feedings were still supplemented by naso-gastric tube. This mother said:

You know yourself that the baby could feed. You just had to give him a chance. You cannot rush the baby. They're going to feed when they want to feed. They're going to burp when they want to burp and you can't look at a clock, and the nurses can't look at a clock.

All the mothers indicated that the nursing staff answered their questions and had given them pertinent information in most instances. One primipara who was breastfeeding had one criticism of the information she received from the nursing staff. She had received information on breastfeeding from a number of different nurses with different ideas rather than an overall plan. This mother said she found it frustrating and stated that it would have been better to have a lactation consultant or one designated person or several nurses with a little more knowledge about breastfeeding.

Thirteen mothers stated they had referred to reading materials when their infants were in hospital such as books or pamphlets on child care, preterm infants and child behavior and had found the readings helpful. One mother stated that she would have liked access to more information. She perceived that physicians felt too much information was not always helpful. The nurses acted as advocates when the mother ran into opposition with medical residents over her need to be well informed. She was interested in research articles and the residents thought the

articles were in too much depth. She stated that the nurses were supportive of her quest for knowledge.

#### Mother-Infant Attachment

As an indication of attachment the mothers were asked "when did you first begin to feel that the infant was really yours"? Table 8 shows the various responses to this question.

**TABLE 8**

#### Mother - Infant Attachment

Time of perceived attachment	Frequency
When infant was born	2
When infant was 2-3 week old	3
When infant was 3-4 months old	1
When infant came home	7
Not completely yet	1
Total	14

Seven of the fourteen mothers responded that they did not feel that the infant was theirs until the infant came home. At the time of the interview one mother still did not feel that the infant was completely hers. This mother had visited the hospital

on a regular basis during her infant's two month hospitalization. She had a supportive partner and family but stated that she felt abandoned by the health care system because of lack of follow-up care.

Behaviors encouraging attachment. Nine of the fifteen infants were transferred to the pediatric referral hospital following delivery because the infants required intensive care. One infant was transferred a month following delivery. The mothers were able to visit their infants while they themselves were still in a different hospital.

Initially the infants were adjusting to extrauterine life and receiving various treatments. Mothers involvement in infant care at that time was limited, depending on the infants' health status. One mother held her infant for the first time when the infant was three weeks old. Another three weeks elapsed before she was allowed to hold the infant again. She had to be content with observing and touching her infant only. When the infants' health status stabilized and there was less equipment or the infants were transferred to the nursery in the case of the referral hospital, it meant that the mothers could

become more involved in their infants' care. As one mother said:

There's so many people looking after him. It was a little different in the nursery. In ICU you go in, it was so technical, so mechanical. You just didn't feel like, I didn't feel like doing things to him where he had so many tubes and wires.

Three mothers felt that the infant was really theirs when they were two-three weeks old and they first held them or when the infants began to gain weight. Weight gain was perceived as a sign that the infants' health status was improving.

The mother who first began to feel that the infant was really hers when the infant was three to four months old, recalled an event which probably was the beginnings of attachment for her. She had made a tape for her daughter. The tape consisted of lullaby music, the mother reading stories, and talking to her baby. She mentioned that when the infant was irritable the nurses would play the tape and the mother's voice would soothe the infant. This mother believed that for her, being able to care for the infant and the response of the infant to her and the tape were the beginnings of the attachment process.

Limited time spent with the infants and routines



of the nursery were considered as deterrents to mother-infant attachment. Although most mothers visited regularly and were encouraged by the nurses to care for their infants, they were involved in only some aspects of care. This was due to work or home commitments. The nursery routines were cited by two mothers as a factor in delaying attachment. One mother explained that she had to wait for another shift to come on before she could give her infant his bath. She could not do it at her own time or pace. These two mothers began to feel that the infants were really theirs when they took the infants home because now they had control and responsibility for their own infants. As one mother said:

I felt I could do things at my own pace ... it was more or less like he was my baby now. Like it was all me who had to take care of him right. Nobody else involved, no nurses involved.

Another mother stated now that the infant was home she felt that the infant was real. She said:

So it's been a week and I think finally it's set in now that she's here and she's here to stay and she's ours. It was hard in hospital... she didn't feel like mine. And people were asking how does it feel to be a mom and of course you don't know.

One mother stated that when her infant responded to her voice was the time when attachment occurred for

her. Her infant began responding to her voice during the first week at home.

### Mothers' Support System

When mothers were asked the question "when you have a concern about your baby, to whom do you turn for help or advice?", they named various support persons.

Table 9 shows the mothers' support system. The support persons are presented according to the frequency of responses.

**TABLE 9**

### Mothers' Support System

SUPPORT PERSONS	FREQUENCY
Own Mother	10
Partner	9
Family Physician	9
Public Health Nurse	8
Neonatal Nurse	8
Friend	5
Sister	4
Sister-in-law	2
Mother-in-law	2
Clergy	1

Note. Mothers named more than one support person.

Ten of the mothers discussed concerns about their infants with their own mothers. Eight of the grandmothers lived in close proximity to their daughters and were viewed as accessible and supportive. The mothers discussed a variety of concerns with their own mothers such as feeding, constipation, and taking the infant outdoors. One of the mothers discussed all medical concerns with her own mother who was a registered nurse.

Nine mothers discussed some or all of their concerns about their infants with their partners. One of these mothers felt that the experience had brought them even closer because they understood each other's coping methods. These mothers also viewed their partners as being the most supportive to them during the first week the infant was home.

Nine of the mothers discussed their concerns with the family physician during routine scheduled visits. The infants' weight was the major concern discussed with the physician. Other concerns discussed with the physician were elimination, feedings, and respiratory symptoms.

