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Creating Paths: Living with a very low birth weight infant

Provencio-Vasquez, Elias, Ph.D.

The University of Arizona, 1992

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CREATING PATHS: LIVING WITH A VERY LOW BIRTH WEIGHT INFANT

by

Elias Provencio-Vasquez

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A Dissertation Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

1992
As members of the Final Examination Committee, we certify that we have read the dissertation prepared by Elias Provencio-Vasquez entitled CREATING PATHS: LIVING WITH A VERY LOW BIRTH WEIGHT INFANT and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy.

Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copy of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.
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SIGNED: Elias Provenzo-Vazquez
Dedicated to

My mother, Violeta Provencio-Vasquez

My daughter, Nicole Renee Vasquez

With love and appreciation
ACKNOWLEDGMENTS

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ABSTRACT

Advances in neonatal nursing and medical interventions have made it possible for the very low birth weight (VLBW) infant to survive. However, it is now time to recognize the intangible costs, emotional stress, marital stress, grief, pain, sorrow, and the disruption of the role transition to parenthood. To facilitate progress in the area of neonatal nursing, systematic efforts were undertaken to examine and describe parental adaptation to the VLBW infant and potential risk for parenting problems after hospital discharge.

The purpose of this study was to describe parents' method of adaptation to the problems of caring for a VLBW infant at home. Specifically this study was designed to identify:

1. What strategies parents employed during the adaptation process.
2. What resources parents combined with their strategies of adaptation.
3. What situations promoted or inhibited parental adaptation.

The informants consisted of parents of VLBW infants (<1500 grams) following hospital discharge. The number of subjects for this study was 14. An exploratory design was used to conduct this study. Each subject was involved in three
interview sessions, one month, three months, and five months following hospital discharge of their VLBW infant. Data were sampled theoretically, as guided by the emergent theory. The constant comparative method was used for data analysis. The study was judged for its degree of trustworthiness using multiple procedures.

A basic social process, Creating Paths, was identified as the core category of the theory. Creating Paths is the continuous process experienced by parents living with a VLBW infant the first five months after hospital discharge. The process consists of three stages: Gathering, Emerging, and Affirming.

Results of this investigation provide a beginning theoretical foundation for assessing the adaptation process of parents with VLBW infants the first five months at home. Neonatal nurses can utilize the model to provide anticipatory guidance and support to benefit parents and their VLBW infant. The model is especially germane to community health nurses who provide follow-up visits to these parents and their VLBW infants.
CHAPTER 1

INTRODUCTION

The purpose of this study was to explore the adaptation process that parents experience following hospital discharge of their very low birth weight (VLBW) infant. The concept of adaptation was derived from Roy's (1980) Adaptation Model. Adaptation is a process of ongoing interaction that individuals have with their environment to establish equilibrium. For example, parents grow to depend on the neonatal intensive care nursery culture for their emotional, social, and medical support while their babies are receiving care. The strategies parents employ to deal with feelings of isolation, the first month after the hospital discharge of their VLBW infant, can be viewed as the adaptation process.

Roy proposes that adaptation is a process of responding positively to environmental changes. Adaptive responses are those that promote the integrity of the person in terms of the goals of survival, growth, reproduction, and self-mastery. According to Roy and Roberts (1981) the person is in constant interaction with a changing environment. Environment is defined as all conditions, circumstances, and influences surrounding and affecting the development of an organism or a group of organisms. Thus, adaptation is a positive process in
response to the changing environment. For this study, the adaptation model is an approach that focuses on individuals who have the potential of experiencing difficulty in coping and integrating changes in their lives—the daily interaction of parents and their VLBW infant is constant and changing as they grow and adapt to each other.

The adaptation process to a stressful event may be effective or ineffective. Effective adaptation emphasizes the ability of the individual to come to terms with the demands of the environment. Ineffective adaptation is exemplified by the person who experiences long-term disorganization, emotional stress, and turmoil to an event which threatens their personal goals (White, 1974). Not all parents who give birth to a VLBW infant can adapt effectively to that infant. Retrospective studies show that a greater percentage of abused or neglected children are born prematurely than can be accounted for by random chance (Behrman, 1990; Ayoub & Milner, 1985; Klein & Stern, 1971; Elmer & Gregg, 1967).

A striking change in recent years has been the conversion of relatively quiet centers for prematurely born infants into bustling, high technology intensive care units for high risk infants. During the past two decades, we have witnessed spectacular progress in the nursing and medical care of premature infants. Very low birth weight infants—those weighing less than 1500 grams were expected to die, as were
most neonates with malformations. There has been a dramatic improvement in the rate of survival and the quality of life for VLBW infants (Scott & Spiker, 1989; Brandt, 1984; Thornton, Berry, & Dal Santo, 1984; Jung & Bose, 1983; Hein & Brown, 1981; Maugurten, Slade, & Fitzsimons, 1979; Hack, Fanaroff, & Merkatz, 1979). Very low birth weight infants are considered viable at earlier gestational ages and most often successfully progress into childhood, adolescence and adulthood. Nurses play a crucial part in the outcomes of these infants, attending to their basic physical and psychosocial needs. As a result, the increasing survival rate of VLBW infants leads to an expanding group of parents who must cope with the full time care of their VLBW infant once discharged from the hospital. Moreover, this situation may place VLBW infants and their parents at increased risk for a variety of psychosocial sequelae, including child abuse, neglect, and failure to thrive (Perrault, Coates, Collinge, Pless, & Outerbridge, 1986; Hunt, 1984).

Experiencing a premature birth can have short or long term effects on the parents. According to Powell (1974) prematurely born infants are poorly parented more frequently than are infants born after normal gestation. The interruption of pregnancy by a premature birth is a crisis for the parents. Tarbert (1985) and Noga (1982) report that parents who are experiencing a premature birth are encountering one of the most stressful events in their lives. Supportive intervention can
assist parents to accept their premature infant and their situation (Ross, 1984; Shwartz, 1981; Mercer, 1977). Parents who are most successful at adapting to the birth of a premature infant are those who express their feelings openly, have adequate support systems and are "informed" parents (Bull & Lawrence, 1985; Leahy, Cobb, & Jones, 1977). Health care providers play a major role in helping parents with premature infants to cope.

Over the past 20 to 25 years a great deal of time, energy, and money have been directed towards acute care of the VLBW infant, resulting in a steady decline in neonatal mortality (Hernandez, Offutt, & Butterfield, 1986; Fitzhardinge & Pape 1981). Lowering the mortality for these high risk infants has resulted in an increased number of normal survivors but has also, in some instances, resulted in an absolute increase of children with handicapping sequelae.

Research on the general health of VLBW infants indicates that between 30 and 38 per cent of these infants are rehospitalized at least once during the first year of life, compared with an 8 per cent rate for infants weighing 2,500 grams or more. When all serious illnesses are taken into account, less than 40 per cent of infants weighing below 1,500 grams at birth are free from morbidity during the first year, as compared to more than 70 per cent of all infants (Goodman & Savue, 1985; Hack, DeMonterice, Merkatz, Jones, & Fanaroff, 1981). These studies confirm the continuing toll of perinatal
morbidity among VLBW infants and emphasize the responsibility for continuing care of these infants.

Perinatal or neonatal mortality figures provide only a partial evaluation of the activities of the NICU and need to be supplemented by a constant monitoring of the quality of the survivors. An excellent survival rate does not necessarily mean that a high proportion of the survivors will be normal. High risk infants, especially VLBW infants, require close medical and nursing supervision during their first year of life and often need specialized treatment (Hurt, 1984). In an age of limited health care resources, to inadequately plan for follow-up of VLBW infants means wasting the millions of dollars spent on saving them. Continuing care of the premature infant can provide both information for research and support to families often frightened about caring for their VLBW infant at home (Roncoli & Brooten, 1985).

OVERVIEW OF THE PROBLEM

About seven per cent, or 250,000 of the 3.5 million babies born in America each year weigh less than five and a half pounds and require intensive care (Vital Statistics of the United States; the 1985 U.S. National Natality Survey of the National Center for Health Statistics). It has been estimated that about 60,000 of the 250,000 low birth weight infants born each year may be at high risk for serious lifetime disability.
In addition to the human tragedy, the fiscal impact of this problem on our society is estimated to be in the billions of dollars each year (Gottfried, Hodgman, & Brown, 1984; Fanaroff & Martin, 1983).

Within the past two decades, the mortality rate for premature infants has dropped more than 55 per cent. Before the most striking progress was made, in the early 1970's, only half of all VLBW infants weighing between 1,000 and 1,500 grams survived (Lyon, 1985; Kitchen & Campbell, 1984). At present, with the high technology intensive care units for premature infants, most tertiary neonatal intensive care units are reporting increased survival rates for infants born weighing less than 1000 grams. The proportion of live births made up by infants weighing less than 1500 grams has changed little in the past several decades. However, recent documentation by many investigators report the increasing survival rate of the VLBW infant, particularly for the group weighing 1000-1500 grams (Dunn, & Stirrat, 1984; Philip, Little, Polivy, & Lucey, 1981; Dweck, 1977).

Some VLBW infants will be handicapped as children. The smaller they are at birth, the more prone they are to cerebral palsy, seizures, mental retardation, learning disabilities, blindness, chronic lung disease, and hearing loss. In April 1985, Ernest Kraybill, a professor of pediatrics at the University of North Carolina School of Medicine, presented an analysis of published statistics before the American Academy of Pediatrics. He found that among children who weighed less than
1000 grams at birth, 67 per cent of the survivors were normal at one to two years of age; 14 per cent had mild to moderate handicaps, such as mild cerebral palsy or impaired eyesight; and 19 per cent had severe handicaps, including crippling cerebral palsy, blindness, and mental retardation (Grady, 1985). Moreover, while survival rates have improved, the general health for VLBW infants is poorer and rates of rehospital-ization and acute care visits are greater than that of normal weight infants (McCormick, Shapiro, & Starfield, 1980).

A specific stress situation, one occasioned by birth earlier than expected, can be described as an acute emotional disorder (Caplan, Mason, & Kaplan, 1965). When parents experience the birth of a premature infant, they attempt to cope with the threatening event—one they are not sufficiently psychologically prepared for. What becomes readily apparent to health care providers is the continuing anxiety the parents must deal with. This emotion with the emergence of others such as guilt, helplessness, and sadness, have the potential to generate inadequate coping mechanisms leading to maladaptive behavior.

Research documents the anxiety related to the shortened pregnancy period coupled with images of an incomplete product. Prugh (1953) stated the sources of anxiety that parents felt after infants had been born prematurely. Prugh believed that the anxiety may come from the infants' size, maternal feelings
about the pregnancy, mother's degree of confidence about the maternal role, disturbing home conditions, stress, or mothers' own early family relationships.

A second emotion that parents experience which increases any anxiety present is guilt. Guilt may emerge from resentment towards the premature infant for having been born early, and/or the mother's first feelings on seeing the premature infant, resulting in feelings of "disgust or dismay" (Solnit & Stark, 1961; Prugh, 1953).

In my clinical experience, guilt seems to be the major emotion parents feel when confronted with the birth of a premature infant. When I inform parents of the diagnosis and prognosis of their VLBW infant, a common response is "I thought I took care of myself." Parents, especially mothers, will rationalize that they ate healthy foods, exercised and were faithful to their appointments with the doctor or midwife. "How could this happen to us if we did everything the way we were supposed to?" Parents focus on their behaviors during pregnancy or reflect on the past—as if they are being punished for "something bad or evil we did in the past" e.g. premarital sex, or a history of induced abortions.

These feelings can lead to ambivalent feelings toward the premature infant. Caplan, et al. (1965) studied the reactions of 86 families to the birth of a premature infant and conceptualized these reactions as an acute emotional crisis. They believed the mother's reaction to the stressful event
might have interfered with the healthy personality development of the child. They noted that a mother who had delivered an infant before term tended "to urge the babe to eat and grow as if to reassure herself about her ability as a mother" (p.158). It seems that if the mother's concern over her own satisfaction was greater than her concern for the needs of her infant, that this would lead to an unhealthy relationship between mother and child. This unhealthy relationship would have a subsequent effect on the personality of the child.

As a neonatal nurse practitioner, I witness the emotional trauma parents of a premature infant encounter, for example, the unpredictable medical course and the prolonged hospitalization. When parents realize their infant is going to survive, they begin integrating the premature infant into their world. For example, touching their infant, calling the infant by name, and introducing family members to their new sibling, or grandchild—this occurs over a few days. I view this as a piecing process; parents putting their family together by "bits and pieces." I often wonder, with great concern, how parents continue to incorporate the premature infant into their world following hospital discharge. Moreover, I am disappointed that the burst of energy and care we give to the premature infant and parents often stops at the doors of the Neonatal Intensive Care Unit (NICU).

As a premature infant approaches discharge from the hospital, it becomes evident that parents experience increased
anxiety and apprehension (Gennaro, 1986; Cagan & Meier, 1983; Mahan, 1983). Over the past decade nurses have become increasingly aware of the emotional impact that the birth of a premature infant has on the family at home. Studies concerning family adjustment to a VLBW infant reveal continuous strain and disruption because of the associated demands on the family (Sulllenbarger, Norris, Edgil, & Prosser, 1987; Trahd, 1986).

One of the most important aspects of nursing is the emphasis placed on the family unit. The quality of family life is closely related to the health of individual family members (Friedman, 1981). Recent research supports the need to explore the subsequent quality of family development when dealing with a VLBW infant and the effects over time. No family member remains uninvolved or unaffected by the birth of a VLBW infant. Research and clinical observations suggest that the demands for care of a VLBW infant with a chronic illness tax family relationships as well as individual family members (Stullenbarger, et al., 1987; Barbarin, Hughes, & Chesler, 1985).

The parent-infant relationship is a reciprocal one in which both parent(s) and infant are influenced by the behaviors of one another. When mutually pleasurable interactions between parent and infant begin early, a spiral is set off that leads to satisfaction in parenting and at the same time to optimal development of the infant (Stern, 1985; Beckwith, Cohen, Kopp, Parmelee, & Marcy, 1976).
From interviews and observations Brazelton and Cramer (1990) and Brachfeld, Goldberg, and Sloman (1980) concluded that mothers of VLBW infants worked harder in the first few months of life to engage with their infants, have little synchronous interactions, and receive little gratification from their infants as compared to mothers and their term infants. Furthermore, studies show that VLBW infants are at high risk for neurodevelopmental, psychosocial, and behavior problems. This risk is increased twofold in VLBW infants from families with factors that threaten parenting behavior e.g. parental attitudes, interaction, and attachment (Hunt, Cooper, & Tooley, 1988; Resnick, Armstrong, & Carter, 1988; Beckwith & Cohen, 1978).

