THE SUPPORT NEEDS OF MOTHERS OF HIGH-RISK PREMATURE INFANTS

CENTRE FOR NEWFOUNDLAND STUDIES

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EDNA MARGARET McKIM

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THE SUPPORT NEEDS OF MOTHERS OF HIGH-RISK PREMATURE INFANTS

BY

© Edna Margaret McKim, R.N., Dip.N.Ed., B.Sc.N.

A thesis submitted to the School of Graduate Studies in partial fulfillment of the requirements for the degree of Master of Nursing

School of Nursing
Memorial University of Newfoundland

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ABSTRACT

The purpose of this research was to evaluate the needs of a specific geographically-based sample of mothers of high-risk premature infants in order to provide the groundwork for an improved teaching and support programme.

The objectives for this study were (a) to determine the kinds of information that mothers of premature high-risk infants received prior to the infants discharge from hospital; (b) the kinds of information that the mothers felt they needed, but did not receive; (c) the types of support sought by the mothers in the early post-discharge period; (d) whether the support received by the mothers was felt to be adequate; and (e) to determine what type of support was needed where support provided was perceived to be inadequate.

The subjects were 56 primiparous and multiparous mothers of high-risk premature infants. Data were collected by survey questionnaire and analyzed using descriptive and inferential statistics.

This study found that mothers of high-risk premature infants received information similar to that given to mothers of healthy, full-term newborns. The mothers wanted, but did not receive information on the "colicky", "fussy", or crying infant, noisy breathing, "spitting-up", infant behaviour, and infant illness. Primiparas and mothers attending prenatal classes had an increased need for information.

Mothers who reported that they needed more information

and did not receive it, were more anxious and less confident while the more experienced mothers were less anxious. A difference was found in the amount of information the mothers received from the various hospitals. The primary source of support for the mothers in this study was the husband/boyfriend, and secondly, the mother's mother. Multiparous mothers appeared not to receive the same amount of support as the primiparous mothers.

Many of the mothers found the first week after the infant's discharge from hospital difficult. The only variable that appeared to have any bearing on the difficult first week was the prompt visit of the public health nurse.

The findings from this study suggest that more information needs to be made available to mothers of high-risk premature infants prior to their baby's discharge, and confirms the need for a structured teaching programme. Other needs indicated by the mothers were for a place to call for assistance, a booklet on post-discharge premature infant care, and a visit from the public health nurse during the first post-discharge week. This study emphasized the importance of an assessment of the mother's need for support and the quality of support available to her prior to the infant's discharge, and the necessity of hospital and community nurses working together to support mothers of high-risk premature infants.

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TABLE OF CONTENTS

		PAGE
ABSTRACT		ii
ACKNOWLEDGEMENTS		iv
TABLE OF CONTENTS		vi
LIST OF TABLES		x
CHAPTER		
I	INTRODUCTION	1
	Problem Statement	3
	Purpose	10
	Objectives of the Research	10
	Definition of Terms	11
	Conceptual Framework	12
	Definitions and functions of social support	13
	Theories of social support	15
	Stress and social support	16
	Reciprocity and social support	18
	Social support and social networks	18
	Models of social support	20
	Social support and the study of mothers of high-risk premature infants	21
II	LITERATURE REVIEW	24
	Parenthood and Mothers of Healthy Newborns	25
	Concerns of first-time mothers of healthy newborns	27
	Concerns of multiparous mothers of healthy newborns	30

Differences and similarities between primiparous and multiparous mothers of healthy newborns..... 31

Expressed needs for information and support by both primiparous and multiparous mothers..... 35

Effects of teaching and other methods of intervention on mothers of healthy newborns..... 38

Perception of competence for infant care. 41

Parenthood and the Mothers of Premature Infants..... 43

Concerns of mothers with high-risk premature infants..... 50

Effects of teaching and other methods of interaction on mothers of preterm infants..... 55

Social Support and Pregnancy..... 59

Effects of support in the postpartum period..... 61

Prematurity and social support..... 64

Long-term effects of social support..... 70

Summary..... 71

III METHODOLOGY..... 78

Sample..... 79

Setting..... 80

Instrumentation..... 80

Procedure..... 82

Data Analysis..... 83

Ethical Considerations..... 83

IV RESULTS AND DISCUSSION..... 85

Characteristics of the Study Population..... 86

Study population characteristics for primiparas and multiparas..... 91

Data Presentation for the Objectives..... 91

Objective A:
Information received by mothers of high-risk premature infants..... 91

Objective B:
Information wanted, but not received by mothers of high-risk premature infants..... 94

Relationship between informational needs and anxiety and confidence..... 99

Parity and Objectives A and B:
Information received, and information wanted, but not received by primiparous and multiparous mothers of high-risk premature infants..... 103

Objectives C and D:
Support received by mothers of high-risk premature infants and the adequacy of that support..... 108

Prenatal and hospital classes..... 108

Sources of help..... 111

Public health nurse support..... 114

Family physician support..... 117

Objective E:
Support perceived to be needed by mothers of high-risk premature infants..... 118

Adjustment to Parenthood and the Early Post-Discharge Period..... 120

The difficult first week..... 123

Summary..... 125

V LIMITATIONS AND CONCLUSIONS..... 129

Limitations of the Study..... 129

Conclusions..... 130

Implications of the Study..... 132

Nursing Practice..... 132

Nursing Education..... 137

Nursing Research..... 138

Summary..... 138

REFERENCES..... 141

APPENDIX A: Criteria for Admission to Provincial Perinatal Follow-Up Clinic..... 153

APPENDIX A: Questionnaire..... 154

APPENDIX C: Letter of Information for the Mothers.. 165

APPENDIX D: Consent Form..... 167

LIST OF TABLES

TABLE	DESCRIPTION	PAGE
1	Characteristics of Primiparas and Multiparas	87
2	Percent of Primiparas and Multiparas Indicating They Received Specific Items of Information	93
3	Percent of Primiparas and Multiparas Indicating Items of Information Not Received, But Needed	95
4	Summary of Correlation Coefficients Between Variables in the Study	98
5	Mean Percent of Items Needed and Given, Needed and Not Given, and Not Needed and Given to Primiparas and Multiparas	101
6	Percent of Primiparas and Multiparas Indicating (a) They Received, and (c) They did Not Receive Different Items of Needed Information	106
7	Parity and Attendance at Prenatal and Hospital Classes	108
8	Mean Percent (a) and (c) Responses, and Percent of Needed Information Received (a/a+c) by Mothers From Hospitals A, B, and C	110
9	Parity and Times of Difficulty After Discharge	121
10	Level of Confidence of Mothers who Reported Having a Difficult First Week After Discharge	124
11	Visit of the Public Health Nurse During the First Week After Discharge and Whether the Mother Reported Having a Difficult First Week	125

Chapter I

The initial postpartum period is very often a time of unexpected crisis and this is especially true for parents of premature infants. Whereas, the parents of healthy newborns find themselves in a state of transition, having to cope with a change of role and identity as adaptation to parenthood occurs, the parents of premature infants must deal with these aspects of change, plus an adaptation to being a parent of an often ill, immaturely developed child. Parents of healthy newborns may find their self confidence threatened, become overwhelmed by the sudden sense of responsibility that occurs with the birth of their child, and frequently find themselves with feelings that are quite different from the type of feelings they anticipated they would experience upon the birth of their baby. Parents of premature infants have similar feelings which may be further heightened by a sense of grief and guilt at not producing a "perfect" child, a loss of control because others, not themselves, are now caring for their baby, and fear and anxiety because they face the possibility that their child may die or be permanently damaged as an outcome of the prematurity. Furthermore, parents of preterm infants have not gone through the normal nine-month period of preparation for the birth of their baby and may find themselves even less prepared to assume the role of parenthood. The

parents' healthy adaptation to the role of parenthood is essential for the well-being of the child, and this is especially true in a situation where the infant is premature or has had medical and/or physical complications (Broussard, 1979; Curry, 1983; Donaldson, 1981; Klein & Stearn, 1971; Sameroff & Chandler, 1975).

During the first three months of the baby's life, all parents have both physical and developmental concerns about their infant (Bull & Lawrence, 1985; Censullo, 1986). These concerns are again intensified when the infant arrives prematurely. Information must be given that enables the parents of the preterm infant to care confidently for their baby and to be able to respond appropriately to their infant's behavioural cues.

In addition to information, support is needed in other ways. Emotional, material, and comparison support (House, 1981) are also required in order for parents to overcome anxieties brought on by the occurrence of a preterm birth. It is the perception of all these types of support or lack of support during the initial period after birth that largely determines how parents of preterm infants respond to other situations regarding the child in the years to come. Unresolved anxieties experienced during this period can continue long after the crisis is over.

Two times of crisis faced by parents of premature infants are (a) at the time of birth and the period shortly

after the birth, and (b) just prior to discharge and the initial period at home (Bidder, Crowe, & Gray, 1974). Although there have been a number of research studies and articles written regarding the crisis of prematurity, the effects of preterm birth on mother-infant bonding, and the developmental and neurological outcomes of the premature infant, limited research has addressed the areas of preparing the parents for the discharge of their high-risk premature infant and the support that is perceived by the parents as needed in the weeks and months following the infant's discharge from hospital. Currently, hospitals make an effort to provide opportunity for parents to acquire the basic skills of child care prior to taking their babies home and arrangements are made with public health nurses to visit in the early discharge period. However, the question remains, is this adequate? In order to feel confident in caring for their infant, do parents of premature infants need more information than is currently provided by the hospital and community nursing staff? Secondly, do parents have adequate support services in order to reduce anxiety and enhance family-infant development? What kind of information and support would be most helpful?

Problem Statement

Research has demonstrated that there is a need for

nurses to provide health education programs and support to parents during the postpartum period (Bull, 1981; Curry, 1983; Gruis, 1977; M. Harrison & Hicks, 1983; Hindle 1983; LeMasters, 1957; Robson & Moss, 1970; Sumner & Fritsch, 1983). A limitation to the above is that most of this research deals with the parents of full-term infants. A recent survey by Dempson and Maret (1986) has shown that parents of healthy newborns in the St. John's (Newfoundland, Canada) area feel that the present health education and support programs are inadequate in preparing them for the first 3 to 6 weeks postpartum. The Dempson and Maret (1986) study specifically excluded the parents of the high risk neonate and their information and support needs. If parents of normal, full term infants feel that existing support is inadequate, then existing support may be even less adequate for parents of high risk infants whose needs for information and other support are considerably greater.

Discharge planning and pre-discharge teaching is being done in the neonatal units of the various hospitals. However, in informal conversations with the mothers, the author found that many of the mothers of high-risk premature infants reported feeling stressed and lacking confidence upon their infants' discharge from hospital. Therefore, the investigator felt that an evaluation of the existing programmes was necessary.

There could be several reasons for parents' lack of

confidence in caring for premature infants. Many of these parents find themselves in a situation where, while needing more information, they have less opportunity to learn through the normal ways of caring for and interacting with their infant. As well, these parents are often operating under a state of crisis which is known to interfere with information processing. In many situations, the mothers have not been able to participate in the classes provided in the hospitals for mothers of well-babies. Although mothers and/or fathers usually get a chance to feed, bathe, and change the baby before going home, they still find they are not prepared to take sole responsibility of the care of their child.

Lack of confidence can also be an outcome of the fact that premature infants are quite different from full-term babies. L. Harrison and Twardosz (1986) state, "Infants who are most likely to promote feelings of competence in their parents are those who are readable, predictable, and responsive" (p. 166). A preterm or sick infant, however, does not fall into the above category. The healthy newborn is known to be a powerful elicitor of caregiving responses, but the preterm infant on the other hand may provide minimal or confusing social cues to his/her parents. Primarily concerned with maintaining internal homeostasis, the premature infant has poor self-regulatory capacities and is less available for social interaction (Gorski, Davison, &

Brazelton, 1978). "Preterm infants are often unresponsive, provide few opportunities for eye-to-eye contact, and have exaggerated behavioural responses such as startles, jerky movements, and tremors that are disconcerting to parents who may feel they are frightening or hurting their infant" (Blackburn, 1983, p. 84). Most low birthweight infants are poorly equipped to exert any stabilizing effect on the parent-infant system and consequently parents are less likely to feel satisfied by their early interactions. Parents may feel that the infant's lack of response is a failure on their part, and not as a result of the infant's immaturity. Premature infants, even when they have reached the age of their expected date of birth, show an ability to respond to outside stimulation that is inferior to full-term infants (Als & Brazelton, 1981). However, it is the nurse's role to explain the differences and similarities between full-term and premature infants to the parents, and how the child will change as she or he grows older and the differences diminish.

The need for mothers to develop confidence in their ability to care for their preterm infant prior to discharge is described by Kaplan and Mason (1960) when they outlined the four psychological tasks that mothers of premature infants must accomplish in order to form the basis for a healthy mother-child relationship. These tasks are (a) the preparation for the possible death of the infant, (b) the

acknowledgement of her "maternal failure to deliver a normal full-term baby" (p. 543), (c) "the resumption of the process of relating to the baby" (p. 543), and finally (d) the mother "must come to understand how a premature baby differs from a normal baby in terms of special needs and growth patterns" (p. 544). The importance of mothers being able to master these four tasks is further emphasized by the work of Sameroff (1981) who found that the infant's outcome cannot be predicted solely by effects of prematurity or biological insults; that transactions with the environment are critical determinants of an infant's behavioural progress and that neonatal adversity may be counteracted partially or completely by resourceful parents in a favorable environment (Sameroff & Chandler, 1975). Furthermore, "the impact of the environment appears to become more powerful and the impact of adverse perinatal factors less so as the child matures" (Schraeder, 1986, p. 241).

Sameroff and Abbe (1978) indicate that "until the child appears and acts in accordance with the mother's view of normality, the potential of later caretaking problems exists" (cited in Desmond, Wilson, Alt, & Fisher, p. 23). This is important as it is apparent that premature infants are over-represented among children who suffer from abuse, neglect and failure to thrive (Bidder, Crowe, & Gray, 1974; Elmer & Gregg, 1967; Green & Solnit, 1964; Holman & Kanwar, 1975; Hunter, Kilstrom, Kraybill, & Loda, 1978; Kempe &

Helfer, 1972; Klein & Stern, 1971).

Parents of premature infants often think that since the baby is feeding well, gaining weight, and sleeping and eating on a regular schedule in hospital that this will continue at home. However, the preterm baby in the first few months at home often sleeps irregularly, feeds slowly, and cries more than is expected. It may take some time before the baby adapts to a predictable sleep-awake, day-night pattern which permits the family to develop practical daily schedules (Desmond, Wilson, Alt, & Fisher, 1980, p. 13). No parent is expecting a four to five month old to develop colic. Family, friends and neighbours begin to have some input. Parents find that babies are compared and "speculations concerning the future development of the child emerge intermittently or constantly in the thoughts of the parents and are reinforced by the experiences or anxieties of friends and relatives" (Desmond et al., 1980, p. 13).

The effects of (a) adapting to a period of crisis, (b) an interference with a normal learning process regarding child care and behaviour, and (c) the feeling of a lack of confidence in their ability to care for their preterm infant leaves the family at the time of discharge of their infants "often emotionally stressed, socially isolated and economically vulnerable" (Desmond et al., 1980, p. 6). Frequently the family and child go home to be followed by a physician who is unfamiliar with the child and the care that

he or she requires. Not only is the physician unaware of many of the facets of the infant's medical history, he/she does not know or understand the anxieties the parents have just experienced and "is at great disadvantage in understanding the base from which post-nursery development will proceed" (p. 10).

At the present time, in Newfoundland, a public health referral is made at the time of the infant's discharge, and a home visit is made by the public health nurse. However, the nurse may not have had previous contact with the family, and one visit is too limited to assess and meet the education or support needs of the family. In the situation of a high risk infant, the public health nurse may not be well prepared to handle the kinds of questions and problems that may occur. In addition, the public health nurse may not visit the home soon enough to provide the help required immediately after discharge.

Dempson and Maret (1986) showed the need for hospital and community health nurses to plan, prepare, and implement teaching programs together. Therefore, it is important for both hospital nurses and community health nurses to identify parents' specific information requirements and their need for assistance with child care. When hospital and community health nurses are aware of the parents' needs they can use this awareness to provide improved health promotion and support programs for parents of high risk infants.

Purpose

The present study was initiated to determine the kinds of information the mothers of preterm infants received from hospital nursing staff and teaching programmes, to assess the mothers' perception of the adequacy of this information, to assess the support systems presently available to these mothers, and to determine the need for other support systems.

Objectives of the Research

1. To determine the kinds of information the mothers of high-risk premature infants received from hospital nursing staff and teaching programmes prior to their baby's discharge from hospital.

2. To determine the kinds of information that the mothers of high-risk premature infants felt they needed, but did not receive prior to their baby's discharge from hospital.

3. To determine the type of support received by mothers of high-risk premature infants after their baby's discharge from hospital.

4. To determine if mothers of high-risk premature infants felt the type of support given was adequate.

5. To determine the type of support needed in situations where support provided was perceived to be inadequate.

"The Expert Committee of the World Health organization states that a program of health services will be effective if it is built on the needs of the people served" (World Health Organization. Expert Committee on Nursing. Technical Report Series, no. 167. Geneva. 1959, cited in Brown, 1967, p. 45). This present study was designed to assess the needs of a specific geographically-based population, in order to provide the basis for the development of an improved health education and support programme for parents of high-risk premature infants.

Definitions of Terms

The term "support" is used here to refer to House's (1981) definition of social support (as modified by Cronenwett, 1985b, p. 348) which describes four types of support; emotional, material, informational, and comparison support.

Emotional support. The person communicates love, caring, trust, or concern.

Material support. The person directly helps such as through gifts of money, help with house chores, help with work, and so on.

Informational support. The person provides useful information and helps solve problems by sharing information or finding things.

Comparison support. The person helps the client learn about himself/herself just by being someone in the same situation or with similar experience. The client feels supported because he/she is able to share ideas and feelings with someone like himself/herself.

The term "need" may be viewed as a perceived deficiency or as a gap between what is required or desired but not yet acquired. (Hindle, 1983, p. 20).

Conceptual Framework

In a "normal" pregnancy both maturational and, to some extent, situational crises occur. Frequently stressors such as physiological, role conflict, and infant needs are

present. However, in a high-risk pregnancy, illness adds to the crises of pregnancy and parenthood, and therefore past coping mechanisms, as well as new coping mechanisms are needed to deal with unanticipated stressors.

Bronfenbrenner (1979) suggests that opportunities for child development may depend upon the support given to the parents at the time of the crisis (cited in Crockenburg, 1987). Cochran and Brassard (1979) state that social support influences the parent's attitudes and behaviour and thereby have direct and indirect effects on the development of the child. Other researchers have found that access to social support is associated with a variety of positive health outcomes (Cobb, 1976; Dean & Lin, 1977; Nuckolls, Cassel, & Kaplan, 1972). For the purposes of this study, the assumption is made that the provision of social support leads to an enhancement of parental coping abilities, increased self-esteem, reduced parental anxiety, increased feeling of control and mastery of the situation, and thereby is a factor in providing a positive outcome for high-risk premature infants. The conceptual framework for this project is based on the concept of social support.

Definitions and functions of social support.

Social support is viewed as a "health behaviour that influences states of health and illness" (Tilden, 1985, p.

