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THE IMPACT OF HOME APNEA MONITORING ON FAMILY FUNCTIONING

by

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ABSTRACT

THE IMPACT OF HOME APNEA MONITORING ON FAMILY FUNCTIONING

By

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The use of a home apnea monitor to detect or limit the duration of episodes of prolonged apnea and to prevent Sudden Infant Death Sydrome in infants and the resulting stress raises a number of questions applicable to the health profession and nursing about the effect of apnea monitoring on family processes or functioning. The problem under study was to describe how family functioning is impacted by home apnea monitoring.

Through mailed questionnaires, descriptive data were obtained from families who had an infant with prolonged apnea on a monitor at home. The sample was voluntary and subjects were participants in a hospital-based Home Monitor Program. The test instrument included a sociodemographic questionnaire; scales addressing Beliefs About Home Apnea Monitoring, including Family Stress Scale, Family Impact Scale, and Family Support Scale; and, the Family Functioning Index developed by Pless and Satterwhite (1973). Correlations were computed between each scale score and the FFI score. No relationships were found between length or disposition of monitoring, perceptions of severity of infant's condition, impact of home monitoring, or support available and the level of family functioning.

Dedicated to the Greater Lansing Chapter of the National Sudden Infant Death Syndrome Foundation in the hope that every child may live. To G. M. Perry, the calm in my storm.

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The completion of this thesis and my graduate education was not a solo undertaking. It was done with the encouragement and support of many individuals to whom I will be eternally grateful.

The original research that served as a stimulus for this study was done by Black, Herscher, and Steinschneider (1978). Personal experience with home monitor families in my capacity as the nurse coordinator for a hospital-based Home Apnea Monitor Program prompted further investigation. The study could never have been completed without the willingness of home monitor families to share their experiences.

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To Barbara Given, R.N., Ph.D., F.A.A.N., scholar and mentor, I thank you for your faith in my professional abilities. To my classmates and lifelong friends, Karen, Jody, Barbara, Patricia, and Margaret, I thank you for making graduate school tolerable and, at times, delightful. To Sue Milton, my friend and typist, I thank you for your neverending patience.

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CHAPTER I

Introduction

The use of an apnea monitor to detect or limit the duration of episodes of prolonged apnea and to possibly prevent Sudden Infant Death Syndrome in infants has been moved from the hospital setting to the home. Since there is no way of anticipating how long the problem of prolonged apnea may last in any infant, employment of an apnea monitor at home is often medically advised rather than keeping the infant in the hospital indefinitely (Black, 1978). The use of such devices in the home raises a number of questions applicable to the health profession about the effect or impact of apnea monitoring on family life and functioning.

Background of the Problem

Prolonged apneic spells in infants may lead to morbidity and occasional mortality, the sudden unexpected death of an infant. Prolonged apnea is defined by the American Academy of Pediatric Task Force on Prolonged Apnea as "cessation of breathing for 20 seconds or longer, or as a briefer episode associated with bradycardia (in infants, heart rate less than 80 beats per minute), cyanosis, or pallor" (1978). Causes of prolonged apnea include seizure disorders, infections or sepsis, anemia, gastroesophageal reflux, metabolic disorders, cardiac arrhythmias and anomalies, and impaired respiratory regulation (American Academy of Pediatrics Task Force on Prolonged Apnea, 1978).

The most prominent hypothesis postulated as a cause of Sudden Infant Death Syndrome (S.I.D.S.) is impaired respiratory regulation due to a malfunction in the respiratory control mechanism of the brainstem (Jordan, 1979). The malfunction could involve one of several different pathways, chemical or electrical. The hypothesis of prolonged apnea as a cause of SIDS resulted from close observation of "near-miss" or "aborted" SIDS infants (Steinschneider, 1972). A "near-miss" infant is defined as an infant who has experienced an episode of prolonged apnea with bradycardia, cyanosis, or pallor, and required vigorous stimulation or resuscitation to recover from the episode (Kelly and Shannon, 1978). Thus, it seems likely that some victims of Sudden Infant Death Syndrome may have succumbed to unrelieved prolonged apnea (American Academy of Pediatrics Task Force on Prolonged Apnea, 1978).

Close surveillance with an apnea monitor, along with treating any underlying disorder, is critical to the management of prolonged apnea and possible prevention of Sudden Infant Death Syndrome. As life-threatening apnea may occur until an infant is several months old or for an indeterminable period of time, home apnea monitoring was initiated to extend the surveillance previously available only in hospitals (Jordan, 1979). Home apnea monitoring once implemented as part of the management plan for prolonged apnea usually continues for a minimum of 7-8 months to well over one year in cases of apnea associated with seizure disorders. The American Academy of Pediatrics Task Force on Prolonged Apnea takes the stand that home monitoring should only be undertaken with close health care supervision and that caregivers be "trained in infant cardiopulmonary resuscitation and provided with continuing medical, technical, and psychosocial support" (1978).

Home monitoring is considered for two types of patients; the otherwise healthy premature infant whose hospitalization is prolonged because of recurrent apneic and cyanotic episodes, and the infant who, at home, "develops apneic and cyanotic episodes of unknown etiology"(Steinschneider, 1976). Additionally, home monitoring is frequently recommended for otherwise clinically well infants who appear to run a high risk of having prolonged apnea or succumbing to SIDS, for example, infants who are siblings of SIDS infants (Black, 1978).

Because nurses are involved with teaching, support, and follow-up of home monitor families, nursing needs to further study the impact of home apnea monitoring on families. The goal of nurses in expanded roles, whether in the hospital or in providing primary care, is to assist the family to an optimal level of adaptation in response to the stress of having an apneic child requiring home monitoring. From analysis of the information gained from this study, therapeutic nursing and health team interventions and support systems could be developed and implemented to decrease any negative outcomes in family functioning and help families cope with and adapt to home monitoring.

Statement of Problem

According to Black, Herscher, and Steinschneider, the issues that confront parents and a family who agree to home monitoring as a treatment for their infant include: 1. the diagnosis of a chronic, self-limiting condition has been made; 2. the fear or threat of the child's sudden death has been raised; 3. a mechanical device with limitations and certain operating requirements must be dealt with; and, 4. direct and full-time responsibility for appropriate intervention, should apnea or bradycardia occur, has been assumed by the parents (Black, 1978). Finally, a successful outcome for every infant with prolonged apnea or at risk for prolonged apnea cannot be guaranteed despite continuous surveillance, with or without monitoring, and appropriate intervention (American Academy of Pediatrics Task Force on Prolonged Apnea, 1978).

This management plan utilizing use of a home apnea monitor imposes many burdens and has a significant psychosocial impact on all members of the family of an infant with prolonged apnea or at risk for prolonged apnea.

Therefore, the problem under study is: to describe how home apnea monitoring impacts or affects the level of family functioning.

Purpose of the Study

This study is undertaken to describe the effects and outcomes the impact home monitoring has on family functioning. It is assumed by the researcher that families identify or perceive having an apneic infant requiring home monitoring as a stress. It is postulated that this stress has an impact on the family's level of functioning.

Definition of Concepts

Impact or scope of impact will be defined as the spread of stress upon the family (Chrisman and Riehl, 1974). Stress is defined by Chrisman and Riehl as the dynamic force which produces strain or tension within the organism or unit (1974). The scope of impact includes the effect or variety of effects stress has on the family. The scope of impact may apply to both the stress state of the family and the adaptation resulting in the family stressed change (see Conceptual Framework).

Family will be defined as a social system comprised of a group of interdependent persons who have established relationships by continued interaction and are linked by economic and emotional bonds that exist for the physical, psychosocial, and spiritual support of its members over time (MSU Graduate School of Nursing, 1978). This unit must include as a member an infant with prolonged apnea or at risk for prolonged apnea for whom apnea monitoring has been chosen as part of the management plan.

Family functioning will be defined as the processes by which a family operates including such factors as the way members relate to one another, the manner and ease with which they communicate, the extent to which activities are carried out jointly, the level of satisfaction of the spouses, and the happiness and closeness of the unit as a whole, as measured by the Pless and Satterwhite Family Functioning Index (1973). The Family Functioning Index includes the principal categories of; marital satisfaction, frequency of disagreements, happiness, communications, weekends together, and problem-solving (Pless and Satterwhite, 1973).

Home monitoring will be defined as the use of an infant apnea/respiratory and cardiac monitor at home as part of the health management plan by families that have as a member an infant with prolonged apnea and/or bradycardia or at risk for prolonged apnea to warn of episodes of apnea and/or bradycardia.

Research Objective and Questions

As the study sample will be small, rather than hypotheses, the following research objective and questions will be addressed in this study.

The overall objective of this study is: to describe the impact home apnea monitoring has on the level of family functioning. Specific research questions are:

1. How is the overall length of home monitoring related to the level of family functioning?
2. How is the time aspect of whether home monitoring is ongoing or discontinued related to the level of family functioning?
3. How is the family's perceived threat of loss of their infant or perceived severity of their infant's condition related to the level of family functioning? (Operationally defined and measured by the Family Stress Scale -- see Appendix F, Section I of Beliefs About Home Apnea Monitoring.)
4. How is the family's perception of the scope of impact of home apnea monitoring related to the level of family functioning? (Operationally defined and measured by the Family Impact Scale -- see Appendix F, Section II of Beliefs About Home Apnea Monitoring.)
5. How is the family's perception of support available to the family during home monitoring related to the level of family functioning? (Operationally defined and measured by the Family Support Index -- see Appendix F, Section III of Beliefs About Home Apnea Monitoring.)

Assumptions

In this study the researcher is making the following assumptions:

1. It is assumed that home apnea monitoring is perceived as a stress by families with an apneic infant requiring home monitoring and actually serves as a stress.
2. It is assumed that the perceptions of the infant's primary caretaker in the family will be representative of the family's perceptions.
3. As a stress, it is assumed that home apnea monitoring has an impact on the level of a family's functioning.
4. It is assumed that all families with an infant who has experienced prolonged apnea/bradycardia or is at risk for prolonged apnea and is being monitored at home experience some impact or effect on the family's functioning from the stress of monitoring.
5. It is assumed family functioning can be identified and measured by the instrument used in this study.
6. It is assumed that the instrument used in this research study is sensitive enough to measure pertinent dimensions and issues of home apnea monitoring.
7. It is assumed that the parents of monitor families can read and understand the instrument.
8. It is assumed that the family's perception of threat of loss or severity of their infant's condition can be expressed and measured by the instrument.

9. It is assumed that the monitor family's perception of the scope of impact of home apnea monitoring can be expressed and measured by the instrument.
10. It is assumed that the family's perception of support during home monitoring can be expressed and measured by the instrument.
11. As the study sample will include families who have discontinued monitoring and families who are currently monitoring, it is assumed there may be a difference in these families perceptions about home apnea monitoring and in their levels of family functioning.
12. It is assumed responses of the infant's primary caretaker, as representative of the family, to the instrument are real and honest.
13. It is assumed the data analysis done as part of the research study will be thorough and correct.

Limitations

In this study the researcher is noting the following limitations:

1. Subjects are limited to those who voluntarily participate and therefore results will not be generalizable to nonvolunteers.
2. Subjects were contacted through phone contacts from a list of participants of a hospital-based home monitor program and therefore generalizability of results will be limited to the study sample.

3. Sample size will be small thereby limiting generalizability.
4. Sections of the instrument adapted and designed by the researcher include information drawn from literature and personal interaction with monitor families. Therefore, it is possible items the researcher identified for the families to respond to may not be most impacting to the family. The items designed or adapted by the researcher address selected aspects of home apnea monitoring and are not comprehensive in their content.
5. Due to the small sample size, the areas of the instrument designed and adapted by the researcher cannot be subjected to a pilot test as it would bias study subjects and reduce sample size. Therefore, reliability and validity for the sections of the instrument designed or adapted by the researcher cannot be established.
6. The infant's primary caretaker as primary respondent to the instrument, may not truly represent the perceptions of the family to home apnea monitoring.
7. The researcher serving as an active provider of care for infants of the study sample may influence or bias subjects' responses.

Overview of Chapters

This research study is presented in six chapters. In Chapter I, the introduction to the study, background of the study problem, statement of the problem, purpose of the study, definition of concepts, research objectives and questions, and assumptions and limitations are presented.

Chapter II discusses the conceptual framework of the study and the conceptual framework to a broader model of nursing process. Pertinent literature and research concerning the problem is reviewed in Chapter III. In Chapter IV, the research design and methodology and rationale for data analysis are described. In Chapter V, research data and analysis and evaluation of the research data and results are provided and discussed. In Chapter VI, the research study is summarized, conclusions are drawn, and recommendations for nursing are made.

CHAPTER II

CONCEPTUAL FRAMEWORK

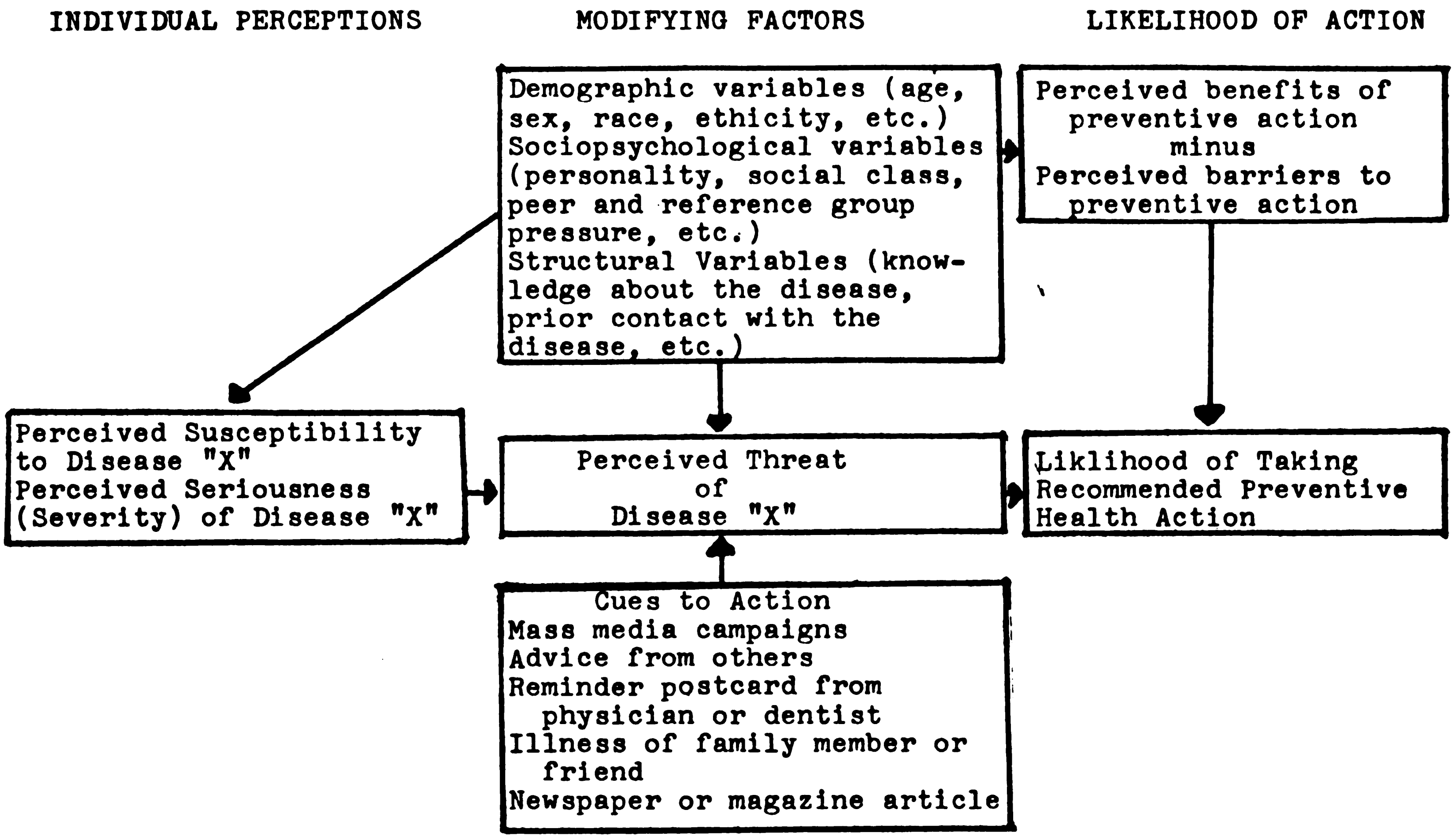
In this chapter, the conceptual framework of the research study will be discussed. Further, the conceptual framework will be related to a broader conceptual model for nursing practice.

Griffin (1980) states that although physical illness can assume a variety of forms, the usual context in which illness occurs and is resolved is within the family. Since the family is an interdependent system (as defined in concepts), change in one member of the system is followed by change in other members (Griffin, 1980). Thus, the onset of illness may alter the interdependent structures of the family, such as relationships and roles. Ultimately the functions and process of the family, which are identified by Sedgwick (1974) to include decision-making, determining policies, acknowledging feelings and providing support, may be altered. The interdependence of organizational structures and the nature of family functioning mean that no illness can be seen as an isolated event (Griffin, 1980). This chapter will attempt to define the connections between an illness of a family member, such as an infant with prolonged apnea and/or bradycardia or at risk for prolonged apnea and/or bradycardia or at risk for prolonged apnea with home monitoring as a part of the health management plan, and the effect or impact it has on family process or functioning.

Prolonged apnea may be analyzed from an illness or health problem perspective for "when discussing SIDS, the term apnea is called a symptom as well as a cause" (Favorito, 1979). Apnea in infants can be a symptom of several diseases such as seizure disorders, cardiac arrhythmias and anomalies, and other conditions as discussed in the introduction of this research study. Prolonged apnea is also postulated as a cause of Sudden Infant Death Syndrome.

As prolonged apnea in relation to SIDS can be viewed as an illness, characteristics of the Health Belief Model can be applied in predicting health and illness behavior related to the condition. These characteristics may ultimately influence or impact the level of family functioning. The characteristics of the Health Belief Model that are most pertinent to the framework include areas of perception; perceived susceptibility, perceived severity, and perceived threat (See diagram of Health Belief Model, page 14).

Rosenstock (1974) states that in order for an individual to take action to avoid a disease he would need to believe or perceive (1) that he was personally <u>susceptible</u> to it, (2) that the occurrence of the disease would have at least



The "Health Belief Model" as predictor of preventive health behavior moderate severity on some component of his life, and (3) that taking a particular action would in fact be beneficial by reducing his susceptibility to the condition or, if the disease occurred, by reducing its severity, and that it would not entail overcoming important psychological barriers such as costs, convenience, pain, embarrassment.

Perceived susceptibility, as operationally measured as a characteristic of the Health Belief Model, refers to the subjective risks of contracting a condition (Rosenstock, 1974). Rosenstock suggests the beliefs or perceptions concerning the severity of a given health problem may vary from person to person and may be determined both by the degree of emotional arousal created by the thought of the disease as well as by the kinds of difficulties the individual believes a given health condition will create for him. He further proposes that a person may see a health problem in terms of its medical or clinical consequences and the perceived severity of a condition may include broader and more complex implications as the effects on the disease on family life or on social relations (Rosenstock, 1974).

In the case that some diagnosis of illness has occurred, Becker (1974) argues that the concepts of perceived susceptibility and severity must be modified. The modifications he purposes to the concept of perceived susceptibility that are pertinent to the framework include examining the individual's estimate of (or belief in) the accuracy of the diagnosis and extending the concept to the individual's estimate of "resusceptibility", or the likelihood of recurrence of the illness if he or she has had it before. The presence of physical symptoms probably exerts an elevating or "realistic" effect on perceived severity (Becker, 1974).

In discussing perceptions thus far, the person's views as applied to him or herself have been considered. In the case of children and health care, typically the parents are responsible for making decisions about care, so their health beliefs on behalf of a child would be critical (Kirscht, 1974).

In studies cited by Kirscht (1974) and as represented in the schematic of the Health Belief Model, perceived susceptibility and particularly perceived severity by parents resulted in perceptions about threat of illness. These perceptions about threat of an illness may be affected by demographic, psychosocial, or structural variables or by "cues to action", including mass media campaigns, advice from others, or the illness of a family member or friend. These modifying factors' influence on perceptions of susceptibility, severity, or threat is beyond the scope of this research study.

Considering parents' perceptions of susceptibility, severity, and threat in relation to having an infant with prolonged apnea and/or bradycardia or at risk for prolonged apnea is a complex task. First, parents' perceptions of apnea as a symptom of an illness may be related to the diagnosis of prolonged apnea or risk for prolonged apnea in their infant by medical personnel or the actual emergence of symptoms in their infant. Generally, diagnosis of prolonged apnea occurs in both prematures who are hospitalized and infants who experience at home an acute episode of cessation of breathing with associated cyanosis and bradycardia which required vigorous stimulation or resuscitation to recover.

Such an acute episode in an infant may be viewed by the parents as life-threatening (Favorito, 1979) and lead to perceptions about threat of losing the child even before a formal medical diagnosis is made. When a diagnosis of prolonged apnea is made and if the relationship between prolonged apnea and Sudden Infant Death Syndrome is drawn, perceptions of susceptibility to SIDS and potential threat of loss of the child may result. With a diagnosis of prolonged apnea, parents may view their child as no longer being "normal" and they may grieve the loss of their "normal" child.

The diagnosis of an infant being at risk for prolonged apnea is usually based on a family history of the loss of a previous child to Sudden Infant Death Syndrome. Because the family has experience with SIDS, the parents may already have formed views regarding this infant's susceptibility to SIDS and the potential or threat of losing this child. Again, if a diagnosis of an infant being "at risk" for prolonged apnea is made and if the relationship between prolonged apnea and Sudden Infant Death Syndrome is drawn, perceptions of susceptibility to SIDS and potential threat of loss of the child may result.

Prolonged apnea according to Black (1978) is a chronic, if self-limiting condition with an acute, sudden onset of symptoms. Griffin (1980) states by definition, chronic illness includes all conditions that require long periods of supervision, observation, or care. Prolonged apnea fits in this classification as it may occur until an infant is several months old or for an indeterminable period of time (Jordan, 1979). Close observation and supervision for long periods of time of an infant with prolonged apnea or at risk for prolonged apnea, along with treating any underlying disorder, is critical to the management of the prolonged apnea and possible prevention of SIDS.

Griffin feels that the major difference between acute and chronic illness is that chronic illness has no predictable short-term outcome (Griffin, 1980). According to the American Academy of Pediatrics Task Force on Prolonged Apnea, a successful outcome for every infant with prolonged apnea or at risk for prolonged apnea cannot be guaranteed despite continuous surveillance, with or without monitoring, and appropriate intervention (1978). Thus, prolonged apnea does not have a predictable outcome--the infant with prolonged apnea or at risk for prolonged apnea may succumb to an unresolved episode; he may survive but experience residual effects; or he may survive with no residual effects as a "normal, healthy" child.

Strauss (1973) listed some problems surrounding chronic illness with which both patient and family must deal. These problems include: (1) preventing and dealing with medical crisis as they occur, (2) controlling symptoms, (3) following a medical regimen, (4) normalizing interactions with others, (5) arranging payment for treatment, and (6) adjusting to recurrent patterns in the course of the illness. A family's experience with these problems may influence the family's or parents' perceived severity of their child's illness and the potential outcome of the illness.

According to Sutterly (1979), stress lies in the perception of events, not in the events themselves. Further, she states stress is an internal mechanism; it is the individual's response to life events. Thus, the parents' perceptions of susceptibility, severity, or potential threat of loss related to having an infant with prolonged apnea or at risk for prolonged apnea may serve as a psychosocial stress.

Because a family is defined in this research study as an interdependent social system and the illness of one member may later the interdependent structures of the family, the stress created by these perceptions of susceptibility, severity, or potential threat of loss will involve the entire family unit and result in a stressed state and stressed change for the family unit. The stressed state may be different for each family, dependent upon the family's perceptions. The stressed change experienced by each family unit may also be different for each family dependent upon the coping mechanisms used by the family in response to the stress.

After a diagnosis of prolonged apnea or risk for having prolonged apnea is made in an infant, close surveillance and observation with an apnea monitor is usually recommended as part of the management plan and as a possible preventive measure for Sudden Infant Death Syndrome. Any underlying disorder that is found to be causing prolonged apnea is also treated. Since there is no way of anticipating how long the problem or risk for prolonged apnea may last in any infant, employment of an apnea monitor at home is often advised rather than keeping the infant in the hospital indefinitely, as apnea or risk for apnea may occur for an indeterminable period of time. Caregivers of infants on home apnea monitors are trained in the mechanical use of the monitor and necessary intervention including infant cardiopulmonary resuscitation should an apneic and/or bradycardic episode occur.

The introduction of home apnea monitoring as a vital part of the management plan of an infant with prolonged apnea or at risk for prolonged apnea likely will compound the stressed state the parents and family unit may experience and may also serve as a modifying factor. Home apnea monitoring compounds the stressed state in two ways. First, home apnea monitoring may change the perceptions of susceptibility, severity, and threat of loss the parents and family of an infant with prolonged apnea or at risk for prolonged apnea have about their child's condition. The introduction of such an intervention will likely increase the parents' perception of severity of the infant's condition, but may change their perceptions about threat of loss as they now have a device to warn them of any life-threatening apneic episodes although a successful outcome cannot be guaranteed.

Second, the introduction of a home apnea monitor in itself may be perceived by the parents or the family as a stress because now they have a mechanical device with limitations and certain operating requirements to deal with and they now assume direct and full-time responsibility for appropriate intervention should apnea or bradycardia occur. This full-time responsibility for intervention adds to and may change roles the parents and family assume in the care of their infant.

As a social system, the family unit will respond to the stress it perceives in an attempt to withstand, overcome or reorganize to achieve a new steady state or new state of functioning. This response results in use of coping strategies involved in the process of adaptation.

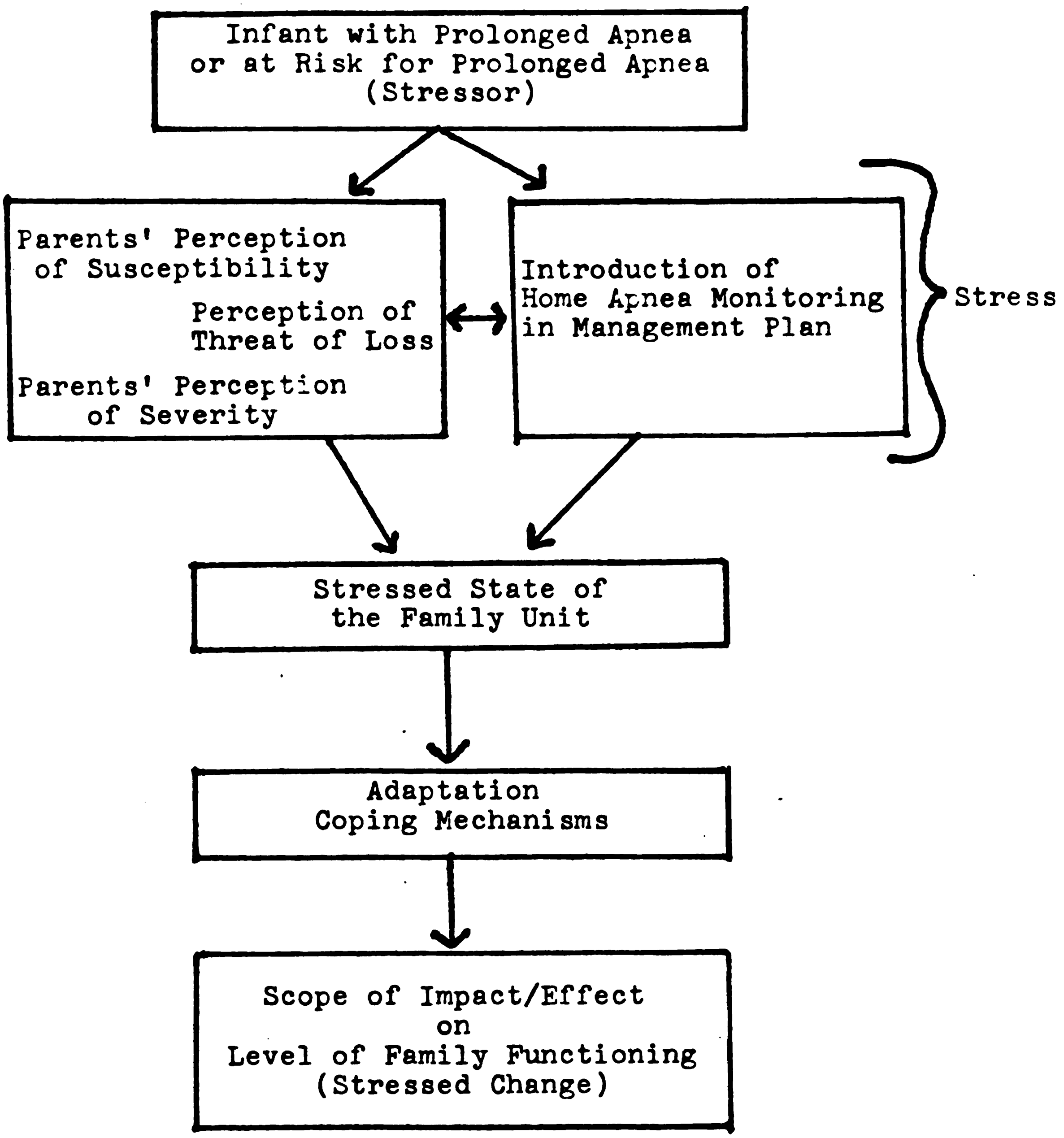
According to Aguilera and Messick (1978), the response to stress and coping with the stress depends on three factors; the perception of the event, situational supports available to the family unit, and coping mechanisms. A family's previous experience with stress may affect the family's perceptions of the present stress. Situational supports recognized and utilized by a family in response to previous stress may affect the family's recognition and use of support systems they perceive as available to them in response to the current stress being experienced. Finally, past coping mechanisms used by a family in response to stress and perceived as successful may affect coping mechanisms utilized for the present.

Lazarus (1966) in his discussion of the coping process refers to "coping" as use of strategies in dealing with threat. Thus, coping results from perceptions of threat or potential for threat as Lazarus (1966) states much coping is also anticipatory activity.

McCubbin (1979), in an explanation of Family Stress Theory, states that it seems reasonable to argue that successful family adaptation to stress involves at least two major sets of family resources. "First, the family must have or develop such internal resources as integration and adaptability in order to withstand the social and psycological stresses it experiences. Second, the family must have or develop a range of coping behaviors directed at strengthening its internal organization and functioning, at procuring community and social supports, and in some cases, at diverting, reducing, or eliminating the sources of stress." (McCubbin, 1979) McCubbin's explanation supports Reuben Hill's (1958) conceptual framework of the family as an interacting and transacting organization. Thus, in using coping behaviors to adapt to stress and achieve a state of reorganization, the family's level of functioning will change. Further discussion of coping behaviors and family stress theory is beyond the scope of this study.