PILOT STUDY

To provide insight, I conducted a pilot study to explore how parents interact with their premature infant at home. The pilot study used a naturalistic observation method for data collection, nonparticipant observation. This method allowed complete recording of all the observed care giving activities while they were occurring. Parents of four premature infants were recruited as subjects for this study. The observations focused on the following activities; feeding, eye-to-eye contact, verbal interaction, touching, dressing, and efforts to relieve distress (crying). A checklist was developed to
categorize the observations. The checklist was based on both the literature (Harrison & Twardosz, 1986; Minde, Perrotta, & Marton, 1985; Funke & Irby, 1978) and my clinical experience. The checklist served as a guide and allowed me to quantify the observations of care giving activities in the home.

The results showed that the majority of care giving activities were provided by mothers, though both parents were present during the four observations. Perhaps the father's lack of involvement was influenced by my presence, or it may be that mothers interact more with their premature infants, thus providing the majority of care. Interviews would have been helpful in exploring these questions about the relative involvement of mothers and fathers with infant care. Another element of consideration would have been to assess the degree and quality of parent-infant interaction, since this is known to be a powerful influence on the development of VLBW infants. The current study identifies ways parents attempt to get to know their VLBW infant—establishing patterns of interaction between parent and infant.

Health care providers have begun to question the neurological and psychosocial developmental consequences of VLBW infants requiring intensive care. The aftercare of discharged VLBW infants has become of significant concern for nurses. Research shows that early diagnosis of developmental delays, family dysfunction, and the mobilization of community resources coupled with early intervention programs that provide
parents with developmental stimulation and interactional
skills, will optimize the developmental outcome for the VLBW
infant (Resnick, Eyler, Nelson, Eitzman, & Bucciarelli, 1987;
Carroll, 1985; Ross, 1984; Avery, 1981; Fitzhardinge, 1976).

However, many problems can not be quickly resolved and
are not fixed by follow-up programs e.g. social/family
dynamics, social support, and chronic problems. Therefore,
many important questions remain unanswered. For example,
research is needed to evaluate how social/emotional functioning
and family adapting affect cognitive outcome for the VLBW
infant. Long term intervention programs (beyond the VLBW
infants second year of life) which continue to provide
surveillance and support to VLBW infants and their families
require further exploration. Finally, information about the
presumed interactions between biomedical risk factors and
social-familial risk factors is incomplete.

THE PURPOSE OF THE STUDY

Although several descriptive studies have been done
regarding the concerns and teaching/learning needs of parents
of VLBW infants (Brooten, Gennaro, Knapp, Brown, & York, 1989;
Butts, Brooten, Brown, Bakewell-Sachs, Gibbons, Finkler, Kumar,
& Delivoria-Papadapoulos, 1988; Strauss & Munton, 1985; Arney,
Nagy, & Little, 1978), an extensive search of the literature
did not reveal studies reporting the adaptation process that parents experience after hospital discharge of their VLBW infant. Consequently, the purpose of this study was to explore the adaptation process parents experience at one month, three months, and five months following hospital discharge of their VLBW infant.

Three research questions were explored:

1. What strategies do parents employ during the adaptation process?

2. What resources do parents combine with their strategies of adaptation?

3. What situations promote or inhibit parental adaptation?

The answers to these questions will reveal ways to facilitate the adaptation process that parents experience after hospital discharge of their VLBW infant.

SIGNIFICANCE TO CLINICAL PRACTICE

Nurses play a major role in helping parents integrate the VLBW infant into their world following hospital discharge. The goal of nurses dealing with parents of VLBW infants is to prevent and/or reduce high risk family problems by promoting satisfaction and interaction among the parents and infant. One example of a nursing intervention is to help parents identify their own behavior so that they can mobilize their resources to help
resolve the problem (Johnson, 1979). Improving intervention and identifying social support will enhance positive caretaking abilities and promote family development. Supportive intervention can assist parents in accepting their VLBW infant and their situation. Working with parents after discharge of the VLBW infant is identified as important in preventing failure to thrive, child abuse, accidents as well as improving the developmental level of these infants (Resnick, et al., 1987; Hayes, 1980; Larson, 1980).

Suddenly being responsible for the care of a VLBW infant can be a frightening experience. Parents may not always be able to anticipate what they will need to know once they are home with their infant. The ability to understand the adaptation process that parents of VLBW infants experience following hospital discharge will allow nurses to recognize behavior patterns which place the infant and parents at risk for disunity. Moreover, this will provide valuable clues to anticipatory planning for prevention as well as intervention.

Therefore, the significance of the problem to nursing is related to the impact nurses have on the long-term health outcomes for VLBW infants. The medical profession is currently providing follow-up evaluations for premature infants with the emphasis on growth and development e.g. neurophysiologic development. Nurse researchers should take the lead in concern with the social-psychological processes of parents of VLBW infants following hospital discharge, i.e. their adaptation.
Clinical research is essential to the development of nursing science. In practice sciences, knowledge is sought for some purpose. In nursing this purpose is the promotion of health, viewed as a state of well being that can be identified and altered by the health care provider (Parse, 1987). It is important to study phenomena from a nursing perspective, with a focus on person, health-illness, environment, and nursing. Orientation and philosophies regarding nursing can influence the way nurses view subject matter, and provide the general frameworks within which theories and research methodologies are developed in nursing (Kim, 1983).

Lately nurse scientists are rediscovering the qualitative method of generating knowledge, especially adopting the position taken by Glaser and Strauss (1967) for "discovering grounded theories" (Kim, 1983). By grounding theoretical formulation from practice and aligning practice problems for research, nursing can expand its scientific richness. The underpinning of all research is theory which guides scientific inquiry and serves to produce explanatory and predictive statements about phenomena under study (Tripp-Reimer & Dougherty, 1985). The generation of grounded theory in our profession would provide substantive middle-range theories, useful in their own right as bridges from theory to practice (Hutchinson, 1986). Moreover, the emergence and continuation
of theory development in nursing will strengthen the profession and reinforce the claim of social significance and the assertion of providing a unique service to society.

SUMMARY

The mortality rate for VLBW infants has improved. Much of the improvement for these infants has been achieved only in the last 25 years, since the introduction of high technology newborn intensive care units. Technology, however, cannot operate in a vacuum. It is now time to recognize the intangible costs, emotional stress, marital stress, grief, pain, sorrow, and the disruption of the role transition to parenthood. To facilitate progress in the area of neonatal nursing, systematic efforts should be undertaken to examine and describe how parental adjustment to the VLBW infant potentiates risk for parenting problems after hospital discharge. It has become increasingly important for centers which provide neonatal intensive care to also provide and ensure follow-up of their VLBW infants and their parents and families.
CHAPTER II

CONCEPTUAL ORIENTATION

This chapter discusses the conceptual orientation which directs the research study. Constructs of the conceptual orientation model (Figure 1) include Adaptation and Adaptive Nursing Care, grounded in Roy's (1980) Theory of Adaptation. The review of literature will follow discussion of the conceptual orientation.

OVERVIEW OF ROY'S ADAPTATION MODEL

The overall perspective for this study is adaptation which is conceptualized according to Roy's Adaptation Model (Roy, 1984; 1980). Roy's Model of Adaptation proposes that individuals strive for adaptation in response to stimuli from their environments.

ADAPTATION

The first construct identified in the conceptual orientation is adaptation, which is defined as a positive response to changes in the individual's internal or external environment that maintains the individual's health and integrity (Roy, 1980). The adaptation model views the individual as an adaptive system utilizing two major internal
Figure 1. Conceptual Orientation: Relationship of Parent's Adaptation and Adaptive Nursing Care (Based on Roy, 1984)
processor subsystems, the regulator and cognator. These subsystems are the coping mechanisms used by the individual for adapting to internal and external environmental stimuli. Regulator and cognator activity is manifested through four adaptive modes; physiologic, self-concept, role function, and interdependence (Roy & Roberts, 1981).

Roy (1980) states that the adaptation level of the individual is the result of the pooled effect of focal, contextual, and residual stimuli. Focal stimuli are the stimuli immediately confronting the individual. Contextual stimuli include all other internal and external stimuli affecting the situation. Residual stimuli are beliefs, attitudes and other factors from past experiences which are relevant to the present situation.

Behavioral responses of adaptation to a threatening situation may be effective or ineffective. Effective adaptation refers to behavioral responses that promote the individual's mastery, growth, and survival (Roy & Roberts, 1981). Effective adaptation implies the advancement of goals by changing the environment or changing oneself in response to events which threaten health and survival. The antithesis of an effective adaptive response is the adaptational outcome which is ineffective and inappropriate in resolving the demands of the environment. According to Roy (1980), ineffective responses occur when the quantity or quality of internal and external stimuli exceed the ability of the human system to maintain a state of equilibrium. When problem solving and decision making techniques are severely impaired then effective adaptation to
difficult and unusual conditions is often not achieved (White, 1974).

ADAPTIVE NURSING CARE

The second construct identified is adaptive nursing care, which is defined as nursing activity aimed at promoting an individual's adaptation in the physiologic, self-concept, role function, and interdependence modes during health and illness (Roy, 1980). Nursing is concerned with the individual as a total being, interacting with a changing environment and responding to stimuli present because of that person's position on the health-illness continuum. When unusual stressors or weakened coping mechanisms make an individual's usual attempts to cope ineffective, then the individual needs nursing care. Nursing aims to increase the individual's adaptive responses and to decrease ineffective responses.

The Roy (1980) Adaptation Model can be viewed primarily as a systems model. The adaptation model of nursing is an approach that focuses on individuals who have the potential of experiencing difficulty in coping with changes in their lives—such as parents of a VLBW infant might be. This model uses a problem-solving method to assist and support people in achieving an adaptive state.

PARENTS' ADAPTATION TO A VERY LOW BIRTH WEIGHT INFANT AT HOME

Recent clinical studies indicate that the problems for VLBW infants do not end with their discharge from the hospital,
but tend to continue or even to increase when they go home
(Kenner & Lott, 1990; Brooten, Brown, Munro, York, Cohen,
Roncoli, & Hollingsworth, 1988; Censullo, 1986; Perrault, et
al., 1986; Stewart & Reynolds, 1974). There is a high
frequency of illness and other conditions requiring rehospital-
ization during the early years of life for VLBW infants.
Moreover, the transition to home care is often accompanied by
parental concerns about managing the full time care of their
VLBW infants.

A major problem is uncertainty about the prognosis.
There are no clinical or laboratory means to assess precisely
the neurologic potential in the VLBW infant. In extreme cases,
there is little doubt that brain damage is catastrophic and
recovery is impossible, but the prognosis of VLBW infants is
colored with every shade of ambiguity (MacDonald, 1986). The
uncertainty of neurological sequelae can make the transition to
home care a significant event. Thus, health care providers
need to follow-up each infant in order to ensure provision of
ongoing primary/secondary care after discharge and to promote
the adaptation of parents and the VLBW infant within the home
environment.

The internal and external environments are sources of
inputs into the adaptive system. In Roy's Adaptation Model of
Nursing, the inputs take the form of stimuli. Three classes of
stimuli are identified; focal, contextual, and residual (Roy &
Roberts, 1981). The pooling of focal, contextual, and residual
stimuli make up what Helson (1964) describes as the individual's level of adaptation. For the purpose of this study, the VLBW infant serves as the focal stimulus. In this study, contextual stimuli are defined as the parents' description of present events or factors (stimuli) which influence their adaptation to their VLBW infant at home. The relevant residual stimuli will be identified from the parent's description of his or her personal traits, past experiences, attitudes and cultural beliefs.

Each parent has a zone of adaptation when living with a VLBW infant. The parent's adaptation zone is limited and can be exhausted by the presence of external or internal stimuli. The parent's adaptive responses to the stimuli help him or her develop new responses that readjust the limits of his/her adaptation zone. Nursing activity should be aimed at promoting positive adaptation of parenting role function. For example, parents should be informed that during the first months after discharge from the hospital, VLBW infants frequently develop feeding, crying, and sleeping difficulties. Parents should be encouraged to call the NICU for emotional support after discharge. Such communication is particularly critical in the first few weeks after the VLBW infant is at home. Fears and uneasiness can be dispelled by communicating with health care providers with whom they have developed some relationship during their VLBW infant's hospitalization (Philipp, 1984).

As stated, the parent's ability to adapt to their VLBW
infant at home is determined by the pooled effect of focal, contextual, and residual stimuli. The parents set up a zone of adaptation, such that any stimuli falling within it will lead to a positive response by the parent(s), and any stimuli falling outside the zone will lead to an ineffective response. Responses that do not contribute to goals of self mastery, growth, and survival are considered ineffective (Roy & Roberts, 1981). For example, VLBW infants have a different behavioral repertoire than full-term infants; routine care and feedings may be more difficult than the parents expect. The first 5 months at home with a VLBW infant can be quite stressful. Some of this stress may come from the parent's overconcern for their VLBW infant's health and welfare and may be expressed in their unwillingness to take the baby out of the house or in their continuing unnecessary night feedings (Butts, et al., 1988).

The success of adaptation between the individual and environment depends on the maintenance of a balanced internal structure, autonomy, and the securing of adequate environmental information. The human system has a natural tendency to maintain equilibrium by the rebalancing process of adaptation which is developed over a considerable length of time (White, 1974). Roy (1984) states that modification of adaptive responses occurs as judgments are made by the individual on the basis of the long-term success of their behavior.

HOME HEALTH NURSING CARE

Recent studies demonstrate the importance of home health
nursing follow-up of the family and VLBW infant (Ritchie & Mertens, 1987; Jacknik, Gumerman, & Parker, 1983; Noga, 1982). Unfortunately, the focus has been channeled more to acute care than to long term follow-up services for these infants and their families. The stress of the VLBW infant becomes compounded by the realization that, at home, the parents must care for their infant alone. In making the difficult transition between hospital and home care, parents often report feelings of fear, loss, inadequacy, and anger. The home health nurse is in an ideal position to bridge this gap- in providing follow-up care (Raff, 1986). This appropriate nursing intervention can promote the adaptation of VLBW infants and their families within the home environment.

