

HOME APNEA MONITORING:  
FAMILY FUNCTIONING, CONCERNS, AND COPING

by

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## ABSTRACT

Sudden Infant Death Syndrome (SIDS) is the leading cause of death in infants between one week and one year of age. The mainstay of therapy to reduce SIDS mortality is evaluation and subsequent home monitoring of infants at risk for SIDS. This study explored the concerns and responses of families of 13 infants to having an infant on a home apnea monitor. These concerns and responses were reported by the mother at three time points in the home apnea monitoring experience. The Neuman Systems Model served as the theoretical basis for the investigation. The study design was longitudinal with event partitioning, and used the following instruments: Hymovich's Parent Perception Inventory, the Feetham Family Functioning Survey, the Monitoring Flowsheet, and the Early Infancy Temperament Questionnaire. Data analysis included repeated measures analyses of variance and correlational coefficients. Maternal concerns and coping response scores were positively correlated with family functioning discrepancy scores at the initiation of monitoring. Parental coping response scores were negatively correlated with infant temperament at the termination of monitoring, as are severity of illness and sibling coping behavior. Patterns were apparent in the frequencies of various concerns and coping strategies at different points in the home monitoring experience.

Because nurses are in key positions to coordinate the development of strategies for families to use in coping with the stressor of home apnea monitoring, this study is particularly beneficial to practicing nurses. Information about concerns and coping



responses along with determination of the relationship with family functioning and infant temperament provide a basis for nurses to develop interventions to assist families in positively coping with the home apnea monitoring experience.

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## CHAPTER I

### Problem Derivation

Sudden Infant Death Syndrome (SIDS) is the leading cause of death in infants between one week and one year of age (Keens & Ward, 1993). The mainstay of therapy to reduce this mortality rate is evaluation and subsequent in-home monitoring of infants at risk for SIDS. In-home monitoring of the cardiac and respiratory status of infants and children exerts stress on the family unit (NIH, 1987; Ridgell, 1993). Nurses are in key positions to develop intervention strategies for families to cope with the concerns and needs involved in home apnea monitoring. An accurate description of the way family members respond to the monitoring experience during the various phases of monitoring is necessary for developing these interventions (Ridgell, 1993). Initial exploration by other researchers of the impact of home monitoring and other aspects of high technological pediatric care on the family focused only on maternal responses to these innovations at a single point in time. The impact of the stressor of home apnea monitoring on all family members and at varying points during the home monitoring experience must also be studied. These findings will serve as the basis for tailoring nursing interventions to assist families in positive coping with the home apnea monitoring experience.

### Statement of Purpose

To lay the groundwork for future intervention studies, this project investigates the effects of home apnea monitoring on members of the infant's family and on the family's

functioning as perceived by the mother at three points in the home apnea monitoring experience.

### Significance/Justification

SIDS is “the sudden death of any infant or young child, which is unexplained by history and which a thorough post-mortem examination fails to demonstrate an adequate explanation of cause of death” (NIH, 1987, p. 4). SIDS, the number one cause of death of infants between one week and one year of age, kills over 4890 infants per year nationally (US Department of Commerce, 1995a & 1995b) and over 75 infants per year in South Carolina (SC Department of Health and Environmental Control, 1995). The incidence of SIDS in the general population is 2 cases per 1000 live births (Keens & Ward, 1993), rising to 5 to 10 cases per 100 live births in twins of SIDS victims and 2 cases per 100 live births in other siblings of SIDS victims (Spitzer & Fox, 1984a). To reduce this mortality, evaluation and subsequent home monitoring of the cardiac and respiratory functioning of at-risk infants are frequently used techniques (Keens & Ward, 1993; Spinner, Gibson, Wrobel, & Spitzer, 1995). Accurate prevalence rates are difficult to estimate due to the lack of a systematic registry; however, an estimated 45,000 infants/children require home apnea monitoring each year (Whitaker, 1995).

Apnea is the “cessation of respiratory air flow” (NIH, 1987, p. 3; Spinner et al., 1995). Home apnea monitoring consists of placing an infant on an electronic device to monitor the cardiac and respiratory systems continuously for 24 hours each day. Some infants require monitoring only during sleep when respiratory effort is minimal or at other times when direct monitoring is not possible (Keens & Ward, 1993; Spinner et al., 1995). Indications for home monitoring include infants with a history of severe apneic episodes or

“apparent life-threatening events” (ALTE) (NIH, 1987), documentation of apnea or increased periodic breathing via sleep pneumograms, twins or siblings of SIDS victims, history of severe feeding difficulties such as gastroesophageal reflux with apnea and/or slowing of the infant’s heart rate, and a variety of miscellaneous physiological alterations (Spitzer & Fox, 1984b, 1986; Spinner et al., 1995). The usual monitoring episode begins when the infant is placed on the cardiorespiratory monitor on discharge from the hospital, either during the neonatal period or at two or three months of age. Monitoring continues until the infant is no longer thought to be at risk for ALTE episodes, i.e. when the infant has been free of significant alarms or apneic episodes for two to three months (Keens & Ward, 1993; NIH, 1987)

The technical requirements of home apnea monitoring are numerous. The monitor is fastened to the infant via two electrodes which are attached by adhesive to the infant’s abdomen or incorporated into an electrode belt which encircles the infant’s chest. Special attention to skin care at the location of the electrodes is necessary to prevent skin breakdown. Lead wires run from the electrodes to a cable attached to the monitor. Parents and all other adult caretakers must be able to respond properly to alarms. Infant movement, misplacement of the electrodes, power surges, or dry electrodes can cause false alarms. True alarms occur when the infant has a change in breathing pattern with a 20-second period of apnea, often accompanied by a color change. A parent/caretaker must be able to hear the monitor alarm and must be no more than 10 seconds away from the infant at all times (Graber & Balas-Stevens, 1984). A parent/caretaker must then stimulate the infant to initiate breathing and institute cardiopulmonary resuscitation (CPR) if required. The family/caretaker must have a dependable electrical supply and must be

able to notify the ambulance, pediatrician, and pediatric intensive care unit immediately if resuscitation efforts are necessary.

The magnitude of stress associated with home apnea monitoring may affect family functioning. Current literature addresses the need to explore the concerns and coping responses of families and their members experiencing stressors to family functioning (NIH, 1987; Ridgell, 1993). Family support is critical to facilitate an infant's normal growth and development during both wellness and illness. Health care providers, therefore, must assess family strengths and needs so that they can develop strategies to assist these families with positive coping (Shelton, Jeppson, & Johnson, 1987). Research to date focuses primarily on maternal anxieties and coping. Limited research addresses the areas of paternal and sibling impact and coping mechanisms in families of infants on home apnea monitors. Additionally, the National Institutes of Health (1987) recommend investigation of both the short-term and the long-term effects of in-home monitoring on the family and each of its members when there is an infant on home apnea monitoring. This investigation considers the effects of home apnea monitoring on individual family members and on the family as a whole as perceived by the mother.

#### Theoretical/Conceptual Framework

The family unit is an open system interacting with the internal and external environments in a reciprocal manner (Hinds, 1990). In addition, the family system encompasses individual family member/systems in interaction with each other and interacting with those outside the family. The Neuman Systems Model (1995) organizes these interacting individual systems of family members into a global family system.

Consistent with other systems models, Neuman's model includes concepts of stress, conflict, equilibrium, and feedback (Fawcett, 1995).

Neuman's (1995) model focuses on assessment of client stressors and responses to those stressors and the appropriate nursing actions as a result of that assessment. The Neuman Systems Model (1989, 1995) (Figure 1) assumes a holistic view of clients and their needs, whether an individual family member is the client or whether the family system is the client. As a functioning system, anything which affects any member as well as the individual characteristics of each family member can affect the family as a whole (Reed, 1993).

According to Neuman (1995), the strengths and weaknesses of the family members together constitute the core of the family system. Surrounding and protecting this central core are the lines of resistance of the system which include the values and beliefs of the family system. A normal line of defense surrounds these lines of resistance. An example of a normal line of defense is the family's relatively stable patterns of communication, such as problem solving, coping, and intimacy which the system has developed over time. Finally, the flexible line of defense comprises the outer boundary of the family system and consists of those day-to-day changes in tasks, rules, and roles which the family system undertakes in response to conflict or change (Neuman, 1995).

In Neuman's model (1995), stressors arise from the environment, whether intrapersonal, interpersonal, or extrapersonal in nature, and have the potential to disrupt the stability of the family system, whether in the physiological, psychological, sociocultural, developmental, or spiritual variable area (Neuman, 1995). The intensity of

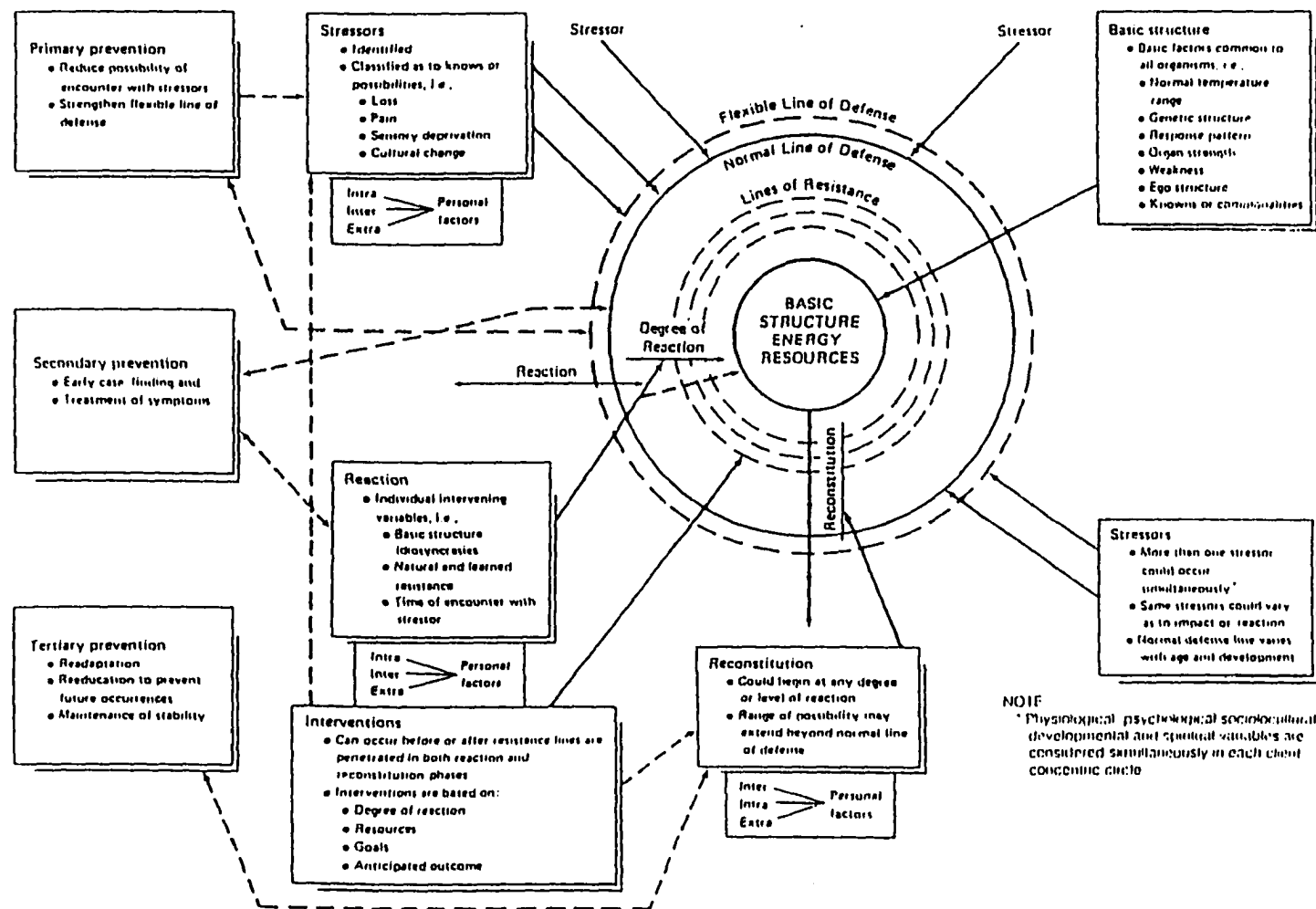


Figure 1-3. The Neuman Systems Model. Original diagram copyright © 1970 by Betty Neuman.  
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the stressor and the strength of the flexible line of defense determine the degree of stressor penetration through the lines of defense and lines of resistance towards the inner core of the family system. The role of the nurse is to analyze the stressors which are affecting the family system and to assist the family in either retaining, attaining, or maintaining the system's stability in response to these stressors (Neuman, 1995).

The experience of having an infant on a home apnea monitor constitutes a stressor to the family system as defined by Neuman (Ridgell, 1993). The National Consensus Conference on Infantile Apnea concludes that "because of the extra demands, the changes in task and time allocation, and the extra effects on social life and on family resources that monitoring imposes, everyone in the family is visibly connected to the machine" (NIH, 1987, p. 5-1). In addition, the Consensus Conference notes that these disruptions in family life are the result of the home apnea monitoring experience (NIH, 1987, pp. 6-17 & 6-18). As a stressor, home apnea monitoring elicits various responses from the family system and its members in one or several variable areas (Ridgell, 1993). These responses may differ at various points in the home apnea monitoring experience. Wasserman (1984) identified a period of doubt/acceptance in the initial two to four weeks of monitoring, a period of dependence/frustration in the middle months of monitoring, a period of discontinuance with termination of monitoring, and a late effects phase lasting five years after the initiation of monitoring.

Based on these findings, Neuman's model was adapted to be specific to the home apnea monitoring experience (Figure 2). In this adaptation, the family is the client/system of concern. The basic core of the family/client includes the infant who was recently placed on a home apnea monitor, the infant's birth mother, plus any other persons living in the



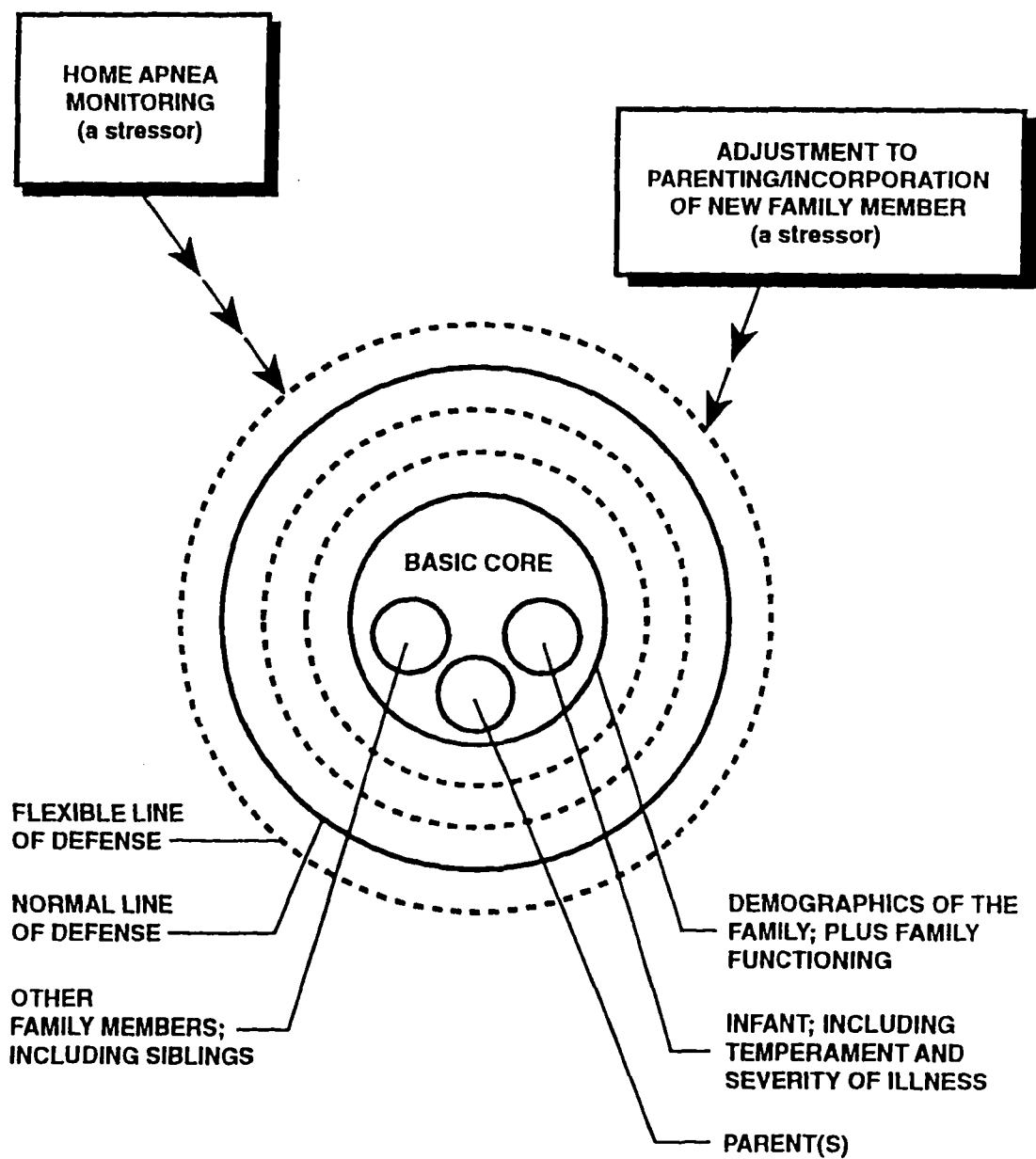


FIGURE 2: NEUMAN SYSTEMS MODEL ADAPTED FOR FAMILIES WITH INFANTS ON HOME APNEA MONITORING

home who are related to the infant by blood or marriage. These family members contribute their individual strengths and weaknesses to the family, including the temperament of the infant and the severity of illness. The family's demographics as well as its functioning serve to unify this basic core. Surrounding this basic core are the lines of resistance, normal line of defense, and flexible line of defense. The home apnea monitoring experience serves as an extrapersonal stressor to the family and to its members which must be prevented from penetrating the protective boundaries surrounding the basic core. At the same time, the home apnea monitoring family is confronting another stressor, that of adjusting to parenting or incorporating a new family member into an already existing family structure. When the client/family system encounters the stressor of home apnea monitoring, several responses or variances from wellness are elicited. These variances from wellness indicate weaknesses in the family's lines of defense and occur in one or more of the five variable areas (J. Fawcett, personal communication, March 22, 1997). Identification of these responses to home apnea monitoring will be useful to the nurse in planning specific strategies to assist the family in dealing with the stressor of having an infant on a home apnea monitor (Ridgell, 1993).

Studies by Black, Hersher, and Steinschneider (1978), Davis and Sweeney (1989), Mark and Zahr (1986), McElroy, Steinschneider, and Weinstein (1986), Ray and Ritchie (1993), Sweeney (1988), and Wasserman (1984) support the view that the decisions, emotions, and responses which families have during the time an infant is undergoing home apnea monitoring are similar to those experienced by families of children with chronic illnesses. Similarities between the two situations include persistence over time, often

unknown etiologies, the fact that both are usually manageable but not curable, uncertain prognoses, and similar stages of adaptation (Davis & Sweeney, 1989).

In 1979, Hymovich developed a framework for assessing the family's responses to the stress of having a child with a chronic illness. Hymovich's framework fits well with Neuman's model. As part of her framework, Hymovich (1984) notes that the client's perception of the environment determines his/her responses to it; therefore descriptions by family members are the best indicator of the impact of chronic illness on families.

According to Hymovich (1979), several mediating variables influence the coping responses which families use, including the underlying characteristics of the client system, the world view of the system, and the functional level of the client system. The net balance of the system's resources, both positive and negative, is the capability of the family system. The combination of these responses and resources determines the needs of the client system for nursing interventions (Hymovich, 1979).

In 1982, Roberts and Feetham addressed the concept of family functioning, i.e. the interrelationships of individual members in the context of the family. Their perspective also is congruent with Neuman's Systems Model since Roberts and Feetham view the family as a dynamic system greater than the sum of its individual members. According to Roberts and Feetham (1982), "family functioning consists of those activities and relationships among and between persons and the environment which in combination enable the family to maintain itself as an open system" (p. 231). Since the family is an open system, the characteristics of each family member can influence family functioning. The family's perceptions of the degree of family functioning and satisfaction with that

level of functioning are helpful to the nurse in identifying the needs of the family system and priorities for subsequent intervention.

The integration of a new infant into the family system influences the entire system. Temperament or behavioral style is a very strong infant characteristic and has an impact on the family's responses to a stressor (Melvin & McClowry, 1995), including family functioning (Ahmann, 1989). Schraeder (1995) notes that temperament "regulates the nature of transactions between parent and child" (p. 167). Nine variables, including activity level, rhythmicity, approach-withdrawal, adaptability, intensity, threshold, mood, attention-persistence, and distractibility, compose the infant's temperament (Carey & McDevitt, 1978). Carey (1983) sees temperament as a relatively stable trait throughout infancy and childhood.

In summary, according to the Neuman Systems Model (Neuman, 1995), a stressor elicits specific responses from the members of the family system and from the family system as a whole. The responses to having an infant on a home apnea monitor are noted to be similar to the concerns and coping strategies utilized by families of children with chronic illnesses. The temperament of an infant also has an impact on the family's response to a stressor such as home apnea monitoring.

### Research Questions

This study addressed the following research questions:

1. How do mothers' perceptions of the concerns of individual family members change as they progress through the three phases of home apnea monitoring?
2. How do mothers' perceptions of personal coping strategies for managing concerns change as they progress through the three phases of home apnea monitoring?

3. How do mothers' perceptions of the discrepancy between expected and perceived family functioning change as they progress through the three phases of home apnea monitoring?
4. What is the relationship between the concerns of family members as perceived by the mothers and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring?
5. What is the relationship between the coping strategies of family members as perceived by the mothers and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring?
6. What is the relationship between mothers' perceptions of infant temperament and the concerns perceived by the mothers during the home apnea monitoring experience?
7. What is the relationship between mothers' perceptions of infant temperament and the coping strategies perceived by the mothers during the home apnea monitoring experience?
8. What is the relationship between mothers' perceptions of infant temperament and discrepancy between expected and perceived family functioning during the home apnea monitoring experience?
9. What is the relationship between mothers' ratings of the infants' severity of illness and the concerns perceived by the mothers as families progress through the three phases of home apnea monitoring?

10. What is the relationship between mothers' ratings of the infants' severity of illness and the coping strategies perceived by the mothers as families progress through the phases of home apnea monitoring?
11. What is the relationship between mothers' ratings of the infants' severity of illness and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring?
12. What is the relationship between mothers' perceptions of infant temperament and the infants' severity of illness during the home apnea monitoring experience?

#### Definitions of Terms

This investigation uses the following theoretical and operational definitions of terms.

Concerns. Self-reports of responses to a stressor which family members perceive (Hymovich, 1987) constitute the theoretical definition for the concept of concerns. For this investigation, the concept of concerns is operationalized as the mothers' responses on the Concerns subscale and the Spouse Concerns subscale of the Parent Perception Inventory (PPI) (Hymovich, 1989) (Appendix D).

Coping responses. The mechanisms which the family uses to mediate the effects of the stressor on the family system (Hymovich, 1987) constitute the theoretical definition for the concept of coping responses. For this investigation, the mothers' responses on the Coping subscale, the Spouse Coping subscale, and the Sibling Behaviors subscale of the PPI (Hymovich, 1989) operationally define the concept of coping responses.

Family. Hymovich's definition of a family as "a unit of interdependent interacting individuals who are related to one another by marriage, birth, adoption, or mutual

consent” (1990, p. 132) serves as the theoretical definition of the concept of family. The family is the environmental context for its individual members or a social system or single unit of analysis, the whole of which is greater than the sum of its parts (Neuman, 1995). For purposes of this study, a family is operationally defined as one or two parents living with an infant who was recently placed on a home apnea monitor plus any other individuals related by blood or marriage living in the home.

Family functioning. The theoretical definition of the concept of family functioning includes “those activities and relationships among and between persons and the environment which in combination enable the family to maintain itself as an open system” (Roberts & Feetham, 1982, p. 231). For purposes of this investigation, the discrepancy scores obtained on the Feetham Family Functioning Survey (FFFS) (Roberts & Feetham, 1982) (Appendix E) operationally define family functioning.

Home apnea monitoring. An electronic surveillance system which uses a belt or electrodes placed on the infant’s chest to detect heart rate and/or breathing status (Graber & Balas-Stevens, 1984) theoretically defines the concept of home apnea monitoring. An apnea monitor is designed to alarm when an abnormality in the infant’s breathing and/or heartbeat is detected so that timely intervention can be initiated (Keens & Ward, 1993). For this study, placement of an infant on a cardiorespiratory monitor at home continuously each day or during the infant’s sleep operationally defines home apnea monitoring.

Infant temperament. The behavioral style or manner in which an infant interacts with his environment (Fullard, McDevitt, & Carey, 1984, p. 205) constitutes the theoretical definition of the concept of infant temperament. For purposes of this investigation, scores on the Early Infancy Temperament Questionnaire (EITQ) (Medoff-

Cooper, Carey, & McDevitt, 1993) (Appendix F) operationally define the concept of infant temperament.

Mother. The female parent who assumes the role of maternal caretaker of the infant within the family system is the theoretical definition of the concept of mother. Usually, the mother is the birth mother with or without a father figure (Castiglia & Harbin, 1992). For purposes of this investigation, the mother is viewed operationally as the birth mother with or without her spouse/significant other who lives with the infant.

Phases of the monitoring experience. The three time periods during home apnea monitoring which are marked by the differing responsibilities imposed on the family theoretically define the concept of phases of the monitoring experience. During the initial phase, the family brings the infant/monitor unit from the hospital and begins the home apnea monitoring experience. During the maintenance phase, the family incorporates the infant/monitor unit into its routines. During the termination phase, home apnea monitoring is completed and the infant and monitor no longer are connected (Wasserman, 1984). In this study, the initial monitoring phase is the first three weeks after monitoring is initiated and the infant/monitor unit arrives home. The maintenance phase of the home apnea monitoring experience is approximately three months after monitoring is initiated (i.e. midway through the home apnea monitoring experience). The termination phase of the home apnea monitoring experience is the period from termination to three weeks following discontinuance of the monitor.

Severity of illness. Theoretically, the concept of severity of illness is defined as the seriousness of an illness (Mish, 1994). For purposes of this study, severity of illness is



operationally defined as the total score on the first two sections of the Monitoring Flowsheet (MF) (Appendix G).

Stressors. Environmental events, whether intrasystem, intersystem, or extrasystem in origin, that strain or exceed the system's adaptive capabilities (Hymovich, 1987; Neuman, 1995) serve as the theoretical definition of stressors. Such stressors possess the ability to alter the functioning of the family. This study operationally views the home apnea monitoring experience as a stressor to the family system.

#### Assumptions

Hymovich (1984) notes that an individual's perception of the environment determines the individual's responses to it; therefore, descriptions by family members are the best indicator of the impact of chronic illness on families. This study assumes that the mother's perceptions of the families' concerns, coping responses, and functioning as well as determination of the infants' temperaments are one index of the impact of home apnea monitoring. This investigation also assumes that the mothers' answers to the questionnaires are truthful and that the mothers follow the instructions given.

#### Limitations

Several limitations of the study exist. First, the subjects comprise a small convenience sample of families with infants on home apnea monitoring, which were participating in monitoring programs from two institutions. The longitudinal nature of the study and the high level of commitment required of the participants may have contributed to the limited sample size, which in turn limits generalizability of findings. Second, all of the subjects are from two geographical regions of the state of South Carolina, thereby limiting possible variations in lifestyle, weather, and cost of living. Third, these families

simultaneously were adjusting to the stressor of parenting a new infant or of incorporating a new infant into an existing family system, so that family responses may also reflect the impact of this stressor. Fourth, no control of the effects of other stressors which may be influencing the family was undertaken. Fifth, although the study is broader than most other studies by including the impact on spouses and/or siblings, only the mothers provided their perceptions of the impact of the stressor of home apnea monitoring on themselves and on the other family members.

Other limitations of the study arise in relation to the instruments used. The reading level of the Parent Perception Inventory (PPI) may have limited the comprehension of the participants and so that their responses may not be an accurate reflection of their perceptions of family impact. Also, respondents with less than a high school education may have had difficulty completing the Feetham Family Functioning Survey (FFFS) because of the use of the Porter format for the questionnaire. This format may have resulted in responses which are not an accurate reflection of perceptions of the degree of family functioning. Also the Monitoring Flowsheet (MF) was a new instrument developed by the investigator to quantify severity of illness in this study and therefore its reliability and validity were unknown at the initiation of the project.

Additionally, because the questionnaires were completed by the mothers at home, lack of control over the administration of the instruments allowed for possible contamination of the responses even though the mothers were instructed to complete the instruments independently of help and not to collaborate on the answers with other family members. Also, because the PPI was designed for use with families of children with chronic conditions and includes questions about concerns and coping over the last three

months, the PPI may not have been appropriate for use during the initial monitoring period since the infants and families were new to the home apnea monitoring experience.

### Summary

In summary, home apnea monitoring is a frequently used strategy to decrease the number of deaths during infancy due to SIDS, but as such serves as a stressor to the family system. The purpose of this study is to delineate the responses of families to the stressor of home apnea monitoring at three points in the monitoring experience.

## CHAPTER II

### Literature Review

Home apnea monitoring is a frequently used strategy to decrease the number of deaths during infancy but as such serves as a stressor to the family system. According to the Neuman Systems Model (Neuman, 1995), a stressor such as home apnea monitoring elicits specific responses from the members of the family system and from the family system as a whole. These responses include, but are not limited to, psychosocial concerns, coping mechanisms, and changes in family functioning. Responses to having an infant on a home apnea monitor are noted to be similar to the concerns and coping strategies utilized by families of children with chronic illnesses. The temperament of an infant also has an impact on the family's response to a stressor such as home apnea monitoring.

For the present study, home apnea monitoring and infant temperament affect the family while the concerns, coping responses, and alterations in family functioning are the responses of interest. To understand thoroughly the effects of home apnea monitoring on the family system, the literature review focuses on the following areas: the stressor of home apnea monitoring; family responses to the stressor, the effect of stressors on family functioning; the effects on the family of having a child with a chronic health problem; and infant temperament.

## Home Apnea Monitoring

### Technical Aspects

In-home monitoring of the cardiorespiratory status of infants at risk for an apparent life-threatening event (ALTE) or for Sudden Infant Death Syndrome (SIDS) has been an accepted treatment strategy for the last 20 years. Home apnea monitoring consists of placing an infant on an electronic device to monitor the cardiac and respiratory systems continuously for 24 hours each day, although some infants require monitoring only during sleep when respiratory effort is minimal. The usual monitoring episode begins when the infant is placed on the cardiorespiratory monitor on discharge from the hospital, either during the neonatal period or at two or three months of age. Monitoring continues until the infant is no longer thought to be at risk for ALTE episodes, i.e. when the infant has been free of significant alarms or apneic episodes for two to three months (NIH, 1987, p. 8).

The technical requirements of home apnea monitoring are abundant. The monitor is secured to the infant via two electrodes which are attached by adhesive to the infant's abdomen or incorporated into an electrode belt which encircles the infant's chest. Special attention to skin care at the location of the electrodes is necessary to prevent skin breakdown. Lead wires run from the electrodes to a cable attached to the monitor. Infant movement, misplacement of the electrodes, power surges, or dry electrodes can cause false alarms, which can account for as many as 92% of all monitor alarms (Weese-Mayer, Brouillette, Morrow, Conway, Klema-Walden, & Hunt, 1989). True alarms occur when the infant has a change in breathing pattern with a 20-second period of apnea, often accompanied by a color change.

The literature emphasizes numerous considerations inherent in the home apnea monitoring process. Parents and all other adult caretakers must be able to respond properly to alarms (Duncan & Webb, 1983; Graber & Balas-Stevens, 1984; Norris-Berkemeyer & Hutchins, 1986). A parent/caretaker must be able to hear the monitor alarm and must be no more than 10 seconds away from the infant at all times (Graber & Balas-Stevens, 1984). A parent/caretaker must then stimulate the infant to initiate breathing and institute cardiopulmonary resuscitation (CPR) if that is required (Duncan & Webb, 1983; Graber & Balas-Stevens, 1984; Norris-Berkemeyer & Hutchins, 1986). The family/caretaker must have a dependable electrical supply and must be able to notify the ambulance, pediatrician, and intensive care nursery immediately if resuscitation efforts are necessary (Graber & Balas-Stevens, 1984; Norris-Berkemeyer & Hutchins, 1986). Peeke and Levell (1992) note that strong electrical signals from televisions, radios, air conditioners, or even remote telephones may interfere with the operation of the monitor, and may result in misinterpretation as heart rate and/or breathing signals by the monitor. Additionally, Norris-Berkemeyer and Hutchins (1986) emphasize the economic effect of home apnea monitoring, since monitor rental may be as high as \$265 a month. Home pneumograms that cost as much as \$300 are performed periodically and many of the mothers are not working during the home apnea monitoring experience. These financial considerations contribute to the fact that having an infant on a home apnea monitor constitutes a stressor to the family system.

Another factor which contributes to home apnea monitoring as a stressor is the thorough decision-making process which is undertaken before a recommendation of home apnea monitoring is made. Spitzer and Fox (1984a, 1984b, 1986) extensively detail the

decision-making process a physician must follow when caring for a child with infant apnea or SIDS including home apnea monitoring. They briefly note that families of infants on home apnea monitors require "substantial support on a 24-hour basis" (1984a, p. 132) but do not discuss what this support should entail.

The literature related to home apnea monitoring contains controversy regarding what population would obtain the greatest benefit from home apnea monitoring, what the patient outcomes are when home apnea monitoring is instituted, and what the prognostic clinical features are for using home apnea monitoring. Rowland, Donnelly, Landis, Lemoine, Sigelman, and Tanella (1987) conducted a five-year follow-up of 211 infants, who initially went home on home apnea monitors, in an effort to identify which infants would obtain the greatest benefit from home apnea monitoring and which infants would benefit from less expensive strategies but were unable to predict infants at risk for recurrence of apnea. In another study, Nathanson, O'Donnell, and Commins (1989) also were unsuccessful in their attempt to differentiate significant recordings of an apnea event from those that were non-significant in order to identify more accurately which infants would receive the greatest benefit from home apnea monitoring. Oren, Kelly, and Shannon (1986) concluded that, except for siblings of SIDS infants, the infant's physical examination, past medical history, and laboratory evaluation were not significant predictors of outcome in infants who are resuscitated for sleep apnea. In one of the earliest studies conducted to determine the effectiveness of home apnea monitoring in infants at risk for SIDS, Kelly, Shannon, and O'Connell (1978) reported that 43% of 60 infants who had experienced previous apneic episodes required resuscitation at least once

during the home monitoring experience. These reports emphasize the uncertainty parents encounter during the home apnea monitoring experience.

Decisions about monitor and vendor selection to provide necessary technical support to the family throughout the home apnea monitoring experience increase the strain on families of infants on home monitoring. Equipment and vendor selection are the focus of articles by Webb and Duncan (1983), Hartsell and Ward (1985), and Peeke and Levett (1992). All three articles provide concise requirements to consider in selecting a home apnea monitor, such as reliability, sensitivity, cost, and servicing. These articles mention the need for 24 hour support from an equipment service technician, i.e. a respiratory therapist or trained salesperson, who could assist the family with "dropped equipment, monitor cables chewed by the family dog, [or] 'crazy monitor alarms'" (Hartsell & Ward, 1983, p. 26).