In summary, due to the interdependence of the structures of the family as a social system, the onset of prolonged apnea in an infant member will result in some change in the whole family unit. Based on the Health Belief Model, the condition of prolonged apnea may generate perceptions of susceptibility, severity, or threat of loss in family members, especially parents, as typically parents make decisions about health care on behalf of the child.

CONCEPTUAL FRAMEWORK



Perceptions of susceptibility, severity, or threat of loss may be defined by the family as a stress. The stress, as defined by the family, is likely compounded by the introduction of home apnea monitoring as part of the management plan for the infant. Home apnea monitoring itself may be perceived by the family as a stress.

The stress generated by perceptions of the family results in a stress state for the family unit. The family, as an interacting, transacting system, uses coping behaviors to adapt to the stress state. The coping behaviors used, whether interactional or transactional, will result in some change in the level at which the family functions. Thus, the structure of the family system can affect its adaptation to stress and its level of functioning.

Nursing Conceptual Model Components and Implications for Nursing

The Systems-Developmental Stress Model by Chrisman and Riehl (1974) provides a general framework for practice and a conceptual approach for the nursing process. This conceptual framework, as utilized in this study, can be used to identify the effect family structure as a developmental system has on the stress process and can be used to develop nursing strategies to facilitate the stress process at an optimal level and aid in achievement of desired functioning.

In the systems-developmental structural framework, man is defined "as a set of dynamic systems interacting within an environment and along a developmental continuum" (Chrisman and Riehl, 1974). Certain assumptions about man are made. These include: (1) man's development includes biologic, intrapersonal, and interpersonal change and each perspective interrelates with every other and influences health; (2) man moves along the continuum by a gradual mediation from one developmental state to another and information and effects from the past are stored, incorporated into the present, and projected into the future; (3) change is inherent to life and systems attempt to maintain stability within change; and (4) man's situation can be described as the interface between the human system and time-environment (Chrisman and Riehl, 1974).

As a set of dynamic systems, the family interacts between member systems and with systems of the larger environment throughout its development. Input from the family's past will affect its perceptions of present and future and what it defines as stress.

Health is not defined in this model but the researcher defines it as the optimal adaptation of man to the stress processes that occur through interactions of his dynamic systems and with the environment along the developmental continuum he experiences. Chrisman and Riehl define the stress process as "the sequence of reactions which occur in response to a stressor" (1974). The stressor is the precipitating or initiating agent which activates the stress process. Stress is defined as the dynamic force which produces strain or tension within the organism. The reactive condition of an organism which occurs as a result of stress is called the stress state. Adaptation is defined as the coping response of the organism to the stress-state and/or the stress. Stressed change is the outcome or difference in the organism as a result of the stress process and not directly related to the change due to normal development (Chrisman and Riehl, 1974).

As the Systems-Developmental Stress Model is only a conceptual framework for nursing versus a theoretical framework, the authors do not define nursing. Ingrained in the model are elements of the nursing process to be used as a problem-solving guide including; assessment, generating a nursing diagnosis, developing objectives, intervention, and validation. The nursing assessment involves examining the man's developmental variables, determining temporal-environmental impact, analyzing the function and adaptability of his biologic, intrapersonal, and interpersonal subsystems and how his stress process is related to his system-development. The nursing diagnosis describes real or potential problems inherent for man in the stress process.

A nursing objective is generated from the nursing diagnosis and should be directed towards achieving a predicted or desired end behavior (stressed change). Nursing intervention involves the choice of an interception for the stress process based on knowledge of systems-development. Evaluation of the nursing process can be directed toward any or all of the following conditions: (1) occurrence of the stressor, (2) effect of the stress, (3) successful adaptation, and (4) man's functioning level after stressed change (Chrisman and Riehl, 1974).

The occurrence of or diagnosis of prolonged apnea or risk for prolonged apnea in an infant may serve as a catalyst to provide a stress state in the family. Stress, being the force which produces strain or tension within the family unit, occurs as a result of the family's perception of the situation or condition. Home apnea monitoring may increase the perceptions of stress and may be perceived as a stress itself. Stress results in a stress state for the family, which describes the turmoil and disorganization the family is experiencing internally and interactionally with the environment. The stress state describes the force or impact of the stress.

Adaptation involves the use by the family of coping behaviors in response to the stress state or stress. The process of adaptation for the family results in change. The coping mechanisms used by the family in response to the stress having an infant on a home apnea monitor depend on the family's perception of the situation/stress, situational supports available to them, and previous coping behaviors used in response to previous stress.

The process of adaptation by the family unit results in a change in the family's functioning level, or a stressed change as a result of the stress process. The change in the family's functioning level is the family unit's resultant steady state or state of reorganization.

Therapeutic intervention by nursing in this situation may involve manipulation of the stress process based on assessment of the family from a systems-development perspective. The nurse must assess who the member subsystems of the family are. He/she must also assess the intra-actional, interactional, and biologic links and systems of the family. Finally he/she must determine where the family is developmentally in the time-life continuum and consider tasks the family must meet to accomplish that stage and effects these tasks may have on the family's perceptions.

Intervention could occur at any level of the stress process of a family with an infant on a home apnea monitor. Intervention may be aimed at reducing, eliminating, or resolving stress. Nursing may also intervene to assist the family in adapting positively to the stress through recognition and acquisition of situational supports and use and strengthening of coping mechanisms to promote a higher level of family functioning (stressed change).

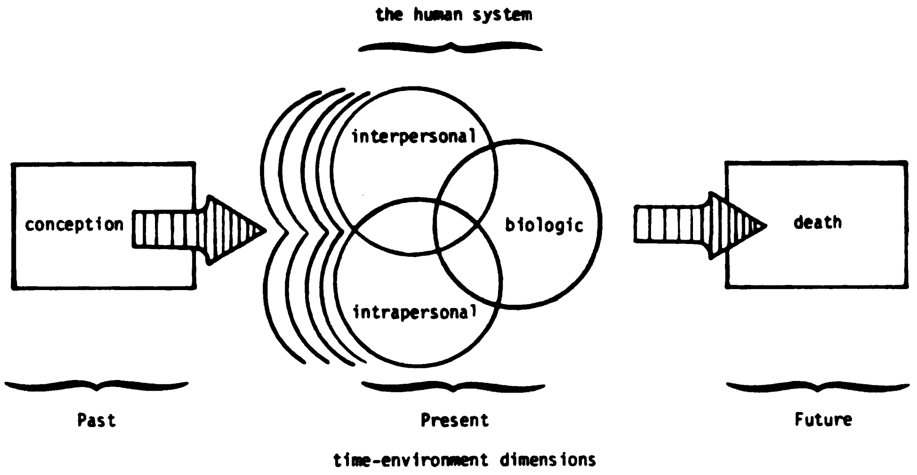
Evaluation of nursing intervention can also occur at any level of the stress process. Evaluation could include: (1) effect of the stress on the family--the stress state or disorganization the family experiences, (2) the adaptation process--the coping mechanisms used, and (3) the family's level of functioning (stressed change).

Utilization of systems--developmental theory, stress theory, and the nursing process as defined in the Systems-Developmental Stress Model by Chrisman and Riehl, can be used to assess real or potential problems experienced by families who have an infant on a home apnea monitor. Considering family stress theory as described by McCubbin (1979), these problems or needs can be jointly assessed by nursing and the family. The family as a social system in stress theory is an active participant not a reactive agent. As active participant in health care, the family can mutually set objectives and evaluate its level of functioning with nursing.

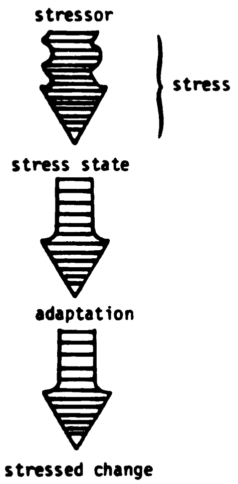
Nursing can assist a family in recognizing health problems, setting objectives, and evaluating its level of functioning related to stress through teaching and serving as a support system for the family. Nursing can also help a family deal with the stress of having an infant on a home apnea monitor through anticipatory guidance. Potential problems and areas of concern can be raised. Nursing can also assist the family in positive adaptation by helping them define their perceptions related to the situation, assess coping mechanisms that have been effective in the past, and recognize family strengths and support systems available to them.

Nursing can work with other health care providers to assist families during the time the infant is monitored to provide interdisciplinary support. Nursing must educate these other health care providers in stress theory, the effects of illness on the family system, and family functioning.

Further implications for nursing will be discussed in Chapter III, the review of literature.

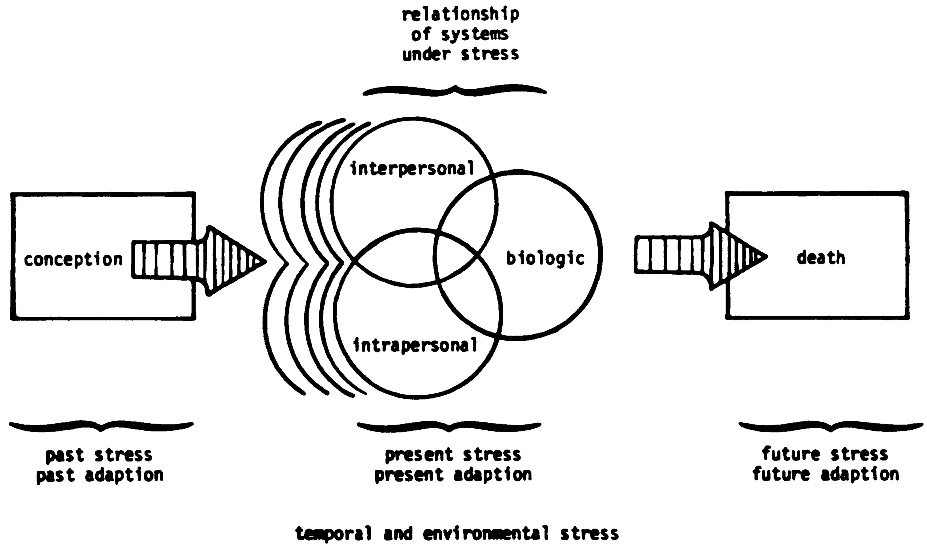


The Structural Framework of the SDS Model



Representation of the Stress Process

THE STRESS PROCESS



Application of the Stress Process to the Systems Development Continuum.

CHAPTER III

REVIEW OF LITERATURE

Through the review of literature, significant and current concepts related to prolonged apnea or risk for prolonged apnea in infants, including the introduction of home apnea monitoring as part of the health management plan for such infants and the effect of this intervention on the family are identified. As there is a lack of pertinent literature related to issues that arise as a result of home apnea monitoring, some of these issues are identified by reviewing related literature. Because Black (1978) views prolonged apnea in an infant as a chronic, self-limiting condition and because prolonged apnea in an infant raises the fear of the infant's sudden death for the family, literature related to chronic disease in children and threat of loss of a child is discussed in this chapter. Finally, the concept of family functioning is analyzed to identify aspects pertinent to the research study.

Prolonged Apnea and Sudden Infant Death Syndrome

Sudden Infant Death Syndrome (SIDS) accounts for approximately 7,000 to 10,000 deaths yearly in the United States or a rate of 2-3 deaths per 1,000 live births (Beckwith, 1975 and Valdes-Dapena, 1975). Much has been done to outline the epidemiology and probable risk factors for SIDS (Beckwith, 1975, Valdes-Dapena, 1975, Naeye, 1976, and

Lewak, 1979). There are also many theories as to the possible causes of SIDS.

Much of the current thinking on SIDS is directed towards abnormal breathing patterns and bradycardia (low heart rate) as possible causes. Recent studies have suggested that some SIDS victims are chronically hypoxemic prior to death. The hypoxemia may be due to chronic alveolar hypoventilation. This hypothesis is based on the finding by Naeye (1976) of an increased mass in the small pulmonary arteries, retention of brown fat, and extramedullary hemopoiesis in about one half of infants who succumb to SIDS. These anatomic changes are a result of hypoxemia (Williams, 1978).

Kelly and Shannon (1978) state infants who have multiple or repeated episodes of prolonged apnea are experiencing intermittent alveolar hypoventilation, which can result in chronic hypoxemia. Thus, episodes of apnea can explain the pathologic changes found by Naeye (1976) in SIDS victims. Kelly and Shannon (1978) also found alveolar hypoventilation and disturbed ventilatory response to carbon dioxide in breathing during quiet sleep in "near-miss" SIDS infants which can also result in these pathological changes. A "near-miss" SIDS infant is defined as an infant who has experienced an episode of prolonged apnea with bradycardia, cyanosis or pallor, and required vigorous stimulation or resuscitation to recover from the episode

(Kelly and Shannon, 1978). Thus, it seems likely some victims of SIDS may have succumbed to unrelieved prolonged apnea (American Academy of Pediatrics Task Force on Prolonged Apnea, 1978).

Although protracted apnea may be a part of the pathogenic mechanism in some instances of SIDS, apnea may be of central origins in some cases, mixed in others, but upper airway obstruction induces the greatest and most dangerous changes (Valdes-Dapena, 1980). Oxygen desaturation is much more pronounced in obstructive apnea than in central apnea of similar duration, and cardiac changes such as bradycardia occur earlier and are more severe (Guilleminault, 1975, and Steinschneider, 1976). Steinschneider (1976) states that obstructive apnea may be induced by feeding of the infant. Tonkin (1975) theorizes long periods of apnea may be induced by transient airway obstruction at the oropharyngal level during muscle relaxation, associated with REM sleep,of a hypermobile mandible. Apnea may also be precipitated by certain positions assumed with neck flexion causing upper airway obstruction (Thach and Stark, 1979). One study postulates obstructive apnea may be due to gastroesophageal reflux resulting in larynogealspasm (Herbst, 1978).

There are several theorized causes of protracted apnea, whether central or obvious, and its possible relationship to the Sudden Infant Death Syndrome. Due to pathologic changes demonstrated by Naeye (1975) on autopsy of SIDS victims and other related studies, it can be assumed prolonged apnea may be a part of the mechanism of death in some instances of SIDS.

Home Apnea Monitoring

Critical to the management of prolonged apnea and as a possible preventive measure for Sudden Infant Death Syndrome are close surveillance with an apnea monitor and treating any underlying disorder causing the apnea. As life-threatening apnea may occur until an infant is several months old or for an indeterminable period of time, home apnea monitoring was initiated to extend the surveillance previously available only in hospitals (Jordan, 1979).

The American Academy of Pediatrics Task Force on Prolonged Apnea (1978) has taken the stand that home apnea monitoring should only be undertaken with health care supervision and caregivers should be trained in infant cardiopulmonary resuscitation and provided with continuing medical, technical, and psychosocial support systems. Kelly and Shannon (1978) state that their experience with home monitoring indicates that supervision of home monitoring should include 24-hour availability of medical, technical, and counselling assistance. With this type of support system, no parent involved with the Massachusetts General

Home Apnea Monitor Program discontinued monitoring prematurely. Without this type of support system before referral to the Massachusetts General program, one parent had a frustrating experience with home monitoring, refused to continue monitoring, and the infant died of SIDS one week later (Kelly and Shannon, 1978). The use of apnea monitors in the home thus raises a number of questions about the impact of home monitoring on family life and functioning.

Home apnea monitoring is usually advised for three types of patients to allow for early intervention and termination of prolonged sleep apnea. These patients include; (1) infants who have experienced a near-miss SIDS episode, (2) premature infants with prolonged sleep apnea whose hospitalizations are prolonged because of recurrent apneic and cyanotic episodes (Steinschneider, 1976), and (3) clinically well infants who appear to run a high risk of having prolonged apnea or succumbing to SIDS, for example, SIDS siblings (Black, 1978). Some factors which may place infants at risk for SIDS include; maternal smoking, younger maternal age, short interpregnancy intervals, fewer than 11 prenatal visits, gestational age of less than 40 weeks, birth weight less than 3,000 grams, lower socioeconomic status, and being of the male sex (Lewak et al, 1979).

The issue of home apnea monitoring has generated considerable controversy in the health care community. Health care providers disagree on the efficacy and practicality of home monitoring as well as equipment reliability (Jordan, 1979). Home monitoring has also been opposed in the past by some as being excessively stressful and disruptive to the normal development of parent-child relationships (Cain, 1980). Nelson (1978) poses three arguments against home monitoring as a management intervention for infants with prolonged apnea, including: (1) the fatality rate among monitored infants has not impressively improved over that of similar groups who were not monitored at home; (2) signs and symptoms in a given apneic infant may lead to unnecessary resuscitative intervention by volatile parents that would not have produced such a reaction in those more stoic; and, finally (3) the emotional and financial costs paid by parents of monitored infants.

In the debate about using apnea monitors at home to prevent Sudden Infant Death Syndrome in infants at risk, Stark (1978) raises similar questions: (1) Who should be monitored? (2) What kinds of monitors are most effective? (3) Does monitoring work? (4) Are other approaches apt to be simpler and more efficacious? Lucey (1978) states that impedance monitors (monitors which detect chest movement as respiratory activity) are unreliable as they are incapable of detecting upper airway obstruction, broken apnea, disorganized breathing, and hypoxemia and hypoxia, which are the most important effects of apnea.

Steinschneider (1976) opposes prescription of monitors for several reasons: (1) prescription of home monitors except in closely evaluated cases may lead to widespread misuse; (2) conclusive proof that SIDS is preventable through use of home monitors is lacking at present; (3) the monitors currently on the market are not well adapted to home use; (4) there are many types of apnea, both obstructive and nonobstructive; and (5) there is reason to be seriously concerned about adverse effects of monitors on parental behavior and familial emotional health. Steinschneider (1976) feels that the problem of the adverse effects of monitoring on parental behavior and family psychological health requires serious study before monitors are released for general home care.

Monitoring, although an imperfect intervention, has been accepted as part of the health management plan for infants with apnea or bradycardia (Steinschneider, 1976, and Lucey, 1978). The problem comes in the decision to employ monitoring systems in either the hospital or at home. According to Steinschneider (1976) hospitalization for an indefinite period of time is associated with high costs, utilization of nursing personnel, separation of the infant from the family unit, and general disruption of family activity. On the other hand, employing a monitor system at home alters the family lifestyle and requires parents be available and capable of providing effective intervention, including resuscitation, if necessary. The cost of home care of an apneic infant in comparison to hospital care is less, and the home atmosphere allows for nurturing of the parent-infant bond. Obviously, not all families are capable of providing the emotional and physical care of an infant requiring monitoring for apnea. Ultimately the final decision as to whether or not to employ the use of a home apnea monitor must be made on an individual basis involving the parents in the decision.

Impact of Home Apnea Monitoring on the Family

For monitoring at home to be effective and to decrease its disruptive effects, a better understanding of the impact of a home monitoring situation on family members is needed. Appropriately, Steinschneider (1976) has called for investigative efforts in this area. The objective of this research study is to gain a better understanding of the impact of home apnea monitoring on families.

Barr (1979), herself a home monitor parent and a parent who lost a child to SIDS, in 1974, conducted a survey of 15 monitor families of the Massachusetts General Hospital program through use of a questionnaire and follow-up interview. As a result of the findings of the survey, Barr wrote a pamphlet as a guide for home monitor parents entitled "At Home With A Monitor". In the pamphlet, Barr (1979) describes life at home with the monitor, phases of adjustment to monitoring most families go through, and questions and fears that arise as a result of monitoring. She describes life with a monitor at home as difficult, but not impossible (Barr, 1979).

For the most part, parents in the survey talked about three different phases of life with a monitor; the initial or breaking-in phase, the adjustment phase, and the time afterward when the monitor has become a part of the family (Barr, 1979). The initial phase consists of the first days at home when the parents may be in crisis and full of fears about whether the monitor is working, whether they will hear the monitor when it alarms, and whether they will respond appropriately if an alarm sounds or if they will panic. During this phase, the parents tend to experience severe problems sleeping and are distrustful of the monitor (Barr, 1979). This distrust is reflected in behaviors of staying with the infant and watching the monitor blink. During this phase, real alarms may occur which give rise to more fears.

The adjustment phase is described by Barr (1979) as beginning when the initial phase tapers off. As the parents become more confident the monitor will alarm if the infant is apneic, they tend to relax. There are still problems related to monitoring that the family must learn to live with during this phase. Someone must always be available to answer an alarm. In some cases, this requires changes in home arrangements, limiting noisy housework, such as vacuuming, and making special arrangements for travel (Barr, 1979).

The transfer from the adjustment phase to the phase where the monitor becomes a trusted friend to the family is basically a psychological phenomenon (Barr, 1979). During this phase, the parents have faith in the monitor and are more confident in the care of their child. Parents may also feel resentment during this phase due to constraints monitoring places on them and feelings their infant has outgrown the need for the monitor.

Barr (1979), in her pamphlet, discusses questions that arise with many monitoring parents. These questions include: (1) Could my baby die? (2) Will the monitor interfere with my relationship with the baby? and (3) How will the monitor affect other members of the family?

According to Black, Herscher, and Steinschneider, the issues that confront parents and a family who agree to home monitoring as a treatment for their infant include: (1) the diagnosis of a chronic, self-limiting condition is made; (2) the fear or threat of the child's sudden death is raised; (3) a mechanical device with limitations and certain operating requirements must be dealt with; and, (4) direct and full-time responsibility for appropriate intervention, should apnea or bradycardia occur, is assumed by the parents (Black, 1978). Finally, a successful outcome for every infant with prolonged apnea or at risk for prolonged apnea cannot be guaranteed despite continuous surveillance, with or without monitoring, and appropriate intervention (American Academy of Pediatrics Task Force on Prolonged Apnea, 1978).

Black, Herscher, and Steinschneider (1978) conducted a descriptive study to identify problems associated with home monitoring and to describe the adaptation of families to the monitor as well as its effects on family life and the child. Through interviews and questionnaires, descriptive data were obtained from 31 families who recently or currently had an infant on a monitor. The infants being monitored all were prone to prolonged apneic spells and the study involved no controls.

Results of the study were organized around the major issues raised by the interviews and questionnaires. These areas include the monitor, the family, and the infant. The apnea monitor itself was found to have several shortcomings when used in the home. Nearly half of the families modified the monitor equipment in some way, generally to amplify the alarm. Two-thirds of the families were plagued with frequent or serious mechanical problems and many parents felt the false alarm rate was inordinately high (Black, 1978).

A majority of the monitor families felt that the monitor had a significant impact on their lives that varied with the passage of time. Nearly 90% of the parents reported that the monitor increased their general tension level and fatigue, but the mother, as primary caretaker, was the family member whose life was most affected (Black, 1978). Nearly half of the respondents reported that the experience of monitoring had drawn the family closer and that marital discord resulted most commonly from differing attitudes toward the necessity of the monitor. The monitor appeared to have little impact on the lives of siblings or on the way the parents treated the monitored infant.

In summary, Black's (1978) research demonstrated that most families believed that using an apnea monitor had a significant but temporary impact on their personal and social lives including altering daily living and child-care routines. Technical limitations of the machine severely aggravated parents, and parents' anxieties tended to be attributed to an awareness of the severity of the infant's apneic episodes and feedback that the monitor provided. Generally, most parents believed the monitor decreased their overall anxiety level and was not seen as a deterrent to normal parent-child relations (Black, 1978). In summary, parents did cope effectively with the imperfect mode of treatment offered.

In a study by Cain, Kelly, and Shannon (1978), feelings, perceptions, reactions to stress, and satisfactions of 133 parents (74 families) during periods of home apnea monitoring were assessed and reported. From data collected through structured interviews, the researchers found although extreme anxiety was prevelant initially, only 27.4% of the parents felt that severe anxiety extended beyond the first month. Job attendance was seldom affected but social life was restrictive for 55.7% of the study sample. Of the sample, 14.2% reported that marital relations worsened during the home monitoring period. The majority of parents found their spouses most supportive during the period of monitoring. The majority of the sample (72.9%) reported the monitor made them feel more comfortable with their child and if provided with support, monitoring could be a satisfying experience (Cain, Kelly, and Shannon, 1978).

Kelly and Shannon (1978) outlined attempts by the Massachusetts General Home Apnea Monitor Program to relieve the stress of monitoring by building a support system for families, so that they may care for their infants at home. This support system includes; a referral for every family to a local visiting nurse association, a referral to a hospital social worker or psychologist, contact from local home monitor parent groups, and the family's local physician, and the home monitor program staff (Favorito, 1979).

Favorito (1979) specified the role of nursing, in hospital, as part of this support system. He states the nurse's role is expanding--not only with dealing with the family in the hospital setting, but also in preparing the family for the physical and emotional care of the apneic infant at home (Favorito, 1979). According to Favorito (1979), the use of a primary nurse for the infant and family is vital to decreasing the stress of hospitalization. Assessments of the parents' understanding of the situation, their emotional and psychological status, the appropriateness of their crisis intervention techniques, and the infant's daily normal routine are necessary. The nurse's major role according to Favorito (1979), is teaching in preparing the family for discharge, understanding the monitor, responding appropriately to alarms, including infant cardiopulmonary resuscitation, anticipating problems, and securing necessary resources or support.

Jordan (1979) has discussed the home care of an apneic infant from the home health care company viewpoint in supplying home apnea monitors. The home health care company supplying a monitor can also serve as a support to families through technical assistance, regular contact, help with financial arrangements, and reinforcement of teaching done in the hospital regarding the operation of the monitor.

In summary, there has been debate surrounding the use of home monitors as a management intervention in the treatment of infants with prolonged apnea. Arguments against the use of monitors in the home are centered around the unreliability of the monitors available and the financial, emotional, and psychological effects on monitoring on parents and family, as they are ultimately responsible for intervention should their infant experience an apneic episode. Although two recent studies (Black, 1978, and Cain, 1980) indicate families feel that home monitoring does significantly impact their lives, overall, parents believe that the monitor reduces the anxiety they feel due to their infant's condition. Cain, Kelly, and Shannon (1980) state that the stress of home monitoring can be relieved or reduced by providing home monitor families with an appropriate support system, including nursing.

Threatened Loss of an Infant

One issue confronting parents of apneic infants is the fear or threat of their infant's sudden death (Black, 1978). Because a loss is threatened, the parents may be grieving or experiencing anticipatory grief. The grieving process may interfere with normal parent-child attachment and relationships. As the threat of loss of an infant may significantly impact a family, literature related to the subject is reviewed in this chapter.

The grief reactions of families to the actual loss of an infant due to Sudden Infant Death Syndrome or other neonatal causes have been well documented (Smialek, 1978, Rowe, 1978, Krien, 1979, Benfield, 1978, and Mandell, 1975). These reactions include: shock, disbelief, and denial; negativism, hostility, and anger; self-reproach and guilt; demonstration of former unresolved grief; verbalization of previous fears of loss; and sometimes, even, relief (Smielek, 1978).

Green and Solnit (1964) describe a group of clinical features constituting a vulnerable child syndrome in a group of 25 children with a history of an illness or accident in infancy from which they recovered although the parents feared or were expecting a fatal outcome. Some parents appear to experience a modified grief reaction when they fear or become convinced that their child will die (Green and Solnit, 1964).

Often children whose death is threatened and feared by parents react with a disturbance in psychosocial development and in the parent-child relationship (Green and Solnit, 1964). Outstanding clinical features of the vulnerable child syndrome include difficulty with separation, infantile behavior, bodily over-concerns, and school underachievement. Infantilization in these children may be due to parents being overprotective, overindulgent, oversolicitous, and having difficulty setting disciplinary limits. These reactions represent pathological aftereffects of a persistent, disguised mourning reaction or fear that was evoked by what is perceived as a life-threatening experience of the child (Green & Solnit, 1964). As parents of an apneic infant may fear their child's death, there is risk for that child developing and displaying the vulnerable child syndrome.

Constanza (1968) in a retrospective study of 44 children with a history of serious illness suggests a shift in approach to the vulnerable child syndrome. It is not the child who is made vulnerable by a life-threatening illness, but rather the vulnerable family members who react to illness in a child (Constanza, 1968).

Carey (1969) in a review of literature concerning psychologic sequelae of early infancy health crises draws four main conclusions: (1) the most important etiologic factor in any subsequent behaviorial disturbance in the child is the variable reaction to the baby's illness by the parents, especially the mother--not the health care provider's opinion as to the objective severity of the illness; (2) the maternal reaction to the health crisis is a compound of several factors besides the illness itself and the mother's vulnerability; (3) the variety of parent-child interactions resulting from these health crises apparently leads to a wide range of psychologic sequelae in the child;

and, (4) inadequate data should not lead the health care provider to belittle the importance of infant health crisis, nor should it deter him/her from conscientious attempts to manage them to the best of his/her ability.

In summary, as the parents and family of an infant with apnea may fear their infant's death, they may be grieving. This grief may block development of normal parent-child relationships and if unresolved, may lead to significant psychologic sequelae in both infant and parents in the future.

Family Response to Life-Threatening Chronic Illness in a Child

The diagnosis of a chronic illness in a family represents a crisis, a disequilibrium which threatens the steady state of family functioning (Harding, 1979). Parad (1975) defines a crisis situation as a stressful event that poses a problem not solvable in the immediate future and is seen as a threat to the life goals of family members. Miller (1978) states a true crisis develops only when there is an inability by the family to adequately respond to a stressful event. Therefore, a stressful event interacting with a family's resources for coping and with the perception or definition the family has of the event produces the crisis (Hill, 1958).

The crisis period associated with the diagnosis of chronic illness in a child member of a family has two general phases; acute and chronic, the first occurring at the birth of the infant or when the chronic illness is diagnosed (Harding, 1979). The acute phase is followed by a chronic phase characterized by more adaptive coping of the family in attempting to deal with ongoing problems related to the chronically ill child.

Familial responses in the acute phase of crisis are well documented (Waechter, 1977, Harding, 1979, Binger, 1979, Salk, 1972, and Steinhauer, 1974). These responses to the initial diagnosis may include shock, anger, resentment, rejection, denial, sadness, and shaken religious beliefs as manifestations of anticipatory and subsequent grief reactions.

With the initial diagnosis of a life-threatening illness, the family experiences dual grief reactions. They grieve over the loss of a perfectly normal child and over the possible eventual death of the child. The child may be perceived as vulnerable, which produces further fear and insecurity for the family (Steinhauer, 1974 and Waechter, 1977) and presents particular dangers for parent-child relationships and the child's future development.

For a family to cope with a child with a life-threatening illness, a number of psychological tasks must be accomplished. One, cognitive confrontation, involves acknowledging the child's limitation and searching from realistic information as to the manifestation and cause of the illness or abnormality

(Caplan, 1965). Other tasks the family must face are changes in role structure and task allocation as a result of the illness (Bruhn, 1977).