MODES OF ADAPTATION

The individual is an adaptive system with two major internal processor subsystems acting to maintain adaptation, the regulator and cognator. The regulator and cognator are seen as acting in relation to four adaptive modes; physiologic, self concept, role function, and interdependence. The modes provide the particular manifestations of regulator and cognator activity (Roy, 1984).

Physiological

The physiological mode is associated with the way the individual responds as a physical being to stimuli from the
environment. Behavior in this mode are the manifestation of the physiological activities of all the systems comprising the human body. The physiological mode responds to stimuli that activate coping mechanisms that produce effective or ineffective adaptive behavior. The two needs identified in the physiological mode in this study, relative to living with a VLBW infant, include nutrition, activity and rest. For example, when a parent's eating patterns are disrupted because of the increased stress related to the care of their VLBW infant, nutritional status may be altered.

NURSING ASSESSMENT OF PARENTS' ADAPTATION

The Roy Adaptation Model includes a problem-solving procedure for assessing results in relation to nursing activity aimed at promoting adaptation. This procedure is called the problem-solving nursing process. The problem-solving nursing process encompasses six steps—assessment of parent(s) behaviors, assessment of influencing factors, problem identification, goal setting, selection of intervention approaches, and evaluation (Roy, 1984). The system of the individual and her interaction with the environment are the units of analysis of nursing assessment, and manipulation of parts of the system or the environment is the mode of nursing intervention.
REVIEW OF THE LITERATURE

The following literature review looks at articles that provide information about:
- premature infant development,
- the experience of parenting these infants, and
- follow-up and continuing care.

The adaptation process that parents experience after hospital discharge of their VLBW infant possibly may be influenced by the three perspectives above.

The definition "premature baby" recommended by the World Health Assembly and the expert group on prematurity (WHO, 1980) has now been replaced by that of "low birth weight infant." Thus, any infant weighing 2500 grams (5 1/2 lbs.) or less at birth is now regarded as a low birth weight infant. Although there is no internationally accepted definition of VLBW infant, by common consent this term applies to the infant weighing less than 1500 grams at birth. For the purpose of this study, premature and VLBW infant will be used interchangeably.

PREMATURE INFANT DEVELOPMENT

The incidence and severity of developmental sequelae in premature infants remain controversial. This in part relates to the heterogeneity of the premature infant population in regards to etiologic factors, degree of growth retardation, gestation, socioeconomic status (SES), and age at assessment. Studies in the 70's focused on the premature infant's
biological status and medical complications to predict developmental outcome (Pape, Buncic, Ashby, & Fitzhardinge, 1978; Hunt & Rhodes, 1977; Lubchenco, Delivoria-Papadopoulos, & Searls, 1972). More recent studies show that a biopsychosocial perspective incorporating both biologic and social risk should be used to evaluate the developmental outcome of the premature infant (McCain, 1990; Lancaster, 1986). Further, the literature indicates the way that parents perceive their VLBW infant and caregiver-infant interaction are essential to the developmental outcome of the VLBW infant (Vohr & Williams, 1983; Sameroff, 1981; Widmayer & Field, 1981).

Several investigators (Rice & Feeg, 1985; Ross, Lipper, & Auld, 1985; Cohen, Sigman, Parmelee, & Beckwith, 1982) have studied the developmental progress in VLBW infants during the first year of life. Developmental progress was viewed as the product of interrelated medical, biological, and environmental spheres of influence. The investigators worked under the assumption that although an infant may be exposed to serious medical and biological risk factors, these factors can be ameliorated or exaggerated by the dynamic relationship between the infant and environment. The results suggest that environmental factors can assist or sabotage developmental progress in an infant who was originally at biological risk. Developmental progress in VLBW infants may be more sensitive to subsequent environmental influences than to past perinatal insults. The findings are consistent with recent research
which has found that the impact of the environment appears to become more powerful than the impact of adverse perinatal factors as the infant matures (Schraeder, 1986).

Sigman, Cohen, Beckwith, and Parmelee (1981) studied 106 premature infants assessed at 4, 9, 18, 24 and 25 months. The purpose of this study was to examine the influence of birth order, language background, SES, and caregiver-infant interaction on the premature infant's developmental competence. The results indicate that the influence of developmental progress in premature infants is transmitted by the nature of their interactions with caregivers and their ordinal position in their families. For example, firstborn infants performed more competently throughout the first 18 months.

Sociocultural factors (language and SES status) did not have an impact until two years when developmental assessments begin to reflect language skills. The authors note that children from Spanish-speaking families continue to perform poorly as a group—this may be because their SES was actually lower than that of the English-speaking low-SES group and/or the developmental measures may be only partly accurate assessments of the abilities of the Spanish-speaking children.

Escalona (1982) also examined a group of low birth weight infants who required neonatal intensive care. These infants and their families were followed intensively and extensively for a period of 3.5 years; from birth to age 40 months. The majority of these infants were doubly at risk on the basis of
prematurity combined with significant illness during the neonatal period, but also because they were born to poor urban families living in the Bronx, New York. The major aim of this study was to investigate the interaction between biologic and social factors that impinge upon the mental and psychosocial development of low birth weight infants. The results show that among infants demonstrably at risk on biologic grounds alone (low birth weight), social and emotional conditions were, if anything, even more vitally important to the developmental outcome among low birth weight infants.

In another study, Hayes (1980) investigated the relationship of neonatal stimulation, birth condition and home environment to the development of premature infants. Forty seven infants were recruited for this study. The infants were divided into two groups: 1) full term control and 2) premature. The findings showed no difference between premature infants and full term in terms of cognitive development. However, the difference between male premature and female premature subjects on cognitive development was significant; the males had a lower mean score.

Minde and colleagues (1988) conducted a study looking at events that precede a diagnosis of developmental delay by comparing 16 VLBW infants whose condition was diagnosed as developmental delay with 16 matched developmentally normal infants. All infants were observed with their mothers during maternal visits to the NICU and during home visits one, three,
six, and nine months after discharge. The results indicate that most parents had usually been told of their child's handicap by the time the child was six to nine months old; yet mothers of the delayed children had changed the interactions with their children as early as one month after discharge from the hospital. This could mean that mothers of delayed infants have a sense that things are "not right" with their babies within the first month after discharge from the hospital—responding to the suspicion by being more active with their "unusual" baby.

In sum, developmental follow-up studies show that VLBW infants are at high risk for developmental delay. Research has emphasized the importance of social and familial influences on the development of premature infants. However, there is a need for more research into the elements that influence developmental outcome in VLBW infants: the interrelated spheres of biological, medical risk, and environment.

PARENTING THE PREMATURE INFANT

Parents associate the birth of a premature infant with great fear and anxiety (Trause & Kramer, 1983). In many ways, this situation parallels what other parents and infants experience. However, when parents learn that their infant must be admitted into a NICU, the transition to parenthood is disrupted. The feelings of uncertainty are pronounced (not having a normal baby, neurological sequelae, and even death). Parents also begin to experience guilt and grief as they
attempt to deal with an entirely new situation.

A number of studies have shown that parents who are experiencing a premature birth are encountering an emotional event (Gennaro, 1985; Schraeder, 1980). Feelings of shock at the time of delivery, fear of death of the infant (Trout, 1983), grief for not having a healthy full term infant, and guilt are common among parents of premature infants (Glassanos, 1980; Mercer, 1977). Other work has confirmed that the birth of a premature infant represents a crisis for most parents and may adversely affect the development of the parent-infant relationship (Tarbert, 1985; Crnie, Greenberg, Ragozin, Robinson, & Basham, 1983; Klaus & Kennell, 1982).

Gennaro (1985) was concerned with maternal problem-solving ability and maternal anxiety and how they were related to maternal adaptation in the early postpartal period; within the first week of the infant's admission to the NICU. The investigator studied 35 mothers of premature infants. The results show that problem-solving ability was positively correlated with anxiety. That is, mothers who reported having higher anxiety levels had better problem-solving abilities. Gennaro notes that anxiety in mothers of premature infants may function as a motivator for mobilizing resources and resolving problems so that mothers can adapt to and care for their premature infants. Moreover, she concludes that in consideration of these findings, nursing interventions aimed at reducing anxiety in mothers of premature infant might require reexamination.

Jeffcoate, Humphrey, and Lloyd (1979) and more recently Pederson, Bento, Chance, Evans, and Fox (1987) studied the
emotional effect the birth of a premature infants has on parents. In these two studies, parents were asked to recall their experiences of having a preterm infant. The data indicated that the parent's major concerns centered on the infant's survival and long term care. In contrast Philipp (1983) found that parents of VLBW infants did not demonstrate any greater degree of anxiety or depression than the parents of term infants, during the VLBW infant's hospitalization. Unfortunately, the above mentioned studies had a number of differences in sampling characteristics and/or the definition of prematurity.

In another study, Affleck, Allen, McGrade, and McQueeny (1982) explored the relationships among maternal mood and caretaking difficulties of high risk infants at the time of the infant's discharge from a NICU and approximately nine months later. The sample consisted of 38 mothers of infants with severe perinatal medical problems posing high risk for developmental disability. Family SES varied widely, with members of the sample drawn from low income inner city areas, rural communities, and suburban middle class neighborhoods. The results suggested that mothers who reported greater mood disturbance at hospital discharge of their infant also judged their infant to be more difficult to care for. The authors note that early maternal moods, particularly extent of reported anger and fatigue, were most highly correlated with extent of reported problems with infant feeding at nine months.
Brooten, Gennaro, Brown, Butts, Gibbons, Bakewell-Sachs, and Kumar (1988), using the Multiple Affect Adjective Checklist, studied anxiety, depression, and hostility of mothers of preterm infants. They report that mothers of preterm infants were more anxious and depressed before their infant was discharged than when the infant was nine months old (adjusted gestational age). Additionally, mothers whose infants remained in the hospital longer than the mean of 51 days were less depressed at infant discharge than were mothers whose infants had shorter hospital stays. The authors speculate that mothers whose infants were hospitalized longer may feel greater relief when the infant is discharged and may have had a longer period in which to regain their own equilibrium. This finding supports the work of Trause and Kramer (1983), who found less distress at 1 and seven months postdischarge in mothers of preterm infants than in the week following the infants' birth.

Another approach has been to look at the long-term outcomes of children who had been born prematurely (Culley, Perrin, & Chaberski, 1989). This study explored a possible precursor of the "vulnerable child syndrome," a constellation of behaviors thought to develop as a result of excessive parental anxiety. The term vulnerable child syndrome refers to physically healthy children who are perceived by their parents to be at high risk for medical or developmental problems. In this study, healthy three-year old children who had been born
prematurely (n=39) were compared to children born at term (n=41) using the Forsyth Child Vulnerability Scale.

The data demonstrates that health problems in infancy may have long-term effects on parental perceptions of the child's well being. The children in this study were appropriate in their development and had no evidence of chronic illness. However, the caretakers of the children who had been born prematurely had more concerns about their children's health status than did parents of children born at term. In contrast, Scheiner, Sexton, Rockwood, Sullivan, and Davis (1985) failed to find an increase in parents' sense of vulnerability about their premature infant.

FOLLOW-UP AND CONTINUING CARE

The discharge of a VLBW infant from the intensive care nursery does not always signify resolution of the infant's problems. Studies show poor growth, anemia, seizures, chronic lung disease, questionable development, and parenting problems that may accompany the VLBW infant home. They may require special and frequent feeding techniques, cry and be irritable, be inattentive, be unresponsive and give few distinctive cues to guide parental caregiving (Davis, 1984; Hurt, 1984; Goldson, 1981). Therefore, health care providers must accept responsibility for more and longer follow-up care of these survivors—those who not only survive the first hurdle of life, premature birth, but also the rigors of the NICU.

A study conducted by Goodman and Sauve (1985) sought to
determine the concerns of mothers of high risk newborns recently discharged from a NICU and to compare these concerns with those of mothers of normal newborn infants. Concern was defined as a feeling of anxiety or apprehension, a worry, or something seen as a problem. The following are concerns expressed by mothers of high risk infants and mothers of normal newborns: appearance, feeding, sleeping, and maternal-infant attachment.

The results of this study determined the concerns of mothers of high risk infants after they had assumed full time care of their infants, and how their concerns differed from those of mothers of normal newborn infants. As was anticipated, all new mothers had concerns. Apart from the infant's appearance and maternal-infant attachment, mothers of high risk infants differed only in the degree of concern perceived. Whereas mothers of normal newborns felt a little concerned, for example, about infant feeding; mothers of high risk infants felt highly concerned. Moreover, there was a tendency for mothers of normal newborn infants to have a more positive perception of their infants.

Butts, et al (1988) describe a study of a telephone on-call service for parents of VLBW infants after discharge from the NICU. The sample consisted of 36 families followed from the births of their infants to 18 months' postdischarge. The findings show that parents initiated 287 telephone calls during the 18 months following hospital discharge of their infants.
Reasons for parent-initiated telephone calls during the first five months after discharge, when the major number of calls occurred, were ranked according to frequency per month. Concerns regarding newborn health problems ranked first in four of the first five months following discharge, followed by normal newborn concerns, giving information, soliciting information, and maternal concerns. Brooten, Brown, et al (1988) report similar results for parents of premature infants following hospital discharge.

In their study on the effects of home intervention on premature infants with low (less than 1500 grams) and higher (between 1500-2000 grams) birth weights, Barrera, Cunningham, and Rosenbaum (1986) report the effectiveness of two home intervention approaches. One intervention approach focused on the development of the infant, and the other focused on the parent-infant interaction. Eighty preterm infants (n=32 less than 1500 grams, and n=48 between 1500-2000 grams) were randomly assigned to one of two treatment groups, a developmental or a parent-infant treatment group, or to a control group. Home visits were weekly for the first three months, every other week for the following six months, and once a month during the last quarter of the year. The control group received home visitations only for assessment— the home visitor answered any questions parents may have regarding their infant's development, reading material, or community resources.