199) or "anything which strengthens the individual's ability to function capably and to function to his or her satisfaction" (Wiedenbach, 1964, p. 114). Cobb (1976) defines social support as "information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations" (p. 300). Kahn (1979) defines social support as "interpersonal transactions that include the expression of positive affect of one person toward another; the affirmation or endorsement of another person's behaviours, perceptions, or expressed views; and the giving of symbolic or material aid to another" (cited in Kemp & Page, 1986, p. 234). House's (1981) concept of social support is multidimensional including emotional, appraisal, informational and instrumental support.

Social support functions as a moderating variable that assists the individual to cope with the crisis and to adapt to change (Cobb, 1976). Social support, either by acting as a buffer or by mediating the effects of the stressors, helps the individual to adapt (Dean & Lin, 1977; Mitchell & Trickett, 1980). Social support can also be seen to function as a coping resource for parents as seen in the coping model described by Folkman, Schaefer, and Lazarus, 1979; Lazarus, Kanner, and Folkman, 1980. This model outlines five resources described as health/energy/morale; problem-solving skills; social-support networks; utilitarian resources, and general and specific beliefs (cited in Crnic

& Greenberg, 1987). These resources may be utilized by individuals in times of stress.

Theories of social support.

The concept of social support can be analyzed from the viewpoint of many different theories. Kahn and Antonucci (1980) originated their conceptualization of social support from attachment and role theories. Humans are social beings and therefore social support is linked to attachment and the need for human contact such as in the mother-infant relationship. Attachment provides a strong supportive relationship that allows the individual to cope better with environmental stresses.

Kalish and Knudtson (1976) describe attachment as related to feelings of competency and that "self-initiated attachment behaviours produce feedback from the attachment object that provides a sense of mastery, thereby reducing feelings of vulnerability and helplessness" (p. 180).

"Relationships tend to be role related and often role specific" (Tilden, 1985, p. 202) as seen in the husband-wife, parent-child relationships. Role theory describes the changing nature of relationships such as when parenthood occurs. These changes in roles affect the need for social support.

McCallister and Fischer (1978) in their social exchange

theory describe the social support exchange of their sample as "interdependence between two actors where the actions of each directly affects the outcome of the other" (cited in Tilden, 1985, p. 202).

Stress and social support.

There is evidence which shows that social support systems appear to protect the individual from the effects of stress (Cassel, 1974; Cobb, 1976) and are important for individual well-being (Caplan, 1974; Erickson, 1975). Cobb (1976) postulates that social support facilitates coping and adaptation responses thereby moderating the effects of stress and Cassel (1974) suggests that changes in the social environment appear to act as predisposing factors for susceptibility to disease because individuals who are deprived of meaningful social contacts do not receive adequate feedback regarding their actions and consequently are not buffered from the physiological and psychological outcomes of being exposed to stressor situations.

Research by LaRocco, House, and French, 1980; Kaplan, Cassel, and Gore, 1977; Nuckolls, Cassel, and Kaplan, 1972, found "social support to be correlated with favorable health outcomes only in the event of stress and to be unrelated in situations of low stress" (Tilden, 1985, p. 202).

Studies by Bieliauskas and Webb (1974), Casey,

Thoresen, and Smith (1970), Holmes and Holmes (1970), Holmes and Rahe (1967), and Rahe (1974) have shown that significant life changes occurring within a 2 year period place the individuals more at risk for illness than individuals whose life is more stable. Marriage, education, vocation, and community changes as well as changes to parenthood often occur within a two year period of each other. The effect of these changes on pregnancy outcomes is seen in studies by Gorsuch and Key (1974), Nuckolls, Cassel, and Kaplan (1972), and Williams, Williams, Griswold, and Holmes (1975). These studies suggest that a positive relationship exists between life changes and physical obstetrical complications. Furthermore, there is some evidence to indicate that mothers of premature infants may have been subjected to more life stresses in the prenatal period than mothers of healthy, fullterm infants (Gunter, 1963) and that a relationship exists between severe physical and emotional stress during pregnancy and negative outcomes such as low Apgar scores, mental retardation, and congenital deformities (Crandon, 1979; Sontag, 1941; Stott, 1957). In such cases, a mechanism is needed to help these mothers cope effectively so that the pattern of stress-related illnesses and outcomes does not continue to occur thereby affecting both her, her child, and her immediate family. Several studies (Cronenwett, 1984, 1985a, 1985b; Norbeck & Tilden, 1983; Nuckolls, Cassel, & Kaplan, 1972; Richardson & Kagan, 1979)

have found that access to support from a social network has a positive effect on physical and psychological outcomes of pregnancy and on psychological outcomes of the postpartum period (Cronenwett, 1985b, p. 347).

Reciprocity and social support.

It is important to note that social support is most effective when it is mutually reciprocated and "reciprocity occurs more within informal relationships (kin, friend, neighbor) than within formal relationships (with professionals)" (Tilden, 1985, p. 202). This is important because often nurses and social workers feel that by giving empathy, information, financial and other assistance that they have provided all the necessary support, whereas it is the informal support system that counts the most and should be investigated and enhanced when possible.

Social support and social networks.

The concept of informal and formal support systems can be viewed in context with social support networks. "A social support network is a set of interconnected relationships among a group of people that provides enduring patterns of nurturance and provides contingent reinforcement for efforts to cope with life on a day-to-day basis"

(Garborino, 1986, p. 33). These networks involve a process of support, which includes interpersonal exchanges that provide a person with information, emotional reassurance, physical or maternal assistance, and a sense of the self as an object of concern" (p. 31).

It is important to note that social networks can provide sources of conflict as well as support (Crawford, 1985). The help offered may not be wanted by the mother, or if wanted, the help may be delivered in such a manner that the mother perceives herself as "incompetent" and therefore needs the help. The support offered may be viewed as intrusive. The informational support given may conflict with information provided by another source and this lends itself to confusion and further stress.

In assessing the environmental determinants of social networks the researcher must consider the family unit, the immediate setting in which people live, and the larger community itself (Mitchell & Trickett, 1980). Individuals who are well supported by other family members are more likely to have access to other available support, whereas "an isolated individual within an isolated social system would seem to have minimal opportunities for increasing network support" (Mitchell & Trickett, 1980, p. 33). Furthermore, it is important to consider the size, density, and reciprocity of the support network. In general, it appears that factors associated with a low degree of support

and a higher incidence of health related problems are (a) the smaller the size of the support network, (b) the lower the degree of density, and (c) the lack of reciprocity within relationships (Mitchell & Trickett, 1980).

Models of social support.

Cronenwett's (1985b) model of social support depicts relationships among network structure, social support, and psychological responses to parenthood (p. 347). Cronenwett (1985b) describes the basic tenets of her model as being (a) the "properties of the individual (such as gender, educational level, stage of life development, social competence) influence both perceived social support and social network structure", (b) "properties of the social network (such as size, density, frequency, composition) influence both perceived social support and psychological responses to parenthood", (c) "a person's perception of social support (emotional, instrumental, informational, and appraisal) influences both social network properties and psychological responses to parenthood", and (d) "having a child causes changes to occur both in the properties of person's social network and in perceived social support" (p. 347).

Norbeck (1981) describes her model for social support as having properties of the person (age, other demographic

characteristics, needs and abilities) and properties of the situation such as role demands, resources, and stressors. Both the properties of person and situation determine the need for social support, as well as the support available. There can be both stressors and stress-buffering elements present in the situation. An assessment is done that looks at the need for social support versus the support available and determines whether this support is adequate. This assessment provides the basis for planning, intervention, and evaluation of outcomes. The assumptions is again made that "persons with adequate social support or those who have benefitted from successful intervention have a greater likelihood of a positive outcome" (Norbeck, 1981, p. 47) and that those with "inadequate social support without effective intervention have a greater likelihood of a negative outcome" (p. 47).

Social support and the study of mothers of high-risk premature infants.

Since data are available that indicate the mother's perceived satisfaction with her support sources may be "more influential than the amount or availability per se" (Crnic & Greenberg, 1987, p. 36) it is important to determine what the mother's perceived needs are. Another factor that plays an important role in whether support is adequate is the

individual's coping mechanisms which allow him/her to use the available social resources. A family that is used to functioning independently may not know how to seek help or accept the help that is offered. Social support is beneficial if the individuals needing the support can use it effectively. The present study of the support needs of mothers of high-risk premature infants assesses the mothers' perceived need for support versus the actual social support available and whether this support was or was not adequate. This assessment is based on the mothers' need for information, expressed need for other support, and anxiety and confidence measures. The conceptual model for this study is Norbeck's (1981) model of social support although the basic tenets of Cronenwett's (1985b) model are also incorporated. The information obtained from this study will enable the researcher to plan, intervene, and evaluate the outcomes of the intervention.

For the purposes of this study the assumptions are made that the care of a high risk infant can be stressful. During periods of stress, humans seek support in the form of information, material assistance, emotional support, and the sharing of similar ideas and feelings. The provision of support assists individuals in their adaptation to the stressful situation. Since nurses are expected to provide social support this concept has important implications for nurses in their nursing interventions in affecting clients'

adaptation and interaction with environment. Nurses are caregivers and part of their role is to assist clients and families to adapt positively. Therefore, one of the purposes of the proposed research is to assess the perceived need for social support of mothers of high-risk premature infants' in order to gain an insight into ways that, as nurses, we can help other mothers in similar situations.

The construct of social support in research is especially pertinent to nursing and nursing theory because it relates "those foci that guide the discipline of nursing, specifically health, environment and person" (Tilden, 1985, p. 204) with the ultimate goal of improvement of nursing practice.

Chapter II

LITERATURE REVIEW

The purpose of the literature review is to examine and analyze the literature relating to the needs of mothers of premature infants for information and social support. A number of studies have assessed the effects of the transition to parenthood and the concerns, problems, and need for knowledge of parents of healthy newborns (Bull & Lawrence, 1985; Curry, 1983; Dempson & Maret, 1986; LeMasters, 1957; Robson & Moss, 1970; Sheehan, 1981; Sumner & Fritsch, 1983). Parents of preterm infants appear to have similar concerns, problems, and need for knowledge and support, however, their situation is intensified by the effects of the prematurity of their infant and therefore their needs may differ in the type and degree of support. Since the literature indicates an overlapping of concerns between mothers of healthy newborns and mothers of preterm infants, this literature review will examine the informational, emotional, comparison, and material support needs of mothers of both healthy and high-risk premature infants covering topics such as the transition to parenthood, the concerns of both primiparous and multiparous mothers and whether there are differences, the influence of anxiety and confidence on the need for information and

support, and the effect of teaching and other intervention methods on mothers of healthy and premature infants.

Parenthood and Mothers of Healthy Newborns

It has been shown that the ease with which the transition to parenthood occurs is determined by many factors, some of these being: how well the woman is prepared for motherhood (Leifer, 1977; Rossi, 1968); the adequacy of the mother's support system (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Crockenburg, 1981; Cronenwett, 1985a, 1985b; Curry, 1983; Kahn & Antonucci, 1980); the mother's perception of confidence in her own abilities (Rutledge & Pridham, 1987); the mother's self-concept (Cronenwett, 1985a; Curry, 1983; Mercer, Hackley, & Bostrom, 1982); the mother's predelivery expectations about her new baby (Sholder, 1981); and, the mother's maternal role expectation (Burr, 1972).

LeMasters (1957) found that the majority of parents (83%) considered the first experience of parenthood to be a period of severe crisis. The sample consisted of 46 middle-class American couples aged 25 to 35 who were first-time parents. These parents cited loss of sleep, worry over appearance, social isolation, and lack of preparation for parenthood as factors in the difficult adjustment. The results of this study were substantiated by Dyer (1963) who

also found that 12 months after the child was born, 40% of the parents still experienced problems as parents.

When Pleshette, Asch, and Chase (1956) studied the anxieties of primiparas, they found "50% reported they were glad to go home, but when they arrived, wanted to return to the hospital. By 6 weeks postpartum 70% reported having no anxiety and indicated increased security in their abilities as mothers" (cited in Hall, 1983, p. 203). The majority of the mothers felt that the crisis period occurred during the first few days after discharge.

Curry (1983) examined the experiences of 20 healthy, normal primiparas and found that 25% of the group had a difficult adaptation to motherhood. Factors that assisted in the adaptation process were previous experience with infants and children, husbands' support, help during the first week at home, postpartum self-concept, and perception of support from the postpartum nurses. All the "difficult adapters" felt the first week at home had been traumatic, whereas only 33% of the easy adapters thought it had been hard. The difficult adapters were less likely to have had help at home during that time, so, in addition to being poorly prepared to care for their infants, these women had to confront the responsibilities of motherhood without the support of family and friends, a factor known to contribute to difficult parental role transition.

Concerns of First-Time Mothers of Healthy Newborns

Curry (1983) found that the primiparous mothers' perception of support from the postpartum nurses played an important role in their adaptation to parenthood. A knowledge of the concerns of these mothers is important in order for nurses to provide the kinds of support needed by these mothers.

Robson and Moss (1970) assessed the development of 54 primiparous mothers' concerns regarding their infants. They found that during the first 3 to 4 weeks after birth, mothers were concerned about handling their infants and about behaviours such as fussing, crying, food intake, and sleep patterns, and inability to communicate with their infants. "At three weeks, positive feelings and "love" were first felt for the infant-related to increased maternal competence and changes in infant behaviour" (cited in Hall, 1983, p. 203).

Bull (1981) examined the change in concerns of primiparous mothers after one week at home and found the concerns regarding self care and infant care persisted after the week at home and concerns relating to emotional self increased significantly after this period of time. Bull (1981) concluded from these results that the increase of concerns relating to emotional self indicated a need for support and guidance during the first two weeks postpartum

(p. 393). Some of this guidance should centre on ways the mother can conserve her energy, where and how she can get assistance, and by informing her about the physiological and psychological changes that are occurring within her that are affecting her emotional self. More information about infant behaviours is also needed. It is interesting that Bull (1981), for this study, defined concern as "questions, worries or areas of marked preoccupation or interest related to the puerperium" (p. 391). Concerns were classified as they related to self, family, husband, baby, and community. Other researchers have examined mothers' concerns, as well, but have defined concern in different ways and therefore obtained slightly different results.

Using the "anxiety" model of concern postulated by Adams (1963) and L. Brown (1967), Fillmore and Taylor (1976) examined six areas of infant care concern, those being feeding, crying, bathing, elimination, routine care and sleeping. Their sample was comprised of 52 primigravidas. These researchers found that mothers who attended prenatal and/or child care courses had higher mean concern scores than non-attenders. Mothers who breast fed their infants had lower concern scores than mothers who bottle fed. Except for the average score for crying concern, the hypothesis that stated that mothers in the modal first-child age category would have lower average concern scores than mothers below and above the modal age was not supported (p.

16). The amount of reading on infant and child care was negatively correlated with concern scores if mothers were reading books such as Canadian Mother and Child and Up the Years, but positively correlated if mothers read Spock's Baby and Child Care. Negative correlations were found between years of education and child care experience and concern scores. The research showed that the amount of in-hospital demonstration of infant care practices were positively correlated with concern scores. Interestingly, it was found that the amount of assistance at home with the infant and the larger the number of sources of advice on infant care problems were correlated with increased concern scores rather than decreased scores. Fillmore and Taylor (1976) concluded the "anxiety" model of concern was not adequate to give insight into the data and it would be better to consider that there were at least two components in the concept of concern; those being interest and anxiety and that the data should differentiate between the two. Fillmore and Taylor state that Adams (1963) used the "anxiety" model of concern (p. 15). However, careful reading of Adam's paper shows that she did differentiate between anxiety and interest in her definition of concern, although it is not clear how she managed to analyze her data using both of these concepts.

Concerns of Multiparous Mothers of Healthy Newborns

Moss (1981) surveyed 56 multiparas on their third postpartum day in hospital. She found that the main areas of concern to multiparas were issues such as how the children at home would act toward the newborn, and being a good mother. "Multiparas were concerned about their infants, but were interested in behaviour, growth, and development rather than physical care" (Moss, 1981, p. 423). Moss also found the greatest number of concerns were found in women under 20 years of age, having one other child at home, and delivering a male infant (p. 421). For her study, Moss used Fillmore and Taylor's definition of concern.

Hiser's (1987) study dealt with identifying the concerns of 20 multiparas during the second postpartum week. This researcher adapted a card-sort tool used in Moss's study (1981) and coded items according to worry, interest, and no concern categories. Items of concern were, in order of priority: meeting the needs of everyone at home, mother's weight and flabby figure, finding time for self, baby's health and safety, how the children at home act toward their mother, being a good mother, feeling on edge, knowing how babies grow and develop, feeling tired, how the child/children at home act toward the baby, care of the baby's cord, making decisions, and change of figure (p.

199). During the early postpartum period, these mothers were mainly concerned with caring for themselves and their newborns (p. 201). "Multiparas with male newborns sorted significantly more mother-items as concerns and more family items as worries, than participants with female newborns" (p. 201). These results agreed with Moss's (1981) findings and those of Sumner and Fritsch (1977). Mothers who took prenatal classes had more concerns in the areas of family, mother, and infant, than mothers not participating in these classes. When Hiser (1987) separated the data into worry and interest categories, "the results showed that participants with classes had sorted more items as interests, but not as worries. Participants who mentioned taking classes, sorted more items in the category of wanting to learn more, not feeling anxious" (p. 202).

Differences and Similarities Between Primiparous and Multiparous Mothers of Healthy Newborns

Primiparous and multiparous mothers have been found to share similar concerns about common problems with their infants (Greenberg, 1971). However, as noted in the previous discussion, there are, as well, some differences and, in order to understand what information and support is needed by both groups, an insight into the differences and similarities is needed.

In Sumner and Fritsch's (1983) study, primiparous mothers called about three and one-half times more frequently than multiparous women. However, multiparous women asked more questions per call. Gruis (1977) found that, while primiparous and multiparous mothers shared some similar concerns, primiparas were concerned solely with the newborn and his/her specific behaviours and the multiparous women were concerned about fitting the child into the family; with the differences of appearances between children; and with the relationships of siblings to the infant. Gruis also found the majority of her sample of study sought help from their husbands and none of the mothers perceived the nurses as a source of support and information. This latter fact was substantiated by Sheehan (1981) who found that the women in her study complained about the lack of support and inaccurate counseling from nurses during the postpartum hospital stay.

Pridham and Schutz (1981) in examining the issue of preparation of parents for birthing and infant care, found no significant differences in the primiparous and multiparous parents' perception of adequacy of preparation for infant care (p. 188). They found, as well, that their sample gave physicians high ratings of usefulness in the area of prenatal discussions. In fact, their sample indicated that the physicians' discussions were more useful than other forms of preparation (p. 187). Even then,

discussions were perceived to be inadequate "regarding 5 of 11 prenatal and birthing issues for between 40 and 50 percent of respondents concerning the family, and regarding 8 of 14 feeding issues for at least 33 percent of respondents" (p. 187).

In a study by Pridham, Hansen, Bradley, and Heighway (1982) logs were kept by 62 primiparous and multiparous mothers. These logs recorded the mothers' concerns and the methods used to deal with the concerns during their babies' first 91 days. "Of the issues reported, 91.5 percent were issues concerning the baby as such" (p. 1082). Another 6 percent of issues concerned the mother, herself, and the remainder centred on someone else, such as father, friends, grandparents, or siblings. This study indicated the mothers most frequently sought help from the nurses during the first postpartum month particularly about feeding issues (p. 1083). The physicians were consulted for illness issues. Over the next couple of months, the requests for help steadily decreased. Initially, mothers expressed concern about infant illness, although this concern decreased over time. Another issue during the early period was parenting. These researchers found that parity did not seem to affect the number of issues identified (p. 1085).