Eight of the mothers in this study were visited by

the Public Health Nurse within five days following the infants' discharge from hospital. One mother did not indicate during the interview if she had received a visit from the Public Health Nurse. Five mothers stated that they had not been visited in their homes by the Public Health Nurse. Two of these five mothers had been contacted by telephone, and it was mutually agreed that a visit was not necessary at the time, and if they had a concern they would contact the Public Health Nurse. One of these mothers was a friend of the Public Health Nurse. Three of the five mothers had no contact with the Public Health Nurse since their infants' hospital discharge. Three of the mothers who had not received a home visit from the Public Health Nurse were primiparas. Four of the eight mothers who were visited by the Public Health Nurse did not mention the nurse as a support person in their diary however, the Public Health Nurse was named as a support person during the interview. Infant concerns which were discussed with the Public Health Nurse included feeding, constipation, medication side effects, taking infant outdoors, fussiness, and grunting noises.

The mothers were informed at the time of the

infants' hospital discharge to contact the nurses in the neonatal nursery at anytime if they had a concern. Eight mothers took advantage of the suggestion. They telephoned the neonatal nurses to discuss a wide range of infant concerns such as constipation, fussiness, car seat, medications, and feeding.

Mothers also discussed infant concerns with their female friends, sisters, and sister-in-laws. These individuals had children of their own, and were viewed by the mothers as good sounding boards, and they valued their opinions. One of the mothers-in-law was a registered nurse and the mother consulted her for all medical concerns.

#### Summary of Findings of Factors Influencing the Taking on of the Role of Mother

Although mothers in the sample said that they were looking forward to bringing their infants home from the hospital, 10 indicated that they were apprehensive about their infants' homecoming. All mothers had participated in discharge teaching although two stated that they had limited involvement until the last two weeks before the infants' discharge. The majority felt that the discharge teaching helped to prepare them to

care for their infants at home.

Seven of the mothers did not feel that the infants were really theirs until the infant came home and one said that she did not feel it "completely yet." The mean hospital stay for the infants of these eight mothers was 7.56 weeks as compared to the mean hospital stay of all infants in this study, 12.43 weeks.

The most frequently named support persons when mothers had concerns were their own mothers, their partners, family physicians, Public Health Nurses, and the neonatal nurses. Five of the fourteen mothers and infants were not visited in their homes by Public Health Nurses following the infants' hospital discharge. Three of those not visited were primiparas.

#### Role Strain - The Mother

Role strain was defined by Goode (1960) as "the felt difficulty in fulfilling role obligations" (p. 101). A scale by Burr et al. (1979) was adapted to assess role strain (Appendix G). The amount of role strain experienced by the mothers was measured during the analysis of the interview and diary data and designated as mild to severe based on the criteria

outlined in the adapted scale.

Analysis of the data showed that ten mothers experienced low role strain. Eight of these mothers were primiparas. All these 10 mothers had concerns regarding their infants, themselves, their partners, and families. They felt that there was never enough time to do everything but indicated that they had everything under control. These mothers were coping with their concerns and had strong support systems in place.

Three mothers showed moderate role strain. Two of these mothers were multiparas. One of these multiparas indicated that she had no support persons since she brought the infant home from hospital except her school age child. She was not visited by the Public Health Nurse. She viewed her partner as not supportive to her. She however, indicated that she was managing the infant care with minimal difficulty. The other multipara indicated during the interview that she was having difficulty meeting the needs of all family members including two other children and her sick mother. She had a good support system. One primipara was upset with what she perceived as lack of follow-up

for her infant. She also had not been visited by the Public Health Nurse.

Only one of the mothers, a primipara, showed high role strain. She expressed that the first week at home with her infant was scary, and nerve wracking, and she was finding it hard to get everything done. She had many concerns. This mother expressed guilt and tended to seek reasons for the preterm birth. She seemed to have a support system in place although she articulated that she wished her partner would become more involved with household activities and be more communicative with her. This mother indicated that she had limited involvement in discharge hospital teaching.

For the first couple of days, four of the mothers found it strange or could not believe that the infants were actually home. As one mother stated:

It was odd having her in the house. For so long we went to see this little baby. I heard the sounds in the house of a baby and it was strange, very strange. It was lovely and strange at the same time.

There were other various responses to the infants' first day or two at home. Seven of the mothers stated that the first days at home with their infants were good days and that the infants had adjusted to the new



environment. Indications that the infants had adjusted were regular feeding and sleeping patterns. Three of these mothers were multiparas. Trying to keep up with schedules was described as hectic by four mothers. Two primiparas described the initial days at home as nerve wracking. One of these mothers indicated that it was the first time that she had spent the whole day with her infant and she missed not having the nurses to consult with when she was concerned. The other primipara who found the first day at home with her infant nerve wracking described the first night at home with the infant as awful and scary. She was afraid the infant would smother or that she would choke during her feeding.

The responses to the question "How would you describe this past week"? varied. Ten of the mothers expressed that the week was tiring but that it was an otherwise rewarding week. These mothers made comments such as: "it's been great", "exciting", "tiring", "wonderful", "it's been good but far from normal", and "a rewarding and happy week". And as one mother expressed:

I'm tired, not eating much, not getting out much but having her home has been great. I love her so

much and seeing her struggle and seeing her fight for her life, I can't get down myself. Maybe that's the thing about a premature baby, that you just can't get down because you think back.

Three primiparas described the week as hectic. One of these also stated that it was a hard week. This mother had described her early adjustment to the infant's homecoming as nerve wracking and scary. She stated that she did not visit her infant in hospital as much as she would have liked to and wished that her partner was more supportive. She described her week, "I've been feeling a lot of different things. First you're happy, sad, afraid ... I think I'm after feeling all there is to feel. Scared, happy, and worried." One other primipara described her week as "full of lots of ups and downs" and because of sleep deprivation the "feeling of in control usually disintegrates at night."

All mothers indicated that they felt better at the end of the week than they did when they first brought their infants home. Five of the mothers stated that their concerns regarding the infant had been resolved for the present time. Nine mothers continued to have concerns regarding the infant, themselves, partner, or other children. One mother was taking the infant to an emergency department to have the infant assessed

because of respiratory concerns. Another mother continued to be concerned about lack of follow-up-care of the infant and her own medical problem. A mother was very tired from dealing with the infant, and two other young children, and other responsibilities. Two mothers continued to be concerned regarding lack of support from partners. One of these, a primipara still had concerns regarding "bradys" and stated she would feel better if she had a monitor. She had felt depressed during the week and she had phoned her mother for advice and her mother became impatient with her. She stated, "I mean should I be able to know all this. I got right down. I don't know a lot about being a mother. I still don't know much, I'm learning, so."