Barrera, Cunningham, and Rosenbaum (1986) found greater
vulnerability of low birth weight than high birth weight premature infants for developmental delay, and possibly for parental difficulties. This finding supports other developmental studies of premature infants' "vulnerability" (Siegel, Saigal, Rosenbaum, Morton, Young, Berenbaum, & Stoskopf, 1982; Beckwith, Cohen, Kopp, Parmelee, & Marcy, 1976). In the Barrera study both control and treatment VLBW infants had a great deal of room for improvement of the mental scores (Bayley scale), yet only the treatment groups improved significantly, suggesting that the improvement was due primarily to intervention. More importantly, this study demonstrates that low birth weight infants (less than 1500 grams) and their parents make more significant gains in response to educational/therapeutic early home intervention, than do the high birth weight infants (between 1500-2000 grams) and their parents.

Another study evaluated a program of hospital and home-based developmental interventions (Resnick, Armstrong, & Carter, 1988). The purpose of this study was to develop a preventive model of developmental interventions for premature infants. Treatment and contrast groups consisted of 41 premature infants weighing less than 1800 grams at birth (treatment group n=21, contrast group n=20). Treatment took a preventive approach, consisting of daily multimodal interventions in-hospital and twice-monthly interventions by child development specialists in the infant's home, through 12
months adjusted age. Infants in the contrast group received traditional, remedially oriented care—referrals made for social services, physical therapy, parenting education, or infant development.

The results indicate that a preventive approach to developmental intervention produces outcomes superior to those resulting from the traditional remedial approach. The experimental group had significantly more improvement in mental scores, as per the Bayley scale, than the contrast group. Analysis of the data show that the higher quality of parent-infant interactions probably held the key to these cognitive gains. Specifically, gain in mental development scores were not achieved without concomitant gain in the parent-infant behavioral interactions scores. These findings are consistent with the work of Resnick, Eyler, Nelson, Eitzman, and Bucciarell (1987).

The studies above support the need for continuity of care for VLBW infants and their families. Several researchers report that parents need more information and direction in caring for their infant at home. Recent research also suggests that SES, parent-infant interactions and the type of developmental intervention program affects the developmental outcome of VLBW infants. Moreover, the effects of intervention might vary depending on the infant's sex, initial health, birth weight, and/or related perinatal complications.

To summarize, this literature review presents three
perspectives that may be relevant to the purpose of this study. The study assumes that to understand the adaptation process and factors that influence it, one must look at the interaction among: 1) premature infant development, 2) the experience of parenting these infants and, 3) follow-up care.

Parents of premature infant are at risk for psychosocial sequela. The parent-infant acquaintance process, in the first several months, is crucial as they adapt to each other. During the early parent-infant acquaintance process, parents attempt to get to know their VLBW infants and compare the real infant with expectations (Kennedy, 1973). Logically, it follows that a more realistic measure of the adaptation process would occur from one to five months after hospital discharge. While most studies discuss what parents do with their VLBW infant at home, they do not describe this process. This study does so. An extensive review of the literature revealed a deficit in research about the adaptation process that parents experience after hospital discharge of their VLBW infant. This study takes a closer look at exploring and describing this process.

METHODOLOGIC PROBLEMS

There are methodologic problems in research focusing on premature infants, their parents, developmental outcome, and follow-up care. Common methodologic problems include unclear and incomplete description of the sample; inadequate measures of social factors, such as parent-infant interaction; undocumented technological advances that may affect developmental outcome; and how long follow-up intervention occurs.
SUMMARY

This chapter describes the conceptual orientation and three general headings of perspectives of possible relevance of this research study: premature infant development, parenting the premature infant, and follow-up and continuing care.

It is not possible to predict which infants will have developmental problems based on medical complications. Nevertheless, the medical complications the infant sustains do place the infant at risk. Social and environmental factors may amplify or attenuate problems the infant might have. Therefore, the social context in which a premature infant develops is very important.

Parents who are experiencing a premature birth are encountering an emotional event. This experience can have short or long terms effects on the parents. Parents who are most successful at adapting to the birth of a premature infant are those who are well informed. Health care providers play a major role in helping parents cope with a premature infant.

Newborn follow-up studies document that premature infants are at high risk for developmental delays. Current research reports the contribution of parent-infant interactions to developmental outcomes for the premature infant. Moreover, developmental intervention programs are designed to reduce the developmental risks of this population.
CHAPTER III

METHODOLOGY

This chapter presents the following aspects of the study: the design of the study, the sample and setting, protection of subjects rights, the data collection protocol, and data analysis plan. Also addressed in this chapter are credibility and trustworthiness of findings.

DESIGN

The dearth of literature on the adaptation process of parents of VLBW infants after hospital discharge led to the selection of an inductive methodology, grounded theory. According to Stern, Allen, & Moxley (1984) the strongest case for the use of grounded theory is in investigations of relatively uncharted waters. Currently, there is no theory regarding the adaptation process of parents of VLBW infants following hospital discharge, nor identified patterns of behavior/s parents use during the adaptation process. Therefore, it was necessary to investigate the adaptation process that parents of VLBW infants experience following hospital discharge in order to facilitate effective adaptation for these parents and their infants.
Grounded theory is an inductive, theory-generating method used to search out factors or to identify and describe related factors that pertain to the research problem at hand (Glaser & Strauss 1967). The term "grounded theory" refers to data grounded in fact and generating theory from the data. Grounded theory describes a method to study fundamental patterns known as basic social-psychological processes which account for variation in interaction around a phenomenon or problem. Grounded theory is rooted in the social sciences, specifically in the symbolic interaction tradition of social psychology and sociology. Symbolic interaction is concerned with the inner aspects of human behavior, specifically, how people define events and how they act in relation to their beliefs. Meaning guides behavior and situations are deliberated prior to action (Chenitz & Swanson, 1986). The aim of grounded theory is to generate theory about social and psychological phenomena.

SAMPLE AND SETTING

The number of informants for this study was 14. The informants consisted of parents of VLBW infants (<1500 grams) following hospital discharge. Additional criteria for informants included: parents who had a VLBW infant who did not require complex home care (dependent on oxygen and/or ventilator), participated voluntarily, and were willing to participate in three interviews. The length of each interview
varied, ranging from one to two hours. Informants were selected from the medical charts of all preterm infants (<1500) born or transported to Children's Hospital, San Francisco.

I invited informants to participate approximately two weeks before hospital discharge of their VLBW infant. Phone calls followed (three weeks after discharge) to ascertain the informant's decision to participate and to schedule the initial home visit. At that time they were reminded that participation involved three interview sessions; one month, three months, and five months following hospital discharge of their VLBW infant. This schedule is based on the literature suggesting follow-up evaluations of VLBW infants which documented problems of inadequate family adjustment, catch-up growth, and severe neurologic abnormalities that might require intervention at these time periods (Minde, et al., 1988; Pena, Teberg, & Hoppenbrouwers, 1987; Ritchie & Mertens, 1987; Stewart & Reynolds, 1974).

PROTECTION OF SUBJECTS' RIGHTS

The human rights of the informants were protected according to the guidelines set by the University of Arizona Human Subject's Committee and the Children's Hospital of San Francisco Research and Human Experimentation Committee. Approval was obtained prior to the start of data collection (Appendix A & B). All informants were given a written consent
form (Appendix C) to read before giving their consent to participate in the research project.

Once the informants were identified, they were given a description of the study. Participation for all informants was voluntary with the right to withdraw from the study at any time. Each informant was assured anonymity by assigning a code number to all interviews and reporting of findings. All informants were encouraged to ask questions prior to and throughout the data collection stage.

DATA COLLECTION PROTOCOL

The informants were chosen according to the sample criteria set. The informants were selected with the purpose of obtaining data specific to the phenomenon under study. This is called purposive sampling. The data were collected coded, and analyzed using data-based inferences to guide future data collection.

Information specific to VLBW infants was obtained by reviewing the Neonatal Intensive Care discharge log book. The log book included information on gestational age, birth weight, admitting and discharge diagnosis, and date of discharge. This information was documented on the neonatal information form (Appendix D). Informants were assessed against the criteria set for ability to participate. The initial interview was conducted at a place of convenience for the informant(s). At
the same time I completed the family information form (Appendix E).

The questions below began the initial data collection:

1. Tell me what happened when you first arrived home with (baby's name).

2. What effects has (baby's name) had on your life? Experiences as a mother/father? The relationship with your partner, family, and friends?

3. What did you imagine would happen once (baby's name) was discharged from the hospital?

4. Tell me what it's like taking care of (baby's name) at home? How did reality compare with what you expected.

5. Tell me about your life since (baby's name) was discharged from the hospital. Has this affected your eating and sleeping patterns? Arranging for someone to care for (baby's name)?

DATA COLLECTION TECHNIQUES

Several investigators recommend the use of multiple perspectives for illuminating phenomena (Brewer & Hunter, 1989; Brink, 1989; Lincoln & Guba, 1985). A formal interview and participant observation were the methods of data collection. A formal interview is conducted when an investigator desires in-depth information (Swanson, 1986). In grounded theory, formal interviewing is usually combined with participant observation. The use of formal interviews and participant observation increased the ability to collect and validate data (Chenitz, 1986).
Interview

The interview is one of the most powerful methods in the qualitative armory. For certain descriptive and analytic purposes, no instrument of inquiry is more revealing (McCracken, 1988). Initial data were gathered by using a formal interview guide that contained a set of brief, general questions. Examples of questions are: How did your manage at home after the baby was discharged from the hospital? What were your thoughts? Feelings? These questions served as a guide that encouraged informant's to answer in their own words. Further questions were modified according to the emerging theory. An example of these type of questions can been seen in Appendix F. All interviews were tape recorded.

DATA ANALYSIS PLAN

Tapes were transcribed verbatim using a word processor. Data analysis involved examining the transcribed interviews line by line to identify the adaptation process as it seemed to emerge from the data. Data were coded, compared with other data and assigned to categories (coded data which seem to cluster together) according to obvious fit. By fit Glaser (1978) means that the categories of the theory must fit the data. Data should not be forced or selected to fit pre-conceived or pre-existant categories or discarded in favor of keeping an extant theory in tact. Thus, I constantly modified
categories as successive data demanded.

In developing concepts, three major steps served to both expand and densify the emerging theory: reduction, selective sampling of the literature, and theoretical sampling; through these steps categories were identified which explained the major action in the social process under study (Glaser, 1978).

1. Reduction: When an underlying uniformity is discovered in the established categorizations, the data can then be reduced. Reduction techniques are used to compare categories to see how they cluster or connect. For example, when categories and incoming data were examined, I considered some higher order of category describing several original categories. This technique was a vital step in discovering the core variables (the process that explain what is occurring in the scene) and providing increased scope in the applicability of the theory (Stern, 1980).

2. Sampling of the literature: The existing literature was used as data and was woven into a matrix consisting of data, category, and conceptualization. For example, I searched the literature in order to expand the theory, and relate it to other theories.

3. Theoretical sampling: As the main concepts or variables become apparent, an analysis of the data determined under what conditions they occurred, and if they seemed central to the emerging theory. Additional data were collected at this time in a selective manner for the specific purpose
of developing the hypotheses, and identifying the properties of the main categories or variables (Stern, 1980). For example, if I discovered incomplete or missing parts of the emerging theory, additional data were collected based on what I already knew about the phenomenon under study.

The "sampling data" process is a systematic attempt to collect additional data, regardless of the source, to advance the theory.

Constant Comparative Method

Data were analyzed by the constant comparison method (Strauss, 1987; Chenitz & Swanson, 1986). This method is designed to aid in generating a theory which is integrated and consistent. Constant comparison allows for the continued integration of accumulated knowledge. Through concurrent data collection and data analysis, patterns of integration within the data emerged and focused questioning guided further collection of data. Theoretical saturation occurred when no new properties of a given category emerged from the data and the same properties continually were present.

Concept modification and integration were dominated by two processes: theoretical coding and memo writing. It is through these processes that the emerging theory was finally integrated and delimited. Theoretical coding provided a way of thinking about data in theoretical rather than descriptive terms. This means applying a variety of analytical schemes to
the data to enhance their abstraction (Strauss, 1987; Glaser, 1978). For example, I chose to place the data within a table or diagram to help depict the adaptation process. Memoing, another method, was a way of preserving emerging hypotheses, analytical schemes, hunches, and abstractions (Stern, 1980). For example, any ideas that occurred during the concurrent process of coding and analysis were written in memo form. These memos were used in combination with the data obtained from the additional questions in identifying categories and hypotheses.

The observational data were categorized and compared to the interview data. This is called concurrent validation. Concurrent validation was achieved by utilizing different methods of data collection. The parent-infant interaction occurring during the interviews was relevant to the purpose of this study. I made an effort to schedule parent interviews during infant feeding time so that I could observe the parent-infant interaction. Direct observation allowed me to examine what parents said about their adaptive responses and what actually occurred during feeding and other care-giving activities. For example, as mothers developed adaptive behaviors to their infants, they demonstrated sensitivity to the cures of their infants and were more easily able to quiet their crying infant.
Concerns pertaining to reliability and validity in qualitative methods have been raised by several authors (Brink, 1987; Leininger, 1985; Miles & Huberman, 1984; Aamodt, 1982). Goodwin and Goodwin (1984) proposed that the concepts of validity and reliability should not be irrelevant for qualitative studies. Kirk and Miller (1986) noted that the main thrust of methodological development in qualitative research during the last century has been toward greater validity—in contrast to the concerns of many nonqualitative traditions, issues of reliability have received little attention. Moreover, several authors suggest that the most basic issue in qualitative reliability and validity is "credibility," that is, how believable are the data and how confident is the researcher in the study results. For qualitative research to produce credible findings, the data should be collected in a consistent reliable way, and must be valid indications of reality (Chenitz & Swanson, 1986; Goodwin & Goodwin, 1984; Lofland & Lofland, 1984).

Generally, qualitative researchers avoid the terms reliability and validity. However, they deal with these issues by the term "establishing trustworthiness." Lincoln and Guba (1985) use the term trustworthiness, which encompasses confidence in the truth of the findings, the degree to which the findings are applicable in other contexts, the consistency
of the findings, and the degree to which the findings are determined by the subjects. In grounded theory the criteria for judgment are based on the detailed elements of the actual strategies used for collecting, coding, analyzing, and presenting data when generating theory, and on the way in which people read the theory (Glaser & Strauss, 1967). In order to judge this study for its degree of trustworthiness, three areas were assessed; truth value, dependability and confirmability (Lincoln & Guba 1985).