Norr, Block, Charles, and Meyering (1980) examined the birth experience of 249 women and found primiparas prepared themselves better for the birth experience and, although

multiparas have had previous experience with birth, they are no better informed from more objective sources than are primiparas. "Multiparas frequently get less support from people around them, especially from their husbands" (p. 35). Although this study dealt mainly with parity and the labour aspect of the birth experience, the researchers did look at factors such as rooming-in, breastfeeding, difficulties feeding baby, doing seven or more things with the baby, and husbands participation in the care of the baby. Norr et al. (1980) found that primiparous women were far more likely to want rooming-in, participated in the care of their infants to a greater extent, were more likely to want to breastfeed, reported slightly more problems with infant feeding, and their husbands were much more likely to participate in the care of the new baby. This study has implications for nurses to examine closely the information and support needs of multiparous women and not to assume that since these mothers have experienced birthing previously, they know all about it and do not need as much support.

M. Harrison and Hicks (1983) surveyed 64 primiparas and 94 multiparas four weeks postpartum. Eighty percent of the primiparas and 37% of the multiparas attended prenatal classes. Sixty-eight percent of the total group received a postnatal visit from the public health nurse. M. Harrison and Hicks (1983) found that 70% of the total sample had concerns about "regulating demands of husband, housework and

children, return of the figure to normal, fatigue, emotional tension, diet and finding time for personal interests" (p. 325). Primiparas had "significantly more minor concerns than other mothers but there was no significant difference in the number of major concerns" (p. 325). Similar to Hiser's (1987) study, mothers who had attended prenatal classes had significantly more postpartum concerns (p. 325). Husbands were found to be the most frequent source of help whereas nurses were the least frequently used source of help (p. 325). A source of information regarding diet, exercise, and the return of their figure was that of books and pamphlets. Although these researchers do differentiate between primiparous and multiparous mothers, in reading their report it is difficult to determine to what extent the two groups do differ. M. Harrison and Hicks (1983) used a modification of a questionnaire developed by Gruis (1977). The term "concern" appears to be defined by the items on the questionnaire.

Expressed Needs for Information and Support by Both Primiparous and Multiparous Mothers

Sumner and Fritsch (1983) documented the spontaneous requests by new parents for information and support through telephone calls to the neonatal units from where their babies were discharged. They found that the highest

percentage of questions was about feeding (31%), particularly breastfeeding. Other questions in order of frequency of calls were about colic, constipation, spitting-up, diarrhea, face care, skin rash including diaper rash, cord care, stuffy nose, birthmarks, blocked tear ducts, the fussy infant, length of sleep, and how long the infant should be left to cry when all his/her apparent needs have been met.

Bull and Lawrence (1985) describe the results of their study which focused on both the primiparous and multiparous mothers' need for knowledge during the first postpartum weeks. The majority of mothers requested information about self care (p. 318). Ninety-four percent of the mothers reported that information on bathing, cord care, genital care, shampooing, and spacing infant feedings was useful (p. 317). Information regarding the infant's formula was requested by 75% of the bottle-feeding mothers. Approximately 66% of the sample found information on infant behaviour helpful (p. 318). More information was needed regarding the time involved in feeding, burping, bathing, and dealing with the infant's fussy periods. Three of the multiparas expressed particular interest in the area of preparing the siblings for the new infant (p. 319). The mothers' most frequent requests dealt with the need for more information regarding infant care (p. 319). However, while the mothers in the study expressed a desire for more

information regarding infant care and feeding, "the most frequent request was for information regarding infant behaviour" (p. 319). This need to know more about infant behaviour may increase during the first weeks at home as the mother becomes more involved in her infant's care and as the infant begins to change developmentally.

Dempson and Maret (1986) surveyed the perceived postpartum needs and concerns of 60 primiparous and multiparous mothers of healthy, full-term infants that were discharged from one of the hospitals in this present study. The study assessed the "postpartum patient information and education services available in the hospital and the community" (p. 4) and identified "changes in mothers' concerns and needs 3 to 6 weeks postpartum" (p. 4). Another objective of the study was to evaluate the post-natal home visiting by the public health nurses. This study found mothers with two or more children had fewer concerns than the primiparous mothers; mothers attending prenatal classes had increased numbers of concerns; family and friends were the most frequently used source of help whereas hospital and public health nurses were the least likely source. Taking the baby's temperature, securing the baby safely in the car, coping with infant crying, and dressing the baby for outdoors were the four areas of infant care in which at least 70% of the mothers did not feel confident and these were topics not generally discussed by the nurses. Mothers

did feel confident in bathing, burping, positioning their babies after feeding, and in the care of the infant's cord. These areas were discussed by the nurses in approximately 90% of cases. Formula preparation was not discussed for the majority of the mothers and there was inadequate information about infant rashes.

Effects of Teaching and Other Methods of Intervention on Mothers of Healthy Newborns

Both primiparous and multiparous mothers have indicated a need for information and support, but a problem occurs regarding the best methods to meet these needs. Nurses must not only have a thorough knowledge of the content regarding infant care and development and an awareness of the support resources and how to make them available to the mothers, but also have the skills to facilitate the learning process of the mothers and focus this learning process to the individual needs of each mother.

Hall (1983) examined the effect of teaching on the primiparas' perception of their newborn. The purpose of her research was to see if there was a relationship between structured, informative in-home nursing intervention concerning infant behaviour which occurs two to four days post discharge and the primiparas' perception of their newborn as measured by the Neonatal Perception Inventories I

and II. The sample size was small (n = 30) and there may have been a Hawthorne effect, however, this study "implies that teaching about normal infant behaviour during the "taking-hold" phase of the puerperium for these women had a positive influence on perceptions of their newborns" (p. 207).

Golas and Parks (1986) examined the effectiveness of teaching primiparous mothers about infant behaviour. The mothers in the experimental group (n = 17) viewed a film depicting the behaviour of a normal newborn and participated in a demonstration of selected items from the Brazelton Neonatal Behavioral Assessment Scale when their infants were approximately 2 weeks old. The contrast mothers (n = 16), two weeks postnatally, completed a Newborn Information Checklist. The control mothers (n = 13) received neither the teaching programme nor the checklist. The researchers determined that at four weeks postnatally the experimental mothers had more knowledge about infant behaviour and appropriate responses than either the contrast or control mothers. The results indicated no difference among the groups regarding the mothers' confidence in interpreting their infants' behavioural cues (p. 209). The contrast mothers requested information about topics included in the teaching intervention (p. 209). It was found that "parenting knowledge was enhanced by teaching the content instead of administering the scale" (p. 213).

L. Brown (1967) hypothesized that primiparous mothers who had visits from the public health nurses during and at the end of their first four weeks of home would have fewer, and less intense concerns (worries) about infant care than mothers who did not have these visits (p. 45). She found that this was true for concerns regarding feeding, but not supported in other areas such as crying, sleeping, bathing, elimination, and routine care, (p. 48). Other studies evaluating the effectiveness of public health visits have had similar findings (Barkauskas, 1983).

Stanwick, Moffat, Robitaille, Edmond, and Dok (1982) describe the results of an evaluation of routine postnatal public health nurse home visits to both primiparas and multiparas during the three weeks after delivery. It was found that these visits appear to help the primiparous mother, but that the multiparous mother, having already had previous experience which now results in her having the confidence, skill, and knowledge, did not appear to benefit from the visit (p. 204). It is interesting to note that mothers without problems "were more likely to have received a nurse visit" (p. 204). The visits occurred within twenty-one days of birth and not necessarily during the first week post-discharge, a period when mothers are known to experience difficulty.

Perception of Competence for Infant Care

A mother's perception of competence for infant care appears to be an important factor in the adjustment to parenthood (Rutledge & Pridham, 1987) and the infant's long-term development (Kaplan & Mason, 1960; Sameroff, 1981). Broussard (1979) by using the Neonatal Perception Inventory (NPI) as a screening measure to identify infants at high risk for psychosocial disorder found that:

> mothers of infants at high risk were noted to (1) have poor self-esteem, lack of confidence in themselves as mothers, and be dependent on the external world yet often not able to use help when offered; (2) view their environmental support systems as less helpful than the mothers of low-risk infants (they make many references to the health professionals as being of no help or not to be trusted, and husbands and mothers are often considered to be "not much help"); (3) report having more trouble in caring for their infants in regard to sleeping, feeding, colic, crying, and elimination; and (4) often seemed depressed and anxious (p. 98).

In Broussard's (1979) study, the mothers who did not have a positive perception of their infants had difficulties in being able to respond to the infants needs.

Walker and Erdman (1984) examined the relationship

between confidence and knowledge in regards to preparation for coping with labour. They found that the primiparous mothers perceived that they had a lower level of knowledge before classes than did the multiparous mothers. However, after the childbirth classes this difference disappeared. After the classes, anxiety about labour was significantly reduced in primiparous mothers, but not in the multiparas. This decreasing anxiety in primiparas was associated with increasing confidence. It is not unreasonable to assume that similar findings can be found in data regarding in-hospital preparation of parents for discharge of their high-risk premature infants.

Rutledge and Pridham (1987) describe their findings in regards to postpartum mothers' perception of competence for infant care. They found that mothers with in-hospital preparation had significantly higher perceptions of competence for infant feeding and care. Breastfeeding mothers had the highest total perceived competence score (TPCS). Analysis of the results partially supported the hypothesis that mothers who had adequate rest in hospital would have greater perceived competence. A finding that was consistent with Curry's (1983) results was that parity had a significant effect on the total perceived competence score, in that multiparas perceived themselves more competent in areas of infant feeding and care (p. 191). The results showed a lack of relationship between infant's risk status

and the total perceived competence score and this can be explained by the low number of at-risk infants in the hospital during the period of the study; the fact that few of these infants spent time in the special-care nursery or remained in hospital after the mother's discharge from hospital; and that perhaps "mothers who had relatively little experiences with their infants before discharge may have overestimated competence for infant care" (p. 192).

Parenthood and the Mothers of Premature Infants

The birth of an ill infant constitutes a crisis for the family. The parents are faced with a maturational crisis in becoming parents, but also a situational crisis in becoming parents of a "less than perfect" child. Caplan (1957) describes the crisis period evoked by this situation as lasting from one to six weeks "during which time a solution is sought to restore the sense of equilibrium" (cited in Elsas, 1981, p. 204). One way of resolving the crisis is for the parents to be able "to develop patterns of seeking and using help from interpersonal and institutional resources" (Elsas, 1981, p. 204). Unless nurses recognize the need to assist these families to use resources, many parents will continue to lack the resources and support which could help them through the immediate crisis and early stages of parenting.

Discharge of the high risk infant precipitates another period of crisis for the parents, as they realize that they must now care for their infant alone. During this period of transition, parents report "feelings of fear, loss, inadequacy, and anger" (Censullo, 1986, p. 146). As we have seen, many parents face this experience with little preparation, experience, or perception of support. Looking after any infant is demanding, but caring for a child that has been premature or ill is time consuming, exhausting, and stressful. Practical problems occur in the home that did not arise during hospitalization. This finding was substantiated by Goldberg and DiVitto (1979) who found that premature infants become more fussy and less predictable during the transition from hospital to home.

Lissenden (1984) conducted a descriptive survey of a non-random sample of 33 parents of low birthweight infants. The author found, "in spite of preparation, for most parents, the actual day of the baby's homecoming was a shock" (p. 135). Twenty of the mothers sought advice during the first week at home. "The majority found their baby hard to settle after feeds. It appeared they cried more at night and suffered more 'colic' than other babies" (p. 136). Ten parents described difficulties they had with relatives and acquaintances commenting about the infant's size and age (p. 136). Parents did not clearly understand what was meant by corrected and chronological age and how development related

to these two measures. These parents also stated they did not understand about what was entailed in providing infant stimulation. "Several requests were made for books about prematurity and with particular attention to feeding the premature baby including the storage, freezing and expressing of breast milk; skin contact and/or massage for premature babies; stimulation; jaundice and anaemia" (p. 142).

L. Harrison and Twardosz (1986) state in their study that many parents of high risk infants lack knowledge of their infant's capabilities and of parenting skills they could use to enhance their child's development. As well, they lack knowledge of basic infant care skills. Terres and Levitt (1982) report that parents of high risk infants express a strong desire to "learn more about well-infant care and about normal expectation for growth and development of their infant" (cited in Censullo, 1986, p. 152). The parents in their study also expressed a need for reassurance and understanding that could not be met by friends or other family members.

As stated previously, two reasons for the mothers of preterm infants' lack of knowledge and confidence regarding infant care could be the early separation of the mother and infant, and bonding difficulties arising out of the crisis situation. Studies (Leifer, Liederman, Barnett, & Williams, 1972; Liederman & Seashore, 1975; Seashore, Leifer, Barnett,

& Liederman, 1973) have compared maternal behaviour of mothers who were separated from their infants and mothers who were not separated. The results indicated that non-separated mothers report more satisfaction with the maternal role and more confidence in their ability to care for their infants than did the separated mothers. Similarly, Jeffcoate, Humphrey, and Lloyd (1979) examined the possible early bonding difficulties experienced by parents of preterm infants and compared these results with those results from parents of full-term infants. Both groups were carefully matched according to a variety of variables including previous experience of caring for small babies, and the amount of available social support from relatives, friends, neighbours, and professional social and health personnel. These researchers found mothers of preterm infants had "difficulty in feeling that the baby was really theirs while still in hospital's care, and sometimes this feeling persisted after the baby's discharge" (p. 347). When parents' scores on the Neonatal Perception Inventory were compared it was shown that the preterm mothers perceived their babies "as having been more difficult than expected" (p. 347). Many of the parents of the premature infants expressed feeling extreme anxiety and fear following the birth of their child. Almost 60% reported, "they feared at some stage that their baby would die" (p. 347). In measuring the parents' level of anxiety at the time of the

interview, the parents, whose infants were then aged 12 to 15 months, were asked about their willingness to leave their child with a baby-sitter. The control group expressed 'some anxiety', however, the preterm-group parents were still 'very anxious' (p. 348). The fact the study found parents of preterm infants having persistent anxiety about leaving their infant with a babysitter "appears to bear out the hypothesis of Green and Solnit (1964) of a 'vulnerable child syndrome', in that parents react by over-protecting a child for whose life they once feared" (p. 349). Other findings indicated that, while 69 percent of the control-group parents were satisfied with their care following delivery, 72 percent of preterm-group parents stated that they would have liked more help, such as information, instruction, and help in caring for the baby in hospital or at home, and reassurance. Jeffcoate et al. (1979) state that, whereas parents of healthy newborns expressed confidence about infant care at the time of their hospital discharge, only 50% of the parents of premature infants expressed confidence at discharge. The findings of anxiety, lack of confidence, need for help and information, as well as evidence of early bonding difficulties and disorders in mothering, indicate a definite need for sensitive handling of parents at the times of birth and discharge of their infants. Support, such as encouraging parents to talk about their anxieties, problems, and need for information, and reassurance that early

difficulties with premature infants are not uncommon, but usually temporary, may all help in assisting parents of preterm infants to adapt positively to parenthood. To further emphasize some of the findings of Jeffcoate et al. (1979), Bidder and Crowe (1974) note that mothers of preterm infants persist in viewing them as weak, even at 3 years of age and that this perception is related to maternal anxiety during the perinatal period rather than the current status of the child (cited in McCormick, Shapiro, & Starfield, 1982, p. 542). Mothers of premature infants often report fears about the appearance of the infant, the absence of maternal affection, and concern about future development (Goodman & Sauve, 1985; Lewis & Rosenblum, 1974). There is some evidence that these concerns persist and that many parents continue to regard their preterm infants as needing extra care and attention (Mussen, 1969).

McCormick, Shapiro, and Starfield (1982) examined factors associated with maternal opinion of infant development and found that mothers under 18 or over 34 were more likely to consider their infant slow in development; mothers with no prior live births were more likely to consider their children normal than those with one or more prior pregnancies; low birth weight infants were more likely to be considered slow; infants hospitalized during the first year of life, enrolled in special programmes or clinics were also of increased risk of being considered slow (p. 539);

infants with particularly mild or moderate congenital anomalies were more often thought to be slow, and males were more likely to be considered slow (p. 541).

It must be kept in mind though, that there are problems with using premature or ill infants in these studies and being able to generalize the findings. For example, it is difficult to get a group of prematures who are equivalent. Some are more premature or more ill than others. Birth and delivery conditions differ. The infants have a variety of complications that require varying periods of isolation, and their developmental status and their age at discharge from hospital can be quite different.

To emphasize this point further, Minde, Whitelaw, Brown, Trehub, and Fitzhardinge (1981) found that the degree of illness also has an effect on the parent-child interactions. These researchers reported that parents of initially ill low birthweight infants interacted with their babies less than parents of healthy prematures even after the infants were behaving like healthy prematures. This relative lack of interaction continues at least during the first three months at home. Other researchers (Adams, 1963; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Rutledge & Pridham, 1987) have reported on the outcomes of their studies using mothers of healthy preterm infants and have found only transitory differences between these mothers and mothers of full-term healthy infants. Therefore, it is

important to look closely at the variables considered within the sample before coming to any conclusions.

Concerns of Mothers with High-Risk Premature Infants

Since the literature regarding the concerns of primiparous and multiparous mothers of preterm infants is limited and few studies have dealt with comparisons of the two groups, the concerns of both primiparas and multiparas of premature infants will be covered under this section.

Adams (1963) surveyed primiparous mothers of both full-term and premature infants and found that feeding was the major area of concern during the first month at home for both groups. Concern was defined as "areas of special interest or worry to mothers as indicated by questions pertaining to a particular areas of care" (p. 72). All of the mothers wanted to know more about the amount and frequency of feeding. Crying was the next most frequent concern for both groups, followed by the category of "other" which included problems such as elimination, hiccups, when to first take the infant out of doors, rashes, weight and sleeping (p. 74). More questions about infant care activities were asked after mothers had looked after their infants for one week, and fewest questions were asked after one month of care. "The amount of experience the mother had had in caring for small children seemed highly related to

the amount of concern expressed" (p. 76). If mothers cared for their baby in hospital they had more questions about feeding, bathing, and crying at two days, and fewer questions about bathing, care of the navel and/or circumcision at the end of the first week. Attending hospital classes decreased the concerns of both groups in areas of bathing, crying, and care of the navel and circumcision, but did not seem to lessen the concerns with regard to feeding and "other" concerns (p. 76).

In the above study, there was very little difference found between the concerns of mothers of premature and fullterm infants. However, the mothers of the preterm infants had a higher level of formal education, and seemed to be better informed about infant care (p. 74). These mothers also had more help at home from professionals as well as family and friends. It was found that "mothers of prematures asked slightly more questions at two days, but thereafter mothers of infants of normal weights expressed more concerns" (p. 74). Mothers of preterm infants had slightly more questions regarding infant crying prior to the infant's discharge from hospital. However, both at one week and one month post-discharge these mothers had fewer questions about crying than mothers of full-term, healthy infants. Similarly, mothers of preterm infants had more concerns about their infants' hiccupping at one week of age. Again, mothers of the full-term group expressed more

concerns regarding this area when their infants were one month of age. Over 32 percent of mothers of premature infants described their husbands as most helpful in the care of their infant at one week post-discharge, whereas only 5 percent of mothers of full-term babies found their husbands helpful. At the end of the first month, both groups found their husbands as equally helpful (p. 76). The physician was the main source of advice and information for over half the sample. Relatives and friends came next (25%), followed by nurses (10%).