The presence of any pre-existing emotional disturbance is another factor affecting a family's response to a life-threatening illness. The entire family unit is affected by life-threatening illness in any family member (Bruhn, 1979, and Griffin, 1980). The greatest psychological or social problems are likely to develop when chronic illness occurs in an already disturbed family situation (Steinhauer, 1974).

The nature and effects of the illness itself may further affect a family's response. The nature and effects of apnea may evoke further feelings of fear in the child's parents. Recurrent apnea, as it causes chronic hypoxia and may result in brain damage, may raise further fears for the parents.

Some illnesses, such as apnea, involve a demanding program of home management and limitations for the family. These demands may be resented by the family and the limitations prove frustrating for the family. Because parents are ultimately responsible for intervention should an apneic episode occur, home management of apnea raises fears related to the parents capability to appropriately respond to an alarm. Often, the message conveyed to parents is the length their child has to live depends on the quality of daily care, watchfulness, and protectiveness carried out at home. This situation also leads to over-solicitation on the part of parents, to a restrictive environment, and reluctance to separate from the child (Waechter, 1977). The restrictive environment constructed by the parents threatens the development of a healthy parent-child relationship.

Other factors influencing a family's response to illness in a child and accomplishment of tasks related to coping with the stress of such a crisis include repeated hospitalizations or surgical procedures due to the illness and the cost of the illness. Repeated hospitalizations of a child due to a life-threatening, chronic illness may exaccerbate the family's grief reactions. Finally, the cost of a child with a chronic illness places a financial strain on the majority of families (Gayton and Friedman, 1973 and Salk, 1972).

In response to these variables, the family attempts to cope and reorganize. As a result, family routines and patterns of relating can be disrupted, causing stresses to develop. The total family environment can be altered following the diagnosis of a life-threatening or chronic illness in a child member (Feetham, 1980).

Gayton and Friedman (1973) in a review of literature indicated the effect of cystic fibrosis on communication between family members and interactions between spouses. They also evaluated the presence or absence of significant social and financial stresses associated with the disease. In relation to financial and social stresses, most families had little time and energy available for leisure activities, less time for self, and increased concern over finances. Marital partners, as a rule, had less time alone with the spouse and experienced a decrease in frequency of sexual relations. Most families experienced problems in communication between family members which prevented them from maintaining usual patterns of family relationships. A child in a family having cystic fibrosis was found to have negative effects on other siblings. The child with cystic fibrosis showed increased anxiety, used denial more frequently, and had a tendency to regress in stressful situations.

Salk (1972) described the psychosocial impact of hemophilia on the patient and his family in a study of 34 families with a child having hemophilia. Having a child with hemophilia caused the husband and wife to draw together, but in over one-half of studied families, the marriage was negatively affected. Most families reported paying extra attention to the ill child, neglecting other children. Having a child with hemophilia, negatively impacted family mobility but only 43% of the families felt they were socially restricted. Finally, most families questioned having more children.

Bruhn (1977) stated the chronic disease disrupts family relationships and hampers a family's ability to overcome the effects of the disruption. Chronic illness of one family member may create or revive symptoms in other family members, especially as family roles are changing (Bruhn, 1977). Bruhn (1977) reported a high rate of breakdown in families with chronic disease resulted because family members would not or could not change roles and reallocate tasks. Other problems confronting families with a chronically ill child include social isolation and losses (Harding, 1979).

Turk (1964) in a study of the impact of cystic fibrosis on family functioning found that the family was deprived of time and energy but was not deprived of the essentials of living--food, clothing, and shelter. There were also significant problems in communication between family members which in many instances led to misunderstanding and tension in the family (Turk, 1964).

Feetham (1980) in a longitudinal study of parents and their infants with myelodysplasia found significant relationships among variables pertaining to parents, infants, and the family environment with family functioning at five time intervals in the first 18 months of life of the infant. Suprisingly, variables related to the infant and his/her defect were not more predicting of family functioning than variables related to the parents (Feetham, 1980).

In a retrospective study of 16 families, Kerner (1979) evaluated the impact of the death of a cystic fibrosis child on subsequent family functioning. There was a high incidence of emotional problems in the family including a high incidence of incomplete mourning, as many families kept the dead child's room or possessions as a shrine. Siblings had less difficulty adjusting to the loss than siblings of leukemic children (Kerner, 1979).

Parents' sense of emotional well-being is labile and based on the status of the ill infant or child (Travis, 1976). Significant stress is also demonstrated in parents with chronically ill or mentally retarded children (Cummings, 1976). Fathers tend to show significant guilt, fear bonding to the ill child, and mourn the partial loss of the ideal child related to the role components of father (Cummings, 1976). Fathers may exhibit longer periods of mourning than mothers and show more feelings of rejection and denial toward the ill child (Harding, 1979). Travis (1976) observed that over time mothers of children with chronic illness become exhausted due to additions in care brought on by the child.

Siblings often resent the ill child's special position in the family because of deferment of their own needs and additional task assignment (Harding, 1979). Lavigne (1979) in a study of 203 siblings of chronically ill children noted significant social withdrawal, immaturity, and irritability which varied with type of illness and sex of the child as affected by traditional sex roles. Behavioral problems were seen especially in the 3-6 year age range. Surprisingly, the severity of the illness did not correspond to the degree of problems noted among siblings (Lavigne, 1979).

In a study of families of 209 chronically ill children, Pless and Satterwhite (1972), found that frequently families needed but were not receiving many forms of assistance. These areas of need included: explanation of the child's illness; utilization of various supportive professional and paraprofessional workers; effective coordination of existing services; help with educational and behaviorial problems; and, the benefits of a therapeutic listener.

Whether parents receive help or support from outside resources often is especially important in families with children with handicaps or chronic illness (Feetham, 1980). Supportive care of families with a chronically ill child helped parents accomplish tasks necessary for self-acceptance and constructive parent-infant interaction (Waechter, 1977). If families receive the environmental support they need to cope effectively, they can deal with their own feelings and will have the energy required to extend concern to the immediate and long range needs of their child.

Harding (1979) stated a child with a chronic illness must be considered in the context of his family. The illness itself has less impact on a child's perception of himself than does his parents' perceptions of him and his disability. Variables influencing the parents' perceptions of an infant with a chronic illness or defect include the process of being informed of the diagnosis, the number and duration of hospitalizations of the infant, and the infant's developmental status (Price-Bonham and Addison, 1973). Parents' perceptions are also a significant variable affecting family functioning and the ill child's psychological adjustment.

Pless and Roghmann (1971), reviewing the results of three epidemiologic surveys, found a high incidence of serious psychological and social problems in chronically ill children. These problems were seen as a consequence of the child's physical condition and family structure and functioning.

The chronic illnesses of the children surveyed in the study (Pless and Roghmann, 1971) were categorized by type, duration, and severity. The findings of the study revealed: the greater the severity of the condition, the greater the extent of educational underachievement in the child; the risk of behavioral pathology was found to be roughly proportionate to the duration of the disorder and to a lesser degree, to its severity; and, frequency of emotional symptoms, such as social isolation, were also related to the duration of the disorder and to its severity (Pless and Roghmann, 1971).

Pless, Roghmann, and Haggerty (1972) documented the extent to which children with chronic disorders can be considered at high risk for psychosocial disorders and assessed the contribution of family life style as a mediating variable in assessment of children at high risk. The incidence of psychological problems, as assessed by self, parent, and teacher ratings, was found to be 10-15% greater among the chronically ill than among healthy controls. The relative risk for problems with psychological consequences was influenced by the combined effects of health status and family functioning. Also in the prediction of each of the psychological measures, family functioning counted more heavily than family structure (Pless, Roghmann, and Haggerty, 1972).

Bedell (1977) and McArarney (1974) also concluded that social-environmental influences were important in determining the psychological well-being of chronically ill children. Life stress is associated with the degree to which acute symptoms associated with chronic illnesses appear in children (Bedell, 1977). Those chronically ill children who experienced a high level of stress associated their family and social environment had poor self-concepts, had more psychological problems, and experienced more acute episodes of illness (Bedell, 1977).

In conclusion, families with a child having a life-threatening disease or chronic illness, may initially react to the acute phase of the crisis with grief reactions. They grieve both the loss of their normal child and the potential death of the child. The grief may continue throughout the child's illness and block development of normal parent-child relationships.

After the acute phase of crisis, the family moves into a chronic phase where they try to adaptively cope with the child and his need, their own feelings, and disruption of the family unit and lifestyle. Families attempt to reorganize after the disruptions which results in a change in the families' functioning.

The relationship between the family and the child with a chronic illness is a reciprocal, changing one. The nature of the child as a person and his illness all have an effect or impact on the family unit. Of equal importance is the effect that the quality of family life may have on the child (Pless and Satterwhite, 1975).

The final section of the review of literature analyzes further studies that have been completed in the area of family functioning. Conceptual approaches to family functioning are also discussed.

Family Functioning

The concept of family functioning in the past has been poorly defined. As the concept itself was not well understood, frameworks needed to operationalize the concept in everyday practice were limited. A clear definition of the concept of family functioning would provide researchers with an orientation in which to further investigate family relationships.

Feetham (1980) states that family function may be defined in terms of process, content, and outcomes. Functions of the family are seen as patterns of relationships among and between people and their environment and functions are vital to the survival of the family (Feetham, 1980).

It has been shown that some responses to illness depend on structural features of the family such as size, type of family unit, and the state of family development (Pless and Satterwhite, 1975). Other characteristics particular to a family such as ethnic origin, faith, and social class may also be predictors of responses to illness. Viewing a family from a structural framework may aid understanding outcomes and content of family responses, but it gives no insight into the processes of family response to illness.

In an attempt to define the concept of family functioning, many family researchers have specifically delineated or described what they view as family functions. These descriptions may or may not be based on a specific model or framework.

Geismer, LaSorte, and Ayres (1962) imply family functions are measured through outcomes of social behaviors. The behaviors are categorized into the following areas; family relationships and family unity, individual behavior and adjustment, care and training of children, social activities, economic practices, health condition and practices, and use of community resources. Gersten (1976) also implies that a family functions through behaviors but is measured in terms of processes and outcomes, including; the fulfillment of role functions by family members, the qualities of and satisfaction with marriage, and family communication patterns and processes.

Duvall (1971) looks at family from a developmental framework. She focuses on the functions or duties and responsibilities of marital partners. These duties include; maintaining marital and family ties, maintaining effective communication between family members, sharing responsibilities, nurturing development of family members, providing a safe environment, and protecting the family against the unexpected. The focus of these duties change and are dependent on where the family falls along a developmental continuum.

Pless and Satterwhite (1973) and Smilkstein (1978) attempted to focus on family functioning from a holistic approach with emphasis on the functioning versus structural aspect. According to Pless and Satterwhite (1975), the functional aspects of family life include such factors as the way members relate to one another, the manner and ease with which they communicate, the extent to which activities are carried out jointly, the level of marital satisfaction of the spouses, and the happiness and closeness of the unit as a whole.

Smilkstein (1978) defines five areas of a family's functional health from themes common in social science literature. These areas include adaptation, partnership, growth, affection, and resolve. Smilkstein (1978) emphasizes the importance of each aspect of functioning but also stresses the interrelationship of all components with the whole.

Feetham (1980) utilizes a structural-functional framework to explain family functions. Family functioning is conceptualized holistically by Feetham (1980) as the activities of everyday life or the way in which the family as a system operates across many dimensions. Feetham goes beyond other researchers in the area of family functioning by actually incorporating a conceptual framework into her definition of family functioning.

Many researchers have attempted to operationalize the concept of family functioning into instrument form for use in clinical practice. Few of the instruments deal with the multi-dimensions of the concept of family functioning (Pless and Satterwhite, 1973). Geismer's, LaSorte's, and

Ayres' Family Functioning Scale (1962) was developed for use with multi-problem families likely to experience disorganization of the family unit. Hill's Family Integration Scale (1958) was developed to describe the generic features of families under stress due to the loss of a member. Farber's various instruments (1963) were developed to analyze family organization and parent-child communication in families with a retarded child. None of these instruments are in a form that could easily be administered in a clinical setting due to time and length constraints.

Pless and Sattarwhite (1973) initially developed a family functioning index for use in research in studying the adjustment of children with chronic diseases. The index was adapted to eliminate biases so it could be used with both families with chronically ill and healthy children in clinical situations. The purpose of the index was to help identify children at risk for psychological pathology related to poor family functioning as family characteristics influence health. The knowledge gained from administration of the family functioning index would allow the health care provider to identify families who require further evaluation or for whom supportive mental health or social services may be beneficial. The Family Functioning Index included the principle components of marital satisfaction, frequency of disagreements, happiness, communications, weekends together, and problem-solving.

Initially, the Family Functioning Index consisting of 15 questions was administered to parents of 399 children of school age. Two hundred and nine of the children had chronic disorders at the time of the study and the remainder were healthy and served as controls. The psychological adjustment of all 399 children was also assessed through ratings obtained from the subjects themselves, the parents, and teachers.

Results of the study showed that mean scores of the two broad groups of families did not differ significantly, nor was there any significant relationship between the index score and the severity of the child's disability. As a result, the Family Functioning Index was used to examine the relationship between the family's scores on the assumption that the family functioning was influencing the adjustment, not the reverse (Pless and Satterwhite, 1975).

Several means for validation of the index were used. A case worker was requested to rate each family on a five-point scale designed to reflect the content of the index. Correlations between husband and wife scores and case-worker rating scales were high causing the researchers to conclude the index was reasonably valid. Another estimate of validity was provided through a comparison of mean scores of the random sample of 399 with that of a sample of families from counselling agencies, assumed to have low scores. The reliability of the index was indicated by the high correlation of 0.72 between the FFI score of husbands and wives obtained independently.

To assess the stability of the FFI over time, 30 families were selected for repeat assessment five years after initial administration. The correlation between the FFI scores obtained on test-re-test basis was 0.83, indicating a remarkable degree of stability over time (Satterwhite, Zweig, and Pless, 1974).

The Family APGAR was developed by Smilkstein (1978) to elicit a data base that would reflect a patient's view of the functional state of his/her family and was designed for use in clinical settings where time constraints require a utilitarian instrument to measure family functioning. The acronym APGAR was used to define five components of family functioning; adaptation, partnership, growth, affection, and resolve.

The construct validity of the Family APGAR Index was reported by Good et al (1979) in a study in which the Family APGAR Index score was compared to the scores of the Pless and Satterwhite Family Functioning Index (1973) and scores of clinical therapists. A clinical group of psychiatric outpatients and a nonclinical group of normal families were sampled. The results of the study showed a low to moderate internal consistency between the five items of the APGAR Index for each sampled group and a significant difference between the APGAR scores for each sampled group. There was a strong correlation between the APGAR Index and Pless and Satterwhite's Family Functioning Index, and a moderate correlation between the Family APGAR Index and the clinical therapists' evaluation score for the clinical group. Based on these findings, it was concluded by the researchers that the Family APGAR Index was a valid instrument.

Feetham (1980) in a longitudinal study of 66 parents and 38 infants with myelodysplasia examined relationships among variables pertaining to the parents, the infant, and the family environment with family functioning at five time intervals in the first 18 months of the infant's life. Family functioning served as the dependent score and was measured as a composite score across 21 indicators. The validity and reliability over time of the family functioning instrument utilized by Feetham (1980) have not been established.

The previous studies were reviewed because they conceptualized family functioning holistically and attempted to operationalize the concept of family functioning in instruments applicable to clinical practices. Whall (1980) states the reformulation of theories of family functioning so as to achieve consistency with present nursing approaches is important. Theories which conceptualize family functioning holistically may easily be reformulated in terms of nursing theory.

No studies have specifically investigated the relationship between a child with prolonged apnea requiring home monitoring and family functioning. The study by Pless and Satterwhite (1973) may be considered applicable as it investigated the adjustment of children with chronic illness and family functioning. Black (1978) stated that apnea may be considered a chronic, if self-limiting, condition. Therefore the Family Functioning Index score of a family with an apneic child being monitored at home may reflect the child's future psychological adjustment and the adjustment of the family to the impact of the child's illness and management intervention.

Summary

In summary, the review of literature reveals that two studies have been completed to determine the impact of home apnea monitoring on family life (Black, 1978) and parents' perceptions (Cain et al, 1980). These studies used interview and questionnaires as research tools to measure areas of family life most impacted including family, parent, and infant outcomes, and to measure sources of support helpful during the home monitoring period. The main drawback of these studies is that they specifically do not measure the relationship between home apnea monitoring and family functioning.

The prominent theme that can be drawn from the literature on home apnea monitoring is that most families are significantly impacted by having a child with prolonged apnea requiring monitoring but most do effectively cope with the stresses and issues related to monitoring. These issues include: the fear or threat of the child's death is raised; the diagnosis of a chronic, self-limiting condition is made; a mechanical device with limitations and certain operating requirements must be dealt with; and, direct and full-time responsibility for appropriate intervention, should apnea or bradycardia occur, is assumed by the parents (Black, 1978). One article also addresses the role of nursing in the hospital as a support person to families experiencing the crisis of home apnea monitoring (Favorito, 1979).

The literature related to the threatened loss of an infant reveals that because parents of an infant with apnea may fear their infant's death, they may be experiencing anticipatory grief. The grief process may block development of normal parent-child relationships and if unresolved, may lead to significant psychological sequelae for both infant and parents in the future.

The review of literature on family response to a life-threatening or chronic illness in a child was even more informative. Several studies indicate that having a child with a life-threatening or chronic disease significantly affects a family as they have several tasks to accomplish and issues to resolve in coping with the crisis of chronic illness. The coping of the family requires reorganization of the family and results in a change in the level of family functioning. As the relationship between child and family is a reciprocal one, one study (Pless, Roghmann, and Haggerty, 1972) demonstrates that even though the child with a chronic illness affects the family lifestyle, family functioning combined with the child's health status affect the child and his/her psycological adjustment.

The literature on family functioning demonstrates a lack of a concise definition of the concept family functioning and a lack of frameworks or models used to operationalize the concept. Two instruments developed to measure the multi-dimensional concept of family functioning holistically have been shown to be valid and reliable for use in clinical practice. One instrument developed by Feetham (1980) shows great promise for future use as its reliability over time is established. Results of studies on family functioning demonstrate that family functioning does influence a child's adjustment to chronic illness even as the family is impacted by the crisis of the illness.

From the review of literature related to the impact of home apnea monitoring on family functioning, several conclusions and implications for further research can be drawn. The specific phases of crisis a family faces with the diagnosis of apnea in a child and the prescription of the management intervention of monitoring must be more specifically outlined. Family and parent perceptions of the impact of home monitoring must be further measured. The perceptions measured should include their views on their own feelings and their views on the child during monitoring and at several intervals in the future to determine if the child is at risk for psychological maladjustment in the future. Obviously, measures of the level of family functioning should also be done at the same times to determine if the functioning of the family may place the child at risk. Perceptions of both parents about the level of family functioning should be measured to assess if the family is at risk for disorganization and eventual breakup or if there is a discrepancy between partner perceptions that may indicate family disorganization.

Specific information is needed on identifying areas where families undergoing monitoring most need help or support. Further, types of support most helpful to the family especially during the acute phase of monitoring must be specified. From this information base, using a conceptual framework in the approach, specific nursing interventions addressing potential and real family needs must be generated. Finally, data needs to be collected to assess if supportive intervention actually affects family functioning in terms of process, content, and outcome measures.

As there is a lack of concise definition of the concept of family functioning and a lack of conceptual frameworks as a result, nursing must be willing to reformulate family functioning approaches in terms of nursing theory to provide an avenue for conceptualizing the approaches. To conceptualize family functioning in terms of nursing theory, further nursing research must address family functioning related both to health and illness and to family development along a time continuum.

In Chapter IV, the research design and methodology of the study will be presented, including operational definition of variables, a description of the study sample and data collection procedure, a description of the instrument and scoring, a discussion of statistical analyses, and a presentation of research questions posed.

CHAPTER IV

METHODOLOGY AND PROCEDURE

Overview and Research Design

This research study was designed to describe how family functioning is impacted or affected by home apnea monitoring as perceived by the monitored infant's primary caretaker. The investigation was also designed to identify relationships between a family's perceived severity of their infant's condition and threat of loss of their infant, perceived scope of impact of home apnea monitoring, perceived support available to the family during home monitoring, and family functioning. The study also sought to determine the relationship between length of monitoring, disposition of monitoring, and family functioning. The research methodology was descriptive.

Through mailed questionnaires, descriptive data were obtained from parents of families who have had or currently have an infant with prolonged apnea on an apnea and cardiac monitor at home. The study sample included 22 primary caretakers of monitored infants. The study sample was voluntary and subjects were obtained from a list of participant families in a hospital-based Home Apnea Monitor Program. The test instrument included a sociodemographic questionnaire; scales addressing Beliefs About Home Apnea

Monitoring including the Family Stress Scale, the Family Impact Scale, and the Family Support Index and the Family Functioning Index developed by Pless and Satterwhite (1973).

In this chapter, the research study variables are defined, the study sample's characteristics are described, the data collection procedure is outlined, and human rights protection is described. Further, the instrument and scoring of the instrument are described and statistical analysis to be done on data obtained from administration of the instrument is described.

Operational Definition of Variables

Independent Variables

The independent descriptive variables in this study include: length of monitoring; disposition of monitoring, whether ongoing or discontinued; family's perceived severity of their infant's condition or potential threat of loss of their infant; family's perception of scope of impact of home apnea monitoring, and family's perceived support available during the home monitoring period. The variables, length of monitoring and disposition of monitoring were designated in the Sociodemographic section of the instrument (See Appendix F).

a. Length of monitoring was determined by the age of monitored child when monitoring was started and discontinued (See Appendix E, questions #15.A and #15.C).

b. Disposition of monitoring was determined by whether the child was still being monitored and if the monitor had been discontinued, the length of time the child had been off the monitor (See Appendix E, questions #15.B. and #15.D).

The variables involving perceptions were designated in three separate scales in the section of the questionnaire entitled Beliefs About Home Apnea Monitoring (See Appendix F). Perception of impact is defined by King (1971, p. 22) as an individual's representation or image of reality; an awareness of objects, persons, and events. According to Sutterly (1979), stress lies in the perception of events, not in the events themselves. Thus, a family's perceptions of severity of their child's condition or potential threat of loss of their child serve as a stress. The variable, family's perception of severity or threat of loss, was designated in the Family Stress Scale (See Appendix F, Section 1). The variable, family's perception of scope of impact of home apnea monitoring, was designated in the Family Support Index (See Appendix F, Section 3).

The above variables were not inclusive of the variables which may affect family functioning related to home apnea monitoring. The selected variables were identified from the literature related to home monitoring and impact of childhood chronic illness on the child's family and from the researcher's personal experience in working with home monitor families.

As it was assumed by the researcher that the monitored infant's primary caretaker was most impacted by home apnea monitoring and as the Family Functioning Index was initially developed by Pless and Satterwhite (1973) to be completed by mothers of chronically ill children, who usually serve as primary caretakers, it was the monitored infant's primary caretaker or mother who served as respondent to the instrument. Thus, the infant's primary caretaker's perceptions were measured by the instrument and were assumed to be generally representative of the monitored infant's family.

Beliefs About Home Apnea Monitoring:

a. Primary caretaker during monitoring period was determined by who was primarily responsible for the monitored child's care during the home monitoring period (See Appendix E, question #13).

b. Family's perceived severity of their infant's condition or potential threat of loss of their infant was operationally defined and measured by the Family Stress Scale as completed by the infant's primary caretaker (See Appendix F, Section 1, questions #1-5).

c. Family's perception of scope of impact of home apnea monitoring was operationally defined and measured by the Family Impact Scale as completed by the infant's primary caretaker (See Appendix F, Section 2, questions #1-12).

d. Family's perception of degree of support available during home monitoring was operationally defined and measured by the Family Support Index as completed by the infant's primary caretaker (Appendix F, Section 3, questions #1-9).

Dependent Variable

The dependent variable in the research study was the level of family functioning. The concepts of family and family functioning were defined to provide a better understanding of the level of family functioning.

Family will be defined as a social system comprised of a group of interdependent persons who have established relationships by continued interaction and are linked by economic and emotional bonds that exist for the physical, psychosocial, and spiritual support of its members over time (MSU Graduate School of Nursing, 1978). This unit must include as a member an infant with prolonged apnea or at risk for prolonged apnea for whom apnea monitoring has been chosen as part of the management plan.

Family Functioning will be defined as the processes by which a family operates including such factors as the way the members relate to one another, the manner and ease with which they communicate, the extent to which activities are carried out jointly, the level of satisfaction of the spouses, and the happiness and closeness of the unit as a whole, as measured by the Pless and Satterwhite Family Functioning Index (1973). The Family Functioning Index includes the principal categories of marital satisfaction, frequency of disagreements, happiness, communications. weekends together, and problem-solving (Pless and Satterwhite, 1973).

The level of family functioning as operationally defined and measured by Pless and Satterwhite includes the following subcategories (See Appendix G):

a. Time spent together was operationally defined and measured by question #1 of the Family Functioning Index.

b. The concept of sibling relations, was operationally defined and measured by question #2 of the Family Functioning Index. This question was applicable only if the family had more than one child.

c. The concept child-father communications, was operationally defined and measured by question #3 of the Family Functioning Index.

d. Mother-father communication was operationally defined and measured by question #4 of the Family Functioning Index.

e. The concept father-child activities-evenings, was operationally defined and measured by question #5 of the Family Functioning Index.

f. The concept, father-child activities-weekends, was operationally defined and measured by question #6 of the Family Functioning Index.

g. Family happiness was operationally defined and measured by question #7 of the Family Functioning Index.

h. The concept, problems discussed with partner (problem-solving), was operationally defined and measured by question #8 of the Family Functioning Index.

i. Decision-making was operationally defined and measured by question #9 of the Family Functioning Index.

j. Marital satisfaction was operationally defined and measured by question #10 of the Family Functioning Index.

k. Husband-wife disagreements was operationally defined and measured by question #11 of the Family Functioning Index.

l. The concept, frequency of disagreements, was operationally defined and measured by question #12 of the Family Functioning Index.

m. Closeness was operationally defined and measured by question #13 of the Family Functioning Index.

n. Marital satisfaction including subdivisions of feelings of standard of living, understanding of problems and feelings, feelings of love and affection, and feelings of companionship was operationally defined and measured by question #14 of the Family Functioning Index.

o. Work communication was operationally defined and measured by question #15 of the Family Functioning Index.

Extraneous Variables

In order to study the family's perception of the impact of home apnea monitoring on the level of family functioning, it was necessary to collect data on extraneous variables that may influence a family's perceptions and thus influence the outcome of the study. Functioning of a family is related to the developmental tasks that family must meet. Data related to the developmental level of the family and its members such as parent age, level of education, income, etc. was collected in the Sociodemographic questionnaire. Situational variables such as how the child's condition was discovered and household and family composition as well as length of monitoring and disposition of monitoring, may also affect the family's level of functioning by influencing how the family or primary caretaker defines the event or stress or attempts to cope or adapt to it (See Conceptual Framework, Chapter II).

Sociodemographic Developmental and Situational Variables:

a. Age of parent responding to questionnaire (See Appendix E, question #2).

b. Level of income was determined by the indicated total family income for the past 12 months (See Appendix E, question #4).

c. Level of education was determined by the level of schooling completed by responding parent (See Appendix E, question #6).

d. Household and family composition was determined by the parent(s)' marital status, their total number of children, and others living with the child during the home monitoring period (See Appendix E, questions #3, #9, and #10).

e. Diagnosis of child's condition was determined by how the child's condition was initially discovered and the child's gestation at birth (See Appendix E, questions #12 and #14).

In summary, the major variables of the study included the length of monitoring, disposition of monitoring, the family's perception of stress, the family's perception of scope of impact of home apnea monitoring, the family's perception of support available during the home monitoring period, and the level of family functioning. Extraneous variables that may influence the level of family functioning included age of parent responding to the questionnaire (the monitored infant's primary caretaker), the family's level of income, the level of education of the responding parent, the family and household composition during the home monitoring period, and how the monitored child's condition was discovered. These variables were measured and operationally defined in a three part questionnaire that will be detailed later in this chapter.

Sample

The sample for the research study included subjects who met certain selection criteria. Study subjects were the parents, specifically the primary caretaker, of families in which one member was an infant who had had or currently at time of study, had prolonged apnea and/or bradycardia or was at risk for prolonged apnea and/or bradycardia. The families used or had used an infant apnea and cardiac monitor at home as part of the infant's health management plan and were or had been participants in a particular hospital-based Home Apnea Monitor Program. Families who had an infant with prolonged apnea and/or bradycardia due to certain seizure disorders or due to tracheal obstruction were excluded from the study sample.

The subjects' infants were of either sex, the product of either premature or full term delivery, hospitalized for evaluation of prolonged apnea and/or bradycardia or at risk for prolonged apnea in conjunction with a certain hospital-based Home Apnea Monitor Program, and between the ages of two weeks and eighteen months during the home monitor period. The period of monitoring for the infant may have been completed or ongoing.

Subjects were of any ethnic, cultural, or socioeconomic group. Subjects resided in the state of Michigan and were participant families in a particular hospital-based Home Apnea Monitor Program within the state of Michigan. Subjects were literate in the English language and verbalized a willingness to participate in the research study.

Subjects in the research study met the above criteria and the study sample was comprised of 22 monitored infants' primary caretakers. Random sampling was not applicable or useful for the research study due to the small sample meeting the criteria for participation. In summary, study subjects met the following criteria: (1) subjects were parents and primary caretakers of an infant who once had or currently had prolonged apnea and/or bradycardia or was at risk for prolonged apnea and/or bradycardia and who used an infant apnea and cardiac monitor as part of the infant's health management plan; (2) subjects must have resided in the same household with the infant during the home monitoring period; (3) subjects resided in the state of Michigan and were participants in a certain hospital-based Home Apnea Monitor Program; and, (4) subjects were literate in the English language and verbalized a willingness to participate in the research study.

The small study sample size posed some major limitations. Due to the small sample size and the sample being voluntary and not randomly selected, the generalizability of the study results will be limited to the sample size. Therefore, study results cannot be inferred to a larger population. Distribution of results may be artificially positively skewed and there may be error in variance. Characteristics specific to this sample may affect responses to the instrument's scales.

Data Collection Procedure

The researcher made contact with the director of one of two hospital-based Home Apnea Monitor Programs in the state of Michigan. The study was explained to the director of the program and a summary of the study results were offered to the program as incentive for participation in the study. The results from the study may serve as a stimuli for further investigation by the home monitor program and development of supportive nursing and health care strategies and interventions for home monitor families.

The director of the program was provided with two research study proposals to be given to the human subjects review committee of the hospital in which the program was based. The director of the program wrote a letter of recommendation endorsing the proposal to the Institutional Research Review Committee of the participant hospital. Tentative approval was given by the chairman of the committee to contact potential subjects who were no longer receiving care from the hospital as participants of the Home Apnea Monitor Program. After the research proposal was accepted at the hospital's Institutional

Research Review committee's next scheduled meeting, permission was given to the researcher to contact potential subjects who were currently participants in the hospital's Home Apnea Monitor Program.