The truth value of this study was established in the following ways. The developing grounded theory, concepts and definitions were shared with study participants to increase clarity and relevance. This sharing is called member checks (Lincoln & Guba, 1985). The constant comparative method of data analysis consistently guide the conceptual development of the labels and definitions for categories and properties as well as their interrelationships (Atwood & Hinds, 1986). Thus, this method of data analysis assures the fit between the categories of the theory and data. A literature review was conducted during the study to enhance the developing theory. Illustrations (diagrams and tables) of data bits were used to exhibit the generation of categories, properties, and hypotheses. These illustrations helped to set forth the developing theory. Three interviews with the same informant provided the opportunity to compensate for any distortions created by either my presence or the initial interview. This
also provided a chance to test my own biases and perceptions.

According to Lincoln and Guba (1985) there can be no credibility without dependability—a demonstration of the former is sufficient to establish the latter. However, for this study peer debriefing was used to monitor dependability. Peer debriefing is a process of exposing the process of inquiry to a peer for the purpose of establishing dependability of the inquiry. For example, my peer examined the data, findings, interpretations, and recommendations and attested that they are supported by the data. Periodic contact with other neonatal nurse practitioners/neonatal nurses served as peer debriefing sessions.

One way to evaluate confirmability is by conducting an audit (Lincoln & Guba, 1985). In order to conduct an audit all raw data, data reduction and analysis products, data reconstruction and synthesis products must be saved. These records were available for auditing. In addition, data collection involved a variety of methods (triangulation) to enhance the opportunities for cross-validating the emerging theory e.g. formal interview, participant observation.

**SUMMARY**

An exploratory design was used to conduct this study. The informants consisted of parents of VLBW infants (<1500 grams) following hospital discharge. Data were collected by
CHAPTER IV

PROCEEDINGS

This chapter presents the research phases and methods required to generate a grounded theory of the adaptation process experienced by parents after hospital discharge of their VLBW infant. I make no attempt to present the process of theory discovery in its entirety. Thus, only a piece of the complex analyses—based on interviews, observations and experiential data—appears in the chapter. Theoretical sampling procedures leading to the next data to collect, coding to discover and name categories/core category, and methods to affirm trustworthiness, are addressed.

THEORETICAL SAMPLING

Theoretical sampling, a distinct feature of grounded theory, was essential to ensure conceptual development and density of the theory emerging from this research. This multidirectional feature proved to be a challenge—not only in intellect—but in creativity as well.

Initially, I developed descriptive questions to direct the early phase of data collection (Appendix F). This marked the start of an arduous journey to capture the complexity of
the adaptation process. Later, data collection, comparative analysis, and coding (the discovery and naming of categories) directed theoretical sampling strategies.

For example, I asked parents how they coped with the feeling of isolation after discharge of their VLBW infant. I also asked them about the factors that contributed to their sense of isolation. For example, the effect of the VLBW infant's size and weight on their sense of isolation, and how they protected both their infant and themselves. These questions generated data that enhanced the development of the emerging categories. Memo writing was the second major research method used to direct the sampling process. Memos were part of the dialogues to keep records of insights, hunches, hypotheses, and discussions about the emerging categories.

Preliminary, more informal memos evolved from scattered ideas and thoughts jotted down on scraps of paper—often occurring at odd times. For example, premature babies are like major parasites—and need much more care than a "full term" baby. In contrast, theoretical memos formally tracked emerging categories and their interrelationships. Theoretical memos also helped track the emerging core category.

For example, parents continue to protect their infant; however not as intensely as during the first month. Parents gradually expose their infant to people and the outside world. They discuss the need to expose the infant but only in a very
protective way. Parents also begin reconnecting with family and friends; visiting rules became less strict. Other theoretical sampling decisions included observational notes, analytical diary, and diagrams. Observational notes helped to keep track of non-verbal behavior during the interviews, such as facial expressions or actions. An analytical diary guided sampling with ideas stimulated from reviewing the data throughout the data collection and analysis. Diagrams helped to visually pull everything together.

Unexpectedly, the longitudinal study design challenged the use of the sampling process. For example, each informant was interviewed at one, three, and five month intervals following discharge of their VLBW infant. Even though parents discussed different issues over the three interviews, their comments contained significant similarities. Theoretical sampling helped to maintain a separate focus for each interview and kept the study on track by sorting out peripheral information.

PROCEDURAL AND METHODOLOGICAL FINDINGS

This section presents an overview of the data collection, analysis and theoretical ideas that occurred during the course of the research project. They provided essential procedures for discovering, verifying, and generating the grounded theory.

Of 23 informants invited, 19 agreed to participate.
Table 1. Demographic Characteristics of Parents

<table>
<thead>
<tr>
<th>Infant</th>
<th>Parent(s)</th>
<th>Age</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A Mother</td>
<td>31</td>
<td>Daycare Provider</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>33</td>
<td>Sales Person</td>
</tr>
<tr>
<td>2</td>
<td>A Mother</td>
<td>23</td>
<td>Admin. Assistant</td>
</tr>
<tr>
<td>3</td>
<td>A Mother</td>
<td>36</td>
<td>PhD-Researcher</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>60</td>
<td>Attorney</td>
</tr>
<tr>
<td>4</td>
<td>A Mother</td>
<td>33</td>
<td>Homemaker</td>
</tr>
<tr>
<td>5</td>
<td>A Mother</td>
<td>38</td>
<td>Teacher</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>44</td>
<td>Sales Person</td>
</tr>
<tr>
<td>6</td>
<td>A Mother</td>
<td>38</td>
<td>Secretary</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>38</td>
<td>Architect</td>
</tr>
<tr>
<td>7</td>
<td>A Mother</td>
<td>34</td>
<td>Engineer</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>35</td>
<td>Engineer</td>
</tr>
<tr>
<td>8</td>
<td>A Mother</td>
<td>28</td>
<td>Homemaker</td>
</tr>
<tr>
<td>9</td>
<td>A Mother</td>
<td>22</td>
<td>Homemaker/Student</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>22</td>
<td>Skilled Worker</td>
</tr>
<tr>
<td>10</td>
<td>A Mother</td>
<td>30</td>
<td>Executive/Stock Exchg</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>34</td>
<td>Medical Clerk</td>
</tr>
<tr>
<td>11</td>
<td>A Mother</td>
<td>21</td>
<td>Homemaker/Student</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>28</td>
<td>Businessman</td>
</tr>
<tr>
<td>12</td>
<td>A Mother</td>
<td>27</td>
<td>Nurse/LVN</td>
</tr>
<tr>
<td>13</td>
<td>A Mother</td>
<td>36</td>
<td>Interior Designer</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>38</td>
<td>Contractor</td>
</tr>
<tr>
<td>14</td>
<td>A Mother</td>
<td>31</td>
<td>Homemaker</td>
</tr>
<tr>
<td></td>
<td>B Father</td>
<td>34</td>
<td>Harbor Master</td>
</tr>
</tbody>
</table>
### Table 2. Demographic Characteristics of Infants

<table>
<thead>
<tr>
<th>Infant</th>
<th>Weight (grams)</th>
<th>Gestational Age (weeks)</th>
<th>Length of Hospital Stay (days)</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1020</td>
<td>32</td>
<td>42</td>
<td>White</td>
</tr>
<tr>
<td>2</td>
<td>950</td>
<td>26</td>
<td>53</td>
<td>Black</td>
</tr>
<tr>
<td>3</td>
<td>750</td>
<td>25</td>
<td>71</td>
<td>White</td>
</tr>
<tr>
<td>4</td>
<td>1500</td>
<td>31</td>
<td>28</td>
<td>Black</td>
</tr>
<tr>
<td>5</td>
<td>1120</td>
<td>29</td>
<td>94</td>
<td>Hispanic</td>
</tr>
<tr>
<td>6</td>
<td>1210</td>
<td>29</td>
<td>49</td>
<td>Philippino</td>
</tr>
<tr>
<td>7</td>
<td>1420</td>
<td>30</td>
<td>32</td>
<td>White</td>
</tr>
<tr>
<td>8</td>
<td>1000</td>
<td>28</td>
<td>71</td>
<td>Black</td>
</tr>
<tr>
<td>9</td>
<td>1490</td>
<td>31</td>
<td>24</td>
<td>Hispanic</td>
</tr>
<tr>
<td>10</td>
<td>1260</td>
<td>27</td>
<td>68</td>
<td>Philippino</td>
</tr>
<tr>
<td>11</td>
<td>1410</td>
<td>30</td>
<td>34</td>
<td>Mid Estrn</td>
</tr>
<tr>
<td>12</td>
<td>570</td>
<td>26</td>
<td>112</td>
<td>White</td>
</tr>
<tr>
<td>13</td>
<td>1500</td>
<td>32</td>
<td>36</td>
<td>White</td>
</tr>
<tr>
<td>14</td>
<td>760</td>
<td>29</td>
<td>77</td>
<td>White</td>
</tr>
</tbody>
</table>

Weight (grams) | Gestational Age (weeks) | Length of Hospital Stay (days) |
--- | --- | --- |
570-1500 | 25-32 | 24-112 |

Mean = 1140 | 29 | 57
However, when I tried to schedule the first interview, 5 had moved and left no forwarding telephone number or address. The remaining 14 informants were eager to share their stories. Over 14 months, I held 42 interviews with parents of VLBW infants. Their demographic profiles are shown in Tables 1 and 2.

These interviews produced nearly 2,100 pages of data, transcribed in tabular format. After review, I discovered that there were thousands of data bits—far too many for this study's needs. As I coded, I extracted significant data and deleted nonessential information. Concurrently, I developed theoretical memos about the relationship among substantive codes, as Table 3 illustrates.

The discovery of categories occurred through the process of repeated coding, as shown in Table 4. Theoretical codes then allowed me to organize and compare evolving categories. The codes also revealed relationships and illuminated variations of the events taking place, and helped track possible core categories. These code results essentially reflected the informants' key concerns about the adaptation process.

Determining the core category took significant time and energy. I constantly looked for what appeared to be relevant. I continued theoretical sampling, selective sorting and data reduction. I often lost track because it was difficult to select the core category that best fit data important to the evolving theory.
<table>
<thead>
<tr>
<th>Data Bit</th>
<th>Substantive Code</th>
<th>Theoretical Memo</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;She is different and, you know, I'm trying real hard not to treat her like she's different, 'cause I don't want to do that. I don't want her to feel privileged. I don't really look at her as a premie anymore. I just want to treat and consider her normal.&quot; (1A)</td>
<td>Protective</td>
<td>I'm confused and very uncomfortable asking questions, particularly to these parents who deny that their infant was/is a premie. I find myself being careful how I address questions about premature infants. Are they wanting to be normal or just trying to establish balance?</td>
</tr>
</tbody>
</table>
Table 4. Discovering Categories

<table>
<thead>
<tr>
<th>Data Bit</th>
<th>Initial Code</th>
<th>Recode</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;At first the nurses wouldn't let me do anything for her (baby).</td>
<td>not having</td>
<td>mythical baby</td>
</tr>
<tr>
<td>One nurse even told me, literally, sit there by the isolette and don't</td>
<td>control</td>
<td></td>
</tr>
<tr>
<td>touch her—and I wanted to.&quot; (1A)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;When I finally saw the baby, she looked like a piece of bacon. I was</td>
<td>remembering the</td>
<td>memories/</td>
</tr>
<tr>
<td>afraid. I thought poor thing. He (husband) shouldn't get to attached</td>
<td>hospital experience</td>
<td>perceptions</td>
</tr>
<tr>
<td>to this baby.&quot; (2A)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;The awkward part was when we first took him out. I really don't like</td>
<td>taking the baby</td>
<td>public concerns</td>
</tr>
<tr>
<td>when people come up to see the baby.&quot; (11A)</td>
<td>out for the first</td>
<td></td>
</tr>
<tr>
<td>&quot;She's really matured, she's more responsive, and she's bigger—dramatically different&quot; (13B)</td>
<td>noting changes in my baby</td>
<td>getting to know my baby</td>
</tr>
<tr>
<td>&quot;Fear of him getting sick or that he is still going to die. At night I get up and if I don't hear him, I'll go and like—see if he's still breathing.&quot; (10A)</td>
<td>different ways of caring for my baby</td>
<td>fragile/vulnerable</td>
</tr>
</tbody>
</table>
For example, establishing the norm was assumed to be an early core category. This core category emerged quickly but could not withstand the rigors that lead to theoretical completeness—further data collecting, analyzing, and memoing. I discontinued trying to formulate this suspected core category after several unsuccessful months.

I reviewed again the criteria of what makes up a core category (Glaser, 1978). I then realized that it's possible to have a core category in disguise, as part of the discovery process. Finally, I was able to cautiously commit to the core category that had emerged and earned its way into the theory.

TRUSTWORTHINESS

The trustworthiness of the generated theory was judged using methods suggested by Lincoln and Guba (1985). Three areas were addressed; truth value, dependability and confirmability.

Truth Value

Truth value was established by sharing the emerging subcategories, categories, and core category with the informants. For example, the informants verified significant activities that encompass the subcategory "protect" at interview—time 1 (Table 5). This "sharing" increased clarity and relevance of the emerging categories, core category, and theory.
Table 5. Informants Verifying Significant Activities that Encompass the Subcategory "Protect" at Interview—Time 1

<table>
<thead>
<tr>
<th>Data Bit</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;We wouldn't let anybody come over that had a cold or brought their kids.&quot; (3A)</td>
<td></td>
</tr>
<tr>
<td>&quot;We don't let anyone touch her. A friend of ours brought his kids over and they wanted to see the baby so.....we showed her (baby) through the window. It was just like the nursery.&quot; (13B)</td>
<td></td>
</tr>
<tr>
<td>&quot;When I first took the baby out, I found myself lying, saying that she was a newborn or a couple of weeks old. People were comparing my baby to a rump roast (the infant's size/weight). (2A)</td>
<td>Protect</td>
</tr>
<tr>
<td>&quot;I know that we were very blunt to alot of people; people calling to ask about the baby. We didn't have the energy to deal with their emotions. We had to deal with our own.&quot; (14A)</td>
<td></td>
</tr>
<tr>
<td>&quot;We stopped telling people that she's premature.&quot; (1B)</td>
<td></td>
</tr>
<tr>
<td>&quot;I always screen all our friends; have you had a cold in the last two weeks. If the answer is yes-sorry you won't be able to come over.&quot; (7A)</td>
<td></td>
</tr>
<tr>
<td>&quot;I showed my inlaws the baby through the patio window.&quot; (11A)</td>
<td></td>
</tr>
</tbody>
</table>
Additional assurances of truth value were made by using visual devices and comparative analysis. Diagrams of data bits, generated properties, and categories gave visualizations of what was going on during various steps of the analysis. These visualizations suggested new categories and helped identify holes during the discovery process.