Several articles address the teaching needs of families with infants on home apnea monitors. Duncan and Webb (1983) and Graber and Balas-Stevens (1984) discuss the entire discharge teaching plan for parents of infants on home apnea monitors. The checklists included in these articles reinforce the tremendous amount of information about home apnea monitoring which parents of these infants must process prior to the infant's discharge from the hospital. Also, discharge teaching about home apnea monitoring generally occurs over a very short time, often as few as two days prior to taking the infant and monitor home. The extensive teaching required coupled with the short time available for parents to integrate all the information contribute to the stress of home apnea monitoring.



### Psychosocial Effects

Besides the technical effects outlined above, the home apnea monitoring experience has psychosocial effects on the family. Black, Hersher, and Steinschneider (1978) obtained descriptive data from parents in 31 families of monitored infants regarding the impact of the apnea monitor on family life. The concerns expressed by the parents were those related to the monitor itself, changes in family dynamics along with an increase in parental anxiety, and changes in interaction patterns with their infants.

Dimaggio and Sheetz (1983) identify the concerns of 29 mothers caring for infants on apnea monitors. The concerns expressed by these mothers are divided into four categories: accommodating a new member by alterations in lifestyle, technical concerns such as using a monitor and understanding cardiopulmonary resuscitation, learning to care for and establishing a relationship with the infant, and restoring the mothers' physiological health (Dimaggio & Sheetz, 1983). When asked to rank order their concerns, these mothers indicated that changes in lifestyle to accommodate the infant were of highest concern for monitoring mothers whereas physical restoration of the mother and incorporation of the infant into the family were of highest concern to postpartum mothers (Dimaggio & Sheetz, 1983).

Sweeney (1988) investigated two small samples of two-parent dyads of infants with apnea, one group of 12 pairs of parents with monitored infants and a second group of 9 pairs of non-monitored infants on theophylline alone. Sweeney's (1988) investigation did not yield statistically significant differences between these two groups as to parental feelings, parental perceptions of the impact of chronic illness on their infants, or on family functioning. However, significant differences were found within the parent pairs in each

of these areas, with fathers ranking money/work concerns a priority and mothers ranking child care issues a priority (Sweeney, 1988).

Stengel, Echeveste, and Schmidt (1985) describe the results of a clinical experience for registered nurse students in a community health nursing course of a baccalaureate nursing program. In analyzing the students' anecdotal notes from their clinical experiences in this course, the authors grouped the problems of monitoring families into four general categories: parenting skills, health status of family members, environmental risk factors, and general family coping.

Several researchers explored the problems of diverse groups of families involved in home apnea monitoring. Andrews, Nuttall and Nielson (1987) studied families in the intermountain western United States. Desmarez, Blum, Montauk, and Kahn (1987) described a prospective study of European families, and Nuttall (1988) reported on retrospective interviews of mothers whose infants had completed home apnea monitoring. Findings from all of these studies support the premise that home apnea monitoring is stressful to the family, especially to the mother. Nuttall (1988) described the process of infant apnea monitoring as "a prototype for other medical technologies now being used in the home" (p. 357) and emphasized the need for research into the impact of such technological advances on the family.

The family's concerns and coping strategies change as families move through the home apnea monitoring experience. Wasserman (1984) prospectively followed 14 families with infants requiring home monitoring by conducting psychiatric interviews at intervals during monitoring and during the post-monitoring months. From these interviews, four distinct phases of parental reactions to monitoring emerged: a doubt/acceptance phase

during the first 2 to 4 weeks of monitoring, a dependence/frustration phase which constituted the bulk of the monitoring experience, a discontinuance phase during which weaning from the monitor occurred, and a late effects phase following termination of monitoring (Wasserman, 1984). Parents reported substantial distress both during and after monitoring in the form of depression, fatigue, anxiety, disruption of family life, and long-term financial burdens. Following monitoring, parents described their monitored children as being spoiled, under-achieving, and having short attention spans. Generalized anxiety was the most common response noted in older siblings (Wasserman, 1984).

In a later prospective study conducted in 1989, Saylor, Purohit, Ford, Norris, and McIntosh compared anxiety levels in mothers of monitored versus non-monitored infants at the initiation of monitoring, at 1 to 3 months into monitoring, and within 2 weeks after completion of monitoring. Findings from this study did not indicate a significant difference between these two groups on overall baseline level of anxiety at the three monitoring points but did indicate higher anxiety in mothers at the initiation of monitoring (Saylor et al., 1989).

In one of the few intervention studies found, Komelasky (1990) reported on the effects of the nurse's home visits on the level of anxiety and on the retention of knowledge of CPR by parents of infants on home apnea monitors. Parental anxiety was measured at the beginning of a CPR class and at 6 weeks after discharge from the hospital. Home visits were made by a registered nurse every 2 weeks for the first 6 weeks after hospital discharge. Although no statistically significant difference was evident in parental anxiety or in the retention of CPR knowledge at the measurement points, the pattern of the

anxiety scores in the group which received the home visits did decrease from the pretest scores.

Knecht (1991) compared home apnea monitoring, mothers' mood states, family functioning, and support systems for two groups of mothers of infants on home apnea monitoring at six time periods, at 1 week, 1 month, and 3 months into monitoring as well as 1 week, 1 month, and 3 months after discontinuance of monitoring. One group of mothers were receiving care through an established home monitoring program while the other group of mothers were receiving care through private physicians. Discrepancy between expected and perceived family functioning was highest in both groups at the initial monitoring period and demonstrated a consistent decrease as monitoring progressed in the home monitoring program group, whereas the family functioning discrepancy scores for the private physician group peaked again when monitoring was discontinued.

These four reports (Knecht, 1991; Komelasky, 1990; Saylor et al., 1989; Wasserman, 1984) utilize time divisions that parallel each other, except for Komelasky's study (1990). Their findings appear to confirm a pattern of a decrease in maternal anxiety or concerns as families progress through the home apnea monitoring experience. This pattern was not supported by Lyman, Wurtele, and Wilson (1985), however, who reported that anxiety levels of parents in their study remained high throughout monitoring. In a comparative study by Phipps and Drotar (1990), parenting stress was moderately elevated throughout the first two phases of home apnea monitoring.

Ahmann (1989, 1992, 1993) and Ahmann, Wulff, and Meny (1992) address home apnea monitoring and patterns of family life. Their review of the literature focused on relationships between family members' health and behavior, family members' roles and

relationships, family-social relationships, ease of daily activities, and technical difficulties resulting from the home apnea monitoring experience (Ahmann, 1992 & 1993). Case and comparison mothers differed significantly on only one of these variables - parental health. They concluded that except for maternal health risk, families of infants on home apnea monitors possess adequate resources with which to cope with the stressor of home apnea monitoring. The families in their samples, however, were predominantly white, were married, and had commercial health insurance (Ahmann, 1989; Ahmann, et al. 1992), a very different composition from populations studied by other researchers.

The decisions, emotions, and responses that families express during the time an infant is undergoing home monitoring appear to be similar to those experienced by families of children with chronic illnesses (Ray & Ritchie, 1993). Black and colleagues (1978) observe that among the issues that parents of monitored infants face is the chronic although self-limiting condition of the child with a possibility that the child is at risk for sudden death. Wasserman (1984) also observed that monitoring an infant is similar to having a child with a chronic illness. However, Wasserman (1984) contradicts Black et al (1978) when he adds that in most chronic illnesses the possibility of death is not ever-present and may be denied more easily than with the infant on a monitor.

Monitoring alarms do not allow the parents or the siblings the luxury of such denial. This awareness of the child's possible death, coupled with the constant vigilance required by monitoring alarms, inevitably lead to stress and emotional and adjustment problems similar to those described in parents of children with chronic illnesses (Wasserman, p. 327).

Mark and Zahr (1986) also view having an infant on a home apnea monitor as being similar to having a child with a chronic illness and even mention the possibility that the diagnosis of apnea in an infant might initiate a grieving process in the parents.

McElroy, Steinschneider, and Weinstein (1986) prospectively document the consequences of home apnea monitoring and note that the same factors influencing the family's response to childhood chronic illness, i.e. illness, presence of affected symptoms, program of home management, preexisting family disturbances, and financial costs of illness, are also factors when planning care for home apnea monitored infants. Sweeney (1988) and Davis and Sweeney (1989) concluded that apnea monitoring and chronic illness in childhood are similar since they are both persistent over time, have an unknown etiology, are manageable but not curable, have an uncertain prognosis, and often require parallel stages of family adaptation.

In summary, extensive literature exists about the technical aspects of home apnea monitoring, such as decisions regarding who should be monitored, how to select the right monitor, and what information should be included in the discharge teaching for the parents. Studies of the needs of parents, primarily mothers, whose infants are on home apnea monitors were also found. Five of these reports indicated that the concerns of these parents can be divided into distinct phases as the infant and family progress through the home apnea monitoring experience. Several studies also founded that the decisions, emotions, and responses that families express during the time an infant is undergoing home monitoring appear to be similar to those experienced by families of children with chronic illnesses.

### Family Functioning

Family functioning is the interrelationship among individual family members and the environment and provides the means for the family's remaining an open system (Roberts & Feetham, 1982, p. 231). The three areas of functioning emphasized in the work of Roberts and Feetham include the functioning of the family with society, the interactions of the family subsystems for the family and each other, and the functions of individual family members.

This view of family functioning is congruent with a family ecological or family-as-system perspective which views the family as "a dynamic unit, greater than the sum of its parts" (Roberts & Feetham, 1982, p. 231). Inherent in this ecological systems perspective is the premise that events that affect one family member may ultimately affect the family system and that the characteristics of each family member may affect the family as a whole (Becker, Chang, Kameshima, & Bloch, 1991). McClowry (1992) noted that both family strengths and family vulnerabilities must be considered when attempting to delineate the impact of a stressor on a family unit and its functioning.

The Circumplex Model (Olson, 1985) links family cohesion, family adaptability, and family communication as critical factors in determining family behavior when confronted with stress. The Model further postulates 16 types of family systems exhibiting different degrees of these factors. Families with these factors in balance are noted to be the healthiest, while families with extremes of these factors are considered to function least effectively (Olson, 1985, p. 3).

Patterson, McCubbin, and Warwick (1990) identified family resources and coping behaviors as crucial components in the family's ability to handle the stresses that the family

unit encounters. They concluded that the success with which the family functions is related to successful health outcomes in children with cystic fibrosis (Patterson et al., 1990, p. 163). Since the concept of family functioning emphasizes the interdependent nature of all family members, this conclusion is not surprising.

As a basic characteristic of the family system, family functioning is vulnerable to stress from life events. Mercer and Ferketich (1990) compared prenatal and postpartum family functioning in women of high-risk and of low-risk pregnancies and their corresponding male partners. They found no significant difference in family functioning prenatally and postnatally. However, family functioning in the parents in the low-risk groups was slightly decreased postpartally, consistent with the degree of family disorganization that follows any birth. Additionally, they note that family functioning worsened as the high-risk families proceeded through new parenting (Mercer & Ferketich, 1990).

Sawyer (1992) compared family functioning in families of children with cystic fibrosis and in families with "healthy" children. The mothers in the two groups reported little discrepancy between total expected and total perceived family functioning. Also, no significant difference existed between the groups on three areas of family functioning. Only the responses to the question about the amount of time spent with their spouses differed significantly between the two groups. This finding is consistent with the need for extra time and care required by children with chronic illnesses (Sawyer, 1992).

In the previously cited study by Black and colleagues (1978), changes in family dynamics were noted by a majority of parents of infants on home apnea monitors. Adjustments in sleeping arrangements of the parents, curtailing of social interactions with



friends, an increase in marital discord, and role changes within the family were reported by these parents (Black et al., 1978).

To summarize the literature on family functioning, the family's ability to maintain itself as an open system, i.e. family functioning (Roberts & Feetham, 1982), is of concern to nurses working with families. As a system, there is an interdependence between the members of the family where events involving individual members of the family system can affect the functioning of the family as a whole.

### The Impact of Having a Child with a Chronic Health Problem

Studies cited earlier (Black et al., 1978; Davis & Sweeney, 1989; Mark & Zahr, 1986; McElroy et al., 1986; Ray & Ritchie, 1993; Sweeney, 1988; and Wasserman, 1984) regard the decisions, emotions, and responses that families express during home apnea monitoring as similar to those experienced by families of children with chronic illnesses. A wide diversity exists in chronic illness in childhood resulting from differing diagnoses, treatments, and outcomes (Perrin, 1986). However, even with these differences, most pediatric chronic illnesses require regular access to "high tech" care, are expensive, result in extreme family burdens in time and emotional investment with limited respite services available, result in problems with conflicting advice and poor coordination of services, are unpredictable, and are minimally understood by the community (Perrin, 1986). Ray and Ritchie (1993) include these factors in their "components of caregiving" element (p. 224) that contributes to the stressful nature of caring for a child with a chronic illness. These are also characteristics of home apnea monitoring.

Additionally, Revell and Liptak (1991) noted that chronic illnesses in childhood cause discomfort and often pain, require treatments which are often difficult and

embarrassing, and result in chronically ill children appearing different from their peers. The families of children with chronic illnesses frequently experience feelings of loss of the "perfect child", neglect of siblings and subsequent behavioral problems in these siblings, and social isolation since the burden of care rests almost exclusively on the family (Ray & Ritchie, 1993; Revell & Liptak, 1991). The communities in which these children live frequently have limited access to appropriate public services or play opportunities plus poor coordination of services (Revell & Liptak, 1991).

In a 1984 study, Holaday focused on identifying effective coping strategies parents used in managing the care of a child with chronic illness. Using family stress theory, Holaday (1984) noted that parents demonstrated positive coping when they assigned meaning to the illness, attempted to normalize family life and member routines, and utilized social supports. Holaday (1984) also noted that since many families are successful in positively coping with pediatric chronic illness, research should focus on the positive adaptation strategies rather than on processes which are maladaptive for families.

Thomas (1984) and Fife, Huhman, and Keck (1986) proposed instruments for clinical assessment of families with a chronically ill child. Thomas (1984) focused on 4 areas of assessment - the anatomical and physiological impairment of the child, the deviations from expected functioning, physical appearance, and/or behavior, the degree of visibility of the condition, and the impact of the situation on the family. The psychometric testing of the instrument which Fife and colleagues (1986) reported emphasized assessment of the psychosocial aspects of the chronic illness on the child and family.

McCubbin (1993) presented the Resiliency Model for use with families of children with chronic illnesses. This model identified two phases of family response to crisis

situations - a phase of family adjustment and a phase of family adaptation. Propositions from the Resiliency Model (McCubbin, 1993) included a negative relationship between the "pileup" of family demands and family adaptation, while positive relationships were postulated between family adaptation and the family's typology based on family strengths, resources, appraisal of the situation, and coping and problem-solving strategies.

In analyzing the concept of a chronically ill child as a family member, Clawson (1996) refers to chronic illness as "a multidimensional experience with similar aspects despite varying disease processes" (p. 54). Clawson (1996) also assumes that the family can be affected in positive as well as in negative ways by the chronic illness of a family member and that the relationship between the family and the chronic-illness-of-a-family member situation is reciprocal in nature.

Canam (1993) identified eight adaptive tasks which parents of children with chronic illnesses must face. These eight adaptive tests are accepting the child/infant's condition, managing the infant's needs on a daily basis, addressing developmental needs, addressing the needs of each of the other family members, assisting others to manage their feelings, educating others about the child's condition, and establishing a support system. According to Canam (1993), utilizing an adaptive tasks focus is advantageous since it enables one to approach disease from a non-categorical perspective.

The literature contains many descriptive studies of family responses to a variety of chronic illnesses in childhood. Iles (1979) examined the perceptions of siblings of children with cancer and noted gains as well as losses perceived by these siblings. Derouin and Jessee (1996) also studied the perceptions of siblings and report similar findings to Iles' study. Parents and siblings of children with cystic fibrosis interviewed by Kruger,

Shawyer, and Jones (1980) reported that nurses could be of assistance to these families by supporting, guiding, teaching, doing for the person, and fostering personal development. In a study of families of children with epilepsy, Austin and McDermott (1988) suggested a direct relationship between positive parental attitudes and positive family coping behaviors, although they did not examine negative coping behaviors. Horner, Rawlins, and Giles (1987) surveyed parents' perceptions of their own needs when a child had a chronic health problem (including apnea of prematurity); they divided their findings into service/program needs such as empowering the family, and informational needs, such as child care in emergencies. Brett and Davies (1988) conducted a qualitative study of parents and siblings of children with leukemia in remission; they focused on the family's coping strategies and reappraisal of the stressor and related their findings to the need for family centered nursing care which considers all family members.

Christian (1989) found that family coping status for both mothers and fathers of children with cystic fibrosis correlates with parental self-concerns and perceived spouse concerns. Concern about the child's future was reported by the majority of parents of children with developmental disabilities (Heaman, 1991). In Heaman's study (1991), the mothers of these children revealed seeking social support, problem solving, and positive reappraisal as the major coping strategies, whereas fathers indicated use of self-control and problem-solving most frequently. Williams, Lorenzo, and Borja (1993) reported complementary changes in role patterns of mothers and siblings of Filipino children after the onset of long-term neurological or cardiac problems.

McCubbin (1984, 1989, & 1993) conducted extensive work in family adaptations. In a study of coping with 100 families of children with cystic fibrosis (1984), she reported

that the promotion of family adaptation required strategies directed at five areas - intrafamily relations, social support, self-esteem of the family members, health care consultation, and a maintained balance of coping patterns. McCubbin (1989) also compared stresses and strengths in one-parent and two-parent families of children with cerebral palsy but found no significant differences in family stress between these two groups. McCubbin (1989) recommended further research on the demands, on the family strengths, and on the children's health with single-parent families of children with other chronic illnesses and also encouraged longitudinal investigations of these groups over time.

In summary, several studies cited reported that the concerns and coping responses of families with an infant on a home apnea monitor are similar to the concerns and coping responses of families with a child with a chronic health problem. This section of the literature review delineated the concerns and/or coping responses utilized by families of children with a variety of chronic health problems. These findings would relate to caring for all families of chronically ill children, including infants on home apnea monitors.

#### Infant Temperament

In 1956, Thomas and Chess began a study of infant temperament, known as the New York Longitudinal Study (NYLS) (Chess and Thomas. 1996). They defined temperament as the "behavioral style of the individual" (Chess & Thomas, 1986). Chess and Thomas (1996) identified nine subcategories of temperament as follows: activity, rhythmicity, approach/withdrawal, adaptability, intensity, mood, persistence, distractibility, and threshold. Various combinations of these subcategories identify the infant's temperament as being difficult, easy, or slow to warm up (Chess & Thomas, 1996). Other

definitions of temperament were identified in a review by Goldsmith, Buss, Plomin, Rothbart, Thomas, Chess, Hinde, and McCall (1987). These views were that temperament was “an inherited personality trait” (p. 507), an “individual difference in self-regulation and reactivity of an infant” (p. 510), and an individual difference “in the probability of experiencing and expressing the primary emotions and arousal (p. 510). Reflected in all of the definitions of temperament, including that of Chess and Thomas (1996), are the generalities that temperament is an individual characteristic of each infant, is demonstrated early by an infant, and influences the infant’s relationship with the environment.

Based on the various definitions of temperament identified above, several instruments have been developed for measuring aspects of temperament. Carey (1972, 1983, 1985p) built on the work of Chess and Thomas and developed an instrument to assess the temperament of an infant between 4 and 8 months of age. Carey (1983) reported that temperament is fairly stable throughout infancy and childhood. Subsequently, instruments for determining temperament in other age groups were also developed based on temperament as the “behavioral style of the individual” (Chess & Thomas, 1996).

There is controversy in the literature as to the age of onset of temperament as a significant factor in the infant-environment relationship. Carey's (1982, 1983, 1985b) work supports the view that temperament appears as a significant factor around four months of age. Green, Bax, and Tsitsikas (1989) conducted a longitudinal study of temperament in the first six months of life and noted that there was consistency in five of the nine temperament components as early as six weeks of age. Jones and Parks (1983)

established a positive correlation between parental perception of neonatal temperament with subsequent determinations of infant temperament at one year of age.

Studies by Houldin (1987), Marino and Lipshitz (1991), Oberklaid, Prior, Nolan, Smith, and Flavell (1985), and Oberklaid, Sewell, Sanson, and Prior (1991) support the premises of Chess and Thomas (1986) and Carey (1982, 1983, 1985b) regarding infant temperament. Houldin (1987) noted that the mother's perception of her infant's temperament was critical in the nurse's understanding of the maternal-infant relationship. Temperament as a factor in maternal role attachment was emphasized in a report by Koniak-Griffin (1993). Marino and Lipshitz (1991) reported differences in temperament between infants and toddlers with cardiac disease and published norms for healthy children, but found increasing severity of illness did not appear to influence extremes in temperament ratings. Carey (1985a) reported that infants with "difficult" temperament gained more weight than the general sample of infants, possibly related to increased feedings to soothe and quiet a fussy infant. Australian infants demonstrated no significant differences between temperament and behavior of preterm infants and their full-term controls in studies by Oberklaid and colleagues (1985; 1991). However, these results contrast sharply with earlier studies of very low birth weight infants who demonstrated significantly different temperament patterns when compared to full-term infants via standardized norms (Medoff-Cooper, 1986; Medoff-Cooper & Schraeder, 1982).

In a study addressing the relationship between infantile apnea, early development, temperament, and maternal stress, Bendel, Culbertson, Shelton, and Carter (1986) compared 25 mother/infant dyads with interrupted infantile apnea with matched controls.

Mothers perceived the case infants as significantly more active than control infants, a finding opposite to what has been suggested in other literature (Bendel et al., 1986).

To summarize the literature on infant temperament, as noted by Johnson (1992), there is a diversity of opinion on what temperament is and how best to measure it. Temperament as viewed by Chess and Thomas (1986) is the behavioral style of the infant. Studies cited support the concept of temperament as a factor in the infant-environment relationship as early as the neonatal period (Jones & Parks, 1983). Temperament is a fairly stable trait of the individual over time (Carey, 1983).

### Summary

In summary, the literature supports the view that having an infant on a home apnea monitor constitutes a stressor which affects the family system in various ways. Often, the family's responses are similar to those associated with having a child with a chronic health problem. The temperament of the infant and the presence of a new baby can also have an impact on the family system. The literature addresses the need for exploring the concerns, coping, and family functioning of families with infants on home apnea monitoring and their members. Research to date has primarily studied the technical aspects of home apnea monitoring. Studies of the psychosocial impact of home monitoring have focused primarily on maternal anxieties and coping with only limited exploration of paternal and sibling impact and coping mechanisms. Health care providers need to assess family strengths and needs so that interventions to assist these families with positive coping can be developed (Shelton, Jeppson, & Johnson, 1987).



## CHAPTER III

### Methodology

Consistent with the variables identified in the conceptual model, the literature review supports the need for further research on the concerns and responses of families to having an infant on a home apnea monitor. The impact on individual family members as well as on the functioning of the family as a unit needs exploration. Chapter Three delineates the methodology used in determining the effects of having an infant on a home apnea monitor on members of the infant's family and on family functioning at various points in the home apnea monitoring experience.

### Research Design

A longitudinal design with event partitioning (Burns & Grove, 1997) structured this investigation. The same group of mothers was observed at each of three time points in the home monitoring experience, thereby eliminating the need for a separate control group of mothers. This longitudinal design permitted collection of data on attitudes, images, decisions, needs, behavior, lifestyle, affiliations, and demographics over time (Alrecht & Settle, 1985). The current investigation elicited mothers' perceptions of concerns, coping mechanisms, and changes in family functioning experienced by members of families with infants on home apnea monitors at three time points. Such information provides the basis for development and testing of nursing interventions for use with these families. The longitudinal design permitted exploration of the phenomenon of interest

over time which is necessary in the study of dynamic units such as families. The longitudinal design also allowed the identification of trends over time, a dimension not permitted by a cross-sectional design alone. The merging of longitudinal and cross-sectional designs allows a maximal sample size with minimal effects of history on the study results (Burns & Grove, 1997).

### Sample Selection

Data for the study were collected from clients of two home apnea monitoring programs. The first program, a children's sleep disorders center (CSDC), was located at a 421-bed general community hospital in South Carolina. This CSDC opened in January, 1985, was fully accredited by the Association of Sleep Disorders Centers in March, 1987, and was reaccredited in 1992. Approximately four to six new families begin the monitoring experience each month at the CSDC, with 30 to 40 families involved in monitoring at any point in time. The average length of monitoring is six months, with a range of 5 to 12 months. The majority of families served by the CSDC are single-parent families (Marshall, personal communication, 1994).

The second program, associated with a special care nursery (SCN), was located in a 292-bed general medical center in South Carolina. The number of infants sent home on monitors from the SCN varies. The SCN has 20 bassinets and serves patients from a single county outside the area served by the CSDC.

The original study protocol projected recruiting mothers of 40 infants. However, mothers of only 13 infants agreed to participate during the thirteen months of subject recruitment and therefore these mothers comprised the study sample. Mothers were approached about participating in the study prior to their infants' discharge from the

hospital. At the CSDC, this initial contact was by the polysomnography technician responsible for the discharge teaching for the CSDC, using an introductory letter from the investigator (Appendix C). At the SCN, this contact was made by the nurses caring for the infants and using the same introductory letter from the investigator (Appendix C). If the mothers indicated an interest in participating in the study, they then signed a release for the CSDC or SCN staff to share their names and addresses with the investigator (Appendix A).

Midway through the data collection period, an additional method of recruiting potential study mothers was instituted. Nurses from the local health district approached potential subjects in the 6-county region surrounding the CSDC using the same letter from the investigator as was used at the CSDC and SCN. Interested mothers were provided with pre-addressed and stamped postcards (Appendix I) to return to the investigator. The postcards enabled the investigator to contact potential study participants and proceed as with the participants from the CSDC and the SCN. Study participants recruited in this way were involved in the monitoring program from the CSDC.

All mothers recruited for the study agreed to allow the investigator into their homes at three different times during the home monitoring experience. The mothers of the eight infants from the CSDC lived in the 6-county area surrounding the CSDC. (Three of these eight were recruited by the health district nurses as described previously.) The five participants served by the SCN lived in three counties surrounding the SCN.

In order to control the influence of intervening variables on study results, several groups of families were excluded from the study. These included: (a) families with previous monitoring experience, because they may have had fewer concerns than new-to-

monitoring families and may already have developed coping responses from previous monitoring experiences; (b) families with another child with a serious or chronic illness, to avoid family responses to multiple stressors rather than the single stressor of home apnea monitoring; (c) families who had experienced a previous SIDS death because their degree of comfort over the home monitoring experience and possibility of death of their infant was assumed to differ from families who had not experienced a SIDS death; and (d) families in which the mother had less than a seventh grade education because of the reading level of one of the instruments. Of the 49 infants placed on home apnea monitors during the 12 months of subject recruitment through the CSDC, 21 families were excluded for one or more of the above criteria, 20 refused to participate, and eight agreed to participate. The SCN does not maintain records of the numbers of infants who begin monitoring each year. During the four months subjects were recruited from the SCN, five mothers agreed to participate in the study. No participants were lost from the study during the time their infants were on the monitor.

#### Study Variables

Consistent with the Neuman Systems Model, home apnea monitoring is a stressor to the family (Ridgell, 1993) and is therefore the focus of the study. Infant temperament plays a significant role influencing family member and family unit responses to the stressor of home apnea monitoring and was viewed as an independent variable. The infant's severity of illness, i.e. the presence of apneic episodes as reflected by the occurrence of true and false alarms during monitoring, was another independent variable. The demographic make-up of the family served as a background variable (Figure 3).

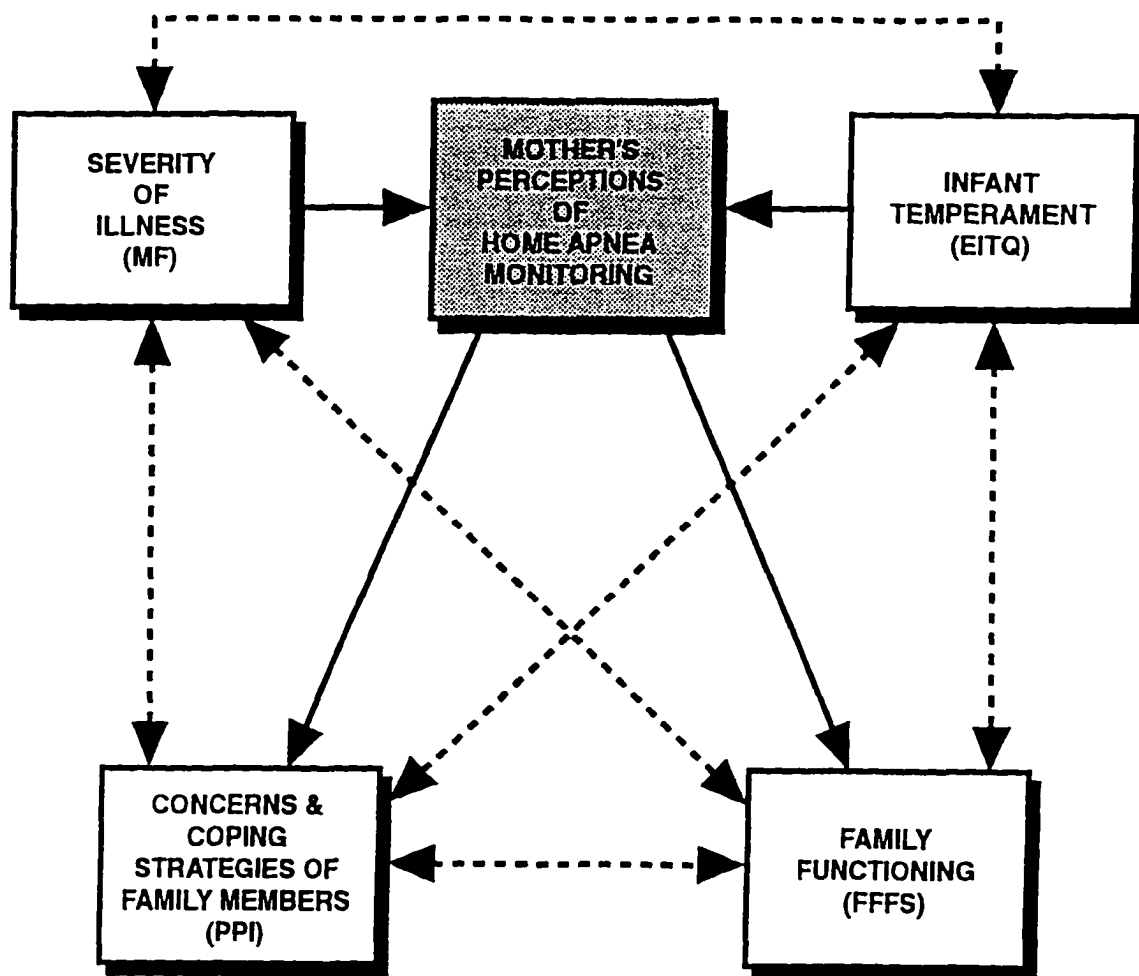


FIGURE 3: THEORETICAL RELATIONSHIPS OF STUDY VARIABLES

This study examined the influence of the independent variables on two dependent variables, the individual family members' responses to the stressor of home apnea monitoring as perceived by the mother, and the response of the family unit to the stressor of home apnea monitoring as perceived by the mother. The individual family members' responses to the stressor were of two types, the family members' concerns and their coping mechanisms. The family unit's functioning as perceived by the mothers was also a reflection of the response of the family unit.

Measurements of the dependent variables were made at each of three points in the home apnea monitoring experience. Demographic characteristics of the family were identified at the initial monitoring point. Information on the severity of illness was gathered at each of three points in the home monitoring experience. Data on the independent variable of infant temperament were gathered only at the mid-monitoring point since there is evidence that temperament is a fairly stable component of the infant's character (Carey, 1983).

### Instrumentation

#### Parent Perception Inventory

The Parent Perception Inventory (PPI) (Appendix D) developed by Hymovich (1988) was used to gather data regarding concerns and coping responses in families of infants on home apnea monitors. The PPI is a derivation of the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) (Hymovich, 1981, 1983, 1984). Both instruments were developed from Hymovich's framework for assessment of the chronically ill child and family. The PPI focuses on assessing the second and third components of Hymovich's framework: the variables which affect the impact of the child's

chronic illness. Hymovich (1984) notes that the Impact-of-Illness Scale (Stein & Reisman, 1980) and the Coping Health Inventory for Parents (McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983) look individually at the impact of chronic illness and at coping strategies but fail to combine these two dimensions as does the CICI:PQ. The CICI:PQ was used with parents of children with spina bifida (Cleve, 1989), with families of children with cystic fibrosis (Hymovich & Baker, 1985; Christian, 1989), and with families of children who had undergone heart transplants (Uzark & Crowley, 1989). Aitken and Hathaway (1993), Heaman (1991, 1995), Samuelson, Foltz, and Foxall (1992), and Stutts (1994) used the PPI in their studies of families of children with cancer, parents of developmentally disabled children, families of children with myelomeningocele, and parents of technology-dependent children, respectively. The PPI was appropriate in the present study because mothers could provide their perceptions of the concerns and coping responses that they and their family members were experiencing related to having an infant on a home apnea monitor. Also, a self-report measure such as the PPI was appropriate since the focus of the study was what Dashiff (1984) calls "the respondent's subjective reality".

Initial development of the CICI:PQ used a field methodology to draw critical incidents from the interviews of parents of children with cystic fibrosis. These critical incidents were translated into an instrument addressing the categories of problems, coping resources, and satisfactions. Hymovich (1981) conducted necessary psychometric testing and revised the instrument. A final instrument, the CICI:PQ, which contained 167 closed-ended items, grew from these revisions. Internal consistencies via Hoyt's coefficient were .94 and .93 for the concerns and the coping categories respectively (Hymovich, 1984).

A few years after construction and testing of the CICI:PQ, Hymovich developed the PPI (Appendix D). The PPI is a composite of six instruments which can be administered separately or in selected combinations. The PPI is composed of 279 closed-ended items seeking nominal and ordinal-level data. The items on each of the subscales of the six instruments are summed, yielding scores related to the family members' concerns and coping strategies. The PPI is designed to be self-administered by the parents and has an average reading level of grade 6.4 (Hymovich, personal communication, 1988). Hymovich reports that completion of all six components of the PPI takes approximately 45 minutes.

Hymovich (personal communication, 1989) used the PPI with 22 parents of children with cystic fibrosis in order to determine its psychometric properties. Internal consistency reliability was determined using Cronbach's coefficient alphas while test-retest reliability was determined using t-tests for seven of the twelve subscales of the PPI (Hymovich, personal communication, 1989) (Appendix D).

For the current study, five of the twelve subscales were used. From the PPI-Concerns instrument, the Concerns subscale was chosen to indicate the mothers' concerns related to relationships, resources, child care, and maternal needs; and the Spouse Concerns subscale from the PPI-Spouse Concerns and Coping instrument was used as an indicator of the concerns of the spouses/partners as perceived by the mothers. Indicators of coping responses of the various family members included the Coping subscale of the PPI-Coping instrument, the Spouse Coping subscale of the PPI-Spouse Concerns and Coping instrument, and the Sibling Behavior subscale of the PPI-Siblings instrument. All of the five subscales chosen for the current study had reported internal consistency alphas



of between .62 and .88 (Hymovich, 1989). The Feelings and Beliefs instrument of the PPI was not used due to an extremely low alpha level (.33) on the Beliefs subscale (Hymovich, 1989). The reliability data for the five subscales used in this study as reported by Hymovich (1989) are presented in Table 1.

Table 1

The PPI Scales, Subscales, Numbers of Items, and Reliability Data

Instruments	Subscales	# of Items	Cronbach's alpha	Test/Retest
Concerns	Concerns	34	.88	.82
Coping	How Often	29	.62	.78
Spouse Concerns & Coping	Spouse Concerns	26	.88	.92
	Spouse Coping	29	.66	.82
Siblings	Sibling Behavior	8	.72	

Content validity of the PPI was determined from the retroductive method on which the CICI:PQ and hence the PPI were developed (Hymovich, 1993b). No comparisons to other instruments measuring the same or different constructs have been made; therefore, decisions regarding the criterion or concurrent validity of the PPI are not available.

