

MATERNAL-INFANT RESPONSES TO HOME
APNEA MONITORING

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ABSTRACT

The research sought to describe types of upset experienced by the mothers ($n = 74$), parenting behaviors, and infant development and behavior ($n = 74$). The goal was to identify characteristics of maternal upset that may be associated with developmental and behavioral problems in monitored infants.

For this retrospective study, a 1-group descriptive design was employed, using both qualitative and quantitative analyses. The qualitative component provided the context analyses of unstructured interviews with the mothers. The quantitative component consisted of mothers' responses to rating scales on parenting behaviors, infant behavior and stress. Quantitative assessments of infant development and the environment were conducted by the investigator. Other variables analyzed were social support, duration of monitoring and modifying factors (parents' age, education, occupation, religion and marital status).

Six instruments were utilized to answer the research questions. The Parental Experiences Interview was an unstructured interview used to assess mothers' experiences during monitoring. Two rating scales constructed by the

investigator were used to assess infant behavior and parenting practices. Stressful life events were assessed by the standardized UTAH (IVS) rating scale. Infant development was assessed by the standardized Bayley Scales of Infant Development (BSID), and the home environment was assessed through the standardized HOME scale.

The analyses demonstrated four major findings. The first finding was a description of nine categories of upset experienced by mothers of monitored infants. Second, mothers who felt less positive about parenting had infants with lower scores of infant development and more behavioral problems. Third, longer duration of monitoring was significantly related to mothers who were unsupported and fearful. Fourth, lack of support was significantly related to high levels of maternal upset, longer duration of monitoring, mothers who felt less positive about parenting, lower scores of infant development and high incidence of infant behavior problems. Suggestions are given for formulation of nursing interventions that may assist families of monitored infants, as well as suggestions for further research.

Dedicated to the mothers and infants
who participated in this research.

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CHAPTER I

OVERVIEW OF THE RESEARCH

Statement of the Problem

Infant apnea in this research refers to breathing pauses that develop in some healthy infants for periods long enough to evoke significant alteration of oxygen saturation of the blood and heart rate. The American Academy of Pediatrics has defined infantile apnea as cessation of respiration for 20 seconds or longer, or shorter episodes accompanied by bradycardia or cyanosis (Brooks, 1982). Infants who are diagnosed to have significant apnea have an increased risk for subsequent sudden death (2% as compared with the general population of infants whose risk is 1.6 to 3.8 in 1,000) (Ward et al., 1986).

Identifying apneic infants who are at actual risk for death is complex, as medical diagnoses must often be based on the subjective opinion of parents that a life threatening apneic event occurred. In addition, parents sometimes perceive shorter apneic events as life threatening, even though these breathing pauses may be normal.

Characteristically, the infant who experiences apnea

is found in a nonbreathing state but is able to be revived. Infants are usually taken to a health care facility where efforts are undertaken to detect the cause of the apnea. Although multiple causes for some types of infantile apnea are known and treatable, in a certain other group of infants, no cause can be found. Due to some evidence linking infant apnea with Sudden Infant Death Syndrome, many medical practitioners recommend that infants with unexplained apnea undergo 24-hour surveillance with home apnea monitors until the apneic episodes resolve. Recent literature has documented the extraordinary and extreme stress placed upon parents of the infant who requires home monitoring and of the disruption that accompanies the process (Black, Hersher & Steinschneider, 1978; Dimaggio & Sheetz, 1983; Shannon & Kelly, 1982).

It is known that when stress upon families is in crisis proportion, detrimental effects often occur and the increased anxiety in parents and infants can potentially be harmful to both. Parenting responses toward the infant may be altered if the mother experiences high levels of stress and upset that potentially might influence infant development or interfere with establishment of the mother-infant relationship. An assumption of this study was that home apnea monitoring is stressful for families and a goal was to obtain information that could be used to assist

nurses to help mothers, infants and families who must utilize home apnea monitoring.

Purposes of the Research

The purpose of this investigation was to describe maternal responses to home apnea monitoring, parenting behaviors of the mothers, and development and behavior of infants who received monitoring. A further purpose was to describe the quality of the home environments of monitored infants. A final goal was to describe the relationship of maternal responses to the other variables.

Summary

This research was important and necessary because of the need for knowledge about the impact of home apnea monitoring upon mothers and infants. The research has salient implications for promoting and maintaining health in other similar children and families. While the findings may contribute to a variety of disciplines, a major justification for this study was to develop information that would help guide nursing practice. The research problem was unique in that although the apneic infant is diagnosed with a potentially life-threatening condition for a short period of time, the child is actually well, but in need of supportive care. The quality of that unique care is highly dependent upon the parent's ability to respond appropriately during the monitoring process.