The subjects were obtained from a list of participant families in the hospital-based Home Apnea Monitor Program. After the subjects were identified from the list of participant families, the researcher contacted each potential subject (parent of an infant with apnea and/or bradycardia). The researcher was able to contact the subjects as she was or had been involved in the direct care of subjects' infants in the hospital-based Home Apnea Monitor Program in her role as nurse coordinator of the program.

Subjects who met the selected criteria for participation were initially contacted by the researcher by telephone. The researcher introduced herself by name, position, and association with the Home Apnea Monitor Program participating in the study. The researcher explained how she obtained the subject's name and provided an explanation of the research study. She indicated the amount of time and effort needed on the subject's part to participate in the study and requested the subject's participation in the study. The researcher allowed questions and assured the subject's anonymity and confidentiality. She also assured the subjects they could refuse to participate in the study and such a decision would not affect their infant's present or future care.

The researcher allowed subjects to discuss participation privately with the infant's other parent before agreeing to participate in the investigation if so requested by subjects. She allowed one day, or longer if requested by subjects, for such discussion and then recontacted subjects by telephone for their answers. Again, the researcher allowed questions and indicated that the subjects may withdraw from the study at any time.

If an infant's parent(s) agreed to participate in the investigation, the researcher gave the subjects detailed instructions for completing the instrument. The researcher then sent subjects in the mail a cover letter explaining the researcher's intent (See Appendix B), a consent form for both parents' signature (See Appendix C), the Socio-demographic questionnaire (See Appendix E), Beliefs About Home Apnea Monitoring (See Appendix F), the Family Functioning Index (See Appendix G), and a self-stamped, addressed envelope for return of the questionnaire and consent form to the researcher.

The data was received after completion by study subjects through the mail at the hospital where the Home Apnea Monitor Program participating in the study was based. The completed instruments and consent forms were stored separately in a locked file drawer. Upon completion of data collection, the questionnaires were scored, coded on Fortran coding sheets, and key-punched in preparation for data analysis.

Human Rights Protection

The Michigan State University Committee on Research Including Human Subjects and the Institutional Research Review Committee of the participant hospital have established specific criteria to be followed by researchers to follow in studies including human subjects. These procedures and criteria were followed in this research study to ensure protection of the rights of the subjects.

To make all subjects aware of potential risks, all subjects received a letter of introduction and explanation along with the questionnaire. The cover letter explained the purpose of the research, how results would be utilized, requirement for participation, and potential risks to research subjects. The letter also informed the subject that participation or unwillingness to participate in the research study would not affect the health care the subject's infant currently received or would receive in the future. The subject was also informed in the letter of his/her right to withdraw from the study at any time. Results of the study following completion were offered to subjects. The researcher's statement also specified that questions were allowed at any time during the study and would be answered and that proper support would be obtained for subjects through referrals to appropriate, accessible people should concerns or stressful emotions arise as a result of the study. The researcher's name, addresses, and phone number were provided to subjects and if questions arise, subjects were instructed to call the researcher collect.

The consent form required signature of both parents of a monitored child. The consent form stated that the subjects voluntarily agreed to participation in the research study and understood what was required of them as a participant.

Initial consent was obtained verbally from subjects by telephone. In the telephone contact, information about the purpose and confidential nature of the study was emphasized. Further, the researcher specified requirements for participation and the subject's right to refuse or withdraw from the study at any time.

To protect subjects and keep their responses anonymous, the questionnaires were precoded with a subject case number and date. Upon completion and return of the questionnaires to the researcher, the signed consent forms and questionnaires were kept separately in a locked file drawer. Data was recorded from questionnaires and analyzed in aggregate form.

The research study was presented to the Human Subjects Review Committee of the College of Nursing and was approved by that Committee on October, 1980. The research study was presented to the Institutional Research Review Committee of the hospital participating in this study on November 14, 1980. Tentative approval was given by the committee chairman on December 2, 1980, to begin data collection with children and parents who were not actively involved in treatment through the hospital. On January 6, 1981, final approval for the research study was given by the hospital Institutional Research Review Committee and the hospital Executive Committee.

Instrument

Black (1978) carried out a research study to determine the impact of apnea monitoring of family life. Through interviews and questionnaires, descriptive data were obtained from 31 families who recently or currently had an infant on a monitor. The questionnaire consisted of 29 questions, some open-ended, 13 rating scales, and some rank-order items. The questionnaire's content was generated from interviews with these families (Black, 1978). No section of the instrument specifically dealt with measurement of family functioning.

Cain, Kelly, and Shannon (1980) conducted a study to assess parents' feelings, perceptions, reactions to stress, and satisfactions during periods of home monitoring. Data were obtained from a structured interview with each of 133 parents and from a self-administered graphic five-part rating scale. Again, no part of the interview or scale measured family functioning.

No other published research has been completed on the family's perception of the impact of home apnea monitoring on the family's level of family functioning and no standard instruments are available to measure these variables. The instrument developed to measure the study variables included sections adapted from Black (1978) and designed by the researcher from personal experience with home apnea monitor families. These sections were developed to measure the family's length of monitoring and disposition of monitoring, and the family's perceptions of the severity of their child's condition, perceptions of impact of home monitoring on aspects of family life, and perceptions of support available to the family during the monitoring period.

The total instrument, including the Sociodemographic questionnaire, Beliefs About Home Apnea Monitoring, and the Family Functioning Index, was submitted to various persons involved in the hospital based Home Apnea Monitor Program for content and readibility. The instrument designed and adapted by the researcher was not pretested as it may have biased study subjects and reduced the sample size. Therefore, reliability and validity for the sections of the instrument designed or adapted by the researcher were not established before use of the instrument in this study.

Family Functioning Index

The section of the instrument used to measure the family's level of functioning was the Family Functioning Index developed by Pless and Satterwhite (1973). The FFI was developed for the purpose of identifying families receiving health care in primary care settings who may be at risk for family problems and required further intervention to prevent or resolve such problems. The FFI was initially given to primary caretakers of families of 399 school age children, 209 were chronically ill and 190 were healthy and served as a control population. Before administration of the FFI, case workers assessed the psychological adjustment of all children and rated each child's family on a five-point scale designed to coincide with the content of the FFI.

Validity for the FFI was established through comparing FFI scores with the scores assigned by case workers. Reliability was established by showing a high correlation between wives' and husbands' scores. Satterwhite et al

(1976) demonstrate a five year test-retest reliability for the Family Functioning Index by repeating the instrument with 29 families with chronically ill children of the original 399 tested families. A high correlation was demonstrated between the original FFI scores and retest FFI scores.

An instrument consisting of 59 items, including the Family Functioning Index, divided into three parts was completed by each subject. Part one of the questionnaire, the Sociodemographic questionnaire, consisted of 15 sociodemographic items which included multiple choice and fill-in-the-blank questions (See Appendix E). Items in the sociodemographic questionnaire addressed the subject's age, marital status, occupation, level of education, and total family income. Other items in the sociodemographic questionnaire include the sex of the subject's child, the child's ethnic group, the household composition during the home monitoring period, how the child's condition was discovered, who the child's primary caretaker or mother was, the child's gestation at birth, the length of the home monitoring period, and the disposition of monitoring, whether completed or ongoing.

Beliefs About Home Apnea Monitoring

Part two of the questionnaire, Beliefs About Home Apnea Monitoring, consisted of 29 items (See Appendix F).

Beliefs About Home Apnea Monitoring was divided into three separate scales, the Family Stress Scale, the Family Impact Scale, and the Family Support Index. Each item in Beliefs About Home Apnea Monitoring was stated in ordinary, easy-to-understand language. As yet, this section of the instrument has not been tested for reliability or validity. Although scoring and statistical analysis were done only on the primary caretakers' questionnaires, the questionnaire was also administered to the children's other parents to allow for testing for validity in the future. Testing for validity in this manner is beyond the scope of this research study.

The Family Stress Scale, the first section of Beliefs About Home Apnea Monitoring consisted of five items which had responses in a five-choice Likert scale form ranging from "Very Serious", "Serious", "Moderately Serious", "Slightly Serious", to "Not Serious at All". The five items of the Family Stress Scale addressed the subject's beliefs about; (1) the seriousness of his/her child's condition, (2) how the need for a home monitor affected the subject's beliefs about the seriousness of the child's condition, (3) how the number of alarms the child experienced affected the subject's beliefs about the child's condition, (4) how having to stimulate the child to breathe affected the subject's beliefs about the seriousness of the child's condition, and (5) the subject's beliefs about the potential threat of death of his/her child.

The next three items of Beliefs About Home Apnea Monitoring were developed to describe study subjects' perceptions about the future related to the experience of having a child on a home monitor. The respondents were asked to agree or disagree with each individual item by checking responses; _____Yes or _____No. If the subject checked the yes response, he/she then was asked to elaborate on his/her response. Specifically, these three items addressed the subject's perceptions about how his/her child's need for a monitor might affect the subject's treatment of the child in the future, how the experience of having a child on a monitor affected his/her views on having more children, and finally, how the experience of having a child on a monitor affected the subject's own future plans.

The Family Impact Scale, the second section of Beliefs About Home Apnea Monitoring, consisted of 12 items with responses in a five-choice Likert scale form ranging from "Very Much", "Somewhat", "Moderately", "Slightly", to "Not at All". The Family Impact Scale included items addressing the subject's beliefs about what impact or effect home apnea monitoring had on aspects of family life, including; finances, fatigue of other family members, arrangements of furnishings in the family home, the family's social life, family travel, tension the family experienced, friction between family members, health of other family members, relatives, the family's ability to carry out daily activities, and other children in the family.

The Family Support Index, the third section of Beliefs About Home Apnea Monitoring, consisted of nine items developed to address subject's beliefs about sources from whom the family received help during the home monitoring period. The subject was asked to agree or disagree with a question by checking responses; _____Yes or _____No. If the subject checked the yes response, he/she was then asked to elaborate on what type of help the source provided and to rate the help with responses in a three-choice Likert scale form ranging from "More Than Adequate", "Adequate", to "Inadequate".

Part three of the instrument consisted of the Family Functioning Index developed by Pless and Satterwhite (1973). The Family Functioning Index consisted of 15 items with responses in various rating forms including multiple choice, rank order, and three choice scale forms (See Appendix G). The items of the Family Functioning Index addressed 15 areas of family functioning including communication, decision-making, problem-solving, marital satisfaction, togetherness, closeness and child orientation.

Scoring

Assignment of a numerical value for scoring purposes was done according to the type of scale form used in each item. No specific scoring was done or was appropriate for the Sociodemographic questionnaire.

In the Family Stress Scale, Beliefs About Home Apnea Monitoring, the five items had responses in a five-choice Likert scale form (See Appendix F, pages 3-4). Assignment of a numerical value to each choice was done in descending order from "5" to "1", from "Very Serious" to "Not Serious at All" with "Very Serious" assigned the score of "5". A subject's total score for the five scale items was determined by adding together individual item scores. The minimum possible score for the Family Stress Scale was "5" and the maximum possible score was "25".

The responses for the next three items in the Beliefs About Home Apnea Monitoring were scored as follows. The respondent was asked to agree or disagree with a question by checking "Yes" or "No" as a response. If a person disagreed with the question, he/she was assigned a score of "1". If the subject agreed with the question, he/she was assigned a score of "2". If the respondent agreed with the question, he/she was asked to go to part "a." of each question, he/she was assigned a score of "1" for answering that part of the question. According to this score assignment, a subject was assigned a total score of "3" for each item if he/she agreed with the item and qualified hes/her answer in part "a.". Or, a subject was assigned a total score of "1" for each item, if he/she disagreed with the question.

The Family Impact Scale, the second section of Beliefs About Home Monitoring, had 12 items with responses in a five-choice Likert scale form. Assignment of a numerical value to each choice was done in descending order from "5" to "1", from "Very Much" to "Not at All" with "Very Much" assigned a score of "5" and "Not at All" assigned a score of "1". After each item was handled in the above manner, a subject's total score for the Family Impact Scale was determined by adding together individual item scores. The maximum score possible for the Family Support Scale was "60" and the minumum score possible was "12".

The Family Support Index, the third section of Beliefs About Home Apnea Monitoring, consisted of nine items which were scored as follows. The respondent was asked to agree or disagree with the question by checking "Yes" or "No" as a response. If the subject disagreed with the question, he/she was assigned a score of "1" for that entire item. If the subject agreed with the question, he/she was asked to complete part "a." of the question and describe what type of help was provided by that particular source, and then go to part "b." of the question and rate on a 3-choice Likert scale the amount of help the source gave. If the respondent then rated the amount of help the source gave, assignment of a numerical value to each choice was done in descending order from "3" to "1", from "More Than Adequate" to "Inadequate", with "More Than Adequate" assigned a score of "3", "Adequate" assigned a score of "2", and "Inadequate" assigned a score of "1".

During the data analysis, it was found that all subjects' scores for each item totaled "1", "4", "5", or "6". The score "1" signified the respondent had answered "No" to the question. The scores "4", "5", "6" signified the respondents had agreed with the question, had described what type of help was provided and rated the amount of help provided from "Inadequate" to "More Than Adequate".

To simplify summation of item scores and decrease the range of total index scores during the data analysis, individual items were recoded. If the item previously was scored "1", it was reassigned a score of "0". If the item was previously scored "4", it was reassigned a score of "1". If the item was previously scored "5", it was reassigned a score of "2". If the item was previously scored "6", it was reassigned a score of "3". After each item was handled in the above manner, a subject's total score for the Family Support Index was determined by summing item scores. The minimum score possible for the Family Support Index was "0" and the maximum score possible was "27".

The third part of the instrument, the Family Functioning Index, was scored according to the scoring key developed by Pless and Satterwhite (1973) (See Appendix H, Scoring Key for Family Functioning Index). The maximum score possible for the Family Functioning Index was "35". The normative data now available suggests any family scoring below "20" as "high-risk" and above "20" as "low-risk" (Pless and Satterwhite, 1975).

Statistical Analysis

Purpose of Scaling

Polit and Hunger (1978, p. 359) stated social-psychological scales are devices aimed at making comparisons among individuals concerning the degree to which they possess a trait, attitude, or emotion. Further, scales are measuring instruments that permit inter-individual comparisons along some dimension of interest and measure these attributes quantitatively (Polit and Hunger, 1978), or demonstrate undimensionality related to a concept or attribute.

Crano (1973) indicated that when assessing individual differences on scales, the stimuli being assessed are called items, and a respondent to the scale is asked to endorse or reject each item to some degree. Reliability of the scale, Crano stated, has come to mean the degree to which items within a scale are related to one another or the degree of interrelationship among items (1973). Reliability of scales will be discussed in more depth later in this chapter.

A Likert method scale consists of several statements or questions expressing a viewpoint on a topic and respondents are asked to indicate the degree or level to which they disagree with the opinion expressed in the statement or question (Polit, 1978). The aim of using the Likert method is to spread out subject responses along a continuum of favorability (Polit, 1978). Crano (1973) stated that a subject's attitude is assumed to be reflected by the score he/she receives over all the items of the scale. According to Polit (1978), item responses should reflect some variability and should only be summed if they relate to a similar concept.

Crano (1973) indicated that the Likert scale method is considered a reliable attitude measurement device and is effective in developing scales of high reliability.

Therefore, Likert scales were used to measure the perceptions of a family about the seriousness of their infant's condition and the impact of home apnea monitoring on the family (See Appendix F, Family Stress Scale and Family Impact Scale).

Reliability and Validity

As previously discussed, Crano (1973) defined the reliability of a scale to be the degree of interrelationship among items of the scale. The term internal consistency best describes the condition in which there is a high degree of interrelatedness among items (Crano, 1973).

According to Crano (1973), coefficient alpha represents the average interitem correlation of all items constituting a scale and probably represents the best estimate of internal consistency. A scale must have a high degree of interrelatedness among all items to justify summing all item responses to produce an overall "attitude score" (Crano, 1973).

Coefficient alpha was calculated for two sections of Beliefs About Apnea Monitoring, the Family Stress Scale and the Family Impact Scale. To determine coefficient alpha for these sections of Beliefs About Home Apnea Monitoring, each item of the individual scale was correlated with the total score for the specific section. If the coefficient alpha was at least .80 or greater, the scale satisfied the criterion for internal consistency. The more positive and greater the item-total correlation was for each specific item, the more predictive that item was for the attitude or perception being measured.

To determine the undimensionality of the Likert scales used in the research study, the Family Stress Scale and the Family Impact Scale, exploratory factor analysis of interitem correlations was done with each particular attitude scale. Polit (1978, p. 584) stated that the major purpose of factor analysis is to disentangle complex interrelationships among variables and identifies which variables go together as concepts. Factor analysis offers an empirical method for elucidating the underlying dimensionality of a large number of measures (Polit, 1978).

To provide further description of the perception scales, the Family Stress Scale and the Family Impact Scale, the Family Support Index, and the items addressing perceptions about the future, means, modes, ranges, and standard deviations of total scale scores were done. Further, frequency distributions were done for each specific scale.

Means, modes, ranges and standard deviations were also figured for the Family Functioning Index scores. A frequency distribution was also done for the FFI. Means and modes were also used to describe sociodemographic variables, including length of monitoring and disposition of monitoring.

Validity refers to the degree to which an instrument or scale measures what it is supposed to measure (Polit, 1978). Further, Crano stated "validity of a scale refers to the extent of correspondence between variations in scores on the instrument and variation on the underlying attribute under investigation" (1973, p. 249). The more valid the scale, the greater this correspondence. An instrument or scale measuring an attribute of interest which is not reliable cannot possibly be valid.

Content validity is concerned with the sampling adequacy of the content area being measured (Polit, 1978). Crano (1973) indicated that content validity is determined by the degree to which items constituting a scale represent all possible positions on the particular domain under construction and assessment of the content validity of scales is usually subjective. In an attempt to ensure content validity of a scale, most researchers generate many diverse items, all focused on the attribute or domain of interest (Crano, 1973). Items related to the domain of interest were generated in development of the perception scales included in Beliefs About Home Apnea Monitoring.

Factors which may influence a scale and subject's responses to the scale and lower the validity of the scale serve as threats to validity. Threats to validity pertinent to this study include response bias, social desirability, extreme response set and acquiescence. As Beliefs About Home Apnea Monitoring was not pretested, and due to the sensitive content of items, the wording of items may have influenced or determined a subject's responses, irregardless of the actual content of scale items and served as response bias.

Social desirability bias may have served as another threat to the validity of the perception scales and the research study. Subjects may have made responses biased in a socially desirable way or refused to answer items because of a lack of self-knowledge, denial or lack of awareness of true beliefs, or refusal to be completely honest (Crano, 1973). If a respondent's feelings varied with those accepted by society, as may have occurred with negative feelings about his/her child, the respondent may have been tempted to answer in the socially acceptable ways.

Extreme response sets represented another threat to the validity of the study. Respondents may have had a tendency to choose extreme responses of each particular perception scale.

Acquiescence served as a final threat to validity. A respondent may have tended to agree with positively worded items as Likert scale items were not stated in alternating positive and negative form.

Research Questions Posed

The following research questions were tested in this study:

1. How is the overall length of home monitoring related to the level of family functioning?
2. How is the disposition of monitoring related to the level of family functioning?
3. How is the family's perceived threat of loss of their infant or perceived severity of their infant's condition (measured by the responses of the monitored infant's primary caretaker to the Family Stress Scale) related to the level of family functioning?
4. How is the family's perception of the scope of impact of home apnea monitoring (measured by the responses of the monitored infant's primary caretaker to the Family Impact Scale) related to the level of family functioning?
5. How is the family's perception of support available to the family during the home monitoring period (measured by the responses of the monitored infant's

primary caretaker to the Family Support Index) related to the level of family functioning?

To provide the most complete use of data, as statistics are relatively robust and will compensate to some extent for the problems of skewed distribution due to the small study sample, measures of association or relationship were used. Such measures are useful in research studies in which an attempt is made to discover or clarify relationships through the use of correlation coefficients. A correlational approach permits the researcher to measure a great number of variables and their interrelationships simultaneously and provides the researcher with the degree of relationship between variables being studied (Borg and Gall, 1971).

Analysis of variance is a parametric procedure utilized to test the significance of differences between means. Analysis of variance is utilized to analyze the differences between means of three or more groups and is computed as the F-ratio statistic. One-way analysis of variance deals with the effect of one independent variable on a dependent variable (Polit and Hunger, 1978).

The t-test is a parametric procedure for testing differences in group means (Polit and Hunger, 1978) when small samples are studied (N=29 or smaller) (Borg and Gall, 1971). A two-tail t-test of significance is used when both tails of the error curve are considered (Borg and Gall, 1971).

To test research question 1, the length of monitoring for all subjects' infants was computed and the infants were divided into four groups according to length of monitoring. The means for the scores of the subjects' on the Family Functioning Index was computed and an analysis of variance expressed as an F-ratio was calculated to determine the differences between the four groups. The means for the scores of the infants' primary caretakers on the Family Stress Scale, the Family Impact Scale, and the Family Support Index were also computed and analysis of variance were calculated to determine the differences between means for the four groups on those measures.

To test research question 2, subjects were divided into two groups according to disposition of monitoring. The mean for the subjects' scores on the Family Functioning Index was figured and a two-tail t-test was calculated to determine the differences between means for the two groups. To determine differences between means for the groups on scores of the Family Stress Scale, the Family Impact Scale, and the Family Support Index, two-tail t-tests were also calculated for the groups on those measures.

Pearson Product Moment Correlation is used when both variables are expressed as continuous scores. In order to test research questions 3, 4, and 5, individual total scores for each subject were totaled for each section of Beliefs About Home Apnea Monitoring (the Family Stress Scale, the Family Functioning Scale, and the Family Support Index) and the Family Functioning Index. A Pearson Product Moment Correlation was figured between each perception scale or index and the FFI component to test research questions 3, 4, and 5.

The extraneous variables of the study were also evaluated to determine if a relationship existed between the extraneous variables and family functioning or other study measures.

In summary, data was analyzed and summarized to describe the impact home apnea monitoring has on the level of family functioning.

Summary

In Chapter IV, the research variables used in the study were specified, operationally defined and measured. The study sample and criteria for selection were specified and discussed. The data collection procedure was outlined and the instrument used to measure variables was discussed. Scoring of the instrument and techniques used in analysis of data were described. Research questions posed and human rights protection were also presented. In Chapter V research data and analysis and evaluation of the data and results are provided and discussed in relation to research questions posed.

Chapter V

DATA PRESENTATION AND ANALYSIS

Overview

The data presented and analyzed in this chapter describes the study sample and describes how family functioning is impacted by home apnea monitoring as perceived by the monitored infant's primary caretaker. Specifically the data presented describes the relationship between the family's perceived severity of their infant's condition, perceived scope of impact of home monitoring, perceived support available during home monitoring, and family functioning. The data presented also describes the relationships between length of monitoring and disposition of monitoring and family functioning and perceived severity of the monitored infant's condition, perceived scope of impact of home apnea monitoring, and perceived support available during the home monitoring period.

In addition, the data presented describes the relationship between extraneous variables (sociodemographic) and family functioning and perception measures. The study sample was a voluntary, convenience sample of 22 primary caretakers or mothers of monitored infants. Study subjects were participants in a hospital-based Home Apnea Monitor Program. In Chapter V is included the data presentation for research questions posed. The following research questions were tested:

1. How is the overall length of monitoring related to the level of family functioning?
2. How is the disposition of monitoring (whether completed or ongoing) related to the level of family functioning?
3. How is the family's perceived threat of loss of their infant or perceived severity of their infant's condition related to the level of family functioning?
4. How is the family's perception of scope of impact of home apnea monitoring related to the levels of family functioning?
5. How is the family's perception of support available to the family during the home monitoring period related to the level of family functioning?

Descriptive Findings of the Study Sample

The study consisted of 22 women who were mothers of or primary caretakers of 22 monitored infants. All the subjects were legally married and maintained an ongoing, intimate relationship with their spouses during the home monitoring period.

The study sample ranged in age from 19 to 36. The mean age of the subjects was 27.5 years. The actual number and percent of women by age and range can be seen in Table 1.

The income ranges for subject families for the past 12 months were from $0 - 4,999 to $25,000 and over. The mean income range for subject families was $15,000 - $19,999.

The actual range of incomes can be seen in Table 2. One case is missing because the family felt the income question was too personal.

The study sample included 10 women (45.5%)

Table 1

Age of Study Subjects

Age	Number of Subjects	Percentage
19-23	5	22.7
24-28	8	36.4
29-33	6	25.1
34-36	3	13.6
Total	22	100.0

Table 2

Income Range of Study Families (n=21)

Range	Number of Subject Families	Percentage
$0-4,999	2	9.1
$5,000-9,999	3	13.6
$10,000-14,999	3	13.6
$15,000-19,999	3	13.6
$20,000-24,999	5	22.7
$25,000 or over	5	22.7
Total	21	95.5
Missing Cases	1	4.5

who worked in some capacity and 12 (54.5%) whose daily activities were related to child care and being housewives. Of the 10 who worked, two (9%) were professionals, three (13.6%) worked in a technical/clerical capacity, three (13.6%) worked in a part-time capacity, one (4.5%) worked in a factory position, and one (4.5%) worked in a vocational area.

The level of education for the study sample ranged from completion of high school to advanced schooling. Of the study sample only 68.2% (n=15), completed high school. The actual distribution of levels of education completed by the study sample can be seen in Table 3.

Subject families lived in various areas. The majority (54.5%) (n=12) lived in rural areas. Those who lived in suburban areas totaled 27.3% (n=6) and 18.2% (n=4) lived in urban areas.

The number of children of families in the study ranged from one to four as can be seen in Table 4. The mean number of children per family was two. Eight families (36.4%) had only one child.

The subjects' monitored infants included 12 male infants and 10 female infants. Of the monitored infants 21 were Caucasian and one was an American Indian.

Table 3

Levels of Education of Study Sample (n=22)

Highest Level Of Education Completed	Number of Subjects	Percentage
Elementary School	0	0
High School	15	68.2
College	4	18.2
Technical/Vocational School	1	4.5
Advanced Schooling	1	4.5
Other	1	4.5
Total	22	100.0

Table 4

Number of Children in Study Families (n=22)

Number of Children	Number of Families	Percentage
1	8	36.4
2	6	27.3
3	5	22.7
4	3	13.6
Total	22	100.0

During the home monitoring period, the total number of household members for study families ranged from three to six depending on the number of children in the family. All the monitored infants lived with both parents (36.4%) (n=8) or both parents and other siblings (63.6%) (n=14) during the home monitoring period. All study families (n=22) were in the developmental stage of childrearing, as defined by Duvall (1971), because all included an infant member.

In 18 (81.8%) of the study families, the infant's mother was primarily responsible for the infant's care during the monitoring period. In four families (18.2%), both mother and father shared equally in the care of the child.

The monitored infants' conditions of apnea and/or bradycardia or risk of apnea were discovered in a variety of ways. Nine infants experienced an episode of apnea, bradycardia, or cyanosis at home. Seven infants experienced an episode of apnea, bradycardia, or cyanosis while hospitalized for other problems, primarily prematurity. Four infants were considered at risk for apnea and/or bradycardia because a sibling had died from Sudden Infant Death Syndrome. Three of these four later displayed apnea and/or bradycardia on pneumogram testing and one of the four later had clinical symptoms of apnea and/or bradycardia associated with cyanosis. Two of the monitored infants were found to have apnea and/or bradycardia upon pneumogram testing. (A pneumogram is a 12 hour trend study of respiratory and cardiac patterns done during sleep.)

Ten (45.5%) of the monitored infants were full term at delivery. Twelve (54.5%) of the infants were premature (37 weeks gestation or less).

The disposition of monitoring for subjects' infants fell into three categories. Eleven of the infants (50%) were still being monitored. Ten (45.5%) infants were off the monitor and one infant (4.5%), was being weaned off the monitor at the time the study was conducted. Weaning off the monitor technically refers to decreasing the time the monitor is used until it is discontinued. The infant being weaned off the monitor was included in the category of infants currently on monitors for purposes of data analysis of subjects.

The age of the infants when the monitor was first prescribed ranged from birth to seven months and two weeks as can be seen in Table 5. Sixteen infants (72.7%) had a monitor prescribed before or at six weeks of age.

The length of monitoring for all subjects' whether monitoring was ongoing or discontinued ranged from four months to twelve months and three weeks, as can be seen in Table 6. The length of monitoring for those infants still on monitors or being weaned off the monitor (n=12) at the time of the study ranged from one month to twelve months and three weeks (See Table 7). The mean length of monitoring for those infants still being monitored was

Table 5

Age of Subjects' Infants When Monitor Prescribed (n=22)

Age of Infant	Number of Infants	Percentage
0 - 1 month	12	54.5
1 - 2 months	4	18.2
2 - 3 months	3	13.6
3 - 4 months	3	13.6
7 months and over	1	4.5
Total	22	100.0

Table 6

Length of Monitoring for All Subjects' Infants (n=22)

Time monitored	Number of Infants	Percentage
1 - 2 months	2	9.1
2 - 3 months	4	18.2
6 months	1	4.5
7 months	1	4.5
8 - 9 months	2	9.1
9 months	6	27.3
10 months	1	4.5
11 months	2	9.1
12 - 13 months	3	13.6
Total	22	100.0

Table 7

Length of Monitoring for Infants Currently Being Monitored (n=12)

Time Monitored	Number of Infants	Percentage
1 - 2 months	2	16.67
2 - 3 months	4	33.33
7 months	1	8.33
9 months	2	16.69
10 months	1	8.33
11 months	1	8.33
12 - 13 months	1	8.33
Total	12	100.00

5.9 months. The range of length of monitoring for infants who had discontinued monitoring (n=10) was six months to twelve months and three weeks (See Table 8). The mean length of monitoring for those infants who had discontinued monitoring was 9.4 months.

For infants who had discontinued monitoring (n=10), the time they had been off the monitor ranged from two weeks to seven months and one week (See Table 9). The mean time the infants had been off the monitor was four months.

Table 8

Length of Monitoring for Infants Who Have Discontinued Monitoring (n=10)

Time Monitored	Number of Infants	Percentage
6 months	1	10
8 - 9 months	2	20
9 months	4	40
11 months	1	10
12 - 13 months	2	20
Total	10	100

Table 9

Time Infants Have Been Off Monitors (n=10)

Time	Number of Infants	Percentage
Less than 2 months	2	20
2 - 3 months	2	20
3 months	1	10
5 - 6 months	2	20
6 months	1	10
7 - 8 months	2	20
Total	10	100

Description of Subject Scores on the Family Stress Scale, the Family Impact Scale, the Family Support Index, and the Family Functioning

The perception scales, the Family Impact Scale and the Family Stress Scale, and the Family Support Index were measures developed to address subjects' beliefs about home apnea monitoring (See Appendix F, Beliefs About Home Apnea Monitoring). The Family Stress Scale addressed the subjects' beliefs about the seriousness of the child's condition and how the need for a home monitor affected those beliefs (See Appendix F, section 1 of Beliefs About Home Apnea Monitoring). The Family Impact Scale addressed the subjects' beliefs about what impact or effect home apnea monitoring had on aspects of family life (See Appendix F, section 2 of Beliefs About Home Apnea Monitoring). The Family Support Index addressed subjects' beliefs about sources from whom the family received help during the home monitoring period (See Appendix F, second 3 of Beliefs About Home Apnea Monitoring).