Two other mothers continued to have concerns regarding their infants and apnea. One of these mothers was dealing with an instability of her diabetes. Trying to get her twins on similar feeding schedules and attempting to get enough sleep were still concerns for one breastfeeding mother. One other mother was still concerned about her infant's congenital anomaly (shortened femur).

### Summary of Results

The majority of preterm LBW infants in this sample were VLBW infants. More than one-half of the sample of infants were less than 2500 grams at discharge. The majority of mothers and their partners had received an educational level beyond high school. Mothers over 30 years of age and multiparas expressed fewer infant concerns than younger mothers and primiparas.

Over half of the mothers' total concerns were related to the infant. The major infant concerns were in the categories of health, followed by the categories of feeding, growth and development, and elimination. The major concerns about themselves were in the categories of feeling tired, their emotional state, and schedules.

Major support persons were the mothers own mothers, partners, and nurses. Most of the mothers received a visit from the Public Health Nurse within five days following the infants' discharge from hospital. Five mothers had not been visited by the Public Health Nurse up to the time of the interview.

Mothers were looking forward to taking their infants home from the hospital although a number of

mothers were apprehensive. The mothers participated in discharge teaching. Two of these had limited involvement with their infants until two weeks prior to the infants' discharge from hospital.

Seven primiparas and one multipara articulated that they did not feel that the infant was really theirs until the infant was home and one primipara said "not yet." The mean hospital stay for these infants was less than the mean hospital stay for the entire sample.

Most of the mothers found that the first week at home with their infants was rewarding even though they were tired. Three primiparas described the week as hectic and one of these mothers also found the week hard and scary. Although the mothers felt that they were more relaxed with the infant at the end of the week, nine mothers continued to have concerns.

Ten mothers showed evidence of low role strain. Of the remaining four mothers, three were assessed as having experienced moderate role strain, and one with high role strain.

The findings seem to suggest that clear role expectations, role learning, support from partners,

family, and health professionals may reduce mothers' concerns, and therefore, reduce role strain for multiparas and primiparas. This in turn, may facilitate the taking on of the mother role during the first week following the preterm LBW infants' discharge from the hospital.

## CHAPTER VI

### Discussion

In this chapter the discussion of results is presented. The purpose in this study was to explore and describe the concerns of mothers of preterm LBW infants during the first week following the infants' discharge from the hospital. The discussion of findings is presented under the following headings: the demographic characteristics the sample, the concerns of mothers of preterm LBW infants, factors which influence the taking on the role of mother, and role strain - the mother.

As well, the implications for nursing, suggestions for future nursing research, and the limitations of the study are presented. The conclusions of the study follow.

#### Demographic Characteristics of the Sample

All but one of the mothers in this sample continued their education beyond high school indicating that they were middle class and well educated. They all lived within travelling distance of the hospitals and with one exception, travelling to visit their infants in hospital was facilitated. The data

indicate that the mothers in the sample were homogeneous in terms of educational level and learning ability which may have helped them take on their mother role.

Nine infants were discharged from hospital weighing less than 2500 grams. This indicates that preterm LBW infants were discharged home before they reached the lowest birth weight of a normal term newborn infant. If preterm LBW infants continue to be discharged with low discharge weights, follow up of the mothers and infants is imperative to provide continuity of care and to address mothers' concerns.

Concerns of Mothers of Preterm LBW Infants Following  
the Infants' Discharge from the Hospital

Taking on the mother role can not be seen in isolation, for within her role she interacts with others who are members of the role-set, for example, her infant, partner and family. Members of the role-set can offer support or be nonsupportive.

The taking on the mother role is not without its' concerns, all of which are felt by the mother because she takes on the role of prime caregiver to her



infant (Jeffcoate et al., 1979). The findings in this study show that the mothers had concerns about their infants, themselves, their partners, and their family.

The focus of mothers' concerns was the infant and themselves which was also found by Kenner and Lott (1990). Over half (59.82%) of the total concerns articulated by the mothers in this study were related to the infant and 23.29% were related to concerns about themselves. These findings were expected as the majority of the preterm LBW infants in this study were hospitalized for prolonged periods and mothers spent many hours visiting their infants. The mothers had witnessed the ups and down of their infants' progress. They had become increasingly involved with their infants' care and had gained some confidence in their caregiving skills prior to the infants' discharge from hospital. However, it was not until the infant was home from hospital that the mother's role in caring for the LBW preterm infant was truly enacted and concerns not thought of previously, surfaced. Because enactment of the mother role also includes the taking on of responsibility of the infant's welfare, it is not surprising that mothers articulated so many concerns

since they were now faced with the reality of being in the role. This finding supports the work of Gennaro, Zukowsky, et al. (1990). It is, therefore, important for nurses to understand what concerns mothers have when they take on the day-to-day responsibility of the infant without the continuous support of the nursing staff (Kenner & Lott, 1990). Nurses can incorporate these concerns into discharge teaching plans and, in so doing, help mothers to take on the full-time role of mother.

#### Concerns of Mothers About Their Preterm LBW Infants

Primiparas in this study expressed more concerns about their infants when compared to multiparas. The primipara may be delayed in taking on the mother role because of the unexpected birth and prolonged hospitalization of the infant. The size and appearance of the preterm LBW infant may not meet her expectations of an ideal infant (Jeffcoate et al., 1979; Rubin, 1984). The primipara must make a mental readjustment in order to accommodate the preterm LBW infant.

The three multiparas had older children and previous infant care experiences, as well as in hospital experiences with their preterm LBW infants.

It is therefore not surprising that they voiced fewer concerns about their infants. However, even though these mothers had previous experience, they still needed to learn and readjust to the needs of the preterm LBW infant. It was in the processes of role enactment and role learning the specifics needed in looking after a preterm LBW infant that they also expressed concerns. These findings are supported by Kenner and Lott (1990) and McKim (in press-a)

The major categories of infant concerns were as follows: health, feeding, bowel elimination and growth and development.