Goodman and Sauve (1985) describe the results of a study to determine the concerns of mothers of high-risk infants and whether these concerns differ from those of mothers of normal newborns. Concern was defined "as a feeling of anxiety or apprehension, a worry, or something seen as a problem" (p. 236). The particular concerns that were examined were based on concerns identified in the literature and from the mothers' comments in the hospital. Thirty mothers of the high-risk group (infants either preterm, small for gestational age, or full-term with medical problems that required hospitalization for a minimum of 14 days in a tertiary neonatal intensive care unit) and another group of thirty mothers of normal newborns were interviewed in their homes at two weeks and then again at six weeks post infant discharge. A semi-structured questionnaire format was used combined with Broussard's

(1979) Neonatal Perception Inventory. These mothers "were asked to rate their concerns in several areas and to specify concerns they may have had which were not identified in the questionnaire" (p. 235). The mothers of the high-risk infants expressed concerns regarding "feeding, gastrointestinal problems, sleeping, crying, attachment, rashes, appearance, and concerns about the mother herself, her husband, and other children" (p. 235). Mothers of normal newborns expressed similar concerns but had fewer and lower degree of concerns than those expressed by the high risk group. Mothers of the high-risk infants were particularly concerned about the amount of feeding, the baby's weight gain, and the quality and quantity of their breast milk and had more concerns than the control mothers about their infant's sleep pattern, specifically the time at which the baby sleeps, the duration of this sleep, and whether the "baby would stop breathing during sleep" (p. 237). No mother in the healthy, full-term group expressed concern regarding the infant's appearance and mothers of normal newborns tended to have a more positive perception of their infant. Interestingly, sixty-six percent of the mothers of normal newborn infants stated that they felt their babies knew their mother on the first day after birth and none of the mothers of high-risk infants indicated similar feelings (p. 238). Even at 28 days after hospital discharge, forty percent of mothers of high-risk infants

felt their babies did not know them compared with 17 percent of the controls. One of the mothers of the high-risk group felt it took more than three months after the baby's birth for recognition to occur. "It was perhaps of significance that only 40 percent of the high risk mothers felt that the baby was theirs when they came home with them compared to 93 per cent of the control group" (p. 239).

Minde, Perrotta, and Marton (1985) examined maternal caretaking and play with full-term and premature infants. Their findings indicated that feeding was a problem for both groups of mothers during the first and second month. However, by the third month, feeding was no longer regarded a problem by the majority of full-term mothers, whereas the mothers of premature infants reported continuing difficulties. These feeding difficulties included other behaviours such as vomiting 30 minutes after the feed, the frequency and amount of food taken in per feed, the number of burpings, and the weak or irregular sucking patterns and the longer time taken for feeding to occur. These mothers of premature infants stated that their babies consumed less per feed than did the full-term infants (p. 238). Initially, the premature infants appeared to show less focused behaviour. However, after 3 months at home there were few observable behavioural differences between the two groups. Both groups showed similar patterns of waking, sleeping, and crying after discharge from hospital. Even

though both groups of mothers "reported concerns about their baby's development, nearly all seemed to be enjoying their babies" (p. 239). There were differences in concerns between the two groups. The mothers of the premature infants worried about cerebral palsy or mental retardation, "while full-term mothers were concerned about overweight, bad temper, and whether they spoiled their babies" (p. 239).

Effects of Teaching and Other Methods of Intervention on Mothers of Preterm Infants

"Concerns exist regarding the impact of the early neonatal intensive care unit environment on preterm and other high-risk infants and the lack of stimulus geared to the infant's individual needs and status" (Blackburn, 1983, p. 76). Besides this, many hospitals are now sending premature infants home earlier and the mother finds herself responsible for the infant's total care while he is still sucking weakly and breathing irregularly (Johnson & Grubb, 1975, p. 20). Therefore, it is very important that the nurse intervenes and teaches the parents about the premature infant reflexes as these responses also influence the mother's feelings and actions (Johnson & Grubb, 1975, p. 15). This knowledge will enable the mother to deal with concerns such as feeding and sleeping in a more constructive manner. It will also help her to provide the infant with

positive stimulation, aid in his/her development, and assist in the interaction process between mother and child.

Rauh, Nurcombe, Ruoff, Jetti, and Howell (1982) examined the effect of an intervention programme on the adjustment of mothers with low birthweight infants. The sample consisted of 86 infants weighing less than 2200 grams, with gestational age under 37 weeks, and hospitalized for at least 10 days in the intensive care nursery of the Vermont Medical Centre Hospital between April, 1980 and December, 1981. Excluded were multiple births, infants with severe congenital anomalies, and those born to single mothers. The subjects were randomly assigned to experimental (36 subjects) and control (40 subjects) groups. An additional comparison group of 40 full-term, normal birthweight infants was randomly selected from the regular nursery. An intervention programme was offered by the nurses to the experimental group. This programme consisted of seven one-hour sessions during the week before discharge. The home phase consisted of four sessions over a three month period after discharge. This intervention centred on the mother-father enjoyment of the infant; their recognition and response to the infant's cues; and the initiation of appropriate caretaking and socialization on the part of the mother. Both comparison and control groups received routine nursery services. The results showed enhanced adaptation to the mothering role in the experimental group and it was felt

that potential difficulties in adjustment to premature delivery may be ameliorated by intervention. It was interesting that one of the findings was that the intervention programme was associated with greater maternal adaptation to mothering among less educated mothers of premature infants, but was not related to adaptation among more highly educated mothers.

Studies by L. Harrison and Twardosz (1986) and J. Brown, LaRossa, Aylward, Davis, Rutherford, and Bakeman (1980) concluded that short-term hospital interventions do not result in long-term beneficial effects. J. Brown et al. (1980), describe a programme in which a nurse taught mothers in hospital how to stimulate their premature infants and respond appropriately to their infants' behavioural cues. The researchers failed to demonstrate any long term effects on either infant development or mother-infant interaction during the follow-up assessment at 3 and 9 months after the intervention. L. Harrison and Twardosz (1986) hypothesized that mothers of preterm infants who received instruction about the physical and behavioural characteristics of the preterm infant would demonstrate more positive perceptions of their infants and show more positive maternal behaviours than would mothers who did not receive instruction (p. 167). However, they concluded that "short-term teaching programs about characteristics of preterm infants did not significantly affect the perceptions or behaviors of mothers

of premature infants" (p. 170).

On the other hand, Field, Widmayer, Stringer, and Ignatoff (1980) reported on a study that evaluated the effects of a home-based intervention programme for teenage, lower-class black mothers and their preterm infants. Follow-up assessments revealed that infants in the intervention group received higher scores on developmental tests, and the intervention mothers demonstrated more positive interactions with their infants (p. 434).

Another long term effect was found by Bromwich and Parmalee (1979) who evaluated a home-based education programme for high-risk preterm infants and families. At the end of the intervention mothers scored higher on a measure of maternal attentiveness and reciprocity (cited in L. Harrison and Twardosz, 1986, p. 167).

Noga (1982) describes the results of a one year follow-up of the beneficial effects of visits by public health nurses on high risk infants and families. Parents were very positive about having the public health nurse visits and repeatedly expressed the need to have their babies checked between the time of discharge and the baby's first pediatric check-up at approximately 6 weeks post-discharge. Parents also said that "many of the nurses were able to help with general advice for new mothers, advice that many of these parents lacked because of the infant's illness" (Noga, 1982, p. 113). The parents were pleased

when told the nurse would return at regular intervals and be available by phone.

Barrera, Rosenbaum, and Cunningham (1986) describe the outcome of a one year home intervention programme with a sample of premature infants randomly assigned to a developmental intervention group, a parent-infant intervention group, and a no-treatment control group. A no-treatment control group of full-term infants was also used. "The results suggest that although both intervention approaches were effective in modifying some aspects of the home environment and, to a lesser degree, in improving infants' cognitive development, the parent-infant interaction approach seemed to have the greater impact" (p. 20). This study pointed out that the special needs of both the infants and the parents must be considered. The study also noted that "as parents become more sensitive to their infants' cues they also appear to become more receptive to changing their behavioural styles and modifying the home environment to suit the child's developing needs" (p. 31).

Social Support and Pregnancy

The theme of social support has been evident throughout the literature reviewed. Curry (1983) and Gruis (1977) cited husband support as necessary for positive adaptation to motherhood. Bull (1981) mentioned the need for support

and guidance during the first 2 weeks postpartum. Sheehan (1981) described how the mothers in her sample felt a lack of support and inaccurate counseling from the nurses. Norr, Block, Charles, and Meyering (1980) pointed out the lack of support experienced by the multiparas in their study. Research by Jeffcoate et al. (1979) indicated that the preterm group of their sample would have liked more help, such as information and material support. Adams (1963) mentioned the physician as the main source of information for both her full-term and preterm mothers. Family and friends were the next most commonly used resource, followed by nurses.

Norbeck, Lindsey, and Carrieri (1981) describe the concept of social support as a major psychosocial variable in health-related research. For example, Nuckolls, Cassel, and Kaplan (1972) found the rate of complications during pregnancy to be three times greater among women with high stress and low psychosocial assets (including social support) than among women with equally high stress but with high psychosocial assets during early pregnancy (cited in Norbeck, Lindsey, & Carrieri, 1981). Norbeck and Tilden (1983) found significant relationships exist between certain psychosocial variables and specific types of pregnancy complications and indicated a need to identify early in pregnancy, women with high life stress and low psychosocial support (p. 43). Crandon (1979) showed a relationship

exists between highly anxious mothers and low Apgar scores of their infants, and Sosa, Kennell, Klaus, Robertson, and Urrutia's (1980) study suggests that having a support person available during labour and delivery may provide major perinatal benefits such as a decrease in complications and need for caesarian sections. Gunter's (1963) study suggests that stresses during the prenatal period are related to outcomes such as prematurity. The sample for this study (n = 20) was small and the results cannot be generalized.

It is important to note researchers do not agree on whether social support has a unidimensional or multidimensional construct. M. Brown (1986) tested a multidimensional formulation of social support during pregnancy and concluded that multidimensionality of social support was not confirmed (p. 8). There may be a variety of support activities but the expectant parents "may experience relationships that inextricably link these activities" (p. 8).

Effects of Support in the Postpartum Period

Cronenwett (1985a) showed that access to social support has a positive effect on psychological outcomes of the postpartum period. In this study, Cronenwett (1985a) found that a network consisting of an increased number of relatives and an overlap with the spouse's network were

important factors associated with positive postpartum outcomes for men, but not for women (p. 93). "Emotional and instrumental support were important variables in explaining six-week postpartum outcomes, whereas information and appraisal support were not significant variables at this time" (p. 93). In a study that examined the parental network structure and the perceived support of both first-time mothers and fathers, Cronenwett (1985b) found that "between 67% and 91% of the women in this sample perceived themselves as having an increased need for the four types of support 5 months after childbirth" (p. 349). Fewer of the men indicated such a need. At five months postpartum, between 63% and 85% of both groups felt satisfied with their available support.

Social support can be viewed as having both positive and negative effects. Crawford (1985) describes how conflict can occur within support networks especially for first-time mothers and that it is important for nurses to recognize this so that measures can be taken to reduce or avoid conflict.

A study by Crockenburg (1987) examined the sources of help for adolescent mothers and found that the baby's father and the mother's mother were again the most frequent source of social support. Friends, other relatives, and professionals also had some input. Teenage mothers with good social support displayed more affectionate behaviour

and were more available towards their infants. Mothers who get more social support do better as caretakers than do mothers with less support. The effect of social support was particularly significant with mothers with irritable infants. In this study, mothers with high stress did not seem to be affected by social support as much as mothers with low stress. There was no significant relationship between parity and marital status and any maternal behaviour. Mothers reported professional support was provided in the form of listening, encouragement, and giving advice. "There was no evidence that high professional support was associated with more appropriate mothering within either high- or low-risk groups" (p. 16). In fact, mothers expressed more dissatisfaction with the support given by professionals rather than any other group. Some of these mothers asked for information they didn't get, but instead received negative responses from the professionals. Doctors were reported as hard to talk to. Professional advice conflicted between professional groups and between family members.

Mercer, Hackley, and Bostrom (1983) describe their findings that the husband/boyfriend emotional support "is more predictive of positive perception of the birth than other types of support" (p. 207). In another study by Mercer, Hackley, and Bostrom (1984b) it was concluded that adolescent mothers at one month postpartum expressed

stronger feelings of love toward their babies and a greater sense of competency in their maternal role if they receive high instrumental and emotional support. Similarly, Wandersman and Unger (1983) found adolescent mothers that received social support from the baby's father displayed more adequate caretaking at one month postpartum, and Unger and Powell (1980) noted that highly stressed mothers of young infants were more actively involved with their infants, if these mothers were well supported.

Wandersman, Wandersman, and Kahn (1980) "found that attending postpartum parent-support groups did not have a significant positive impact on the parents' postpartum adjustment, although emotional support from the spouse did facilitate positive postpartum adjustment" (cited in Crnic & Greenberg, 1987, p. 26).

Prematurity and Social Support

Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) studied the effects of stress and social support on mothers of premature and full-term infants. These researchers hypothesized that mothers of preterm infants would report greater stress than mothers of full-term healthy infants and that adequate emotional support would moderate the effect of the stress (p. 210). They discovered that no group differences were found and that both groups of mothers

"perceived social support and life stress significantly predicted their general life satisfaction" (p. 212). Other factors such as intimate and friendship support "significantly predicted mothers' attitude toward parenting and community support showed a strong trend as in predicting same" (p. 213). In this study, less stressed mothers with greater social support "reported more pleasure in their infants and their parenting roles" (p. 213). "Mothers reporting greater stress were rated as less sensitive" (p. 213). "The greater the stresses reported by the mother the less optimal was the infant's behaviour" (p. 214). This suggests a circular feedback loop may exist between mother and infant.

Feiring (1985) studied the relationship between social support (material goods, services, money, advice from friends and family) and mother-infant interactions of either healthy or sick, term and preterm infants. He found that mothers of sick infants reported receiving the least services such as baby-sitting, household care. "Mothers of sick premature infants reported fewer friends, and fewer total number of people giving material help than mothers in the other groups" (cited in Boukydis, Lester, & Hoffman, 1987, p. 63). Feiring (1985) found "relationships between the provision of goods and services and mother-infant interactive behaviour at three months" and concluded "the giving of goods and services indirectly affects parent-

infant relationship by giving parents more time with their baby" (cited in Boukydis, Lester, & Hoffman, 1987, p. 63).

Herzog (1979) found that the most negatively affected mothers having preterm births felt that they lacked both social support and the emotional resources needed to care for their infants.

Both Minde, Trehub, Corter, Boukydis, Celfoffer, and Marton (1978), and Boukydis's (1982) research indicated "that early infant attentional behaviour, high levels of parent-infant interaction, and positive social support in the parents' immediate network of family and friends was correlated with amount of visiting to the neonatal intensive care unit" (cited in Boukydis, Lester, & Hoffman, 1987, p. 61).

Boukydis, Lester, and Hoffman (1987) reported results of a study comparing 13 families of healthy, preterm infants and 14 families of term babies, in areas related to social support, infant temperament, and transition to parenthood (p. 66). They found that the parents of preterm infants sought more help from health professionals than parents of fullterm babies. However, most of this help centred on aspects of the infants' state organization and behavioural responsiveness rather than on the infants' risk status. Parents of term babies who sought help from health professionals had "less overall adjustment difficulties" (p. 77). Parents of preterms who had contact with other parents

of preterms needed less help from the professionals. The size of the social support network was similar for both groups during the first month post-discharge. Boukydis et al. (1987) found that fathers of preterms were more likely to do household chores during weekdays in comparison to fathers of term babies who did both household and child-care responsibilities. Parents of preterms found (in order of rank) pediatricians, pediatric nurse, spouse, parents of prematures, and mother's mother were the people and services found to be the most helpful, whereas parents of full-terms listed friends with children, pediatrician, own mother, parenting class, pediatric nurse, relative and spouse. Parents of prematures got information about child care from intensive care unit staff, other parents of prematures, pediatrician, previous experience, books, own mother, and nurse, whereas parents of full-terms got it from books, friends with children, parenting class, own mother, previous experience, relatives, and nurse. When asked to list what kinds of people/services would have been helpful, parents of prematures listed other parents of prematures, hired help, health professionals, and own mother. Parents of full-terms listed hired help, other parents, health professionals, and parenting class (p. 69).

Trause and Kramer (1984) studied the effects of premature birth on first-time, well-supported parents and found that during the first week after the infant's birth,

mothers of preterm infants cried more, felt more helpless, experienced guilt feelings about their baby's condition, worried more about future pregnancies and about their coping abilities, and felt a greater need to talk to hospital staff than did the parents of healthy, full-term infants. However, one month after the infants had been discharged from hospital found the situation reversed in that the term mothers reported more distress (p. 460). The results of this study suggest that, for parents who are well-supported during the crisis period of prematurity, there is no long term effect.

Crnic and Greenberg (1987) measured social support, stress, satisfaction with parenting and general life satisfaction on 52 mother-preterm and 53 mother-full-term infant pairs during the first year postpartum. The study looked at social support in intimate relationships, friendships, and neighbourhood and community support. Again it was found that there was no difference on support and life stress between the preterm and full-term groups. The authors suggest this result was probably because the preterms were healthy and matched on variables other than health status and that infant health was no longer viewed as in jeopardy by the mothers. As well, the data was collected about one month post-discharge and the effects of the neonatal crisis may no longer be felt by the mothers of the preterm infants. Crnic and Greenberg (1987) concluded,

"mothers with high support are more satisfied with their babies, their parental roles, and their lives in general and are more positive in their behavioural interactions with their infants. Conversely, mothers who report high stress are less satisfied and less positive in their behavioural interactions than are mothers with low stress" (p. 31). The authors felt that the effects of social support on maternal functioning were greatest during the transition period from hospital to home until four months of age (p. 32) and that it may be that social support networks "are most influential at particular times in both the parents and children's development" (p. 35). Crnic and Greenberg (1987) stated that they felt that maternal social support is a multidimensional concept in that different levels of types of support affect maternal parenting differentially. Intimate support was more important than friendship and community support. Their results indicated that measures of social support must consider both the amount and availability of support and the individual's satisfaction with the support available. Other results showed that few relationships were found in which social support moderated the adverse effects of high life stress, even during the early postpartum period. Crnic and Greenberg (1987) concluded that there is a need to measure the mothers' perceived satisfaction with their support sources.

Long Term Effects of Social Support

As stated earlier, Cochran and Brassard (1979) found that social support has direct and indirect effects upon child development. Other researchers have given us some indication why this is so. Ventura (1986) in examining parent coping in relation to infant temperament and parent psychological responses found that her sample of mothers of healthy, full-term infants "who viewed their infant as of optimal temperament sought social support, maintained family integrity, and reported being religious, thankful, and content" (p. 77). Crockenburg (1981) examined the influence of infant irritability, mother responsiveness, and social support on the development of a secure mother-infant attachment. She found that social support was the best predictor of secure attachment and that this is more important for mothers with irritable babies (p. 857). Again, this study involved mothers with healthy, full-term infants. Feiring and Taylor (1982) examined the social support of low-income, black, inner-city mothers and found that mothers that were involved with and responsive to their children had a high amount of positive support from either the mother's mother or the baby's father. Finally, Pascoe and Earp (1984) in looking at the effect of mothers' social support and life changes on the stimulation of children who had required neonatal intensive care, found that "mothers

with high and low levels of life changes provided the same amount of stimulation to their infants, but mothers who perceived more social support provided more stimulation to their children, an effect that was unrelated to the amount of life changes they experienced" (p. 359).