During data analysis when scores for individual items on each scale and index were coded, it was found that 11 subjects had left some items blank because they felt the item was not applicable or they felt could not answer the item. It can be assumed that these responses were lost unrelated to the conduct of the study (Kirk, 1968). Under these conditions, the analysis should be carried out using an unweighted-means solution (Kirk, 1968). From the unweighted-mean solution, computations calculated what the average score for the missing response would have been based on the average of scores for that item and the missing value was replaced with the expected average value (Kirk, 1968). Items missing responses included Family Stress Scale (FSS) item 4 and certain items of the Family Functioning Index (FFI).

In order to test the research questions posed, raw scores were totaled for the Family Stress Scale, consisting of FSS items 1 to 3, the Family Impact Scale (FIS), the Family Support Index (FSI), and the Family Functioning Index (FFI). Raw scores were also computed and treated individually for the Family Stress Scale items 4 and 5.

The total scores of study participants for the Family Stress Scale (See Family Stress Scale, Appendix F) (FSS items 1-3) ranged from 5 to 15 (See Table 10). The mean score for the Family Stress Scale was 11.64 with a standard deviation of 2.38 (See Table 18).

The individual scores of study subjects (n=20) for FSS item 4 (See Appendix F, Family Stress Scale) ranged from 1 to 5 (See Table 11). The mean score for FSS 4 was 3.6 with a standard deviation of 1.54. Two cases were missing as the respondents felt the item was not applicable (See Table 18).

Table 10

Scores on the Family Stress Scale (n=22)

Score	Absolute Frequency	Percentage
5	1	4.5
7	1	4.5
9	1	4.5
10	3	13.6
11	1	4.5
12	6	27.3
13	5	22.7
14	3	13.6
15	1	4.5
Total	22	100.0

Table 11

Scores on FSS Item 4 (n=22)

Score	Absolute Frequency	Percentage
1	4	18.2
2	1	4.5
3	1	4.5
4	7	31.8
5	7	31.8
Blank	2	9.1
Total	22	100.0

Table 12

Scores on FSS Item 5 (n=22)

Score		Absolute Frequency	Percentage
1		1	4.5
2		5	22.7
3		4	18.2
4		3	13.6
5		9	40.9
	Total	22	100.0

The total scores of study subjects for the Family Impact Scale (FIS) (See Appendix F, Family Impact Scale) ranged from 14 to 45 (See Table 13). The mean score for the FIS was 29.57 with a standard deviation of 2.38. One case was missing (See Table 18).

Individual total scores after recoding of individual item responses for the Family Support Index (FSI) ranged from 4 to 26 (See Appendix F, Family Support Index). The mean score for the FSI was 12.32 with a standard deviation of 5.30 (See Table 18).

The individual total scores for the Family Functioning Index (FFI) (See Appendix G) ranged from 17 to 30 (See Table 14). The mean score for the FFI Was 23.66 with a standard deviation of 3.63 (See Table 18).

Table 13

Scores on the Family Impact Scale (n=22)

Score	Absolute Frequency	Percentage
14 - 19	3	13.6
20 - 23	7	31.7
28 - 31	3	13.6
39 - 40	3	13.6
43 - 45	5	22.7
Missing Data	1	4.5
Total	22	100.0

Description of Responses to Scales and Indices

Family Stress Scale

In the Family Stress Scale, the majority of study respondents judged their child's condition to be serious as seen in responses to FSS items 1-3. Eighteen subjects (81.8%) believed their child's condition was serious or very serious when he/she was diagnosed. Seventeen respondents (77.3%) believed the need for the home monitor made them feel their child's condition was serious or very serious. Thirteen subjects (59.0%) believed the number of "real" alarms their child experienced made them feel their child's condition was serious to very serious.

Table 14

Scores on the Family Functioning Index (n=22)

Score	Absolute Frequency	Percentage
17-19	2	9.1
20-22	7	31.8
23-25	6	27.3
26-28	4	18.2
29-30	3	13.6
TOTAL	22	100.0

Family Stress Scale Items 4 and 5

FSS item 4 was developed to measure subjects' beliefs about how serious having to stimulate their child to breathe made them feel the child's condition was and FSS item 5 addressed subjects' beliefs about how serious they felt the threat of death for the child was.

A majority of respondents (63.6%) (n=14) believed having to stimulate their child to breathe or pick up his/her heart rate made them feel their child's condition was serious or very serious. Twelve of 22 subjects (54.5%) believed the threat of death for their child was serious or very serious.

Belief Items

The Belief items (See Appendix F, Family Stress Scale, items 6-8) were developed to describe study subjects' perceptions about the future related to the experience of having a child on a monitor. A majority of the sample (n=15) (68.2%) felt the need for a monitor would not affect the way the subject treated the child in the future. Of the sample, 59.1% (n=13) felt the experience of having a child on a monitor would not affect their views for having more children. The remainder of the sample (n=9) (40.9%) feared having more children because the problem of apnea and need for a monitor might recur with a subsequent child. Overwhelmingly, the study sample (n=19) (86.4%) felt the experience of having a child on a monitor did not affect their own future plans.

Family Impact Scale

The Family Impact Scale (See Appendix F) was developed to assess subjects' beliefs on what impact or effect home apnea monitoring had on aspects of family life. Of the study sample, 31.8% (n=7), felt that home monitoring affected the family's finances somewhat to very much. A large percentage (45.5%) (n=10) of the study sample felt that home apnea monitoring affected the level of fatigue family members experienced somewhat to very much. Also, 45.5% (n=10) of the sample felt that home monitoring affected the family's outside social life somewhat to very much, but only 22.7% (n=5) felt home monitoring affected the family's at home social life. Seven subject families (31.8%) felt that home monitoring affected the family's travel. Half of the sample (n=11) felt that home monitoring affected the anxiety or tension the family experienced somewhat to very much, but only 22.7% (n=5) felt that monitoring affected the amount of friction between family members.

A large majority (77.3%) (n=17) of the study sample felt that home monitoring had not affected the arrangement of furnishings in the home, the health of family members, the family's relatives, the family's ability to carry out daily activities, and other children in the family only moderately to not at all.

Family Support Index

The Family Support Index was developed to address subjects' beliefs about sources from whom the family received help during the home monitoring period. The sources most subject families received support from during the monitoring period included; relatives, friends, the staff of the home monitor program, community health nurses, their child's primary physician, and community agencies.

During the home monitoring period 59.1% (n=13) of the study sample received help from relatives. The type of help relatives provided included emotional and moral support, relief from care of the monitored child or other children through babysitting, and comfort by just trying to understand the monitored family's situation. All the families that received help from relatives during the monitoring period rated the help they provided was adequate to more than adequate.

Ten of 22 subject families (45.5%) stated they received help from friends during the home monitoring period. The type of help they provided included babysitting, financial help with medical and travel expenses, and emotional support. The subject families that received help from friends rated the help provided as adequate to more than adequate.

Twenty subject families (90.9%) reported they received help from the staff of the home monitor program. The type of help the home monitor staff included anticipatory guidline, counselling and teaching related to use of monitor and care of the infant, clinical assessment of the monitored infant's progress and episodes of apnea, answered questions, and technical assistance with the monitor. Six of this group (30%) rated the help provided by the home monitor staff as adequate and 70% (n=14) rated the help provided as more than adequate.

During the home monitoring period, 14 of 22 (63.6%) families received support from community health nurses as a result of referrals from the home monitor program. The help they provided included moral support, information about child care and family planning, explanation of community and public health services and resources available, physical assessment of the infant, and respite care.

During the home monitoring period, 16 out of 22 subject families (72.7%) received help from their child's primary physician. The type of help provided by primary physicians included referral for evaluation of apnea and prescription of the home apnea monitor, checkups, reassurance, emotional support, and information about apnea and related testing. Of these 16 families, 15 (93.6%) rated the help provided by their child's primary physician as adequate (43.6%) to more than adequate (50%). One family reported their child's physician initially provided them with support but felt he began to consider them over-anxious and thus rated support provided by him as inadequate.

Fourteen out of 22 subject families (63.6%) received support from other community agencies during the home monitoring period. These agencies included Division of Services to Crippled Children, the home health care companies providing rental of the monitor, and chapters of the National Sudden Infant Death Foundation. DSCC provided financial help with medical expenses and rental of the home apnea monitor and provided respite care. Home health care companies provided information about and technical assistance with the monitor. Families who had previously lost an infant to SIDS received emotional support and information about SIDS and apnea from local chapters of the National Sudden Infant Death Syndrome Foundation. Five of this group (38.5%)rated the help these community agencies provided as adequate and 61.5% of the group (n=8) rated the help provided as more than adequate.

Sources that provided little or no support for subject families during the home monitoring period included other monitor families, people of the families' faith or church, or neighbors. Only two subject families (9.1%) reported receiving help from other monitor families and only seven families (31.8%) reported receiving help from people of their faith or church. Finally, only five families (22.7%) reported receiving help from their neighbors during the home monitoring period.

Family Functioning Index

The Family Functioning Index (See Appendix G) was initially developed by Pless and Satterwhite (1973) to be used as a tool in clinical practice to measure the levels of family functioning in families with a chronically ill child in relation to the child's adjustment. The purpose of the index was to help identify children at risk for psychological pathology related to poor family functioning.

According to Pless and Satterwhite (1975), the functional aspects of family life include such dimensions as the way members relate to one another, communications, happiness, level of marital satisfaction, activities carried out jointly, and problem-solving. The total FFI score reflected the overall level of family functioning and scores on individual items reflected components of family functioning.

The concept of family time spent together was measured by question #1 of the Family Functioning Index. Twenty of 22 subjects (90.9%) listed family activities done in the evenings and weekends such as reading, talking, watching television, playing games, and visiting relatives. Two subjects left these items blank. Only 15 of 22 subjects (58.2%) described family activities on vacations. Seven subjects (31.8%) left this item blank as not applicable since they never took family vacations.

The concept of sibling relations was measured by question #2. Eight families (36.4%) left this item blank as not applicable because they had only one child. Fourteen (63.6%) stated that they thought that their children got along the same or better compared with other families.

The concept father-child communications was measured by question #3 of the Family Functioning Index. Ten families (45.5%) left this item blank as not applicable as their child or children was/were not old enough to communicate with the father. Twelve (54.5%) stated their child found it easy to talk to their father about their problems sometimes or often.

The concept of mother-father communication was measured by question #4 of the Family Functioning Index. Nineteen of the study sample (86.9%) stated they found their spouse an easy person to talk to at least sometimes.

Father-child activities were measured by items #4 and #5 of the Family Functioning Index. Twenty-one of 22 subjects (95.5%) stated that the father of the family spent a lot of time with the children at least sometimes in the evening. All of the study sample (n=22) stated the father spent a lot of time with the children at least sometimes on the weekends.

The majority of subject families (54.5%) (n=12) rated their family's happiness as about the same as other families and 40.9% (n=9) rated their family's happiness as better than other families. One subject rated her family as less happy than most others.

The entire study sample (100%) stated they had discussed the most important problem their family had to deal with in the last year with their spouse. The types of problems subject families had to deal with included their child's condition and need for a monitor, unemployment, and financial problems.

Item #9 of the Family Functioning Index measured joint decision-making. Twenty of the study sample (90.9%) reported that decision-making in regards to what house or apartment to take was joint. Thirteen families (59.1%) reported that a decision about whether or not to quit a job and about what doctor to have when someone was sick was usually a joint decision between spouses. Sixteen families (72.7%) reported the decision about where to go on vacation was joint. Final decisions about what kind of car to get, whether or not to buy some life insurance, about what job to take, and how much money to budget for food were not joint decisions with one spouse influencing the decision over the other as rated by subjects (n=11) (50%).

Item #10 of the Family Functioning Index asked subjects to rate certain aspects of marriage. Ten subjects (45.5%) rated their spouse's understanding of their problems and feelings as the most valuable part of marriage. Seven subjects (31.8%) felt their spouse's expression of love and affection as the most valuable part of marriage. Nine subjects (40.9%) rated their spouse's understanding of their problems and feelings and five subjects (22.7%) rated the chance to have children as the next most valuable part of marriage. Twenty-one subjects (95.5%) rated their standard of living as the least valuable part of marriage.

Ten subjects (45.5%) reported that disagreements were resolved with their spouse on a 50/50 basis. The remainder (54.5%) (n=12) reported they usually gave in to their husband's way.

Fourteen subjects (63.6%) reported that disagreements came up in their household about the same as in other families. Five subjects (22.7%) reported their families disagreed more often than others and three subjects (13.6%) reported their families agreed less often than others.

Fifteen subjects (68.2%) reported that they felt their family was closer compared to most families. Twenty-one subjects (95.5%) reported that they talked about work with their spouse at least sometimes.

In rating some feelings about marriage, thirteen subjects (59.1%) felt quite satisfied with their standard of living. Fifteen of the sample (68.2%) were satisfied with or enthusiastic about the understanding they got for their problems and feelings and about the love and affection they received. Finally, half of the sample was satisfied with or enthusiastic about the companionship of doing things with their spouses.

Reliability of the Perception Scales -- The Family Stress Scale and the Family Impact Scale

Coefficient alpha was computed to measure the reliability and internal consistency of the Family Stress Scale and the Family Impact Scale, the first two sections of Beliefs About Home Apnea Monitoring. Coefficient alpha represents the degree of relatedness among scale items. If coefficient alpha was at least .80 or greater, the scale met the criterion for internal consistency and justified summing all scale item responses to produce an overall scale score (Crano, 1973).

Initially, an exploratory factor analysis was done on all five items of the Family Stress Scale (FSS). FSS items 4 and 5 were found to share a low interitem correlation (less than .50) not only with the first three FSS items, but also with each other. Thus, it was assumed FSS items 4 and 5 tapped different concepts than the first three FSS items and those items were treated differently and individually. FSS items 4 and 5 were deleted from the scale because they were found not to be consistent with the first three items. The reliability coefficient for the Family Stress Scale after deletion of FSS items 4 and 5 was .80. This alpha coefficient represented a marked internal consistency among the first three FSS items.

The reliability coefficient for the Family Impact Scale (FIS) was .90. This alpha coefficient represented a high degree of interrelatedness of all twelve items and a high internal consistency. No deletion of items were needed to attain this alpha coefficient.

No testing for construct validity of the Family Stress Scale or Family Impact Scale was done. The questionnaire was administered to the monitored infants' other parents to allow for testing for validity in the future.

Data Presentation for Research Questions Posed and Related Extraneous Variables

In order to test the research questions posed various statistical analysis were computed. The total scores for each section of the instrument were computed including the Family Stress Scale (FSS items 1-3), the Family Impact Scale (FIS items 1-12), the Family Support Index (FSI items 1-9), and the Family Functioning (FFI), (See Appendix F and G). Scores were also computed for Family Stress Scale items 4 and 5 individually. Length of monitoring for each subject's infant was also calculated. Subjects' infants were classified into one of two groups according to disposition of monitoring.

Research Question 1: How is the overall length of monitoring related to the level of family functioning?

To test research question 1, the length of monitoring for all subjects' infants was computed and the infants were divided into four groups dependent on length of monitoring. Group 1 included infants monitored less than two months and two weeks (6 infants). Group 2 included infants monitored between two months and two weeks (4 infants). Group 3 included infants monitored nine months (6 infants) and Group 4 includes infants monitored for longer than nine months (6 infants).

The mean for the scores of subjects on the Family Functioning Index was computed and an analysis of variance (ANOVA) expressed as an F-ratio was calculated to determine the differences between means of the four groups. Analysis of variance is utilized to test the significance of differences between means and the effect of one independent variable on a dependent variable (Polit and Hunger, 1978). For this statistical test, in order to present significant differences between means of groups, the significance level was set at .05. The means of scores of subjects on the Family Stress Scale, FSS items 4 and 5, the Family Impact Scale, and the Family Support Index were also computed and F-ratios were calculated to determine the differences between means for the four groups on those means. See Table 15 for group means on the Family Functioning Index, the Family Support Index, the Family Impact Scale, the Family Stress Scale, and FSS items 4 and 5. See Table 16 of F-ratios for the differences between means for the four groups categorized by length of monitoring on each of the above measures.

An F-ratio describing the differences between the mean scores of four monitoring groups on the Family Functioning Index was .78 and had a significance of .52 (See Table 16). This was not significant at the .05 level and thus there was no relationship between the overall length of monitoring and the level of family functioning.

Table 15

Group Means (Length of Monitoring) for the FFI, FSI, FIS, FSS, and FSS Items 4 and 5 (n=22)

Group According to Length of Monitoring	FFI	FSI	FIS	FSS	FSS4	FSS5
Group 1 (less than 2 months)	26.67	16.66	33.00	12.33	4.33	3.33
Group 2 (2½ - 8½ months)	25.00	10.00	31.25	12.50	3.75	3.75
Group 3 (9 months)	23.33	12.67	24.50	12.00	3.83	3.67
Group 4 (greater than 9 months)	23.50	14.00	35.17	10.83	3.33	3.67
Total Mean	24.26	13.16	30.63	11.79	3.74	3.63

Table 16

Univariate F-ratio Demonstrating the Differences Between the Means of Monitoring Groups for Each Section of the Questionnaire

Instrument Section (Variable)	F-Value	Degrees of Freedom	Significance
FFI	.78	15	.52
FSI	1.01	15	.42
FIS	1.01	15	.42
FSS	.50	15	.69
FSS4	.30	15	.83
FSS5	.49	15	.99

*=Significant at the .05 level when compared with significant values of F table.

An F-ratio describing the differences between mean scores of four monitoring groups on the Family Support Index was 1.01 and had a significance of .42 (See Table 16). This was not significant at the .05 level and thus there was no demonstrated relationship between overall length of monitoring and perceived support available to the family during the home monitoring period.

An F-ratio describing the mean scores of four monitoring groups on the Family Impact Scale was 1.01 and had a significance level of .42 (See Table 16). This was not significant at the .05 level and thus there was no relationship between the overall length of monitoring and the family's perceived scope of impact of home apnea monitoring.

F-ratios describing the mean scores of four monitoring groups on the Family Stress Scale and Family Stress Scale items 4 and 5, respectively, were .51 and had a significance of .69, .30 and had a significance of .83, and .47 and had a significance of .99. These were not significant at the .05 level and thus there was no relationship between overall length of monitoring and the family's perceived severity of their infant's condition, the family's perception of how serious having to stimulate their child to breathe made them feel their child's condition was,or the family's perceived threat of loss of their infant.

Research Question 2: How is the disposition of monitoring related to the level of family functioning?

To test research question 2, subjects were divided into two groups according to disposition of monitoring. The mean for the subjects' scores on the Family Functioning Index was computed and a two-tail t-test was calculated to determine the differences in group means when study samples are small (Polit and Hunger, 1978, and Borg and Gall, 1971). For this statistical test, in order to present significant differences between means of two groups, the significance level was set at .05. The means of scores of subjects on the Family Support Index, the Family Impact

Scale, the Family Stress Scale, and FSS items 4 and 5 were also figured and two-tail t-tests were calculated to determine the differences between means for the currently monitoring group and the discontinued monitoring group on those measures (See Table 17).

A two-tail t-test describing the difference between the mean scores of the ongoing and discontinued monitoring groups on the Family Functioning Index was .30 with a probability of .76. This was not significant at the .05 level and thus there was no relationship between disposition of monitoring, whether ongoing or discontinued, and the level of family functioning.

A two-tail t-test describing the differences between mean scores of ongoing and discontinued monitoring groups on the Family Support Index was .38 and had a probability of .71. This was not significant at the .05 level and hence there was no relationship between disposition of monitoring and perceived support available to the family during the home monitoring period.

The t-value of a two-tail t-test describing the differences between the mean scores of the ongoing and discontinued monitoring group on the Family Impact Scale was -.62 and had a probability of .54. This value was not significant at the .05 level. Hence, there is no relationship between disposition of monitoring and the family's perception of the scope of impact of home apnea monitoring.

Table 17

T-Test Demonstrating the Differences Between Mean Scores of Ongoing and Discontinued Monitoring Groups for Each Section of the Questionnaire (n=21)

Section of Questionnaire (Variable)	T-Value	Degrees of Freedom	2-Tail Probability
FFI	.30	19	.76
FSI	.38	19	.71
FIS	-.62	18***	.54
FSS	.48	19	.63
FSS4	1.11	17****	.28
FSS5	1.20	19	.24

* = Significant at the .05 level

** = 1 case excluded as subject's infant was being weaned off monitor

*** = 1 missing case

**** = 2 cases left blank as not applicable

The t-value of a two-tail t-test describing the differences between mean scores of ongoing and discontinued monitoring groups on the Family Stress Scale was .48 and had a probability of .64. This value was not significant at the .05 level and thus there was no relationship between the disposition of monitoring and the family's perceived severity of their infant's condition. A two-tail t-test describing the differences between mean scores for the above groups and FFS items 4 and 5 were 1.11 and 1.20

respectively and had probabilities of .28 and .24 respectively. Neither value was significant at the .05 level. Thus, there was no relationship between disposition of monitoring and the family's perception of how serious having to stimulate their child to breathe made them feel their child's condition was or the family's perceived threat of loss of their infant.

Research Question 3: How is the family's perceived threat of loss of their infant or perceived severity of their infant's condition related to the level of family functioning?

Research Question 4: How is the family's perception of the scope of impact of home apnea monitoring related to the level of family functioning?

Research Question 5: How is the family's perception of support available to the family during the home monitoring period related to the level of family functioning?

To determine the relationships between the family's perception of their infant's condition and perceived threat of loss of their infant, the family's perception of the scope of impact of home apnea monitoring, the family's perception of support available to the family during the monitoring period, and the level of family functioning, Pearson Product Moment correlations were computed for each section of the questionnaire. The size of the correlation coefficient is indicative of the degree of relationship between variables, and a low correlation indicates a low relationship (Borg and Gall, 1971).

The correlation coefficient may be interpreted in terms of two major dimensions. First, the correlation is statistically significant or not significant. Secondly, the correlation has a meaning for prediction, either group or individual. The interpretation of r computed between the variables in the study were:

1. Correlations from .20 - .35 represent a slight relationship although this relationship may be statistically significant. Correlations at this level are of no value either individual or group prediction.
2. Correlations from .35 - .65 represent a moderate or fair correlation and are statistically significant. With correlations around .50, crude group prediction may be achieved.
3. Correlations ranging from .65 - .85 represent marked or somewhat high relationships and make possible group predictions.
4. Correlations over .85 represents high or close relationships (Borg and Gall, 1971, p. 359).

When a correlation coefficient is statistically significant, the coefficient is sufficiently high so the researcher may be reasonable confident a true relationship exists between the variables correlated (Borg and Gall, 1971). The level of confidence was set at .05 in this study in order for correlations to be considered statistically significant and demonstrate relationships between variables.

Individual total scores for each subject were totaled for each section of the questionnaire, the Family Support Index, the Family Impact Scale, the Family Stress Scale, FSS items 4 and 5, and the Family Functioning Index and mean scores computed (See Table 18). Pearson Product Moment correlations were computed between each perception scale or index to test research questions 3, 4 and 5 (See Table 19).

In testing research question 3, the Pearson Product Moment correlation between mean scores of the Family Stress Scale and the Family Functioning Index was .23 (See Table 19) and was not significant at the .05 level Thus, there was no relationship between the family's perceived severity of their infant's condition and the level of family functioning.

Table 18

Mean Scores on Each Section of the Questionnaire -- FFI, FSI, FFS Items 4 and 5, FSS, and FIS

Section of Questionnaire (Variable)	Cases	Mean	Standard Deviation
FFI	22	23.66	3.63
FSI	22	12.32	5.30
FSS4	20*	3.600	1.54
FSS5	22	3.64	1.36
FSS	22	11.64	2.31
FIS	21**	29.6	10.98

* = 2 cases missing as respondents felt item not applicable

** = 1 case missing

The Pearson Product Moment correlation between mean scores on FSS item 4 and the Family Functioning Index was .56 and was significant at the .05 level (See Table 19). There is a moderate relationship between the family's perception of how serious the having to stimulate their child to breathe made them feel their child's condition was and the level of family functioning.

The Pearson Product Moment correlation between mean scores on FSS item 5 and the Family Functioning Index

Table 19

Pearson Product Moment Correlation Between the Mean Scores on FFI, FSI, FSS4, FSS5, FSS, and FIS (n=22)

Variables	FFI	FSI	FSS4	FSS5	FSS	FIS
FFI	1.00	.33	.56*	.36	.23	.14
FSI	.33	1.00	.40	.24	.08	-.05
FSS4	.56*	.40	1.00	.71**	.45*	-.02
FSS5	.36	.24	.71**	1.00	.16	.13
FSS	.23	.08	.45*	.16	1.00	.26
FIS	.14	-.05	-.02	.13	.26	1.00

* = Significant at the .05 level

** = Significant at the .001 level

FFI = Family Functioning Index
FSI = Family Support Index
FSS4 = Family Stress Scale Item 4
FFS5 = Family Stress Scale Item 5
FSS = Family Stress Scale
FIS = Family Impact Scale

was .36 and was not significant at the .05 level (See Table 19). Thus, there was no relationship between the family's perceived threat of loss of their infant and the level of family functioning.

In testing research question 4, the Pearson Product Moment correlation between mean scores of the Family Impact Scale and the Family Functioning Index was .41. This was not significant at the .05 level. Thus there was no relationship between the family's perception of the scope of impact of home apnea monitoring and the level of family functioning.

In testing research question 5, the Pearson Product Moment correlation for the Family Support Index and the Family Functioning Index was .33 and was not significant at the .05 level. There was no significant relationship between the family's perception of support available to the family during the home monitoring period and the level of family functioning.

Pearson Product Moment correlations were also computed between mean scores on all other related variables (See Table 19). The Pearson Product Moment correlations between the Family Support Index and FSS items 4 and 5 were .40 and .23 respectively. Neither of these values was significant at the .05 level and thus there is no significant relationship between the family's perception of support available during the home monitoring period and their perception of how serious having to stimulate their child to breathe made them feel their child's condition was or the family's perceived threat of loss of their infant.

The Pearson Product Moment correlation between FFS item 4 and FSS item 5 was .71 and was significant at the .001 level (See Table 19). Thus, there was a high relationship between the family's percention of how serious having to stimulate their child to breathe made them feel their child's condition was and the family's perceived threat of loss of their infant.

The Pearson Product Moment correlation between FFS item 4 and the Family Stress Scale was .45 and was significant at the .05 level. Thus, there was a fair or moderate statistically significant relationship between the family's perception of how serious having to stimulate their child to breathe made them feel their child's condition was and the family's perceived severity of their infant's condition.

The Pearson Product Moment correlation between FSS item 5 and the Family Stress Scale was .16 and was not significant at the .05 level. There was no significant relationship between the family's perceived threat of loss of their infant and their perception of the severity of their child's condition.

The Pearson Product Moment Correlations between FSS items 4 and 5 and the Family Impact Scale were -.02 and .13 respectively and were not significant at the .05 level. There were no significant relationships between the family's perception of how serious stimulating their child to breathe made them feel their child's condition was or the family's perceived threat of loss of their infant and the family's perception of the scope of impact of home apnea monitoring.

Between the Family Stress Scale and the Family Impact Scale, the Pearson Product Moment correlation was .26 and was not significant at the .05 level. There was no significant relationship between the family's perceived severity of their infant's condition and their perception of the scope of impact of home apnea monitoring.

Between the Family Stress Scale and the Family Support Index, the Pearson Product Moment correlation equaled .08. This value was not significant at the .05 level and thus there was no relationship between the family's perceived severity of their infant's condition and their perception of support available to the family during the home monitoring period.

Finally, the Pearson Product Moment correlation between the Family Impact Scale and the Family Support Index was -.05 and was not significant at the .05 level.

There was no significant relationship between the family's perception of scope of impact of home apnea monitoring and the family's perception of support available to them during the home monitoring period.

In summary, during testing of research questions, there were no significant relationships between the length of monitoring, disposition of monitoring, the family's perceived threat of loss of their infant or perceived severity of their infant's condition, the family's perception of scope of impact of home apnea monitoring, or the family's perception of support available to the family during the home monitoring period and the level of family functioning. However, there was a moderate significant relationship between the family's perception of how serious having to stimulate their child to breathe made them feel their child's condition was and the level of family functioning.

During investigation of relationships between other variables in the study, it was found there was a high relationship between the family's perception of how serious having to stimulate their child to breathe made them feel their child's condition was and the family's perceived threat of loss of their infant. There was also a moderate relationship between the family's perception of how serious having to stimulate their child to breathe made them feel their child's condition was and the family's perceived severity of their child's condition. No other significant relationships were found between study variables.

Sociodemographic Variables

The extraneous, including sociodemographic, variables of the study were also evaluated to determine if any relationships existed between the extraneous variables and the level of family functioning or other study variables (ie. FSI, FSS, FSS items 4 and 5, and FIS). Pearson Product Moment correlations were computed between mean scores or values on those variables. See Appendix J for definition of sociodemographic variables and Tables J.1 and J.2 for correlations computed between sociodemographic variables and the FFI, FSI, FSS4, FSS5, FSS, and FIS.

The Pearson Product Moment correlation between the monitored infant's sex (SD 7) and the Family Support Index was .51 and was significant at the .05 level (See Table J.1). Thus, there was a moderate relationship between the monitored infant's sex and the family's perception of support available to the family during the home monitoring period. The majority of the infants in this study (54.5%) (n=12) were male.

The Pearson Product Moment correlation between the total family income for the past 12 months (SD 4) and FFS item 4 was -.48 and was significant at the .05 level (See Table J.1). There was a moderate negative relationship between total family income and the family's perception of the seriousness of their child's condition related to having to stimulate the child to breathe.

The Pearson Product Moment correlation between the respondent family's total number of children (SD 9) and the Family Functioning Index was .46 (See Table J.2). This value was significant at the .05 level and thus there was a moderate relationship between the subject family's total number of children and the level of family functioning.

There was also a marked relationship between the household composition or whom the child lived with during the monitoring period (SD 10A) and the level of family functioning. The Pearson Product Moment correlation between SD 10A and the Family Functioning Index was .67 and was significant at the .001 level. All monitored infants included in the study sample lived with both parents (36.4%) (n=8) or both parents and other siblings (63.6%) (n=14).