Infant health. Infant health accounted for 47.33% of the infant concerns voiced by mothers in this study. The findings that infant health was a major concern for mothers of preterm infants is supported in previous studies (Affonso et al., 1992; Butts et al., 1988; Gennaro, Zukowsky, et al., 1990; Kenner & Lott, 1990; McKim, in press-b). Infections and illness, apnea and SIDS, taking the infant outdoors and keeping infant warm, fussy periods, and medications were the most frequent health concern expressed by mothers in this study.

Ten mothers were concerned about infections and illness, the possibility of setbacks in their infants' progress, and their ability to cope in such eventuality. The threat of infection is a reality to mothers of preterm LBW infants because of their immature immune system and also, in some instances, because of the infants' chronic lung problems. Butts et al. (1988) and Kenner and Lott (1990) also found that the threat of illness or infections was a concern for mothers. Brooten et al. (1988) noted that the mothers needed more information about infant health problems such as infections.

The finding that apnea was a major concern for mothers of preterm infants following the infants' discharge from hospital is supported by other studies (Gennaro, Zukowsky, et al., 1990; Goodman & Sauve, 1985; Kenner & Lott, 1990; McKim in press-a). The fear of apneic attacks may have resulted from witnessing similar episodes in hospital and the quick response of the nurses to re-establish the infant's breathing. The swift action by the nurses reinforced for the mother the urgency of the situation. This experience seemed foremost in the mothers' minds when they brought their

infants home from hospital. They still envisioned that their infants might stop breathing and they did not have the skills, knowledge, and equipment to deal with such an emergency.

Because in preterm birth the mother is separated from the infant it is not possible to note some of the infants' fussy behaviors which are usually displayed early on after birth. Seven mothers expressed concern about their infants' fussy periods which was also reported by Adams (1963). McKim (in press-a, in press-b) reported that mothers would have liked information on fussy periods and colic. McHaffie (1990) stated that mothers were amazed at how much their infants cried and viewed the infants' crying as their inability to understand and interpret the infants' needs. McHaffie reported that mothers had not witnessed this behavior while the infant was in hospital. One mother in this study questioned if her infant had colic and wished she had been told if this was typical behavior for her infant prior to his discharge. Keefe and Froese-Fretz (1991) stated mothers reported that colic created a crisis situation. They stated that mothers needed reassurance, support,

empathy, and validation that their infants' irritability was real and not imagined. The long periods of the infants' crying may erode the mothers' confidence and cause tension within the mother-infant role-set. Medoff-Cooper and Schraeder (1982) reported that preterm VLBW infants were difficult to soothe, less adaptable, negative in mood, and withdrawing, and concluded that VLBW is associated with difficult temperament. They found that mothers tended to respond to these infants negatively. Mothers need to be given information on colic and infant behavior such as fussy periods prior to the infants' discharge as mothers rarely witness this behavior in hospital. Discharge teaching plans should include information on behaviors of preterm LBW infants.

Some mothers in this study had concerns about taking their infants outdoors because they worried about their infants becoming "sick" because of exposure to damp and cold weather. This was also a concern for mothers in the studies of Adams (1963) and McKim's (in press-b).

Five mothers had concerns about the infants' medications, specifically Ferrous Sulphate. As two of

these mothers stopped giving the medication to their infants because of emesis and constipation, nurses need to include in the teaching plan the importance of this medication to the infant. Medications were cited as a concern in studies by Butts et al. (1988) and Gennaro, Zukowsky, et al. (1990). Brooten et al. (1988) found that mothers needed teaching in the administration and monitoring of medications.

Infant feeding. One of the most important duties or obligations of the mother role is the mother's ability to feed her infant successfully. Feeding can be viewed as a yardstick that some mothers use to measure their role performance.

Feeding was the second largest category of infant concerns for mothers in this study. Only three of the fourteen mothers were providing their infants with breast milk at the time of the study. The small number of breastfeeding mothers in this sample and the fact that three mothers had stopped expressing milk needs to be addressed by nurses working with mothers of preterm LBW infants. It is evident that mothers who choose to breastfeed their infants need further encouragement and teaching so that they can breastfeed successfully.

Brooten et al. (1988) found that mothers of preterm infants needed intense teaching on breastfeeding following the infants' discharge. This indicates that concerns regarding breastfeeding continue when the mother takes the infant home and that follow-up is essential.

Infant feeding was cited as a concern for mothers of preterm infants in other studies (Adams, 1963; Butts et al., 1988; Goodman & Sauve, 1985; McKim in press-b). Major infant-feeding concerns for mothers in this study were: spitting up, amount of milk intake, and weight gain. Mothers reported that they were concerned about the infants' weight in previous studies (Adams, 1963; Brooten et al., 1988; Gennaro, Zukowsky, et al., 1990; Goodman & Sauve, 1985; Kenner & Lott, 1990). Infant feeding schedules were a concern for the mothers in this study and they reported that when the infants came home they wanted to be fed more frequently. They had not anticipated this change in feeding patterns. Nurses should inform mothers that the infants' feeding schedules may alter because of the change of environments, routines, and the infants' growth spurts. The infant needs time to adjust from the controlled,



over stimulating environment of the neonatal intensive care unit to the less controlling environment of home. The mothers most likely did not learn their infants' hunger cues because of nursery feeding routines. In addition to hunger, other factors such as sleep patterns, environmental conditions such as noise and temperature will determine how frequently the preterm infant will want to be fed (Sammons & Lewis, 1985). It is also possible that the more frequent feeding caused the infant to regurgitate.

Bowel elimination. Seven mothers were concerned about the infants' bowel elimination. Bowel elimination can be a concern for mothers especially if they do not understand the normal bowel habits of their preterm infants who are breastfed or of those who are formula fed. To overcome constipation five mothers added various amounts of sugar to water or to formula. None of the breastfeeding mothers cited constipation in their infants as a concern. The teaching of mothers regarding stool patterns is included in discharge planning, however this is an area in which mothers would benefit from reinforcement and clarification. The mothers' action of giving the infants sugared water

or sugar in formula needs to be closely examined to determine the frequency and amount of sugar given to the infants and the effect on the infants' health.