To establish the usefulness of the PPI, a pilot study was conducted by this investigator in which six mothers of children with chronic health problems were asked to complete the PPI. One mother returned the completed PPI spontaneously, four returned the PPI after phone reminders, and one returned her PPI after the pilot study was completed. Comments from the mothers were used to guide decisions regarding length of time for PPI completion, presentation methods, and editorial changes necessary for the current study.

### Feetham Family Functioning Survey

Roberts and Feetham (1982) developed the Feetham Family Functioning Survey (FFFS) (Appendix E) to measure family functioning as based on relationships. The FFFS focuses on three areas: relationships between the family and broader societal units such as the community and the economy, relationships within the family, and relationships between the family and each individual. The use of the Porter format (Porter, 1962) allows the respondents to indicate the magnitude, importance, and degree of need satisfaction in the relationships assessed. The FFFS consists of 25 ordinal-level items to which the respondent indicates the amount of existing family functioning, the amount of expected family functioning, and the degree of importance of the item to the respondent's perception of family functioning. Scores are calculated for each of the three areas - existing, expected, and importance - followed by calculation of a discrepancy score reflecting the absolute difference between the amount of the family functioning item perceived as present and the amount of the item which the respondent believed should be present. The higher the score on the FFFS, therefore, the larger the discrepancy between perceived family functioning and expected family functioning. The FFFS yields ratio-level data. The FFFS is designed to be self-administered or to be used as an interview guide.

Reliability of the FFFS was determined by Roberts and Feetham (1982) using a study of 103 mothers of children with myelodysplasia. Internal consistency via computation of Cronbach's coefficient alpha was .81 for the discrepancy score. Alpha coefficients on the three individual scales were moderate, ranging from .66 to .84 (Roberts & Feetham, 1982).

Validity of the FFFS was established in several ways. First, the FFFS is based on the family functioning literature, on previous research of families of children with chronic health problems, and on clinical observations of families of children with myelodysplasia. Content validity arises from the review by a panel of experts and from the pretesting of the FFFS conducted during its development. Roberts and Feetham (1982) present evidence of concurrent validity since they simultaneously administered the FFFS and another measure of family functioning of chronically ill children, the Family Functioning Index (FFI) by Pless and colleagues, to a sample of 103 mothers. A negative correlation of  $-.54$  was obtained (Roberts & Feetham, 1982) which supports a conclusion of concurrent validity for the FFFS, since high scores on the FFI indicative of more optimal family functioning would be correlated with lower discrepancy in family functioning on the FFFS. Factor analysis using a varimax rotation was conducted with this same sample of 103 mothers to establish construct validity of the FFFS. All but three of the items on the FFFS had high factor loadings on one of the three factors included in family functioning: relationships between family members, between the family and subsystems, and between the family and societal systems (Roberts & Feetham, 1982).

The FFFS has been used in over 50 studies reported in the literature, either as a single indicator of family functioning, or as one of several indicators of family functioning, and with a variety of cultural groups. The FFFS was appropriate to the present study because it is a "well-established self-report instrument" (Sawin & Harrigan, 1995, p. 42) for measuring family functioning. Also, as a self-report instrument, the FFFS enabled measurement of the perceptions of family members in a quantitative manner (Sawin & Harrigan, 1995).

### Early Infancy Temperament Questionnaire

The Early Infancy Temperament Questionnaire (EITQ) (Appendix F) developed by Medoff-Cooper, Carey, and McDevitt (1993) is composed of 76 objective items which address the nine characteristics of temperament. The EITQ presents each item with a 6-point Likert-type scale ranging from "almost never" to "almost always". Items are summed in order to obtain a score for the infant on each of these nine temperament subscales. Lastly, the infant's performance is placed in one of four temperament categories - difficult, easy, slow-to-warm-up, or intermediate (Medoff-Cooper et al., 1993). The EITQ also includes an additional page of subjective responses titled, "Mother's General Impressions of Infant Temperament". The instrument takes about 20 minutes to complete and approximately 10 minutes to score (Appendix F). The EITQ is intended for use with parents of 1 to 4 month-old infants (Medoff-Cooper et al., 1993).

The EITQ was developed from the Revised Infant Temperament Questionnaire (RITQ) (Carey & McDevitt, 1978) which was developed for use with infants between 4 and 8 months of age and which has been used extensively by pediatricians and nurses in clinical practice and in research activities. Medoff-Cooper and colleagues (1993) revised and standardized the EITQ with 404 infants between one and four months of age, corrected for prematurity. These infants were primarily white, full-term, and from working and middle class American families. Scores on the EITQ are computed for two subgroups, from 1 to 2 months of age and from 3 to 4 months of age. No research studies using the EITQ were found in the literature. The EITQ was too recent to be included in a review of instruments measuring temperament by Ryan-Wenger (1994), although the other temperament instruments by Carey and McDevitt and colleagues were listed.

Psychometric properties of the EITQ included moderate to low internal consistency coefficient alphas ranging from .43 to .76 for the individual temperament categories for the 1 to 2 month-old subgroup and from .42 to .68 for the 3 to 4 month-old subgroup (Medoff-Cooper, et al., 1993). Correlations between scores on the EITQ and mothers' general impressions of their infants' temperaments were varied, ranging from 0.32 to 0.65 for five temperament characteristics (approach-withdrawal, adaptability, activity, persistence, and rhythmicity) and below 0.30 on the remaining four temperament characteristics (intensity, mood, distractibility, and threshold) (Medoff-Cooper, et al., 1993). These low to moderate correlations indicate a discrepancy between temperament scores and mothers' general impressions of their infants' temperament, although they are positively related. No determination of validity of the EITQ was found in the literature, although Medoff-Cooper and colleagues (1993) note that comparisons between the EITQ and other indicators of development, behavior, and personality will be possible as the EITQ is utilized in clinical practice and research (p. 234).

#### Monitoring Flowsheet

The Monitoring Flowsheet (MF) (Appendix G) developed by the researcher was completed at each of the three monitoring periods. The MF included information about the length of time since the institution of monitoring, events in the monitoring experience to the present time including an estimate of the number and causes of alarms, determination of the severity of apneic episodes using Wasserman's criteria (1984), and maternal expectations about the remaining home apnea monitoring experience. Data on the MF were obtained by having the mothers note each alarm as it occurred and the measures employed to end the spell (Section I), by the investigator reading a list of

negative events in the home monitoring experience (Section II), and by the mothers completing three subjective items about the remaining home apnea monitoring time (Section III). The items on the first two sections of the MF were weighted and their weights were summed. These scores indicated the severity of the infant's illness with higher scores reflecting increased severity of illness. This scoring method is consistent with established measures of severity of illness such as the Pediatric Risk of Mortality (PRISM) score used by Youngblut and Lawson (1995) in a study of family functioning after their children had been in a pediatric intensive care unit. Because the MF was a new instrument developed specifically for the current study, no information on reliability of the instrument was available. Face validity was established by review of the instrument by three experts in apnea monitoring, a neonatal nurse, a pediatric nurse, and a pediatric polysomnography technician.

#### Demographic Information

Demographic information about the respondents and their families was elicited using the closed-ended PPI-General Information (Appendix D) questionnaire. Data gathered included hospitalizations of the monitored infant, numbers, ages, and health status of siblings, the family's religious affiliations, employment, educational and income levels, marital status, and consistency of work.

In addition to the PPI-General Information form, an open-ended questionnaire generated by the researcher, the Monitoring Background Questionnaire (MBQ) (Appendix H), elicited more detailed information about the home apnea monitoring experience. Categorical data were gathered concerning the birth and neonatal history of the monitored

infant, the specific reason for institution of home apnea monitoring, and details regarding the components of the monitoring program in which the family was participating.

#### Data Collection Procedures

Mothers of infants recently enrolled in either of the home monitoring programs were contacted by the CSDC technician, community health nurses, or the SCN nurses asking if they were willing to participate in a survey of families of infants on home apnea monitors and utilizing the parent letter from the researcher (Appendix C). Using this approach, the identities of those approached were unknown to the researcher until the parents indicated they were interested in participating in the study by signing the respective hospital's release form, or by returning the signed, self-addressed, stamped postcard (Appendix I) to the researcher who then obtained written informed consent (Appendix B). Mothers of infants in the first two weeks of the home apnea monitoring experience were approached in this manner until mothers of 13 infants on home apnea monitors had agreed to participate. The time required for the study and the potential availability of subjects at the CSDC and SCN necessitated that a minimum of 12 months be allocated for data collection.

Data were collected at three points in the home apnea monitoring experience - within the first three weeks of the initiation of home apnea monitoring, at three months into the monitoring experience, and within 3 weeks following termination of home apnea monitoring (Table 2). The researcher chose these measurement points to be consistent with Wasserman's (1984) periods of doubt/acceptance (the initial 2-4 weeks of monitoring), dependence/frustration (the middle months of monitoring), and

Table 2

Schedule of Measurements

Phase of Monitoring	Initial	Maintenance	Termination
Home Visit	#1	#2	#3
Time Description	2 weeks into monitoring	3 months into monitoring	3 weeks after the end of monitoring
Instruments Completed	PPI-Concerns PPI-Coping PPI-Spouse PPI-Sibling FFFS MF PPI-General MBQ	PPI-Concerns PPI-Coping PPI-Spouse PPI-Sibling FFFS MF EITQ	PPI-Concerns PPI-Coping PPI-Spouse PPI-Sibling FFFS MF

Key: PPI Parent Perception Inventory (Hymovich, 1989)  
 FFFS Feetham Family Functioning Survey (Roberts & Feetham, 1983)  
 MF Monitoring Flowsheet  
 MBQ Monitoring Background Questionnaire

discontinuance (termination of monitoring). Wasserman included a late effects phase lasting five years after the initiation of monitoring, the reality of the timetable for this study only permitted examination of families during the first three phases of monitoring.) These intervals also were consistent with those used by Saylor and colleagues (1989) who measured maternal anxiety levels at the initiation of monitoring, at the one to three month follow-up visit, and two weeks following termination of monitoring.

At the initial monitoring period, the investigator conducted a visit to the home at a time convenient for the mother. Informed consent (Appendix B) to participate in the study was signed at the beginning of the home visit. Following this, the researcher verbally administered the MBQ. Each mother then was given with the PPI (PPI-General Information questionnaire, the four applicable parts of the PPI (PPI-Concerns, PPI-Coping, PPI-Spouse, and PPI-Siblings), the FFFS, and MF to complete at her



convenience. A stamped, self-addressed return envelope was provided. The researcher offered to verbally administer the instruments for all participants, although no mothers utilized that avenue. The questionnaires were coded numerically to enable data at each measurement period to be used in answering research questions addressing the changes over time. In order to increase response rates, one week following the initial visit, non-respondents were telephoned requesting that they complete and return the questionnaires as soon as possible. After two weeks, further non-respondents were telephoned and, if necessary, sent a new set of questionnaires and a stamped self-addressed return envelope. This mixture of media maximized response rates to the survey while minimizing the cost of administration. Siemiatycki (1979) studied mail, telephone, and home visiting strategies and concluded that although the home interview schedule resulted in the highest response rate (84%), the mail strategy had a slightly lower response rate (70.3%) but greater validity of responses when compared to a governmental data base.

Approximately three months into the monitoring experience, visits to the homes of participants were repeated in order to obtain family participation during the maintenance phase of the home apnea monitoring experience. Mothers were asked to complete the four parts of the PPI, the FFFS, the EITQ, and the MF. As in the first home visit, each mother was instructed to complete the instruments and to return them in the stamped, self-addressed envelope provided. Again, the researcher offered to read the instruments if desired, and no participants chose this option. Phone and mail follow-ups were conducted as specified earlier.

At the second visit, mothers were provided with a stamped postcard (Appendix I) and asked to return this to the investigator or to call the investigator when each infant's

home apnea monitoring experience was ended. A final home visit was conducted within three weeks after termination of monitoring. Mothers were asked to complete the four sections of the PPI, the FFFS, and the MF, using the same procedure as earlier. Again, follow-up procedures involved the combination of phone calls and mailings as identified earlier.

Rudy, Estok, Kerr, and Menzel (1994) present support for the use of incentives as a strategy for increasing the retention of study participants in longitudinal studies. In order to encourage completion and subsequent return of each set of research instruments at each phase in the current study, participants were given photographs of their infants following the investigator's receipt of each set of research instruments. The investigator took at least three photographs of each infant during each home visit. In this way, families received at least none different photographs of their infant. A small baby album for the family to keep accompanied the final photographs.

#### Human Subjects Assurance

The following institutional review board approvals were obtained at the onset of the study (Appendix A): University of South Carolina (USC) College of Nursing Ethics Committee, a duly appointed subgroup of the USC Institutional Review Board; and the Nursing Research and Ethics Committee of the hospital where the CSDC was located. Subsequently, permission was obtained from the Institutional Review Board for Human Research of the South Carolina Department of Health and Environmental Control (DHEC). Also, permission was obtained from the medical center where the SCN was located since it has a collaborative agreement to accept the USC-IRB approval. Informed consent (Appendix B) was obtained from each participating mother as outlined earlier.

Data collection instruments were numerically coded and did not contain information which could be used to identify participants. All completed questionnaires and informed consent documents remained confidential and were retained separately in a locked file. A master code list was kept in a locked file apart from other study documents. No record of participation or non-participation in the study was included in the infant/family's file at the CSDC, DHEC, or SCN.

### Data Analysis

#### Preparation of Data

Statistical analysis of the data was conducted using the Lander University, Greenwood, South Carolina computer facilities and the Student Edition of EXECUSTAT 3.0® Data Analysis System (Strategy Plus., Inc., 1993). To determine the accuracy of data entry procedures, all data were entered twice and validated. Each of the mothers' scores on the applicable subscales of the PPI were computed according to scoring directions provided with the instrument (Appendix D). The three scales of the FFFS were computed by summing the scores across items. The discrepancy score was calculated by subtracting the absolute expectation score from the absolute occurrence score on each item and then summing the scores across times to provide a measure of the degree of dissatisfaction with family functioning (Appendix E). The EITQ was scored according to instructions provided with the instrument (Appendix F). The infant's score on each of the nine temperament characteristics was computed and temperament type identified. Items on the first two sections of the MF (Appendix G) were summed according to their item weights so that a single score indicative of the infant's severity of illness was obtained.

### Sample Description

Demographic characteristics from the PPI-General Information form and from the MBQ were determined using summary statistics including frequency distributions, measures of central tendency, and measures of dispersion. Infant birth characteristics and characteristics of the monitoring experience were determined from the MBQ using the same summary statistics.

### Instrument Summaries

Summary statistics for each observation period including frequency distributions, measures of central tendency, and measures of dispersion on applicable scales and/or subscales of the PPI, FFFS, EITQ, and MF were computed. Internal consistency reliabilities of these instruments for the current sample were estimated with coefficient alphas for each of the subscales of the PPI, the discrepancy scores on the FFFS, and the nine temperament scales of the EITQ. Coefficient alpha is appropriate for use with all levels of data (Waltz, Strickland, & Lenz, 1984). Hymovich (1989) used Cronbach's coefficient alpha in determining the internal consistency reliability of the PPI as did Roberts and Feetham (1982) with the FFFS. Medoff-Cooper and colleagues (1993) used the K-R 20 formula to compute coefficient alphas on the EITQ.

### Analysis of the Research Questions

All analyses were conducted using a two-tailed .05 level of significance since the research questions were non-directional in nature (Burns & Grove, 1997). Parametric analyses were employed since the PPI, FFFS, MF, and EITQ yielded interval data. Tests chosen were those which were deemed to be the most powerful for the desired analysis.

1. How do mothers' perceptions of the concerns of individual family members change as they progress through the three phases of home apnea monitoring? Repeated measures analyses of variance (ANOVA) were computed to address this question. With this analysis, scores on the concerns subscales of the PPI for the same individual at each of the three monitoring points were dependent samples (Glass & Hopkins, 1996). The repeated measures ANOVA computation emphasized the test occasion as the effect of primary interest rather than the differences among individuals (Glass & Hopkins, 1996).

2. How do mothers' perceptions of coping strategies of individual family members change as they progress through the three phases of home apnea monitoring? Repeated measures ANOVAs were computed to address this question. With this analysis, scores on the coping subscales of the PPI for the same individual at each of the three monitoring points were dependent samples (Glass & Hopkins, 1996). The repeated measures ANOVA computation emphasized the test occasion as the effect of primary interest rather than the differences among individuals (Glass & Hopkins, 1996).

3. How do mothers' perceptions of the discrepancy between expected and perceived family functioning change as they progress through the three phases of home apnea monitoring? Repeated measures ANOVA was computed to address this question. With this analysis, scores on the discrepancy scores on the FFFS for the same individual at each of the three monitoring points were dependent samples (Glass & Hopkins, 1996). The repeated measures ANOVA computation emphasized the test occasion as the effect of primary interest rather than the differences among individuals (Glass & Hopkins, 1996).

4. What is the relationship between the concerns of family members as perceived by the mothers and the discrepancy between expected and perceived family

functioning as families progress through the three phases of home apnea monitoring?

Pearson product-moment correlation coefficients (Pearson  $r$ ) were computed between the family members' concerns on the PPI as perceived by the mother and their discrepancy scores on the FFFS at each of the three monitoring periods. Use of the Pearson  $r$  indicated the relationship between the concerns of the family members on the PPI and the discrepancy between expected and perceived family functioning as indicated on the FFFS (Glass & Hopkins, 1996).

5. What is the relationship between the coping strategies of family members as perceived by the mothers and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring?

Pearson  $r$ 's were computed between the family members' coping strategies on the PPI as perceived by the mother and their discrepancy scores on the FFFS at each of the three monitoring periods. Use of the Pearson  $r$  indicated the relationship between the coping strategies of the family members on the PPI and the discrepancy between expected and perceived family functioning as indicated on the FFFS (Glass & Hopkins, 1996).

6. What is the relationship between mothers' perceptions of infant temperament and the concerns perceived by the mothers during the home apnea monitoring experience? Pearson  $r$ 's were computed to address this question. The analyses were conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers' EITQ scores. Use of the Pearson  $r$  indicated the relationship between mothers' ratings of infant temperament on the EITQ and the concerns of family members as perceived by the mothers on the PPI (Glass & Hopkins, 1996).

7. What is the relationship between mothers' perceptions of infant temperament and the coping strategies perceived by the mothers during the home apnea monitoring experience? Pearson  $r$ 's were computed to address this question. The analyses were conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers' EITQ scores. Use of the Pearson  $r$  indicated the relationship between mothers' ratings of infant temperament on the EITQ and the coping strategies of family members as perceived by the mothers on the PPI (Glass & Hopkins, 1996).

8. What is the relationship between mothers' perceptions of infant temperament and discrepancy between expected and perceived family functioning during the home apnea monitoring experience? Pearson  $r$ 's were computed to address this question. The analyses were conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers' EITQ scores. Use of the Pearson  $r$  indicated the relationship between mothers' ratings of infant temperament on the EITQ and the discrepancy between the expected and perceived family functioning on the FFFS (Glass & Hopkins, 1996).

9. What is the relationship between mothers' ratings of the infants' severity of illness and the concerns of family members as perceived by the mothers as families progress through the three phases of home apnea monitoring? Pearson  $r$ 's were computed between the mothers' ratings on the MF and the concerns of family on the PPI at each of the three monitoring periods. Use of the Pearson  $r$  indicated the relationship between the

infant's severity of illness as indicated on the MF and the concerns of family members as perceived by the mothers on the PPI (Glass & Hopkins, 1996).

10. What is the relationship between mothers' ratings of the infants' severity of illness and the coping strategies of family members as perceived by the mothers as families progress through the phases of home apnea monitoring? Pearson  $r$ 's were computed between the mothers' ratings of severity of illness on the MF and the coping strategies of family members on the PPI at each of the three monitoring periods. Use of the Pearson  $r$  indicated the relationship between the infant's severity of illness as indicated on the MF and the coping strategies used by family members as perceived by the mothers on the PPI (Glass & Hopkins, 1996).

11. What is the relationship between mothers' ratings of the infants' severity of illness and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring? Pearson  $r$ 's were computed between the mothers' ratings of infant severity of illness on the MF and their discrepancy scores on the FFFS at each of the three monitoring periods. Use of the Pearson  $r$  indicated the relationship between the infant's severity of illness as indicated on the MF and the discrepancy between expected and perceived family functioning on the FFFS (Glass & Hopkins, 1996).

12. What is the relationship between mothers' perceptions of infant temperament and the infants' severity of illness during the home apnea monitoring experience? Pearson  $r$ 's were computed to address this question. The analysis was conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers'



EITQ scores. Use of the Pearson  $r$  indicated the relationship between the mothers' ratings of infant temperament on the EITQ and their ratings of severity of infants' illness as indicated on the MF (Glass & Hopkins, 1996).

### Summary

In summary, the purpose of this study was to delineate the responses of families to the stressor of home apnea monitoring at various points in the monitoring experience. The methodology employed was longitudinal with event partitioning, following mothers of 13 infants on home apnea monitoring. The primary research instruments and measurement periods were the following: (a.) initially, the Parent Perception Inventory (PPI), the Feetham Family Functioning Survey (FFFS), and the Monitoring Flowsheet (MF); (b.) during the maintenance period, the PPI, FFFS, MF, and Early Infancy Temperament Questionnaire (EITQ); and (c.) at termination of monitoring, the PPI, FFFS, and MF. The data were described and the research questions analyzed by Parametric statistics using a two-tailed .05 level of significance (Glass & Hopkins, 1996).

## CHAPTER IV

### Data Analysis

The literature review supported the need for further research on the concerns and responses of families to having an infant on a home apnea monitor, including the impact on individual family members as well as on the functioning of the family as a unit. A longitudinal study with event partitioning was designed to obtain information from mothers of infants on home apnea monitors regarding the impact on themselves, on other family members, and on the family as a whole. Chapter Four presents the results of this investigation into the effects of having an infant on a home apnea monitor on members of the infant's family and on family functioning at three points in the home apnea monitoring experience as perceived by the mother.

### Description of Sample

#### Demographics

Data were collected over an eighteen-month period beginning in September, 1995 and continuing through January, 1997. Recruitment of mothers into the study from two different sites using three recruitment methods lasted for 13 months, with mothers of 13 infants consenting to participate. (Mothers of two sets of twins agreed to participate and completed different sets of questionnaires for each of their infants.) No mothers dropped out of the study, although one infant came off the monitor after only six weeks so that the mid-monitoring measurement was omitted. Questionnaires from the twelfth mother were

never received and the last infant was still on the monitor at the conclusion of the study so only data from the first two measurement points on each of these participants was included in the analysis.

The study sample consisted of birth mothers of 13 infants who were undergoing home apnea monitoring. All of the families included the mother and infant living together, with ten families including the natural father, and with ten families including at least one sibling. Of the thirteen families, the number of children of any age ranged from one to six with an average number of 2.4. Of these children, all were under five years of age except for the children in one family which had three children between six and twelve and two children older than thirteen. All except two of the mothers were white (n=11). Nine of the mothers were married and four had never been married. Of the nine married women, two had been married less than 2 years, five had been married between two and five years, and two had been married between six and twelve years. Eleven mothers responded to the question about religious preference, with ten reporting that they were Protestant, and one reporting "other" religion. At the initiation of monitoring, the mothers were either unemployed and at home (n=10) or on maternity leave (n=3) from full-time jobs. By the termination of monitoring, four of the mothers were working full-time. The average income for the families was between \$20,000 and \$29,999, and ranged from \$5,000 to \$9999 (n=1) to \$40,000 to \$49,000 (n=3). With one exception, all of the mothers had at least a high school education, with four mothers indicating that they had had some college, four listing themselves as college graduates, and one stating that she had a master's degree. All of the mothers were over 18 years of age at the onset of the study, with most mothers between 19 and 24 years old (n=7), with three mothers between 25 and 29 years

of age, two mothers between 30 and 34 years old, and one mother between 35 and 39 years old.

### Infant Birth Characteristics

Information on the birth characteristics of the 13 monitored infants (Table 3) was gathered from the Monitoring Background Questionnaire (MBQ) (Appendix H). The typical infant in this study was a white female (11 of 13 white; 8 of 13 female) who had been delivered vaginally (7 of 13) at 33.7 weeks gestation (ranging from 31 to 40 weeks), with a birth weight of 2083 grams (ranging from 1051 to 3920 grams) and a birth length of 43.4 centimeters (ranging from 34 to 53 centimeters), and who spent an average of 3.4 weeks in either the Special Care Nursery (SCN) or Neonatal Intensive Care Unit (NICU)

Table 3

### Infant Birth Characteristics

	Sex	Race	Type of Delivery	Gestational Age	Birth Weight	Birth Length	SCN/ NICU	Length of Stay
1	F	White	vaginal	31 wks.	1732 g	42 cm	3.0 wks.	4.0 wks.
2	M	White	C-section	31 wks.	1932 g	41 cm	4.0 wks.	4.0 wks.
3	F	White	vaginal	38 wks.	3550 g	50 cm	0.8 wks.	1.0 wk.
4	F	White	C-section	29 wks.	1222 g	40 cm	7.0 wks.	7.0 wks.
5	F	White	C-section	29 wks.	1108 g	37 cm	8.0 wks.	8.0 wks.
6	M	White	C-section	32 wks.	1222 g	38 cm	6.0 wks.	6.5 wks.
7	F	White	C-section	32 wks.	1051 g	34 cm	7.5 wks.	8.5 wks.
8	F	White	C-section	35 wks.	2358 g	49 cm	0.8 wks.	0.5 wks.
9	F	White	vaginal	36 wks.	2869 g	45 cm	0.5 wks.	1.5 wks.
10	M	White	vaginal	40 wks.	3920 g	53 cm	0.5 wks.	0.5 wks.
11	F	White	vaginal	40 wks.	2559 g	48 cm	1.8 wks.	1.5 wks.
12	M	Black	vaginal	29 wks.	1165 g	38 cm	2.5 wks.	10 wks.
13	M	Black	vaginal	36 wks.	2386 g	49 cm	2.0 wks.	2.0 wks.
<b>Mean</b>				<b>33.7 wks.</b>	<b>2083 g</b>	<b>43.4 cm</b>	<b>3.4 wks.</b>	<b>4.2 wks.</b>

(ranging from 0.5 to 8.0 weeks). The total length of hospitalization averaged 4.2 weeks with a range of 0.5 to 8.5 weeks.

#### Characteristics of the Monitoring Experience

Information on the monitoring program components was obtained from the MBQ and is presented in Table 4. The typical monitoring experience began with the infant's being placed on the home apnea monitor at the time of discharge from the hospital as a result of documented episodes of apnea (10 infants) and/or low heart rate (6 infants). The

Table 4

#### Characteristics of the Monitoring Experience

	Reason for Monitoring	Monitoring Time	Electrode Type	Program Site	Length of Monitoring
1	↓ HR; apnea	24°	belt	CSDC	4.8 mos.
2	apnea	24°	belt	CSDC	5.4 mos.
3	↓ HR; apnea, feeding difficulty	sleep only	belt	CSDC	3.6 mos.
4	apnea	24°	belt	CSDC	5.6 mos.
5	apnea	24°	belt	CSDC	5.4 mos.
6	↓ HR	24°	skin; Δq2d	CSDC*	6.8 mos.
7	↓ HR	24°	skin; Δq2d	CSDC*	6.4 mos.
8	↓ HR; apnea	24°	belt	SCN	1.5 mos.
9	↓ HR; feeding difficulty	24°	belt	SCN	4.6 mos.
10	apnea	24°	belt	SCN	4.3 mos.
11	apnea	24°	skin; Δq2d	SCN	7.1 mos.
12	apnea	24°	belt	SCN	3.4 mos.
13	apnea, feeding difficulty	sleep only	belt	CSDC*	
<b>Mean</b>					<b>4.9 mos.</b>

Key: ↓ HR = decreased or low heart rate  
 24° = 24 hours  
 belt = electrodes held in place by a belt encircling the infant's abdomen  
 skin; Δq2d = skin electrodes which are changed every other day  
 CSDC = Children's Sleep Disorders Center  
 CSDC\* = Children's Sleep Disorders Center, recruited by public health nurses  
 SCN = Special Care Nursery program

infant wore an electrode belt (10 infants) and was monitored continuously for the entire 24 hour period (11 infants). The average length of the monitoring experience was 4.9 months with a standard deviation of 1.5 months and a range from 1.5 months to 7.1 months. This average length of monitoring is slightly lower than the six month average quoted by personnel at the CSDC (T. Marshall, personal communication, 1994).

#### Reliabilities of the Instruments in This Sample

Cronbach's alpha coefficient of internal consistency was computed on each of the instruments used in this study at each of the three measurement points (Table 5). High

Table 5

#### Reliabilities of Instruments Used in Study

Instruments	Reliabilities From This Study			Reliability from Literature
	Initial Monitoring	Maintenance Monitoring	Termination of Monitoring	
PPI-Concerns	.90	.95	.90	.92
PPI-Coping	.91	.87	.85	.62
PPI-Spouse Concerns	.90	.93	.92	.88
PPI-Spouse Coping	.71	.83	.77	.66
PPI-Sibling Behavior	.58	.67	.63	.72
FFFS	.77	.86	.80	.81
MF	.35	.57	NA	NA
EITQ-Activity	NA	.73	NA	.58
-Rhythmicity		.73		.66
-Approach		.31		.63
-Adaptability		.33		.65
-Intensity		.36		.43
-Mood		.41		.68
-Persistence		.30		.51
-Distractibility		NA		.42
-Threshold		.28		.49

Key: PPI = Parent Perception Inventory (Hymovich, 1989)  
FFFS = Feetham Family Functioning Survey (Roberts & Feetham, 1982)  
MF = Monitoring Flowsheet  
EITQ = Early Infancy Temperament Questionnaire (Medoff-Cooper, et al., 1993)

alpha coefficients on the PPI-Concerns, PPI-Coping, PPI-Spouse Concerns, PPI-Spouse Coping, and FFFS instruments are consistent with the alphas reported in the literature for these instruments (Hymovich, 1989; Roberts & Feetham, 1982). The relatively high internal consistency indicates that these measures are homogeneous. The moderate to low alpha coefficients on the PPI-Sibling Behavior subscale, on the MF, and on several of the temperament characteristics indicate that these measures are not homogeneous. These findings are consistent with the short lengths of these instruments (the PPI-Sibling Behavior subscale has eight items, the MF has three items, and the temperament characteristics have between six and eleven items each) and with the small sample size in the current study. Coefficient alpha could not be obtained on the MF at the termination of monitoring because none of the mothers reported any true monitor alarms (Item #2), thereby reducing the total number of items on the MF to two. Coefficient alpha could not be obtained on the Distractibility portion of the EITQ because several of the mothers omitted answers on two of the items.

#### Description of Sample Performance on Instruments

Data from mothers of 13 infants were analyzed for this study. Mothers of ten infants completed the PPI-Concerns, PPI-Coping, PPI-Spouse, PPI-Siblings, FFFS, and MF at each of the three monitoring periods. One infant came off of the monitor after only 1.5 months; therefore her mother completed only the first and third set of measurement questionnaires plus the EITQ. Questionnaires from the mothers of the last two infants had not been received by the conclusion of the study so only data from the first two measurement points with these families were included in the analysis.

The average length of time on the monitor at the initial monitoring point was 2.1 weeks. The average length of time on the monitor at the maintenance monitoring point was 14.5 weeks. The average length of time off the monitor at the termination of monitoring point was 4.5 weeks. Only four of the mothers returned the postcards indicating their infants were off the monitor, resulting in the long average time for the third measurement point.

The mothers' mean scores on applicable scales of the PPI, FFFS, and MF at each of the three measurement points are presented in Table 6. Trends in the data are presented in Tables 7 through 13.

Table 6

Mothers' Scores on the PPI, FFFS, and MF at Each Measurement Point

	Initial Monitoring (n = 13) Mean (SD)		Maintenance Monitoring (n = 12) Mean (SD)		Termination of Monitoring (n = 11) Mean (SD)	
PPI-Concerns	56.7	(21.2)	44.8	(24.5)	38.2	(22.7)
PPI-Coping	37.4	(14.4)	34.6	(13.0)	33.1	(12.7)
PPI-Spouse Concerns	46.5	(20.7)	42.3	(21.0)	34.5	(21.2)
PPI-Spouse Coping	37.0	(10.3)	31.8	(10.8)	32.7	(10.2)
PPI-Sibling Behavior	15.1	(4.3)	4.4	(3.9)	14.6	(5.2)
FFFS	17.2	(11.3)	15.2	(12.0)	14.6	(13.0)
MF	29.2	(23.6)	100.7	(138.3)	9.8	(9.3)

Mothers' Perceptions of Concerns and Coping Strategies of Family Members at Each Measurement Point

The scores reflecting the concerns expressed by the mothers (Table 6) via the PPI-Concerns instrument decreased as monitoring progressed, with a mean concerns score of 56.7 and a range of 25 to 85 initially, a mean score of 44.8 with a range of 14 to 77 at mid-monitoring, and a mean score of 38.2 with a range of 8 to 71 at termination of



monitoring. The mothers' scores reflecting their perceptions of the concerns of their spouses/partners as reflected on the PPI-Spouse Concerns instrument decreased slightly as monitoring progressed, with a mean score of 46.5 and a range of 6 to 78 initially, of 42.3 and a range of 10 to 72 at midmonitoring, and of 34.5 and a range of 0 to 61 at termination of monitoring.

The scores reflecting the coping strategies expressed by the mothers (Table 6) via the PPI-Coping instrument decreased slightly as monitoring progressed, with a mean coping score of 37.4 and a range of 9 to 59 initially, a mean score of 34.6 with a range of 7 to 54 at mid-monitoring, and a mean score of 33.1 with a range of 12 to 55 at the termination of monitoring. The mothers' perceptions of the coping strategies of their spouses/partners as reflected by the mothers' scores on the PPI-Spouse Coping instrument decreased as monitoring progressed, with a mean score of 37.0 and a range of 18 to 59 initially, of 31.8 with a range of 7 to 42 at midmonitoring, and of 32.7 with a range of 21 to 50 at the termination of monitoring. The mothers' perceptions of the coping strategies of their other children as reflected by their scores on the PPI-Sibling Behavior instrument decreased during the first half of monitoring, with a mean score of 15.1 and a range of 8 to 20 initially, decreasing to a mean score of 4.4 with a range of 8 to 20 at midmonitoring, but increased during the last half of monitoring, with a mean score of 14.6 with a range of 8 to 21 at the termination of monitoring.

#### Mothers' Perceptions of Family Functioning at Each Measurement Point

The mothers' perceptions of their family functioning (Table 6) as reflected by the total discrepancy score on the FFFS decreased slightly as monitoring progressed. The initial mean family functioning discrepancy score was 17.2 with a range of 0 to 42 ,

decreasing to 15.2 with a range of 0 to 38 at midmonitoring, and of 14.6 with a range of 0 to 44 at the termination of monitoring.

#### Mothers' Perceptions of Infants' Severity of Illness at Each Measurement Point

The mothers' perceptions of the severity of their infants' illness (Table 6) as reflected by the scores on the MF increased and then decreased as monitoring progressed. The initial mean severity of illness score was 29.2 with a range of 5 to 79, which increased dramatically to 100.7 with a range of 0 to 397 at midmonitoring, and decreasing to 9.8 with a range of 4 to 31 at the termination of monitoring.