The Pearson Product Moment correlation between the subject family's total number of children (SD 9) and the Family Support Index was .46 and was significant at the .05 level (See Table J.2). There was a moderate relationship between the family's total number of children and the family's perception of support available to them during the home monitoring period.

The Pearson Product Moment correlation between the description of whom the child lived with during the monitoring period (SD 10A) and the Family Support Index was .47 and was significant at the .05 level (See Table J.2). Thus, there was a moderate relationship between household composition and the family's perception of support available to them during the monitoring period.

The Pearson Product Moment correlation between the description of whom the child lived with during the monitoring period (SD 10A) and FSS item 4 was .48 and was significant at the .05 level (See Table J.2). There was a moderate relationship between the household composition and the family's perception of how serious having to stimulate their child to breathe made them feel their child's condition was.

Finally, there was a moderate relationship between the total number of household members during the monitoring period (SD 10B) and the family's perceived threat of loss of their infant (FSS item 5). The Pearson Product Moment correlation between SD 10B and FSS item 5 was .50 and was significant at the .05 level. There were no other significant correlations between sociodemographic variables and other study variables.

In summary, there were significant relationships demonstrated between the subject family's total number of children and the level of family functioning and the family's perception of support available during the home monitoring period. There were also significant relationships between the description of whom the child lived with during the monitoring period and the level of family functioning, the family's perception of support available during the home monitoring period, and FSS item 4. There also was a significant relationship between the total number of household members during the home monitoring period and the family's perceived threat of loss for their infant.

Other Extraneous Variables

During the data analysis, it was found that 11 out of 22 subjects left items on the Family Functioning Index blank, excluding items that were not applicable because the subject family only had one child (FFI items 2 and 3). There were eight subject families with only one child.

To determine if there were differences between the mean scores for groups who were missing data and who had completed all items on the Family Functioning Index, a two-tail t-test was computed (See Table 20). The t-value was -2.75 (df=20) and had a probability of .02. This was significant at the .05 level and thus there was a statistically significant relationship between whether or not subjects answered all items on the Family Functioning Index and the level of family functioning.

Table 20

T-Test Demonstrating the Differences Between Mean Scores for Groups Who Had Missing Data and Who Completed All Items for the Family Functioning Index (n=22)

Variable	T-Value	Degrees of Freedom	2-Tail Probability
FFI	-2.45*	20	.02

* = Significant at the .05 level

The mean score for the group with items missing on the Family Functioning Index was 21.95 with a standard deviation of 3.44. The group who completed all items had a mean score of 25.36 on the Family Functioning Index with a standard deviation of 3.06 (See Table 21). To figure scores for subjects with missing items the unweighted mean solution (Kirk, 1968) was used.

Table 21

Mean Scores for Groups Who Had Missing Data and Who Completed All Items for the Family Functioning Index (n=22)

Group	Number of Cases	Mean	Standard Deviation
Group 1*	11	21.95	3.44
Group 2**	11	25.36	3.06

* Group 1 = Subjects missing data

** Group 2 = Subjects who completed all items

Summary

Chapter V presented data that described the study sample and how home apnea monitoring impacts the level of family functioning as perceived by the monitored infant's primary caretaker. The relationship between certain study variables and the level of family functioning were investigated. Characteristics of the study sample were also described in this chapter. Various extraneous and sociodemographic variables were correlated and reliability coefficients were computed for two perception scales and the construction of the scales discussed.

Chapter VI will summarize the research study and the data presented in Chapter V. In addition, conclusions will be drawn and recommendations for nursing will be made.

CHAPTER VI

SUMMARY OF FINDINGS

Overview

In Chapter VI, findings of the research study are summarized and an interpretation of the findings is presented. In addition, conclusions are drawn and recommendations for nursing practice, education, and future research are made.

Summary and Interpretation of Findings

Descriptive Findings of the Study Sample

Much has been done to outline the epidemiology of SIDS victims (Beckwith, 1975, Valdes-Depena, 1975, 1980, and Lewak, 1979), but little is available in the literature to describe the population that experiences morbidity related to apnea requiring home monitoring. Three studies of small sample populations are available that describe home monitored infants and their families (Kelly and Shannon, 1978, Black, 1978, and Cain, 1980).

The monitored infants in the studies by Black (1978) and Kelly and Shannon (1978) were divided into three basic groups: (1) those who experienced an apneic or cyanotic episode at home or in the hospital, including prematures; (2) those who were monitored because of prolonged apnea discovered on pneumogram, also including prematures; and (3) those who were identified at risk for

SIDS, usually because a previous sibling had died from SIDS. Monitor use in the study conducted by Black (1978) began on an average at about four weeks of age with an average duration of seven months. The average length of monitoring in Kelly and Shannon's sample of 84 infants (1978) was also seven months. The minimum length of monitoring in both groups was four to six weeks with 21% of Black's (1978) sample still being monitored. Less than one-quarter of the sample in Black's study were monitored over one year. The range of length of monitoring in Kelly and Shannon's (1978) group extended to 27 months. In both of the above studies, the ratio of male infants to female infants was about equal.

These reports from studies by Black (1978) and Kelly and Shannon (1978), were fairly consistent with the sample of this research study. All the monitored infants in this sample could be categorized into one of four groups used in previous studies: (1) those who had an episode of apnea or cyanosis at home (n=9); (2) those who had an episode of apnea or cyanosis in the hospital (n=7); (3) those who initially displayed prolonged apnea upon pneumogram testing (n=2); and (4) those considered at risk because a sibling had died of SIDS (n=4). Over half the monitored population was male (n=12) and over half (n=12) were less than 37 weeks gestation at birth. The majority of the population (72.7%) were six weeks of age or less when the monitor was first prescribed. Over half of the sample (n=12) (54.0%) were still on monitors or being weaned off the monitor at the time of the study. The length of monitoring ranged from one month to over 12 months. The mean length of monitoring for those infants still being monitored was 5.9 months and for those who had discontinued monitoring 9.4 months. Those infants who had discontinued monitoring had been off the monitor for an average of four months.

In studies conducted by Black (1978) and Cain (1980), families of monitored infants were predominantly white and middle class. The average age of mothers responding in Black's study (1978) was 26 and few worked outside the home. The majority of parents in both studies had completed high school and a fifth had completed college.

The reports from studies by Black (1978) and Cain (1980) are also fairly consistent with the findings of this research study sample. The study sample was also predominantly white and middle class. The sample had a much higher proportion of middle and upper class families (n=13) (68%) than is generally associated with risk for SIDS (Lewak, 1979 and Valdes-Dapena, 1975). Since the conduct of this study, the number of lower socioeconomic class families referred to the hospital-based Home Apnea Monitor Program has increased due to the economic status of the state of Michigan and due to the hospital-based Home Apnea Monitor Program becoming better known. If this research study had been conducted at a later date, the sample may have included more lower socioeconomic families. The sample of the study was entirely voluntarily and twelve potential subjects who likely would have represented lower socioeconomic class families did not complete or return questionnaires which may account for the high number of middle class families represented in the study.

The average age of the study subjects was 27.5 years and 68.2% (n=15) had completed high school and over a fifth (n=5) had completed college or had advanced schooling. Over one-half of the sample (n=12) were primarily housewives and the remainder worked outside the home in some capacity.

The mean number of children per subject family was two, with eight monitor families having only one child. All of the monitored infants lived in households comprised of both parents or both parents with other siblings along with the monitored infant. All subject families were intact at the time of the study and most (n=12) lived in rural areas.

Descriptive Findings of Scores on Scales and Indices

Family Stress Scale

The Family Stress Scale was developed to measure the subject's beliefs about the seriousness of his/her child's condition, how the need for the home monitor affected those beliefs about the seriousness of the child's condition, and how the number of real alarms the child experienced affected the subject's beliefs about the seriousness of the child's condition. The alpha coefficient for the first three items of the scale was.80 showing these items comprised a scale that was reliable and internally consistent. Two other items initially included in the scale addressing how stimulating the child to breathe affected the subject's beliefs about the seriousness of child's condition and the subject's beliefs about the potential threat of death for his/her child were later deleted and treated as individual variables in the study because they appeared to tap different concepts than the remainder of the Family Stress Scale.

The mean score for the Family Stress Scale was 11.64. From the range of scores and the mean score on the Family Stress Scale it can be concluded that most subjects believed their child's condition to be serious. The introduction of the home apnea monitor and the number of real alarms the child experienced also affected subjects' beliefs about the seriousness of the child's condition. These beliefs about the seriousness of the child's condition and the introduction of home apnea monitoring may serve as a stress for the family and lead to a stressed state in the family unit (See Conceptual Framework, p.24).

The mean scores for subjects on FSS items 4 and 5 were 3.60 and 3.64 respectively. FSS item 4 addressed the subjects' beliefs about how serious having to stimulate the child to breathe affected how serious they felt the child's condition was. FSS item 5 addressed the subjects' beliefs about the threat of loss for their child. The mean scores on these items indicate that the subjects believe the potential for threat of loss of their child was serious and their child's condition was serious related to having to stimulate the child to breathe. Both of these beliefs may also serve as a stress for the family and lead to a stressed state in the family unit (See Conceptual Framework, p. 24).

These findings reinforce conclusions drawn by Black (1978) in a study conducted to measure the impact of home monitoring on family life. Black (1978) concluded that parents' anxieties tended to be realistically related to feedback the monitor itself provided. When alarm frequency diminished or when stimulation was rarely necessary, parents tended to worry less, although they remained vigilant and conscientious (Black, 1978).

Family Impact Scale

The Family Impact Scale was developed to measure a family's perceptions of the scope of impact or effect of home apnea monitoring on aspects of family life. The alpha coefficient for the Family Impact Scale was .80 demonstrating the scale to be reliable and internally consistent.

The mean score for the Family Impact Scale was 29.58. The range of scores and the mean score for the Family Impact Scale demonstrate that subjects believed home apnea monitoring affected their family life overall only slightly to moderately. However, certain aspects of family life were significantly impacted. The areas of family life that subjects felt home monitoring affected somewhat to very much included; family's finances (31.8%, n=7), level of fatigue family members experienced (45.5%, n=10), the family's outside social life (45.5%, n=10), family's travel (31.8%, n=7), and anxiety or tension the family experienced (50%, n=11).

The high percentage of subjects reporting that home monitoring affected the level of fatigue family members experienced and the anxiety or tension the family experienced demonstrates that home monitor families are under added stress related to monitoring. The subject families also reported home monitoring caused restrictions on their social life outside the home. The inability to get relief from the restrictions of monitoring outside the home may add to stress monitoring families experienced.

The findings that home monitoring causes restrictions on outside family life and affects the level of fatigue and the amount of anxiety the family experiences are consistent with findings in studies conducted by Black (1978) and Cain (1980). Cain (1980) reported 71.5% of the parents in her study experienced anxiety related to monitoring and 55.7% reported monitoring placed restrictions on their outside social life.

Although home monitoring is an expensive undertaking (rental of a monitor alone costs between $185-$295/month), only 31.8% (n=7) felt that home monitoring affected family finances. For most at the time of the study, monitoring was largely assumed by insurance, outside assistance programs such as Division of Services to Crippled Children or Medicaid, or was absorbed into an adequate family income. The latter may be reflective of the high percentage (68%, n=13) of middle and upper class families in the study sample.

Family Support Index

Because it was assumed that home monitoring can be stressful for families, one aim of the study was to assess outside support systems from whom the subject families received help during the monitoring period. Availability of and use of support systems during periods of stress are strongly related to effective coping and adaptation to the stress (Aguilera and Messick, 1978). An effectively coping family system interacts and transacts with interfacing systems within the larger community environment (McCubbin, 1979).

The mean score for the Family Support Index was 12.32 which represents a low score when the maximum score possible was 27. The mean score and range of scores for the Family Support Index would indicate that overall subject families received help from few situational supports.

This assumption appears to be misleading on further inspection of subject responses to individual items. The sources most subject families reported receiving help from during the home monitoring period included; relatives (59.1%, n=13), friends (45.5%, n=10), the staff of the home monitor program (90.9%, n=20), community health nurses (63.6%, n=14), the child's primary physician (72.7%, n=16), and community agencies, such as Division of Services to Crippled Children and local chapters of the National Sudden Infant Death Foundation (63.6%, n=14). Sources that provided little or no support for subject families included other monitor families, people of the families' faith or church, or neighbors.

The high percentage of families that used several outside sources of support would indicate that most family units in the study sample functioned as open systems. As open systems, they interacted with and exchanged with outside systems in attempting to continue to function as a system and cope with and adapt to the stress of monitoring.

Belief Items

The Belief items (See Appendix F, Family Stress Scale, items 6-8) were developed to describe subjects' perceptions about the future related to the experience of having a child on a home monitor. Most subjects felt the need for a monitor would not affect the way the subject treated the child in the future (68.2%, n=15), would not affect their views on having more children (59.1%, n=13), and would not affect their own future plans (86.4%, n=19), although 40.9% (n=9) stated home monitoring would affect their views on having more children.

These findings are fairly consistent with those of Black's previous study (1978). Few parents appeared to harbor doubts about their infant's future development after the need for the monitor had passed, and they anticipated few behavior problems related to their treatment of the child in the future (Black, 1978). Black (1978) stated that parents' feelings about future children are a likely indicator of long-range effects. One third of the parents believed that the monitor had affected their views on having more children .

Considering the high number of families (n=9) in this study who felt the monitor affected their views on having more children and Black's (1978) contention that parents' feelings about future children are a likely indicator of long-range effects, it would appear these families may need long-range follow-up to assess possible effects of having a child on a monitor. Further, as one issue confronting parents of a monitored infant is the fear of the infant's sudden death and because Green and Solnit (1964) described the <u>vulnerable</u> <u>child</u> <u>syndrome</u> developing in children with a history of a life-threatening illness in infancy, it would appear fears about the monitored child may be transferred to subsequent children whether or not they experience apnea. In future studies concerning home monitor families, the families' beliefs about the severity of the monitored child's condition and potential threat of loss and their views about having more children should be investigated further.

Family Functioning Index

Smilkstein (1978) and Pless and Satterwhite (1973) attempted to conceptualize family functioning holistically and operationalize the concept of family functioning in instruments applicable to clinical practice. Smilkstein (1978) defined the five areas of a family's functional health to include adaptation, partnership, growth, affection, and resolve and stressed the interrelationship of all components with the whole. Pless and Satterwhite (1973) defined the family functioning as the processes and operations of family life. The functional aspects of family life include the dimensions of family relations, family communications, family activities, marital satisfaction, and the happiness and closeness of the family unit.

The Family Functioning Index (Pless and Satterwhite, 1973) was initially developed to measure the level of family functioning in families with a chronically ill child in relation to the child's psychological adjustment. The total FFI score reflected the overall level of family functioning and scores on individual items reflected components of family functioning. Normative data available suggests any family scoring below "20" on the Family Functioning Index as "high-risk" and above "20" as "low-risk" (Pless and Satterwhite, 1973).

Individual total scores in this study on the Family Functioning Index ranged from 17 to 30 with a mean score of 23.66. According to Pless and Satterwhite's criteria (1975) only 2 families (9.1%) of the sample can be considered "high-risk" as they scored below 20. The mean score for the sample on the FFI may indicate that the level of functioning of the group overall to be only low to moderate considering the maximum score on the FFI is 35. Few families (n=2, 9.1%) scored 30. The majority of subjects' scores (n=18) ranged from 21 to 29.

The assumption that the mean score on the FFI represents a low to moderate level of family functioning for the group as a whole appears to be misleading on further inspection of subject responses to individual items. When considering individual components of family functioning measured by the FFI, most of the sample rated moderate to high on the following components: family activities (n=22, 90.9%); sibling relations (n=14, 63.6%); father-child communications (n=12, 54.5%); mother-father communication (n=19, 86.4%), family happiness (n=21, 95.5%); problem-solving (n=22, 100%); joint decision-making in various areas (n ranged from 13-20, 59.1% - 90.9%, depending on decision); marital satisfaction, regarding understanding and love and affection as most valuable aspects of marriage (n=17, 77.3%); joint resolution of disagreements (n=10, 45.5%); family closeness (n=15, 68.2%); and work communication (n=21, 95.5%). From this information, it appears many families may be functioning higher in certain components of family functioning than their overall FFI score would indicate.

From use of the Family Functioning Index in this study, the researcher found the Family Functioning Index to be a weak research tool and not applicable for use in clinical practice. Conceptually, Pless and Satterwhite's attempt (1973) to operationalize family functioning as a tool for use in clinical practice, has many weaknesses. First, an overall Family Functioning Index Score does not appear to reflect a family's level of functioning. Thus, it appears the Family Functioning Index is not sensitive enough to measure the overall level of family functioning and may not truly indicate families at-risk for current or future problems.

Second, a family's score on the Family Functioning Index does not appear to reflect specific problem areas of the family's functioning. Thus, health care practitioners cannot use a family's score on the Family Functioning Index to assess specific dimensions of a family's functioning that may be particularly troublesome and require specific interventions to resolve.

Finally, the content and wording of items in the Family Functioning Index make it difficult to utilize in clinical practice. The Family Functioning Index addresses father-child communications and father-child activities which makes the instrument unacceptable for use with some single-parent families and families with children who are not yet talking. The researcher also found subjects of this study refused to answer items because of their sensitive nature or because of lack of self-knowledge, denial, or refusal to be completely honest.

In conclusion, for the Family Functioning Index to be acceptable for use in clinical practice, it must be refined. Content and wording of items must be revised to make the Family Functioning Index universally applicable. Scoring of the Family Functioning Index must also be revised so it reflects specific problem areas of a family's functioning.

Research Questions Posed

Research Question 1: How is the overall length of monitoring related to the level of family functioning?

Length of monitoring was determined by the age of the monitored child when monitoring was started and discontinued. All monitored infants were divided into one of four groups dependent on length of monitoring. To determine the differences between mean scores of the four groups on the Family Functioning Index, an analysis of variance expressed as a F-ratio was calculated. The F-ratio was .78 (15 df) and was not significant at the .05 level. Thus, there was no relationship between length of monitoring and the level of family functioning.

Limitations of assessing the level of family functioning based on the overall Family Functioning Index score have been previously discussed. The range of length of monitoring for the study sample was from four months to less than thirteen months. It would appear there is not a wide enough range of length of monitoring to affect the level of family functioning. Perhaps if data were collected for a home monitor population with a wider range in length of monitoring, differences in overall scores of family functioning and components of family functioning may be seen.

Another reason no differences in the level of family functioning between groups dependent on length of monitoring were seen is because all subject families were in the adjustment phase of monitoring as described by Barr (1979). None were in the initial crisis phase of monitoring as the minimum time any family had monitored was one month. Perhaps differences in the level of family functioning for length of monitoring groups would be seen if the study sample had included families in the initial phase of monitoring as described by Barr (1979), or if the study was conducted longitudinally.

Research Question 2: How is the disposition of monitoring related to the level of family functioning?

Disposition of monitoring was determined by whether a child was still being monitored or if the monitor had been discontinued. The subjects' infants were divided into two groups according to disposition of monitoring. To determine the difference between mean scores of the groups on the Family Functioning Index, a two-tail t-test was calculated. The t-value was .30 (df 19) which was not significant at the .05 level. The data indicates there is no difference between groups according to the disposition of the monitoring in levels of family functioning.

Again, the limitations of predicting the level of family functioning from an overall score on the Family Functioning Index without considering specific components of functioning may serve as reasons that no differences in levels of functioning were seen. There also was not a broad range in length of time infants had not been using the monitor (ranged from less than one month to less than eight months). The experience of monitoring may have been too recent for this group and stresses and perceptions related to monitoring may not have changed as yet and may be related to the developmental phase of child-rearing they are in. The small groups on subjects with infants on (n=12) and off (n=10) monitors may not have been representative of a larger population.

Research Question 3: How is the family's perceived threat of loss of their infant or perceived severity of their infant's condition related to the level of family functioning?

Research Question 4: How is the family's perception of scope of impact of home apnea monitoring related to the level of family functioning?

Research Question 5: How is the family's perception of support available to the family during the home monitoring period related to the level of family functioning?

Pearson Product Moment correlations were computed for each section of the question to determine the relationships between these measures. In testing research question 3, the correlation between mean scores of the Family Stress Scale and the Family Functioning Index was .23 and was not significant at the .05 level. The data indicates there was no significant relationship between the family's perceived severity of their infant's condition and the level of family functioning.

Because FFS items 4 and 5 were treated individually, Pearson Product Moment correlations were computed between them and the Family Functioning Index. The Pearson Product Moment correlations between FSS items 4 and 5 and the Family Functioning Index were .55 and .36 respectively. The correlation between FSS item 4 and the Family Functioning Index was significant at the .05 level and thus there was a moderate relationship between the family's perception of the seriousness of the child's condition related to having to stimulate him to breathe and the level of family functioning. The correlation between FSS item 5 and the Family Functioning Index was not significant at the .05 level. Thus, there was no significant relationship between the family's perception of threat of loss of the child and the level of family functioning.

The Pearson Product Moment correlation between the Family Impact Scale and the Family Functioning Index in testing research question 4, was .14 and was not significant at the .05 level. Thus, there was no significant relationship between the family's perception of the scope of impact of home apnea monitoring and the level of family functioning.

In testing research question 5, the correlation between the Family Support Index and the Family Functioning Index was .32 and not significant at the .05 level. The data indicates that there is no significant relationship between the family's perception of support available to them during the home monitoring period and the level of family functioning.

In summary, there was a moderate significant relationship between the family's perception of the seriousness of the child's condition related to having to stimulate the child to breathe and the level of family functioning and no other significant relationships between study variables were found. This relationship implies that the level of family functioning may be related to parents' anxieties related to being directly responsible on a full-time basis for appropriate intervention should apnea occur. Implications for practice drawn from this relationship include providing parents with appropriate intervention skills should an apneic episode occur, including infant cardio-pulmonary resuscitation, providing parents and family members with opportunity to express feelings and anxieties related to this burdensome responsibility, and providing them with counseling and support systems to help work out anxieties and provide relief for time away from the responsibility of intervention.

Extraneous Variables

Pearson Product Moment correlations between other related study variables were also computed (including the Family Stress Scale, FSS items 4 and 5, the Family Impact Scale, and the Family Support Index). The Pearson Product Moment correlation between FSS items 4 and 5 was .71 and significant at .001 level. The data indicates there was a high relationship between the family's perception of the seriousness of their child's condition related to having to stimulate the child to breathe and the family's perceived threat of loss of their infant. This relationship indicates the family's perceptions about these issues are very closely tied although they are different and distinct concepts as evidenced by their being treated individually rather than as part of a scale. If the study had been conducted to include families in the initial or crisis phase of monitoring, the correlation may have been higher. If the study have been conducted longitudinally, the correlation between these variables may have decreased over time.

The Pearson Product Moment correlation between FSS item 4 and the Family Stress Scale was .46 and significant at the .05 level. This data thus indicates there was a moderate significant relationship between the family's perception of the seriousness of the child's condition related to having to stimulate him to breathe and their perceptions about the severity of their infant's condition. Again, this relationship indicates the familys' perceptions about these issues are closely tied but distinct. In future research regarding perceptions related to home monitoring, these separate variables must be considered and their relationships further investigated. Perhaps clarification of wording for FSS items 4 and 5 would allow them to be used as part of the Family Stress Scale in future research if the alpha coefficient for all five items was .80 or greater.

No other significant relationships were found between family's perceptions of severity of their infant's condition, scope of impact of home apnea monitoring, and support available to the family during the monitoring. Perhaps this lack of significant relationships occurred because these perceptions were individually related to different stages or levels of the stress process related to home monitoring (See Conceptual Framework, p. 24).

The parents' perception of the severity of their infant's condition related to the introduction of home apnea monitoring may serve as a stress which results in a stressed state for the family unit. Perceptions of support available to the family may be related to the adaptation phase which results from use of coping mechanisms by the family in response to its stressed state. Finally, perceptions of scope of impact of home monitoring may be related to the final level of the stress process, stressed change, which is a result of adaptation.

It could be argued on the other hand that in a larger study sample, relationships may have been found between variables. Implications for further research would include repeating correlations between the variables with a larger study sample. If such a study showed no significant relationships, it could be argued that perceptions dealing with different levels of the stress process cannot be correlated because they deal with different levels of the process and may change as a result of the process.

Sociodemographic Variables

Pearson Product Moment correlations were also computed between sociodemographic variables and other study variables. A significant relationship was found between the monitored infant's sex and the family's perception of support available to the family during the monitoring period (r=.51, significant at the .05 level). It could be argued that this correlation demonstrated that preference for male infants was shown by sources of support as the majority of infants in this study were male.

A significant negative relationship was found between the family's level of income and the family's perception of the seriousness of their child's condition related to having to stimulate him to breathe (r=-.48, significant at the .05 level). The family's perception of the seriousness of their child's condition related to having to stimulate him to breathe is an illustration of fears or anxieties resulting from direct responsibility for intervention should apnea occur. It could be argued the family's level of income or standard of living may be related to the amount of worry or anxiety they experience due to their responsibility for intervention. The family's standard of living may be related to their educational level and understanding of their situation, and may be related to the coping mechaniisms they have available to deal with the responsibility for intervention.

There also was a significant relationship between the family's perception of the seriousness of their child's condition related to having to stimulate the child to breathe and the household composition during the home monitoring period (r=.48, significant at the .05 level). Because all monitored infants lived with both parents or both parents and other siblings, all families were considered intact. Perhaps this relationship demonstrates both parents shared the responsibility for intervention should an apneic eipsode occur and previous experience with another child may facilitate coping. Future research related to home monitoring should investigate intra-family support systems such as support from spouse and other siblings, and family coping mechanisms related to dealing with the stress of monitoring, such as task reassignments and role changes.

Significant relationships were also found between the total number of children in a family and the household composition during the monitoring period and the level of family functioning (r=.46 and .67, and were significant at the .05 and .001 levels, respectively). Monitored infants in the study sample lived with both parents or both parents and other siblings. All study families were considered intact. Thus, it can be argued that the level of family functioning may be related to the intactness of the family and previous experience in child-rearing. Further research should investigate the relationship between household composition and specific aspects of family functioning, such as family communication, family activities, frequency of disagreements, problem-solving and decision making.

Significant relationships were also found between the total number of children and the household composition during the home monitoring period and the family's perception of support available to them during the home monitoring period (r-.46 and .47 respectively and both are significant at the .05 level). This relationship may demonstrate that intact family units, which have member subsystems which interact, are more likely to function as an open system and use support systems available to it in coping with stress. Further research should investigate actual interactions between family and community used by the family in coping with stress. In other words, family stress theory and use of family support systems require further investigation related to home apnea monitoring to specify the type of interactions monitor families have with the larger community and to identify the type of coping mechanisms they use.

There was a significant relationship demonstrated between the total number of household members during the home monitoring period and the family's perception of the seriousness of the threat of loss of the infant (r=.50 and was significant at the .05 level). Further research should investigate individual family member's perceptions of the seriousness of the threat of loss of a monitored infant and determine which family member's perceptions influence others' perceptions.

During the data analysis, it was found one half of the study sample left blank items on the Family Functioning Index. A two-tail t-test was calculated to determine differences between mean scores for groups who were missing data and who had completed all items on the Family Functioning Index. The t-value was -2.75 (df=20) and was significant at the .05 level. The data indicates a significant relationship between whether or not subjects completed the Family Functioning Index and the level of family functioning.

It can be assumed that wording of items may have determined whether or not a subject responded to all the items of the Family Functioning and resulted in response bias. Subjects may have refused to answer because of the sensitive nature of items or because a lack of self-knowledge, denial or lack of awareness of true beliefs, or refusal to be completely honest (Crano, 1973). Perhaps whether or not the items were answered was related to coping mechanisms they use. There was a significant relationship demonstrated between the total number of household members during the home monitoring period and the family's perception of the seriousness of the threat of loss of the infant (r=.50 and was significant at the .05 level). Further research should investigate individual family member's perceptions of the seriousness of the threat of loss of a monitored infant and determine which family member's perceptions influence others' perceptions.

During the data analysis, it was found one half of the study sample left blank items on the Family Functioning Index. A two-tail t-test was calculated to determine differences between mean scores for groups who were missing data and who had completed all items on the Family Functioning Index. The t-value was -2.75 (df=20) and was significant at the .05 level. The data indicates a significant relationship between whether or not subjects completed the Family Functioning Index and the level of family functioning.

It can be assumed that wording of items may have determined whether or not a subject responded to all the items of the Family Functioning and resulted in response bias. Subjects may have refused to answer because the sensitive nature of items or because a lack of self-knowledge, denial or lack of awareness of true beliefs, or refusal to be completely honest (Crano, 1973). Perhaps whether or not the items were answered was related to

subjects' socioeconomic status and level of education. Based on these assumptions, perhaps the lack of significant results on the Family Functioning Index is because all subjects did not answer all items. If the research study were repeated, use of structured interviews rather than questionnaires may eliminate the problem of missing data or refusal to answer items.

Conclusions

The occurrence of or diagnosis of prolonged apnea may serve as a stressor for a family unit. Stress is defined by Chrisman and Riehl (1974) as the force which produces strain or tension within the family unit. The data from the research study indicates the family's perceptions of the seriousness of the child's condition, the need for the home monitor, and potential threat of loss do serve as stresses for the family and the family thus moves through the stress process (See Conceptual Framework, p. 24).

Stress results in a stress state for the family which describes the turmoil the family is experiencing internally and interactionally with the environment. The stress state describes the force or impact of the stress (Chrisman and Riehl, 1974). The data from the study demonstrates the family is moving through the stress process during the home monitoring period as most of the sample felt that home apnea monitoring did significantly impact certain aspects of family life. The scope of impact can also be measured in the resultant stress changed in the family. The change results from adaptation.

The coping mechanisms used by the family in response to the stress of having an infant on a home apnea monitor depend on the family's perception of the stress, situational supports available to them, and previous coping behaviors used. Data from this research study indicates family perceive many support systems available to them and find the support provided by the sources as adequate. Thus, it can be concluded the monitor families in this study are effectively coping through use of situational supports.

The process of adaptation by the family unit results in a change in the family's level of functioning. The data demonstrated no relationships between the family's perceptions of severity of the child's condition, the scope of impact of home monitoring, and support available to the family during the home monitoring period, and the level of family functioning. This leads the researcher to conclude that although having a child with apnea and requiring a home monitor serves as a stress for a family and significantly impacts family life, most monitor families use effective coping mechanisms in adapting to the stress after the initial crisis phase of monitoring. Thus, family disorganization as evidenced by low levels of family functioning is not seen.

Effective use of coping mechanisms by the study sample may be related to the predominance of middle class families and the fairly high level of education in the sample. Perhaps in a study with a larger percentage of lower socloeconimic families, less effective use of coping mechanisms may be seen resulting in more family disorganization and poor levels of family functioning. Because, according to Aguilera and Messick (1978), such families perceive fewer situational supports available to them and have fewer effective coping mechanisms.