Infant growth and development. All mothers in this study seemed to have realistic expectations regarding their infants' physical and social developmental milestones. The mothers viewed their infants' development according to the infants' corrected age. This had been emphasized by the nurses in the pre-discharge teaching plan. This finding differs from the results reported in other studies (Brooten et al., 1988; Gennaro, Zukowsky, et al., 1990). They reported that the mothers had unrealistic expectations regarding the achievement of the infants' milestones. Brooten et al. (1988) stated that mothers needed constant reinforcement that their infants' growth and development should be assessed according to the infants' corrected age and not their chronological age.

The infants' sleep and awake patterns were a concern for 10 mothers in this study. This finding was also reported by Goodman and Sauve (1985). When infants stayed awake at night following a feeding the

mothers were surprised. This interrupted the mothers' own sleep more frequently than anticipated. Sleep and awake patterns of preterm infants are not included on the list for discharge teaching. Therefore, mothers would benefit by having this aspect of development included in the hospital's teaching plan.

#### Mothers Concerns About Themselves

Mothers expressed concerns about themselves. The major concerns about themselves were feeling tired, their emotional state, and keeping tight schedules. Mothers expressed that they were tired from sleep interruption at night and role responsibilities and demands. Gennaro et al. (1992) found that mothers got less sleep and were more tired than they expected following the infants' discharge from hospital but seemed to accept the responsibilities and demands as a part of taking on the mother role. The mothers in this study seemed to have formulated their own role expectations. The clearer the role expectations the easier it is to take on the mother role (Burr et al., 1979). Most of the mothers felt that they were the center of all activities and it was their responsibility to meet the needs of their infants and

partners, both of whom are important individuals affecting the mothers' role-set. A few mothers felt confined because of their role demands and responsibilities to their infants. Gennaro et al. (1992) stated that mothers reported there was less time to spend with significant others. Anticipated changes in mothers' lifestyle should be included as part of the discharge teaching process.

The mothers in this study experienced various emotional reactions since their infants were discharged from hospital. The most frequently expressed emotional reaction was irritability which was also reported by Affonso et al. (1992). Gennaro, York and Brooten (1990) found that mothers of VLBW infants had higher levels of anxiety and depression for the first two months of the infants' delivery than mothers of LBW infants. Brooten et al. (1988) reported that mothers of infants who were in hospital for long periods (mean of 51 days) were less depressed than mothers whose infants were hospitalized for a shorter time. They suggested that this may have been due to the mother having adjusted physically and emotionally prior to the infants' discharge from hospital. Only two mothers in

this study indicated that they had periods of depression during the week since their infants were discharged. The low incidence of depression may be due, in part, to the long hospital stay of the infants (mean of 12.43 weeks), the higher educational level of the mothers, better support systems, and discharge teaching and planning.

#### Factors Which Influence the Taking on the Role of Mother of a Preterm LBW Infant

The findings show that there were three factors which influenced mothers in taking on the mother role. These were: discharge teaching plan, education and past experience, and mother-infant interaction.

#### Discharge Teaching Plan

All mothers in this study participated in the discharge planning process prior to the infants' discharge from hospital, although for two mothers the experience was limited, eleven mothers reported, without hesitation, that they felt ready to take their infants home. Cagan and Meier (1979) and (1983) found that the discharge planning process helped relieve the anxiety which accompanied the infants' discharge from

hospital. The teaching plans did prepare the mothers well for skills but did not minimize feelings of apprehension for the majority of mothers in the present study. It is possible that these feelings were intensified by the knowledge that now the mothers were on their own without the continuous support of the nursing staff. Also teaching plans are infant oriented and the mothers' lifestyle changes are not as well documented in the present study.

Sammons and Lewis (1985) emphasized when the preterm infant is discharged from hospital, parents have feelings of failure and incompetence. Although mothers participated in discharge teaching and gained confidence in infant care, they are taking their preterm LBW infants home when they are still afraid that their infants might not survive (Kenner & Lott, 1990; McKim, (in press-b). They view their infants as weaker (Bidder et al, 1974), and sicker than term infants (Kenner & Lott, 1990). Also, they are taking home infants with more difficult temperaments than full-term infants (Medoff-Cooper & Schraeder, 1982). As well, the lack of positive reinforcement from their infants may cause mothers to doubt their ability to

care for their infants (Kenner & Lott, 1990). It is, therefore, important that teaching plans are designed to address concerns of mothers, infant behavior, and the lifestyle changes which might occur when the infants are discharged from hospital.

#### Education and Past Experience

It should be noted that the majority of mothers in this study were middle class, well educated, and lived within travelling distance of the hospital. The majority visited their infants frequently, and became involved in their care during the infants' hospitalization. The aforementioned factors most likely contributed to the mothers feelings of readiness for discharge. Similar findings were reported by Zahr (1991) who found that the mothers' education and family income as well as social support correlated positively with the mothers' confidence. Zahr also found that mothers who were confident in their ability to care for and understand their infants perceived their infants' behavior as more predictable, less difficult, and more adaptable.

In this study three multiparas and three primiparas with previous child care experience

indicated that they felt confident in giving infant care. Previous child care experience has been identified as an important positive factor in mothers feeling of confidence (Jeffcoate et al., 1979; Zahr, 1991). It helped mothers in this study adapt to the mother role with greater ease than those who did not have previous child care experiences.