CHAPTER II

REVIEW OF THE LITERATURE

The literature reviewed for this investigation includes historical and current findings for the aspects of infant apnea, home apnea monitoring, and maternal response to monitoring. Since monitoring is stressful for mothers, the concepts of stress and social support were also reviewed as social support can influence stress states.

Infant response was reviewed in the context of infant development and behavior, and aspects of the home environment that influence infant development were also considered important. The rationale and concepts considered relevant to the study and drawn from the review of literature are summarized in the Conceptual Framework section of Chapter III.

Infantile Apnea

Infantile apnea refers to a condition in which an infant develops irregular and sporadic breathing patterns. Apnea is generally defined as an episode in which breathing ceases for a period of 20 seconds or longer. The term also refers to shorter episodes of apnea that are ac-

accompanied by bradycardia, pallor, or cyanosis (American Academy of Pediatrics, 1978).

Although nearly all infants experience brief pauses and slight irregularities in breathing, this occurrence is considered normal and without adverse sequelae. In contrast, when a previously healthy infant suddenly develops prolonged apneic episodes that may be accompanied by cyanosis, pallor, or flaccidity, these physiologic changes are considered life-threatening. Apneic episodes most commonly occur in infants between 1 and 6 months of age. The causes vary due to the numerous processes which can interfere with the integrated system of breathing, including age, sleep state, disease, genetic variability, congenital malformations, pharmacologic agents, feeding activities and others (Anas & Perkin, 1984). In many cases, no known cause can be found. In some instances, harmful sequelae such as pulmonary and/or systemic hypertension, subtle damage to cerebral white matter, motor delays, and Sudden Infant Death Syndrome (SIDS) have been attributed to apneic episodes (Korobkin & Guillemineault, 1981; Naeye, 1980; Shannon & Kelly, 1982; Weinstein & Steinschneider, 1980).

At the present time, considerable controversy surrounds the issues of: (a) evaluation and treatment of infantile apnea (including the use of home monitors); (b) the potential contribution of apneic episodes to the

occurrence of SIDS, and (c) ability to predict which infants are at actual risk for SIDS whether or not the infant has apnea.

Justifiably, infantile apnea and a possible relationship to Sudden Infant Death Syndrome have been the subject of intensive research over the past decade since SIDS is the leading cause of death in infants between 1 week and 1 year of life. Statistically, this represents approximately 8,000 to 10,000 deaths or 2 of 1,000 live births per year in the United States (Spitzer & Fox, 1984). The incidence of SIDS occurs most often in infants between 2 and 4 months of age, with less than 1% of deaths occurring in the first 2 weeks of life, and over 90% occurring within the first 6 months. SIDS is known to occur more frequently in males (60%), in siblings of SIDS victims (4 of 1,000 live births), in twins of SIDS victims (5 to 10 of 100 live births) (Spitzer & Fox, 1984) and infants who are of low birthweight and who are small for gestational age (Shannon & Kelly, 1982). SIDS is also more frequent in families of low socioeconomic status and occurs more often in winter months when infants experience an increased incidence of upper respiratory infections. SIDS occurs most often during sleep with 50 to 80% of deaths occurring between midnight and 6 am (Brooks, 1982).

Current literature on infantile apnea, its relationship to SIDS and the use of home monitoring reveals that

accounts of deaths compatible with SIDS have been historically described and various medical theories have attributed SIDS to nearly 100 separate etiologies. During the past 30 years, however, SIDS has been recognized as a distinct clinical entity. Importantly, during the past 10 years, abnormal breathing patterns were detected in infants who later died of SIDS. This important finding was subsequently associated with infants who experienced one or more apneic episodes but survived.

The theory relating apnea and SIDS is known as the "apnea hypothesis" and was instrumental in the 1978 recommendation (updated in 1985) by the American Academy of Pediatrics that infants with documented apnea be monitored until the episodes resolve. This decision was based on a series of studies spanning a 10-year period that linked apnea with SIDS.