Review of the individual responses of the participants on each of the items on the three instruments revealed patterns in their responses. Table 7 details the mothers' concerns at the three monitoring points, while Table 8 presents the mothers' perceptions of the concerns of their spouses/partners at the three monitoring points. The mothers' coping strategies at the three monitoring points are found in Table 9. Table 10 includes the mothers' perceptions of the coping strategies of their spouses/partners. Table 11 includes the mothers' perceptions of the behaviors of their other children at the three monitoring points. The mothers' perceptions of the discrepancy in family functioning at the three monitoring points are presented in Table 12. Table 13 presents the mothers' perceptions of the severity of their infants' illnesses at the three monitoring points.

#### Trends in Mothers' Concerns at Three Measurement Points

As reflected in Table 7, of the 34 concerns the mothers identified using the PPI-Concerns subscale, the items of greatest concern (ranked as "quite a bit" or "a great deal" by at least eight of the mothers at any time) included "making my child comfortable or happy", "wondering about my child's future", "having enough money to meet family's

Table 7

Frequency Distribution of Mothers' Concerns at Three Monitoring Points

Mothers' Concerns	N/A or Not Sure			Little Bit			Quite-a-Bit or a Great Deal		
	I	M	T	I	M	T	I	M	T
1. Extra demands on my time	6	4	8	4	5	2	3	3	1
2. Feeling worn out	2	2	1	5	10	6	6	0	4
3. Having enough fun & relaxation	8	4	5	2	6	4	3	2	2
4. Enough time alone w/ spouse/partner	2	2	5	8	7	5	3	3	1
5. Understanding my spouse/partner	5	2	5	5	5	5	3	5	1
6. Sexual relationship w/ spouse/partner	5	5	5	6	5	4	2	2	1
7. Making child comfortable or happy	3	4	5	2	2	1	8	6	5
8. Time or attention from spouse/partner	2	3	5	6	6	5	5	3	1
9. Respite w/ spouse/partner, no children	4	3	7	5	7	1	4	2	3
10. Getting out of house by myself	7	5	6	3	6	4	3	1	1
11. Doing activities together as a family	5	4	6	4	5	3	4	3	2
12. If I am taking care of child in best way	5	5	6	4	4	3	4	3	2
13. Traveling too far for medical/child care	10	9	9	2	2	2	1	1	0
14. Weather affecting what child can do	10	8	7	1	3	3	2	1	1
15. Enough insurance for child care	5	8	7	3	2	3	5	2	1
16. Community agencies for child's needs	9	9	10	2	1	0	2	2	1
17. Wondering about child's future	0	2	2	4	4	6	9	6	3
18. Worrying re: child care responsibility	5	8	6	5	1	2	3	3	3
19. Enough money to meet family's needs	3	5	6	2	3	2	8	4	3
20. Having money for extra pleasures	4	7	6	3	3	1	6	2	3
21. Someone to talk w/ about my worries	3	7	7	7	3	4	3	2	0
22. Finding someone to stay with my child	9	8	9	0	2	2	4	2	0
23. Wondering how child feels about self	11	10	9	0	1	1	2	1	1
24. Getting enough sleep for myself	1	3	6	7	7	4	5	2	1
25. Talking w/ child re: his/her condition	12	12	11	0	0	0	1	0	0
26. Talking w/ friends re: child's condition	10	9	11	3	3	0	0	0	0
27. Other children have same condition?	9	11	7	2	0	3	1	0	1
28. The cost of my child's medical care	6	8	9	3	3	0	4	1	1
29. Recognize changes in child's condition	3	6	6	5	6	2	5	0	3
30. Information on child's condition	2	8	9	3	2	1	8	2	1
31. Child cooperate w/ meds or treatments	9	10	10	2	2	0	2	0	1
32. My spouse/partner's health	8	5	7	2	6	3	3	1	1
33. My own health	7	7	6	3	4	3	3	1	2
34. My child(ren)'s health	2	3	2	3	1	3	8	8	6

Note: A few items were left blank so frequency totals may not add up to the total n.

needs”, “information on child’s condition”, and “my child(ren)’s health”. These five concerns were evident at the initial monitoring period but had decreased in importance by the termination of monitoring. No items were of greatest concern when monitoring was terminated.

Items of the least concern to the mothers (ranked as “N/A” or “Not Sure” by at least eight of the mothers at any time) included “traveling too far for medical help or child care”, “weather affecting what child can do”, “community agencies for child’s needs”, “finding someone to stay with my child”, “wondering how child feels about self”, “talking with child about his/her condition”, “talking with friends about child’s condition”, “wondering if other children will have the same condition”, and “having the child cooperate with medications or treatments”. These items were of the least concern throughout monitoring. Additionally, “having enough fun and relaxation” and “my spouse/partner’s health” were of least concern initially but increased in concern as monitoring progressed. Two items, “the cost of my child’s medical care” and “information on child’s condition”, were of concern to the mothers initially but that concern decreased as monitoring progressed.

#### Trends in Spouse/Partners’ Concerns at Three Measurement Points

As reflected in Table 8, of the 26 concerns of the spouses/partners as perceived by the mothers using the PPI-Spouse Concerns subscale, the items of greatest concern to the spouses/partners (ranked as “quite a bit” or “a great deal” by at least eight of the mothers at any time) included “having enough fun and relaxation”, “talking with or understanding you”, “having enough money to meet the family’s needs”, and “the children’s health”.

Table 8

Frequency Distribution of Mothers' Perceptions of Their Spouse/Partners' Concerns at Three Monitoring Points

Spouse/Partners' Concerns	N/A or Not Sure			Little Bit			Quite-a-Bit or a Great Deal		
	I	M	T	I	M	T	I	M	T
1. Extra demands on time	5	3	6	1	8	5	7	1	0
2. Feeling worn out	2	0	3	7	7	7	4	5	1
3. Having enough fun & relaxation	2	4	4	3	4	4	8	4	3
4. Having enough time alone with you	2	3	6	4	5	2	7	4	3
5. Talking with or understanding you	4	5	5	1	2	5	8	5	1
6. Sexual relationship with you	5	4	6	3	5	4	5	3	1
7. Making child comfortable or happy	5	3	3	2	3	6	6	6	2
8. Having enough time/attention from you	4	2	5	2	4	4	7	6	2
9. Respite with you but without children	5	3	7	3	7	2	5	2	2
10. Getting out of house alone	8	8	7	2	1	2	3	3	2
11. Doing activities together as a family	4	1	4	4	6	5	5	5	2
12. Whether taking care of child best way	5	5	4	4	3	6	4	4	1
13. Traveling too far for medical/child care	13	11	11	0	1	0	0	0	0
14. Weather affecting what child can do	12	10	9	0	1	1	1	1	1
15. Enough insurance for child care	5	7	8	2	1	2	6	4	1
16. Community agencies for child's needs	11	8	10	0	2	0	2	2	1
17. Wondering about child's future	3	4	4	7	4	2	3	4	5
18. Worrying re: child care responsibility	5	4	7	3	4	1	5	4	3
19. Enough money to meet family's needs	1	5	4	4	3	4	8	4	3
20. Having money for extra pleasures	2	5	6	6	3	2	5	4	3
21. Someone to talk w/ about worries	9	9	6	0	1	3	4	2	2
22. The cost of our child's medical care	3	7	7	4	1	2	6	4	2
23. His own health	6	7	6	2	3	4	5	2	1
24. Your health	5	6	5	4	3	4	4	3	2
25. The children's health	4	3	3	1	3	4	8	6	4
26. Talking to child about his/her condition	13	11	9	0	1	0	0	0	2

Key: I = Initial monitoring point (n = 13)

M = Mid-monitoring point (n = 12)

T = Termination of monitoring (n = 11)

No. of items left blank = 0

No. of items left blank = 0

No. of items left blank = 0

These four concerns were evident at the initial monitoring period but had decreased in importance by the termination of monitoring. No items were of greatest concern when monitoring was terminated.

Items of least concern to the spouses/partners as perceived by the mothers (ranked as “N/A” or “Not Sure” by at least eight of the mothers at any time) included “traveling too far for medical help or child care”, “weather affecting what child can do”, community agencies for child’s needs”, and “talking to child about his/her condition”. These items were of the least concern to the spouses/partners throughout monitoring. Additionally, “getting out of the house alone” and “having someone to talk with about worries” were of least concern to the spouses/partners initially through the middle of monitoring but increased in concern as monitoring progressed. One item, “having enough insurance for child care” was perceived by the mothers as of concern to their spouses/partners through the middle of monitoring but their perceived concern had decreased by the termination of monitoring.

#### Trends in Mothers’ Coping Strategies at Three Measurement Points

As reflected in Table 9, of the 29 coping strategies the mothers identified using the PPI-Coping subscale, the strategies used most frequently (ranked as “sometimes” or “very often” by at least eight of the mothers at any time) included praying, using the advice of others, trying to figure out what to do, and trying to relax. These four strategies were used by at least two-thirds of the mothers throughout the monitoring experience. Additionally, several coping strategies were used by at least two-thirds of the mothers at various times during the monitoring experience. Two strategies, crying and asking for help, were used only in the initial phase of monitoring, while busying myself with other things was used frequently during the middle of monitoring, and weighing choices was noted only during the termination of monitoring. Four strategies were utilized frequently during two of the three monitoring periods. These strategies included talking with

Table 9

Frequency Distribution of Mothers' Coping Strategies at Three Monitoring Points

Mothers' Coping Strategies	Do Not Do This			Very Rarely			Sometimes or Very Often		
	I	M	T	I	M	T	I	M	T
1. Cry	3	5	7	1	5	1	8	2	3
2. Busy myself with other things	1	2	3	3	3	2	7	8	6
3. Talk with someone about feelings	0	2	1	1	3	1	10	7	9
4. Ignore/try to forget	5	9	7	5	1	3	3	2	1
5. Look at options	3	1	1	2	1	1	7	10	9
6. Get away for a while	3	3	3	6	6	3	4	3	5
7. Hide feelings	6	5	6	3	1	1	4	6	4
8. Change my expectations	5	6	6	4	2	3	3	4	2
9. Blame someone	10	12	10	3	0	1	0	0	0
10. Yell/scream/slam doors, etc.	9	10	9	3	2	1	1	0	1
11. Exercise	4	5	7	1	3	1	7	4	3
12. Ask for help	0	3	2	3	3	4	8	6	5
13. Take alcohol or medicine	12	11	10	1	1	1	0	0	0
14. Pray	0	0	1	2	1	2	9	10	8
15. Blame myself	4	10	9	5	1	0	4	1	2
16. Ask questions	0	2	2	0	1	2	12	9	7
17. Use advise of others	0	1	0	0	3	3	12	8	8
18. Try to figure out what to do	1	1	1	0	1	1	11	10	9
19. Sleep	3	3	3	4	5	4	6	4	4
20. Find help	2	3	1	0	1	3	9	8	7
21. Smoke	9	7	7	1	0	0	3	4	4
22. Try to laugh or joke about it	7	5	7	2	3	1	3	4	3
23. Eat	8	8	8	1	1	1	3	3	2
24. Try to relax	0	0	1	0	1	2	10	11	8
25. Read about the problem	3	7	2	1	0	3	7	5	6
26. Wish problems would go away	5	5	6	4	2	2	4	5	3
27. Weigh choices	2	4	2	2	2	1	7	6	8
28. Get information	1	3	2	2	0	1	7	9	8
29. Try to change things	3	6	4	1	0	2	7	6	5

Key: I = Initial monitoring point (n = 13)

M = Mid-monitoring point (n = 12)

T = Termination of monitoring (n = 11)

No. of items left blank = 30

No. of items left blank = 1

No. of items left blank = 0

someone about feelings which was frequently used during the initial and termination

phases of monitoring; looking at options and getting information, frequently used during

the last two phases of monitoring; and finding help, a frequently used strategy during the first two phases of home monitoring.

Coping strategies never reported to be used by the mothers (ranked as “do not do this” by at least eight of the mothers at any time) included blaming someone, yelling/screaming/slamming doors, etc., taking alcohol or medicine, and eating. At least two-thirds of the mothers indicated never using these strategies throughout the monitoring experience. Additionally, ignoring/trying to forget was not used at the middle of monitoring, while smoking was not used by the mothers initially but increased in usage as monitoring progressed. Although several of the mothers blamed themselves for their infant’s condition at the initial monitoring period, at least two-thirds of the mothers no longer blamed themselves by the middle and termination of monitoring.

#### Trends in Spouse/Partners’ Coping Strategies at Three Measurement Points

As reflected in Table 10, of the 29 coping strategies which the mothers identified their spouses/partners using via the PPI-Spouse Coping subscale, the strategies used most frequently (ranked as “sometimes” or “very often” by at least eight of the mothers at any time) included busying themselves with other things, looking at options, praying, trying to figure out what to do, and trying to relax. These five strategies were used by at least two-thirds of the spouses/partners throughout the monitoring experience. Additionally, several coping strategies were used by at least two-thirds of the spouses/partners at various times during the monitoring experience. Five strategies, talking with someone about his feelings, getting away for a while, exercising, asking for help, and trying to change things, were used only in the initial phase of monitoring. Five strategies were utilized frequently



Table 10

Frequency Distribution of Mothers' Perceptions of Their Spouses'/Partners' Coping at  
Three Measurement Points

Spouses'/Partners' Coping Strategies	Do Not Do This			Very Rarely			Sometimes or Very Often		
	I	M	T	I	M	T	I	M	T
1. Cry	9	11	11	4	1	0	0	0	0
2. Busy self with other things	1	0	3	1	4	0	11	8	8
3. Talk with someone about feelings	0	2	0	3	3	4	10	7	7
4. Ignore/try to forget	8	6	5	0	2	1	5	4	5
5. Look at options	1	3	2	3	1	0	9	8	9
6. Get away for a while	3	3	4	2	4	3	8	5	4
7. Hide feelings	7	5	4	0	4	1	5	3	5
8. Change expectations	7	6	6	2	4	1	4	2	4
9. Blame someone	8	9	7	5	3	4	0	0	0
10. Yell/scream/slam doors, etc.	9	9	7	3	3	3	1	0	1
11. Exercise	4	6	6	1	3	3	8	3	2
12. Ask for help	1	2	1	4	6	3	8	4	7
13. Take alcohol or medicine	12	11	10	0	1	0	1	0	1
14. Pray	1	1	2	1	2	1	11	9	8
15. Blame self	8	9	6	3	1	1	2	2	4
16. Ask questions	1	2	1	1	1	3	11	9	7
17. Use advice of others	1	1	0	1	5	1	11	6	10
18. Try to figure out what to do	0	2	0	1	2	0	12	8	11
19. Sleep	2	5	3	8	4	5	3	3	3
20. Find help	2	1	2	2	4	1	9	7	8
21. Smoke	9	9	7	2	0	0	2	3	4
22. Try to laugh or joke about it	8	5	8	3	4	0	2	3	3
23. Eat	8	8	8	4	1	2	1	3	1
24. Try to relax	1	0	2	4	2	0	8	10	9
25. Read about the problem	5	5	5	0	1	3	8	6	3
26. Wish problems would go away	7	6	6	3	2	0	3	4	5
27. Weigh choices	3	4	5	2	0	1	8	8	5
28. Get information	1	2	3	3	2	2	9	8	6
29. Try to change things	1	4	3	2	1	3	10	7	5

Key: I = Initial monitoring point (n = 13)  
M = Mid-monitoring point (n = 12)  
T = Termination of monitoring (n = 11)

No. of items left blank = 1  
No. of items left blank = 0  
No. of items left blank = 1

during two of the three monitoring periods. These strategies included asking questions, weighing choices, and getting information which were frequently used during the initial and middle phases of monitoring, and using the advice of others and finding help which were frequently used by spouses/partners in the initial and termination phases of monitoring.

Table 11

Frequency Distribution of Mothers' Perceptions of the Behaviors of Their Other Children at Three Measurement Points

Mothers' Views of Siblings' Behaviors	N/A or Never True			Sometimes True			Always True		
	I	M	T	I	M	T	I	M	T
1. Jealousy	5	2	3	4	8	5	0	0	0
2. Fight with each other	6	7	6	2	3	2	1	0	0
3. Protective of child	2	2	2	3	4	4	4	4	2
4. Anger	8	9	8	1	1	0	0	0	0
5. Worried about child	4	7	4	4	2	3	1	1	1
6. Worried about self	6	8	6	3	2	1	0	0	1
7. Helps with child's therapy	7	10	6	2	0	0	0	0	2
8. Teases	8	7	8	1	3	0	0	0	0

Key: I = Initial monitoring point (n = 9)      No. of items left blank = 0  
M = Mid-monitoring point (n = 10)      No. of items left blank = 0  
T = Termination of monitoring (n = 8)      No. of items left blank = 0

Trends in Siblings' Behaviors at Three Measurement Points

As reflected in Table 11, of the eight behaviors of the siblings as perceived by the mothers using the PPI-Sibling Behavior subscale, no behaviors were exhibited most frequently by the siblings (ranked as "always true" by at least six of the mothers at any phase of monitoring). Of the behaviors demonstrated by the siblings on occasion (ranked as "sometimes true" by at least 6 of the mothers at any phase of monitoring), the mothers

of eight infants observed their other children exhibiting “jealousy” during the mid-monitoring phase.

Behaviors never demonstrated by the siblings (ranked as “not applicable” or “never true” by at least six of the mothers at any phase in the monitoring experience) included “fighting with each other”, “anger”, “worried about self”, “helps with child’s therapy”, and “teases”. At least two-thirds of the mothers indicated that their other children never demonstrated these behaviors at any of the three phases of home apnea monitoring. Additionally, seven of the mothers indicated that their other children never exhibited concern for the monitored infant during the middle of monitoring.

#### Trends in Mothers’ Perceptions of Family Functioning at Three Measurement Points

As reflected in Table 12, the mothers’ perceptions of family functioning using the discrepancy score on the FFFS varied as monitoring progressed. In reviewing the frequencies for various items, no discrepancies in expected and perceived family functioning were cited by at least two-thirds of the mothers through all three phases of home apnea monitoring. Two items were cited by at least two-thirds of the mothers during one or more phase of monitoring. These items included “time spent with spouse/partner” which was cited by eight mothers as problematic during the initial monitoring phase, and “time spent in leisure/recreational activities” which was cited by ten mothers as problematic initially, by eight mothers at the mid-monitoring phase, and by five mothers by the end of monitoring.

Of the mean discrepancy scores, no items were noted by the mothers to have the greatest discrepancy (calculated as 3.0 or greater by at least two mothers) across all

monitoring phases. Items with the greatest discrepancy initially included “time spent on housework” and “time you miss from work”. No items had the greatest discrepancy at the mid-monitoring point. At the termination of monitoring, “time with health professionals”,

Table 12

Mothers' Perceptions of Family Functioning Discrepancy During Home Apnea Monitoring

Family Functioning Discrepancy Items	Initial f Mean Range			Middle f Mean Range			Termination f Mean Range		
1. Discussion w/ friends	3	1.33	1-2	4	1.0	1	1	1.0	1
2. Discussion w/ relatives	3	2.0	1-3	5	1.4	1-2	3	1.67	1-2
3. Time spent w/ spouse	8	2.13	1-3	5	2.6	1-3	5	2.4	2-3
4. Discussion w/ spouse	6	2.0	1-3	4	2.5	1-3	5	2.2	1-4
5. Time spent w/ neighbors	7	1.86	1-3	6	2.17	1-4	3	2.33	2-3
6. Time spent leisure/recreation	10	2.3	1-5	8	2.25	1-3	5	2.6	2-3
7. Help from spouse w/chores	5	2.2	1-4	6	2.67	1-5	5	2.6	1-4
8. Help from relatives w/chores	6	2.33	1-3	4	2.0	1	5	1.8	1-3
9. Time w/ health professionals	2	2.0	1-3	0			2	4.0	2-6
10. Help from friends w/ chores	1	1.0	1	2	1.0	1	1	1.0	1
11. Problems w/ child(ren)	4	1.33	1-3	4	2.0	1-4	3	1.33	1-2
12. Time spent w/ child(ren)	4	1.75	1-2	4	1.25	1-2	5	1.4	1-2
13. Time child(ren) miss school	1	1.0	1	1	2.0	2	1	3.0	3
14. Disagreements w/ spouse	6	1.83	1-2	7	1.57	1-3	3	1.67	1-3
15. Time you are ill	6	1.33	1-3	3	1.33	1-2	4	1.0	1
16. Time you spend on housework	5	3.0	1-5	5	2.2	1-5	2	2.5	2-3
17. Time you miss work	3	3.33	3-4	4	2.0	2	2	3.5	2-5
18. Time spouse misses work	1	1.0	1	2	1.0	1	2	1.5	1-2
19. Emotional support from friends	4	1.25	1-2	3	1.33	1-2	0		
20. Emotional support from relative	5	1.6	1-3	5	1.0	1	2	1.5	1-2
21. Emotional support from spouse	5	2.5	3-5	1	1.0	1	4	1.75	1-4
22. Time your routines disrupted	7	2.71	1-5	6	1.67	1-2	5	2.8	2-4
23. Time spouse's work disrupted	6	1.5	1-3	3	1.33	1-2	2	3.0	2-4
24. Satisfaction w/ your marriage	3	2.0	2	4	1.75	1-3	4	2.0	2
25. Satisfaction w/ sexual relations	4	1.5	1-2	3	2.67	2-4	2	2.5	1-4

Key: I = Initial monitoring point (n = 13)

M = Mid-monitoring point (n = 12)

T = Termination of monitoring (n = 11)

No. of items left blank = 24

No. of items left blank = 13

No. of items left blank = 6

“time you miss from work”, and “time spouse’s routine disrupted” had the greatest discrepancy in family functioning.

One item, “time child(ren) miss from school”, was listed least frequently (cited by none or only one of the mothers) throughout the three phases of monitoring. Initially, “time spouse misses from work” was listed least frequently. By the middle of monitoring, “time with health professionals” and “emotional support from spouse” were chosen the least frequently. By the termination of monitoring, “discussion with friends” and “emotional support from friends” were chosen the least frequently.

Table 13

Mothers’ Perceptions of the Severity of Their Infants’ Illnesses at Three Measurement Points

<b>Indicators of Severity of Illness</b>	<b>Initial (n=13) Mean (SD) Range</b>	<b>Maintenance (n=12) Mean (SD) Range</b>	<b>Termination (n=11) Mean (SD) Range</b>
1. Total number of monitor alarms	18.83 (17.2) 1 to 56	51.33 (67.8) 0 to 180	5.33 (10.6) 0 to 31
2. Number of alarms for apnea or low heartbeat	2.54 (2.0) 0 to 6	11.17 (21.2) 0 to 60	0
	<b>f (n=13)</b>	<b>f (n=12)</b>	<b>f (n=12)</b>
3. Infants experiencing true alarms	10	7	0
4. Stimulation required by infants in #3	Simple touch	Simple touch	N/A
5. Infants experiencing other problems	5	9	9
6. Other health problems			
- to doctor/clinic for sickness	4	7	11
- needed ambulance/EMS help	0	0	0
- admitted to hospital	1	2	0
- fever/cold/diarrhea	4	10	13
- seizure(s)	0	0	0
- loss of weight/irregular weight gain	0	1	0
- difficulty feeding	0	0	0
- referred for developmental followup	0	1	0

Trends in Infants’ Severity of Illness at Three Measurement Points

As evidenced in Table 13, the mean total number of alarms increased from the initial monitoring point of 18.83 to the middle monitoring point mean of 51.33 and then

decreased by the termination of monitoring to 5.33. The number of alarms which were true alarms followed the same pattern as monitoring progressed, with a mean of 2.54 initially, increasing to 11.17 by the middle monitoring point, and ending with no true alarms at the termination of monitoring. The amount of stimulation required for the true alarms was “simple touch only” throughout the monitoring experience.

As monitoring progressed, the mothers reported that their infants confronted other health problems. The most frequently encountered health problems included visits to the doctor or clinic for sickness and experiencing a fever/cold/or diarrhea. Both of these health problems were noted by only a third of the mothers initially, but became of increasing concern as monitoring progressed, so that by the termination of monitoring almost all of the infants had encountered these two health problems.

#### Correlations Between Study Variables at Three Measurement Points

As noted earlier, correlation analysis was performed on all independent and dependent variables included in the study. Pearson’s product-moment correlation coefficients for the variables at each of the measurement points are presented in Tables 14 through 16.

The correlation coefficients for the variables measured at the initial monitoring point are presented in Table 14. Statistically significant positive correlations were found between the mothers’ concerns and their coping strategies, between the mothers’ concerns and their perceptions of family functioning, between the mothers’ concerns and their spouse/partners’ concerns, and between the mothers’ coping strategies and their perceptions of family functioning when monitoring was initiated. A statistically significant negative correlation was obtained between the spouse/partners’ coping strategies as

perceived by the mothers, and the behaviors demonstrated by the infants' siblings at the initial monitoring point. No other statistically significant findings between the variables were obtained at the initial monitoring period.

Table 14

Correlations Among Variables at the Initiation of Monitoring

Variables	n	Correlation Coefficient	p-value
Concerns-1 & Coping-1	13	0.6456*	.0172
Concerns-1 & FFFS-1	13	0.5776*	.0387
Concerns-1 & Severity of Illness-1	13	-0.0617	.8412
Concerns-1 & Spouse Concerns-1	13	0.8432*	.0003
Concerns-1 & Spouse Coping-1	13	0.1563	.6100
Concerns-1 & Sibling Behavior-1	9	0.0793	.8392
Coping-1 & FFFS-1	13	0.8117*	.0008
Coping-1 & Severity-1	13	-0.3919	.1854
Coping-1 & Spouse Concerns-1	13	0.5058	.0778
Coping-1 & Spouse Coping-1	13	0.1563	.6100
Coping-1 & Sibling Behavior-1	9	0.0793	.8392
FFFS-1 & Severity-1	13	-0.0023	.9940
FFFS-1 & Spouse Concerns-1	13	0.3651	.2199
FFFS-1 & Spouse Coping-1	13	0.2053	.5011
FFFS-1 & Sibling Behavior-1	9	-0.4644	.2079
Severity-1 & Spouse Concerns-1	13	-0.3533	.2363
Severity-1 & Spouse Coping-1	13	-0.5356	.0592
Severity-1 & Sibling Behavior-1	9	0.6330	.0673
Spouse Concerns-1 & Spouse Coping 1	13	0.4167	.1566
Spouse Concerns-1 & Sibling Behavior-1	9	-0.2847	.4578
Spouse Coping-1 & Sibling Behavior-1	9	-0.8070*	.0086

\* $p < .05$ .

The correlation coefficients for the variables measured at the maintenance monitoring point are presented in Table 15. Statistically significant positive correlations were found between the mothers' concerns and coping strategies, between the mothers' concerns and their spouse/partners' concerns, between the mothers' coping strategies and their perceptions of their spouse/partners' concerns, between the mothers' coping

strategies and their perceptions of their spouse/partners' coping strategies, and between their perceptions of their spouse/partners' concerns and their perceptions of their spouse/partners' coping strategies midway through monitoring. A statistically significant negative correlation was obtained between the infants' severity of illness and the behaviors demonstrated by the infants' siblings at the middle monitoring point. No other statistically significant findings between the variables were obtained at the maintenance of monitoring period.

Table 15

Correlations Among Variables at the Middle of Monitoring

Variables	n	Correlation Coefficient	p-value
Concerns-2 & Coping-2	12	0.7486*	.0051
Concerns-2 & FFFS-2	12	0.1944	.5449
Concerns-2 & Severity of Illness-2	12	-0.0224	.9450
Concerns-2 & Spouse Concerns-2	12	0.8748*	.0002
Concerns-2 & Spouse Coping-2	12	0.4901	.1058
Concerns-2 & Sibling Behavior-2	10	0.3839	.2734
Coping-2 & FFFS-2	12	0.2490	.4352
Coping-2 & Severity-2	12	0.1510	.6395
Coping-2 & Spouse Concerns-2	12	0.7098*	.0097
Coping-2 & Spouse Coping-2	12	0.6305*	.0280
Coping-2 & Sibling Behavior-2	10	0.0766	.8334
FFFS-2 & Severity-2	12	-0.0188	.9536
FFFS-2 & Spouse Concerns-2	12	0.3394	.2804
FFFS-2 & Spouse Coping-2	12	-0.1430	.6576
FFFS-2 & Sibling Behavior-2	10	0.2982	.4026
Severity-2 & Spouse Concerns-2	12	-0.0412	.8987
Severity-2 & Spouse Coping-2	12	0.4851	.1099
Severity-2 & Sibling Behavior-2	10	-0.8952*	.0005
Spouse Concerns-2 & Spouse Coping 2	12	0.6059*	.0368
Spouse Concerns-2 & Sibling Behavior-2	10	0.4099	.2395
Spouse Coping-2 & Sibling Behavior-2	10	-0.4142	.2341

\*p < .05.



The correlation coefficients for the variables measured at the termination of monitoring are presented in Table 16. A statistically significant positive correlation was found between the mothers' concerns and their spouse/partners' concerns when

Table 16

Correlations Among Variables at the Termination of Monitoring

Variables	n	Correlation Coefficient	p-value
Concerns-3 & Coping-3	11	0.3626	.2732
Concerns-3 & FFFS-3	11	0.4502	.1647
Concerns-3 & Severity of Illness-3	11	-0.0155	.9639
Concerns-3 & Spouse Concerns-3	11	0.9358*	.0000
Concerns-3 & Spouse Coping-3	11	0.3987	.2245
Concerns-3 & Sibling Behavior-3	8	0.0358	.9329
Coping-3 & FFFS-3	11	0.3818	.2466
Coping-3 & Severity-3	11	0.3730	.2585
Coping-3 & Spouse Concerns-3	11	0.3272	.3260
Coping-3 & Spouse Coping-3	11	0.3987	.2247
Coping-3 & Sibling Behavior-3	8	0.0358	.9329
FFFS-3 & Severity-3	11	0.0937	.7840
FFFS-3 & Spouse Concerns-3	11	0.4134	.2063
FFFS-3 & Spouse Coping-3	11	0.2706	.4209
FFFS-3 & Sibling Behavior-3	8	-0.0452	.9154
Severity-3 & Spouse Concerns-3	11	-0.0132	.9693
Severity-3 & Spouse Coping-3	11	0.5105	.1086
Severity-3 & Sibling Behavior-3	8	-0.7111*	.0480
Spouse Concerns-3 & Spouse Coping 3	11	0.4183	.2004
Spouse Concerns-3 & Sibling Behavior-3	8	-0.2163	.6068
Spouse Coping-3 & Sibling Behavior-3	8	-0.4199	.3003

\*p < .05.

monitoring was terminated. A statistically significant negative correlation was obtained between the mothers' perception of the severity of their infants' illness, and the behaviors demonstrated by the infants' siblings when monitoring was terminated. No other statistically significant findings were obtained at the termination of monitoring.

### Mothers' Ratings of Infant Temperament

Infant temperament was determined via the EITQ, with the mothers providing general impressions of their infants' temperaments as well as rating each of 76 behaviors indicating different characteristics of temperament. The participants completed the EITQ (Table 17) at the mid-monitoring period, when the average age of their infants was 3.5 months old, corrected for prematurity.

Table 17

### Mothers' Ratings of Infant Temperament

	Temperament Scores Mean (SD)	Interpretation of Temperament Scores	Mothers' General Impressions
Overall Temperament		Intermediate/Low	Easy
-Activity	3.76 (.82)	slightly < mean	high
-Rhythmicity	3.12 (.89)	slightly > mean	arrhythmic
-Approach	3.25 (.62)	slightly > mean	variable
-Adaptability	2.47 (.42)	slightly > mean	variable
-Intensity	3.67 (.79)	slightly < mean	generally mild
-Mood	2.55 (.52)	slightly < mean	pleasant
-Persistence	2.16 (.57)	1 SD < mean	persistent
-Distractibility	2.35 (.41)	slightly < mean	easy to soothe
-Threshold	4.51 (.40)	slightly > mean	variable

### Correlations Between Infant Temperament Categories and Characteristics

Correlation analysis was performed on the mothers' general overall impression ratings and the total EITQ scores of their infants and was performed on the nine subcategories of temperament identified on the instrument. The correlation coefficient of -0.0373 between the mothers' general overall impression ratings and total questionnaire scores was not statistically significant. Statistically significant results were obtained between the activity and rhythmicity subscales, the rhythmicity and approach subscales,

Table 18

Correlations Between Subcategories of Temperament

Temperament Categories	Correlation Coefficient	p-value
Activity & Rhythmicity	0.6461*	.0170
Activity & Approach	-0.3604	.2264
Activity & Adaptability	-0.0631	.8379
Activity & Intensity	-0.0242	.9373
Activity & Mood	0.0255	.9342
Activity & Persistence	0.4351	.1373
Activity & Distractibility	0.2398	.4301
Activity & Threshold	0.3756	.2060
Rhythmicity & Approach	-0.5884*	.0344
Rhythmicity & Adaptability	0.1745	.5685
Rhythmicity & Intensity	0.0031	.9920
Rhythmicity & Mood	0.4056	.1691
Rhythmicity & Persistence	0.4780	.0985
Rhythmicity & Distractibility	0.6731*	.0117
Rhythmicity & Threshold	0.0713	.8171
Approach & Adaptability	0.1502	.6243
Approach & Intensity	0.1649	.5903
Approach & Mood	0.2072	.4970
Approach & Persistence	-0.6692*	.0124
Approach & Distractibility	-0.2581	.3945
Approach & Threshold	0.4111	.1629
Adaptability & Intensity	0.1838	.5477
Adaptability & Mood	0.6003*	.0301
Adaptability & Persistence	-0.4681	.1067
Adaptability & Distraction	0.1816	.5526
Adaptability & Threshold	-0.0146	.9622
Intensity & Mood	0.1108	.7186
Intensity & Persistence	-0.5819*	.0370
Intensity & Distractibility	-0.3210	.2849
Intensity & Threshold	0.3829	.1965
Mood & Persistence	-0.1507	.6232
Mood & Distractibility	0.4772	.0992
Mood & Threshold	0.0782	.7994
Persistence & Distractibility	0.3769	.2043
Persistence & Threshold	-0.3743	.2076
Distractibility & Threshold	0.0184	.9524

\* $p < .05$ .

adaptability and mood subscales, persistence and approach subscales, persistence and intensity subscales, and rhythmicity and distractibility subscales of the EITQ (Table 18).

#### Correlations Between Infant Temperament and Other Study Variables

Correlation analysis was performed on the independent variable of infant temperament as measured on the EITQ and the other variables included in the study. The analysis was conducted twice, once using the temperament scores calculated on the EITQ and once using the general temperament categories which the mothers had listed. Pearson's product-moment correlation coefficients for the variables at each of the three measurement points are presented in Tables 19 through 21.

Table 19

#### Correlations Between Temperament and Variables at the Initiation of Monitoring

Variables	n	Correlation Coefficient	p-value
Temperament Score & Concerns-1	13	0.2828	.3492
Temperament Score & Coping-1	13	0.1487	.6278
Temperament Score & FFFS-1	13	0.2329	.4439
Temperament Score & Severity Illness-1	13	0.2442	.4443
Temperament Score & Spouse Concerns-1	13	0.1286	.6755
Temperament Score & Spouse Coping-1	13	-0.4878	.0908
Temperament Score & Sibling Behavior-1	9	-0.4217	.2582
Temperament Group & Concerns-1	13	-0.2657	.3802
Temperament Group & Coping-1	13	-0.3601	.2268
Temperament Group & FFFS-1	13	-0.4745	.1014
Temperament Group & Severity Illness-1	13	0.1162	.7053
Temperament Group & Spouse Concern-1	13	-0.3123	.2989
Temperament Group & Spouse Coping-1	13	-0.4049	.1699
Temperament Group & Sibling Behavior-1	9	0.5325	.1399

\* $p < .05$ .

The correlation coefficients for both measures of the independent variable of infant temperament and the variables measured at the initiation of monitoring are presented in

Table 19. No statistically significant findings were obtained at the initial phase of home apnea monitoring.