In conclusion, from relating the study results to the conceptual framework, a major weakness of the research study appears to be the lack of focus on and measurement of coping mechanisms used by home monitor families in the adaptation process. Also, feedback loops need to be added to the schematic of the conceptual framework to indicate the influence different levels of the stress process, stressed state, adaptation, and stressed change have on family perceptions. Finally, family perceptions must be recognized as both potential stressors and stress.

Nursing Implications for Practice

The purpose of this study was do describe how home apnea monitoring impacts or affects the level of family functioning. The results of the study indicated that most families are significantly impacted by having a child with prolonged apnea requiring monitoring but must do effectively cope with the stresses and issues related to monitoring. The family's ability to cope effectively with the stress or situation of home monitoring is influenced by the family's perceptions of the situation/stress, situational supports available to them, and previous coping behaviors used in response to previous stress. The extent of the impact of monitoring on the level of fatigue and anxiety family members experience underscore the ongoing stress process related to home monitoring and the need for an ongoing support system.

From the review of literature, it is apparent that the experience of having a child with a life-threatening illness requiring monitoring affects the entire family unit. Thus, the family is viewed as a system. Both these views hold several implications for nursing practice and the nursing.

Nursing must approach interaction with monitoring families from a model in which elements of the nursing process are used as a problem-solving guide. These elements include; assessment, generation of a nursing diagnosis, development of objectives, intervention, and validation.

Families with infants on monitors tend to go through phases related to stress of monitoring and their ability to cope with the stress. The phases include an initial or crisis phase, the adjustment phase, and the time afterward when the monitor has become part of the family (Barr, 1979). Nursing may interact with families during any of these phases in the hospital or in a primary care setting, individually or as a member of a health care team.

Families involved in this research study were in the adjustment or final phase of monitoring. Ten families had completed monitoring. No literature describing this phase after discontinuation of monitoring is available. No families in the study sample were in the initial crisis phase of monitoring.

During the adjustment phase and final phase of monitoring, nursing can aid families by serving as one of many situational supports to them. Through counseling and anticipatory guidance, nursing can help families identify and deal with frustrations, problems, and fears that occur during these phases.

Therapeutic intervention by nursing in interacting with monitor families may involve manipulation of the stress process based on an assessment from a systems-developmental perspective. The nurse must assess who the member subsystems of the family are, what roles they assume, and what tasks they are assigned or have taken on related to having an infant member on a home monitor. The nurse must also assess the interactional, intraactional, and biologic links of systems of the family and those the family has with its larger environment. Finally, the nurse must assess where the family is developmentally on the time-life continuum and where the family is developmentally related to the phases of monitoring and consider tasks and issues the family must meet and deal with to accomplish that stage or phase. The nurse must also consider effects these tasks and their accomplishment may have on the family's perceptions of the situation.

Again, the families in this research study were in the adjustment phase or final phase of monitoring. Many (n=10) had discontinued monitoring. During the adjustment phase of monitoring, families are attempting to cope with the stress of a child on a monitor through use of family resources and situational supports. They also experience frustrations related to the limitations monitoring places on family life including finances, social life, and travel. They also must deal with continuing fears about recurrence of an apneic episode, their responsibility in intervening, and the possible sudden death of the child. Many of these fears continue after the monitor is discontinued.

The results of this study indicate that most subject families utilized outside supports to aid in their coping with the stresses of monitoring, particularly in the areas of finances, moral support, and need for relief from the care of the child. The study results also indicated they did not use other support sources, such as other home monitor families and neighbors. Nursing could aid families in recognition of these additional available support systems and aid in formation of linkages between these systems and home monitor families.

Nursing intervention may occur at any level of the stress process with an infant on a home apnea monitor. Intervention may be aimed at reducing, eliminating or resolving the stress.

Nursing should intervene to assist the home monitoring family in adapting positively to the stress through recognition and acquisition of intra- and extra-family situational supports and use and strengthening of coping mechanisms to promote a positive or higher level of family functioning. Nursing is in a unique position to serve as a support system to a family with an infant on a monitor throughout the phases.

Families in this study overall were found to be functioning at a moderage level. Two families who scored below 20 were found to be functioning at a low level and considered at risk. These families especially need assistance from nursing in recognition, acquisition, and utilization of support systems during and after the monitoring period with regular planned followup of home monitoring and the stress process, either in hospital or in a primary care setting.

Evaluation of nursing intervention can also occur at any level of the stress process in relation to home monitoring. Evaluation should include the effect of the stress on the family, the coping mechanisms in the adaptation process, and the family's level of functioning.

Theory frameworks, including systems-developmental stress theory and family stress theory must be used to assess real and potential problems that may be experienced by home monitoring families. If the family is truly viewed as a system by nursing, these problems and needs must be mutually identified by nursing and the family. If treated as an active participant in health care, the family can effectively set objectives, plan interventions, and evaluate outcomes of care.

The families included in this research study were predominantly middle class and appeared to be coping effectively with the stresses of monitoring as evidenced by the sample's overall moderate level of family functioning and use of support systems. As these families appeared to be able to utilize coping mechanisms and outside resources, this researcher concludes that most of these families have or could with nursing aid, acquire the skills to recognize family problems, set objectives, plan interventions, and evaluate outcomes.

Nursing can best assist a home monitoring family in recognizing family problems, setting objectives, planning interventions, and evaluating outcomes by serving as a support. Nursing can work with other health care providers in providing interdisciplinary support to the family during the home monitoring period.

The results of this study and previous studies (Black, 1978 and Cain, 1980) indicate home monitor families use situational supports in coping with the stress of monitoring. These supports include nursing individually, as community health nurses, and as part of an interdisciplinary health care team, the Home Apnea Monitor Program staff.

Nursing can also assist a family deal with the stress of having an infant requiring home monitoring through anticipatory guidance. Potential problems and areas of concern can be raised. Nursing can also assist the family toward positive adaptation by helping them define and become aware of their perceptions related to the situation, coping mechanism that have been effective in the past, and recognize family resources and support systems available to them, both within the family and outside the family.

The literature related to the threatened loss of an infant reveals that the family of an infant with apnea may fear their infant's death and thus they may be experiencing anticipatory grief. The grief process may block development of normal child relationships and aspects of family functioning and if unresolved may lead to significant psychological sequelae for both parents and infant, such as the vulnerable child syndrome, and family disorganization and poor functioning. Nursing must assist families experiencing grief reactions to move through their grief by allowing them to air their own feelings and their feelings about the child. The family and child should be followed at regular intervals throughout the monitoring period to school age if possible to determine if the child is at risk for psychological maladjustment or behavior problems.

The results of this study indicated that most subject families did believe their child's condition and the threat of loss of the child to be serious. However, most families indicated they would not treat their child differently in the future as a result of his/her condition and need for a monitor. Thus, this researcher expects that most subject families would eventually resolve their feelings about the child.

Measures of the level of family functioning using a reliable family functioning tool which also assess specific dimensions of functioning must be done at the same time intervals to determine if the functioning of the family may place the child at risk. Utilizing a tool which measures specific dimensions of family functioning may aid in recognition of specific problem areas for the family. Perceptions of both parents about the level of family functioning should be measured to assess if the family is at risk for disorganization and eventual breakup or if there is a discrepancy between partner or family member perceptions that may indicate family disorganization. If problem areas are identified, referral to a family counselor should be made available to the family unit.

There are several implications for nursing related to the hospitalization of an infant experiencing apnea and requiring home monitoring as part of the infant's health management plan. When a family agrees to home apnea monitoring as part of their infant's therapy, they are accepting full responsibility for the care of the infant and intervention should an apneic episode occur. This responsibility raises several fears and anxieties for the family.

The role of the nurse during hospitalization of the infant should be aimed at helping the family deal with the stress of the hospital setting and fears related to the threatened loss of the child. The nurse should also be preparing the family for the physical and emotional care of the child at home including procuring local support systems for the family such as a primary physician, visiting nurses, social workers, other monitor parents, and other community agencies for such things as financial help. According to Favorito (1979), the use of a primary nurse for the infant and family is vital in decreasing the stress of monitoring. Nursing assessments during hospitalization should include physical and developmental assessment of the child, parents' perceptions of the situation, their own emotional, psychological and physical status, the appropriateness of their coping mechanisms, the infant's normal daily routine, assessing the level of family functioning related to the crisis the family is experiencing. The nurse's role thus includes teaching in preparing the family for discharge, understanding the monitor, responding appropriately to alarms, anticipating problems, securing necessary resources or support.

There are various nursing implications for the time period after the child goes home from the hospital. This period may be the most stressful for families as they are now fully responsible for the care of a child with a life-threatening illness that is not well understood by the community.

To make transition from hospital to home easier and to provide for continuity of care, a community health nurse referral should be made and the nurse should meet the child and family in the hospital before discharge or in the home as soon after discharge as possible. This nurse or a nurse from a Home Apnea Monitor Program can serve as both a support for the family and as a liaison person between family and other support systems.

Families in this research study who were in the adjustment or final phase of monitoring indicated they received support from both the nurses of the Home Apnea Monitor Program staff and home health care agencies. They also did not utilize other support systems available to them such as other home monitor families and neighbors. Nursing can aid families in developing linkages between themselves and these support systems.

No families in this study were in the initial crisis phase of monitoring. As monitoring families in this phase are facing a crisis, they may be disorganized and not able to mobilize resources. Thus, support for nursing during this phase is vitally important.

Monitoring consumes time and energy and requires constant vigilance on the part of the parent. Nursing in primary care settings can help relieve the stresses of monitoring by helping families explore sources for babysitters and sources of power in case of power failures and sources for mutual support such as other home monitor families in the community. The nurse can help the family make preparations for resuscitation emergencies and can help parents deal with feelings of fear, anger, and resentment. Nurses need to emphasize the infant's normal growth and development and help parents express feelings of resentment that may inhibit nurturance.

Subjects in this research study reported that home monitoring significantly impacted certain aspects of family life including the level of fatigue members experienced, the amount of tension family members experienced, outside social life, and travel. These reports would indicate family members, especially mothers, need relief away from the care of the child.

Study findings also indicated parents had serious feelings related to having to intervene should their child experience an apneic episode. The nurse can perhaps ease these feelings by aiding parents in being prepared for intervention.

Along with helping monitor families explore available outside support systems, the nurse must help them assess internal family supports, such as their spouse, and other children and effective coping measures, such as sharing infant care responsibilities and reassigning tasks to other family members. If the family has other children, the nurse must help parents realize the children may have difficulty expressing their fears and feelings of resentment and that these feelings may be exhibited through behavior problems. Ways of dealing with these problems should be discussed with the entire family.

Although no significant relationships were found between a family's perceptions of severity of their infant's condition, the scope of impact of home monitoring, and supports available to the family during the home monitoring period and the level of family functioning, measures of these variables should be administered at regular intervals throughout the monitoring period and after discontinuation for at least one year. No subject families were in the initial phase of monitoring. Because families may be disorganized during this phase, measures done at that point in time may be critical. These measures (Family Stress Scale, Family Impact Scale, and Family Support Index) should all be utilized as separate assignment tools because there was no relationship found between the perceptions measured by these tools and the level of family functioning.

In summary, nursing interventions for practice should be based on stress theory and nursing process and should begin from the onset of diagnosis of apnea in an infant ghrough discontinuation of monitoring to school age if possible. Use and involvement of support systems included throughout the monitoring period to facilitate effective coping and positive adaptation of the family was emphasized. Roles of nursing related to hospitalization, transition from hospital to home, and home care during the monitoring period were discussed. Roles involving teaching, anticipatory guidance, problem-solving, and counseling were explored. Interventions including measurements of perceptions related to the child and monitoring and of the level and specific aspects of family functioning at regular intervals were stressed. Nursing through the use of such interventions can help reduce or relieve the stress a family experiences related to home monitoring.

Implications for Future Research

Although several implications for future research drawn from results of the study have already been discussed, more will be presented. Although there were no significant differences found among study variables and the level of family functioning, the researcher believes that repeating the study with a more representative sample including lower socioeconomic families would provide significant results. The present study population were predominantly white and middle class and probably had effective coping mechanisms to adapt to the stress of home monitoring, positively skewing the results of the study, and thus no effect was seen in the level of family functioning.

The study sample's effective use of coping mechanisms may have been related to the fact all had been monitoring at least one month and were in the adjustment phase of monitoring.

The researcher also believes that through altering the methodology, the research study would provide significant results. Rather than using a mailed questionnaire, a structured open-ended interview should be conducted with study subjects. This would all but eliminate the problem of missing data as a result of response bias. Further, if wording of questions were refined, response bias may also be eliminated. If the length of time for collecting data was extended, a larger study sample could be obtained.

The researcher believes that the level of family functioning is related to a family's perceptions of severity of their child's condition, scope of impact of home apnea monitoring, and support available during the home monitoring period as they are all components in the stress process related to family functioning. The researcher also believes length of monitoring and disposition of monitoring are related to the level of family functioning. The researcher believes that since the range of time the monitor had been discontinued for families was short (less than eight months), perceptions related to monitoring had not significantly changed as perhaps they would over an extended period of time.

The following suggestions are made for future research resulting from the researcher's personal experience in working with home monitor families and in researching the impact of home apnea monitoring on the level of family functioning. Suggestions include:

1. A larger sample size in whom the range of length of monitoring is wider. A wider range of length of monitoring may result in greater variation in responses and provide significant results for the study.
2. Relationships between perception variables and socio-demographic variables should also be explored in more depth with a larger and more varied sample.
3. The Family Functioning Index developed by Pless and Satterwhite (1973) needs to be refined so it measures parent-child communications and parent-child activities versus father-child communications to make it more universally applicable (ie. to single parent families).
4. A family functioning tool needs to be developed or the Family Functioning Index needs to be refined so scores represent overall the level of functioning and the level of functioning on specific component areas to detect specific problem areas, (ie. decision-making, problem-solving, communication, etc.) With refinement the Family Functioning Index could be used as an assessment tool in practice settings to be utilized in families with healthy or chronically ill children.

5. A study should be conducted with partners of the marital dyad to determine differences in perceptions of the severity of the child's condition, the scope of impact of home monitoring, and support available to the family during the home monitoring period and the level of family functioning. Reliability and validity for the Family Stress Scale, the Family Impact Scale, and the Family Support Index could be established if high correlations were demonstrated between partners' scores. Large differences between partners' Family Functioning scores may indicate family disorganization and need for further invesitigation
6. The refined Family Functioning tool should be used in several studies with large populations to determine ranges for "low", "medium", or high family functioning versus identifying "high-risk" and "low-risk". Levels of family functioning may be easier to understand and delineate than the concept of "risk".
7. There should be further study of larger groups of subjects divided into groups according to disposition of monitoring. The length of monitoring variable should be treated separately for each group and not combined as in the present study. This probably served as a major limitation for the present study.

8. A longitudinal study needs to be carried out to study how a family's perceptions related to monitoring and the child and level of family functioning changes over time. The time intervals should include before one month during the initial phase of monitoring, once during the adjustment phase of monitoring, at the time monitoring is discontinued, three and six months after discontinuation, and yearly after to school age if possible to rule out the vulnerable child syndrome, psychological maladjustment of the child, or family disorganization.
9. A support group intervention study could be carried out after hospitalization of the infant. The new home monitoring family could meet with a group of monitor parents during the initial crisis phase of monitoring. The refined family functioning tool would be administered to the parents before and after participation in the support group to determine if changes occurred as a result of participation.
10. A quasi-experimental design study could be conducted to determine if nursing support as an intervention would make a difference in levels of family functioning. The refined family functioning instrument could be administered 2-4 weeks after prescription of the monitor. The control group would include families

who received no help from nurses in primary care settings or from community health nurses after discharge. The experimental group would include families who did receive help from nurses from community health agencies or primary care settings after discharge.

11. A study using a larger, more representative sample of home monitor families should investigate the types of coping mechanisms, role changes, intra-family supports, and task reassignments members of the family use in the adaptation process compared to their level of family functioning, using a refined family functioning instrument.

On a broader note, nursing must reformulate family functioning approaches to provide an avenue for conceptualizing and operationalizing such approaches. To conceptualize family functioning in terms of nursing theory, further nursing must address family functioning related both to health and illness and to family development along a time continuum. Relating family functioning to the stress process may aid nursing in better understanding the stages of stress.

To summarize, implications for further research include: revising the present study methodology to include a structured, open-ended interview and revision of wording on items; use of a larger study sample; continuation of study of the relationships between extraneous variables; conduction of support intervention and longitudinal follow-up studies; and, suggestions for refinement of a family functioning tool.

Implications for Education

Several suggestions for nursing education are drawn from the results. From the review of literature, the researcher found little literature has explored the occurrence of a life-threatening illness in a child member of a family unit using the stress process as a focus. Therefore, nursing curriculum, both graduate and undergraduate, should further deal with the crisis or stress experienced by families with a child member having a life-threatening illness. Nursing education must also continue to deal with the effects of illness, acute or chronic, on the family system, stressing the family's perceptions about their members health.

Ingrained in education dealing with illness in a member of the family unit should be theoretical or conceptual frameworks, such as family stress theory or the systems-developmental stress model.

Most nursing school curriculum deal with family theory and family content, the concept of family functioning using a conceptual framework needs to be stressed. The concept of family functioning should be used to assess the health and illness of the family unit. Along with the broader concept of family functioning, specific dimensions of functioning should be studied.

As little information has been dispersed to the larger community concerning apnea and home apnea monitoring, nursing is in a unique position to educate members of its own profession, other health care disciplines, especially primary physicians, and the larger community. Educational presentations about apnea in infants should deal with known etiologies, morbidity, and risk of mortality due to SIDS. Such presentations should discuss home apnea monitoring as part of the health management plan for an infant with apnea and the stresses it places on the family. Interventions for these families, both nursing and interdisciplinary, should be explored. Present professional standards of care for the state of Michigan, including nursing, for the infant with apnea requiring home monitoring and the family should be presented and perhaps expanded. Finally, the results of this study and other studies dealing with the impact of home monitoring should be presented.

Dispersion of information by nursing about infants with apnea requiring home monitoring can be done at several levels. Nursing school curriculum should deal with apnea in infants and the nurse's role both in the hospital and in primary settings in regards to a home monitoring family.

Inservice education for both hospital staff nurses and nurses in primary care settings or community health agencies should delineate the nurse's role specific to those settings. Nursing interventions aimed at reducing or relieving stress should be explored for nurses in both settings. These interventions must focus on what developmental phase of monitoring the family is in and may include administering a family functioning instrument at regular intervals. To facilitate profession-wide knowledge of the impact of home apnea monitoring on families, it would be beneficial to have the results of this and future related studies in professional nursing journals and interdisciplinary journals.

Professional education among nurses about home monitoring should stress the need for continuity of care to ease the family's transition from hospital to home. Continuity of care can be accomplished through use of nursing referrals initiated usually from the hospital setting and regular contact between nurse members of a hospital-based Home Apnea Monitor Program staff and nurses in primary care settings or community health agencies. Referrals by nurses in primary care settings to nurse members of a Home Apnea Monitor Program can be initiated for families who have had monitors prescribed but have received no teaching or support services. Interdisciplinary referrals, social services, support groups, and community agencies for financial support, should also be stressed. Nurses must be educated in ways to aid families in finding and utilizing such support services.

Nursing must also participate in the education of other health care providers regarding infants with apnea and the needs of home monitoring families. Primary physicians must be educated about their role as a vital support person to home monitoring families. Police, fire departments, and emergency service people must be educated in the importance of their role in a resuscitation emergency. Finally, social workers, both in the hospital and in primary care settings need to be educated about the problems of stresses of home monitoring families. Nursing must stress to other disciplines points of interface with home monitor families and the need for an interdisciplinary approach to care of a home monitoring family.

Finally, nursing must participate in the education of the community at large about infants with apnea and home monitoring to dispel any fears or misconceptions. If the condition of apnea and the needs of home monitor families are better known, perhaps monitor families will receive more understanding and support from people in their community and not experience isolation as a result of their situation. Education of the community should include educating representatives of insurance companies and state legislators about the financial aspects of home monitoring and the need for reimbursement of medical costs by insurance companies and state assistance programs.

To summarize, suggestions for nursing education include focusing nursing curriculum dealing with families facing the stress of home monitoring on a theoretical framework, stressing the concept of family functioning, and developing interdisciplinary interventions for home monitir families. Nursing education must also provide inservices for nurses in hospital and primary care settings stressing nursing roles and continuity of care through use of appropriate referrals. Finally, nursing must participate in the education of the community at large.

Summary

In Chapter VI, a summary and interpretation of research findings was presented. Conclusions were drawn and recommendations for nursing in the areas of practice, education, and future research are made.

BIBLIOGRAPHY

Aquilera, D.C. and Messick, J.M. Crisis intervention: Theory and Methodology. St. Louis: C.V. Mosby, Co., 1978.

American Academy of Pediatrics Task Force on Prolonged Apnea. Prolonged apnea. In U.S. Department of Health, Education, and Welfare Publication (HSA) 78-5261, 1978.

Barr, A. At home with an apnea monitor: A guide for new parents. National Foundation for Sudden Infant Death Syndrome Publication, 1979.

Becker, M.H. The health belief model and sick role behavior. In Becker, M.H. (Ed.), The health belief model and personal health behavior. Thorofare, New Jersey: C.B. Slack, Inc., 1974.

Beckwith, J. The sudden infant death syndrome. U.S. Department of Health, Education, and Welfare Publication, DHEW Publication No. (HSA) 75-5137, 1975.

Bedell, J. Giordani, B., Amour, J., Tavormina, J., and Boll, T. Life stress and the psychological and medical adjustment of chronically ill children. Journal of Psychosomatic Research, 1977, 21, 237-242.

Benfield, D., Leib, L., and Vollman, J. Grief response of parents to neonatal death and parent participation in deciding care. Pediatrics, 1978, 62:2, 171-177.

Bergman, A. Sudden infant death syndrome: An approach to management. Primary Care, 1976, 3:1, 1-8.

Bergman, A.B., Beckwith, J.B., and Ray, C.G. The apnea monitor business. Pediatrics, 1975, 56:1, 1-2.

Bhattacharyya, G. and Johnson, R. Statistical Concepts and Methods. New York: John Wiley and Sons, 1977.

Binger, C.M. Childhood leukemia: Emotional impact on siblings. In Anthony, E.J. and Koupernik, C. (Eds.), The child in his family: The impact of disease and death. New York: John Wiley and Sons, 1973.

Binger, C.M., Ablin, A.R., Feuerstein, R., Kusher, J., Zoger, S., and Mikkelsen, C. Childhood leukemia: Emotional impact on patient and family. *New England Journal of Medicine*, 1969, *280*:8, 414-418.

Black, L., Herscher, L., and Steinschneider, A. Impact of the apnea monitor on family life. *Pediatrics*, 1978, *62*:5, 681-685.

Blood, R.W. and Wolfe, D.M. *Husbands and wives: The dynamics of married living*. New York: The Free Press, 1960.

Borg, W.R. and Gall, M.D. *Educational research: An introduction*. New York: David McKay Co., 1971.

Bruhn, J. Effects of chronic illness on the family. *Journal of Family Practice*, 1977, *4*:6, 1057-1060.

Cain, L.P., Kelly, D.H., and Shannon, D.C. Parents' perceptions of the psychological and social impact of home monitoring. *Pediatrics*, 1980, *66*:1, 37-41.

Caplan, G., Mason, E., and Kaplan, D. Four studies of crisis in parents of prematures. *Journal of Community Mental Health*, 1965, *1*, 149-161.

Carey, W. Psychologic sequelae of early infancy health crises. *Clinical Pediatrics*, 1969, *8*:8, 459-463.

Chrisman, M. and Riehl, J. The systems-developmental stress model. In Riehl, J. and Roy, C. (Eds.), *Conceptual Models for Nursing Practice*. New York: Appleton-Century-Crofts, 1974.

Committee on Infant and Preschool Children. Home-monitoring for sudden infant death. *Pediatrics*, 1975, *55*, 144.

Constanza, M., Lipsitch, I., and Charney, E. The vulnerable children revisited: A followup study of children three to sic years after acute illness in infancy. *Clinical Pediatrics*, 1968, *7*:11, 680-683.

Crano, W.D. and Brewer, M.B. *Principles of research in social psychology*. New York: McGraw-Hill Book Co., 1973.

Cummings, S.T. The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically ill children. *American Journal of Orthopsychiatry*, 1976, *46*:2, 246-255.

Cyntryn, L., Moore, P., and Robinson, M. Psychological adjustment of children with cystic fibrosis. In Anthony, E.J. and Koupernik, C. (Eds.), *The child in his family: The impact of disease and death*. New York: John Wiley and Sons, 1973.

Duvall, E.M. *Family Development*. Philadelphia: J.B. Lippincott Co., 1971.

Farber, B. and Jenne, W.C. Family organization and parent-child communication: Parents and siblings of a retarded child. *Monographs of Research in Child Development*, 1963, *2*, 7.

Favorito, J., Pernice, J., and Ruggiero, P. Apnea monitoring to prevent SIDS. *American Journal of Nursing*, 1979, *79*:1, 101-104.

Feetham, S. *The relationship of family functioning to infant, parent, and family environment outcomes in the first 18 months following the birth of an infant with myelodysplasia*. Unpublished doctoral dissertation, Michigan State University, 1980.

Futterman, E. and Hoffman, I. Crisis and adaptation in families of fatally ill children. In Anthony, E.J. and Koupernik, C. (Eds.), *The child in his family: The impact of disease and death*. New York: John Wiley and Sons, 1973.

Gayton, W. and Friedman, S. Psychological aspects of cystic fibrosis: A review of literature. *American Journal of Diseases in Children*, 1973, *126*, 856-859.

Geismer, L., LaSorte, M., and Ayres, B. Measuring family disorganization. *Marriage and Family Living*, 1962, *24*, 52-60.

Gersten, J.C. Measures of family functioning. In Graves, G.D. and Pless, I. (Eds.), *Chronic childhood illness: Assessment of outcome*. DHEW Publication No. (NIH) 76-877, 1976.

Good, M., Smilkstein, G., Good, B., Shaffer, T., and Arons, T. The family APGAR index: A study of construct validity. *Journal of Family Practice*, 1979, *8*:3, 577-582.

Green, M. and Solnit, A. Reactions to the threatened loss of a child: A vulnerable child syndrome. Pediatrics, 1964, 34, 58-66.

Griffin, J.Q. Physical illness in the family. In Miller, J.R. and Janosik, E.H. (Eds.), Family-focused care. New York: McGraw-Hill, 1980.

Guilleminault, C., Perarita, R., and Souquet, M. Apnea during sleep in infants: Possible relationship with sudden infant death syndrome. Science, 1975, 190, 677-685.

Harding, R., Heller, J., and Kesler, R. The chronically ill child in the primary care setting. Primary Care, 1979, 6:2, 311-324.

Herbst, J., Book, L., and Bray, P. Gastroesophageal reflux in the "near-miss" sudden infant death syndrome. Journal of Pediatrics, 1978, 92, 73-80.

Hill, R. Families under stress. Connecticut: Greenwood Press, 1949.

Hill, R. Generic features of families under stress. Social Casework, 1958, 39, 139-169.

Johnson, S.H. The premature infant. In Johnson, S.H. (Ed.), High-risk parenting: Nursing assessment and strategies for the family at risk. New York: J.B. Lippincott Co., 1979.

Jordan, D. Home-monitoring for near-miss SIDS infants. Home Care, October/November, 1979, 36-40.

Kelly, D. and Shannon, D. Periodic breathing in infant with near-miss sudden infant death syndrome. Pediatrics, 1979, 63:3, 355-360.

Kelly, D., Shannon, D., and O'Connell, K. Care of infants with near-miss sudden infant death syndrome. Pediatrics, 1978, 62:5, 511-514.

Kennell, J.H. and Klaus, M.H. Caring for parents of a sick or premature infant. In Klaus, M.H. and Kennell, J.H. (Eds.), Maternal-infant bonding. St. Louis: C.V. Mosby Co., 1976.

Kerner, J., Harvey, B., and Lewiston, N. The impact of grief: A retrospective study of family functioning following loss of a child with cystic fibrosis. Journal of Chronic Disease, 1979, 32, 221-225.

Kerscht, J.P. The health belief model and sick role behavior. In Becker, M.H. (Ed.), The health belief model and personal health behavior. Thorofare, New Jersey: C.B. Slack, Inc., 1974.

King, I.M. Toward a theory of nursing: General concepts of human behavior. New York: John Wiley and Sons, 1971.

Kirk, R.E. Experimental design: Procedures for the behavioral sciences. Belmont, California: Brooks/Cole Publishing Co., 1968.

Krein, N. Sudden infant death syndrome: Acute loss and grief reactions. Clinical Pediatrics, 1979, 18:7, 414-422.

Lazarus, R.S. Psychological stress and coping in adaptation and illness. International Journal of Psychiatry in Medicine, 1974, 5:4, 321-333.

LaVigne, J. and Ryan, M. Psychologic adjustment of siblings of children with chronic illness. Pediatrics, 1979, 63:4, 616-627.

Lefton, E. and Lefton, M. Health care and treatment for the chronically ill: Toward a conceptual framework. Journal of Chronic Diseases, 1979, 32, 339-344.

Lewak, N., van den Berg, B., and Beckwith, J. Sudden infant death syndrome risk factors. Clinical Pediatrics, 1979, 18:7, 404-411.

Lucey, J. False alarms in the nursery. Pediatrics, 1978, 61:4, 665-666.

McAnarney, E., Pless, I., Satterwhite, B., and Friedman, S. Psychological problems of children with chronic juvenile arthritis. Pediatrics, 1974, 53:4, 523-528.

McCubbin, H.E. Integrating coping behavior in family stress theory. Journal of Marriage and the Family, May, 1979, 237-244.

Mechanic, D. Stress, illness, and illness behavior. Journal of Human Stress, June, 1976, 2-6.

Miller, C. Working with parents of high-risk infants. *American Journal of Nursing*, 1978, *78*:8, 1228-1230.

Naeye, R., Landis, B., and Grage, J. Sudden infant death syndrome. *American Journal of Diseases in Children*, 1976, *130*, 1207-1210.

Nelson, N. But who shall monitor the monitor? *Pediatrics*, 1978, *61*:4, 663-664.

Olshansky, C. Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 1962, 190-193.

Parad, H. and Caplan, G. A framework for studying families in crisis. In Parad, H. (Ed.), *Crisis intervention*, New York: Family Service Association of American, 1965.

Pless, I. and Roghmann, K. Chronic illness and its consequences: Observations based on three epidemiologic surveys. *Journal of Pediatrics*, 1971, *79*:3, 351-359.

Pless, I., Roghmann, K., and Haggerty, R. Chronic illness, family functioning, and psychological adjustment: A model for the allocation of preventive health services. *International Journal of Epidemiology*, 1972, *1*:3, 271-277.