The constant comparative method of data analysis assessed the fit between the theory and data. For example, questions were asked that generated comparisons between and among activities directed by the evolving categories. Once the categories were identified and committed to, I continued to seek and relate the categories, thus gradually densifying the emerging core category and grounded theory. A concurrent literature review was conducted as a source of information to help illuminate the developing theory.

Dependability

Peer debriefing sessions were conducted during various stages of the inquiry. The purpose of these sessions were to expose the data, findings, interpretations, and to brainstorm during the integrating process; how to make everything come together. Five sessions were held with other neonatal nurses not familiar with the study. The sessions enhanced theoretical understanding of the emerging categories. Moreover, aspects of the inquiry which were undeveloped or implicit in my mind were explored. Three additional sessions were held with a colleague, a psychiatric nurse, familiar with the study.
Theoretical sorting of the evolving categories and core category were discussed in these sessions. Sorting gave maximum control over the conceptual density of the emerging categories and their interrelations. Analytical notes and diagrams also assisted to maintain theoretical sensitivity (Strauss, 1987).

Confirmability

In order to evaluate confirmability, an audit trail was maintained. All raw data, data reduction and analysis products, and rough drafts of the integrated memos/graphic representations were available for review. In addition, two methods of data collection were used to enhance the opportunities for cross-validating the emerging grounded theory, i.e. formal interview and nonparticipant observation. After each interview observational notes were written. They reflected non-verbal actions, such as the types of caring behavior parents engaged in and reasons for performing them. The observational notes became part of the data analysis during my attempt to derive knowledge about events, actions, and the "actors" of the phenomena under study. For example,

DATA BIT

"We're keeping a log. Keeping track of how much he is eating, sleeping, and if patterns develop. We also keep color coded bottles, because one of the bottles has certain vitamins (vitamin A and iron); that one is yellow. It's the most important one. Then there is the red one, the one with premie
vitamins. So we check each bottle off, to make sure that we gave him the two most important ones. The yellow one, that's the first bottle he gets in the morning... " (5B)

OBSERVATIONAL NOTE

I was amazed with the set up these parents had. A BIG table in the living room with several note books, pens, colored pencils, bottles, medicine bottles (vits/iron), diapers, bulb syringe, and infant CPR card (taped on the wall above the table). They had made an area where the majority of care took place. These parents really organized their care. They wanted to make sure nothing went wrong. Is this a control thing?

SUMMARY

In this chapter, a number of essential research operations used to generate the grounded theory were discussed. Examples of the discovery process were provided, including theoretical sampling and procedural and methodological findings. Methods used to maintain trustworthiness were presented.
CHAPTER V

THE GROUNDED THEORY

This chapter provides a description of the grounded theory; 'Creating Paths' that evolved from my study. As a core category, the grounded theory of 'Creating Paths' tracks and describes the basic social process of parents as they adapt to living with their VLBW infant during the first five months after hospital discharge. 'Creating Paths' illustrates this basic social process by delineating the relationships among its categories, subcategories, and in turn, their properties.

This chapter will also review the three stages of 'Creating Paths': Gathering, Emerging, and Affirming. These three integrated, linear stages apparently build on each other when viewed as a whole. However, each stage also stands independently because of its specific boundaries and response characteristics.

The discovered basic social process of 'Creating Paths' represents a relatively small amount of time with a VLBW infant. It's likely that this process continues—in one form or another—for life.

Each subcategory, along with its properties and exemplary data bits will be described. These subcategories represent conditions, strategies, and the consequences of
living with a VLBW infant. They help to illustrate the
diversity of the parents' behavior. The chapter concludes with
a review of the theory's structure, 'Creating Paths'.

STAGE 1: GATHERING

Gathering refers to collecting special resources that are
required to rear and cope with situations unique to a VLBW
infant. Often, the need to gather these special resources
becomes apparent only after the infant leaves the hospital.
Until then, parents have had very limited access to their VLBW
infant.

In other words, the parenting process actually begins
only after technology releases control, usually at discharge.
Once home, parents can truly begin to understand the scope and
demands of rearing their VLBW infant. Figure 2 illustrates
this stage.

SUBCATEGORY: SUSTENANCE

Parents seek ways to sustain the life of the VLBW infant
by gathering and collecting information. As their infant nears
discharge, they actively solicit help and information. For
example, parents initially ask many questions about their
infant's care and personality. And they usually ask those who
most likely will have the answers; the nurses who have served
as surrogate parents and technological taskmasters during the
first several months of the infant's life.

An "acquaintance phase" takes place in the first few days
after hospital discharge. Parents use trial and error in
Figure 2. Stage I: Gathering

Gathering

Protect

Sustenance
caring for their infant—with a simple, critical goal in mind—keeping their infant alive. As their knowledge grows, parents reach beyond sustenance to cultivate and nurture their VLBW infant. That is, they start to incorporate the human and social elements in the rearing their infant.

Facial expressions, vocalizing, and gestures all become more important. It is now that parents strive for more than just maintaining life. The following data bits illustrate the parents' first few days at home:

"When we first got home—I remember it clearly—I just wanted to be alone with my baby and have her all to myself. My mother drove us home and I was wishing that she would just leave." (12A)

"We were anxious most of the time for the first few days after her discharge. Our anxiety increased during her feedings... we didn't want to hurt her by doing something wrong." (3B)

"When you have a term, normal baby, you're assuming that they're going to survive. But with a premie, there's an ever present sense of danger... which means that we watch her very close." (13A)

Preparation for their infant's arrival home included much reading and research about premature infant care. Parents usually maintain detailed journals about initial caregiving techniques and routines for their "special baby". They often
try various feeding, holding, and interactive techniques to learn what elicits the best responses from their infant.

Thus, experience is the best teacher in showing parents what works. It also helps them deal with pertinent caregiving issues. These data bits underscore strategies that many parents use:

"I learned a lot from the nurses because I really didn't know anything about babies... Can you imagine knowing about a premature baby that weighed only two pounds?" (14A)

"We had to read a lot before she came home. We have a library of premature infant books at home." (7B)

"Parent tricks: You walk in and put your hand on her face to make sure she's warm... Then you put your hand on her chest to make sure it's going up and down..." (3A)

"We just spent a lot of time holding her... I think we ran to look at her every 15 minutes to make sure she was OK." (1B)

Parents are often rewarded for their efforts. These rewards come in many ways, like parents watching a previously very fragile infant grow. Parents gain confidence particularly when they finally believe that they actually know their baby better than the initial caregivers or nurses. They no longer must play the role of substitute parents. As this confidence grows, so does trust in other people, though many parents still find it very difficult to release control to others, such as
babysitters. Lingering memories of a critically ill infant continue to haunt them. These data bits shed light how some parents adjust to their infant:

"In the beginning, the baby slept with me. My husband would sleep on the floor... 'cause he didn't want to crush the baby. Now, we all sleep in our normal places... the baby in his own bed." (10A)

"We worried a lot! So it was about five weeks when there was a decrease amount of 'worries'—but not a sense of normalcy... Just a guarantee that everything was OK." (7A)

"Being so terrified... I was afraid to put her down in her crib. I kept thinking... she could die. That only lasted for about two weeks." (12A)

SUBCATEGORY: PROTECT

In this stage, parents provide their VLBW infant with nonstop protection. They defend—actually guard—their infant from potential hazards, such as exposure to germs from strangers, friends, and even close family members. Parents also shield their VLBW infant from comments made by outsiders. Data indicates that this stage may be the starting point for actual real-life parenting. For example, parents avoid unsolicited, and often unintentional, insults from friends and family, who may ask about the infant and its size and fragility. Parents don't want people to pity their infant. Often, parents will limit these remarks by limiting outside
contacts. They direct all their energy and attention to the most important thing in their life, their infant. These data bits indicate how parents may protect or shield themselves and their infant:

"When people come over... mostly relatives... I did tell them that they couldn't touch the baby. I felt so bad, and a bit awkward." (11B)

"It's really hard when you start taking the baby out in public. The first thing people ask is, 'How old is your baby?' And after explaining that she was a premie, weighing only 1 1/2 pounds... they think it's your fault. One woman on the bus... her mouth just dropped and she looked at me like: 'What kind of person are you to have a 1 1/2 pound baby?" (2A)

"I know I'm very sensitive when somebody says, 'Oh, she's so tiny.' Everyone says something like that about our baby. I don't like that. I don't want to hear that she's 'tiny.'" (1A)

In addition to psychological shields, parents develop strategies and defense mechanisms to protect their VLBW infant from possible physical harm. Many do this simply by isolating themselves and their infant. By being reclusive, they gain and maintain tight control of their environment.

This process may continue until the infant reaches predetermined targets or goals as set by the caregivers and parents. For example, weight gain often becomes a key marker.
Once their infant attains a certain weight, parents will invite people to their home and take the infant out in public.

Parents also cope by hedging about the actual age of their infant. They develop strategies to protect their infant and their self-esteem, as these data bits reveal:

"I tell people he's a newborn... he's really 5 months old. When strangers ask, it's not worth getting into the whole emotional thing." (10B)

"We didn't have anyone over in the first month or 7 weeks after the baby's discharge." (7B)

"We stopped telling people that she's premature. I can't deal with it anymore... making up stories." (3A)

Nothing is very easy for parents of a VLBW infant. Some people will tell them they're too protective. They offend family and friends by not allowing them to visit and actively participate in the "new baby" experience. In time, pressure builds, and many parents feel like prisoners in their home. A trip to the grocery store becomes a major logistical nightmare. Socializing goes by the wayside. Some parents often blame health care providers for making them too afraid to return to normal living. This pressure and fear becomes clear in this data:
"Some of the information scares you... You really don't know what to expect with your baby once you bring him home." (4A)

"My sister came to visit from Michigan for five days. I'm sure she paid a lot of money for the airfare. She woke me up in the middle of the night, and said... I have the worst sore throat I've ever had in my life. So my husband and I decided to get her out of the house. I told her that she was sick and that she had to go to a hotel... she freaked. She started crying and left. She didn't even try to understand our concern for the baby. We felt so bad and ugly." (14A)

"Even to this day his dad [husband's father] will ask, "Is there is anything wrong with her—can she see and hear?"" (13A)
"We wouldn't let anybody come over who had kids. In fact, that's one thing that really, over the past month, alienated us from some of our friends and family. We're just not ready to have kids come over." (7B)

As the first two subcategories indicate, parents initially spend most of their time adjusting to and keeping their VLBW infant alive. Along the way protection becomes basic in avoiding potential danger.

STAGE 2: EMERGING

Throughout this stage, roles start to emerge and differentiate. The infant now becomes expressive and begins to give parents cues about what it does and does not like. Parents are overjoyed to discover their infant actually has a personality.
Figure 3. Stage II: Emerging
In turn, this prompts parents to re-emerge and re-establish relationships with family and friends. People and relationships neglected during the early phases of their infant's homecoming once again become important. See Figure 3 for this stage.

**SUBCATEGORY: SURVEILLANCE**

This surveillance subcategory starts with the lowering of the guard. While parents still closely monitor their infant and surroundings carefully, they do start to introduce their infant to family, friends, and the world at large.

Though still protective, the need to resurface grows—for both parents and their infant. Parents also start weaning themselves from the infant. However, major events like moving the infant into its own room may take several tries, because parents frequently back down. This probably has less to do with the infant's readiness than it has to do with the parents' readiness.

Family and friends now may visit under protective conditions. Interestingly, parents may feel intruded upon by unannounced visits. That's probably because the control issue remains paramount. Generally, the more time that passes and the more the infant develops, the more parents relax. But as the following data bits show, many parents still do not want to share their infant:
"She's still pretty fragile... It's tough when people get around her and want to touch her. You don't want to be rude... Get your hands off my kid." (12A)

"We didn't go to restaurants until... 3 months after discharge... We didn't take her out much those first couple of months. And we still don't go to very many restaurants..." (7B)

"When we go out I don't want people breathing on my baby, she's still so little. When she gets bigger and strong enough to fight off germs, then it's okay." (1B)

"I think there is sort of an underlying level of anxiety about his well-being... Even though the way we handle him is quite different than when he first came home, we still watch..." (11B)

These watchful tendencies diminish when parents begin to invite people over, usually at first a few friends who have no children. Before taking their infant anywhere, parents develop something that's akin to a strategic plan, illustrated by these data bits:

"If somebody is coughing in the store, I steer away from them..." (4A)

"We're not as protective... But we still ask people to wash their hands before they hold her." (13B)
Babysitters now may also become an option, though it's a particularly difficult step to take. Many parents remark that if their infant were normal, selecting a babysitter would not be such a major production.

That's because parents cannot accept the traditional babysitter for their infant, such as a caregiver or daycare that cares for several children. Thus, selecting—and then actually using—a babysitter involves a lengthy research process. Until now, parents did not trust anyone, including family, to care for their infant. Here is an example about the use of a babysitter:

"Leaving her with a babysitter, a little bit at a time, made it easier to make that change. At first I was nervous, but now I'm getting better... a little bit at a time."

(7A)

Parents also face picking and choosing who can and cannot visit. They must also confront people that simply don't understand or accept their caregiving strategies. By now, emerging parents realize the extent of isolation they have been experiencing.