#### Mother-Infant Interaction

Fifty percent of the mothers in this study did not feel that the infant was their own until the infant came home from hospital. One mother did not feel that the infant was completely hers up to the time of the interview. The findings from this study concurred with those of previous researchers (Goodman & Sauve, 1985; Jeffcoate et al., 1979). The birth of a preterm infant often causes separation of mother and infant and often delays the attachment process (Klaus & Kennel, 1982). Following the infants' birth, over half of the infants in this study were transferred to the pediatric referral hospital. All mothers were discharged home without their infants. Rubin (1984) emphasized that when a preterm birth occurs the "binding in" to their infants which is the beginning of attachment and occurs



prior to delivery, is interrupted. Therefore, she becomes a mother before she is ready to take on that role. The findings seem to indicate that attachment was facilitated when the infants began to respond to their mothers and when they became more involved in the infants' care. The mothers did not cite that the delay in attachment was a concern for them. Therefore, these findings should be interpreted with caution. The mothers interacted with their infants during the interview time and there were no indications that a problem existed. Jeffcoate et al. (1990) reported that the delay in attachment caused some mothers to feel inadequate and several mothers felt hostile towards their infant. This was not a finding in this study as no mothers expressed or displayed hostility towards their infants.

#### Mothers' Support System

The results of this study reveal that the mothers' own mothers, partners, family physicians, Public Health Nurses, and neonatal nurses provided support to the mothers when they had concerns. Less than half of the partners were home during the first week of the infants' discharge from hospital. The majority of

mothers named their partners as being most supportive during the first week which also was a finding in studies by McHaffie (1989), and McKim (in press-b). The finding that two mothers preferred to feed their infants without the help of their partners agrees with the findings of McHaffie (1989).

Five mothers in this study had not been visited by the Public Health Nurse during the first week despite the provincial policy that all mothers of preterm infants are visited during the first week of discharge, preferably within the first two to three days. McKim (in press-b) reported that in her study, only 61% of mothers were visited within the first week of the infants' discharge. Therefore, this is an area which still needs attention. Only one of these mothers was upset because of the lack of follow-up. McHaffie (1989) stated that the mothers in her sample were angry because they had not been visited by the health visitor during the first week and those who were visited were not satisfied with the information and support received. It is noted that the McHaffie study dealt with a British sample, therefore, it is difficult to compare these findings to the provincial scene because

of different health care system and policies. None of the mothers in this study voiced dissatisfaction with the information and support they received from the Public Health Nurse. Censullo (1986) emphasized that mothers can be helped to gain a sense of mastery through counselling and teaching during follow-up visits after the infants' discharge from hospital.

#### Role Strain - The Mother

Taking on the mother role, such as the mother of a preterm LBW infant, involves many challenges such as a change in role expectations, a change in relationships, and the learning of new role skills (Meleis, 1975). Role strain may result if the mother is unable to meet multiple role demands and role expectations (Burr et al., 1979). These factors as well as adequate role learning and social support are important in reducing mothers' concerns and thus reduced role strain for both primiparas and multiparas. A reduction in role strain can consequently assist in taking on the mother role during the first week the infants are home. Using a scale adapted from Burr et al. (1979) to assess role strain felt by mothers, the majority of mothers

experienced low role strain during the first week of the preterm LBW infants' discharge from hospital. The one mother who experienced high role strain articulated seventeen concerns about her infant, was not satisfied with the partner's support, had not visited her infant frequently in hospital, and indicated not feeling comfortable with her role skills. She found the week "hard" and seemed frustrated with meeting role expectations and role demands.

The conceptual framework of the study proposed that adequate role learning, clear role expectations, and support from partners, family, and health care workers helped reduce role strain and this framework has been supported by the findings from this study.

#### Implications for Nursing

The major concerns of mothers about their preterm LBW infants during the first week of the infants' hospital discharge was the infants' health, feeding, and growth and development, and elimination. The majority of mothers in this study were satisfied with their learning experiences with regards to infant care however, they did have concerns when they took their

infants home from hospital. The findings from this study indicate that mothers would benefit from extra teaching and counselling when their infants are in hospital with regard to identified concerns. The inclusion of infant behaviors such as fussy periods and colic, and sleep and awake patterns should be included in the teaching plans. Nurses cannot prepare mothers for all concerns that may surface when the infants are discharged from hospital. However, nurses can better prepare mothers for the infants' discharge by assessing their readiness to learn and by assessing individual needs. A systematic assessment of mothers' learning needs in relation to their infants has been instituted in both hospitals to ensure individualization of teaching needs. No major differences in mothers' concerns were linked to a specific hospital's discharge teaching plan. Nurses in both hospitals should continue assessing each mother's needs so that teaching is based on what mothers want and need to know. It is also important that nurses recognize mothers have concerns about themselves. The neonatal nurses need to help mothers anticipate the lifestyle changes due to the infant's homecoming and provide information about

coping strategies (Gennaro et al., 1992). It is also important that the partner or some other support person be included in the discharge teaching as the mother will need support from that person when concerns arise after the infant goes home.

Since concerns may surface after the infant has been discharged from hospital, it is important the Public Health Nurses recognize the kinds of concerns mothers have during the first week the infant is home. There is a need for continuity of care and follow-up by Public Health Nurses during the first week of the infants' discharge from hospital.

Nurses should question the current practice of advising mothers to add sugar in water or formula to overcome perceived constipation in their infants. If this is a one-time intervention there probably is no need for concern. However, regular inclusion of sugar in the diet increases calories and predisposes the infant to obesity. No literature was found that documented the implications of giving additional sugar to preterm LBW infants. However, it may present a possible danger to some infants.

The findings from this study indicate that there

is a need for nurses to provide consistent information and guidance to breastfeeding mothers in order to facilitate breastfeeding. The immature sucking and swallowing reflexes of the preterm infant often prevents the infant from taking milk directly from the breast. Thus, a mother who intends to breastfeed may be faced with long weeks of expressing her milk and transporting it to the hospital. Nurses have a vital part to play in counselling and encouraging these mothers if they are to succeed. Also, consideration should be given to providing staff education under the direction of a lactation consultant. The latter can help in the development of specific unit policies and protocols that will influence the breastfeeding environment and breastfeeding outcomes for mothers of preterm infants (Barnes, 1991).