Table 20

Correlations Between Temperament and Variables at the Middle of Monitoring

Variables	n	Correlation Coefficient	p-value
Temperament Score & Concerns-2	12	0.4048	.1917
Temperament Score & Coping-2	12	0.1758	.5848
Temperament Score & FFFS-2	12	0.3649	.2435
Temperament Score & Severity Illness-2	12	0.2442	.4443
Temperament Score & Spouse Concerns-2	12	0.4843	.1106
Temperament Score & Spouse Coping-2	12	0.2506	.4320
Temperament Score & Sibling Behavior-2	10	-0.0116	.9745
Temperament Group & Concerns-2	12	0.0035	.9913
Temperament Group & Coping-2	12	-0.3679	.2394
Temperament Group & FFFS-2	12	-0.1599	.6196
Temperament Group & Severity Illness-2	12	-0.3399	.2797
Temperament Group & Spouse Concern-2	12	-0.1574	.6251
Temperament Group & Spouse Coping-2	12	-0.2588	.4166
Temperament Group & Sibling Behavior-2	10	0.4270	.2184

\* $p < .05$ .

The correlation coefficients for both measures of the independent variable of infant temperament and the variables measured midway through the home apnea monitoring experience are presented in Table 20. No statistically significant findings were obtained at the maintenance phase of home apnea monitoring.

The correlation coefficients for both measures of the independent variable of infant temperament and the variables measured at the termination of monitoring are presented in Table 21. Statistically significant negative correlations were obtained between the mothers' general impression category scores on the EITQ and the mothers' coping strategies along with the mothers' general impression category scores and their

spouse/partners' coping strategies as perceived by the mothers. No other statistically significant findings were obtained at the final phase of home apnea monitoring.

Table 21

Correlations Between Temperament and Variables at the Termination of Monitoring

Variables	n	Correlation Coefficient	p-value
Temperament Score & Concerns-3	11	.3460	.2973
Temperament Score & Coping-3	11	-.3622	.2736
Temperament Score & FFFS-3	11	.0978	.7748
Temperament Score & Severity Illness-3	11	.2165	.5226
Temperament Score & Spouse Concerns-3	11	.3005	.3693
Temperament Score & Spouse Coping-3	11	-.2507	.4572
Temperament Score & Sibling Behavior-3	8	-.2680	.5210
Temperament Group & Concerns-3	11	-.4259	.1915
Temperament Group & Coping-3	11	-.6776*	.0220
Temperament Group & FFFS-3	11	-.0844	.8050
Temperament Group & Severity Illness-3	11	-.3688	.2643
Temperament Group & Spouse Concern-3	11	-.3107	.3524
Temperament Group & Spouse Coping-3	11	-.7396*	.0093
Temperament Group & Sibling Behavior-3	8	-.0461	.9136

\*p < .05.

Specific Analyses by Research Questions

All analyses were conducted using a two-tailed .05 level of significance.

Parametric analyses were employed since the PPI, FFFS, MF, and EITQ yielded interval data. Repeated measures analyses of variance (ANOVA) were computed on the dependent variables (concerns, coping strategies, and family functioning). Pearson product-moment correlation coefficients (Pearson r) were computed on the independent variables (severity of illness, infant temperament) and the dependent variables (concerns, coping strategies, and family functioning) included in the study.

1. How do mothers' perceptions of the concerns of individual family members change as they progress through the three phases of home apnea monitoring? As reported in Table 6, the mean concerns score for mothers at the initial monitoring point was 56.7 with a range of 25 to 85, while the mean concerns score at the mid-monitoring point was 44.8 with a range of 14 to 77, and the mothers' mean concerns score for the termination of monitoring point was 38.2 with a range of 8 to 71. Also, the mean concerns score for the spouses/partners at the initial monitoring point was 46.5 with a range of 6 to 78, while the mean concerns score at the mid-monitoring point was 42.3 with a range of 7 to 72, and the mothers' mean concerns score for their spouse/partners for the termination of monitoring point was 34.5 with a range of 00 to 61.

Repeated measures ANOVAs were computed on the scores on the concerns subscales of the PPI to address this question (Table 22). The F-value of 2.2147 for the mothers' concerns, and the F-value of .9923 for the spouse/partners' concerns as perceived by the mothers were not statistically significant.

Table 22

Analyses of Variance for Concerns

<i>Source of Variation</i>	SS	df	MS	F	p
<b>Concerns</b>					
Time	2314.68	2	1157.34	2.2147	.1252
Error	17245	33	522.435		
<b>Spouse Concerns</b>					
Time	870.348	2	435.174	.9923	.3815
Error	14472.6	33	438.564		

2. How do mothers' perceptions of coping strategies of individual family members change as they progress through the three phases of home apnea monitoring? As reported in Table 6, the mean coping scores for mothers at the initial monitoring point was

37.4 with a range of 9 to 59, while the mean coping score at the mid-monitoring point was 31.8 with a range of 7 to 54, and the mothers' mean coping score for the termination of monitoring point was 33.1 with a range of 12 to 55. Also, the mean coping score for the spouses/partners at the initial monitoring point was 37.0 with a range of 18 to 59, while the mean coping score at the mid-monitoring point was 31.8 with a range of 7 to 42, and the mean coping score for the spouses/partners for the termination of monitoring point was 32.7 with a range of 21 to 50. Additionally, the mean coping score for the siblings at the initial monitoring point was 15.1 with a range of 8 to 20, while the mean coping score for the mid-monitoring point was 4.4 with a range of 8.0 to 20, and the mean siblings score for the termination of monitoring point 14.6 with a range of 8 to 21.

Table 23

Analyses of Variance for Coping

<i>Source of Variation</i>	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>
<b>Coping</b>					
Time	115.403	2	57.7014	.319332	.7289
Error	5962.9	33	180.694		
<b>Spouse Coping</b>					
Time	191.124	2	95.56	.880423	.4241
Error	3581.85	33	108.541		
<b>Sibling Behavior</b>					
Time	2.46574	2	1.23287	.06201	.9400
Error	477.164	33	19.8818		

Repeated measures ANOVAs were computed on the scores on the coping subscales of the PPI to address this question (Table 23). The F-value of .3193 for the mothers' coping strategies, the F-value of .8804 for the spouse/partners' coping strategies as perceived by the mothers, and the F-value of .06201 for the siblings' behaviors were not statistically significant.



3. How do mothers' perceptions of the discrepancy between expected and perceived family functioning change as they progress through the three phases of home apnea monitoring? As reported in Table 6, the mean family functioning discrepancy scores for mothers at the initial monitoring point was 17.2 with a range of 00 to 42, while the mean score at the mid-monitoring point was 15.2 with a range of 00 to 38, and the mean family functioning discrepancy score for the termination of monitoring point was 14.6364 with a range of 0 to 44.

A repeated measures ANOVA was computed on the scores on the discrepancy scores of the FFFS to address this question (Table 24). The F-value of .158767 for the family functioning discrepancy scores as perceived by the mothers was not statistically significant.

Table 24

Analysis of Variance for Family Functioning Discrepancy

<i>Source of Variation</i>	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>
<b>Family Functioning</b>					
Time	46.2302	2	23.11512	.158767	.8530
Error	4804.52	33	145.592		

4. What is the relationship between the concerns of family members as perceived by the mothers and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring? Pearson  $r$ 's were computed between the mothers' scores on the concerns subscales of the PPI and their discrepancy scores on the FFFS at each of the three monitoring periods (Tables 14 through 16). The correlation between the mothers' concerns and the mothers' family functioning discrepancy score at the initial monitoring period was statistically

significant, with a correlation of 0.58 at a significance level of .0387. No other correlations between concerns subscales and the discrepancy scores on the FFFS were statistically significant.

5. What is the relationship between the coping strategies of family members as perceived by the mothers and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring?

Pearson  $r$ 's were computed between the mothers' scores on the coping subscales of the PPI and their discrepancy scores on the FFFS at each of the three monitoring periods (Tables 14 through 16). The correlation between the mothers' coping strategies and the mothers' family functioning discrepancy scores at the initial monitoring period was statistically significant, with a correlation of 0.81 at a significance level of .0008. No other correlations between coping subscales and the discrepancy scores on the FFFS were statistically significant.

6. What is the relationship between mothers' perceptions of infant temperament and the concerns of family members as perceived by the mothers during the home apnea monitoring experience? Pearson  $r$ 's were computed between the mothers' temperament ratings on the EITQ and the concerns subscales on the PPI to address this question (Tables 19 through 21). The analyses were conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers' EITQ scores. No statistically significant correlations between concerns subscales on the PPI and infant temperament groups on the EITQ were obtained.

7. What is the relationship between mothers' perceptions of infant temperament and the coping strategies of family members as perceived by the mothers during the home apnea monitoring experience? Pearson  $r$ 's were computed between the mothers' temperament ratings on the EITQ and the coping subscales on the PPI to address this question (Tables 19 through 21). The analyses were conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers' EITQ scores. Statistically significant negative correlations were obtained between the temperament groups according to the mothers' general impressions of their infants and the mothers' coping strategies at the termination of monitoring ( $-0.6776$ ), as well as the mothers' general impressions of their infants' temperament and the spouse/partners' coping strategies as perceived by the mothers ( $-0.7396$ ) at the termination of monitoring. No other statistically significant correlations were obtained.

8. What is the relationship between mothers' perceptions of infant temperament and the discrepancy between expected and perceived family functioning during the home apnea monitoring experience? Pearson  $r$ 's were computed between the mothers' temperament ratings on the EITQ and the discrepancy scores on the FFFS to address this question (Tables 19 through 21). The analyses were conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers' EITQ scores. No statistically significant correlations were obtained.

9. What is the relationship between mothers' ratings of the infants' severity of illness and the concerns of family members as perceived by the mothers as families

progress through the three phases of home apnea monitoring? Pearson product-moment correlation coefficients (Pearson  $r$ ) were computed between the mothers' ratings of severity of illness on the MF and their scores on the concerns subscales of the PPI at each of the three monitoring periods (Tables 14 through 16). No statistically significant correlations were obtained.

10. What is the relationship between mothers' ratings of the infants' severity of illness and the coping strategies of family members as perceived by the mothers as families progress through the phases of home apnea monitoring? Pearson  $r$ 's were computed between the mothers' ratings of severity of illness on the MF and their scores on the coping subscales of the PPI at each of the three monitoring periods (Tables 14 through 16). The negative correlation of -0.8952 between the infant's severity of illness and the sibling behavior at the mid-monitoring period was statistically significant at the .0005 level, as was the negative correlation of -0.7111 between the severity of illness and the sibling behavior at the termination of monitoring period. No other correlations between severity of illness and coping strategies of various family members were statistically significant.

11. What is the relationship between mothers' ratings of the infants' severity of illness and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring? Pearson  $r$ 's were computed between the mothers' ratings of severity of illness on the MF and their discrepancy scores on the FFFS at each of the three monitoring periods (Tables 14 through 16). No correlations were statistically significant.

12. What is the relationship between mothers' perceptions of infant temperament and the infants' severity of illness during the home apnea monitoring experience? Pearson  $r$ 's were computed between the mothers' temperament ratings on the EITQ and the severity of illness ratings on the MF to address this question (Tables 19 through 21). The analyses were conducted twice, once using the temperament groups based on the mothers' general impressions of their infants and again using the temperament groups based on the mothers' EITQ scores. No correlations were statistically significant.

#### Summary

In summary, a longitudinal study with event partitioning was undertaken to obtain information from mothers of 13 infants on home apnea monitoring regarding the impact on themselves, on other family members, and on the family as a whole. The sample was described, necessary calculations performed, and the research questions analyzed using a .05 level of significance. Statistically significant findings were obtained for parts of four out of the twelve research questions.

## CHAPTER V

### Discussion and Implications

The Neuman Systems Model, adapted for home apnea monitoring, was used as the conceptual basis for this longitudinal study with event partitioning. The study was conducted to investigate the concerns and responses of families to having an infant on a home apnea monitor, including the impact on individual family members as well as on the functioning of the family as a unit. Information from 13 mothers of infants on home apnea monitors was gathered concerning the impact on themselves, on other family members, and on the family as a whole. The results and findings of this investigation are presented in Chapter Four. Chapter Five discusses the implications of the study findings, the limitations of the study, and recommendations for use of the study findings and for further research into the effects of having an infant on a home apnea monitor.

#### Discussion of the Methodology

##### Design

A longitudinal design with event partitioning was used in this study so that the effects of home apnea monitoring could be explored over time. The study is broader than most previous studies of home apnea monitoring in that it explores the impact of the stressor not only on the infants' mothers but also on the mothers' spouses/partners and on the infants' siblings. However, all information was gathered from the mothers' perceptions of the impact of the stressor on the various family members.

Recruitment of a sufficient sample of mothers into the study was problematic. Mothers from two different sites were recruited into the study. Since the researcher was not employed by these sites, the recruitment protocol required the staffs of the respective agencies to make the initial contact with potential study participants using a letter from the researcher. Therefore, the researcher had no face-to-face contact with the study participants until the initial home visit. Additionally, each agency required prospective participants to sign a release before the researcher could be given their names and addresses. This signature may have intimidated several prospective study participants. (Of the 28 eligible mothers at one study site, 82% refused to grant the hospital staff permission to release their names and addresses to the researcher.)

If a similar recruitment scheme is employed in the future, several strategies are suggested to increase study response. First, a short videotape of the researcher explaining the study purpose and personally requesting the mothers' participation may increase the mothers' willingness to participate, i.e. the researcher may be viewed as a real person. If this study is replicated, providing the informational letter from the researcher or the videotape to the mothers earlier in their infants' hospitalization, possibly when the sleep studies were first ordered rather than waiting and including it with the infants' discharge teaching, also might increase the percentage of mothers consenting to participate.

Although all mothers completed the questionnaires, as the study progressed follow-up with telephone calls became necessary. Additionally, duplicate copies of the questionnaires were sent to some mothers. By the third measurement point, the average time between the third visit and receipt of completed questionnaires was 3.5 weeks. Additionally, only four of the mothers returned the postcards which were used to notify

the researcher that their infants were off the monitor. Therefore, the researcher was not aware of the status of monitoring until mothers were telephoned to inquire about their infants. These events resulted in the average length of time on/off the monitor at the various measuring points being longer than originally planned. To avoid these problems in future studies, scheduled monthly interactions via letters and/or phone calls by the researcher may be beneficial in maintaining timely contact between the mothers and the researcher.

### Sample Characteristics

The sample consisted of a convenience sample of mothers of 13 infants on home apnea monitors. To control for extraneous variance in the study, several groups of mothers were eliminated from the sample. For example, mothers from families with previous monitoring experience, with another child with a serious or chronic illness, or with a previous SIDS death were excluded because their responses to the stressor of home apnea monitoring may differ from those of mothers from families experiencing home monitoring and/or serious illness of a child for the first time. Elimination of these mothers (43% of the mothers at one site) from the sample significantly limited the available pool of study participants. Inclusion of these mothers in the study by comparing their responses to those of new-to-monitoring families may have yielded useful data and increased the sample size.

The small sample size in this study limits the generalizability of the study findings. Additionally, the small sample size may have resulted in a Type II error, where the null hypothesis is not rejected, yet is untrue (Glass & Hopkins, 1996).



Since the sample was from either of two geographic locations in South Carolina, the lifestyle of the subjects may have been different from other parts of the United States, with less isolation related to weather. The restriction to one geographic location may limit the applicability of the study findings to additional populations.

The infants in the sample were primarily white, from families with non-employed mothers, and with an estimated gestational age of 33.7 weeks. Medoff-Cooper and colleagues (1993) standardized the Early Infant Temperament Questionnaire (EITQ) (Appendix G) with 404 primarily full-term infants from working and middle class families. The interpretation of the infants' temperament ratings obtained with the EITQ with the sample in the current study, therefore, may not be accurate when interpreted using standardizations based on a sample with different characteristics.

#### Instrumentation

Several issues related to the instruments utilized in this study need to be addressed. The EITQ (Appendix F) contains 76 items scored to determine the nine temperament characteristics of each infant. These characteristics were then used to determine the infant's overall temperament category. The mothers also provided their general impressions of their infants' temperaments. The EITQ was administered approximately midway through the home apnea monitoring experience. The mean age of the infants was 3.5 months, corrected for prematurity. The mothers' ratings of their infants' temperaments may have been influenced by the length of the EITQ and by the relatively early timing of its administration, since other temperament measures are not administered until later in the infant's first year of life. Also, the mothers' general overall impression ratings of "easy" or "average" were negatively correlated (-0.0373) with the total scores

of “intermediate” (10 of the 13 infants) on the EITQ. The mothers’ positive ratings may have reflected their need to view their infants as getting better whereas the scores on the EITQ were more objective measures. The lack of statistical significance may reflect the mothers’ acceptance of the disruptions caused by the stressor of home apnea monitoring, resulting in more positive temperament ratings for their infants.

A reading level of grade 6.4 for the Parent Perception Inventory (PPI) (Appendix D) and of high school level for the Feetham Family Functioning Survey (FFFS) (Appendix E) are reported in the literature. Although all except one of the study participants indicated that they were high school graduates, the mothers’ scoring of the instruments may have been influenced by the necessity of high reading levels. Additionally, the PPI and FFFS take between 45 and 60 minutes to complete. Because they were administered at each of the three measurement points, the reading levels and length of the two instruments may have influenced the mothers’ responses to the instruments..

Because the FFFS (Appendix E) utilizes the Porter format (Porter, 1962) study participants were asked to determine three ratings for each question - how much of the indicated characteristic is present, how much of the indicated characteristic should be there, and how important that characteristic is to the respondent. This complicated marking scheme may have influenced the mothers’ scores so that the results may not be an accurate reflection of the mothers’ perceptions of the family units’ responses to the stressor of home apnea monitoring. Future studies may benefit from focus groups of similar subjects to assess whether or not the Porter format is problematic to the sample.

When using the FFFS (Appendix E), the accompanying instructions indicate that the instrument is suitable for both single-parent and two-parent families. The literature

contains reports of the use of the FFFS with both types of families (Mercer & Ferketich, 1990; Sawyer, 1992), although some studies limited participation to two-parent families (Youngblut & Shiao, 1993). However, the FFFS refers to the mother's "spouse" in several of the questions. This wording may have confused the four mothers in this study who were not married. The current study chose to include both single-parent and two-parent families rather than to limit the pool of potential study participants by requiring that the mothers be married. Again, use of focus groups to determine which wording is most effective may be beneficial in future studies.

Because the Monitoring Flowsheet (MF) (Appendix G) is a new instrument developed specifically for this study, no information in the literature on reliability of the instrument is available. The alpha coefficients for the MF of .35 with the first measurement period and .57 with the second measurement period indicate only low to moderate internal consistency reliability for the MF. Since the MF consists of only three items, these findings are not surprising since the coefficient alpha is a function of test length and of sample size (Waltz et al., 1984). Internal consistency reliability of the MF could not be computed for the third measurement period since none of the mothers reported any true alarms (Item #2), thereby reducing the total items on the MF to two. Since reliability of the MF could not be established, validity of the MF is questionable. However, the MF did perform well in the current study, providing objective data on frequency and severity of alarms, and the infant's general degree of wellness which was desired for this study.

Demographic characteristics of the mothers were collected at the onset of the study using the PPI-General Information Form (Appendix D), and the Monitoring

Background Questionnaire (MBQ) (Appendix H). Because the study design was longitudinal, some of the characteristics of the study participants and/or of their families may have changed as the study progressed, i.e. marital status or employment status. Institution of a method for monitoring of changes in the demographics, i.e. resurveying using the same instruments or using a modified version of the instruments, possibly would reduce the mothers' perception of increased discrepancy between expected and actual family functioning as monitoring progressed. Additionally, since the PPI-General Information Form was developed originally for use with families of children with a chronic illness, several of the questions eliciting data regarding the number of hospital admissions the child (infant) had, the length of time since the child's last admission, and the parents' and siblings' health status in the last three months may have misled several of the mothers, as reflected in the wide range of answers to those questions.

There are several questions on the instruments used in this study which the mothers left unanswered. On the PPI-General Information (Appendix D) questionnaire, six of the thirteen mothers omitted the question which asked about time missed from work in the past year in order to take care of the ill child, while the remaining seven mothers indicated that they did not work. This question probably was inappropriate for this study since even the three employed mothers were on maternity leave when they completed the questionnaire at the initial monitoring point. The time frame of one year was not appropriate in the current study since the infants were just beginning the monitoring experience and were not yet one year old.

On the MBQ (Appendix H), none of the infants were on home apnea monitoring because of seizures or needing CPR while hospitalized, because of problems occurring at

home which had not previously occurred during their hospitalizations, or because they were siblings of a SIDS victim. (Mothers from families with a previous SIDS infant were excluded from the current study.) Additionally, ten of the thirteen infants had positive sleep studies but no infant was on home apnea monitoring solely because of a positive sleep study. If the MBQ is used in a future study, careful consideration should be given to whether to retain these indications for home monitoring, especially since the current study is based on a sample size of 13. (The indication concerning being a sibling of a previous SIDS victim could be retained as a reliability check on the exclusion criteria.)

Results on the MBQ indicate that at the onset of the home apnea monitoring experience, two of the thirteen infants were monitored during sleep only, with the remaining eleven infants monitored continuously, regardless of their sleep-wake states. However, by the termination of monitoring, all the infants were on the monitors during sleep only, since a gradual decrease in the monitoring time occurs as part of the weaning process when the home monitor is discontinued. Several of the mothers also reported that the type of electrodes used by the infants changed as the infant became older and as the home monitoring experience progressed. Because the MBQ was only administered at the initial visit, provision for revision of the information would be helpful during the monitoring experience if the MBQ is used in a future study.

Each mother was asked on the MBQ for her infant's estimated gestational age at birth. To score the EITQ, a calculation of the degree of prematurity is necessary. In adjusting the infant's age in this study, 39 weeks was used to indicate full-term, since most authorities define the full-term infant as having a gestational age of 38 weeks to 42 weeks (Castiglia and Harbin, 1992). The scoring and interpretation of the EITQ may be

influenced by which week of gestation is used as the standard in computing adjusted age. Another problem area arising with administration of the EITQ (Appendix F) is the lack of specific directions on interpreting the scores on the nine temperament subcategories once calculated. Information from Carey and McDevitt (1978) regarding interpretation of the RITQ was used to determine overall temperament category. Carey and McDevitt (1978) note that only 10% of the 4 to 8 month olds in their investigations fall into the “difficult” temperament category, while 15% are described as “slow-to-warm-up”, 35% are said to be “intermediate” in temperament, and 40% have “easy” temperaments. These percentages differ from the temperaments determined in the current study, where eleven of the thirteen (85%) infants were in the “intermediate” temperament category, and each of the two remaining infants was in the “easy” or the “difficult” temperament categories. These differences in percentages may be influenced by the small sample size in the current study, by the application of standards determined with an older infant population, or by the difficulty in definitively determining temperament at such a young age. It is also possible that these differences may be true of the very young infant population or of infants being monitored. Sampling bias also may have influenced these percentages, since mothers with difficult babies may have declined to participate in the study. Further studies on temperaments of very young infants, the “goodness-of-fit” between infants and their mothers, and of infants during and following home apnea monitoring are indicated.

#### Data Analysis

The data collected in this study were analyzed using repeated measures analysis of variance (ANOVA) computations or Pearson product-moment correlation coefficients (Pearson  $r$ ) procedures to address the twelve research questions. The significance level

used was .05. This level of significance is customary in studies in education and the social sciences, and sets the probability of committing a type I statistical error, i.e. of incorrectly rejecting the null hypothesis when it is true (Glass & Hopkins, 1996), at a relatively low level. However, because of the small sample size of 13 actually obtained for the current study, it might have been wise to use a larger alpha level of .10 (Glass & Hopkins, 1996). Increasing the alpha level would also increase the power of the statistical tests used since the probability of committing a type II statistical error, i.e. of failing to reject the null hypothesis when it is false, would be decreased (Glass & Hopkins, 1996).

Use of the repeated measures ANOVA assumes that the within subjects factor (13) is a random factor, while the trial factor (3) is a fixed effect (Glass & Hopkins, 1996). Other assumptions which must be made in order to use this statistical test are independence of observation between subjects, homogeneity of variance, normality of error, and sphericity (Glass & Hopkins, 1996). The results of the repeated measures ANOVA computation must be interpreted cautiously since a small non-random sample was used in the current study. Also, the assumption of independence of observations in the current study is questionable for mothers of twins.

Use of a Pearson product-moment correlation coefficient indicates the linear relationship between the variables of interest (Glass & Hopkins, 1996). This correlation coefficient permits comparison of the strength and direction of the relationship between different pairs of variables in the study. Correlation computations are not affected by small sample sizes as in the current study.

### Discussion of the Study Findings

Statistically significant results were obtained for four of the twelve research questions addressed in this study. The implications of the findings for each of the research questions follow.

1. How do mothers' perceptions of the concerns of individual family members change as they progress through the three phases of home apnea monitoring? The results of the ANOVA computations for the mothers' concerns and for the spouse/partners' concerns (Table 22) are not statistically significant at the .05 level, indicating there are no differences in the concerns expressed by the mothers at the three phases of the home apnea monitoring experience. Generally, the mean concerns score expressed by the mothers via the PPI-Concerns instrument decreased as monitoring progressed (Table 6). Spouse/partner concerns scores were obtained by having mothers respond to items regarding their (mothers') perceptions of the spouse/partners' concerns. The PPI-Spouse Concerns scores decreased slightly as monitoring progressed (Table 6).

Prior to the initiation of this study, the researcher participated in a support group for families of infants on home apnea monitors. During the early days of monitoring, the parents in the support group expressed concerns regarding their abilities to take care of their infants if there were alarms and decisions regarding caretakers when the mother returned to work. Concerns during the midmonitoring time expressed by members of the support group included such tasks as household maintenance, taking the infant and monitor shopping, and physical exhaustion. When the infants were off the monitor, parents in the support group were concerned about caretakers for their infants, as well as their abilities to care for their infants without the support of the monitor.



The individual concerns the mothers identified for themselves using the PPI at the various phases of monitoring (Table 7) as a whole are consistent with the concerns discussed in the support group, as are the individual concerns not chosen. Both groups expressed a need for information, concerns about their infants' health and comfort, and uncertainty regarding their infants' futures. The individual concerns the mothers identified for their spouses/partners at the various phases of monitoring (Table 8) are also consistent with the concerns discussed in the support group. Financial items on the PPI were perceived by the mothers to be of concern for their spouses/partners through the middle of monitoring but of decreasing concern as monitoring progressed. However, the concerns perceived by parents in the support group began high, decreased as monitoring progressed, and increased again upon termination of monitoring, a trend which was not reflected in the mothers' PPI scores for themselves and for their spouses/partners in the current study.

The trends in parental concerns scores identified in the current study are roughly consistent with Wasserman's (1984) delineation of parental concerns at the initial (doubt/acceptance), maintenance (frustration/dependence); and discontinuance time periods in the monitoring experience. However, like the support group, the specific anxieties reported by the parents in Wasserman's (1984) report were clearly different as monitoring progressed, whereas in the current study the concerns of the parents were not significantly different at the three time points. Gathering the spouses/partners' concerns directly using the PPI-Concerns instrument might further validate the mothers' perceptions.

2. How do mothers' perceptions of coping strategies of individual family members change as they progress through the three phases of home apnea monitoring?

The F-values for the mothers' coping, for the spouses' coping, and for the sibling behaviors (Table 23) are not significant at the .05 level, indicating there are no differences in the scores for coping strategies used by the parents and by the infants' siblings at the three phases of the home apnea monitoring experience. Generally, the scores for coping strategies used by the mothers as measured by the PPI-Coping instrument (Table 6) decreased slightly as monitoring progressed. Spouse/partner coping scores were obtained by having mothers respond to items regarding their (mothers') perceptions of the spouse/partners' coping strategies. The PPI-Spouse Coping scores decreased to a greater degree than the mothers' coping strategies as monitoring progressed (Table 6). The coping strategies used by the infants' siblings were obtained by having mothers rate the frequency of each of eight behaviors. The PPI-Sibling Behavior scores decreased only slightly as monitoring progressed (Table 6). These trends indicate that the individual family members utilize fewer coping strategies as monitoring progresses. This decreasing trend is consistent with the decrease in the perceived concerns of the various family members addressed earlier (Research Question #1).

Patterns in the individual coping strategies identified by the mothers from options available in the various PPI scales were also noted. The mothers (Table 9) most frequently utilized prayer, the advice of others, tried to figure out what to do, and tried to relax throughout monitoring. Two coping strategies, crying and asking for help, were used by at least 2/3 of the mothers but only in the initial phase of monitoring, while busying myself with other things was utilized frequently during the maintenance

monitoring period and weighing choices was noted only when monitoring was terminated. Coping strategies utilized by the spouses/partners as perceived by the mothers (Table 10) parallel the coping strategies utilized by the mothers at the various monitoring periods.

Coping strategies not used by the parents in the current study also are interesting to note (Tables 9 & 10). Several coping strategies may be influenced by the location of the study and/or by cultural expectations, so that “praying” was a frequently used strategy by both mothers and their spouses/partners while “crying” was not a frequently used strategy by the spouses/partners but was used by several mothers at the initial monitoring point. The mothers reported that taking alcohol or medicine was not a frequently used coping strategy among either group of parents, although this is contrary to expectations since substance abuse is deemed a major health problem in current society. The results in the current study may have been influenced by a sense of social desirability (i.e., drugs and alcohol are bad) as well as by the small sample size.

The effectiveness of the coping strategies utilized by the parents was not addressed in the current study. Hymovich’s battery of instruments also includes the How Helpful subscales for the mothers and for the spouses/partners as well as a PPI-Beliefs and Feelings instrument. Although not used in the current study to guard against response overload, these instruments might elicit useful information on the effectiveness of the coping strategies used by the parents in the current study. Ahmann (1992 & 1993) concluded that families of infants on home apnea monitors possess adequate resources with which to cope with the stressor of home apnea monitoring. Nurses could support these family members in their coping through interventions which encourage parental involvement in support groups, facilitate decision-making and direct participation in their

infant's care, provide and reinforce information throughout the monitoring experience, and foster healthy lifestyles and stress management programs.

Mothers with more than one child ( $n=9$ ) rated the frequency with which their other child(ren) exhibited each of eight behaviors included on the PPI-Sibling Behavior subscale (Table 11). No behaviors were exhibited frequently by the siblings of the infants throughout monitoring according to the mothers. Eight of the nine mothers rated jealousy as being used occasionally by their infants' siblings during the maintenance monitoring period. The paucity of behaviors exhibited by the siblings may reflect the mothers' difficulty in using the PPI since most of the siblings were toddlers or preschoolers. For three of the behaviors included on the PPI-Sibling Behavior subscale, "protective of child", "worried about child", and "worried about self", the mothers needed to be aware of their child(ren)'s thoughts, while "helps with child's therapy" is a behavior which is more apparent in older children. Information from the mothers on behaviors more developmentally specific for toddlers or preschoolers, including regression to previous behaviors such as resumption of bed-wetting or use of a bottle, increased clinging behavior, nightmares, or development of imaginary friends, may have revealed significant results in this group of family members. An alternate version of the PPI-Sibling Behaviors subscale designed for use with younger siblings could incorporate these behaviors and would be useful in future research studies of families.

3. How do mothers' perceptions of the discrepancy between expected and perceived family functioning change as they progress through the three phases of home apnea monitoring? The F-value for the discrepancy scores of the FFFS (Table 24) was not significant at the .05 level, indicating that there were no differences in the degree of family

functioning perceived by the mothers as monitoring progressed. However, the discrepancy scores for family functioning via the FFFS (Table 6) did decrease slightly as monitoring progressed. This finding is consistent with Knecht's (1991) finding that the discrepancy between expected and perceived family functioning was highest at the initial monitoring period, with a consistent decrease as monitoring progressed.

Review of the patterns of responses on the FFFS (Table 12) reveals no clear trends in either items chosen by the mothers or in items not chosen as monitoring progressed. In reviewing the frequencies and the mean discrepancy scores for various items, no discrepancies in expected and perceived family functioning were cited by at least two-thirds of the mothers or had mean discrepancies of 3.0 or greater through all phases of home apnea monitoring. Items cited most frequently or cited as having the greatest mean discrepancy score at any of the three measurement points involved time. Initially, time spent with spouse/partner ( $f=8$ ) and time spent in leisure/recreational activities ( $f=10$ ) were problematic but had decreased in frequency by the end of the monitoring experience. Time spent on housework ( $X=3.0$ ) and time the mothers missed from work ( $X=3.33$ ) were problematic initially, while time with health professionals ( $X=4.0$ ), time the mothers missed from work ( $X=3.5$ ), and time the spouses' work was disrupted ( $X=3.0$ ) were problematic during the last portion of monitoring. These findings indicate that having an infant on a home apnea monitor is time consuming, especially at the initiation of monitoring.

The absence of items cited as problematic during the maintenance phase of monitoring is inconsistent with Wasserman's (1984) reports of frustration and fatigue associated with the demands of monitoring during this period. This inconsistency may be explained by the fact that the mothers in the current study did not report feeling worn out,

problems with getting enough sleep, worry about child care responsibilities, or concern about their own or their spouse/partners' health during the middle of monitoring (Table 7), concerns which would have reflected the frustration and fatigue in this period as noted by Wasserman (1984).

Items cited by the fewest numbers of mothers or having the lowest mean discrepancy scores included items addressing support or assistance from family or friends, and time child(ren) miss from school. These findings reflect the mothers' perceptions of adequate social support from relatives and friends. This perception is probably influenced by the fact that the mothers in the current study reported an average of 4.2 adult relatives living within 30 minutes of their homes. The perception of adequate social support by these mothers is inconsistent with Wasserman's (1984) reports of social isolation resulting from the hesitancy of family and friends to visit because they fear that the infant might experience a negative event. This inconsistency might be explained by the fact that home apnea monitoring and other types of "high tech" care in the home have become more common and are less intimidating to the public than when Wasserman's (1984) study was conducted. Another possibility is that presently more grandparents and other family members are routinely trained in CPR techniques so that families with infants on monitors have more options for respite from the demands of monitoring than they had during the time of Wasserman's (1984) study.

4. What is the relationship between the concerns of family members as perceived by the mothers and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring? The moderate correlation of 0.58 between the mothers' concerns and the mothers' perceived

family functioning discrepancy score at the initial monitoring period was statistically significant (Table 14), indicating that the mothers perceived their families as functioning less well than they expected them to when the families' concerns were at their highest. This correlation did not hold true for the other monitoring points (Tables 15 through 16).

These findings are consistent with the decrease in the mothers' concerns as monitoring progressed noted in the current study. This pattern may indicate that taking an infant home on an apnea monitor serves as a major disruption to the family's ability to interact with the environment and with its members but that the degree of disruption decreases as monitoring progresses. However, the support group (Research Question #1) and the literature (Wasserman, 1984) indicate that stress and anxiety are likely to peak again when the monitor is discontinued. Therefore, a concomitant rise in the discrepancy between expected and perceived family functioning would be anticipated during the termination phase. Although this anticipated rise in correlation between the concerns of the mothers and the family functioning discrepancy scores and between the concerns of the spouses/partners and the family functioning discrepancy scores at the termination of monitoring was not found in the current study, the p-values for these two correlations (.16 and .20, respectively) were much lower at the termination of monitoring than they were midway through monitoring (.54 and .28, respectively).

5. What is the relationship between the coping strategies of family members as perceived by the mothers and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring? The scores for the mothers' coping strategies and the mothers' family functioning discrepancy scores at the initial monitoring period (Table 14) were highly correlated (.81). This

finding indicates that the mothers perceived their families as functioning less well than the they expected them to when the families' coping strategies were at their highest. No other correlations were statistically significant (Tables 15 through 16). This finding is consistent with the decrease in the mothers' coping strategies as monitoring progressed in the current study. This pattern may indicate that taking an infant home on an apnea monitor requires the utilization of more coping strategies secondary to the major disruption inherent in monitoring but that the degree of disruption decreases as monitoring progresses.