It's only now that parents again have the time and energy to reestablish friendships. They once again focus their time and energy on their lives, and not just on their infant. This lets parents diversify, and begin to change their
protective behavior. Here are comments:

"We're not as protective, we have people over now... But we still ask them if they've been sick recently. Our son can now have his friends over." (14B)

"I'm not drilling everybody anymore like I was. She's up to 10 pounds and she's managed not to get sick so far. So, I feel a little better about that. I don't let just anybody touch her when I take her out... I take her to big grocery stores now." (1A)

"We now share him with family and a few friends. Now that he's older, we let them hold him... but we're still cautious." (8A)

New situations may arise as parents and infant gradually emerge from their isolation. For example, relative strangers want to learn about and touch the previously untouchable infant. In confronting the more general public, parents often don't know how to answer personal questions from strangers. These data bits illustrate public issues:

"People come up to us... I don't even know them. They ask to hold her... over my dead body. They grab her hand and kiss it... I pull out the wipes." (3B)

"I wish I had been more prepared... (in) making up stories." (5A)
SUBCATEGORY: EXCHANGE

The exchange subcategory reviews the relationship between parents and their VLBW infant. Initially, there is a one-way exchange between parents and the unresponsive infant, with the parents providing all the exchange.

Parents are the only ones who give. The infant's biological rhythms make the development of a two-way exchange process very tedious and time consuming. These include such basic rhythms as sleeping and eating, since premature infants usually have delayed interaction skills.

However, as the VLBW infant matures, parent-infant exchanges become more apparent and more frequent. A spiral effect occurs during these exchanges, and parents finally receive reinforcement and feedback from their unceasing efforts to nurture their infant. Exchanges also begin to occur at different levels within the family.

It now becomes important to provide not only physical care, but psychological care as well. As parents nurture their infant, the levels of care change. For example, parents now can understand their infant's behavior because they recognize its various cries. They learn to recognize the cries for hunger, a wet diaper or attention. This relieves parents who may have feared that their infant was not responding to their parenting efforts. Parents acknowledge the changes in their infant's behavior.
"She's more responsive... from across the room. Look, she's holding her head up." (3A)

"She's really matured a lot... dramatically different. My husband kept saying somebody took our baby... it's like they switched babies." (13A)

"He lets you know if he doesn't like what you're doing to him. He's very particular... real verbal. He really focuses on me now." (6A)

"She's changed dramatically. It's incredible. She found her hands and started really smiling at us and she watches us, trying to focus. She now plays in her crib by herself. Her attention span has increased... she's awake for a longer period of time and interactive and of course, she's bigger." (14B)

To enhance this emerging period, parents refer to what experts told them about the infant's ability to respond and form a reciprocal relationship. Parents look carefully for positive cues that will further encourage them.

They may also use books that tell how they can interact with their premature infant. Parents cite at least two key points: Don't over-stimulate the infant, and that a premature infant is slower to organize its behavior patterns. These data bits underscore these points:

"I pull out the literature about my baby's development... hoping to learn what's normal for a premie." (8A)
"She has a hard time relaxing. I don't know how much of that is because... of the prematurity. It seems like she can't get organized. We help her relax by turning down the lights and giving her some quiet time." (7A)

Parents—especially mothers—become upset if they can't coax or cajole their infant to look at them. This usually occurs when they change diapers or provide other contact care. Intellectually, parents know that it takes time to develop a higher-level of exchange. But knowing this doesn't make it easier for parents as they wait and watch. They eventually believe that the results are worth waiting for. These data bits help depict the reward:

"Feeding her now is a social event. I feed her... she sits there and talks to me. She'll take a sip, look up... she'll start talking to me." (12A)

"Now I know what my baby likes... That's been a long time coming. She on a schedule now... it's her schedule." (2A)

"Once he starts smiling and listening to your voice, you're getting something back... It's been really hard." (5A)

STAGE 3: AFFIRMING

At affirming, parents and infant emerge more and more as a traditional family. Until now, parents had limited their
Figure 4. Stage III: Affirming
infant's contact to a few selected family and friends. Parents now not only emerge—but affirm and re-affirm—their family unit. And most important, they introduce their VLBW infant to the world outside.

Having made significant progress in living with their VLBW infant, parents now seek positive feedback from others to help validate their nurturing efforts.

All of the parents believed that their families and friends could never understand the extent of their initial traumatic experiences. For example, friends will comment about how well the infant looks, and then question whether the infant was really sick or just over-protected. Family and friends who only now get involved see only the positive results. They cannot know the initially challenging and horrifying experiences sustaining their VLBW infant's life. This stage appears in Figure 4.

**SUBCATEGORY: DEBUT**

Once parents reach the affirming stage, they start to leave the isolation and other initial care issues behind. They finally circulate in public, and initiate the excitement and pride of having a new and emerging healthy infant.

Physically, the infant looks better. It is growing and is healthy enough to deal with the multitude of environmental hazards. This debut phase is critical for parents because it allows family and friends to belatedly celebrate the birth.
Here is an example of what can occur during the debut phase.

"A friend of ours is getting married... He called and said, 'We'll understand if you can't make it... 'We know you have a premie.' What's that got to do with it? We're still coming and we're bringing our baby!" (10B)

Parents initiate their infant's debut in many ways. They may display photographs or actually take the infant to meet their friends and coworkers. Some parents may even show photos of the infant when it was critically ill. In some cases, parents prefer to side step the critical early phase.

It is at this stage that the mother usually chooses to return to work. That's when her coworkers learn details about the infant's birth. Here are two ways parents introduce their infant to coworkers.

"A few people at work were interested and kept bugging me to see pictures of the baby. I finally got some new pictures and went through the old ones. I actually put a couple of the hospital pictures in the pile... It brings back memories of how bad it was..." (6B)

"We have this little photo book... So many people want to know the story. It's a way to explain this experience to all the people that were so concerned." (10A)
Some encounters may be unnerving. People talking about premature babies can offend parents. They already know how fragile their infant once was, and remain concerned and protective.

Parents eventually become desensitized to casual or insensitive remarks and questions about their infant. They no longer apologize for their premature infant who may look different from a full term infant. They no longer explain why the facial features are different, or why there are IV needle scars on its body.

Many people mistakenly assume that all premature infants are fragile, and parents don't like to hear this. People initially may be apprehensive and afraid of the infant. Therefore, despite the joy of having a newborn infant and, finally being able to physically share it, remarks annoy parents. Many parents cite ignorance as a key factor. Here are some situations that parents often face from people.

"They're afraid of him, some people are afraid to touch him... he's so small. I'm talking about relatives, the people that I expect to love him. They love him... but don't show it. They haven't celebrated his birth yet... It's been 7 months." (11A)

"Her head shape is different. Most kids have squat heads with big cheeks. The premie head is so elongated. And then there are the scars on her feet... on both feet. There are IV sticks, little scars on her scalp. I understand and appreciate the fact that it was a way to keep her alive. But it's a little disturbing... A constant reminder." (3B)
This subcategory refers to the measure of time that parents use to gauge and understand their infant's development. These gauges include health, weight, size, and appearance and are very individual for each infant. Parents use these markers and milestones in assessing their infant's developmental progress.

Until now, physical and mental development issues were only background concerns. Now, these fears of potential physical, emotional or mental disabilities once again surface. Parents wonder constantly if permanent health problems will plague their infant. To date, health care providers have not been able to provide definite diagnoses. However, they can provide developmental signs or markers that parents can watch for.

These concerns of development bring a new facet to the VLBW infant; corrected age. Corrected age allows health care providers and parents to adjust the age by taking prematurity into account as they study developmental patterns. Corrected age, then, becomes the difference between 40 weeks and gestational age. Therefore, many parents formulate their expectations based on the infant's corrected age.

For example, parents know that their 32-week premature infant won't be as developed as a 2 month term infant for at least another 4 or 5 months. Understandably, parents look forward to the time when they no longer need to use corrected age. Because then they will know that their infant is on
Several events occur when parents face real time. These include the celebration and acknowledgment of the birth; due date versus actual date of birth. All participating parents remarked that while this was not an overwhelming issue, it was always present.

Again, public exposure remains a challenging issue. For example, people have a preconceived notion of what a baby looks like at a specific age. That's why the actual age of a premature infant is a difficult concept for the public. Here are some real time conditions that occur.

"It's funny, we were shopping the other day and someone asked my husband how old the baby was. He was quiet for a while...then he goes, '3 months.' I said, o-oh...you lied. He said, 'I didn't want to go into detail.'" (5A)

"We think of our baby as normal until someone mentions something about his premature nature...his size and how he looks." (6A)

"Just the other day we were talking about celebrating her birthday. When she turns one...will she really be one? Developmentally, she will be a little behind. We'll just do it on her real birthday, the day she should have been born." (14A)

Correcting the infant's age can help parents justify or
rationalize their infant's late development as it relates to real age/corrected age. Parents exercise their choice by using the one that produces the best results. They also feel it's important to actually plot their infant's growth and development. Weight and size remain an issue, so parents may use corrected age for more reassurance about their infant's progress.

Parents also talk about how they feed their infant more so it will grow faster. They try to force their infant to become a size that's equal to its age. However, some learn that this does not work. So, parents will still exaggerate the infant's age to justify its size. Here are a few examples.

"Overall, the baby is doing great. She's in the 10th percentile of her weight. She's not quite there on height... not on the chart yet, unless you correct her age." (1B)

"You look at a chart and he's on the wrong curve. Our doctor told us not to worry, the baby will catch up with time." (5B)

"I still lie about her age. The last time we got together I told you I didn't lie about her age... but today I did. It depends on who asks me." (2A)

Situations that parents confront about their infant in terms of real versus corrected age become more apparent. What the future holds for their infant remains in limbo because the infant may not function normally for its age.
This creates another issue: finding and trusting a babysitter that understands how to treat a premature infant using real versus corrected age. Here are data bits about the infant's real and corrected age.

"There's definitely a stigma, that whole age thing. I get confused... corrected or when he was born. I don't know which one to use. The sitter doesn't believe me. I tell her that she can't treat him like a 6 month old—even though he is 6 months old." (10A) "She may be caught up on her weight, but developmentally she's not there yet... for her gestational age." (1A)

"People don't understand his real age. He's 9 months old, so they say he should be trying to walk. But he's not really 9 months old. The corrected age idea... just doesn't sink in." (8A)

Gathering, Emerging, and Affirming are the three stages of 'Creating Paths'—the basic social process of parents living with their VLBW infant for the first five months after hospital discharge.

THEORY OF CREATING PATHS

'Creating Paths' is a continuous process that is constantly in flux. As the theory evolved, I saw that parents adapted during the first five months of their VLBW infant's discharge by 'Creating Paths'. This process is comparable to
Creating Paths

Stage 1
Gathering
- Sustenance

Stage 2
Emerging
- Protect
- Surveillance
- Exchange
- Debut

Stage 3
Affirming
- Real Time

Figure 5. Creating Paths: Living With A Very Low Birth Weight Infant
the creative process that an artist experiences. That is, 'Creating Paths' is a multidimensional process that integrates many human elements, such as intellect, culture, and intuition. As parents further experience life with a VLBW infant, the paths they create take them in many directions. They face continual challenges filled with contradictions. For example, when is it really safe to take the baby out in public? What are the markers—weight, time, or months? How do they age their infant? Do they use real or corrected age in terms of social and development stages? Life with a VLBW infant becomes a process of continual and precarious balances: parents modify their behavior and develop strategies to cope with their VLBW infant. The continual process of 'Creating Paths' appears in Figure 5.

As discussed, a key element of 'Creating Paths' seems to be the circumstances that envelop parents—and the subsequent actions required to accommodate these circumstances. They adapt to their VLBW infant by using many tactics to create behaviors and actions. By setting their own pace, parents create a sense of control over the rearing process.

Creating a sense of order helps parents feel they have control. Control becomes a major factor in the early stages of 'Creating Paths'. Parents set personal goals and markers that when met, indicate they have taken the correct path. As parents master their creativity, they are able to move from a random process to a more focused one. This in turn helps
parents create additional paths, setting the stage and pace for forward movement. An awareness of the surrounding environment is an important part of this path.

"Creating Paths" is a process that parents must learn. They quickly learn that doing so helps them to nurture and integrate their VLBW infant within the family. By experimenting, parents learn to effectively engage their path.

The subcategories within each stage of 'Creating Paths' are mutually exclusive. That is, the subcategories of the sequential stage becomes the foundation for the next set of subcategories. Therefore, the structure of 'Creating Paths' is fluid in that it flows from one stage to another. The structure of each stage in 'Creating Paths' will ultimately determine how the parents behave within that stage. Once parents reach stage 3, they have established themselves as both nurturing and effective parents.

SUMMARY

This chapter introduced the theory of 'Creating Paths', which has three stages: Gathering, Emerging, and Affirming. These stages relate to their subcategories, properties, and interview data. As the core category, 'Creating Paths' can be interpreted as a basic social process that occurs and changes over time.
CHAPTER VI

CONCLUSIONS AND RECOMMENDATIONS

This chapter presents conclusions based on this study. This chapter discusses the generated grounded theory of 'Creating Paths,' the emergent stages, its relationship to Roy's Adaptation Model, and related studies. The study implications for theory, research and practice are also discussed, along with recommendations for future study.

CONCLUSIONS

'Creating Paths' evolved during the theory discovery process, which described how parents live with a VLBW infant. The study covers the first five months after the infant's hospital discharge. The 'Creating Paths' grounded theory is illustrated in Chapter V.

'Creating Paths' is the process in which parents learn about, adapt, and provide care for their VLBW infant. 'Creating Paths' as a process begins during the first five months of life with the VLBW infant. After careful analysis, 'Creating Paths' was chosen because it appeared to be the most accurate reflection of what parents of VLBW infants experience. And depending on the parents and their particular needs, many
different paths are chosen.

'Creating Paths' includes three stages: Gathering, Emerging, and Affirming. It is important to note that the timing of the stages did not always correspond with the interview schedule. Many extraneous factors affected and intervened with the stages described. Each stage identifies and accounts for a variety of behavior patterns. These stages reflected change over time. The changes have identifiable stages—each can be viewed with its own conditions, strategies, and consequences. These stages may occur at different times and may replace each other. How long a stage lasts is often determined by events for that given stage. A shorter time could be due to behavior patterns that do not follow a given stage’s events. For example, parents cannot move to stage 2, Emerging, if they still struggle to provide basic infant care and they isolate both themselves and their infant. In contrast, stage 1, or Gathering, could be shorter if parents do not have the time and ability to collect all the information and use the resources that are available. Financial needs may force a parent to leave their VLBW infant with a baby-sitter shortly after discharge. Therefore, the time required to complete the three stages can vary widely.