Some of the earliest investigations into the relationship of apnea and SIDS consisted of a series of studies by Steinschneider (1972). In his preliminary work, Steinschneider observed that apnea tended to occur during episodes of nasopharyngitis and that several infants with nasopharyngitis subsequently died of SIDS. Steinschneider's research prompted further investigation of the possibility that infant apnea was a part of a causal explanation for SIDS. Steinschneider's (1972) research and establishment of the Sudden Infant Death

(SIDS) Act (Public Law #93-270, 1974) led to extended research on the relationship of apnea, sleep disorders and Sudden Infant Death Syndrome (Brooks, 1982; Guilleminault, Peraita, Soquet, & Dement, 1975; Kelly & Shannon, 1981; Luebbert & McIntre, 1982; McCoy, 1981; Naeye, 1980; Read & Jeffrey, 1982; Rigatto & Bradley, 1972; Weinstein & Steinschneider, 1980; Zebal & Friedman, 1984).

Other related studies investigated characteristics of families of victims of SIDS to detect the possibility of familial abnormalities of respiratory control, although these studies proved inconclusive (Berman, Bartlett & Westgate, 1981; Peterson, Chinn & Fisher, 1980; Schiffman, Westlake & Santiago, 1980; Zwillich, McCullough & Guilleminault, 1980).

Numerous other researchers investigated the siblings of SIDS victims. These infants were found to exhibit greater percentage of time, duration and number of periodic breathing episodes during sleep and were consequently determined to be at greater risk for SIDS (Fagenholtz, 1976; Harper, 1978; Hoppenbrowsers, Hodgman, McGinty, Harper & Sterman, 1980; Kelly, Walker & Cahen, 1980), as were infants with apnea (Guilleminault, Ariagno & Korobkin, 1981; Haddad, Walsh & Leister, 1981; Hoppenbrowsers, 1982; Kelly & Shannon, 1978; Mandell, 1983). In addition to research on apnea, other researchers investigated numerous hypotheses such as anaphylaxis, botulism,

biotin and enzyme deficiencies, viruses, and teenage pregnancy as the possible bases for SIDS (Arnon, Midura & Damas, 1978; Babson & Clark, 1983; California, State Department of Health Sciences, 1982; Merritt & Valdes-Dapena, 1984; Peterson et al, 1980).

At the present time, research findings have not substantiated the apnea hypothesis as a causal explanation for SIDS because studies have confirmed increases, as well as decreases, in SIDS rates in different parts of the country which cannot be attributed to specific factors. For example, Weinstein and Steinschneider (1983) presented preliminary data suggesting that over the period of 1972-1977 while apnea monitoring was gaining acceptance in Onondaga County, New York, there was a significant decrease in the SIDS rate compared with the 5-year period immediately preceding it. However, at virtually the same time, the occurrence of SIDS dropped in Philadelphia and other cities where no monitors were in use. As stated previously, there is no method at present to predict accurately which infants are at actual risk for SIDS or to know which infants will die, whether or not they receive apnea monitoring (Hodgman, Hoppenbrowsers & Geidel, 1982; Kahn & Bloom, 1982; Kelly & Shannon, 1978; Southall, 1983).

This brief overview of a decade of research on Sudden Infant Death Syndrome and infantile apnea illustrates a

very important dilemma encountered by health care professionals: the impossibility of predicting which infants are at true risk for SIDS, which apneic episodes may be considered life-threatening, and whether or not home apnea monitoring is a valid procedure for the management and treatment of the apneic infant. The problem is especially complex due to the fact that home monitoring is known to be stressful and disruptive to families.

Home Apnea Monitoring

The Apnea Monitor

The apnea monitor sent home with parents is a small, electric or battery-powered unit. The type of monitor currently in widespread use is a cardiorespiratory impedance monitor that is approximately the size of a citizens' band (CB) radio. These units are designed to monitor both cardiac and respiratory rates and have audio and visual alarms that will sound if either rate drops below a predetermined setting. Monitors are attached to the infant's chest with dry electrodes and fastened by a wraparound velcro belt.

Parents usually receive counseling, training in cardiopulmonary resuscitation (CPR) and should be very familiar and knowledgeable about the monitor and its operation (Kelly & Shannon, 1981). Although some large medical centers have resources to adequately prepare parents for home monitoring, in many cases parents do not

receive sufficient training. One undesirable side-effect of the monitor is that false alarms frequently occur, producing undue fear and stress in the parents, although this problem is not as frequent with newer monitors. Even though monitors must meet rigorous safety standards and controls, parents are often frightened by the machine, and express fear that the monitor may shock or electrocute the infant (Dimaggio & Sheetz, 1983).