Conversely, Hunter, Kilstrom, Kraybill, and Loda (1978) in their study of the antecedents of child abuse and neglect in 255 premature infants, found that the abused children came from homes where there was "severe isolation without adequate social support systems and frequently was characterized by marital maladjustment, financial problems, poor use of medical services, and inadequate child care arrangements" (p. 633). The abused prematures were those with lower mean birth weights, tended to require oxygen and isolettes for longer periods of time, were more likely to have been in hospital for more than 40 days, and were more likely to have congenital anomalies besides prematurity. "This study suggests three essential components that contribute to this risk: (1) vulnerable, unsupported families, (2) biologically impaired infants, and (3) limited parent-infant contact during the nursery period" (Hunter et al., p. 635).

Summary

In summary, the first experience of parenthood for

mothers of healthy newborns appears to be a period of crisis accompanied by anxiety due to lack of preparation for infant care and insufficient support.

Primiparous mothers are concerned about feeding, sleep patterns, fussing and crying behaviours, and other general aspects of child care. Concern was also expressed to a lesser degree about infant behaviour, development, and infant health.

Primiparous and multiparous mothers seem to share similar concerns, however, primiparas were concerned mainly with the care of their infant, whereas the multiparas were concerned about fitting the child into the family, and were more interested in infant behaviour, growth and development. Parity did not seem to influence the extent to which a mother viewed herself to be adequately prepared for infant care especially if the primiparous mothers attended prenatal and/or hospital classes.

The majority of women sought help from their husbands although the multiparas frequently got less support from their husbands and family.

One study (Pridham & Schutz, 1981) gave physicians credit for informational support in the prenatal period. In the Pridham, Hansen, Bradley, & Heighway (1982) study, the mothers sought help more frequently from nurses during the first month post-discharge. However, the other studies (Gruis, 1977; M. Harrison & Hicks, 1983; Sheehan, 1981)

found the nurses were the least frequently used sources of information and support.

Public health nurse visits appeared to help the primiparous mother more than the multiparas (Stanwick, Moffat, Robitaille, Edmond, & Dok, 1982). Mothers seemed to need help from the public health nurses on issues such as feeding, but not so much in other areas of child care (L. Brown, 1967). Mothers that attended prenatal classes had significantly more concerns in the postpartum period (M. Harrison & Hicks, 1983; Hiser, 1987), although when these concerns were analyzed as to whether they belonged to worry or interest categories, they were noted to be more in the interest group.

Bull and Lawrence (1985) showed that the demand is present for further information concerning both infant care and infant behaviour. Hall (1983), and Golas and Parks (1986) showed that teaching about normal infant behaviour had a positive influence on the mothers' perceptions of their newborns.

Parenthood for mothers of premature infants means both a maturational and situational crisis. Despite preparation for the infant's discharge, mothers find the initial period at home difficult having to cope with feeding, sleeping, and crying problems. Mothers viewed their babies as being more difficult than expected (Jeffcoate, Humphrey, & Lloyd, 1979, p. 347) with feeding problems being the primary concern.

Fear of the infant dying and the perception of the child as vulnerable remained long after the initial crisis was over. Parents of preterm infants tend to have less confidence in their abilities to care for their infant at home. Mothers expressed need for more information about both child care and infant development. Goodman and Sauve's (1985) study suggest that the stresses occurring in the immediate post-delivery period do not end when, "upon the infant's subsequent discharge, the mother undertakes the full-time care of a demanding infant, and that the mother's need for support and guidance may be acute" (p. 239).

The literature on social support indicates that the concept of social support is a major psychosocial variable in health-related research. Women with low psychosocial assets and high stress had an increased risk of complications in pregnancy (Norbeck & Tilden, 1983; Norbeck, Lindsey, & Carrieri, 1981). Cronenwett (1985a) showed that access to social support has a positive effect on psychological outcomes in the postpartum period. However, Crawford (1985) does point out that not all the effects of social support can be viewed positively. Conflicts can occur within support relationships which can increase stress responses. Therefore, it is important to assess not only the amount and availability of support, but also the mother's satisfaction with the support available (Crnic & Greenberg, 1987).

Many of the studies showed that the infant's father was the most important source of support, followed by the mother's mother (Crockenburg, 1987; Mercer, Hackley, & Bostrom, 1983; Wandersman & Unger, 1983; Wandersman, Wandersman & Kahn, 1980). There were some differences in the type of support sought between groups of mothers of full-term, healthy babies and mothers of preterm infants (Boukydis, Lester, & Hoffman, 1987) in that, mothers of preterm infants sought more help from health professionals and wanted more support from other parents with premature infants. Mothers of sick infants appear to receive less support such as in areas of baby-sitting and household care (Feiring, 1985), than mothers of full-term, healthy infants.

Several studies (Crnic & Greenberg, 1987; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Trause & Kramer, 1984) have found that if mothers of premature infants are well-supported, then, once the crisis is over, these mothers are able to cope as adequately as mothers of full-term infants. However, many of these studies compare mothers of full-term infants with mothers of healthy, preterm infants and this may be a reason for the lack of differences between groups in the post-discharge period. The effects of social support on the mother appear to be greatest from the time of the infant's discharge from hospital until four to five months of age (Crnic & Greenberg, 1987; Cronenwett, 1985b).

The literature indicates that mothers who are well supported do better as caretakers, were more actively involved with their infants, provided more stimulation to their children, and appear to enjoy their babies more than do mothers with less support (Crockenberg, 1981, 1987; Feiring & Taylor, 1982; Pascoe & Erp, 1984; Unger & Powell, 1980; Wandersman & Unger, 1983). The mothers' positive interaction with their infants has both direct and indirect effects upon long-term child development (Cochran & Brassard, 1979).

Although the literature stresses the importance of teaching parents of high-risk infants; few studies have dealt with an empirical evaluation of the specific types of information and support the parents, themselves, have felt that they needed. The lack of information in this area points to the need for further study. As well, the majority of the published studies deal with parents of healthy premature infants. The researchers have been able to better control the number of variables by limiting their studies to healthy preterm infants, however, it is necessary to investigate the needs of the parents of high-risk premature infants in order to plan appropriate pre-discharge programs of instruction and to provide adequate support in the post-discharge period. The purpose of this research was to evaluate the needs of a specific geographically-based sample in order to provide the groundwork for an improved teaching

and support programme for mothers of high-risk premature infants.

Chapter III

METHODOLOGY

This research was an exploratory descriptive study that surveyed a non-random convenience sample of mothers of high-risk premature infants.

A survey questionnaire was designed to assess the types of information received by the mothers prior to their infant's discharge from hospital, and the kinds of information that these mothers felt they needed but did not receive; the kinds of support received by the mothers in the early post-discharge period; whether this type of support was felt to be adequate; and what type of support was needed where support provided was perceived to be inadequate. This questionnaire was based on information obtained from the literature review and on the author's experience in her interactions with parents of high risk infants and her own experience as a mother of a premature infant. The questionnaire will be discussed fully in the instrumentation section.

A pilot study using a sample of 10 mothers of high-risk infants (infants that were premature, small for gestational age, or full-term with medical problems and whose hospitalization lasted longer than 14 days in a neonatal intensive care unit) was conducted to test the procedure and the instrument. The questionnaire was used and modified

following this study.

Sample

The sample consisted of 62 mothers of high-risk premature infants as defined by the Newfoundland and Labrador Perinatal Programme criteria (see Appendix A) who were discharged from hospital. Two mothers did not attend the clinic. Of the 60 mothers who brought their babies consecutively to the follow-up clinic between the dates of May 28, 1987 to October 15, 1987, four were excluded from the study. One mother preferred not to participate; one mother had adopted a high-risk premature infant immediately after the infant's discharge from hospital; one mother's baby was born outside the province and was not seen until nine months of age in the Newfoundland and Labrador Perinatal follow-up clinic; and one infant's parents were both developmentally handicapped. The remaining 56 mothers comprised the study population group. Of all the mothers that were eligible at the time of the study, the sample of 56 mothers represented 90.3% of the total population available to the Provincial Perinatal Clinic.

There were 35 primiparas and 21 multiparas included in the sample. There was no restriction as far as age of the mother, marital status, or socioeconomic and educational status. Mothers of babies from the ages of 3 months to 9

months were asked to participate in the study. One group of infants were delivered at either one of two large hospitals in the metropolitan area, and remained in the high-risk nurseries at these hospitals or transferred to the intensive care unit at the Children's Hospital. A second group of infants were those delivered in seven other centres providing obstetrical care across the island, and then transferred to the tertiary neonatal intensive care unit at the Children's Hospital.

Setting

The questionnaire was administered to the mothers just prior to their child's assessment as they were waiting to see the physician in the Perinatal Clinic, or during travelling clinics held in six health centres across the island.

Instrumentation

A search of the literature found that an instrument that would specifically evaluate the kinds of information needed to be assessed, was not available. Cagan and Meier (1979, 1983) had developed and evaluated a discharge tool and ideas from this tool were incorporated into the questionnaire developed by the investigator. The

questionnaires's design was based upon a review of the literature, information obtained from the parents themselves, the pilot study, the investigator's own experience as a mother of a premature infant, and consultation with experts both in content and in questionnaire design. A test-retest reliability for items in common between the pilot study questionnaire and the questionnaire used in the present study was done by two of the mothers. Both mothers completed the pilot study questionnaire when their infants were 3 months old and the study questionnaire when their infants were 9 months old. There were differences in the answers in two of the questions on both mothers' questionnaires, therefore indicating 90.3% agreement between question responses. One mother indicated, at the three month visit, that she had been given information regarding when to take the baby outside the house, and how long the baby should sleep between feedings. At the nine month visit to the clinic, she answered this question with response (e) don't know/don't remember. The other mother, on the three month visit, indicated that, where she didn't get information regarding formula preparation and how much formula to give to the baby, she did not want this information. At the nine month visit, she indicated response (c) no, but I would have liked that information.

The questionnaire (see Appendix B) is composed of two

parts. Section A is designed to assess the kinds of information the parents received from the nurses prior to their infant's discharge from hospital, the kinds of information they wanted to have, and what they considered applicable to their situation. This section consists of 30 close-ended questions with the answer of either "yes", "yes, but I didn't want this information", "no, but I would have liked this information", "no, but I didn't want this information", or "don't know/don't remember".

Section B consists of a combination of 32 open-ended and closed-ended questions. These questions are worded to provide demographic information, as well as assessing the support needs of the parents.

The questionnaire requested the mothers to state the age of their baby, how old she/he was when brought home from the hospital, and the number and ages of other children in the family.

Further demographic data was obtained by a review of the medical charts and from the parents, themselves, prior to discharge of their infant.

Procedure

The questionnaire was explained to the mothers who were then asked to complete Section A of the questionnaire. The investigator was present to answer any questions the parents

had. Section B of the questionnaire was presented in the form of a structured interview with the investigator asking each question and recording each response. When the questionnaire was completed, each mother was asked "what other information would have been helpful to you?" and "what concerns did you have about your own care and how you felt during this period of time?" and "did you or do you have any other concerns about your baby that have not been covered in the questionnaire?" The responses were recorded on each questionnaire.

Data Analysis

The results of the questionnaire were analyzed by the use of descriptive and inferential statistics such as mean, frequency, chi square test of independence, t-test, Fisher's exact probability test, analysis of variance, and Pearson product-moment correlation coefficient. The majority of the inferential statistical analysis were done on an IBM compatible computer using Epistat, a statistical analysis program developed by Tracey L. Gustafson.

Ethical Considerations

The proposal was submitted to the Ethical Review Committees of the Memorial University of Newfoundland School

of Nursing and of the Charles A. Janeway Hospital and was accepted by both committees.

Before discussing the questionnaire, the project was explained to the mothers (and fathers, if present) individually by the investigator. Then the mothers were given a written explanation of the study (see Appendix C), asked to read it, and asked to look at the questionnaire before agreeing to participate. The parents were informed that the project was designed to determine the support and information that they received or wanted to receive prior to the baby's discharge from hospital and in the early post-discharge period. The mothers were then asked if they had any questions and if not, could they sign the consent form (see Appendix D) and complete the questionnaire. There were no names on the questionnaire and no means of identifying the parents and children involved. At the completion of the questionnaire the mothers were asked about other information that would have been helpful and not covered by the questionnaire. The mothers' questions and concerns were then discussed with her by the investigator.

Chapter IV

RESULTS AND DISCUSSION

Findings based on the completed questionnaires of 56 mothers of high-risk premature infants will be presented and discussed in this chapter. The presentation of the findings will be divided into (a) a discussion of the characteristics of the study population, (b) data presentation for each of the objectives, and (c) a description of the mothers' reported ease of adaptation to parenthood and to the care of a high-risk premature infant.

The population characteristics will be discussed under two headings; (a) that of the study population in general, and (b), a description of the characteristics of the primiparas and multiparas in the study population. Similarly, the results pertaining to the objectives of the study will be discussed under the heading of the general findings of the group, and then subdivided into data specific for the primiparas and multiparas. Special attention will be given to parity because the results of the studies reported in the literature reviewed in the first section indicate that, although primiparas and multiparas seem to share similar concerns, there are differences in the information perceived to be needed and in the support received by mothers in both of these groups. As well, the

majority of the previous studies have included mothers of full-term infants or healthy, preterm infants, and it was felt that parity might be an important factor when considering mothers of high-risk premature infants.

The objectives of the study were (a) to determine the kinds of information that mothers of premature high-risk infants received prior to the infants' discharge from hospital; (b) the kinds of information that the mothers felt they needed but did not receive; (c) the kinds of support received by the mothers in the early post discharge period; (d) whether this type of support was felt to be adequate; and (e) what type of support was needed where support provided was perceived to be inadequate.

Characteristics of the Study Population

The demographic information regarding the 56 mothers and their 60 (4 surviving twins) high-risk premature infants is presented in Table 1. Of the 56 mothers, 47 (83.9%) were married and 9 (16.1%) were single. The mean maternal age was 26.85 years with the range of maternal age being 18 to 38 years of age. The number of primiparas was 35 (62.5%) and the number of multiparas was 21 (37.5%). The average family size was 1.33 children. Twenty-eight (50%) of the mothers delivered by vertex presentation, 3 (5.4%) were breech deliveries, and 25 (44.6%) were delivered by

TABLE 1

Characteristics of Primiparas and Multiparas

	Total N (%)	Primiparas N (%)	Multiparas N (%)
Number	56	35	21
Sex of infant:			
female	36 (60)	23 (60.5)	13 (59.1)
male	24 (40)	15 (39.5)	9 (40.9)
Marital status:			
married	47 (83.9)	26 (74.3)	21 (100)
single	9 (16.1)	9 (25.7)	0 (0.0)*
No. of babies <1000 gms:	12 (21.4)	7 (20)	5 (23.8)
Type of delivery:			
vertex	28 (50.0)	19 (54.8)	9 (42.9)
breech	3 (5.4)	2 (5.7)	1 (4.8)
C/S	25 (44.6)	14 (40.0)	11 (52.4)
Multiple births: (sets)	7	5 (2 died)	2 (1 died)
	mean (range)	mean (range)	mean (range)
Mean maternal age (years):	26.85 (18-38)	26.0 (18-35)	28.2 (18-38)
Mean birthweight (gms.):	1614.02 (530-3900)	1576.1 (530-3170)	1679.5 (580-3900)
Stay in hospital (days):	54.93 (6-210)	54.66 (6-210)	56.76 (9-165)

* chi-square = 6.43, df = 1, p <.01

caesarian section.

There were 49 (81.7%) single births and 7 sets of multiple births. Of the multiple births, 3 of the infants died within 24 hours of birth. The total number of remaining infants in the sample was 60.

The mean birthweight of the preterm infants was 1614.02 grams, and the range of birthweight was 530 to 3900 grams. The mean gestational age was 31 weeks, the range of gestational age being 23 to 36 weeks. The mean number of days spent in hospital was 54.93. The range of hospital days was 6 to 210 days. The mean chronological age of the infants when the questionnaire was completed was 28.68 weeks. The range of the chronological age was 11 to 46.5 weeks. The mean corrected chronological age when the questionnaire was completed was 19.91 weeks. The range of the corrected chronological age 2 to 38.5 weeks.

The number of male infants was 24 (40%), 2 of which are twins. There were 36 (60%) females (2 of which were twins). The mean maternal age for mothers of males was 26.43 years and for females was 27.13 years. The mean birthweight for males was 1667.50 grams. The mean birthweight for females 1578.36 grams. The mean gestational age for males was 31.92 weeks and for females 30.85 weeks. The mean number of days in hospital for males was 54.9 and for females, 55.8 days. None of these sex differences were statistically significant using a t-test.

All mothers except three were caucasians and all except these three were native Newfoundlanders. The mothers came from all parts of the province. Of the sample, 21 (37.5%) of the mothers were within easy travelling distance (1/2 to 3/4 hours drive) from a level 3 hospital, and 9 (16.1%) were within a similar distance from a level 2 hospital. The remaining 26 (46.4%) of the mothers had some access to a level 1 hospital, but were from 1 to 5 hours away from level 2 or 3 hospitals. The levels of hospital care are usually defined as follows:

Level 3:

> Characterized by a high volume of high-risk cases, availability of advanced diagnostic facilities and subspecialities and the presence of neonatal services.

Level 2:

> Characterized by the presence of a fully-qualified obstetrician and adequate diagnostic and therapeutic services to handle intermediate risk cases.

Level 1:

> All other centres (Mowat & Hyman, 1984).

This information indicates that, although all the 56 mothers had high-risk premature infants, only 37.5% of these mothers had easy access to a Level 3 hospital and 46.4% of the mothers had no access to specialized care. Even then, 42 (75%) of these mothers were identified prenatally as high-risk and delivered in one of the two Level 3 centres,

12 (21.4%) delivered in a Level 2 hospital and 2 (3.6%) delivered in a Level 1 centre. Thirty-seven (61.7%) (2 twins) of the infants of these mothers were transferred to the neonatal intensive care unit of the Children's Hospital. Twenty (33.3%) (1 twin) other infants were cared for in the neonatal intensive care units of the two Level 3 hospitals, and 3 (5%) of the healthier twins remained in two other Level 2 hospitals.

Of the 37 babies that were cared for in the high-risk intensive care nursery at the Children's Hospital, only 19 (51.4%) of their mothers had easy access to their infants during the period of their infant's hospitalization. Similarly, of the 11 infants at Hospital B, only 3 of those mothers had easy access to their infants. However, at Hospital C, all of the 8 mothers had easy access to their infants. The majority of the 26 remaining mothers (46.4%) from all three hospitals were kept informed about their infant's condition through telephone conversations and pictures and had limited interaction with their infants. These mothers did spend a period of time caring for their infant prior to their infant's discharge from hospital. This time period ranged from a few hours to several days.

Study Population Characteristics for Primiparas and Multiparas

The demographic information was further divided into primiparous mothers versus multiparous mothers and presented in Table 1. Chi-square tests and t-tests were applied where appropriate and no significant parity differences were found except for marital status where multiparous mothers are much more likely to be married (chi-square = 6.43, df = 1, $p<.01$).

Data Presentation for the Objectives

Objective A: Information Received by Mothers of High-Risk Premature Infants

The first objective was to determine what information was given to mothers of high-risk premature infants.