Pless, I. and Satterwhite, B. Chronic illness in childhood: Selection, activities, and evaluation of non-professional family counselors. *Clinical Pediatrics*, 1972, *11*:7, 403-410.

Pless, I. and Satterwhite, B. A measure of family functioning and its application. *Social Science and Medicine*, 1973, *1*, 613-621.

Pless, I. and Satterwhite, B. Family functioning and family problems. In Haggerty, R., Roghmann, K., and Pless, I. (Eds.), *Child health and the community*. New York: John Wiley and Sons, 1975.

Polit, D.F. and Hungler, B.P. *Nursing research: Principles and methods*. Philadelphia: J.P. Lippincott Co., 1978.

Price-Bonham, S. and Addison, S. Families and mentally retarded children: Emphasis on the father. *The Family Coordinator*, 1978, *27*, 221-230.

Roghmann, K., Hecht, P. and Haggerty, R. Coping with stress. In Haggerty, R., Roghmann, K., and Pless, I. (Eds.), Child health and the community. New York: John Wiley and Sons, 1975.

Rosenstock, I.M. Historical origins of the health belief model. In Becker, M.H. (Ed.), The health belief model and personal health behavior. Thorofare, New Jersey: C.B. Slack, Inc., 1974.

Rowe, J., Clyman, R., Green, C., Mikkelson, C., Haight, J., and Atoride, L. Followup of families who experienced a perinatal death. Pediatrics, 1978, 62:2, 166-170.

Salk, L., Hilgartner, M., and Granich, B. The psychosocial impact of hemophilia on the patient and his family. Social Science and Medicine, 1972, 6, 491-505.

Satterwhite, B., Pless, I., Zweig, S., and Iker, H. The family functioning index - five year test-re-test reliability. Journal of Comparative Family Studies, 1976, 1, 111-115.

Sedgwick, R. The family system: A network of relationships. Journal of Psychiatric Nursing and Mental Health Services, 1974, 12, 17-20.

Shannon, D., Kelly, D., and O'Connell, K. Abnormal regulation in infants at risk for sudden infant death syndrome. New England Journal of Medicine, 1977, 297:14, 747-750.

Smialek, Z. Observations on immediate reactions of families to sudden infant death. Pediatrics, 1978, 62:2, 160-165.

Smilkstein, G. The family in trouble: How to tell. Journal of Family Practice, 1975, 2:1, 19-23.

Smilkstein, G. The family APGAR: A proposal for a family function test and its use by physicians. Journal of Family Practice, 1978, 6:6, 1231-1239.

Stark, A., Mandell, F., and Taeusch, H.W. Close encounters with SIDS. Pediatrics, 1978, 61:4, 664-665.

Steinhauer, P., Muskin, D., and Rae-Grant, Q. Psychological aspects of chronic illness. Pediatric Clinics of North America, 1974, 21:4, 825-839.

Steinschneider, A. Prolonged apnea and the sudden infant death syndrome: Clinical and laboratory observations. Pediatrics, 1972, 50, 646-650.

Steinschneider, A. A reexamination of the apnea monitor business. *Pediatrics*, 1976, *58*:1, 1-4.

Strauss, A. Chronic illness and the quality of life. St. Louis: C.V. Mosby Co., 1973.

Sutterly, D.C. Stress and health: A survey of self-regulation modalities. *Family and Community Health*, May/June, 1979, 1-57.

Thach, B. and Stark, A. Spontaneous neck flexion and airway obstruction during apneic spells in preterm infants. *Journal of Pediatrics*, 1979, *94*, 275-283.

The family nurse clinician's role in family-focused care. Michigan State University, School of Nursing, Graduate Program, 1978.

Tonkin, S. Sudden infant death syndrome: Hypothesis of causation. *Pediatrics*, 1975, *55*, 650-658.

Travis, G. *Chronic illness in children*. Stanford, California: Stanford University Press, 1976.

Turk, J. Impact of cystic fibrosis on family functioning. *Pediatrics*, 1964, *34*, 67-71.

Valdes-Dapena, M. Sudden unexplained infant death, 1970-1975: An evolution in understanding. *Pathology Annals*, 1975, *1*, 117-145.

Valdes-Dapena, M. Sudden infant death syndrome: A review of the medical literature 1974-1979. *Pediatrics*, 1980, *66*:4, 597-614.

Whall, A. Congruence between existing theories of family functioning and nursing theories. *Annals of Nursing Science*, September/October, 1980, 59-67.

Waechter, E. Bonding problems of infants with congenital anomalies. *Nursing Forum*, 1977, *16*:3, 299-317.

Williams, A., Vawter, G., and Reid, L. Increased muscularity of the pulmonary circulation in victims of sudden infant death syndrome. *Pediatrics*, 1979, *63*:1, 18-23.

APPENDICES

APPENDIX A

PROTECTION OF HUMAN SUBJECTS

APPENDIX A

PROTECTION OF HUMAN SUBJECTS

Potential Risks of Study to Subjects: There are no potential physical risks to subjects involved in this investigation. The administration of the questionnaire to subjects may raise the awareness of the subject to personal concerns and stressful emotions related to home apnea monitoring. To make subjects aware of these potential risks, all subjects received a letter of introduction and explanation along with the questionnaire. This letter specified that participation or unwillingness to participate in the research study would not affect the care the subject's infant would receive now or in the future. The subject was also informed by the letter of his/her right to withdraw from the study at any time. The cover letter also specified that questions are allowed and would be answered and proper support obtained for subjects through referrals to appropriate, accessible people. A telephone number and instructions were provided to the subjects to aid in dealing with questions and concerns. See cover letter in Appendix B.

Consent Procedures of Study: Participation by subjects in this research study was totally voluntary. Initial consent was obtained verbally from subjects by telephone. At any time during the study, subjects were allowed to withdraw. Subjects had an opportunity to ask questions of the researcher prior to consenting to participation and after final consent was given. Final consent was obtained in writing after the subjects had received and had had time to study the consent form and questionnaire. The written consent form was returned through the mail to the researcher, along with the questionnaire.

Protecting Subjects of the Study: All subjects and their responses remained anonymous through assignment of case/code numbers to each subject. Names of subjects did not appear on the questionnaire, in discussion about the research study, or in relation to collected data and its analysis. The case/code number of each subject appeared on and was used on the sociodemographic questionnaire, the section Beliefs About Home Apnea Monitoring, and the Family Functioning Index.

Potential Benefits of Study: The study may aid subjects in identification of specific areas of family functioning and family life that may have been affected by the stress of having a child with or at risk for apnea and the stress of home apnea monitoring. It may also make them aware of both successful and unsuccessful coping mechanisms they used in response to the stress. The study may also aid subjects in identifying supports available to them in times of stress or crisis and aid in anticipation of coping with future stresses to the family unit. The study may assist future monitoring families by stimulating families that have experienced home monitoring to serve as a potential support to new monitoring families during the monitoring period.

This study will benefit nursing and future home monitor families by collecting information about the affect home monitoring may have on family functioning. By gaining such information, nursing can expand its knowledge related to stress on the family, and the use of coping mechanisms in adaptation and outcome in the level of family functioning. Through attainment of such knowledge, nursing can aid families in anticipation and recognition of stress and recognition and acquisition of adaptive coping mechanisms to deal with stress to the family unit through anticipatory guidance and stress counseling or crisis intervention. Development of such nursing strategies will aid families facing the stress of home monitoring to optimal adaptation and serve as a potential support to such families.

APPENDIX B

COVER LETTER AND CONSENT FORM

APPENDIX B

COVER LETTER AND CONSENT FORM

Michigan State University
College of Nursing
Cover Letter

Dear _______________:

You have previously been contacted concerning participation in the home monitoring research study. At that time you indicated that both you and your child's other parent would be willing to participate in this study. Enclosed is the consent form and questionnaires. Both you and your child's other parent will have three questionnaires to complete: (1) The Sociodemographic Form, (2) Beliefs About Home Monitoring, and (3) Family Functioning Questionnaire, in addition to a consent form. You will both sign the same consent form. Please read each question carefully and answer each question with only one response. I ask that you do not consult with one another as it will affect the results of this study.

Catherine S. Goetz, R.N.
Family Nurse Clinician Graduate Student

CSG
Enclosures

APPENDIX C

CONSENT FORM

APPENDIX C

Michigan State University
College of Nursing
CONSENT FORM

Title of Study: IMPACT OF HOME APNEA MONITORING ON FAMILY FUNCTIONING

Investigator: Catherine S. Goetz, R.N., B.S.N.
Graduate Student, Family Nurse Clinician Program
School of Nursing
Michigan State University

Office: (517) 483-2670
Home: (517) 351-0299

Dear _______________:

The study in which you are about to participate is designed to measure the way home monitoring has affected the way your family functions. This study is being conducted by myself as part of the requirements for a master's degree in nursing. The results of the study will be used to determine how nursing can help families who face the stress of having a child with apnea and/or bradycardia or at risk for apnea and the stress of home apnea monitoring.

Please complete the enclosed consent form and the questionnaires and return in the stamped envelope within one week. Participation in the study should take 20-30 minutes of your time and will require you to respond to a series of questions as honestly and accurately as you can. As a result of participation in this study, you may become more aware of problems associated with home apnea monitoring which may cause stressful feelings or emotions to arise. If the questionnaire raises any such personal concerns, please contact the researcher.

Your answers will be kept in complete anonymity and no attempt will be made to identify you in any manner. You are free to withdraw from the study at any time. Withdrawal from the study will in no way affect the care you are now receiving or will receive in the future. Participants may call the investigator at any time should questions arise. You may call the researcher collect at home in the evening after 5:00 p.m. if necessary.

I will be pleased to send you a summary of the results of the study following its completion upon your request.

If you agree to participate, please sign the following statement. Thank you for your time and cooperation.

Catherine S. Goetz
Family Nurse Clinician Graduate Student
(517) 483-2670 or 351-0299

I voluntarily consent to participate in the above described study and understand what is required of me as a participant. I have had an opportunity to ask questions about the study and may change my mind before the study is completed if I so choose.

Date	Signature of Child's Mother
Date	Signature of Child's Father
Date	Signature of Investigator

APPENDIX D

ESTABLISHED CRITERIA FOR PARTICIPATION IN THE STUDY

APPENDIX D

ESTABLISHED CRITERIA FOR PARTICIPATION IN THE STUDY

1. Subjects were parents and primary caretakers of an infant who once had or currently had prolonged apnea and/or bradycardia or was at risk for prolonged apnea and/or bradycardia.
2. As part of the infant's health management plan, the subjects used an infant apnea and cardiac monitor at home.
3. Subjects must have resided in the same household with the infant during the home monitoring period.
4. Subjects resided in the state of Michigan and were participants in a certain hospital-based Home Apnea Monitor Program.
5. Subjects were literate in the English language.
6. Subjects verbalized a willingness to participate in the research study.

APPENDIX E

PARENT QUESTIONNAIRE: CHILD WITH HOME APNEA MONITORS

APPENDIX E

Case No. ____ ____ ____(1-3)
Card No. ____________(4)
Date ___/___/____(5-10)

PARENT QUESTIONNAIRE: CHILD WITH HOME APNEA MONITORS

Sociodemographic:
The following questions describe general things about you and your child. Please answer all the questions to the best of your ability. There are no right or wrong answers.

1. Parent responding to questionnaire:____________ (11)

2. Your age: __________(12-13)

3. Your marital status during home monitoring period (check one): (14)
   _____Married _____Single
   _____Separated _____Widowed
   _____Divorced _____Other (please specify)
   ____

4. Income: Total family income for past 12 months (check one): (15)
   _____0-$4,999 _____$15,000 - $19,999
   _____$5,000 - $9,999 _____$20,000 - $24,999
   _____$10,000 - $14,999 _____$25,000 or over

5. Your work/occupation: _____________________ If you do not work please describe your daily activities:
   ____(16)

6. Your highest education (check one): (17)
   _____Elementary School _____Technical/Vocational School
   _____High School _____Advanced Schooling
   _____College _____Other (Please specify)
   ____

7. Your child's sex (check one):
   _____male _____female (18)

8. Your child's ethnic group (check one): (19)
   ____Caucasian/White _____Asian/Oriental
   ____Black _____American Native
   ____Hispanic _____Other (please specify)
   ____

9. Total number of children: ________(20)

10. A. People who lived in home during monitoring period (check appropriate description of whom child lived with during monitoring period): (21)

_____Lives (lived) with one parent
_____Lives (lived) with one parent and other children
_____Lives (lived) with both parents and other children
_____Lives (lived) with parent(s) in home with other relative(s)
_____Other (please specify) ____________________________

B. Total number of household members during home monitoring period: __________ (22)

11. Description of area in which your family lives (check one): (23)

_____Rural _____Urban
_____Suburban _____Other (please specify)____________

12. How was your child's condition discovered? (check one) (24)

_____Episode of apnea (no breathing), bradycardia (low heart rate), or cyanosis (blueness) at home.
_____Episode of apnea (no breathing), bradycardia (low heart rate), or cyanosis (blueness) in the hospital.
_____Brother or sister died from Sudden Infant Death Syndrome.
_____From medical workup.
_____From sleep respiratory/cardiac study (sleep study)
_____Other (please specify) ____________________________

13. Who is (was) primarily responsible for your child's care during the monitoring period? (check one) (25)

_____Mother
_____Father
_____Other (please specify) ____________________________

14. Was your child? (check one) (26)

_____Full-term infant (delivered near due date)
_____Premature Infant (delivered more than 3 weeks early)

15. A. How old was your child when the monitor was first used? (27-30)

__________/__________
months (27-28) weeks (29-30)

B. Is your child still on the monitor?
(check one) (31)
_____yes _____no _____Other (please specify) ____________________

C. How long was or has your child been on the monitor? (32-35)

________/________
months (32-33) weeks (34-35)

D. If your child is off the monitor, how long has he/she been off? (36-41)

________/________/________
years (36-37) months (38-39) weeks (40-41)

APPENDIX F

BELIEFS ABOUT HOME APNEA MONITORING

APPENDIX F

BELIEFS ABOUT HOME APNEA MONITORING

Family Stress Scale

The following questions concern your feelings about the seriousness of your child's condition and need for a home monitor. Please answer all the questions to the best of your ability. There are no right or wrong answers. Circle one answer for each question. Any additional comments may be written beside each answer.

1. How serious do (did) you think your child's condition is (was) when he/she was diagnosed? (42)

Very Serious	Serious	Moderately Serious	Slightly Serious	Not Serious at all

2. How serious do (did) the need for the home monitor make you feel your child's condition is (was)? (43)

Very Serious	Serious	Moderately Serious	Slightly Serious	Not Serious at all

3. How serious does (did) the number of "real" alarms your child experiences (experienced) make you feel your child's condition is (was)? (44)

Very Serious	Serious	Moderately Serious	Slightly Serious	Not Serious at all

4. How serious does (did) having to stimulate your child to breathe (or pick up his/her heart rate) make you feel your child's condition is (was)? (45)

Very Serious	Serious	Moderately Serious	Slightly Serious	Not Serious at all

5. How serious do (did) you feel the threat of death for your child is (was)? (46)

Very Serious	Serious	Moderately Serious	Slightly Serious	Not Serious at all

6. Will your child's need for a monitor affect the way you treat him/her in the future? (check answer) (47)

_____yes _____no→(GO TO QUESTION 7)

6a. Describe how: (Write in) (48)

7. Will the experience of having a child on a monitor affect your views on having more children? (check answer) (49)

_____yes _____no→(GO TO QUESTION 8)

7a. Describe how: (Write in) (50)

8. Will the experience of having a child on a monitor affect your own future plans? (check answer) (51)

_____yes _____no→(GO TO NEXT SECTION)

8a. Describe how: (Write in) (52)

Family Impact Scale

The following questions concern your views about how home monitoring may affect (may have affected) your family. Please circle the answer which best reflects your feelings about the effect of home monitoring on your family. Circle one answer for each question.

1. How monitoring affects (affected) my family's finances: (53)

   Very Much   Somewhat   Moderately   Slightly   Not at all

2. How monitoring affects (affected) the level of fatigue members of my family experienced: (54)

   Very Much   Somewhat   Moderately   Slightly   Not at all

3. How monitoring affects (affected) the arrangement of furnishings in our home: (55)

   Very Much   Somewhat   Moderately   Slightly   Not at all

4. Home monitoring affects (affected) my family's outside social life: (56)

   Very Much   Somewhat   Moderately   Slightly   Not at all

5. How monitoring affects (affected my family's at home social life: (57)

   Very Much   Somewhat   Moderately   Slightly   Not at all

6. Home monitoring affects (affected) my family's travel: (58)

   Very Much   Somewhat   Moderately   Slightly   Not at all

7. Home monitoring affects (affected) the anxiety or tension my family experiences: (59)

   Very Much   Somewhat   Moderately   Slightly   Not at all

8. Home monitoring affects (affected) the amount of friction between family members: (60)

   Very Much   Somewhat   Moderately   Slightly   Not at all

9. Home monitoring affects (affected) the health of other family members: (61)

Very Much Somewhat Moderately Slightly Not at all

10. Home monitoring affects (affected) my family's relatives: (62)

Very Much Somewhat Moderately Slightly Not at all

11. Home monitoring affects (affected) my family's ability to carry out daily activities (work, keeping house, etc.): (63)

Very Much Somewhat Moderately Slightly Not at all

12. Home monitoring affects (affected) other children in the family: (64)

Very Much Somewhat Moderately Slightly Not at all

Family Support Index

Many families receive help and support from people during times of illness. The next questions deal with the type of help your family receives (received) during your monitoring period. Check or circle one answer for each question.

1. During the home monitoring period, does (did) your family receive help from relatives? (check answer) (65)

_____yes _____no→(GO TO QUESTION 2)

↓
1a. What type of help do (did) they provide? (66) (<u>Write in</u>)

1b. Do you feel the amount of help they give (gave) is (was): (circle answer) (67)

More Than Adequate Adequate Inadequate

2. During the home monitoring period, does (did) your family receive help from friends? (check answer) (68)

_____yes _____no→(GO TO QUESTION 3)

↓
2a. What type of help do (did) they provide? (69) (<u>Write in</u>)

2b. Do you feel the amount of help they give (gave) is (was): (circle answer) (70)

More Than Adequate Adequate Inadequate

3. During the home monitoring period, does (did) your family receive help from the staff of the home monitor program? (check answer) (71)

_____yes _____no→(GO TO QUESTION 4)

↓
3a. What type of help do (did) they provide? (<u>Write in</u>) (72)

3b. Do you feel the amount of help they give (gave) is (was): (circle answer) (73)

More Than Adequate   Adequate   Inadequate

4. During the home monitoring period, does (did) your family receive help from public health nurses or home care nurses? (check answer) (74)

_____yes   _____no→(GO TO QUESTION 5)

4a. What type of help do (did) they provide? (Write in) (75)

4b. Do you feel the amount of help they give (gave) is (was): (circle answer) (76)

More Than Adequate   Adequate   Inadequate

5. During the home monitoring period, does (did) your family receive help from your child's physician? (check answer) (77)

_____yes   _____no→(GO TO QUESTION 6)

5a. What type of help do (did) they provide? (Write in) (78)

5b. Do you feel the amount of help they give (gave) is (was): (circle one) (79)

More Than Adequate   Adequate   Inadequate

Case No. ___ ___ ___ (1-3)
Card No. _______ (4)
Date ___/___/___ (5-10)

6. During the home monitoring period, does (did) your family receive help from other families with monitor children? (check answer) (11)

_____yes   _____no→(GO TO QUESTION 7)

6a. What type of help do (did) they provide? (Write in) (12)

6b. Do you feel the amount of help they give (gave) is (was): (circle answer) (13)

More Than Adequate Adequate Inadequate

7. During the home monitor period, does (did) your family receive help from other community agencies? (check answer) (14)

_____yes _____no→(GO TO QUESTION 8)

7a. What agencies? (Write in) (15)

7b. What type of help do (did) they provide? (Write in) (16)

7c. Do you feel the amount of help they give (gave) is (was): (circle answer) (17)

More Than Adequate Adequate Inadequate

8. During the home monitoring period, does (did) your family receive help from people of your faith or church? (check answer) (18)

_____yes _____no→(GO TO QUESTION 9)

8a. What type of help do (did) they provide? (Write in) (19)

8b. Do you feel the amount of help they give (gave) is (was): (circle answer) (20)

More Than Adequate Adequate Inadequate

9. During the home monitoring period, does (did) your family receive help from your neighbors? (check answer) (21)

_____yes _____no→(GO TO NEXT SECTION)

9a. What type of help do (did) they provide? (Write in) (22)

9b. Do you feel the amount of help they give (gave) is (was): (circle answer) (23)

More Than Adequate Adequate Inadequate

APPENDIX G

FAMILY FUNCTIONING QUESTIONNAIRE

APPENDIX G

FAMILY FUNCTIONING QUESTIONNAIRE

1. What sorts of things do you do as a family? (Fill in)
    a. In the evenings (24) --
    b. On the weekends (25) --
    c. On vacations (26) --

(Put a check on the line corresponding with your choice)

2. How do you think the children get along together compared with other families? (Disregard if only one child) (27) — better   same   worse

3. Do the children find it easy to talk to you or their father about their problems? (Disregard if only one child) (28) — yes   sometimes   no

4. Do you find your wife/husband an easy person to talk to when something is troubling you? (29) — yes   sometimes   no

5. Is your husband/are you able to spend a lot of time with the children in the evening? (30) — yes   sometimes   no

6. Is your husband/are you able to spend a lot of time with the children on the weekend? (31) — yes   sometimes   no

7. Would you say, all in all, that your family is happier than most others you know, about the same, or less happy. (32) — happier   same   less happy

8. What would you say was the most important problem you as a family had to deal with this last year? (List problem) (33)

a. Was a solution arrived at? (34) _____ yes _____ no

b. Did you discuss the problem with your husband/wife? (35) _____ yes _____ no

c. Was everyone satisfied with the solution? (37) _____ yes _____ no

9. In every family someone has to decide such things as where the family will live and so on. Many couples talk about such things with the family first, but the final decision often has to be made by the husband or the wife. If these are situations you have not decided on recently, how would they be decided on should they occur.
(Write in the number corresponding to your choice.)

1 = Husband always
2 = Husband more than wife
3 = Husband and wife exactly the same
4 = Wife more than husband
5 = Wife always

a. Who usually makes the final decision about what kind of care to get? (37) _____

b. About whether or not to buy some life insurance? (38) _____

c. About what house or apartment to take? (39) _____

d. About what job you/your husband should take? (40) _____

e. About whether or not you should go to work or quit work? (41) _____

f. About how much your family can afford to spend per week on food? (42) _____

g. About what doctor to have when someone is sick? (43) _____

h. About where to go on vacation? (44) _____

10. Thinking of marriage in general which one of these five things would you say is the most valuable part of marriage? (Write in the number corresponding to your choice, <u>using each number only once</u>.)

1 = The chance to have children
2 = The standard of living--the kind of house, clothes, car and so forth
3 = The husband's/wife's understanding of the wife's/husband's problems and feelings
4 = The husband's/wife's expression of love and affection for the wife/husband
5 = Companionship in doing things together with the husband/wife

a. The most valuable part of marriage (45) _____

b. The next most valuable (46) _____

c. Third most valuable (47) _____

d. Fourth most valuable (48) _____

e. Fifth most valuable (49) _____

11. Of course, most couples differ sometimes over things, when you and your husband/wife differ about something, do you usually give in and do it your husband's/wife's way or does he/she usually come around to your point of view? (50)

___ Husband's way ___ 50/50 ___ Wife's way

12. Would you say disagreements in your household come up more often, about the same, or less often than in other families you know? (51)

___ More Often ___ Same ___ Less Often

13. Would you say that compared to most families you know, you feel less close to each other, about the same or closer than other families do? (52)

___ Less Close ___ Same ___ Closer

14. The following are some feelings you might have about certain aspects of marriage. (Write in the number corresponding to your choice.)

1 = Pretty disappointed. I'm really missing out on that.
2 = It would be nice to have more.
3 = It's all right, I guess--I can't complain.
4 = Quite satisfied--I'm lucky the way it is.
5 = Enthusiastic--it couldn't be better.

a. How do you feel about your standard of living, the kind of house, clothes, car and so forth? (53) _____

b. How do you feel about the understanding you get for your problems and feelings? (54) _____

c. How do you feel about the love and affection you receive? (55) _____

d. How do you feel about the companionship of doing things together? (56) _____

15. When your husband/you come(s) home from work, how often does he/do you talk about things that happened there? (57)

_____ Very Often _____ Sometimes _____ Never

APPENDIX H

SCORING KEY -- FAMILY LIFE QUESTIONNAIRE

APPENDIX H

Pless, I. and Satterwhite, B.
Community Child Health Study
University of Rochester Medical Center
Department of Pediatrics, Box 666
601 Elmwood Avenue
Rochester, New York 14642

Scoring Key -- Family Life Questionnaire

Q#		Score
1.	a. Evenings	Something = 1
	b. Weekends together	Something = 1
	c. Vacation together	Something = 1
2.	Sib relations	Better = 2 Same = 1
3.	Child father communication	Yes = 2 Sometimes = 1
4.	Mother father communication	Yes = 2 Sometimes = 1
5.	Father child activities evenings	Yes = 1 Sometimes = 1
6.	Father child activities weekends	Yes = 1 Sometimes = 1
7.	Family happiness	Happier = 2 Same = 1
8.	Problem discussed with husband	Yes = 1
9.	Decision Making	Number of 3's (husband & wife same) ÷ 2 Maximum score = 4
10.	Marital satisfaction	(See question 14)
11.	Husband - Wife disagreements	50/50 = 1

12.	Frequency of disagreements	Less often = 2 Same = 1
13.	Closeness	Closer = 2 Same = 1
14.	Marital Satisfaction	For each aspect of marriage rated in Q 10, score as follows: If chosen as 1st most valuable in Q 10, and rated as 1 score = 0 2 " = 1 3 " = 2 4 " = 3 5 " = 4 If chosen as 2nd most valuable in Q 10, and rated as 1 score = 0 2 " = 1 3 " = 2 4 or 5 " = 3 If chosen as 3rd, 4th or 5th most valuable in Q 10 and rated 1 score = 0 2 " = 1 3, 4 or 5 " = 2 If "chance to have children" was chosen as 1st most valuable in Q 10, add 2 Marital Satisfaction score Maximum score = 11
15.	Work communication	Very often = 1 Sometimes = 1 Maximum score (FFI) = 35

APPENDIX I

TELEPHONE INSTRUCTIONS TO POTENTIAL SUBJECTS

APPENDIX I

TELEPHONE INSTRUCTIONS TO POTENTIAL SUBJECTS

Telephone instructions to potential subjects proceeded as follows:

1. The researcher introduced herself by name, position, and association with the Home Apnea Monitor Program participating in the study.
2. The researcher explained how she obtained the subject's name and provided an explanation of the research study.
3. The researcher indicated the amount of time and effort needed on the subject's part to participate in the study.
4. The researcher allowed questions and assured anonymity and confidentiality.
5. Subjects were allowed one day to decide upon participation if so requested.
6. If subjects verbalized a willingness to participate, subjects were asked to sign consent forms and complete the instrument to the best of their ability according to written instructions included in the mailed packet.
7. The subjects were asked to return the questionnaire to the researcher in the addressed, stamped envelope within one week of receiving the questionnaire.
8. The subjects were asked to call the researcher if any questions or concerns resulted from completing the questionnaire and were provided with phone numbers they could call collect in such a situation.

APPENDIX J

PEARSON PRODUCT MOMENT CORRELATIONS BETWEEN SOCIODEMOGRAPHIC VARIABLES AND FFI, FSI, FSS4, FSS5, FSS, AND FIS

APPENDIX J

Definition of Sociodemographic Variables

SD 2 = Age of parent responding to questionnaire

SD 3 = Marital status of respondent

SD 4 = Total family income for the past 12 months

SD 5 = Respondent's (infant's primary caretaker) occupation

SD 6 = Respondent's highest level of education

SD 7 = Monitored infant's sex

SD 8 = Infant's ethnic group

SD 9 = Respondent family's total number of children

SD 10A = Description of whom child lived with during monitoring period

SD 10B = Total number of household members during the monitoring period

SD 11 = Description of area in which respondent family lived

Table J.1

Pearson Product Moment Correlations Between Sociodemographic Variables

SD 2-7 and FFI, FSI, FSS4, FSS5, FSS, and FIS (n=22)

Variable	SD 2	SD 3	SD 4	SD 5	SD 6	SD 7
FFI	.19	.02	.10	-.05	.10	-.02
FSI	.09	.11	-.18	.07	.04	.50*
FSS4	-.30	.21	-.48*	.25	-.11	.20
FSS5	-.15	.22	-.34	.23	.02	.04
FSS	.14	.03	-.23	.23	.12	-.21
FIS	.45	-.33	.21	.21	.02	-.01

* = Significant at the .05 level

Table J.2

Pearson Product Moment Correlations Between Sociodemographic Variables

SD 8-11 and FFI, FSI, FSS4, FSS5, FSS, and FIS (n=22)

Variable	SD 8	SD 9	SD 10A	SD 10B	SD 11
FFI	.36	.46*	.67**	.32	-.05
FSI	-.06	.46*	.47*	.37	-.08
FSS4	.21	.38	.48*	.32	-.18
FSS5	.22	.29	.36	.50*	-.04
FSS	.03	.17	.08	-.01	-.02
FIS	-.16	.01	.18	-.15	.10

* = Significant at .05 level

** = Significant at .001 level

APPENDIX K

LETTER OF APPROVAL BY INSTITUTIONAL RESEARCH REVIEW COMMITTEE AND EXECUTIVE COMMITTEE OF PARTICIPANT HOSPITAL

EDWARD W. SPARROW HOSPITAL
ASSOCIATION
1215 EAST MICHIGAN AVENUE · P. O. BOX 30480 · LANSING, MICHIGAN 48909 · TELEPHONE 517 487-6111

February 4, 1981

Ms. Cathy Goetz, R.N.
Neonatal Intensive Care
1215 E. Michigan Ave.
PO Box 30480
Lansing, Michigan 48909

Dear Ms. Goetz:

This is to advise you that your research project on home apnea monitoring has been approved by both the Institutional Research Review Committee and the Executive Committee of E.W. Sparrow Hospital and you are now free to proceed with all aspects of the research study.

The Committee does require that you notify us of any substantial changes in the research protocol. We also require that a copy of the final report be submitted to the Committee. If the project should run for longer than one year, then it will be necessary for you to recontact the Research Review Committee for an annual review.

Thank you for your continued cooperation with the Institutional Research Review Committee.

Sincerely,

H Anderson

W.H. Anderson Jr., M.D.
Chairman
Institutional Research Review Committee

cc: Dr. Eugene Dolanski