According to Duncan and Webb (1983), parents whose infants require home monitoring must accept three realities: (a) that the infant has a condition that may cause the infant to stop breathing; (b) that the apnea monitor as a mechanical device has certain limitations; and (c) that they must assume full responsibility for resuscitation if the infant stops breathing. From the beginning, most parents whose infants experience apneic episodes have high levels of anxiety. Many parents report that the worst anxiety of all is caused by the knowledge that they alone are responsible for the infant's life and by the fear of not being able to properly execute cardiopulmonary resuscitation (CPR) (Bakke & Dougherty, 1981; Dimaggio & Sheetz, 1983).

Maternal Response to Monitoring and Parenting the Monitored Infant

Although the method of home monitoring has been acclaimed for saving lives, it has also been blamed for

causing excessive stress in families and for being disruptive of the normal development of parent-child relationships (Cain, Kelly & Shannon, 1980). Considerable controversy exists as to whether apnea monitoring significantly increases or decreases anxiety in parents. Some researchers and pediatric clinicians believe that a treatment that reduces anxiety -- whether or not it protects the infant -- is probably a good treatment (Swanson, 1982). Others contend that home monitors decrease parental anxiety and are important in decreasing the need for hospitalization (Kelly & Shannon, 1981). Opponents of this view stress that any treatment that has not been proven to save lives and which produces high levels of anxiety and family disruption is contraindicated (Read, Williams & Hensley, 1979; Southall, 1983).

Arguments against home monitoring emphasize the aspects of fear, anxiety, disruption of family life, and financial hardship that often occurs. Some parents are known to become isolated and to focus on the infant's problems (Bakke & Dougherty, 1981; Brooks, 1982; Dimaggio & Sheetz, 1983; Duncan & Webb, 1983). Parents often must reorganize their activities of daily living around the ability to care for the infant and to hear the alarm. Understandably, parents whose child must be monitored for apnea experience a high level of anxiety and fear, although most parents accept the monitor and "have no

psychological choice but to use the currently recommended procedure" (Smith, 1984, p. 220).

Once the family arrives home with the monitor, a drastic alteration in lifestyle is usually necessary in order to accommodate the special care required for the infant. One of the first studies of the impact of apnea monitoring upon family life appeared in 1978 (Black et al., 1978). This descriptive research involved data from 31 families about the impact of monitoring on the personal and social lives of parents as well as data about the monitor and parental anxiety. Mothers were most profoundly affected by monitoring, with a large number reporting high levels of anxiety and consequently, a loss of confidence in their ability to care adequately for the infant. Other investigators have confirmed that the mother is the most adversely affected by the monitoring experience (Cain et al., 1980; Dimaggio & Sheetz, 1983; Wasserman, 1984). Many mothers viewed the monitor as a necessary evil, although Shannon and Kelly (1981) found that the majority of parents felt the monitor was helpful and reduced anxiety. In nearly all work reported in the literature, parents had concerns about the monitor's effect on the infant, the reliability of the monitor, and their ability to operate the monitor and perform CPR (Black et al., 1978; Cain et al., 1980; Duncan & Webb, 1983). According to two investigators, the ability to

cope during monitoring was related to the health of the infant and more stress was reported in parents of infants experiencing frequent apneic episodes (Kelly & Shannon, 1981).

Several mothers in the study by Black et al. (1978) reported that the experience of monitoring had long-term consequences and they continued to be anxious and depressed after monitoring was discontinued. Several took tranquilizers in order to cope more effectively. Similar results were reported by Wasserman (1984). Lack of sleep was a common concern of mothers of monitored infants because, unlike most new mothers who attended to personal and household duties or slept when the infant slept, these mothers had to be most alert when the infant was asleep (Black et al., 1978; Cain et al., 1980; Dimaggio & Sheetz, 1983).

Monitoring may also affect parents' views about having more children. Many parents said they chose not to have a subsequent child due to the frightening experience of monitoring (Black et al., 1978; Wasserman, 1984). Some researchers and clinical practitioners have expressed the concern that monitoring reinforces the parents' idea that their infant may die, that in turn produces high levels of stress and anxiety.

Kelly and Shannon (1981) argued that a major criticism of monitoring was the adverse effects that the

monitor had on emotional and family health. They indicated the need for social support, and depicted the single or young parent without extended family as extremely vulnerable and in need of social services for assistance. The notable success of support groups for parents of monitored infants in many major cities confirms the importance of social support and the benefit of the opportunity to share experiences and feelings among parents of monitored infants.