Part A of the questionnaire consisted of a series of questions asking whether each of the 30 specific types of information had been given by the nurses prior to the baby's discharge from hospital. For each item, the respondents were asked to check one of the following alternatives:

a) Yes

b) Yes, but I didn't want this information

c) No, but I would have liked this information

d) No, but I didn't want this information

e) Don't know/don't remember

Table 2 lists the items on which respondents indicated receiving information (alternative (a) was checked). Eighty percent of the mothers indicated that they received information regarding how much formula to give at each feeding, how to help their baby feed well, and how to give their baby a bath. Other items covered were how to prepare a formula (77%), immunization schedules (75%), vitamin supplementation (71%), how long a baby should sleep between feeds (63%), if it is normal for a baby to sneeze and hiccup (63%), when to start the baby on cereal (59.9%), and information about baby adjusting to home (59%).

This study indicates that the majority of the mothers received information on areas such as bathing a baby, preparing formula, the amount of formula to give, and helping the infant feed well. Multiparas received less information on these areas than did primiparas, although the differences were not significant. The results of this study were very similar to that of the pilot study (data collected September to November, 1986) with a 70% overlap on the ten most frequently given items. As well, these findings agree with many of the results of the Dempson and Maret (1986) study especially in the areas of bathing and aspects of infant feeding. The Dempson and Maret (1986) study assessed

Table 2

Percent of Primiparas and Multiparas Indicating They Received Specific Items of Information

item	total		primiparas		multiparas	
	%	rank	%	rank	%	rank
How much formula to give	80.0	2	80.0	4	81.0	1.5
How to help your baby feed well	80.0	2	85.7	1	71.4	5
How to give your baby a bath	80.0	2	82.9	2.5	76.2	3
How to prepare formula	77.0	4	82.9	2.5	66.7	10
Information about immunization	75.0	5	71.4	5.5	81.0	1.5
Need for vitamin supplementation	71.0	6	71.4	5.5	71.4	5
How long to sleep between feeds	63.0	7.5	57.4	9	71.4	5
Normal to sneeze and hiccup	63.0	7.5	68.6	7	52.4	13
When to start baby on cereals	59.9	9	65.7	8	47.6	14
Baby adjusting to home	59.0	9	54.3	10.5	66.7	10
Normal behaviour for infants	59.0	9	54.3	10.5	67.7	7.5
How to give medications	54.0	12	45.7	12.5	66.7	10
Temperature and humidity of house	52.0	13	42.9	14	67.7	7.5
Kinds of behaviours to expect	50.0	14	45.7	12.5	57.1	12

the information received by 60 mothers of healthy full-term infants that were discharged from one of the hospitals in this study. This study took place during January and February, 1986. The Dempson and Maret (1986) study did find that their mothers were not taught formula preparation and this project indicates that 77% of the total sample received information on this topic.

Objective B: Information Wanted, But Not Received by Mothers of High-Risk Premature Infants

Table 3 indicates the questions on which the respondents most frequently reported that they did not receive the indicated item, but would have liked the information. Sixty-three percent of the mothers indicated that they would have liked to know about infant colic. Others indicated information needed regarding whether noisy breathing is normal (59%), whether "spitting-up" is normal (57%), whether "fussy-periods" are normal (54%), how to recognize the baby becoming ill (50%), what to do about the baby's crying (48%), what to do if the baby becomes ill (46%), when to start to take the baby outside (45%), what kinds of behaviour to expect from the baby (45%), how to tell if the baby's bowel movement is normal (45%), and how to take the baby's temperature (45%).

These findings are very similar to those reported in Table 3

Table 3

Percent of Primiparas and Multiparas Indicating Items of Information Not Received, But Needed

item	total		primiparas		multiparas	
	%	rank	%	rank	%	rank
Know if your baby has colic	63.0	1	69.0	1	52.0	2.5
Know if noisy breathing normal	59.0	2	60.0	13.5	57.0	1
Know if "spitting-up" is normal	57.0	3	66.0	2	43.0	5.5
Know if "fussy-periods" are normal	54.0	4	57.0	5	48.0	4
Recognize if baby becoming ill	50.0	5	60.0	3.5	33.0	12.5
What to do about your baby's crying	48.0	6	46.0	13.5	52.0	2.5
What to do if baby becomes ill	46.0	7	51.0	8.5	38.0	8.5
When to start to take baby outside	45.0	9.5	46.0	13.5	43.0	5.5
Kinds of behaviours to expect	45.0	9.5	51.0	8.5	33.0	12.5
Baby's bowel movement is normal	45.0	9.5	51.0	8.5	33.0	12.5
How to take baby's temperature	45.0	9.5	51.0	8.5	33.0	12.5
What to do about a diaper rash	43.0	12	54.0	6	24.0	18
Information about baby's breathing	39.0	13.5	40.0	17	38.0	8.5
How to get baby to respond to you	39.0	13.5	46.0	13.5	29.0	16

Table 3 Continued

item	total		primiparas		multiparas	
	%	rank	%	rank	%	rank
Temperature and humidity of house	38.0	15.5	49.0	11	19.0	19.5
How warmly to dress your baby	38.0	15.5	43.0	16	29.0	16
How to give medications	36.0	17	46.0	13.5	19.0	19.5
Normal behaviour of premature infants	34.0	18.5	37.0	18	29.0	16
Normal to sneeze and hiccup	34.0	18.5	31.0	19	38.0	8.5
When to start baby on cereals	32.0	20	29.0	20	38.0	8.5

the literature. Lissenden (1984) indicates that colic and crying at night were major concerns. Adams (1963), Goodman and Sauve (1985) and Robson and Moss (1970) mention infant crying, as well, and Robson and Moss (1970) refer to infant feeding and the "fussy" infant. Sumner and Fritsch (1983) mention mothers' requests for information on topics such as colic, infant "spitting-up", and the "fussy" infant. Minde, Perrotta, and Martin (1985) mention feeding difficulties with premature infants, including the "spitting-up" of feeds. Pridham, Hansen, Bradley, and Heighway (1982) describe mothers' concerns regarding infant illness, and L. Harrison and Twardosz (1986) and Bull and Lawrence (1985)

list mothers' needing information on child behaviour and development. Interestingly, the Dempson and Maret (1986) study indicated that mothers' concerns about infant crying were not discussed at Hospital C when that survey was done.

While Moss (1981) found that women under 20 years of age, having one other child at home, and having a male infant had increased needs for information, and Hiser (1987) and Sumner and Fritsch (1983) found the same effect regarding multiparas with male infants, this present study found that information needs, as measured by percent (a) responses, information needed and given, and (c) responses, information needed and not given, did not correlate with maternal age as indicated in Table 4. However, the sex of the infant did seem to be related to maternal information needs. Mothers of males had an average percent (a) responses of 57.6 while mothers of females had an average of 44.5%, (t = 2.09, df = 53, p = .040). Mothers of males also had lower mean (c) response rates (30.0%), than mothers of females (38.1%). This difference was not statistically significant. The total information demand (a+c) of mothers of males was slightly higher (87.7%) than mothers of females (82.6%), although this difference was not significantly different. It appears as though mothers of males and females seem to have similar demands for information, however, mothers of male infants acquire more of that

TABLE 4

Summary of Correlation Coefficients Between Variables in the Study

	matern age	birth weight	no. of child	hosp stay	anx scale	confid scale	fun times
matern age		.18	.31	-.01	.13	-.16	.15
birth weight			.36*	-.62*	.11	-.10	.10
no. of child				-.65*	.29*	-.08	-.03
stay in hosp					.04	-.18	-.19
anxiety scale						-.39*	-.08
confid scale							-.10
% "a" resp	-.07	.03	.12	-.02	.12	-.23	-.09
% "c" resp	-.01	-.02	-.18	-.03	-.30*	.35*	-.13
% a+c resp	-.14	-.01	-.12	.02	.08	.23	.33*

* $p<.05$

information than mothers of female infants.

Length of hospital stay (see Table 4) and the marital status of the mother were not significantly related to information needs and will not be discussed further.

Several studies (Fillmore & Taylor, 1976; M. Harrison & Hicks, 1983; Hiser, 1987) found that mothers who attended

prenatal classes have increased number of concerns (defined within the interest category of concerns). The findings of this project were similar. Those mothers who attended prenatal classes indicated that they wanted an average of 92.4% (a+c) of the 30 items in part A of the questionnaire, while those who did not attend classes sought 81.3%. This difference is statistically significant (t = 2.50, df = 54, p = .015). Mothers who attended prenatal classes had a higher percent of (a) responses (58.7%) than mothers who did not attend classes (46.1%). This finding approached, but did not reach statistical significance (t = 1.89, df = 54, p = .062). Responses (c) were similar for each group (33.7% and 35.1%, respectively).

Relationship between informational needs and anxiety and confidence.

The questionnaire asked mothers to rate their anxiety about caring for their baby after he or she came home from the hospital. Mothers were asked to indicate their anxiety on a 4-point scale between "very anxious" and "very comfortable". This scale was scored with "very anxious" being 1 and "very comfortable" being 4.

In addition, mothers were also asked, "After your baby came home from the hospital, did you feel you had enough information to make you feel (a) very confident, (b)

confident, (c) slightly confident or (d) not at all confident in caring for your baby?" This question was scored on a 4-point scale with 1 for alternative (a) and 4 for alternative (d).

Table 4 (p. 98) summarizes the Pearson correlation coefficients between these measures and other measures on the questionnaire including the total (a) responses "information wanted and received" and (c) responses, "information wanted, but not received" and total information wanted (a+c). This table shows that the anxiety and confidence scales were significantly correlated with each other ($r = -.39$, $p = .002$). The correlation coefficient was negative because high scores in the confidence scale indicated low levels of confidence and low scores on the anxiety scale indicated a high degree of anxiety. Neither the anxiety or the confidence scale was significantly correlated with maternal age or length of hospitalization of the infant. Length of hospitalization was determined by the degree of prematurity and the severity of the medical complications. Contrary to the findings of Minde, Whitelaw, Brown, Trehub, and Fitzhardinge (1981) the degree of illness does not appear to correlate with the anxiety and confidence measures. The correlation of anxiety and confidence with (a) responses was not significant, but both the anxiety and the confidence scales significantly correlated with item (c) responses, $r = -.30$ and $r = .35$, respectively. This

indicates that mothers who reported that they needed information and did not receive it, were more anxious and less confident. This variable seemed to predict anxiety and confidence better than the total information that mothers received, variable (a) or total information needed (a+c). Rutledge and Pridham (1987) did show that in-hospital preparation improved the mothers' feelings of competence.

The anxiety scale was also inversely correlated ($r = -.29$) with the number of children in the family suggesting that experienced mothers are less anxious. The number of children in the family was not correlated with the measures of information received. However, other analysis (see Table 5) did indicate that primiparous mothers required more information than multiparous mothers. This suggests that primiparous mothers have increased need for information and increased anxiety, and multiparous mothers perceive themselves as more competent in areas such as infant feeding and care.

TABLE 5

Mean Percent of Items Needed and Given, Needed and Not Given, and Not Needed and Given to Primiparas and Multiparas

	(a) needed and given	(c) needed not given	(d) not needed given	(a)+(c) total needed
Primiparas	48.4	39.3	8.3	87.7
Multiparas	52.2	27.4	15.9	79.6

Jeffcoate, Humphrey, and Lloyd (1979) describe how only 50% of the parents of premature infants in their sample expressed confidence at discharge. From the results of the present study it appears that having more information helps to ease some of the anxiety, and that previous experience with other children is also an important factor in reducing anxiety and promoting confidence. Jeffcoate et al., (1979) found, as well, that mothers were unwilling to leave these infants with a babysitter. In the present study, the mean number of times out for fun in the past month was 3.6 with 10 of the mothers not going out at all, and another 15 mothers out once. The mean number of times out for mothers who found the first week after the baby's discharge from hospital difficult was 2.8. The number of times out for fun per month was not significantly correlated with any of the measures of confidence or anxiety, but was significantly correlated ($r = -.33$) with the total need for information (a+c responses), suggesting that mothers who want to know more information are less willing to leave their infant. The amount of information received, however, does not appear to be related to their ability to trust their infant to others. It seems that it is those mothers who believe that care of the premature infant requires a great amount of information who are unwilling to trust the knowledge and skill of anyone else.

Parity and Objectives A and B: Information Received, and Information Wanted and Not Received by Primiparous and Multiparous Mothers of High-Risk Premature Infants

Table 2 also shows the information given to primiparous and multiparous mothers. In general, parity does not appear to influence the kinds of information being given mothers in hospital. Of the 10 most frequently given items of information reported by each group, 8 were common to multiparas and primiparas. A signed ranks test did not indicate a significant difference in the order of items in Table 2 between primiparous and multiparous mothers ($p>.05$).

Table 3, on the other hand, looks at the items that were not provided, but wanted by primiparous and multiparous mothers. Of the 10 most wanted, but not given items, only 5 of these items are common to each group. A signed ranks test indicated that the ranking of these items by primiparous and multiparous mothers was significantly different ($p<.00039$)

Table 5 shows the mean percent (a) responses (information received and wanted), (c) responses (information not received, but wanted), and (d) responses (information not given, but not wanted) for multiparous and primiparous mothers. The average percent (a) responses for multiparas was 52.2 and for primiparas was 48.4. This difference was not significantly different ($t = 0.63$, $df =$

54, $p = .52$). Primiparas indicated an average of 39.3% (c) responses, while the average multiparas' response (c) was 27.4%. This difference did not achieve statistical significance ($t = 1.71$, $df = 54$, $p = .092$). On the average, multiparas indicated (d), information not needed, but given, for 15.9% of the items, while primiparas indicated (d) on 8.3% of the items. This difference approached, but did not achieve statistical significance ($t = 1.9$, $df = 54$, $p = .06$). This indicates that, although multiparous mothers did not receive some information, they also did not want it, probably because of previous experience with children. The total percent of needed information (a+c responses) for primiparas was 87.7 and for multiparas was 79.6. Once again this difference approached, but failed to reach statistical significance ($t = 1.85$, $df = 54$, $p = .06$).

A more in-depth look at the mothers' responses to the questions regarding infant feeding reveals that, only 40% of the primiparas and 23.8% of the multiparas received information on how to breastfeed their baby. While these percentages might indicate that not enough information is being given, only 5.7% of the primiparous mothers and 4.8% of the multiparous mothers indicated that they wanted more information (see Table 6). On the other hand, 82.9% and 80% of the primiparas received information on preparing formula and the amount of formula to give at each feeding, respectively, with 14.3% and 11.4% of the primiparas

indicating that they wanted more information. Similar findings were seen with the multiparas with 66.7% and 81.0% of this group receiving information on the above two topics, and 4.8% and 4.8% of the multiparas wanting more information on preparing formula, and the amount of formula to be given.

It is interesting to note that the mothers received more information on formula preparation than on breastfeeding. When response (b) "yes, but I didn't want this information", and response (d) "no, but I didn't want this information", are considered, it becomes obvious that many of the mothers did not want further information on breastfeeding. Thirty-three percent of the primiparas indicated response (b), in that they had been given the information on how to breastfeed, but didn't want it, and 14% of the multiparas gave a similar response to (b). Similarly, 31% of the primiparas and 57% of the multiparas indicated (d) to the question regarding how to breastfeed. On the question asking whether the baby was getting enough breastmilk, 11% of the primiparas and 5% of the multiparas answered (b), whereas 43% of the primiparas and 62% of the multiparas indicated response (d). When the question asking how to prepare formula is examined, neither of the primiparas or multiparas circled response (b), and 11% of the primiparas and 29% of the multiparas indicated (d). These data indicate that, while the mothers did not receive much breastfeeding information, they did not appear to want

TABLE 6

Percent of Primiparas and Multiparas Indicating (a) They Received, and (c) They Did Not Receive Different Items of Needed Information

item	primiparas		multiparas	
	a)	c)	a)	c)
Items concerning feeding behaviour				
1. How to breastfeed	40.0	5.7	23.8	4.8
2. Is baby getting enough breastmilk	28.6	17.1	23.8	4.8
3. How to prepare formula	82.9	5.7	66.7	4.8
4. How much formula to give	80.0	14.3	81.0	4.8
5. How to help baby feed well etc.	85.7	11.4	71.4	19.1
6. When to start cereals	65.7	28.6	47.6	38.1
7. Need for vitamin supplementation	71.4	28.6	76.2	19.1
Items concerning crying and colic				
14. How to know if baby has colic	20.0	68.6	23.8	52.4
23. If "fussy periods" normal	25.7	57.1	45.7	47.6
24. What to do about baby crying	37.1	45.7	19.1	52.4

it.

Both primiparous mothers and multiparous mothers indicated that they were not given very much information on infant colic, the "fussy" infant, and what to do about infant crying, and that they wanted more information on these topics (see Table 6).

Table 7 shows that 62% of multiparous mothers did not attend either prenatal or hospital classes and 26% of primiparous mothers did not attend either of these classes. Fifteen (43%) of the 35 primiparas attended prenatal classes while only two (10%) of the 21 of the multiparas attended these classes. A total of 22 (63%) of the primiparous mothers attended hospital classes, while 8 (38%) of the multiparous mothers attended these classes. A chi-square test on the class attendance distributions of primiparous and multiparous mothers in Table 7 showed these distributions to be significantly independent (chi-square = 9.52, df = 3, p = .023). A comparison of those who attended any class to those that did not attend a class was accomplished by partitioning the degrees of freedom into a 2x2 chi-square, which indicated parity was significantly related to class attendance (chi-square = 7.21, df = 1, p <.01). The influence of parity on attendance patterns at prenatal classes agrees with the findings of M. Harrison and Hicks (1983) and Norr, Block, Charles, and Meyering (1980).

TABLE 7

Parity and Attendence at Prenatal and Hospital Classes

	Total	Primiparas	Multiparas
Prenatal classes attended only	4 (07%)	4 (11%)	0 (0%)
Hospital classes attended only	17 (54%)	11 (31%)	6 (29%)
Both prenatal and hospital	13 (23%)	11 (31%)	2 (10%)
Not attending either classes	22 (39%)	9 (26%)	13 (62%)*
Total	56 (100%)	35 (100%)	21 (100%).

* independence of parity distribution chi-square = 9.52, df = 3, p = .023

Objectives C and D: Support Received by Mothers of High-Risk Premature Infants and the Adequacy of that Support

Prenatal and hospital classes.

The mothers' sources of information about child care were varied. Table 7 shows attendance at prenatal and hospital classes. Of the 56 mothers, 17 (30.4%) reported attending prenatal classes and 39 (69.6%) did not attend. The small number attending the prenatal classes could have been influenced by the premature termination of the pregnancy prior to the commencement of the prenatal classes. Thirteen (76.5%) of those who attended the classes found them helpful, two (11.8%) did not find them helpful, and two

did not answer this question. Thirty (53.6%) of the mothers attended hospital classes and 26 (46.4%) did not. Of the group of 30, 13 (43%) attended both prenatal and hospital classes. Twenty-seven (90%) mothers that attended hospital classes found them helpful. Two (6.7%) of these mothers stated that they did not find these classes helpful and one of these mothers was one of the mothers that attended prenatal classes and did not find that helpful either. One mother did not answer to either the question regarding the prenatal classes or the question about the hospital classes.

The mean number of (a) responses, "information needed and received", (c) responses, "information needed and not received", and the percent of received information of total needed information (a/a+c) was calculated for mothers discharged from each of the three hospitals in the study. These data are presented in Table 8. An analysis of variance did not reveal any significant differences between the means of all mothers from the three hospitals on any of these measures, however there did appear to be differences in the hospitals when the parity of the mother was taken into account.