The family’s interactions with the environment also affect the pace of this process. When adequate control of the process occurs, the parents and infant start to affirm themselves—as apparent in stage 3. This can lead to an ability
to withstand the stress and constantly changing environment.

'Creating Paths' features characteristics consistent with basic concepts established in the theory of family systems (Whall, 1991; Wedemeyer & Grotevant, 1982). For instance, 'Creating Paths' suggests that parents and their infants constantly exchange energy that takes the form of information and interaction. This exchange affects the development and behavior of those involved. The constantly altering environment affects this exchange and presents new challenges to stimulate parents to respond while adapting.

In the journey down the created path, parents and their VLBW infant emerge as a family that constantly evolves, and increases its individuality. The family assumes unique patterns and organization. These patterns constantly change as the family interacts with the environment. Moreover, when changes occur some may be due to a maturation process, for example, the VLBW infant's developing nervous system.

Roy's model of adaptation provided a perspective and helped identify the major purpose of this study. Roy (1991, 1983) proposes that individuals strive from their environment. The individual and environment are in constant interaction with each other. The individual has the capacity to adapt to and create changes in the environments. The ability to respond effectively to these changes is a function of the individual's adaptation level -- a changing point influenced by the demand of the situation and the individual's internal resources,
including capabilities, hopes, dreams, aspirations, motivations, and all that makes the individual constantly move toward mastery (Roy, 1983).

In this study parents constantly created changes in the environment to protect and nurture themselves and their infant. Parents were able to adapt and create changes in the environment by isolation during the first few weeks at home, and by deciding who may and may not visit. Therefore, parents create behavioral goals and strategies to help them maintain a sense of order, balance, growth, and continuity. This leads to effective adaptation, and supports Roy's (1983) expanded definition of the family. Roy (1983) views the family as an adaptive system that, like the individual, has inputs, internal control and feedback processes, and output. In viewing the family as an adaptive system, the output behavior shows how the family is adapting to environmental change.

Roy's extension of her conceptual model to the family provides direction for middle-range family theory development. Further, family adaptation and nursing practice theories need to be generated and then tested. Family adaptation theories should focus on identifying specific and substantive inputs, processes, and outputs of the family adaptive system.

"Nursing practice theories about the family" as noted by Roy (1983), "will relate to how nurses diagnose and intervene with the family to promote system adaptation" (p.275). 'Creating Paths' accepted this challenge to do just what Roy proposed.
As described by Bass (1991) and found in this study, parents focus the first 3 to 5 weeks on keeping the infant alive and coping with their new situation. Also, feelings of isolation immediately after discharge were well documented.

As indicated in stage 1, Gathering plays a significant and essential role in preventive health. It is well documented by Perrault, et al. (1986) and Hunt (1984) that premature infants often become the abused and neglected. This may be directly related to the parents' perceived inability to meet infant care needs (Kenner & Lott, 1990).

Parents' statements during this study support earlier findings about interaction between parents and their VLBW infant (Easterbrooks, Harmon, & Macey, 1987; Klein & Stern, 1971). Many voiced concerns about how difficult it was to establish a reciprocal relationship with their infant. These comments were often related to the VLBW infant's unique behavioral characteristics.

However, parents did not express concern about the neurodevelopment of their infant. Parents only began to question their infant's development at the third interview, or five months after discharge. This could relate to their priorities in dealing with appropriate issues for the present—simply getting their "act" together. This finding supports the work of Gennaro, Zukowsky, Brooten, Lowell, & Visco (1990).

'Creating Paths' suggest that parents who have information and resources available before their VLBW infant's
hospital discharge, can better carry on the caregiving and nurturing of their infant with little disruption. All parents picked and chose from the information provided from various sources to create their own customized paths.

During this study, it also became apparent that the more comfortable parents became with the basic care of their VLBW infant, the easier it became to nurture and introduce their infant to the outside world.

Empirical data support all the stages that encompass 'Creating Paths'. This theory strongly indicates that these stages do occur and are, by nature, subtle. All of the parents taking part in this study experienced the sequence of stages outlined in this study.

**IMPLICATIONS FOR NURSING THEORY**

Research that generates theory is designed to discover and describe relationships among events that are observed or inferred. This research does so without imposing preconceived notions of the adaptation process. Research applies systematic methods to gain reliable and valuable knowledge about empirical reality. It represents one process of science that may lead to theory as a product (Chinn & Jacobs, 1987; Meleis, 1985). Thus, knowledge gained from research helps build and strengthen the nursing profession.

The findings of this study add to what we know about
parental behavior—and how it partially reflects environmental influences—such as the living with a VLBW infant. The grounded theory depicts the processes that parents employ to adapt to their VLBW infant. 'Creating Paths' further enhances understanding of this process by providing descriptions of the behaviors during adaptation after hospital discharge. 'Creating Paths' provides living with a VLBW infant with new and different perspectives and insights.

It is only recently that nurse researchers have become more conscious and concerned with the VLBW infant's family. These concerns include the total process of the family's well-being and functional levels. Researchers also have become concerned with family behavior patterns—as they interact with the environment (Whall & Fawcett, 1991; Sims-Jones, 1986).

The grounded theory research method offers nurse researchers one more approach to help generate much-needed "middle range" theories. Therefore, this study illustrates how grounded theory may be used to explore complex human phenomena in this unique environment. The theory of 'Creating Paths', on a more abstract level, may also be applied to those newly diagnosed with a terminal illness.

Theory development is greatly needed in nursing, especially the "middle-range" theory that bridges the gap between the metaparadigm concepts and practice (Walker & Avant, 1988).
IMPLICATIONS FOR NURSING RESEARCH

Research plays an ongoing and integral role in developing the practice of nursing. As particularly apparent in the helping professions, human behavior patterns become more clear. As a result, intervention and care can be improved through both qualitative and quantitative research methodology (Thompson, 1987).

Grounded theory provides a method to systematically track the adaptation process that parents of VLBW infants experience following hospital discharge. Thus, using the methodology of grounded theory helped generate 'Creating Paths', which describes a basic social process that accounts for variety in interaction around the process. This "middle range" theory also allows easy application to clinical practice. Therefore, grounded theory methodology becomes useful by providing a framework for the understanding of this human occurrence.

With the advances in neonatal technology, nursing and medicine, these established and continually evolving interventions demand specific scientific investigation. This is true for both the VLBW infants who cannot speak for themselves and for the parents who are overwhelmed with very technical detail from birth. Both parties are, and remain, extremely vulnerable. These factors require investigators to use various methodologies in the scientific inquiry.
IMPLICATIONS FOR NURSING PRACTICE

This investigation provides a beginning theoretical foundation to assess the adaptation process of parents with VLBW infants during the first five months of living at home. Neonatal nurses may use the theory to anticipate and provide guidance and support to parents and their infant.

Also, assessing the parents' adaptation process should include how they integrate the VLBW infant into their lives. This theory becomes especially germane to community health nurses who provide follow-up care to these infants and their parents.

Much time and effort has been placed on developing and purchasing technologically-advanced equipment for the NICU. However, this technology cannot operate in a vacuum. At least as much time and effort must be generated for the continuing study and support for those who actually experience the NICU rigors.

RECOMMENDATIONS

Future studies that address the biopsychosocial links and its effect on premature infants and their parents are required. Research should pay particular attention to the issues that relate to parents as they live with a VLBW infant.

Neonatal technology, nursing and medicine now saves more
lives. However, does this technological intervention create a better quality of life for both the VLBW infant and their families? Are VLBW infants now more prone to future psychosocial limitations and physical disabilities? It becomes apparent that scientific inquiry has not kept pace with the advances of life saving techniques.

This study has also revealed several other questions that merit further investigation:

1. How does the adaptation process change during the first year? Is there a plateau?

2. Would intervention make a difference in the adaptation process? When would intervention be most effective—before or after discharge?

3. How do parents of a VLBW infant with a chronic illness, anomalies, and/or neurological sequelae adapt following hospital discharge?

SUMMARY

It is disappointing that even with the great strides made in the technological, nursing and medical care of the VLBW infant, there has not been a corresponding growth in knowledge of the increasingly apparent psychosocial issues. It is simply a fact of life that we cannot continue providing acute VLBW infant care without addressing the many aspects involved in the subsequent life of these infants and families.
This study increases the knowledge that is particular to parents after their VLBW infants are discharged. From this study, neonatal clinicians may identify additional research questions that interest nursing.
August 8, 1990

Elias Vasquez, R.N., M.S., N.N.P.
Neonatal Services

RE: Protocol 90-022, "The Adaptation of Parents to Their Very Low Birth Weight Infant."

Dear Mr. Vasquez:

As Chairperson of the Research and Human Experimentation Committee, by direction of the full Committee, I have taken the following action in regard to your proposal:

- Approved your protocol.
- X Approved your revised protocol 8-8-90.
- Requests that you complete or amend your proposal/revisions per the attached excerpt from the minutes and resubmit for approval. ALL REVISIONS MUST BE HIGHLIGHTED.
- Tabled your proposal/revisions. See attached excerpt from the minutes of the RHEC for comments and/or further clarification.
- Other: Renewed approval of this protocol for another year.

In keeping with the requirements of the FDA, the NIH and the Children's Hospital Research and Human Experimentation Committee, progress reports must be submitted to this Committee at least annually. A progress report will be due on this protocol in August 1991.

Sincerely,

[Signature]

Robert G. Miller, M.D.
Chairman
Research and Human Experimentation Committee
MEMORANDUM

TO: Elias Vasquez
FROM: Carolyn Murdaugh, Ph.D., R.N.
      Director of Clinical Research
DATE: February 17, 1990

SUBJECT: Human Subjects Review: "The Adaptation of Parents to Their Very Low Birth Weight Infants"

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Subcommittee of the Research Committee and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research if you need access to it.

We wish you a valuable and stimulating experience with your research.

CM:ch
Children's Hospital of San Francisco

THE ADAPTATION OF PARENTS TO THEIR
VERY LOW BIRTH WEIGHT INFANT

Permission to Participate in a Research Study

Principal Investigator: Elias Vasquez, RN, MS, NNP

By signing this consent form, I agree to my participation in a study to find out how parents adapt following the hospital discharge of their premature infant.

My participation depends upon my continuing consent. I understand that I may refuse or I may withdraw my consent at any time.

WHY IS THE STUDY BEING CONDUCTED?

Previous studies have shown that parents have concerns about managing the full time care of their premature infant following hospital discharge. This study will be conducted to find out how parents adjust to taking care of their premature infant at home.

WHAT HAPPENS TO MY BABY AND OTHER STUDY PARTICIPANTS?

Participation will involve three interviews—within 1 to 5 months after my baby's discharge from the hospital. The interview sessions will take place at my home or another location convenient for me. About 1 to 2 hours of my time will be needed for each interview. The conversations will be tape recorded. All tape recordings will be held confidential and will be erased following transcription. My name and the information I give will not be known to others.

WHAT ARE THE RISKS OF THIS STUDY?

The interviews may bring up feelings of "emotional discomfort" (sadness or anger). I may refuse to answer any questions. There are no other risks involved to me or my baby.
WHAT ARE THE BENEFITS OF THIS STUDY?

There is probably no benefit to me. If I agree to participate, perhaps what I talk about will help health care providers understand some of the problems or issues parents of premature infants experience following hospital discharge.

HOW WILL THE STUDY AFFECT MY BABY'S MEDICAL CARE?

This study will not affect my baby's care.

HOW CONFIDENTIAL ARE MY BABY'S MEDICAL RECORDS?

The investigator conducting this study will have access to my baby's records. All records will be treated confidentially and in the event of publication of this study, individual identities will not be disclosed.

WHAT HAPPENS IF I AM INJURED OR HARMED IN SOME WAY BY THE STUDY?

I understand that Children's Hospital of San Francisco and/or the investigator have no special program that provides compensations for medical treatment if any complications arise from participation in this study.

WHERE DO I GO WITH QUESTIONS?

The investigator (Elias Vasquez) listed above will answer any questions I may have about my participation in this study. I may reach him at (415) 750-6211 (a 24-hour number).

WILL I BE TOLD WHAT THE STUDY LEARNED?

Yes, I will be advised of any significant new findings developed during the course of the research, if I request the information.

I have been given a copy of this consent form and the Experimental Subjects Bill of Rights and I have read and understood them.

_________________________________________ Date ____________
Parents

_________________________________________ Date ____________
Principal Investigator
Neonatal Information Form

Code # ___

Date of Birth ___/___/___

Weight _____lbs. ____ounces
______grams

Infant's Admitting Diagnosis ________________________
________________________
________________________

Gestational age at birth ______

Length of Stay in Hospital ______ days

Date of Discharge ___/___/___

Referrals of Follow-up Services ________________________
________________________
________________________
________________________

________________________

________________________
The Family Information Form

Code # __________

1st Interview Date ___/___/___

3rd Interview Date ___/___/___

5th Interview Date ___/___/___

Age of Mother ___

Age of Father ___

Partner Yes ___ No ___

Occupation of Mother _______________________________________

Occupation of Father _______________________________________

Household composition _______________________________________

___________________________________________________________
Formal Interview Guide

The following questions were developed to elicit problems parents may have in caring for their VLBW infant at home. As the problems are identified, the investigator will ask parents to describe (by giving examples) how they dealt with these problems, thus describing the "adaptation process."

1. Tell me what happened when you first arrived home with (baby's name)?
2. What did you know about taking care of a premature infant at home?
3. Tell me what it's like taking care of (baby's name) at home? How did reality compare with what you expected?
4. Describe a situation in which you felt good about taking care of (baby's name)?
5. Describe a situation in which you felt bad about taking care of (baby's name)?
6. Who did you talk to about (baby's name) care and/or problems? (e.g. friends, partner, mother, others) What did they tell you?
7. Who else has helped you with the care of (baby's name)? (partner, friends, mother, sister, brother)
8. Tell me what your life was like before (baby's name) was born?
9. What effects has (baby's name) had on your life? Experiences as a mother/father? The relationship with your partner, family, and friends?
10. Tell me about your life since (baby's name) was discharged from the hospital? Has this effected your eating and sleeping patterns? Arranging for someone to care for (baby's name)?
REFERENCES