Since the concerns of the mothers were at their highest levels (Research Question #1) and since the mothers' coping strategies (Research Question #2) were also highest at the initial monitoring point, these findings are congruent with previous literature (Ahmann, 1992 & 1993). However, if a rise in the coping strategies and in the family functioning discrepancy score is anticipated at the termination of monitoring as indicated in the literature (Wasserman, 1984), and in the support group, a significant correlation between mothers' concerns and discrepancy in family functioning also would be anticipated at this time period. Although this anticipated rise in correlation between the coping strategies of the mothers and the family functioning discrepancy scores and between the coping strategies of the spouses/partners and the family functioning discrepancy scores at the termination of monitoring was not found in the current study, the p-values for these two correlations (.24 and .42, respectively) were much lower at the termination of monitoring than they were midway through monitoring (.43 and .65, respectively).

Although they were not statistically significant, high negative correlations were found between sibling behaviors and family functioning discrepancy scores at the initiation and termination of monitoring (Tables 14 through 16). These findings would appear to



indicate that the siblings exhibited fewer coping behaviors at the times when the families are functioning less cohesively, an opposite relationship from that of the other family members. It is logical that a toddler exhibiting difficult behaviors would more likely disrupt family functioning, resulting in a positive correlation between sibling behaviors and family functioning discrepancy scores. The inappropriateness of the items listed on the PPI-Sibling Behaviors subscale for the present sample of mothers (Research Question #2) may have contributed to these findings.

6. What is the relationship between mothers' perceptions of infant temperament and the concerns of family members as perceived by the mothers during the home apnea monitoring experience? No correlations between either the calculated infant temperament scores or the temperament classification based on the mothers' general impressions of infant temperament and the concerns of the mothers or of the spouses/partners as perceived by the mothers were statistically significant (Tables 19 through 21). These results are not consistent with Melvin and McLowry (1995) who identify temperament as a strong infant characteristic that impacts on the family's responses to a stressor. As a strong infant characteristic, temperament, therefore, should be correlated highly with the degree of concerns perceived by the mothers in the current study. The methodological problems with utilization of the EITQ discussed earlier in this chapter and the homogeneity of infant temperament reflected in the current sample may have influenced these findings. Examination of correlations between individual temperament characteristics and the concerns of family members may assist in understanding this difference. Comparison of the "goodness of fit" (Chess and Thomas,

1996) between the temperaments of the mothers and their infants also might contribute to the understanding of the role or lack of thereof of infant temperament on family coping.

7. What is the relationship between mothers' perceptions of infant temperament and the coping strategies of family members as perceived by the mothers during the home apnea monitoring experience? A statistically significant negative correlation was obtained between the mothers' general impressions of infant temperament and the coping responses of the mothers and of the spouses/partners at the termination of monitoring. This finding indicates that the mothers perceived themselves and their spouses/partners as utilizing fewer coping strategies at the termination of monitoring even though they viewed their infant's temperaments as more difficult. No other correlations between infant temperament and the coping responses of various family members at other points in the home apnea monitoring experience were statistically significant (Tables 19 through 21). This negative relationship between temperament and coping scores at the termination of monitoring may indicate that families have adjusted to their infants' temperaments by this period of time and only require a few coping strategies to deal with the stressor of monitoring.

8. What is the relationship between mothers' perceptions of infant temperament and the discrepancy between expected and perceived family functioning during the home apnea monitoring experience? No correlations between either the calculated infant temperament scores or the temperament classification based on the mothers' general impressions of infant temperament and the discrepancy in family functioning at any of the phases of monitoring were statistically significant (Tables 19 through 21). This contradicts Ahmann's (1989) finding that infant temperament is one of

the factors affecting the family's responses to home apnea monitoring, especially its family functioning. However, the lack of a significant relationship between temperament and family functioning may have influenced the findings of no statistically significant differences in the individual family members' responses or in the family's responses as monitoring progressed (Research Questions 1 through 3).

9. What is the relationship between mothers' ratings of the infants' severity of illness and the concerns of family members as perceived by the mothers as families progress through the three phases of home apnea monitoring? No correlations between the infants' severity of illness and the concerns of the various family members were statistically significant at any of the phases of monitoring (Tables 14 through 16). This finding is not congruent with the literature which reports an increase in concerns/anxiety levels of family members when a child is acutely ill or placed in an intensive care unit (Youngblut & Shiao, 1993). Because severity of illness in the current study was dramatically higher at the midmonitoring point than at the other two monitoring points, a correlation with family members' concerns would be expected at least during the maintenance monitoring point. However, since the overall concerns of the family members were decreasing at this time, any correlation between severity of illness and concerns might not be apparent.

The severity of illness at the midmonitoring period may have been artificially inflated when compared to the other two measurement points. Calculation of severity of illness included the total number of alarms since the onset of monitoring or since the previous measurement point, plus the product of the number of true alarms times the degree of intervention required by the most serious of the true alarms, plus several

indicators of the infant's health. The calculation of severity of illness at the initial measurement point included an average of 2.1 weeks of monitoring, while the maintenance monitoring measurement included 12.4 weeks of monitoring, and the termination of monitoring measurement included an average of 4.5 weeks off the monitor. Additionally, none of the infants in the current study required the initiation of CPR, a situation which would dramatically increase a family's concerns. This may have inflated artificially the severity of illness rating at the midmonitoring period and the overall healthiness of the infants are felt to significantly influence the lack of significance in the current study.

10. What is the relationship between mothers' ratings of the infants' severity of illness and the coping strategies of family members as perceived by the mothers as families progress through the phases of home apnea monitoring? The negative correlation of  $-.8952$  between the infant's severity of illness and the sibling behavior at the mid-monitoring period was statistically significant at the  $.0005$  level. No other correlations between severity of illness and coping responses were statistically significant (Tables 14 through 16).

This finding indicates that as the infant's severity of illness increased the responses by the siblings as reflected in the number of their behaviors noted by the mothers decreased. As noted in the previous discussion (Research Question #9), the mean severity of illness score was highest at the mid-monitoring period (Table 13) although this may have been artificially inflated and may not reflect the true situation. Also, because the majority of the siblings were toddlers or preschoolers, their coping behaviors may not be as evident using the PPI as those of school-age children for the reasons discussed earlier

(Research Question #2). Measurement and interpretation of behaviors in young children continues to be an area of difficulty for nurses and other adults.

Absence of significant relationships between severity of illness and coping responses of the adults is an unexpected finding. This lack may be a function of statistical significance between severity of illness and concerns as noted in the results for Research Question #9. Similarly, since the overall coping responses of the adult family members were decreasing at this time, any correlation between severity of illness and coping might not be apparent.

11. What is the relationship between mothers' ratings of the infants' severity of illness and the discrepancy between expected and perceived family functioning as families progress through the three phases of home apnea monitoring? There were no statistically significant correlations between severity of illness and family functioning discrepancy scores as monitoring progressed (Tables 14 through 16). As noted earlier in this chapter, Knecht (1991) reported a decrease in family functioning discrepancy scores as monitoring progressed after being highest at the initial monitoring period. The lack of significance between these two variables in the current study may be explained by the different peaks of the two variables, with the family functioning discrepancy scores highest initially and the infants' severity of illness ratings highest at the middle of monitoring.

12. What is the relationship between mothers' perceptions of infant temperament and the infants' severity of illness during the home apnea monitoring experience? No correlations between either the calculated infant temperament scores or the temperament classification based on the mothers' general impressions of infant temperament and the infants' severity of illness at any of the phases of monitoring were

statistically significant (Tables 19 through 21). The absence of a correlation is not surprising since these are both independent variables for this study. However, since the severity of illness includes frequency of both false and true alarms, infants with very active temperaments might trigger false alarms, thereby increasing the severity of illness scores, and resulting in a correlation between these variables.

This finding is consistent with a study conducted by Marino and Lipshitz (1991) who also found no statistically significant correlations between temperament and severity of illness in infants or toddlers with cardiac disease. They did find that children with cardiac disease have different temperaments from healthy children and that they display unstable temperaments through the first three years of age (Marino & Lipshitz, 1991). Additionally, Medoff-Cooper (1986) reports that premature infants show differences in temperament when compared to full-term infants. These facts may serve to partially explain why the temperament scores in the current sample (mean gestational age of the infants 33.7 weeks) varied from the norms in the literature.

Several additional statistically significant correlations were obtained (Tables 14 through 16). The mothers' concerns were positively correlated to the mothers' coping strategies at each of the three phases of home apnea monitoring, with the magnitude of the correlation being highest at the initial monitoring period and decreasing as monitoring progressed. In other words, as the mothers' concerns increased, they utilized more coping strategies. This finding is logical since mothers with many concerns would need to develop an arsenal of coping strategies in order to defend against the high degree of perceived stress.

Similarly, the mothers' concerns were positively correlated with their spouse/partners' concerns at each of the three phases of home apnea monitoring. As the mothers' concerns increased, they perceived their spouses/partners as having more concerns. The magnitude of this correlation increased as monitoring progressed. This finding is logical since the mothers' perceptions of the spouses' concerns were the source of the data, and because many mother-father dyads discuss their situations with each other and serve as social supports for each other. Gathering the spouses/partners' concerns directly using the PPI-Concerns instrument might further validate the mothers' perceptions.

The spouses/partners' concerns were positively correlated with their own coping strategies at the mid-monitoring point. As with the mothers, when the spouses/partners' concerns were high, the spouses/partners utilized more coping strategies; conversely, when the spouses/partners' concerns were at their lowest, the spouses/partners' coping strategies were also at their lowest point. However, the absence of significant correlations between the spouses/partners' concerns and coping strategies at the other two measurement points is surprising, since the trends in coping responses have closely paralleled the trends in concerns. (See previous discussion concerning the correlations between concerns and coping strategies at each of the measurement points.) Gathering the spouses/partners' coping responses directly using the PPI-Coping instrument might further validate the mothers' perceptions of the coping responses of the spouses/partners.

The mothers' coping strategies and sibling behaviors were negatively correlated at the initial monitoring point. When the mothers' coping strategies were cited as being high, the behaviors of their infants' siblings were low. This negative relationship persisted

through subsequent measurement points but was not as strong as at the initial phase. This indicates that as the mothers utilize more coping strategies the other children's responses decrease as reflected in their behaviors. This relationship may result from the mothers being more aware of their older children when the mothers utilize numerous coping mechanisms. Another possibility is that when mothers are coping effectively, the siblings perceive less distress so negative sibling behaviors decrease. Also, the behaviors included in the PPI-Sibling Behaviors instrument are not necessarily characteristic of toddlers and preschoolers who were the majority of siblings in the current study. Use of a measure that is more reflective of sibling responses in these age groups might yield more applicable data.

A non-significant negative correlation of  $-.04$  was found between the mothers' general overall impression ratings and the total EITQ temperament scores. This lack of significance is surprising since both scores are supposed to be measuring the same variable, infant temperament, and therefore expected to be positively related. This finding may be influenced by the mothers' viewing all their infants as "normal" or "average", although the calculated scores would be different. Also, as noted earlier, Marino and Lipshitz (1991) found that children with cardiac disease have different temperaments from healthy children and that they display unstable temperaments through the first three years of age, while Medoff-Cooper (1986) reported that premature infants show differences in temperament when compared to full-term infants. Since the current sample had a mean gestational age of 33.7 weeks and since the temperament categorization utilized a norming group of healthy, primarily full-term infants, this may serve to partially explain why the temperament scores in the current sample varied from the norms in the literature.



Also, moderately positive correlations and moderately negative correlations were obtained between several of the nine temperament characteristics. Positive correlations were found between activity and rhythmicity, between mood and adaptability, and between rhythmicity and distraction, while negative correlations were found between rhythmicity and approach/withdrawal, persistence and approach/withdrawal, and persistence and intensity. These findings are consistent with expected findings since examination of several of the individual characteristics on scoring of the EITQ reveals that they are inversely related, i.e. mild intensity is inversely related to low persistence.

#### Implications for Theory Development

The experience of having an infant on a home apnea monitor constitutes a stressor to the family system as defined by Neuman (Neuman, 1995; Ridgell, 1993). The Neuman Systems Model (1995) views the family unit as an open system interacting with the internal and external environments in a reciprocal manner (Hinds, 1990). In addition, the family system encompasses individual family member/systems in interaction with each other and interacting with those outside the family. The Neuman Systems Model (1995) organizes these interacting individual systems of family members into a global family system. Neuman's (1995) model focuses on assessment of client stressors and responses to those stressors and the appropriate nursing actions as a result of that assessment. As a functioning system, anything which affects any member as well as the individual characteristics of each family member affects the family as a whole (Neuman, 1995; Reed, 1993). The role of the nurse is to analyze the stressors which are affecting the family system and to assist the family in either retaining, attaining, or maintaining the family system's homeostasis in response to stressors (Neuman, 1995).

The current study explores the stressor of home apnea monitoring on the family members and on the family unit at three points in the home apnea monitoring experience. The specific responses of the family members to the stressor included their concerns and coping strategies as perceived by the mother. The responses of the family unit include changes in family functioning as perceived by the mother. The patterns in responses identified in this study indicate that the concerns and coping strategies of the individual family members are different at the three time periods - initial monitoring, mid-monitoring, and termination of monitoring. The family unit's ability to maintain itself as an open system, i.e. family functioning, is different at these times also. Additionally, the independent variables used in this study, severity of illness, operationally defined as the number and severity of alarms, and infant temperament were measured. Although no statistically significant relationships were found between temperament and the family's responses to the stressor of home apnea monitoring, severity of illness correlated with individual family members' responses. These findings are congruent with Neuman's (1995) assertion that anything which affects any member of the family system as well as the individual characteristics of each family member can affect the family as a whole.

The literature supports the view that the decisions, emotions, and responses which families have during the time an infant is on a home apnea monitor are similar to those experienced by families of children with chronic illnesses (Black et al., 1978; Davis & Sweeney, 1989; Mark & Zahr, 1986; McElroy et al., 1986; Ray & Ritchie, 1993; Sweeney, 1988; and Wasserman, 1984). Similarities between the two situations include persistence over time, often unknown etiologies, the fact that both are usually manageable but not curable, have uncertain prognoses, and have similar stages of adaptation (Davis &

Sweeney, 1989). The results of the current study support this view as evidenced by many of the concerns cited by the mothers of infants on home apnea monitoring (Research Question #1), by the coping strategies utilized by individual family members (Research Question #2), and by the changes in family functioning over time (Research Question #3).

Neuman (1995), Hymovich (1979), and Roberts and Feetham (1982) believe that assessment of the client's/family's perceptions of the situation is essential before any nursing interventions are developed to assist the client/family system. The current study elicits mothers' views of the responses to the stressor of home apnea monitoring. The mothers' perceptions of the stressor and resulting responses are gathered directly, while the views of the other family members are gathered indirectly, by way of the mothers' perceptions of their responses and coping strategies.

Temperament or behavioral style theoretically is considered a very strong infant characteristic and has an impact on the family's responses to a stressor (Melvin & McClowry, 1995), including family functioning (Ahmann, 1989). Schraeder (1995) notes that temperament "regulates the nature of transactions between parent and child" (p. 167). Carey (1983) sees temperament as a relatively stable trait throughout infancy and childhood. Although no statistically significant linkages were found between temperament and the responses to home apnea monitoring in the current study, temperament was determined for all the infants at an earlier time than the four to eight month age range that had been in common practice (Carey & McDevitt, 1978). Further refinement and validation of the relationships between infant temperament and the responses to home apnea monitoring would be useful. Comparison of temperament data for infants on home

apnea monitoring with temperament data for infants with chronic illnesses, for “healthy” infants, and for older infants would further clarify this concept.

### Implications for Nursing Practice

Nurses need to recognize the varying concerns and coping responses of various family members at different points in the monitoring experience, so they can design specific interventions to facilitate positive coping to the stressor of home apnea monitoring. During the initial monitoring point, the concerns which were cited most frequently by the mothers (Table 7) reflected worry about their children, worry about themselves, and desire for information. Nurses can support these mothers by providing and reinforcing information regarding all aspects of the infant’s condition and care, and by assisting the mothers in adopting healthy lifestyle behaviors such as stress management techniques, adequate sleep/rest patterns, and proper nutrition. Since their children’s health remained a priority for these mothers throughout monitoring, nurses can encourage timely health follow-ups for the monitored infants and for their siblings, can assist the mothers in identifying the positive aspects of their children’s growth, and can provide anticipatory guidance for the mothers regarding what to expect in the future and necessary parenting strategies to deal with these changes. These strategies would also address several of the concerns of the spouses/partners (Table 8) which the mothers perceived as priorities during the home apnea monitoring experience.

Based on the mothers’ coping strategies (Table 9) at various points in the home monitoring experience, nurses could encourage mothers to maintain or strengthen their spiritual ties, to keep the mothers informed regarding normal growth expectations and specific infant progress, and to implement relaxation, respite, and/or stress management

programs. Additionally, nurses could encourage the mothers to participate in support groups for families of infants on apnea monitors or receiving “high tech” care. Such support groups would provide a vehicle for talking with others about the mothers’ feelings, an opportunity to explore options and to obtain input into decision-making, and a way to learn about other sources of help. These strategies also would be useful for the spouses/partners based on the mothers’ perceptions of their coping strategies (Table 10).

Although the PPI-Sibling Behavior subscale was not useful in identifying the coping strategies of the siblings in the current study (Table 11), nurses could provide anticipatory guidance for mothers/families regarding age-appropriate expectations for the siblings and ways to combat sibling rivalry. Additionally, identification of approaches for maintaining/increasing the self-esteem of the siblings and for involving the siblings in the monitored infants’ care might be beneficial.

Strategies for strengthening the family’s cohesiveness as a unit could be identified based on the mothers’ perceptions of the degree of discrepancy between perceived and actual family functioning (Table 12). Encouraging more time together as a family on leisure activities or other common pursuits may be useful. Also, support for existing roles and fostering effective conflict management within the family may be helpful during the home apnea monitoring experience.

Although concerns and coping strategies of family members were highest at the initiation of monitoring, severity of illness as measured by the frequency and severity of monitor alarms peaked midway through monitoring while severity of illness based on health problems of the monitored infants was at its highest in the period surrounding termination of monitoring (Table 13). Nurses must be aware of these differences in infant

health status as monitoring progresses and tailor their discussions/interventions to be most supportive to the families of these infants.

Although no statistically significant relationships were found between infant temperament and family responses to home apnea monitoring across all monitoring periods in the current study, nurses cannot afford to disregard the potential influence which temperament has on infant/family interactions and, therefore, on the family's adjustment to the stressor of home apnea monitoring. Knowledge about the temperaments of their infants (Table 17) could be useful for families when developing the effective coping strategies listed previously, or in simply understanding their infants and their behaviors.

The findings of the current study support the view that the concerns and coping responses of the various family members may be different and that they may change as the home apnea monitoring experience progresses. Nurses, therefore, must develop specific strategies for eliciting these responses and must reassess these responses as home monitoring proceeds, including the time that the infant is able to discontinue monitoring.

#### Implications for Future Research

The current study elicited concerns and coping responses of family members and of the family as a whole at three points in the home apnea monitoring experience.

Replication of this research is warranted, utilizing a larger sample, other geographic regions of the United States, differing cultural populations, and differing medical diagnoses of the children/infants. Because most family research uses reports by mothers to gather information on the impact of a stressor such as home apnea monitoring, there is a need for research into this stressor which directly accesses the responses of the other

family members rather than depending on the mothers' perceptions of the impact. There is also a need for qualitative exploration of the specific concerns of family members to the stressor of home apnea monitoring. Addition of a comparison group of healthy infants would permit determination of which responses are unique to home apnea monitoring and which responses are related to the process of parenting. Further studies could also incorporate the late effects phase of home apnea monitoring identified by Wasserman (1984) but not addressed in this investigation. Studies which identify the interventions most useful at the different points in the home apnea monitoring experience are also warranted. Also, the influence of infant temperament on the home apnea monitoring experience was not solidified by the findings of this study and needs to be delineated further. Although the current study supports the view of home apnea monitoring as a chronic illness, additional exploration of this view is necessary.

Serial measurements of infant temperament beginning in the neonatal period would ascertain the point at which temperament becomes stable. The "goodness-of-fit" (Chess and Thomas, 1996) between mothers and their infants' temperaments also should be explored further. Comparisons of temperaments in young full-term infants, preterm infants, healthy infants, acutely ill infants, and chronically ill infants might reveal interesting differences between these groups.

Future studies are also warranted which further test the Neuman Systems Model (1995) framework included here. Neuman (1996) presents six rules for conducting Neuman-based research and these should be utilized when designing future studies.

Study findings and reliability data determined in this investigation will be forwarded to the respective authors so that more complete psychometric data on each of

the instruments is available for future use. Additionally, the results of this study yield recommendations related to strategies for recruiting subjects, the inclusion and deletion of various items on the instruments, and reading levels. The need for an alternate form of the PPI-Sibling Behaviors instrument designed for use with younger siblings will be shared.

### Summary

Sudden Infant Death Syndrome (SIDS) is the leading cause of death in infants between one week and one year of age. The mainstay of therapy to reduce SIDS mortality is evaluation and subsequent home monitoring of infants at risk for SIDS. This study delineated the concerns and responses of families of 13 infants to having an infant on a home apnea monitor as perceived by the mother at three time points in the home apnea monitoring experience. The Neuman Systems Model served as the theoretical basis for the investigation, with the family as the client so that the responses of the individual family members and of the family as a whole were explored. Additionally, seven studies support the view that the decisions, emotions, and responses which families have during the time an infant is undergoing home apnea monitoring are similar to those experienced by families of children with chronic illnesses. By viewing home apnea monitoring from a chronic illness perspective, Hymovich's framework for assessing individual family member's responses to the stress of having a child with a chronic illness was blended with Neuman's theory for this study. Feetham and Roberts' view of family functioning as the family unit's ability to maintain itself as an open system served as the conceptual base for examining the responses of the family unit to the stressor of home apnea monitoring.

Twelve research questions were addressed. Three research questions examined the changes in individual family members' concerns and coping strategies over time and in



the family functioning of the family as a whole at three time points in the home apnea monitoring experience. The remaining nine research questions explored the relationships between the dependent and independent variables at the three time points.

The study design was longitudinal with event partitioning. The following instruments were administered three times during the home monitoring experience: Hymovich's Parent Perception Inventory, the Feetham Family Functioning Survey, and the Monitoring Flowsheet. The Early Infancy Temperament Questionnaire was administered once approximately half-way through the monitoring experience. Study participants were recruited from two sites in South Carolina - a Children's Sleep Disorders Center at a general community hospital in the upstate region and a Special Care Nursery at a general medical center midstate. Mothers of 13 infants on home apnea monitors agreed to participate. No subjects were lost from the study but final questionnaires were not received from one mother and another infant remained on the monitor at the conclusion of data collection. Data was collected via home visits at three different time periods - within two weeks of the initiation of home apnea monitoring, midway through monitoring at approximately three months, and within three weeks following the termination of monitoring. Incentives for the mothers to persist through the study included snapshots of the infants taken at each home visit by the researcher and a small baby album following return of the third set of questionnaires. Data analysis included repeated measures analysis of variance to address the first three research questions and correlational coefficients to examine the relationships between the variables specified in the remaining nine research questions.

Data collection was conducted over an eighteen-month period beginning in September, 1995 and continuing through January, 1997. All of the mothers were the birth mothers living with their infants, with ten of the families including the infants' fathers, and with ten families including at least one sibling. All of the mothers were over 18 years of age and all except one were high school graduates. Eleven of the thirteen infants were white and two were black. The average length of the home apnea monitoring experience was 4.9 months, slightly less than the reported national average of six months. Statistically significant findings were obtained for parts of four out of the twelve research questions addressed by the study. Repeated measures ANOVA's conducted on the concerns and on the coping strategies of the mothers, fathers, and siblings, and on the family functioning at the three points in the monitoring experience were not statistically significant, although patterns in individual concerns and coping strategies were consistent with several reports in the literature and in the concerns and coping strategies identified by participants in a parent support group. At the initial monitoring point, statistically significant correlations were found between the mothers' concerns scores and the family functioning discrepancy scores and between the mothers' coping scores and the family functioning discrepancy scores. At the termination of monitoring, statistically significant negative correlations were obtained between the temperament groups according to the mothers' general impressions of their infants and the mothers' coping scores and between the temperament groups and the spouse/partners' coping scores as perceived by the mothers at the termination of monitoring. A statistically significant negative correlation was obtained between the severity of illness and the sibling behavior at the termination of

monitoring. No other statistically significant findings were obtained for the remaining research questions.

The small convenience sample in this study limits the generalizability of the study findings. Replication of the study using a larger sample would be useful, as would qualitative exploration of the responses of the individual family members and of the family unit to the stressor of home apnea monitoring. Because nurses are in key positions to coordinate the development of strategies for families to use in coping with the stressor of home apnea monitoring, this study would be particularly beneficial to practicing nurses. Information about the various concerns of the family members and their strategies for coping along with determination of the relationship with family functioning and infant temperament provide a basis for nurses to develop interventions to assist families in positively coping with the home apnea monitoring experience.

**APPENDIX A**  
**Institutional Review Approvals**

University of South Carolina  
College of Nursing

Ethics Committee Application

Title of Project: Family Responses to Home Apnea  
Monitoring: Family Functioning, Family  
Concerns, and Family Coping at Three  
Time Points

Name of Investigator and Telephone Number:

Betsy M. Barnes

(803) [REDACTED]

Name of Faculty Member Supervising Student Research:

Sara G. Fuller

Abstract

(See attached sheet)

Submit three copies of the pages 1-9 of this application,  
your informed consent form and all questionnaires or other  
data collection instruments and the completed proposal.  
Date and sign this form. Students need the signature of  
supervising faculty. Faculty signature indicates approval  
of the application and agreement that the student is ready  
for data collection.

[REDACTED]  
Principal Investigator Date Faculty Research Supervisor

Ethics Committee Action

[REDACTED]  
Ethics Committee Chairperson

[REDACTED]  
Committee Member Reviewing Date



*Department of Pediatrics*

*Department of Pediatrics*

April 3, 1995

To Whom It May Concern:

I am writing in support of Betsy Barne's proposed study "Family Responses to Home Apnea Monitoring: Family Functioning, Family Concerns, and Family Coping at Three Time Points."

I have reviewed her study protocol and her review of the literature and am in support of her completing this project. The project is well designed and will provide additional information on family functioning for babies who require home monitors.

I am concerned that it may difficult to enroll forty families who are willing to cooperate and participate in this study in a nine month time period. It may also be difficult having some of the families who initially participate in the study continue to participate at a later time. However, there are many families who would be willing to complete the questionares with regular involvement of the investigator. These families will need personal contact on each occassion from Ms. Barnes to complete the study.

Please let me know if you require additional information regarding this project.

Sincerely Yours,

Terry A. Marshall, M.D., FAAP  
Director of Nurseries

TAM/td

**SELF MEMORIAL HOSPITAL**  
**Nursing Research and Ethics Committee**

June 16, 1995

Dear Ms. Barnes,

I am pleased to inform you that your research proposal "Family Responses to Home Apnea Monitoring: Family Functioning, Family Concerns and Family Coping at Three Time Points" has been reviewed and approved by the Self Memorial Nursing Research and Ethics committee. Since you will be contacting parents of infants enrolled in the Home Monitoring Program at the Children's Sleep Disorders Center at Self Memorial Hospital and requesting their participation in the study, you need to submit a copy of the study prospectus to Mr. Fred Latham, Chairman of the Self Memorial Hospital IRB Committee for review and approval.

As discussed at our last meeting, it is expected that you will provide us with the results of your study. If you have any questions or if members of the Nursing Research and Ethics Committee can be of assistance to you in this process, please let me know. Good luck with your data collection. We look forward to hearing from you when the study has been completed.

Sincerely yours,



Deborah Natvig, RN, PhD  
Co-Chair, Nursing Research and Ethics Committee

**SELF MEMORIAL HOSPITAL  
Nursing Research and Ethics Committee**

June 16, 1995

Mr. Fred Latham  
Vice President and Chief Operating Officer  
Chairman, SMH IRB Committee  
Self Memorial Hospital  
[REDACTED]  
Greenwood, S.C. [REDACTED]

Dear Mr. Latham:

The Nursing Research and Ethics Committee has reviewed research proposal titled "Family Responses to Home Apnea Monitoring: Family Functioning, Family Concerns and Family Coping at Three Time Points" submitted by Betsy Barnes, RN, MSN. The research study will be completed in partial fulfillment of her PhD in Nursing from the University of South Carolina. After initial review of the proposal, the committee had a few concerns which Betsy has adequately addressed. The proposal was approved at our meeting on June 15, 1995. Members of the Research and Ethics Committee who participated in the review and approval of the proposal included Ms. Carol Burgard, Ms. Gail Waldrop, Ms. Judy Hollingsworth, and myself. In addition, Ms. Barnes has received a letter of support from Dr. Terry Marshall, Director of Nurseries.

Ms. Barnes will be contacting parents of infants enrolled in the Home Monitoring Program at the Children's Sleep Disorders Center at Self Memorial Hospital and requesting their participation in the study. Since there will be contact with the parents prior to the infants being discharged from the hospital, the committee advised Ms. Barnes to forward a copy of the study prospectus to you for review and approval.

If you have any questions about the review conducted by the Nursing Research and Ethics committee, please feel free to contact Ms. Gail Waldrop, Ms. Carol Burgard, or me.

Sincerely yours,

[REDACTED]  
Deborah Natvig, RN, PhD  
Co-Chair, Nursing Research and Ethics Committee

✓ pc: Betsy Barnes, RN, MSN, CCRN



MEMORANDUM

TO: Dr. Terry Marshall  
Neonatology [REDACTED]

FROM: Fred Latham [REDACTED]  
Vice President & Chief Operating Officer

DATE: July 14, 1995

This is to follow-up on our previous conversation regarding the study proposed by Betsy Barnes, R.N. regarding "Family Responses to Home Apnea Monitoring." Since we last talked two things have been accomplished.

- 1) The project was reviewed and approved by the Self Memorial Hospital Institutional Review Committee on July 12, 1995.
- 2) The project has been reviewed by Hospital Legal Counsel to consider any liability that the hospital might be subjected to if involved in the project. As I suspected, the result of this review was the need for a "consent/release" form (attached) to allow hospital employees to release names to Betsy Barnes, R.N.

As far as I can determine, we are now ready to let Betsy begin the project. As we previously discussed, a member of the Neonatology staff will need to get the form signed. It requires at least one parent's signature, both signatures would be preferable. The Self Memorial employee involved would also need to witness the signature(s). The original of the form should be filed in Neonatology and a copy provided to Betsy. As you will note in the consent/release form, the hospital disclaims any involvement with the study or Betsy Barnes or any action she might take. All we are doing is getting consent from the parents to release their names, address, etc.

I have informed Betsy to get in touch with Neonatology the first of the week to get started. If you have any questions/problems, please let me know.

/bdm

**Home Apnea Monitoring  
Family Responses  
Betsy Barnes, RN**

**Consent and Release**

I/We, the undersigned parent(s) or guardian(s) of \_\_\_\_\_, <sup>name of infant</sup>  
hereby authorize SELF MEMORIAL HOSPITAL (the "Hospital") to release our name(s),  
address and telephone number to Registered Nurse Betsy Barnes in order that she may contact  
us to request our participation in her research study on Family Responses to Home Apnea  
Monitoring.

I/We understand that the Hospital is not in any way responsible for such study or for  
Nurse Barnes' actions or conclusions in connection therewith, and I/we release the Hospital from  
any liability in connection with such study and the release of any information to Nurse Barnes.

Date: \_\_\_\_\_ (signature)  
\_\_\_\_\_ (print name)

Address: \_\_\_\_\_ (signature)  
\_\_\_\_\_ (print name)

Tele. No. \_\_\_\_\_ (signature)  
(Witness)



## SELF MEMORIAL HOSPITAL

August 14, 1995

Ms. Betsy Barnes, R.N.  
School of Nursing  
Lander University  
Greenwood, SC [REDACTED]

Reference: Family Responses to Home Apnea Monitoring

Dear Ms. Barnes:

Please be advised that the above referenced protocol which you submitted to me for review has been approved by the hospital and the Institutional Review Committee. I have provided the Neonatology Department through a separate letter the mechanics and terms that should be used in the study at Self Memorial. Please contact Dr. Terry Marshall who has agreed to assist with the implementation of the study.

If you have questions or if I can be of further assistance, please feel free to contact me.

Sincerely,

[REDACTED]  
Fred L. Latham  
Vice President and  
Chief Operating Officer

/bdm

a:Barnea89.wp

Continuing a Tradition of Excellence  
1325 Spring Street, Greenwood, South Carolina 29222-1000

February 29, 1996

**COPY**

MEMORANDUM:

TO: Marilyn Coleman, RN, M.P.H., District Nursing Director  
Upper Savannah Health District

FROM: Murray B. Hudson, M.P.H.  
Director, VRPHS/IRM

SUBJECT: Approval of Research

I have reviewed the dissertation research proposal submitted by you for IRB approval on behalf of Ms. Betsy M. Barnes, RN, MSN, CCRN, entitled "Family Responses to Home Apnea Monitoring: Family Functioning, Family Concerns, and Family Coping at Three Time Points". This study will delineate the concerns and responses of 40 families to having an infant on a home apnea monitor as perceived by the mother at three time points in the home apnea monitoring experience. It is the desire of Ms. Barnes to conduct this study in the Upper Savannah Health District. It is my understanding that the University of South Carolina College of Nursing's Ethics Committee has approved this study.

Federal and DHEC policies related to the protection of human subjects of studies are detailed in the "Belmont Report" which is reprinted in part in DHEC Administrative Policy Manual beginning on page 149. The policy relating to the Protection of Human Research Subjects begins on page 142 in this manual. Section II.f., beginning on page 144, outlines research that is eligible for Expedited Review.

**This is to certify that this research proposal has been reviewed by the IRB and approved (under Expedited Review, Section II.f.(9)) with respect to the study of human subjects as adequately protecting the rights and welfare of the individuals involved, employing adequate methods of securing informed consent from these individuals and not involving undue risk in the light of potential benefits to be derived therefrom.**

Approval of this research, however, is contingent upon agreement of the Principal Investigator to:

#1. report to the Institutional Review Board for Human Research (IRB) any adverse effect or research related injuries which might occur in relation to the human experimentation.

#2. submit in writing for prior IRB approval any alterations to the plan of human research.

#3. submit timely continuing review reports of this research as requested by the IRB.

#4. maintain copies of all pertinent information related to the research activities in this project, including copies of informed consent agreements obtained from all participants.

#5. notify the IRB immediately upon the termination of this project, and/or the departure of the principal investigator from this institution and the project.

cc: Betsy M. Barnes, RN, MSN, CCRN  
John M. Tennis, MD



2720 Sunset Boulevard  
West Columbia, SC 29169  
803-791-2000

June 5, 1996

Ms. Betsy Barnes, R.N.  
School of Nursing  
Lander University  
Greenwood, S.C. [REDACTED]

Reference: Family Responses to Home Apnea Monitoring

Dear Ms. Barnes:

Please be advised that the above referenced protocol which you submitted for review has been approved by the hospital.

If you have questions or if I can be of further assistance, please feel free to contact me.

Sincerely,

[REDACTED]  
Trudy Seylt, RN

Associate Director Women's/Children's Services

**PLEASE NOTE**

**Page(s) missing in number only; text follows.  
Filmed as received.**

**UMI**

## **APPENDIX B**

### **Informed Consent**



## INFORMED CONSENT

### **Family Responses to Home Apnea Monitoring: Family Functioning, Family Concerns, and Family Coping at Three Time Points**

You are asked to be in a study about home apnea monitoring. Ms. Betsy Barnes, RN is doing the study as part of her degree at the University of South Carolina. The purpose of the study is to find out the concerns of families with babies on home apnea monitors. Ms. Barnes will visit your house 3 times while your baby is on the apnea monitor. At each visit, you will be asked to fill out surveys about yourself and family. These surveys take about 45 to 55 minutes. You will be given a stamped envelope to mail the surveys to Ms. Barnes. Also you will be given a postcard to mail to Ms. Barnes when your baby comes off the apnea monitor.