The Public Health Nurses did not contact or visit all of the mothers during the week following the infants' hospital discharge. Because the mothers expressed feelings of apprehension, and had many concerns during the first week at home, and two mothers had limited experience with infant care prior to the infants' discharge, it is important that mothers

receive a prompt visit from the Public Health Nurse. It is possible that there is a need for more communication between the discharging hospital and the Public Health Nurse to ensure that all mothers are visited during the first week. One of the infants who was not visited was discharged on a Friday. There could be a delay in the referral being sent to the Public Health Nurse and thus, a delay in the visit. This could be corrected if telephone contact was made with the Public Health Nurse the day of the infants' discharge from hospital or sooner when the infants' discharge is imminent. Also, because preterm LHW infants are being discharged with low discharge weights and before they have reached 40 weeks corrected age, follow-up by the Public Health Nurse must be assured. Public Health Nurses can help decrease the mothers' apprehension and address their concerns by providing continuity in care to mothers and infants during the first week. Also, it is important that the neonatal nurses continue to encourage the mothers to call the hospital units at any time when they have concerns.



### Suggestions for Future Nursing Research

The findings from this study have implications for further research. The concerns of mothers of preterm LBW infants need to be explored beyond the first week of the infants' discharge from hospital. The sample should be larger including mothers with divergent demographic characteristics. Comparisons could be made between mothers who are able to visit their infants regularly with those mothers who cannot do so because of distance or other reasons.

Research needs to be conducted to determine the needs of mothers of preterm LBW infants when the infants are in hospital and during the first weeks of the infants' discharge from hospital. The study should focus on the mother's learning needs when the mother begins to express her milk and when the infant starts to take milk from the breast. A follow-up of the mother's learning needs when she takes the infant home would be ideal.

A qualitative study is needed to explore and describe mothers' perspectives of when and how they form an attachment to their preterm LBW infants. The study should include the mothers' perceptions of

factors which influence or inhibit attachment behaviors while their infants are in hospital.

#### Limitations of the Study

The generalization of the research findings to the general population are limited because of the following characteristics of the study:

1. The size of the sample was small and included only 14 informants.
2. The sample characteristics are not representative of the province, for example, race, socio-economic status, marital status, and geographical location. The mothers in this study were white caucasian, the majority were middle class, and had continued their education beyond high-school, were married or living common-law with their partners, and lived within a 60 mile radius of the hospital. They were a relatively homogeneous group of mothers. They had similar opportunities for discharge teaching and for regular interaction with their infants. This may have effected the data.

### Conclusions

This study examined the concerns of mothers of preterm LBW infants' during the first week of the infants' discharge from hospital. Concepts from role theory formed the conceptual framework; role taking, role-set, role learning, role expectations, and role strain.

The findings demonstrated that taking on the role of mother of a preterm LBW infants generated concerns during the first week of the infants' discharge from hospital. The focus of the mothers' concerns was the infants and themselves. Within the mother-infant role-set, the mothers experienced concerns about infant health, infant feeding, infant growth and development, and elimination. Multiparas and mothers over 30 years of age expressed fewer infant concerns than primiparas and younger mothers.

The factors that seemed to influence the ease with which the mother took on her role during the first week of the preterm LBW infants' discharge from hospital were: adequate role learning, adequate role expectations, and adequate support from her partner, family, and health professionals.

Mothers in this study experienced role strain during the first week the preterm LBW infants were home. The findings seem to indicate that mothers' concerns were reduced when they had previous experience with children and participated actively in the care of their infants in hospital. When the mothers were comfortable in their mother role, managed their role expectations with minor difficulty, had no unusual concerns about their infants, themselves, their partners, or their family, and had a good support system in place, role strain was minimal.

When one considers the number of social and emotional problems prevalent in todays society that are rooted in early childhood, as health professionals we must address concerns and provide support to mothers of infants who have been placed at high risk from birth.

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## Appendix A

### Explanation to the Mother

To mothers of premature infants. I am a Registered Nurse and a student of the Master's of Nursing Program at Memorial University of Newfoundland.

I am requesting your participation in a research study. The purpose of the study is to find out the concerns of mothers of low birth weight infants when the infant first goes home from the hospital. It is anticipated that the information gained will assist nurses in planning care for mothers of these infants.

I will request that you record your concerns in a diary, following your infant's discharge. I will collect the diary following an interview.

The study involves my visiting you within one week after the infant is discharged. You will be asked questions, which will be taped recorded. The interview will be approximately one hour.

Participation in this study is entirely voluntary.

If you choose not to participate in this study, your decision will in no way affect the care your infant receives.

If you choose to participate, you may choose not to answer some of the questions, and you may withdraw from the study at any time.

All information that you give will remain confidential. The tape used during the interview will be erased at the end of the study.

Prior to meeting with you I will be obtaining the infant's weight and address from the chart.

I will contact you by telephone following the infant's discharge, to confirm the date and time to meet with you.

Thank you for considering this request.

Appendix BInformed Consent Form

RESEARCH STUDY TITLE: Concerns of mothers of preterm  
low birth weight infants  
during the first week  
following the infants'  
hospital discharge.

INVESTIGATOR: Margaret Nowe Telephone: 722-5718

\_\_\_\_\_  
T H I S I S T O C E R T I F Y T H A T

I, \_\_\_\_\_  
(print name)

Hereby agree to participate as a volunteer in the above named study. I understand that there will be no health risks to me resulting from my participation in this study. I understand that, at the end of the study, the tapes will be erased. I understand the information may be published, but my name will not be associated with the research. I understand that I am free to participate in the study as well as to refuse to answer specific questions I may be asked. I also understand that I am free to withdraw my consent and end the interview at any time. I have been given the opportunity to ask whatever questions I wish, and all such questions have been answered to my satisfaction.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

I hereby agree that the transcript(s) of my interview may be used for teaching purposes.

\_\_\_\_\_  
Participant

Appendix C

Date: \_\_\_\_\_

Code Number: \_\_\_\_\_

Diary Sheet

Day:            1            2            3            4            5            6            7

1. How would you describe this day?	2. What are your concerns about your baby today?	3. What are your concerns about yourself today?
4. What are your concerns about your partner today?	5. What are your concerns about your family today? eg. other children, relatives?	6. Did you discuss any of your concerns with anyone today? If so for what problem, and who with?
7. Who has given you the most support today?	8. Do you have any additional comments about what it has been like for you today?	