Dimaggio and Sheetz (1983) identified four areas of concern in parents of monitored infants: (a) change in lifestyle, (b) operation of the monitor and understanding CPR, (c) caring for and establishing a relationship with the monitored infant, and (d) the physiological adaptation of the new mother. The researchers found that social deprivation was a major problem for mothers of monitored infants. This finding was reported in other studies, as well (Cain et al., 1980; Kelly & Shannon, 1981; Wasserman, 1984).

Black et al. (1978) concluded that parents generally felt a lack of support during monitoring and that only 46% of parents had the needed support from friends and relatives. This finding was supported by Geary (1983).

Summary

In summary the literature reviewed illustrates that home apnea monitoring is stressful for most families,

particularly mothers. The variables consistently related to maternal upset were those of anxiety, fear, disruption of family life, isolation, and lack of support. Mothers were fearful of the responsibility for care of the infant and of the inability to perform CPR. Other problems included lack of sleep, financial hardship, indecision about having another child, and concerns about the reliability and operation of the monitor. Mothers stated that anxiety was especially acute during the first several weeks at home and that intervention by health professionals at that time would be very helpful. The mothers reported that they received the majority of support from spouses and that parent support groups would be most beneficial to parents during the monitoring period.

Stressful Life Events

It is recognized that home apnea monitoring is generally stressful for families, and in particular for the mother who assumes the major responsibility for infant care. If other stressful life events occur in addition to monitoring, the mother may experience increased stress that may affect her response to monitoring and her parenting behaviors. Therefore, the concept of stress was considered to be an important variable.

The recognition of stress as a concept has appeared in the literature for approximately 40 years. The general themes pertain to (a) "stressors," (b) the cognitive

appraisal of stressors in the human, and (c) adaptation to stressors, or coping. A large body of literature addresses coping strategies and an equally large body of research involves the effects of stress upon the human organism. There is substantial disagreement as to the definition of stress, as well as to the conceptualization of stress (Dohrenwend & Dohrenwend, 1974; Gunderson & Rahe, 1974; Lazarus, 1976; Lief, 1948; Pelletier, 1977; Selye, 1956; Wolff, 1953).

Within the last decade, science has increasingly focused on the relationship between stressful life events and the onset of organic illness. Selye's work (1956) has been credited with the modern conceptualization of stress as a factor that is inherent in the process of daily living. Selye formulated a model which he termed the General Adaptation Syndrome (GAS). In this model, stress is generally recognized as a three-stage physiologic process of alarm, resistance and exhaustion, and Selye found that some individuals contracted certain stress-induced diseases. Selye's theory of stress and adaptation was limited in that it focused on physiologic reactions and changes, but excluded psychological factors.

In 1967, Holmes and Rahe developed the "Schedule of Recent Experiences" (SRE) scale in an attempt to test the relationship between recent stressful life events and the onset of subsequent illness. Following the work of Holmes

and Rahe, an extensive body of epidemiologic and clinical research documented that Schedules of Recent Experiences, renamed "Stressful Life Events" (SLEs) were causally implicated in illness and disease (Dohrenwend & Dohrenwend, 1974; Fagley, Miller & Sullivan, 1982; Gunderson & Rahe, 1974). Essentially, the model suggests that if a stressful life event impinges on a person together with certain other internal and external mediating factors, dysfunctional behavior and illness may result.

In 1977, Sullivan developed a modification of the Holmes-Rahe Stressful Life Events Scale entitled "Utah Test Appraising Health" (UTAH IVS, 4th ed.) (Sullivan, 1977). The UTAH IVS was used in this research to identify and measure stressful life events experienced by the mothers of infants during the time of monitoring. The measurement of stressful events enabled a comparison of the level of maternal upset to other stressful life events that occurred during monitoring.

Social Support

Social support was believed to be an important variable, as lack of support during monitoring was a universal concern reported by mothers in the literature (Black et al., 1978; Geary, 1983; Kelly & Shannon, 1981).

In this study, social support referred to emotional support, affiliation, and assistance that mothers received from spouses, neighbors, relatives and friends. A goal

was to determine if mothers with the least support experienced higher levels of upset. According to Kutash and Schlesinger (1980), persons who have high stress levels, but also have support, have less symptomatology and are better able to adjust to stressful life events. Social support is recognized as an important component of social relationships, and most people have an intuitive sense of what comprises support for them (Brown, 1986).