TABLE 8

Mean Percent (a) and (c) Responses, and Percent of Needed Information Received (a/a+c) by Mothers From Hospitals A, B, and C.

	primiparas			multiparas			all mothers		
Mean % responses:	a	c	a/a+c	a	c	a/a+c	a	c	a/a+c
Hospital A	46	44	51	55	23	65	53	34	57
Hospital B	61	21	77	19	49	22	46	28	57
Hospital C	40	49	48	-	-	-	40	49	47
			*	*		*			

* the difference between hospitals on this measure is statistically significant, $p<.05$

A similar analysis with only primiparous mothers showed that there were no statistically significant differences between the hospitals in terms of the total information received, (a) responses. Mothers from Hospital C received 40% of the information, a percentage lower than the other two hospitals, and wanted but did not receive 49% of the information, an amount that was higher than the other two hospitals. Mothers from Hospital B were much less likely to indicate (c) response "information wanted, but not given", than mothers from Hospitals A and C. This difference approached statistical significance ($F = 3.05$, $df = 2/31$, $p = .061$). The means of the percent of wanted information that was received (a/a+c) by the mothers were different for

each hospital ($F = 3.48$, $df = 2/31$, $p = .043$), indicating that Hospital B was better at giving primiparous mothers the information they needed, than the other two hospitals.

A t-test was used to assess differences between the means of the multiparous mothers attending Hospitals A and B. No multiparous mothers attended Hospital C. The tests showed that Hospital A provided multiparous mothers with more needed information, (a) responses ($t = 3.25$, $df = 18$, $p = .004$), and had a higher percent of needed information (a/a+c) than Hospital B ($t = 3.37$, $df = 18$, $p = .003$). Hospital A also had a smaller percent of (c) responses, "information needed, but not received" than Hospital B. This difference approached, but did not quite reach statistical significance ($t = 1.83$, $df = 18$, $p = .08$).

It appears as though Hospital B is better at teaching primiparous mothers than the other two hospitals, but does not do as well as Hospital A in teaching multiparous mothers.

Sources of help.

In examining the support that the mothers had at home during the early weeks after their baby's discharge, it was found that 42 (75%) of the mothers had either their husbands or boyfriends helping them, and out of this group, 13 (31%) had others besides their husbands/boyfriends helping.

Twelve out of 13 support persons were family members, mostly the mother's mother. Seven (12.5%) of the mothers had another family member only (in 6 out of the 7, the person was the mother's mother), 4 (7%) had no help, 2 (3.6%) had a friend and 1 (1.8%) had housekeeper only.

Several of the studies cited in the literature reviewed (Gruis, 1977; M. Harrison & Hicks, 1983; Mercer, Hackley, & Bostrom, 1983; Norr, Block, Charles, & Meyering, 1980) listed the husband/boyfriend as the most frequent source of support and this finding is supported in this study. Crockenburg (1987) also states that besides the husband, the mother's mother is the next more frequently cited source of support and this finding was seen in this study.

In replying to the questions "how did this person (these persons) help you?", 43 (81%) of the mothers described material support in the form of assisting with housework, getting meals, babysitting the other children, and sharing the care of the new baby. Another nine (16%) of the mothers mentioned emotional support and comparison support, and one mother commented that her husband "knew more about babies and taught me how to care for her". Boukydis (1987) found that fathers of preterm infants were more likely to do household chores, but less likely to look after the infant. However, it was evident in this study that, although the fathers did provide material support, they were also very involved with the care of their infant.

Forty-six (82%) of the mothers found this help adequate and 4 (7%) did not find it adequate. Six of the mothers did not answer this question, but four of these were mothers with no help at all. Two of the four with no help wanted help, whereas the other two did not want any help. Thus a total of 48 of the 56 mothers, over 85%, received the support they perceived that they needed at home.

The majority of the mothers stated that they felt well supported and were happy with that support. Those mothers who did not find the help adequate explained that they needed "someone when husband was at work", "help holding the baby", "knowledge on babies", "someone to talk to and pass the time of day", "advice on things to do", "someone to talk to about your premature baby" and one mother commented that her "husband didn't know anything more about child care than I did".

Many of these findings, especially those regarding the need for companionship while the husband was at work, were described by Curry (1983) when she examined the variables related to adaptation to motherhood of primiparous women of healthy, full-term infants.

The following differences in support for primiparas and multiparas were found. Twenty-eight (80%) out of the 35 primiparous mothers had help from their husbands/boyfriends. Five (14.3%) had help from family, mostly the mother's mother and one (2.9%) of this group had no help at all.

Eight of these mothers had more than one support person. Fourteen (66.7%) of the 21 multiparous mothers had help from their husbands and 2 (9.5%) had help from their family. Three (14.3%) of this group had no help at all. Five of these mothers had more than one support person. These findings support those of Norr, Block, Charles, and Meyering (1980) who found that multiparous mothers did not receive the same amount of support as did primiparous mothers.

Public health nurse support.

Fifty-two (92.9%) mothers had visits from public health nurses and 4 (7.1%) had no visits. These four also indicated that they did not want a visit from the nurse. Eight (15.4%) had visits within 48 hours of discharge, 26 (50%) had visits in the period beyond 48 hours, but within the first week, 11 (21.2%) had visits within 7 to 14 days of discharge and 6 (11.5%) had visits more than 15 days post-discharge of their infants. Five mothers did not respond to the question. Of the mothers that did not receive a visit in the first week, distance from a public health nursing centre did not seem to make a difference, nor did the timing of the discharge notice to the public health nurses from the hospital.

Seven out of eight of the mothers whose infants were discharged from Hospital C had a visit from the public

health nurse within the first week. All these mothers were primiparas and all were from the metropolitan area. This particular hospital is involved in a joint public health-hospital project involving the obstetrical-neonatal unit and this factor may have influenced the results. Hospital A has a discharge planning programme which involves keeping the public health nurses up to date about the care and discharge planning of the infants in their area. In most situations, the public health nurses are notified by phone when the infant is discharged and a written notice regarding the infant's health status is mailed immediately after the infant is discharged. Even then, only 9 out of 19 (47%) of the infants from the metropolitan area were visited during the first week post-discharge, none out of 6 were visited during the first week in a community outside the metropolitan area, whereas 8 out of 10 mothers living in more remote areas were visited during this period of time. Several reasons could account for these findings. It does, at times, appear that the public health nurses in the more remote areas receive their mail faster than those nurses in the metropolitan area. It is, as well, easier to contact nurses in the more remote areas by phone than the nurses in the city. The infants discharged from Hospital A required a high degree of intensive care nursing, and it is possible that public health nurses may hesitate to visit until they feel confident in their abilities to deal with the situation

of a child that may have suffered perinatal insults. Standwick, Moffat, Robitaille, Edmond, and Dok (1982) noted in their study that mothers without problems with their infants were more likely to have a public health visit. This possibility requires further study.

Of the infants discharged from Hospital B, 8 out of 11 were visited in the first week, 3 out of 3 from the metropolitan area, and 5 out of 8 in other centres across the island.

Forty-three (76.8%) of the mothers found the public health nurse visits helpful and 9 (16.1%) did not. Those that found the visits helpful cited more informational and material support, although it was obvious from their replies that the nurses had also shared emotional and comparison support. Comments were made such as "she answered some questions", "she gave information about how to give iron drops and how much to give", "information on breast feeding and general baby care", "information on weight gain, plus encouragement on how she was behaving", "where to go for needles", "general information about sleeping and feeding patterns", and "instructions about caring for myself and the baby". Several mothers mentioned the importance of having "support", and that the nurse was "interested in the baby" and "left a telephone number" and "visited once a week during the early period and telephoned regularly". The comments of these mothers regarding the public health nurse

visits are very similar to those described by Noga (1982).

The Dempson and Maret (1986) study indicated that 69% of their mothers had public health nurse visits, 74% of these in the first few weeks, and 81% of the mothers said they found these visits helpful. Eighty-six percent of the mothers stated that they would prefer a visit during the first week at home and 12% preferred a visit within 48 hours after discharge.

Family physician support.

The mean number of days at the time of the visit to the family physician was 20.57. The range of days was from 2 to 98 days. Thirty-nine (69.6%) went for a routine check-up. Two (3.6%) went for their immunization, two to get weighed, two for a cold, two for constipation, one (1,8%) was fussy and had problems feeding, one was seen for overheating, one for moniliál infection, one for an eye infection, one for a bloodtest, and one was admitted to hospital for a urinary tract infection. Three mothers did not respond to the question. The majority of the mothers saw the physician's role as treating the problem rather than a source of information.

Forty-five (80.4%) of the mothers found the timing of the visit to the physician appropriate. Six (10.7%) of the mothers indicated that they would have appreciated an

earlier visit. Of these six mothers, the times their infants were seen were at 7 days, 9 days, 30 days, 42 days, and 60 days after discharge. Five of these infants were seen for a checkup and one for a cold. Five mothers did not complete this question.

Objective E: Support Perceived to be Needed by Mothers of High-Risk Premature Infants

The mothers were asked if they wanted a place to call for assistance. Forty-four (78.6%) mothers indicated that they did, whereas 11 (19.6%) did not want this service. One primiparous mother did not answer this question. Parity differences indicated that 27 (77%) of the primiparas and 17 (80.9%) of the multiparas wanted this service.

Similarly, 49 (87.5%) mothers indicated that they would appreciate a booklet covering the common issues regarding care of the premature infant at home. Seven mothers (12.5%) felt that they did not need this resource. Interestingly, 6 out of the 7 mothers also did not want a place to call. Twenty-nine (82.9%) of the primiparous mothers and 18 (85.7%) of the multiparous mothers wanted the booklet. This may suggest the multiparas are not as confident as they seem to be; or that their increased experience with children results in increased concerns or interests; or it may represent an outcome of the decreased amount of support

described by the multiparas.

When mothers were asked "what other information would have been helpful to you?" some mothers responded by requesting more general feeding information; others requested information about when to start juices, give water, and more information about immunization; and "how to know if the baby is getting ill". The mothers stated that they felt that it is important for nurses to discuss caesarian section, prematurity and miscarriage in prenatal classes. One mother wanted to know "what was natural for premature infants?" Another wanted more information directly related to premature babies as most of the information available deals with full-term infants. One baby drank her milk very fast at times and the mother wanted to know how to deal with this problem. Another mother commented that the nurses didn't get her for the infant care classes and she would have liked to have gone. In general, responses to this question reflected the information given in Table 3, information not given, but needed.

When asked "what concerns did you have about your own care and how you felt during this period of time", the majority of the mothers stated that they felt tired and needed more rest. One mother experienced stomach pains, another mother had problems with the healing of an episiotomy, and another was concerned about her high blood

pressure.

The interviewer concluded the questionnaire by asking if the mothers had any other concerns. One mother mentioned the stress of having a baby in hospital for a long period of time. Other mothers mentioned this concern when explaining why they found the initial period after the infants' discharge difficult. There were no other concerns mentioned. On the basis of the literature review (Goodman & Sauve, 1985), it was expected that mothers would be concerned about the appearance of their premature infant, but no mother in this study expressed this as a concern.

Adjustment to Parenthood and the Early Post-Discharge Period

The mothers were asked if they found any period of time after their infants discharge from hospital difficult and why they found it that way. Table 9 summarizes their responses. Twenty-five (44.6%) of the mothers found the first week at home with their infant difficult. Three mothers (5.4%) found week two difficult, six (10.7%) found week three to four difficult, six (10.7%) found the time after week four difficult, one (1.8%) found all weeks difficult, eight (14.0%) found no weeks difficult, one (1.8%) found it difficult when she went back to work, and five mothers did not answer this question.

TABLE 9

Parity and Times of Difficulty After Discharge

	Total	Primiparas	Multiparas
Difficult Time:			
Week 1:	25 (45%)	16 (46%)	9 (43%)
Week 2:	3 (05%)	1 (03%)	2 (10%)
Week 3-4:	6 (11%)	3 (09%)	3 (14%)
After 4 weeks:	6 (11%)	4 (13%)	2 (10%)
No difficult time:	8 (14%)	4 (13%)	4 (19%)
All times difficult:	2 (04%)	2 (06%)	0 -
When went back to work:	1 (02%)	0 -	1 (05%)
No answer:	5 (09%)	5 (14%)	0 -

Curry (1983), in studying the adaptation to parenthood of primiparous mothers of healthy, full-term infants, stated that 25% of her sample found the first week difficult. In the present study, 25 (49%) of 51 mothers stated they found the first week difficult. The majority of these mothers (all except 2) perceived themselves as having adequate support. The prematurity of the infant is likely the reason for the increase in the percentage of difficulty in this sample and some of this is seen in the mothers' comments.

The majority of the mothers stated that they found it difficult to get used to a small baby. Mothers made comments such as "didn't know how to bathe a baby, much less anything else"; "because she was premature, I didn't really know what to expect", and "I was very nervous because he was

my first child and I had no previous experience and didn't know what to expect". Some mothers mentioned the difficulty of the adjustment to parenthood. Others felt anxious because the nurses took care of the baby in the hospital and "all of a sudden I had the sole responsibility" and "for the first time, my husband and I were on our own". Other comments were very similar to those described in the study by Lissenden (1984).

While more primiparous mothers tended to find the first week difficult than multiparous mothers, a chi-square test found no significant parity differences on these measures. This finding differed from that of Curry (1983) who found that mothers with previous experience with small children were more likely to make an easier adjustment to parenthood. The fact that the mothers in this sample were caring for an infant who was premature may have influenced the results. As well, the smallness of the n of both groups (primiparas = 16, multiparas = 9) may have accounted for the lack of statistical significance.

All of the mothers in this study reported an increased sense of confidence in their abilities by the time the questionnaire was administered, even though some of the questionnaires were administered at three months and others at nine months post-discharge. Similar results were found by Pleshette et al. (1956) and Trause and Kramer (1984).

The difficult first week.

There were 25 mothers who identified the first week after discharge of their baby as being a particularly difficult time. The characteristics of this group of mothers were compared with all other mothers in the study in an attempt to identify what factors might cause a difficult first week.

In all cases, the data were analyzed by means of a contingency table as in the following example. Table 10 shows the differences between the mothers who reported a difficult first week and those who did not, in their answers to the question concerning their confidence. The statistical significance of the differences were then determined by means of a chi-square test or, in the case of a 2X2 table, a Fisher's exact test. In this case, level of confidence was not related to first week difficulties (chi-square = 3.24, df = 2, p = .204).

Similarly, the following variables were not found to be statistically related to having a difficult first week; responses to the anxiety question (chi-square = 6.19, df = 4, p = .186), level of hospital (chi-square = 2.91, df = 2, p = .233), parity (chi-square = .004, df = 1, p = .944), marital status (Fisher's exact test, p = .13), whether the child had been admitted to the Children's Hospital (Fisher's

exact test, $p = .281$), whether the mother reported more than one source of support (Fisher's exact test, $p = .327$).

Table 10

Level of Confidence of Mothers who Reported Having a Difficult First Week After Discharge

		very confident	confident	slightly confident	total
difficult first week	yes	7	10	8	25
	no	16	8	7	31
Total		23	18	15	56

It was suspected the amount of information the mother was given might alleviate the stress of this first week, but t-tests indicated the mean percent (a), items given and wanted, and (c), items not given and wanted, were not significantly different for mothers reporting a difficult first week and mothers not reporting a difficult first week (respectively, $t = .499$, $df = 54$, $p = .61$, and $t = .30$, $df = 54$, $p = .75$). Additionally, it did not matter whether the mother had attended prenatal classes (Fisher's exact test, $p = .480$) or hospital classes (Fisher's exact test, $p = .522$). In addition, mothers who had a difficult first week were no more likely to report that they would find a booklet helpful (Fisher's exact test, $p = .360$) or that they wanted a place to call for help (Fisher's exact test, $p = .343$) than other mothers. From the results of the data, it is difficult to

predict which mothers are going to find the first week difficult and what factors affect the adaptation process.

The only variable that appeared to have any bearing on the difficult first week was the prompt visit of the public health nurse. Table 11 shows that of the 34 mothers who were visited by the public health nurse during the first week only 12 (35%) reported a difficult first week. Of the 22 who did not receive a visit within one week after discharge, 13 (59%) reported difficulty during that time. This difference approached, but did not quite reach statistical significance (Fisher's exact test, $p = .070$) at the .05 level.

Table 11

Visit of the Public Health Nurse During the First Week After Discharge and Whether the Mother Reported Having a Difficult First Week

		Visit within one week		
		yes	no	total
difficult first week	yes	12	13	25
	no	22	9	31
Total		34	22	56

Summary

The mothers of high-risk premature infants received very much the same information as is given to mothers of

full-term, healthy infants. Topics such as infant feeding and bathing are covered. Information that these mothers did not receive, but wanted, consisted of items on infant colic, noisy breathing, "spitting-up", the "fussy" infant, the crying infant, when to take the baby outside the house, infant behaviour, and the area of infant illness. Primiparas had an increased need for information over multiparas and those mothers attending prenatal classes appear to want more information. Mothers of male infants appear to acquire more information than mothers of female infants.

Only a limited amount of information regarding breastfeeding is received by the mothers of high-risk premature infants. In comparison, 82.9% of primiparas and 66.7% of multiparas received information on formula preparation. However, the data indicate that, while the mothers did not receive much breastfeeding information, many did not want more information.

Mothers who reported that they needed more information and did not receive it, were more anxious and less confident. The more experienced mothers were less anxious. The data suggests that primiparous mothers have increased need for information and increased anxiety and multiparous mothers perceive themselves as more competent in areas of infant feeding and care.

The number of times out for fun was not significantly

correlated with the measures of confidence and anxiety, but was significantly correlated with total need for information suggesting that mothers who want to know more information, are less willing to leave their infant.

Seventeen (30.4%) of the 56 mothers attended prenatal classes and 15 of these mothers were primiparas indicating that primiparous mothers were more likely to attend these classes than multiparous mothers. Similarly, of the 30 mothers attending hospital classes, 22 were primiparas and 8 were multiparas. A chi-square test showed that the attendance patterns of primiparous and multiparous mothers were independent.

A difference was found in the amount of information the mothers received from the various hospitals. The mothers at Hospital C appeared to receive less, and need more information than did the mothers at the other two hospitals. Hospital B provided significantly more information to primiparas than did Hospitals A and C. However, there was significantly more information given to multiparas at Hospital A.

Seventy-five percent of the total group of mothers had husbands/boyfriends helping them. The second most frequently used source of support was the mother's mother. Forty-three (81%) of the mothers defined the support given in terms of material support. Forty-six (82%) of the mothers found the support adequate. Multiparous mothers

appeared to not receive the same amount of support as did primiparous mothers.

Fifty-two (92.9%) of the mothers had visits from the public health nurses, with 34 (60.7%) of the mothers having visits within the first week following discharge of their infant from hospital. Forty-three (76.8%) of the mothers found the visit helpful.

Forty-five (80.4%) of the mothers found the timing of the visit to the family physician appropriate.

Forty-four (78.6%) of the mothers wanted a place to call for assistance and 49 (87.5%) of the mothers indicated that they would appreciate a booklet covering the care of the premature infant at home.

Twenty-five (44.6%) of the mothers found the first week after the infant's discharge from hospital difficult. The prematurity of the infant appeared to be a major factor in making this period seem difficult. From the results of the data, it is difficult to predict what mothers are going to find the first week difficult and what factors affect the adaptation process. The only variable that appeared to have any bearing on the difficult first week was the prompt visit of the public health nurse.