You will get a snapshot of your baby after you send back each set of surveys. You will get a baby album after the last surveys. This study poses few risks to you or your baby. You may get tired filling out the surveys. If you do, rest and finish the surveys later. As an RN, Ms. Barnes must report any signs of injury to your baby. You do not have to answer all the questions. You can quit the study at any time. The staff at the sleep clinic will not know if you are in the study or not.

Your answers to the surveys are private. No reports of the study will use your name. You may have a copy of the results. No one will contact you after the study is over. If you have questions, you can call or write to Ms. Barnes at the numbers below.

---

I have read about the study. All of my questions have been answered. I received a copy of this consent form to keep. By signing my name below, I agree to be in the study.

---

Signature

---

Witness

---

Date

---

Date

I would like a copy of the results sent to me at:

---

---

---

Ms. Betsy M. Barnes, RN

Waterloo, SC

## **APPENDIX C**

### **Contact Letter to Prospective Parents**

Summer, 1996

Dear Mother of a Baby on a Home Apnea Monitor:

I am a graduate nursing student at the University of South Carolina. As part of my school work, I want to find out how families who have a baby on a home apnea monitor manage the baby and monitor. I would like your help with this study. The results of this study may help nurses and families better understand how families deal with home apnea monitoring.

If you are interested in taking part in this study, these are the things I need for you to do.

1. Consent to have Lexington Medical Center provide me with your name, address, & phone number.
2. I will contact you to set up my first visit to your home. I need to visit your home at 3 different times. I will visit soon after you take your baby home. I will visit again 3 months later. And I will visit after your baby comes off the apnea monitor.
3. At each visit, I will ask you to fill out some surveys. The surveys will take about 45 to 55 minutes to fill out. I will be happy to read them with you while I am at your home or you can fill them out after I leave. If you choose to fill them out after I leave your home, I will give you a stamped envelope to use.
4. At the second visit, I will give you a postcard to send me when your baby does not need the home apnea monitor any more.

If you choose to be in the study, you will receive a snapshot of your baby taken at the time of each home visit. After you have finished the third set of surveys, you will also receive a baby album to keep your pictures in. All information I get during the study is confidential. Also, you have the right to withdraw from the study at any time.

Thank you for your help. If you are interested in being in the study or if you want more information about the study, please call me. You also may call my faculty advisor, Dr. Sara Fuller, RN at USC at (803) [REDACTED]

Sincerely,

[REDACTED]

Betsy M. Barnes, RN, MSN, CCRN

[REDACTED]

Waterloo, SC [REDACTED]

(864) [REDACTED]

## **APPENDIX D**

### **Parent Perception Inventory**

### HYMOVICH'S PARENT PERCEPTION INVENTORY: GENERAL INFORMATION

CODE#

DATE:

The purpose of these questions is to find out some general information about your family that may be useful in helping you manage your child's care.

1. My child has been admitted to the hospital?
    - (0) never
    - (1) 1 time
    - (2) 2 - 4 times
    - (3) 5 - 7 times
    - (4) 8 or more times
  - 1b. How long ago was your child's last admission to the hospital?
    - (1) under 1 month
    - (2) 1 - 5 months
    - (3) 6 - 12 months
    - (4) over 1 year
  2. How many children do you have?
 

1	2	3	4	5	6
7	8	9	10	11 or more	
  3. How many of your children are under 5 years of age?
 

0	1	2	3	4 or more
---	---	---	---	-----------
  4. How many of your children are between 6 and 12 years of age?
 

0	1	2	3	4 or more
---	---	---	---	-----------
  5. How many of your children are 13 years of age or older?
 

0	1	2	3	4 or more
---	---	---	---	-----------
  6. In general, how has the health of your other children been during the past 3 months?
 

(1) Poor/Fair	(3) Very good
(2) Good	(4) Excellent
  7. How has your health been during the past 3 months?
 

(1) Poor/Fair	(3) Very good
(2) Good	(4) Excellent
  8. What is your religion?
 

(1) Catholic	(4) Other _____
(2) Jewish	(5) No religion
(3) Protestant	
  9. How often have you attended religious services in the past 3 months?
 

(1) Never	(3) Sometimes
(2) Rarely	(4) Often
  10. Are you employed now?
 

(1) No	(2) Yes
--------	---------
  - 10a. If yes, what do you do? (Please put the type of work you do, not where you work).
 

---
  - 10b. Do you work...
 

(1) full-time
(2) part-time
  11. Are you satisfied with your current employment status?
 

(1) No	(2) Not sure	(3) Yes
--------	--------------	---------
  12. What is your age?
 

(1) Under 18 years	(5) 35 - 39 years
(2) 19 - 24 years	(6) 40 - 44 years
(3) 25 - 29 years	(7) 45 - 49 years
(4) 30 - 34 years	(8) 50 years or over
  13. How much school have you completed?
 

(1) 7th grade or below
(2) 8th or 9th grade
(3) 10th or 11th grade
(4) high school graduate
(5) some college
(6) community college graduate
(7) college graduate
(8) masters or doctoral degree
  14. How would you describe yourself?
 

(1) White	(4) Spanish-American
(2) Asian	(5) Native American Indian
(3) Black	(6) Other (specify)

15. What is your family's yearly income?
- |                       |                       |
|-----------------------|-----------------------|
| (1) Under \$5,000     | (4) \$20,000-\$20,999 |
| (2) \$5,000-\$9,999   | (5) \$30,000-\$39,999 |
| (3) \$10,000-\$19,999 | (6) \$40,000 or more  |

16. What is your current marital status?
- |                 |               |
|-----------------|---------------|
| (1) Married     | (4) Separated |
| (2) Remarried   | (5) Divorced  |
| (3) Widowed     | (6) Single    |
| (Never married) |               |

17. For how many years have you been married?
- |                   |                   |
|-------------------|-------------------|
| (1) under 2 years | (3) 6 - 12 years  |
| (2) 2 - 5 years   | (4) over 12 years |

18. How many times have you been married?
- |     |     |                   |
|-----|-----|-------------------|
| (1) | (2) | (3) or more times |
|-----|-----|-------------------|

19. If you are separated or divorced, please answer the following questions.

- a. For how many years have you been separated or divorced?

- |                   |                   |
|-------------------|-------------------|
| (1) Under 2 years | (3) 7-12 years    |
| (2) 2-6 years     | (4) over 12 years |

- b. Were you separated or divorced before or after your child's condition was diagnosed?

- |            |           |
|------------|-----------|
| (1) Before | (2) After |
|------------|-----------|

20. In the past year, how often have you had to miss work to take care of your child?

- |                            |                          |
|----------------------------|--------------------------|
| (0) I do not work          | (2) 1-4 times a month    |
| (1) Less than once a month | (3) Over 4 times a month |

# HYMOVICH'S PARENT PERCEPTION INVENTORY: CONCERNS

CODE#

DATE:

This questionnaire is to help us learn more about what you do when caring for your child and how we can help you. Circle the right number for your answer or fill in the blank.

## PART I. CHILD CARE NEEDS

1. Child's age: \_\_\_\_\_ / \_\_\_\_\_  
(years) (months)
2. Child's sex: (1) male (2) female
3. What is your child's illness, condition or disability?
4. How severe is your child's condition?  
(1) not severe (slight)  
(2) moderately severe  
(3) very severe
5. How old was your child when the condition was diagnosed?  
(1) under 6mos (4) 4-5yrs 11mos  
(2) 6-11mos (5) 6-12yrs 11mos  
(3) 1-3yrs 11mos (6) 13yrs or older
6. How are you related to this child?  
(1) mother (6) foster mother  
(2) father (7) foster father  
(3) stepmother (8) grandmother  
(4) stepfather (9) grandfather  
(5) guardian (10) other \_\_\_\_\_
7. Does anyone else in your family have the same illness or disability as your child?  
(1) no (2) yes  
(7a) If YES, is it your child's:  
(1) mother (4) grandparent  
(2) father (5) cousins, aunts, uncles  
(3) brother or sister (6) other \_\_\_\_\_

8. Parents have asked for help with many aspects of their child's development and care, including those listed below. Please let us know if you want to discuss any of the following topics with the health care team.

TOPIC	(1) Do not need now	(2) Not Sure	(3) Would Like
Physical care of child	1	2	3
Diet or nutrition	1	2	3
Sleep habits	1	2	3
Genetic counseling	1	2	3
Care of minor illnesses	1	2	3
Dental needs	1	2	3
Play or recreation activities	1	2	3
Managing child's behavior	1	2	3
School or learning experiences	1	2	3

TOPIC	(1) Do not need now	(2) Not Sure	(3) Would like
Physical development	1	2	3
Social development	1	2	3
Emotional development	1	2	3
Intellectual development	1	2	3
Child's condition	1	2	3
Child's medicines	1	2	3
Child's treatments	1	2	3
Knowing when my child needs to see the doctor	1	2	3
Talking to my child about the condition	1	2	3

9. Is there anything else you would like information about? What?

Debra P. Hymovich (c) 1988

## PART II. CONCERNS AND RESOURCES

1. All parents have some concerns. During the past 3 months, how much have you been concerned with the following? Circle the number in the column that best explains your concern.

CONCERNS	(0) Does not apply	(1) Not Sure	(2) Little Bit	(3) Quite a Bit	(4) Great Deal
Extra demands on my time	0	1	2	3	4
Feeling worn out	0	1	2	3	4
Having enough fun and relaxation as I would like	0	1	2	3	4
Having enough time alone with my spouse or partner	0	1	2	3	4
Talking with or understanding my spouse or partner	0	1	2	3	4
Sexual relationship with my spouse or partner	0	1	2	3	4
Making my child comfortable or happy	0	1	2	3	4
Having enough time or attention from my spouse or partner	0	1	2	3	4
Getting out of house with spouse or partner but without children	0	1	2	3	4
Getting out of house by myself	0	1	2	3	4
Getting to do activities together as a family	0	1	2	3	4
Whether I am taking care of my child in the best way	0	1	2	3	4
Having to travel too far for medical help or child care	0	1	2	3	4
The weather affecting what my child can do	0	1	2	3	4
Having enough insurance to meet expenses of child care	0	1	2	3	4
Having the right agencies in the community to provide the care my child needs	0	1	2	3	4
Wondering what my child's future is likely to be	0	1	2	3	4
Worrying about the responsibility of caring for my child	0	1	2	3	4
Having enough money to meet my family's needs	0	1	2	3	4
Having money for extra pleasures	0	1	2	3	4
Having someone to talk with about my worries	0	1	2	3	4
Finding someone to stay with my child	0	1	2	3	4
Wondering about how my child feels about himself or herself	0	1	2	3	4



CONCERNS (Continued)	(0) Does not apply	(1) Not Sure	(2) Little Bit	(3) Quite a Bit	(4) Great Deal
Getting enough sleep for myself	0	1	2	3	4
Talking to my child about his/her condition	0	1	2	3	4
Talking with neighbors or friends about my child's condition	0	1	2	3	4
Wondering whether my other children will develop the same condition	0	1	2	3	4
The cost of my child's medical care	0	1	2	3	4
Wondering whether I will recognize important changes in my child's condition	0	1	2	3	4
Getting enough information about my child's condition	0	1	2	3	4
Helping my child cooperate with taking medicines or doing treatments	0	1	2	3	4
My spouse or partner's health	0	1	2	3	4
My own health	0	1	2	3	4
My child(ren)'s health	0	1	2	3	4

2. Are you a member of a parents' association related to your child's illness or disability?

(1) no (2) yes

- 2a. If YES, how often do you go to meetings?

(1) never (3) sometimes  
(2) rarely (4) often

- 2b. If you go to meetings, how helpful have they been?

(1) not at all (3) somewhat  
(2) not very (4) very

3. Do you have someone to take care of your child for a day in case of an emergency (such as if you become ill and cannot take care of your child)?

(1) no (2) not sure (3) yes

4. Do you have someone to take your child for a week or more in case of an emergency?

(1) no (2) not sure (3) yes

5. Do you have a regular baby sitter?

(1) do not need (2) no (3) yes

6. Are you responsible for the care of any other ill family members?

(1) no (2) yes, WHO? \_\_\_\_\_

7. How much time do you usually spend taking care of your child's health needs each day?

(1) less than 1 hr (4) 6-8 hrs  
(2) 1-2 hrs (5) over 8 hrs.  
(3) 3-5 hrs

HYMOVICH'S PARENT PERCEPTION INVENTORY: COPING  
(PPICOPS)

CODE#

DATE:

1. Parents cope with their concerns in many different ways. There are times when you may have more problems or concerns because of your child's needs. The first column has a list of some ways people cope. Coping means what a person does in order to make the situation better or to try to make oneself feel better.

1. If you do not use a coping method in the list, circle the 0 in the first column; and leave the center columns blank.
2. Circle the number that shows how often you used the coping method in the past 3 months when you had a problem related to your child's needs.

COPING	HOW OFTEN				HOW HELPFUL			
	(0) DO NOT DO THIS	(1) Very rarely	(2) Some- times	(3) Very often	(0) Never helps	(1) Sometimes helps	(2) Almost always helps	(3) Always Helps
Cry	0	1	2	3	0	1	2	3
Busy myself with other things	0	1	2	3	0	1	2	3
Talk with someone about feelings	0	1	2	3	0	1	2	3
Ignore/try to forget	0	1	2	3	0	1	2	3
Look at options	0	1	2	3	0	1	2	3
Get away for awhile	0	1	2	3	0	1	2	3
Hide feelings	0	1	2	3	0	1	2	3
Change my expectations	0	1	2	3	0	1	2	3
Blame someone	0	1	2	3	0	1	2	3
Yell/scream/slam doors, etc.	0	1	2	3	0	1	2	3
Exercise	0	1	2	3	0	1	2	3
Ask for help	0	1	2	3	0	1	2	3
Take alcohol or medicine	0	1	2	3	0	1	2	3
Pray	0	1	2	3	0	1	2	3
Blame myself	0	1	2	3	0	1	2	3
Ask questions	0	1	2	3	0	1	2	3
Use advice of others	0	1	2	3	0	1	2	3

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COPING	HOW OFTEN				HOW HELPFUL			
	(0) DO NOT DO THIS	(1) Very rarely	(2) Some- times	(3) Very often	(0) Never helps	(1) Sometimes helps	(2) Almost always helps	(3) Always Helps
Try to figure out what to do	0	1	2	3	0	1	2	3
Sleep	0	1	2	3	0	1	2	3
Find help	0	1	2	3	0	1	2	3
Smoke	0	1	2	3	0	1	2	3
Try to laugh or joke about it	0	1	2	3	0	1	2	3
Eat	0	1	2	3	0	1	2	3
Try to relax	0	1	2	3	0	1	2	3
Read about the problem	0	1	2	3	0	1	2	3
Wish problems would go away	0	1	2	3	0	1	2	3
Weigh choices	0	1	2	3	0	1	2	3
Get information	0	1	2	3	0	1	2	3
Try to change things	0	1	2	3	0	1	2	3

- In the past, what sources have you used for information or help related to your child's problems or needs? Circle all that apply.
 

(1) clergy	(9) Social worker
(2) Doctor	(10) Nutritionist
(3) Friend	(11) Therapist
(4) Nurse	(12) Library
(5) Teacher	(13) Newspaper / magazine
(6) Relatives or spouse	(14) Support group
(7) Pharmacist	(15) Community Agency
(8) Other parent	(16) Other
- How often have there been times when you did not know what to do to get information or help related to your child?
 

(0) Never	(2) Often
(1) Sometimes	(3) Always
- In general, how well do you believe you are coping with (managing) problems related to your child's care?
 

(1) Not well	(2) Well
--------------	----------
- In general, when you have problems related to your child's needs, how often are they things you can change or have some control over?
 

(1) Always	(3) Not very often
(2) Almost always	(4) Never
- In general, how well do you believe you are coping with (managing) your feelings and concerns about your child?
 

(0) Not well	(2) Well
(1) Fairly well	(3) Extremely well
- Would you like us to help you with any problems you are having?
 

(1) No	(2) Not sure	(3) Yes
--------	--------------	---------
- How satisfied are you with the way you are able to cope with the stresses you have?
 

(1) Very dissatisfied	(3) Satisfied
(2) Dissatisfied	(4) Very Satisfied

## HYMOVICH'S PARENT PERCEPTION INVENTORY: SPOUSE OR PARTNER CONCERN AND COPING

## PART I. SPOUSE OR PARTNER CONCERNS

CODE# \_\_\_\_\_

DATE: \_\_\_\_\_

1. All parents have some areas of concern. During the past 3 months, how much of a concern do you think the following areas have been for your spouse or partner? Circle the number in the column that best explains your spouse or partner's concern.

CONCERNS	(0) No/Does not apply	(1) Not Sure	(2) Little Bit	(3) Quite a bit	(4) Great deal
Extra demands on time	0	1	2	3	4
Feeling worn out	0	1	2	3	4
Having enough fun and relaxation as would like	0	1	2	3	4
Having enough time alone with you	0	1	2	3	4
Talking with or understanding you	0	1	2	3	4
Sexual relationship with you	0	1	2	3	4
Making your child comfortable or happy	0	1	2	3	4
Having enough time or attention from you	0	1	2	3	4
Getting out of house with you but without the children	0	1	2	3	4
Getting out of the house alone	0	1	2	3	4
Getting to do activities together as a family	0	1	2	3	4
Whether taking care of our child in the best way	0	1	2	3	4
Having to travel too far for medical help or child care	0	1	2	3	4
The weather affecting what child can do	0	1	2	3	4
Having enough insurance to meet expenses of child care	0	1	2	3	4
Having the right agencies in the community to provide the care our child needs	0	1	2	3	4
Wondering what our child's future is likely to be	0	1	2	3	4
Worries about the responsibility of caring for our child	0	1	2	3	4
Having enough money to meet the family's needs	0	1	2	3	4
Having money for extra pleasures	0	1	2	3	4
Having someone to talk with about worries or concerns	0	1	2	3	4
The cost of our child's medical care	0	1	2	3	4
His or her own health	0	1	2	3	4
Your health	0	1	2	3	4
The children's health	0	1	2	3	4
Talking to our child about his or her condition	0	1	2	3	4

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## PART II. SPOUSE OR PARTNER COPING

2. In general, how well do you believe your spouse or partner is coping with problems related to your child's needs?

(1) Not well    (2) Fairly well    (3) Very well

3. Parents cope with their concerns in many different ways. There are times when your spouse or partner may have more problems or concerns because of your child's needs. The first column is a list of some ways people cope (manage their problems). Circle the number in the column that shows how often your spouse or partner uses each of the coping methods.

COPING	(0) DOES NOT DO THIS	HOW OFTEN		
		(1) Very rarely	(2) Some- times	(3) Very often
Cry	0	1	2	3
Busy self with other things	0	1	2	3
Talk with someone about feelings	0	1	2	3
Ignore/try to forget	0	1	2	3
Look at options	0	1	2	3
Get away for awhile	0	1	2	3
Hide feelings	0	1	2	3
Change my expectations	0	1	2	3
Blame someone	0	1	2	3
Yell/scream/slam doors, etc.	0	1	2	3
Exercise	0	1	2	3
Ask for help	0	1	2	3
Take alcohol or medicine	0	1	2	3
Pray	0	1	2	3
Blame self	0	1	2	3
Ask questions	0	1	2	3

COPING	(0) DOES NOT DO THIS	HOW OFTEN		
		(1) Very rarely	(2) Some- times	(3) Very often
Use advice of others	0	1	2	3
Try to figure out what to do	0	1	2	3
Sleep more	0	1	2	3
Find help	0	1	2	3
Smoke	0	1	2	3
Try to laugh or joke about it	0	1	2	3
Eat	0	1	2	3
Try to relax	0	1	2	3
Read about the problem	0	1	2	3
Wish problem would go away	0	1	2	3
Weigh choices	0	1	2	3
Seek information	0	1	2	3
Try to change things	0	1	2	3

### PART III. GENERAL INFORMATION ABOUT SPOUSE

1. How old is your spouse or partner?
 

(1) under 18 years	(5) 35-39 years
(2) 19-24 years	(6) 40-44 years
(3) 25-29 years	(7) 45-49 years
(4) 30-34 years	(8) 50 years or over
2. Does your spouse or partner work?
  - (1) No
  - (2) Yes - If YES
3. What is your spouse or partner's occupation?  
(Please state what kind of work is done, not where he or she works).
4. How much school has your spouse or partner had?
  - (1) 7th grade or below
  - (2) 8th or 9th grade
  - (3) 10th or 11th grade
  - (4) high school graduate
  - (5) some college or community college
  - (6) community college graduate
  - (7) college graduate
  - (8) masters or doctoral degree
5. During the past 3 months, about how much time has your spouse or partner spent each day taking care of your child?
 

(1) less than 30 minutes	(4) 3 to 5 hours
(2) 30 minutes to 1 hour	(5) 6 to 8 hours
(3) 1 to 2 hours	(6) over 8 hours
6. During the past year how has your spouse or partner's health been?
 

(1) Poor/fair	(3) Very good
(2) Good	(4) Excellent
7. How satisfied are you with your relationship with your spouse or partner?
  - (1) very dissatisfied
  - (2) somewhat dissatisfied
  - (3) not sure
  - (4) somewhat satisfied
  - (5) very satisfied
8. What effect has the diagnosis of your child's condition had on your relationship with your spouse or partner?
  - (1) It has moved us apart
  - (2) I am not sure
  - (3) It has not changed
  - (4) It has brought us closer together
9. How do you and your spouse or partner usually make decisions about your child's care?
  - (1) you decide alone
  - (2) your spouse or partner decides alone
  - (3) you decide together

# HYMOVICH'S PARENT PERCEPTION INVENTORY: SIBLINGS

CODE#

DATE:

1. How much have each of the following been true of your child's brothers and sisters during the past three (3) months?

	(1) Does not apply	(2) Never true	(3) Some- times true	(4) Always true
Jealousy	1	2	3	4
Fight with each other	1	2	3	4
Protective of child	1	2	3	4
Anger	1	2	3	4
Worried about child	1	2	3	4
Worried about self	1	2	3	4
Helps with child's therapy	1	2	3	4
Teases	1	2	3	4

2. Please indicate if you would like to have help with, or discuss, any of the following in relation to any of your child's brothers or sisters.

HELP	(1) Do not need now	(2) Not sure	(3) Would like
Managing child's behavior	1	2	3
Physical needs	1	2	3
Emotional needs	1	2	3
Social needs	1	2	3
Intellectual needs	1	2	3
Helping child understand the other child's condition	1	2	3
Helping children get along	1	2	3

3. How much do you agree with each of the following statements?

	(0) Does not apply	(1) Strongly Agree	(2) Agree	(3) Not sure	(4) Disagree	(5) Strongly Disagree
It is hard to punish my children	0	1	2	3	4	5
It is hard to talk with my children about the child's condition	0	1	2	3	4	5
I worry about how my children react to my child's condition	0	1	2	3	4	5
I find it hard to manage my children's jealousy and fighting	0	1	2	3	4	5
It's hard to know how much to tell my children about the child's condition	0	1	2	3	4	5
I try not to talk about the condition with my children	0	1	2	3	4	5
I don't have much time to do things with my children	0	1	2	3	4	5
It's hard setting limits for my children	0	1	2	3	4	5

4. Are there other things you would like us to know about your children?

(1) No

(2) Yes, What?

5. Are there other areas you would like help with?

(1) No

(2) Yes, What?

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## HYMOVICH'S PARENT PERCEPTION INVENTORY

Hymovich's Parent Perception Inventory (PPI) consists of six instruments for use with families of children who have longterm disabilities or chronic illnesses. A modified version of these instruments, The PPI is a revised version of the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) (Hymovich, 1983; 1984; Hymovich & Baker, 1985). The CICI:PQ was modified to make the new version compatible with Hymovich's evolving Contingency Model for Long-Term Care (Hymovich, 1979, 1987; Hymovich & Hagopian, 1992).

The instruments of the PPI were developed so they could be used in their entirety or as separate instruments. Decisions regarding use of the entire PPI, or of selected instruments, will depend upon a number of factors. These factors include: (1) information needed by the researcher or clinician, (2) length of time available to complete the instruments, and (3) family structure (number of parents and children).

The PPI consists of the following six instruments:

CONCERNS (64 items)	GENERAL INFORMATION (30 items)
BELIEFS AND FEELINGS (34 items)	SIBLINGS (25 items)
COPING (60 items)	SPOUSE CONCERNS AND COPING (66)

The OBJECTIVES of the PPI and the PPI-M instruments are to obtain information from parents about:

### CONCERNS

- 1) Developmental topics about which parents want information or help.
- 2) General areas related to illness about which parents want help.
- 3) Concerns related to relationships with spouse and significant others.
- 4) Concerns related to resources.
- 5) Concerns related to child care.
- 6) Concerns related to parent's (respondent's) needs.

### GENERAL INFORMATION

- 1) Family composition and characteristics.
- 2) Relevance of the PPI to the parents.

### COPING

- 1) Frequency of selected coping strategies used by parents.
- 2) Helpfulness of parent coping strategies.
- 3) How well parents believe they are coping.

### BELIEFS AND FEELINGS

- 1) Beliefs about their child's condition.
- 2) Beliefs about ways of coping.
- 3) How often parents experience selected feelings.

### SPOUSE CONCERNS AND COPING

- 1) Perception of spouse concerns.
- 2) Perception of how spouse copes.
- 3) Change in spouse relationships since child's diagnosis.



SIBLINGS

- 1) Perceptions of sibling behavior.
  - 2) Perceptions of child rearing difficulties.
  - 3) Need for information or help related to siblings.
- 

READING LEVELS were obtained for each of the PPI instruments. The average grade reading level of entire set of instruments is grade 6.4. Results for each of the instruments are in Table 1.

Table 1. Reading Levels of the PPI

PPI SCALE	DALE-CHALL <sup>1</sup>	FOG <sup>2</sup>	FLESCH <sup>3</sup>	FRY <sup>4</sup>	SMOG <sup>5</sup>	AV 1,2,3
CONCERNS	7.3	5.7	6.3	3	5	6.4
BELIEF/FEELING	9.1	4.9	7.4	--	5	7.1
COPE	6.7	4.4	6.4	3	5	5.8
GENERAL INFOR- MATION	6.5	5.9	6.8	3	5	6.4
SIBLINGS	6.5	6.3	6.6	3	5	6.5
SPOUSE	7.9	4.3	6.2	3	5	6.2

<sup>1</sup>Dale-Chall Index: measure of reading ease

<sup>2</sup>Flesch Index: estimate of reading & grade level

<sup>3</sup>Fog Index: measure of reading ease

<sup>4</sup>Fry Index: estimate of reading grade level

<sup>5</sup>Smog Index: grade level necessary to fully understand material

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Initial RELIABILITY data for the PPI were obtained from 22 parents of children with cystic fibrosis (12 mothers, 10 fathers). Cronbach's alpha was used to determine internal consistency reliability and t-tests were used to obtain test-retest reliability. Results of the available data are in Table 2.

Table 2. Means, Standard Deviations, and Ranges of the PPI

Scale	N	Items Mean	SD	Range	Theoretical Range	Alpha	Test Retest
CHILDHELP	16	28.4	9.8	18-48	18-54	.92	.86
SELFCONCERN	18	61.64	24.6	24-101	0-136	.88	.82
BELIEFS	12	21.73	3.0	16-29	12-36	.33	
FEELINGS	22	24.05	9.3	5-45	0-66	.88	.74
SELFCOPE	21	50.00	6.8	29-57	21-84	.62	.78
COPEHELPPFUL	21	38.64	7.3	27-51	21-84	.80	.84
SPOUCONCERN	26	58.82	3.2	34-93	0-104	.88	.92
SPOUCOPE	21	49.27	7.6	38-64	21-84	.66	.82
SPOUCOPEHELP	21	37.23	7.7	22-57	21-84	.78	
SIBBEHAVIOR	8	15.17	3.6	7-20	0-24	.72	
SIBHELP	7	12.44	4.9	7-20	7-21	.90	
SIBRELATIONS	8	22.25	7.0	12-36	0-40	.67	

Additional reliability and validity data are being studied and results should be available fall 1994. If you are using the instrument and have returned your contract, these will be sent to you.

\*\*\*\*\*

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Van Cleve, L. (1989). Parental response to their child's spina bifida. Journal of Pediatric Nursing, 4, 172- 176.

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Copies of the Parent Perception Inventory-Modified and guidelines for use are available for \$20.00 within the United States and Canada and \$25.00 (U.S. currency)\* in foreign countries from:

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Professor  
College of Nursing  
University of North Carolina at Charlotte  
Charlotte, NC 28223

\* Make checks payable to UNC Charlotte College of Nursing

# CODEBOOK

## HYMOVICH'S PARENT PERCEPTION INVENTORY: CONCERNS (PPICONC)

VAR NAME	COLUMN WIDTH	QUESTION NUMBER	VALUES and CODING INFORMATION
CODE	3	code no	001-999 if two parents in family, give same number
FAMID	3		001-999
PARID	1		1=mother, 2=father, 9=missing
CHAGEYR	2	1 age	01-20, 99=missing
CHAGEMO	2	1 age	01-12, 99=missing
CHSEX	1	2 sex	1=male, 2=female, 9=missing
DIAG	3	3 disability	999=missing [see last page 2 for disability codes]
SEVERTY	1	4 severity	1=not sev, 2=moderate, 3=very, 9=missing
AGEDIAG	1	5 age diagnosed	1=under 6mo, 2=6-11mos, 3=1-1.11yr, 4=4-5.11yr, 5=6-12.11yr, 6=13+ yrs, 9=missing
RELAT	1	6 relationship to child	1=mother, 2=father, 3=stepmother, 4=stepfather, 5=guardian, 6=foster mother, 7=foster father, 8=grandmother, 9=grandfather, 0=other
OTHER	1	7 same diagnosis	1=no, 2=yes, 9=missing
OTHMO	1	7a who has same	) 1=checked, 2=not checked
OTFA	1		
OTSIB	1	diagnosis	
OTGP	1		
OTCOUS	1		
OTOTHER	1		
H1-H18	1 each total of 18 columns	8 want help	1=not need, 2=not sure, 3=would like, 9=missing
INFO	1	9 anything else	1=yes, 2=no, 9=missing
WHAT	2	9 what	code according to you own categories
CON1-CON34	1 each total of 34 columns	Part II 1 concerns	0=not apply, 1=not sure, 2=little bit 3=quite a bit, 4=great deal, 9=missing
ASSOC	1	2 member assoc	1=no, 2=yes, 9=missing
ATTEND	1	2a go to meetings	1=never, 2=rarely, 3=sometimes, 4=often
HELPFL	1	2b how helpful	1=not at all, 2=not very, 3=somewhat 4=very, 9=missing
CAREDAY	1	3 care for day	1=no, 2=not sure, 3=yes, 9=missing
CAREWK	1	4 care for week	1=no, 2=not sure, 3=yes, 9=missing
SITTER	1	5 regular sitter	1=do not need, 2=no, 3=yes, 9=missing
OTHRESP	1	6 care other ill	1=no, 2=yes, 9=missing
1	who		use own values for "WHO"
TIME	1	7 time for child's health needs	1=less 1 hour, 2=1-2 hours, 3=3-5 hours 4=6-8 hours, 5=over 8 hours, 9=missing

CODES FOR PPICOND ITEM 3. CHILD'S DISABILITY

00 Cardiovascular	50 Neurological (except)
01 Congenital heart disease	brain tumors)
02	51 Blindness (tot/part)
03	52 Cerebral palsy
04	53 Deafness (tot/part)
	54 Hydrocephalus
10 Gastrointestinal	55 Seizures (epilepsy)
11 Biliary atresia	56 Spina bifida
12 Hepatitis	57 Spina bif & Hydroceph
13	58
14	59
20 Hematologic (excluding	70 Renal disorders
malignancies)	71
21	72
22	73
30 Immune metabolic disorders	80 Respiratory disorders
31 AIDS	81 Apnea
32 Diabetes mellitus	82 Asthma
33	83 Cystic fibrosis
34	84
35	85
40 Malignancies	90 Miscellaneous
41 Hodgkin's	91
42 Leukemia (ALL)	92
43 Solid tumors	93
44 Leukemia (other)	94
45 Brain tumors	95

Add any additional codes you need and send copy of your codes

\*\*\*\*\*

CODEBOOK

HYMOVICH'S PARENT PERCEPTION INVENTORY: BELIEFS AND FEELINGS (PPIFEEL)

VAR NAME	COLUMN WIDTH	QUESTION NUMBER	VALUES and CODING INFORMATION
CODE	3	code no	001-999 if two parents in family, give same number
FAMID	3		001-999
PARID	1		1=mother, 2=father, 9=missing
81-812	1 each total of 12 columns	1 beliefs	1=agree, 2=not sure, 3=disagree, 9=missing
F1-F22	1 each total of 22 columns	2 feelings	0=not at all, 1=not often, 2=often, 3=very often 9=missing

## CODEBOOK

## HYMOVICH'S PARENT PERCEPTION INVENTORY: COPING (PP(COPE))

VAR NAME	COLUMN WIDTH	QUESTION NUMBER	VALUES and CODING INFORMATION
CODE FAMID	3 3	code no	001-999 if two parents in family, give same number 001-999
PARID	1		1=mother, 2=father, 9=missing
COFRQ1- COFRQ29	1 each total of 29 columns	1.1 cope how often	0=do not do, 1=very rarely, 2=sometimes, 3=very often, 9=missing
COHLP1- COHLP29	1 each total of 29 columns	1.2 cope helpful	0=never helps, 1=sometimes, 2=almost always, 3=always, 9=missing
PAST1- PAST16	1 each total of 16 columns	1 sources in past	0=not checked, 1=checked
NOTKNOW	1	2 not know what do	0=never, 1=sometimes, 2=often, 3=always, 9=missing
COPEPROB	1	3 cope child care problems	0=not well, 1=fairly well, 2=well, 3=extremely well, 9=missing
CONTROL	1	4 have some control	1=always, 2=almost always, 3=not very often, 4=never, 9=missing
COPEFEEL	1 cope with	5 cope feelings	0=not well, 1=fairly well, 2=well, 3=extremely well, 9=missing
WANTHELP	1	6 want help	1=no, 2=not sure, 3=yes, 9=missing
SATCOPE	1	7 satisfied coping	1=very dissatisfied, 2=dissatisfied, 3=satisfied, 4=very satisfied, 9=missing

## CODEBOOK

## HYMOVICH'S PARENT PERCEPTION INVENTORY: SIBLINGS (PP(SIB))

VAR NAME	COLUMN WIDTH	QUESTION NUMBER	VALUES and CODING INFORMATION
CODE FAMID	3 3	code no	001-999 if two parents in family, give same number 001-999
PARID	1		1=mother, 2=father, 9=missing
SIBBEH1- SIBBEH8	1 total of 8 columns	1 how true of brothers & sisters	0=not apply, 1=never true, 2=sometimes true, 3=always true, 9=missing
SIBHLP1- SIBHLP7	1 total of 7 columns	2 want help	1=do not need now, 2=not sure, 3=would like, 9=missing
SIBAGRE1- SIBAGRE8	1 total of 8 columns	3 agree with following	0=not apply, 1=strongly agree, 2=agree, 3=not sure, 4=disagree, 5=strongly disagree, 9=missing
SIBOTHER	1	4 other things want to know	1=no, 2=yes, 9=missing
HELPSIB	1	5 other areas help	1=no, 2=yes, 9=missing
SIBWHAT	1	5 what help	use own values for "what"