## Appendix D

### Guidelines for Use of Diary

You have been given seven diary sheets, one for each day. Each sheet is identical.

Please keep a record every day for seven days starting the day after you bring your baby home.

You will note that each sheet has a place to record the date and day you are recording. Please ensure that you have completed this section.

For the purpose of this study the term concerns is defined as a feeling of anxiety or apprehension, a worry, or something seen as a problem.

Please feel free to write on the back of the diary sheet if you run out of space. If you do this, please indicate which question you are answering.

If you find that you have questions regarding the use of this diary, please contact me (Margaret Nowe) at 722-5718.

Thank-you for your co-operation.

Appendix E

Date: \_\_\_\_\_ Code Number: \_\_\_\_\_

## Demographic Data (Infant)

Sex:

Birth weight:	_____	grams.
Gestational age:	_____	weeks.
Discharge weight:	_____	grams.
Length of hospital stay:	_____	weeks.
Corrected age at discharge:	_____	weeks.
Discharge:	_____	hospital.
Discharge date:	_____	

Appendix F

Date: \_\_\_\_\_ Code Number: \_\_\_\_\_

## Guide to Interview Topics

## Section I: Interview Schedule

The purpose of the following questions is to identify your concerns that relate to your baby, yourself, your partner, and your family since the baby's discharge from hospital. A concern is defined for the purpose of this study, as a feeling of anxiety or apprehension, a worry, or something seen as a problem.

1. Were you looking forward to bringing your baby home?
2. Did you feel ready to take your baby home? Please explain your response.
3. What further information or experiences would you have liked to help prepare you to care for your baby?
4. Do you feel confident in caring for your baby? Please explain your response.
5. What was the first day at home with your baby like?
6. When did you first begin to feel that the baby was really yours?
7. Have you had prior experience in caring for babies or children? If yes please explain.
8. Have you referred to reading materials about babies? If yes please explain.
9. What do you find most difficult about being the mother of a premature baby.



10. What changes have you had to make in your life since you brought your baby home?
11. What do you find is most difficult about being a wife, mother, and homemaker?
12. Do you find time to give individual attention to your other child or children? Please explain your response.
13. Do you have any concerns about yourself?
14. Do you plan to return to work? If yes, is this a concern?
15. What concerns did you have about your baby during the past week?
16. Which of these have caused you the most concern?
17. How does your baby's growth and development compare to other children of the same age?
18. When you have a concern about your baby, to whom do you turn for help or advice?
19. How involved is your partner in the baby's care?
20. How involved is your partner with household activities, and the care of the other children?
21. How do you feel when relatives phone or visit?
22. How would you describe this past week?
23. Who has supported you most throughout this week?

## Section II: Demographic Data

The following questions are designed to gather general information about the mothers participating in the study.

- 24. Mother's Age \_\_\_\_\_
- 25. Marital Status \_\_\_\_\_
- 26. Number of Children \_\_\_\_\_
- 27. Ages of Children \_\_\_\_\_
- 28. Living arrangements  
at time of interview \_\_\_\_\_
- 29. Mother's Occupation \_\_\_\_\_
- 30. Father's Occupation \_\_\_\_\_
- 31. Highest level of Education  
achieved (mother) \_\_\_\_\_
- 32. Highest level of Education  
achieved (father) \_\_\_\_\_

Appendix GRole Strain Scale

- 1 = no role strain - The mother was comfortable in the mother role. She managed role expectations with no difficulty. She felt that she had everything under control. She had no unusual concerns about the infant, herself, her partner or her family. She had a strong support system.
- 2 = low role strain - The mother felt that she was not able to do everything she wanted but managed role expectations with a minor amount of difficulty. Generally she felt that she had everything under control. She had concerns but no unusual concerns about the infant, herself, her partner or her family. She had a good support system in place.
- 3 = moderate role strain - The mother felt that she was unable to get everything done. She felt uncomfortable and frustrated with role expectations. She had no more than one unusual concern about the infant, herself, her partner or her family. She had good a support system but generally felt that the support system could be stronger.

- 1 = high role strain - The mother had feelings of guilt and anxiety about not being able to perform adequately in the mother role. She found the mother role hard and frustrating. She had no more than two unusual concerns about her infant, herself, her partner or her family. She had a support system but the support system was not always viewed as supportive.
- 5 = Very high role strain - She had feelings of extreme guilt and anxiety. She was extremely uncomfortable, guilty and anxious in the mother role. She was not able to meet role expectations. She had more than two usual concerns about her infant, herself, her partner, and her family. She generally lacked a support system.

Adapted from. Burr, W. R., Leigh, G. K., Day, R. D., & Constantine, J. (1979). Symbolic interaction and the family. In W. R. Burr, R. Hill, F. Nye, L. Reiss (Eds.), Contemporary Theories About The Family: General Theories and Theoretical Orientations (p.p. 42-111). London: Collier MacMillan.

Appendix H

Letter to the Assistant Executive Director of  
Patient Care Services.

Dear \_\_\_\_\_,

I am a Registered Nurse who is a candidate for the  
Master's Degree in Nursing.

The title of my research is, "Concerns of Mothers  
of Preterm Low Birth Weight Infants During the First  
Week Following the Infants' Hospital Discharge."

The purpose of my research is to explore the  
concerns of mothers of low birth weight infants  
(infants with birth weights of 2500 grams or less),  
within one week of the infant's discharge from  
hospital.

I am requesting permission to obtain the names of  
mothers of low birth weight infants who meet the  
criteria of my study. In the week prior to the  
infant's discharge, the nursing supervisor of the  
neonatal unit will make the initial contact with the  
mother, on my behalf, to obtain permission to be  
approached by the researcher.

If the mother agrees, I will meet with her prior  
to the infant's discharge, in order to explain the  
study and to obtain consent. The date and time for an  
interview will be arranged at that time.

If permission is granted, I plan to make contact  
with the Supervisor to explain the study and the  
criteria used for selection of participants.

Thank you for considering my request.

Yours truly,

Margaret Nowe