Chapter V.

LIMITATIONS AND CONCLUSIONS

This chapter will discuss the limitations of the study and the conclusions drawn from the results. Implications for nursing practice, education, and research will be discussed.

Limitations of the Study

This research was an exploratory, descriptive study and no cause and effect conclusions can be reached. This study provides a description of a particular sample.

A non-random, convenience sample was used for this project and this type of sample may present problems in that "the available subjects might be untypical of the population" (Polit & Hungler, 1983, p. 414). This probably prohibits the researcher from generalizing the results to the general population. However, the mothers composing this sample did come from a number of hospitals and were delivered over a period of time and there is little reason to expect that they would differ from the population of mothers of premature high-risk infants in the province.

A second possible limitation was the validity of the instrument. Efforts were made to establish content validity

by having various persons knowledgeable in the area review both the pilot study questionnaire and the final version of the questionnaire and approval was granted on the basis of content. Face validity was established by a similar procedure.

If this study were to be done again, it would be useful to obtain information documenting the mothers' educational preparation; to ascertain if the mothers sought information and support from physicians, nurses, social worker, as well as family and friends (and the order of priorities); and if multiparas attended prenatal classes previously. Some of this information was volunteered by participants in the study, but complete data were not systematically collected on all the subjects.

Conclusions

The purpose of this study was to measure the mothers' of high-risk premature infants perceived need for information and support; the availability of the information and support; and the mothers' perceived satisfaction with their information and support sources. An attempt was also made to determine the types of support needed in cases where support provided was perceived to be inadequate.

The data indicated that mothers of high-risk premature infants received information similar to that given to

mothers of healthy, full-term infants. The results showed, as well, that these mothers wanted more information than they received. This was especially true of the primiparous mothers and the amount of information received correlated with anxiety and confidence levels. Multiparous mothers did not appear to want the same amount of information as did the primiparas. However, multiparas appeared not to be as well supported as did the primiparous mothers. The predominate source of support for both groups was the husband/boyfriend, followed by the family, especially the mother's mother. The mothers indicated that the majority of the support needed was either in the category of information or material support, however, there were data that showed that emotional and comparison support was also very important.

This study indicated that the first week after the infant's discharge from hospital was a difficult week for many of the mothers. From the results of the study, it is hard to predict which mothers are going to find the first week difficult and what factors affect the adaptation process. The only factor that appeared to improve the adjustment process was the early visit of the public health nurse.

The data indicated that hospital teaching programmes can be improved in a variety of ways. One hospital needs to increase the amount of information that is given to the mothers, another needs to encourage the multiparous mothers

to participate more in the classes, and another hospital needs to place more emphasis on the teaching of the primiparas. A structured teaching programme focused on the individual needs of the mothers would help all hospitals to increase the amount of information given to the mothers.

There was a demand for a booklet on post-discharge premature infant care and a place to call for information. While M. Harrison and Hicks (1983) cite books and pamphlets as the main source of information for mothers, for a mother of a premature infant there is still very little information available, especially for the post-discharge period. In addition, many of the books that are available are written for professionals or the "middle-class" and "upper-class" audience.

Implications of the Study

This study has implications for nursing practice, education and research.

Nursing Practice

As stated earlier in this study, the construct of social support in research is especially pertinent to nursing and nursing theory in that it relates the concepts of health, environment, and person with the ultimate goal of

the improvement of nursing practice. This study gives insight into important information that can assist both hospital and community-based nurses in improving their nursing practice.

Mothers of high-risk premature infants often have limited access to prenatal classes. Some hospitals, public health units, and other organizations do offer "early-bird classes" and all mothers should be (and most are) encouraged to attend. However, many mothers do not anticipate that they will have difficulty with their pregnancy and put off going to prenatal classes until the latter part of their pregnancy. By that time, a small percentage of these mothers are either in hospital on the antenatal units, or have already delivered. For those mothers admitted to the antenatal units, there is a perfect opportunity for hospitals to provide the information and support so badly needed, both to the mother and to other members of her family. Unfortunately, this opportunity is often missed. Antenatal teaching should be an essential part of the hospital's teaching program. Not only can topics regularly covered by prenatal classes be taught, but aspects such as caesarian sections, and premature births can be handled in a way to relieve some of the anxiety present. Information on these two areas was particularly requested by the mothers in this study. Anticipatory guidance can be done by showing the mothers and fathers the delivery and neonatal units,

explaining to them what is likely to happen, how soon they can get to see their baby after the birth, and how accessible their infant will be to them.

During the post-delivery period, instruction can be focused toward the care of the premature infant. This instruction should not concentrate entirely on the medical and equipment aspects as it does now, but involve discussions with parents about their feelings regarding their infant's prematurity, and their feelings of guilt, fear, and lack of confidence. Emphasis needs to be placed on topics such as infant care, infant behavioural cues, infant development, and follow-up plans for the infant. Discussion should occur regarding the differences and similarities between full-term and preterm infants and what is meant by chronological and corrected chronological age. The nurses should inquire about the mother's need for support, the size of the mother's support network, and the quality of this support network as perceived by the mother. If the support network appears to be inadequate, the nurses may need to intervene and provide counseling regarding how the mother can achieve more support or accept help that is offered. The nurse can help the mother clarify what support she expects from her husband or other family members. This is especially needed for multiparous mothers who, having previous experience with children, are now assumed to not need as much support in the post-discharge period.

Mothers in this study requested more discussion on caesarian sections and prematurity in prenatal classes. They also wanted to be given the option of attending hospital classes. Most wanted a place to call and most wanted an information booklet covering post-discharge infant care and the development of a preterm baby. It is obvious that a need exists for a well-thought out, structured teaching programme for mothers of high-risk infants that can be tailored to the individual needs of the parents. An adaptation of the teaching manual developed by Fuller and Rovers (1986) could offer an ideal way to present this teaching program. There are many very good videotapes available that can be used in conjunction with the teaching programmes.

There should be better communication between hospitals when an infant has been transferred to a neonatal intensive care unit outside of the hospital in which she or he was born. Hospitals are very good in providing pictures of the infant, and facilitating the parents' access to their infant by means of telephone communication, or by allowing the mother to come to visit for short periods of time while she is hospitalized in another hospital. However, for parents who are too far away to be with their infant, mechanisms such as use of the teleconference system might also provide more adequate information and support. Such a system would allow medical and nursing personnel close to the parents to

hear what the parents are told, thus enabling them to clarify areas not understood by the family. In the future, computers will also enable hospitals to relay information to other health centres, thus enabling the physicians and nurses to give more current information to parents regarding their infant's condition.

Efforts should be made to get mothers and fathers in to be with their baby, and this may require support from social services.

Many mothers lack confidence due to early separation of mother and infant and it is in this area that both hospital and community nurses can play an important role in providing information and support. Hospital nurses should keep the public health nurses well informed from the beginning of the mother's hospitalization so that the public health nurse can visit the mother soon after she is discharged and help in providing communication between hospital and home. Often parents need someone to explain, in simpler terms, what they have been told by hospital staff, or to clarify information. They need someone to help them prepare for their infant's homecoming and provide that continuity of care over the early infant post-discharge period. As well, both hospital and community nurses should give the parents opportunity to talk about their feelings regarding the vulnerability of their infant. Where possible, parents of preterm infants should be linked with parents of other premature infants.

Nursing Education

For the last few years, Health and Welfare, Canada, and other health-related organizations have placed particular emphasis on the prevention of perinatal problems and preventative care for the elderly. It is recognized that nursing students cannot cover all the many complex health problems in existence, however, this investigator feels that the curriculum of the schools of nursing, both in the undergraduate and graduate programmes should reflect the current policies and thinking of the health care community. This means that more emphasis should be placed on the effects of perinatal influences, the needs of mothers of high-risk infants, the needs of the infants, themselves, and the long-term effects of the high-risk situation on the infants and their families. The student well versed in this area can be better prepared as a graduate nurse to assist mothers, whether they are in the community or hospital, or be a support person for family and friends.

Public health nurses need ongoing inservice education programmes that centre, not only on the needs of the mothers and the healthy infants, but also on the needs of the mothers and infants at-risk. Hospital nurses need to have a better understanding of the information required by these mothers prior to their infants' discharge and the methods for best presenting this information. They also need to be

more aware of the mother in the community and ways of bridging the gap between hospital and community.

Nursing Research

Future research should investigate such areas as the public health nurses' feelings about, and preparation for, dealing with the high-risk infant post-discharge; factors affecting the difficult first week; differences in support needs of mothers of high-risk premature infants, high-risk, full-term infants, and mothers of healthy, full-term infants; data on the relationship between social support of the mothers of this sample and the long term outcome of their infants; mothers and fathers' perception of the roles provided by nurses, physicians, and social workers in the high-risk situation; fathers' needs for support and how they perceive they can best support their wives and families; and lastly, other stresses that occur to the family at the time of the delivery of the preterm infant.

Summary

The results of this survey strongly suggest that special attention must be given to preparing the mothers to feel confident in their ability to care for their infants during the post-discharge period and to have a basic

understanding of the infant's behavioural development. As well, services such as early visits from the public health nurse, visits to the family physician within a week post-discharge, and a place for mothers to call if they have questions, need to be provided for these parents after their infant's discharge from hospital.

The purpose of this research was to evaluate the needs of a specific geographically-based sample in order to provide the groundwork for an improved teaching and support programme for mothers of high-risk premature infants. In addition, Newfoundland provides an unique opportunity to study a stable population that has maintained the extended family concept and a strong sense of community support. In many instances, during the collection of the data for this study, a mother would report that her "friend was a nurse and worked in the nursery" and helped her, or that, "the public health nurse lived across the road". Despite the crisis period, many had a sense of confidence that came out of the support that they received. The mothers were eager to share their feelings about their experiences with premature birth and to offer suggestions for an improvement of the teaching programmes. This study, too, has a sense of a "community involvement" with many of the mothers asking about the data results and encouraging the writing of the booklet. The investigator feels that, if mothers in this study expressed a need for support, then the need must be

much greater in areas with large urban populations, a lack of extended family, and without the sense of community that is so evident here on this island.

At the beginning of the thesis, a question was asked regarding the adequacy of the information and support programs currently available to mothers of high-risk premature infants in the Provincial Follow-Up Programme. The mothers have replied by indicating that they need more information and support and that this need is present before and after discharge of their infants from hospital.

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APPENDIX A

PROVINCIAL PERINATAL PROGRAMME

CRITERIA FOR PATIENTS ENTERING FOLLOW-UP SERVICE

1. All infants weighing less than or equal to 1500 grams.
2. All infants with neurological signs persisting beyond 6 hours of age.
3. All infants with neonatal seizures.
4. All ventilated neonates.
5. All infants with meningitis occurring in the first 28 days of life.
6. All infants with Apgar Score 5 or less at 5 minutes.
7. All infants with head circumference 2 standard deviations below the mean at birth and remaining so at time of discharge from hospital.
8. All infants with significant hypoglycemia (a blood glucose level of less than 1.5 umol/litre for 4 hours++ or the symptomatic infant with a blood glucose level of less than 1.5 umol/litre on 2 or more occasions).
9. All infants with signficant metabolic acidosis at birth (cord blood pH less than 7.20 and a bicarbonate value of less than 14 or BE value greater than -12).

* Multiple births: Should one infant of a multiple birth have any of the above criteria, the other infant of that birth will be followed automatically.

APPENDIX B

The following questionnaire is to be used to assess the kinds of information and support that you received, or you felt would have helped you in caring for your baby after he/she left the hospital.

A.

Circle the letter corresponding to your answer. Please circle only one of a), b), c), d), or e), as your answer to each of the following questions.

DO YOU FEEL THAT, DURING YOUR BABY'S HOSPITALIZATION, THE NURSES GAVE YOU ADEQUATE INFORMATION ABOUT:

1. How to breastfeed your baby?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

2. How to know if your baby was getting enough breastmilk?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

3. How to prepare the formula?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

4. How much formula you should give at each feeding?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

5. How to help your baby feed well, e.g. how to burp him/her, hold him/her, and to know when she/he is full?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

6. When to start the baby on cereals and the kind of cereal to begin with?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

7. Whether the baby needs any vitamin supplementation?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

8. How to give your baby a bath?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

9. How to give medicine (if any) to your baby?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

10. How to take your baby's temperature?
   a) Yes
   b) Yes, but I didn't want this information.
   c) No, but I would have liked this information.
   d) No, but I didn't want this information.
   e) Don't know/don't remember

11. The immunization schedule for your premature baby?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

12. How to take care of a diaper rash?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

13. How to know if the baby's "spitting-up" is normal?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/ don't remember

14. How to know if the baby has colic?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

15. How to know if the baby's bowel movement is normal?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

16. How to recognize if your baby is becoming ill?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

17. What to do if you think your baby is becoming ill?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

18. Your baby may have a little problem adjusting to your home for the first couple of days, since she/he has been used to lights and noise 24 hours a day in hospital?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

19. What temperature and humidity to keep your house?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

20. How warmly to dress your baby?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

21. When to start to take your baby outside the house?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

22. How long you should expect your baby to sleep between feeds?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

23. How to know if your baby's "fussy periods" are normal?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

24. What to do about your baby's crying?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

25. What is "normal" behaviour and development for the premature infant may be "different" from the behaviour and development of the full-term baby?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

26. Whether it is normal for a premature baby to "grunt" and "groan", "sneeze" and "hiccup"?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/ don't remember

27. Whether noisy breathing, especially at night, can be normal for premature babies?
    a) Yes
    b) Yes, but I didn't want this information.
    c) No, but I would have liked this information.
    d) No, but I didn't want this information.
    e) Don't know/don't remember

28. Whether your premature baby may have a slightly irregular breathing pattern?

a) Yes
b) Yes, but I didn't want this information.
c) No, but I would have liked this information.
d) No, but I didn't want this information.
e) Don't know/don't remember

29. What kinds of behaviour to expect from your baby during his/her first six weeks at home?

a) Yes
b) Yes, but I didn't want this information.
c) No, but I would have liked this information.
d) No, but I didn't want this information.
e) Don't know/don't remember

30. How to get your baby to respond to you? (smiling, following with eyes, cooing, gurgling)

a) Yes
b) Yes, but I didn't want this information.
c) No, but I would have liked this information.
d) No, but I didn't want this information.
e) Don't know/don't remember

B.

Please answer the following questions in section B by writing short answers or by circling one of the options; a, b, c, d, or e.

1. How many children do you now have?

(a) 1 child - (c) 3 children
(b) 2 children (d) more than three children

2. What are their ages?

---

3. When was your baby born?

---

4. Is your baby (a) boy, or (b) girl?

5. How old was your baby when you brought him/her home from the hospital?

Days:
Weeks:
Months:

6. Did you attend prenatal classes?

(a) Yes (b) No

7. If yes, were these classes helpful?

(a) Yes (b) No

8. Did you attend the infant care classes during your hospital stay?

(a) Yes (b) No

9. If yes, were these classes helpful?

(a) Yes (b) No

10. After leaving hospital, what did you find to be the most difficult period in caring for your baby?

(a) week one
(b) week two
(c) week three to four
(d) after week four

11. Why was this period the most difficult?

---

12. After your baby came home from the hospital, did you have anyone to help you?

(a) No (PLEASE GO TO QUESTION 17)
(b) Yes, my husband, boyfriend, partner
(c) Yes, a friend or neighbour
(d) Yes, another family member
(e) Yes, a house-keeper

13. How did this person (these persons) help you?

---

14. Was this help adequate?

(a) Yes (b) No

15. If no, what kind of help would you have liked?

---

16. How many times in the last month have you been out to have fun and relaxation?

GO TO QUESTION 19

IF ANSWERED NO TO QUESTION 12, PLEASE ANSWER QUESTIONS 17 AND 18.

17. Would you have liked to have had help from family and friends?

(a) Yes (b) No

18. What kind of help would you have liked?

---

19. Did you have a visit from the public health nurse?

(a) Yes (b) No

20. If no, would you have liked to have had a visit from the public health nurse?

(a) Yes (b) No

21. If yes, how soon after the baby came home did this visit occur?

(a) within 48 hours of discharge
(b) a week of discharge
(c) 7-14 days of discharge
(d) more than 15 days

22. Did you find this visit helpful?

(a) Yes (b) No

23. If yes, how?

---

24. When did you first take your baby to your family doctor?

Why?

---

25. Do you think you should have taken the baby earlier to the doctor's?

(a) Yes (b) No

26. After your baby came home from the hospital, would it have helped if you had a particular place to call for information and support regarding your baby's care?

(a) Yes (b) No

27. After your baby came home from the hospital, would it have helped if you had had an informational booklet to which to refer?

(a) Yes (b) No

28. After your baby came home from the hospital, how did you feel about caring for your baby?

very anxious I_____I_____I_____I_____I very comfortable

29. After your baby came home from hospital, did you feel you had enough information to make you feel

(a) very confident in caring for your baby?
(b) had confidence in caring for your baby?
(c) slightly confident in caring for your baby?
(d) not at all confident in caring for your baby?

30. What other information would have been helpful to you?

---

31. What concerns did you have about your own care and how you felt during this period of time?

---

32. Did you or do you have any other concerns not already covered?

APPENDIX C

Information to Participants Regarding the Study of the Support Needs of Mothers of Premature Infants.

You are invited to answer a questionnaire to find out about the kinds of information you received from hospital nursing staff and teaching programs prior to your baby's discharge from hospital, and whether this information was adequate. The questionnaire will also ask about the kinds of support that you received in the post-discharge period; whether this type of support was adequate and what type of support was needed where support provided was perceived to be inadequate.

The study is being conducted by Edna McKim, a Master's student at Memorial University School of Nursing. This study is part of the requirements for a degree in Master's of Nursing. Mrs. McKim may be contacted from 8:00 a.m to 4:00 p.m., Monday to Friday at the Provincial Perinatal Programme, Newfoundland Drive, St. John's (telephone number 778-4657).

If you decide to participate, you will be asked to complete Part A of the questionnaire by circling one of five options regarding the information you received or did not receive about your baby's care. Part B of the questionnaire covers the kinds of support you did or did not have after you took your baby home from hospital. This part of the questionnaire will be completed by Mrs. McKim asking the questions and recording the answers. The questionnaire will take about 15 minutes to complete. The results of this questionnaire will be used to improve the support and information that is provided to families when their baby is discharged from hospital. Any questions you may have regarding the questionnaire or information about your baby's care will be answered.

The questionnaire is anonymous and it will not be possible for anyone to associate your name with any of the answers. The information contained in the questionnaire will be analyzed solely by Mrs. McKim. Reasonable and prudent measures will be taken to ensure the safe keeping of the questionnaire (i.e. questionnaire will be secured in a filing cabinet with a lock).

Participation in the study conducted by Mrs. McKim is voluntary and you may withdraw at any time. You can chose not to answer any questions. Your decision whether or not to participate in this study will not influence your child's present and future medical and nursing care.

If you want feedback on this study you can contact Mrs. McKim at the above address or telephone number. This information should be available by December, 1987.

Thank you for providing your valuable time.

APPENDIX D

The Support Needs of Mothers of Premature Infants

Consent Form

If you are willing to participate could you please sign the consent.

I have read and have a copy of the Information to Participants for the Study on the Support Needs of Mothers of Premature Infants.

I understand that participation in this study conducted by Mrs. McKim is voluntary and that I can withdraw at any time. I can chose not to answer any questions.

I hereby consent to participate in this study, the nature of which has been explained to me.

Signed: Date:

Witness: Date:

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