## CODEBOOK

HYMOVICH'S PARENT PERCEPTION INVENTORY: GENERAL INFORMATION  
(PP1INFO)

VAR NAME	COLUMN WIDTH	QUESTION NUMBER	VALUES and CODING INFORMATION
CODE	3	code no	001-999 if two parents in family, give same number
FAMID	3		001-999
PARID	1		1=mother, 2=father, 9=missing
HOSP	1	1 admitted to hosp	0=never, 1=1 time, 2=2-4 times, 3=5-7 times, 4=8 or more, 9=missing
ADM	1	1b how long ago	1=under 1 mo, 2=1-5 mos, 3=6-12 mos, 4=over 1 yr, 9=missing
#CHLDRN	2	2 number children	01 - 10, 11=11 or more, 99=missing
CHPRE	1	3 children under 5	1-3, 4=4 or more, 9=missing
CHSCH	1	4 children 6-12 yrs	1-3, 4=4 or more, 9=missing
CHTEEN	1	5 children over 13	1-3, 4=4 or more, 9=missing
HLTHCH	1	6 children's health	1=poor/fair, 2=good, 3=very good, 4=excellent, 9=missing
HLTHSELF	1	7 your health	1=poor/fair, 2=good, 3=very good, 4=excellent, 9=missing
RELIG	1	8 your religion	1=Catholic, 2=Jewish, 3=Protestant, 4=Other, 5=No relig, 9=missing
ATTEND	1	9 attend services	1=never, 2=rarely, 3=sometimes, 4=often, 9=missing
EMPLOY	1	10 employed now	1=no, 2=yes, 9=missing
OCCUP	1	10a occupation	use own coding scheme and let me know what it is
AMTWORK	1	10b do you work	1=full-time, 2=part-time, 9=missing
JOBSAT	1	11 satisfied status	1=no, 2=not sure, 3=yes, 9=missing
SELFAGE	1	12 your age	1=under 18 yrs, 2=19-24 yrs, 3=25-29 yrs, 4=30-34 yrs, 5=35-39 yrs, 6=40-44 yrs, 7=45-59 yrs, 8=50 yrs or over, 9=missing
SELFEDUC	1	13 school completed	1=7th or below, 2=8-9th grade, 3=10-11th grade, 4=high school grad, 5=some college, 6=commun col grad, 7=college grad, 8=masters/doc, 9=missing
RACE	1	14 how describe self	1=white, 2=Asian, 3=black, 4=Span-AM, 5=Lat Am Indian, 6=Other, 9=missing
INCOME	1	15 family income	1=under \$5,000, 2=\$5000-\$9999, 3=\$10,000-\$19,999, 4=\$20,000-\$29,999, 5=\$30,000-\$39,999, 6=\$40,000 or more, 9=missing
MARSTAT	1	16 current marital	1=married, 2=remarried, 3=widowed, 4=separated, 5=divorced, 6=single, 9=missing
YRSMAR	1	17 number years	1=under 2 yrs, 2=2-5 yrs, 3=6-12 yrs, 4=over 12 yrs, 9=missing
TINEMAR	1	18 times married	1=1, 2=2, 3=3 or more, 9=missing
YRSSEP	1	19a yrs separated	1=under 2 yrs, 2=2-6 yrs, 3=7-12 yrs, 4=over 12 yrs, 9=missing
SEPDIAG	1 separated before diagnosis	19b sep before diag	1=before, 2=after, 9=missing
MISSWORK	1	20 miss work care to care for child	0=do not work, 1=less than 1 time/month, 2=1-4 times/month, 3=over 4 times/month, 9=missing

# CODEBOOK

## HYMOVICH'S PARENT PERCEPTION INVENTORY: SPOUSE (PPISPOU)

VAR NAME	COLUMN WIDTH	QUESTION NUMBER	VALUES and CODING INFORMATION
CODE	3	code no	001-999 if two parents in family, give same number
FAMID	3		001-999
PARID	1		1=mother, 2=father, 9=missing
SPCON1- SPCON26	1 each total of 26 columns	Part II 1 spouse concern	0=not apply, 1=not sure, 2=little bit, 3=quite a bit, 4=great deal, 9=missing
SPCOPE	1	2 how well spouse coping	1=not well, 2=fairly well, 3=very well, 9=missing
SPC01- SPC029	1	3 spouse coping how often	0=does not do, 1=very rarely, 2=sometimes, 3=very often, 9=missing
SPAGE	1	Part III 1 spouse age	1=under 18 yrs, 2=19-24 yrs, 3=25-29 yrs, 4=30-34 yrs, 5=35-39 yrs, 6=40-44 yrs, 7=45-49 yrs, 8=50 yrs or over, 9=missing
SPEMPL	1	2 spouse work	1=no, 2=yes, 9=missing
SPOCCUP	1	3 spouse occupation	use own coding scheme and let me know what it is
SPEDUC	1	4 spouse years school	1=7th or below, 2=8-9th grade, 3=10-11th grade, 4=high school grad, 5=some college, 6=commun col grad, 7=college grad, 8=masters/doc, 9=missing
SPCARE	1	5 time take care of child	1=under 30 min, 2=30 mins-1 hr, 3=1-2 hrs, 4=3-5 hrs, 5=6-8 hrs, 6=over 8 hrs, 9=missing
SPHLTH	1	6 spouse health	1=poor/fair, 2=good, 3=very good, 4=excellent, 9=missing
RELATSP	1	7 satisfied with relationship	1=very dissat, 2=somewhat dissat, 3=not sure, 4=somewhat satisf, 5=very satisfied, 9=missing
DECIDE	1	9 how make decision	1=alone, 2=spouse alone, 3=together, 9=missing



# HYMOVICH'S PARENT PERCEPTION INVENTORY

## SCALE SCORES

PPI	Scale	Number	Question of Items	Score Number
Ranges				
PPICONC				
PART I	HELP	18	8	18-54
PART II	CONCERNS RESOURCES & RESPONSIBILITIES	34 6	1 2-7	0-136 7-25
PPIFEEL	BELIEFS	12	1	12-36
	FEELINGS	22	*2	0-66
(reverse scoring of items: confident, content, good, happy, hopeful, in control, lucky, pleased, satisfied)				
PPICOPE	HOWOFTEN	29	1.1	0-87
	HOWHELP	29	1.2	0-87
	DOPAST	16	1	0-16
	ABLECOPE	8	2-7	3-20
(reverse scoring of items 2,4,6)				
To obtain a total cope frequency scale, count number of strategies used under HOWOFTEN				
To obtain overall coping effectiveness, multiply HOWOFTEN by HOWHELP				
PPIINFO	(NO SCALE SCORES)			
PPISPOU	SPOUCONC	26	1	0-104
	SPOUCOPE	29	3	0-87
PPISIB	SIBBEHAV	8	1	0-24
	SIBHELP	7	2	7-21
	SIBCONC	8	3	0-40

## **APPENDIX E**

### **Feetham Family Functioning Survey**

# Feetham Family Functioning Survey

Feetham Family Functioning Survey  
Rev. 3/83  
Suzanne L. Feetham, Ph.D., R.N., F.A.A.N.  
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Children's Hospital National Medical Center  
111 Michigan Avenue, N.W.  
Washington, D.C. 20010

Developed in part through Research Funding H.H.S., U.S.P.H.S.,  
Division of Nursing NU00632

Suzanne L. Feetham, Ph.D., R.N., F.A.A.N.  
Children's Hospital National Medical Center  
Washington, D.C. 20010

Family Code \_\_\_\_\_

In this survey you are asked to rate activities (functions) that occur in your family and with family members. For *each* family function you are asked to answer three questions:

How much is there now?

How much should there be?

How important is this to you?

Please answer *all three* questions for *each* family function by circling the number which represents how you feel *now* about the family function.

The term spouse refers to your husband or wife or the person who assumes the functions of a spouse. If you do not have a person in the spouse role answer the questions based on how much you want the functions met.

Please try to answer all items.

1. The amount of discussion with your *friends* regarding your concerns and problems.

a. How much is there now?

Little Much  
1 2 3 4 5 6 7

b. How much should there be?

Little Much  
1 2 3 4 5 6 7

c. How important is this to you?

Little Much  
1 2 3 4 5 6 7

2. The amount of discussion with your *relatives* regarding your concerns and problems (do not include your spouse).

a. How much is there now?

Little Much  
1 2 3 4 5 6 7

b. How much should there be?

Little Much  
1 2 3 4 5 6 7

c. How important is this to you?

Little Much  
1 2 3 4 5 6 7

(X)

3. The amount of time you spend with your *spouse*.

a. How much is there now?  
 Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
 Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
 Little 1 2 3 4 5 6 7 Much

4. The amount of discussion of your concerns and problems with your *spouse*.

a. How much is there now?  
 Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
 Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
 Little 1 2 3 4 5 6 7 Much

5. The amount of time you spend with *neighbors*.

a. How much is there now?  
 Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
 Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
 Little 1 2 3 4 5 6 7 Much

6. The amount of time *you* spend in leisure/recreational activities.

a. How much is there now?  
 Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
 Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
 Little 1 2 3 4 5 6 7 Much

7. The amount of help from your *spouse* with family tasks such as care of children, house repairs, household chores, etc

a. How much is there now?  
 Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
 Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
 Little 1 2 3 4 5 6 7 Much

8. The amount of help from *relatives* with family tasks such as care of children, house repairs, household chores, etc. (*do not include spouse*).

a. How much is there now?  
 Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
 Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
 Little 1 2 3 4 5 6 7 Much

9. The amount of time with *health professionals* (doctors, nurses, social workers, etc.).

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

10. The amount of help from your *friends* with family tasks such as care of children, house repairs, household chores, etc.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

If you don't have a *child(ren)*, check here \_\_\_\_\_ and omit questions 11, 12 and 13.

11. The number of problems with your *child(ren)*.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

12. The amount of time you spend with your *child(ren)*.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

If you do not have a *child* in school, check here \_\_\_\_\_ and omit question 13.

13. The amount of time your *child(ren)* miss school.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

14. The number of disagreements with your *spouse*.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

15. The amount of time *you* are ill.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

16. The amount of time *you* spend doing housework (cooking, cleaning, washing, yardwork, etc.)

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

17. The amount of time *you* miss work (including housework).

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

18. The amount of time your *spouse* misses work (including housework).

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

19. The amount of emotional support from *friends*.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

20. The amount of emotional support from *relatives*.

a. How much is there now?  
Little 1 2 3 4 5 6 7 Much

b. How much should there be?  
Little 1 2 3 4 5 6 7 Much

c. How important is this to you?  
Little 1 2 3 4 5 6 7 Much

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21. The amount of emotional support from your *spouse*.

a. How much is there now?  
 Little 1 2 3 4 5 6 Much 7

b. How much should there be?  
 Little 1 2 3 4 5 6 Much 7

c. How important is this to you?  
 Little 1 2 3 4 5 6 Much 7

22. The amount of time *your* work routine is disrupted (including housework).

a. How much is there now?  
 Little 1 2 3 4 5 6 Much 7

b. How much should there be?  
 Little 1 2 3 4 5 6 Much 7

c. How important is this to you?  
 Little 1 2 3 4 5 6 Much 7

23. The amount of time your *spouse's* work routine is disrupted (including housework).

a. How much is there now?  
 Little 1 2 3 4 5 6 Much 7

b. How much should there be?  
 Little 1 2 3 4 5 6 Much 7

c. How important is this to you?  
 Little 1 2 3 4 5 6 Much 7

24. The amount of satisfaction with *your* marriage.

a. How much is there now?  
 Little 1 2 3 4 5 6 Much 7

b. How much should there be?  
 Little 1 2 3 4 5 6 Much 7

c. How important is this to you?  
 Little 1 2 3 4 5 6 Much 7

25. The amount of satisfaction with the sexual relations with your *spouse*.

a. How much is there now?  
 Little 1 2 3 4 5 6 Much 7

b. How much should there be?  
 Little 1 2 3 4 5 6 Much 7

c. How important is this to you?  
 Little 1 2 3 4 5 6 Much 7

26. What is most *difficult* for you now?

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27. What is most *helpful* for you now?

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b

Feetham Family Functioning Survey  
Suzanne L. Feetham, Ph.D., R.N., F.A.A.N  
Children's Hospital National Medical Center  
Washington, D.C.

Developed under agent #N0063  
H.H.S., U.S.P.H.S. Division of Nursing  
1977-1980. Wayne State University, Detroit.  
Center for Health Research  
Rev. 3/1/83, 5/88

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CHNMC 511 2x

Feetham Family Functioning Survey  
FFFS

SCORING

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The score for the Feetham Family Functioning Survey is calculated by determining a total family functioning discrepancy score based on summing scores from the individual items. The discrepancy score for each item is calculated by determining the difference between the A (how much is there) and B (how much should there be) score. The difference between each A and B score is converted to an absolute score and then these scores for each item are summed for the instrument score. The importance score is not included in the instrument score.

In addition to the total discrepant score, other scoring procedures can be conducted based on the research question. For example, if family members perceive that there is too much or too little of a function, this information may be significant for the research question. In this case, the scores can be left as positive or negative scores.

From a clinical perspective the importance score can indicate areas for intervention. For example, a family member may have a high discrepant score (A-B) on items related to expectations of friends and a high importance score for these same items. Such high discrepancy scores and high importance scores for related items may indicate a need for further assessment and intervention.

The instrument can be used to measure family functioning in single parent families. The respondent scores the spouse-related items in the context of expectation for a person in the spouse role. For example, if the person does not expect to have someone in the spouse role, then the A (how much is there ?) is scored low and the B (how much should there be ?) is scored low. This would result in a low or zero discrepant score for the spouse-related items. In contrast a respondent could score the A (how much is there ?) as low and the B (how much should there be ?) as high. This would result in high discrepant scores for the spouse items.

## **APPENDIX F**

### **Early Infancy Temperament Questionnaire**

# EARLY INFANCY TEMPERAMENT QUESTIONNAIRE

(for 1 to 4 month old infants)

Developed 1985 - 1990

by

Barbara Medoff-Cooper, Ph.D., William B. Carey, M.D.,  
and Sean C. McDevitt, Ph.D.

	<input type="text"/>	Sex:	<input type="text"/>
Date of Birth:	<input type="text"/>	Present Age:	<input type="text"/>
	<input type="text"/>		<input type="text"/>
Date of Rating:	<input type="text"/>		

The purpose of this questionnaire is to determine the general pattern of your infant's reactions to his/her environment.

The questionnaire consists of several pages of statements about your infant. Please circle the number indicating the frequency with which you think the statement is true for your infant. Although some of the statements seem to be similar, they are not the same and should be rated independently. If any item cannot be answered or does not apply to your infant, just draw a line through it. If your infant has changed with respect to any of the areas covered, use the response that best describes the recently established pattern. There are no good and bad or right and wrong answers, only descriptions of what your infant does. When you have completed the questionnaire, which will take about 25-30 minutes, you may make any additional comments at the end.

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SCORING GUIDE						
Almost Never	Rarely	Variable, usually does not	Variable, usually does	Frequently		Almost Always
1	2	3	4	5		6
1. The infant lies still (little squirming) when held in mother's arms between feedings.			Almost never	1	2 3 4 5 6	Almost always
2. The infant's fussy period occurs at about the same time of day (morning, afternoon, night).			Almost never	1	2 3 4 5 6	Almost always
3. For the first few minutes in a new place or situation (new store or home) the infant is fretful.			Almost never	1	2 3 4 5 6	Almost always
4. The infant accepts face washing at any time without protest.			Almost never	1	2 3 4 5 6	Almost always
5. The infant's hunger cry is a scream rather than a whimper.			Almost never	1	2 3 4 5 6	Almost always
6. The infant cries when awake and left alone.			Almost never	1	2 3 4 5 6	Almost always
7. The infant repeats vocalization (coos, babbles) for several minutes.			Almost never	1	2 3 4 5 6	Almost always
8. The infant continues to fuss during diaper change in spite of efforts to distract him/her with patting or singing.			Almost never	1	2 3 4 5 6	Almost always
9. The infant indicates discomfort (fusses or squirms) when diaper is soiled with bowel movement.			Almost never	1	2 3 4 5 6	Almost always
10. The infant lies still (little squirming) during hair brushing.			Almost never	1	2 3 4 5 6	Almost always
11. The infant gets sleepy about the same time each evening (within 1/2 hour).			Almost never	1	2 3 4 5 6	Almost always
12. The infant appears bothered (cries, squirms) when first put down to sleep in a different place than usual.			Almost never	1	2 3 4 5 6	Almost always
13. The infant resists (squirms, pulls away) hair brushing.			Almost never	1	2 3 4 5 6	Almost always
14. The infant vigorously cries when sleepy.			Almost never	1	2 3 4 5 6	Almost always
15. The infant is pleasant (coos, smiles) during face washing.			Almost never	1	2 3 4 5 6	Almost always
16. The infant will continuously look at mobile or toy in crib for 5 minutes or more.			Almost never	1	2 3 4 5 6	Almost always
17. The infant continues to resist when getting dressed and undressed despite efforts to distract him/her (singing, talking).			Almost never	1	2 3 4 5 6	Almost always
18. The infant reacts even to gentle touch (startles, laughs, wiggles).			Almost never	1	2 3 4 5 6	Almost always

SCORING GUIDE						
Almost Never	Rarely	Variable, usually does not	Variable, usually does	Frequently	Almost Always	
1	2	3	4	5	6	
19. The infant moves about much (kicks, waves arms, squirms) during dressing and undressing.			Almost never	1 2 3 4 5 6	Almost always	
20. The infant wants and takes milk feedings at about the same times (within one hour) from day to day.			Almost never	1 2 3 4 5 6	Almost always	
21. The infant objects (cries, frets) if someone other than main caregiver gives care.			Almost never	1 2 3 4 5 6	Almost always	
22. The infant adjusts to change in sleep time within 2 or 3 days.			Almost never	1 2 3 4 5 6	Almost always	
23. The infant displays much feeling (vigorous smile or cry), when dressing and undressing.			Almost never	1 2 3 4 5 6	Almost always	
24. The infant is fussy during a bath (cries, frowns).			Almost never	1 2 3 4 5 6	Almost always	
25. The infant will continuously watch parents during diaper changing.			Almost never	1 2 3 4 5 6	Almost always	
26. If fussing in bath, infant will continue to protest despite efforts to quiet him (talking, singing to him/her).			Almost never	1 2 3 4 5 6	Almost always	
27. The infant reacts (startles, stares) to sudden change in lighting (turning on light).			Almost never	1 2 3 4 5 6	Almost always	
28. The infant lies still (little kicking, splashing) in bath.			Almost never	1 2 3 4 5 6	Almost always	
29. The infant's time of waking in the morning varies greatly (by 1 hour or more) from day to day.			Almost never	1 2 3 4 5 6	Almost always	
30. The infant turns head away and looks for mother when held by new person.			Almost never	1 2 3 4 5 6	Almost always	
31. The infant adjusts to change in place of sleeping within 2 or 3 days.			Almost never	1 2 3 4 5 6	Almost always	
32. The infant displays much feeling (vigorous smile or cry) during diapering.			Almost never	1 2 3 4 5 6	Almost always	
33. The infant is fussy when put down for sleep (cries, frets).			Almost never	1 2 3 4 5 6	Almost always	
34. The infant continuously watches parents during changing of clothes.			Almost never	1 2 3 4 5 6	Almost always	
35. The infant's hunger cry can be stopped for over a minute by picking up or giving pacifier.			Almost never	1 2 3 4 5 6	Almost always	
36. The infant reacts (startles, cries) to sudden loud noises.			Almost never	1 2 3 4 5 6	Almost always	
37. The infant moves much (squirms, bounces, kicks) when lying awake in crib.			Almost never	1 2 3 4 5 6	Almost always	

SCORING GUIDE						
Almost Never	Rarely	Variable, usually does not	Variable, usually does	Frequently		Almost Always
1	2	3	4	5		6
38. The infant takes daytime naps at differing times (over 1 hour difference) from day to day.			Almost never	1	2 3 4 5 6	Almost always
39. The infant does not feed well (fusses) when in new situation.			Almost never	1	2 3 4 5 6	Almost always
40. The infant objects (fusses, squirms) to being bathed by a different person even after 2 or 3 tries.			Almost never	1	2 3 4 5 6	Almost always
41. The infant is noisy (vocalizing loudly) on waking up.			Almost never	1	2 3 4 5 6	Almost always
42. The infant is fussy when burped (cries, fusses) during feeding.			Almost never	1	2 3 4 5 6	Almost always
43. The infant persistently (over 5 minutes) watches parent's face while parent is talking or singing.			Almost never	1	2 3 4 5 6	Almost always
44. The infant can be distracted (singing, patting) from fussing or squirming during hair brushing.			Almost never	1	2 3 4 5 6	Almost always
45. The infant notices (quiets, turns head) to music or voices in the next room.			Almost never	1	2 3 4 5 6	Almost always
46. The infant moves about much (kicks, waves arms, squirms) during diapering.			Almost never	1	2 3 4 5 6	Almost always
47. The infant wants an extra feeding at a different time each day (over 1 hour difference).			Almost never	1	2 3 4 5 6	Almost always
48. The infant accepts right away a change in time of feeding.			Almost never	1	2 3 4 5 6	Almost always
49. The infant resist changes in feeding schedule (1 hour or more) even after two tries.			Almost never	1	2 3 4 5 6	Almost always
50. The infant cries loudly when diaper is soiled with bowel movement.			Almost never	1	2 3 4 5 6	Almost always
51. The infant lies quietly, making happy noises upon waking up.			Almost never	1	2 3 4 5 6	Almost always
52. The infant continuously turns head toward the sound of a person talking (for 5 minutes or more).			Almost never	1	2 3 4 5 6	Almost always
53. The infant can be soothed (patted, rocked) when sleepy.			Almost never	1	2 3 4 5 6	Almost always
54. The infant notices (reacts differently) to a change in person giving care.			Almost never	1	2 3 4 5 6	Almost always
55. The infant moves much during feeding (squirms, kicks, waves arms).			Almost never	1	2 3 4 5 6	Almost always
56. The infant sucks for the same amount of time during a feeding (within 10 minutes).			Almost never	1	2 3 4 5 6	Almost always
57. The infant accepts his/her bath any time or day without resisting.			Almost never	1	2 3 4 5 6	Almost always
58. The infant cries during a bowel movement.			Almost never	1	2 3 4 5 6	Almost always
59. The infant watches parent's face for less than a minute during parent-child play activity.			Almost never	1	2 3 4 5 6	Almost always

SCORING GUIDE						
Almost Never	Rarely	Variable, usually does not	Variable, usually does	Frequently		Almost Always
1	2	3	4	5		6
60. The infant continues to cry when frightened despite several minutes of soothing (picked up, patted).			Almost never	1	2 3 4 5 6	Almost always
61. The infant turns away from parents to look at noise or movements in the room.			Almost never	1	2 3 4 5 6	Almost always
62. The infant lies still during nail cutting.			Almost never	1	2 3 4 5 6	Almost always
63. The infant's period of greatest physical activity comes at different times of the day (morning, afternoon, evening).			Almost never	1	2 3 4 5 6	Almost always
64. The infant resists (squirms, fusses) regular nail cutting.			Almost never	1	2 3 4 5 6	Almost always
65. The infant smiles, or coos during nail cutting.			Almost never	1	2 3 4 5 6	Almost always
66. The infant amuses self for 15 minutes or more in crib (looking at doll or toy).			Almost never	1	2 3 4 5 6	Almost always
67. The infant notices (startles) sudden movements or bumps when in stroller or carriage.			Almost never	1	2 3 4 5 6	Almost always
68. The infant's day time naps are varied lengths from day to day (more than 1 half hour difference).			Almost never	1	2 3 4 5 6	Almost always
69. The infant resists (squirms, fusses) during routine dressing or undressing.			Almost never	1	2 3 4 5 6	Almost always
70. The infant smiles or coos during hair washing.			Almost never	1	2 3 4 5 6	Almost always
71. The infant acts the same when the diaper is wet or dry.			Almost never	1	2 3 4 5 6	Almost always
72. The infant's bowel movements are at the same time each day (within 1 hour).			Almost never	1	2 3 4 5 6	Almost always
73. The infant accepts routine washing of diaper area.			Almost never	1	2 3 4 5 6	Almost always
74. The infant is positive (smiles, coos) when he/she sees mother.			Almost never	1	2 3 4 5 6	Almost always
75. The infant reacts (startles) to differences in the temperature of the bath water.			Almost never	1	2 3 4 5 6	Almost always
76. The infant is fussy for several minutes after feedings.			Almost never	1	2 3 4 5 6	Almost always



Mother's general impressions of infant's temperament

A. How would you describe your baby's temperament in your own words?

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B. When comparing your baby to other babies of the same age – how would you rate your baby in each of the following (circle one).

- I. Activity level. The amount of movement during sleep, feeding, dressing etc.  
 (1) high                      (2) medium                      (3) low
- II. Regularity – regularity of schedule for sleeping, bowel movements, feeding.  
 (1) usually regular                      (2) variable                      (3) no regular pattern
- III. Response to new situations – initial reaction to new stimuli, people, places, procedures.  
 (1) usually accepting                      (2) variable                      (3) non-accepting
- IV. Adaptability to changes in routine – ease or difficulty with which changes can be made.  
 (1) generally adaptable                      (2) variable                      (3) difficult to make changes in routine
- V. Intensity of reaction – the amount of energy displayed regardless of positive or negative behavior.  
 (1) general intense                      (2) variable                      (3) generally mild
- VI. Positive or negative mood – amount of pleasant or unpleasant behavior throughout day.  
 (1) generally pleasant                      (2) variable                      (3) generally irritable
- VII. Persistence or attention span – duration of maintaining a specific activity.  
 (1) persistent                      (2) variable                      (3) nonpersistent
- VIII. Distractability – easy or difficulty in distracting or soothing the baby.  
 (1) easy to soothe or distract                      (2) variable                      (3) difficult to soothe or distract
- IX. Amount of stimulation needed in environment (people, food, sounds) to produce a response in the baby.  
 (1) needs strong stimulation to get response                      (2) variable                      (3) response to any minor change in environment

C. How has the baby's temperament been a problem for you?

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D. In general, temperament of baby is:

- (a) easier than average      (b) about average      (c) more difficult than average.

## EARLY INFANCY TEMPERAMENT QUESTIONNAIRE (1990)

### Basic Information

- I. Purpose of instrument - to gather reliable and valid temperament data for 1 to 4 month old children. The EITQ assesses the nine N.Y.L.s temperament categories by eliciting parent responses to 80 behavioral descriptions.
- II. Methods and subjects - Test construction was accomplished in the same manner as the revised Infant temperament Questionnaire for 4-8 month old infants (Carey & McDevitt, 1978) and the Toddler Temperament Scale for children from 1 to 3 years old (Fullard, McDevitt, & Carey, 1978). The EITQ was standardized on 404 infants in one pediatric practice. There were 218 boys and 186 girls. The majority of the infants were from white, middle class families.

### III. Results

Means and standard deviations - See Profile Sheets (Profile sheet for 1-2 month olds and 3-4 month olds).

Test-retest reliability for 9 categories - range .64 to .79, median  $r$  .68 for 1-2 month olds and .79 for 3-4 month olds. Two to three week interval.  $N=80$ .

Internal consistency for 9 categories - range .51 to .73.

### IV. For further information please contact:

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University of Pennsylvania  
School of Nursing  
Philadelphia, PA 19104-6096  
215- [REDACTED]

Sean C. McDevitt, Ph.D.  
William B. Carey, M.D.

\* When writing for a copy of the EITQ please send a check for \$15.00 to Dr. Medoff-Cooper.

**Age (months):**

[illegible]

- | INSTRUCTIONS  |   |
|---|---|
| 1. NEXT TO THE QUESTION ITEM NUMBER IN THE LIGHTLY SHADED COLUMN, CIRCLE THE ITEM RESPONSE.   | 4. DETERMINE THE NUMBER OF QUESTIONS ANSWERED 1 ON EACH CATEGORY AND ENTER IN THE "NO. ITEMS RATED" BOX |
| 2. COUNT THE RESPONSES IN EACH COLUMN AND ENTER IN THE "COUNT" BOX  | 5. DIVIDE THE "SUM OF PRODUCTS" BY THE "NO. ITEMS RATED" AND ENTER IN THE "CATEGORY SCORE"              |
| 3. CALCULATE THE PRODUCT OF THE "COUNTS" AND THE "FACTOR" AND ENTER IN THE "PRODUCT" BOX. ADD THE PRODUCTS AND ENTER IN SUM OF PRODUCTS BOX | 6. ENTER THE CATEGORY SCORE ON THE "PROFILE SHEET" AND COMPARE WITH STANDARD POPULATION MEANS           |

# **EARLY INFANCY TEMPERAMENT QUESTIONNAIRE – PROFILE SHEET** **FOR 1 TO 2 MONTH OLD INFANTS**

Barbara Medoff-Cooper, Ph.D., William B. Carey, M.D., and Sean C. McDevitt, Ph.D.

Age at Rating: \_\_\_\_\_ months \_\_\_\_\_ days      Date of Rating: \_\_\_\_\_  
 Sex: \_\_\_\_\_

## CATEGORY SCORE FROM SCORING SHEET:

ACTIVITY	RHYTHMICITY	APPROACH	ADAPTABILITY	INTENSITY	MOOD	PERSISTENCE	DISTRACT	THRESHOLD

## PROFILE – PLACE MARK IN APPROPRIATE BOX BELOW:

	ACTIVITY	RHYTHMICITY	APPROACH	ADAPTABILITY	INTENSITY	MOOD	PERSISTENCE	DISTRACT	THRESHOLD
6	high	arrhythmic	withdrawal	slowly adaptable	intense	negative	low persistence	low distract	low
+1S.D.	4.23	3.92	3.21	3.16	4.55	3.94	3.50	3.25	4.72
MEAN	3.58	3.12	2.58	2.49	3.86	3.21	2.79	2.65	4.15
-1S.D.	2.92	2.36	1.94	1.81	3.16	2.48	2.07	2.04	3.57
1	low	very rhyth.	approach	very adaptable	mild	positive	high persistence	high distract	high

Date Scored: \_\_\_\_\_ Scorer: \_\_\_\_\_

Comments: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

REVISED OCTOBER, 1990

# **EARLY INFANCY TEMPERAMENT QUESTIONNAIRE – PROFILE SHEET** **FOR 3 TO 4 MONTH OLD INFANTS**

Barbara Medoff-Cooper, Ph.D., William B. Carey, M.D., and Sean C. McDevitt, Ph.D.

Date of Rating: \_\_\_\_\_  
 Age at Rating: \_\_\_\_\_ months \_\_\_\_\_ days Sex: \_\_\_\_\_

## CATEGORY SCORE FROM SCORING SHEET:

ACTIVITY	RHYTHMICITY	APPROACH	ADAPTABILITY	INTENSITY	MOOD	PERSISTENCE	DISTRACT	THRESHOL

## PROFILE – PLACE MARK IN APPROPRIATE BOX BELOW:

	ACTIVITY	RHYTHMICITY	APPROACH	ADAPTABILITY	INTENSITY	MOOD	PERSISTENCE	DISTRACT	THRESHOL
6	high	arrhythmic	withdrawal	slowly adaptable	intense	negative	low persistence	low distract	low
+1S.D.	4.52	3.63	3.63	3.02	4.64	3.41	3.03	2.99	4.88
MEAN	3.79	2.90	2.84	2.39	3.96	2.79	2.49	2.41	4.32
-1S.D.	3.05	2.18	2.04	1.75	3.27	2.16	1.94	1.82	3.75
1	low	very rhyth.	approach	very adaptable	mild	positive	high persistence	high distract	high

Date Scored: \_\_\_\_\_ Scorer: \_\_\_\_\_

Comments: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

REVISED OCTOBER, 1990

**APPENDIX G**  
**Monitoring Flowsheet**

## Monitoring Flowsheet

Code No. \_\_\_\_\_

### SECTION I

**DIRECTIONS:** From mother's tally sheet, provide the following data.

Total number of alarms since beginning monitoring or since last flowsheet \_\_\_\_\_.

Number of alarms since beginning monitoring or since last flowsheet due to changes in infant's heartbeat/breathing \_\_\_\_\_.

Amount of stimulation necessary to stop the most severe of the infant's spells \_\_\_\_\_.

(0= no alarm so not applicable;	+0
1= simple touch only;	+4
2= vigorous stimulation required;	+6
3= CPR started)	+10

### SECTION II

**DIRECTIONS:** Review preceding time period with mother. Check all that apply.

Since beginning monitoring or since last flowsheet, this infant has

_____ been to doctor/clinic for sickness.	+2
_____ needed ambulance/EMS help.	+8
_____ been admitted to hospital.	+5
_____ had a fever/cold/diarrhea.	+2
_____ had a seizure.	+5
_____ lost weight irregular weight gain.	+3
_____ had difficulty feeding.	+4
_____ been referred for developmental follow-up	+1

**SECTION III**

**DIRECTIONS:** Briefly answer the following questions. (You can use as much or as little space as necessary.)

What changes in family-life, if any, do you expect in the remaining home apnea monitoring time?

How do you expect your infant to do during the remaining home apnea monitoring time?

How do you expect your family-life to change, if any, after completing home apnea monitoring?

Thank you for completing this form.



### Monitoring Tally Sheet

**DIRECTIONS:** Place a ✓ mark or a | mark in the space below each time your baby's apnea monitor alarms.

Circle any of the following actions that were taken in response to the monitor alarm.  
Simple touch only                      Vigorous stimulation                      CPR

### Monitoring Tally Sheet

**DIRECTIONS:** Place a ✓ mark or a | mark in the space below each time your baby's apnea monitor alarms.

Circle any of the following actions that were taken in response to the monitor alarm.  
Simple touch only                      Vigorous stimulation                      CPR

## **APPENDIX H**

### **Monitoring Background Questionnaire**

Monitoring Background Questionnaire

Code No. \_\_\_\_\_

**DIRECTIONS:** Circle all that apply to each item.

Infant's Gender:                      Male                      Female  
Type of Delivery:                      Vaginal                      C-Section

Length of time in NICU or Special Care Nursery:

None  
1 to 3 days  
3 to 7 days 1 to 2 weeks  
2 to 4 weeks  
1 to 2 months  
2 to 3 months  
Longer than 3 months

Specific Reason(s) for Monitoring:

In Hospital:	At Home:
Low heartbeat	Low heartbeat
Apnea spell(s)	Apnea spell(s)
Seizure(s)	Seizure(s)
Feeding problem	Feeding problem
Needed CPR	Needed CPR

Other reasons:

Positive sleep study  
Twin or sibling of SIDS victim  
Other \_\_\_\_\_ .

Daily Monitoring Time:    24 hours                      During sleep only

Type of Electrodes:

Skin electrodes - changed less often than once a day  
Skin electrodes - changed once a day  
Skin electrodes - changed more often than once a day  
Electrode belt

Primary Caretaker During Day:

Mother	Father
Grandmother	Nursery/Daycare
Other	_____

**DIRECTIONS:** Fill in the blanks as indicated.

My infant was due on \_\_\_\_\_.

My infant was born on \_\_\_\_\_.

My infant was estimated to be \_\_\_\_\_ old at birth.

My infant weighed \_\_\_\_\_ at birth.

My infant was \_\_\_\_\_ long at birth.

Infant was discharged from hospital on \_\_\_\_\_

Infant lives with his/her \_\_\_\_\_

\_\_\_\_\_ .

Which of infant's relatives live within 30 minutes? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you for completing this form.

## **APPENDIX I**

### **Postcards**

**POST CARD # 1**

I am interested in the study about babies on home apnea monitors.

My name is: \_\_\_\_\_

Please call me at (phone number) \_\_\_\_\_

or contact me by mail at (adress) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**POST CARD # 2**

Ms. Barnes, my baby is coming off the apnea monitor. Please contact  
me about your last visit.

Sincerely,

\_\_\_\_\_  
(Name)

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