Numerous investigations have been directed toward determining why social support reduces or buffers stress and influences and improves health (Broadhead et al., 1983). These factors are related to various themes, including a sense of community, nurturance, concern, listening, empathy, validating behavior and help. Research validates that social support facilitates adaptation during stressful life changes such as illness, hospitalization, death and others (Barrera, 1981; Brown, 1986; Caplan, 1974; House, 1981). Social isolation is believed to be particularly devastating because without support, one has no protection against loneliness and anxiety.

Geary (1983) interviewed 20 mothers over a 2-month period of home apnea monitoring to determine the qualities and changes in social networks and social support systems which occurred during the time that infants received monitoring. She determined that monitoring an infant

produces an "extreme case of parenting." The purpose of the research was to determine how social and kinship networks supported the mother during the experience of monitoring. Results indicated that a kinship network of a few close female relatives was the most significant variable in the mothers' ability to cope. Spouses were also described as highly supportive. Mothers who were fortunate enough to have close family ties were the most adaptive during the experience of monitoring. Factors which adversely affected adaptation were isolation and lack of affiliation with supportive others.

Home Environment

Within the last decade, a consistent relationship between the home environment, child development, and behavior has been demonstrated. It is generally accepted that growth and development of young children is directly influenced by the quality of the home environment (Caldwell & Bradley, 1984; Deutsch, 1973; Eldaro, Bradley & Caldwell, 1975; Huber, 1982; Majoribanks, 1972; Poresky & Henderson, 1982; Powell, 1981).

The appraisal of the home environments of the infants participating in the study was considered important since monitoring takes place in the home. A goal was to determine the quality of the home environment of monitored infants and to describe how home environments differ between the less upset versus the more upset mothers.

In recent years, research has focused on standardizing tools to assess growth and development, as well as aspects of the environment that would foster or impede the developmental process. Some of the most important research has been that of Caldwell and Bradley (1974). Over the past decade, they have developed the Home Observation for Measurement of the Environment (HOME) scale. Development of the HOME was based on the premise that the characteristics of the child's environment are the most important variables in predicting developmental outcomes in young children. The HOME scale is one of the most widely recognized and reliable tools for measuring factors in the child's environment that impact development. The HOME specifically assesses the qualities of social, emotional, and cognitive support available to the child. One rationale for use of the HOME by health professionals is to detect problems that may adversely affect child development, but that may not be manifest until later in life, either because of the course of development, or because of problems of measurement in children. Specific aspects of the HOME scale are discussed in the Instrumentation section of the study.

Infant Development and Behavior

For this investigation, the infant's response to apnea monitoring was described in terms of mental and psychomotor development scores achieved on the Bayley

Scales of Infant Development (Bayley, 1969). The ages of infants participating in the study ranged from 7 months to 2 1/2 years. This age range is considered to be a critical and vulnerable period of infancy because of the rapid physical and mental development that occurs and lays the foundation for future development. An assumption was that mothers who experienced high levels of upset during monitoring might be unable to provide adequate parenting to the infant and that infant development could be affected. Numerous theories have supported the importance of early infant development, the relationship of early developmental outcomes to subsequent levels of development, and the critical impact that life events (such as illness, malnutrition, ineffective parenting, neglect and abuse) can have upon the infant (Ainsworth, Blehar, Waters & Wall, 1978; Bowlby, Robertson & Rosenthal, 1952; Erikson, 1963; Freud, 1960; Gessell, Ames & Ilq, 1974; Kohlberg, 1976; Mahler, Pine and Bergman, 1975; Piaget, 1963; Skinner, 1953).

Infant development is generally separated into three components: (a) the physical domain (body change and motor skills), (b) the cognitive domain (thought and language), and (c) the psychological domain (emotions, personality and relationships with others, including attachment and development of self-concept). A brief overview of the physical and cognitive domains of develop-

ment with implications for monitored infants will be presented here, as these are the domains assessed by the Bayley Scales of Infant Development and were used in this study to describe infant response to monitoring. The purpose was to suggest how development might possibly be compromised if inadequate parenting during monitoring occurs in this critical stage of development.

Overview of Physical Development

The stage of development that takes place between birth and approximately 2 1/2 years of age has been termed the "sensorimotor" period because it is during this time that the infant develops senses and perceptual abilities that are used to understand the environment (Berger, 1983; Piaget, 1963). In infancy, certain motor abilities develop that facilitate the child's orientation toward the environment and influence the quality of interaction with the environment. Locomotion and body control promote the possibility for new and varied experiences. According to Bayley (1969), the development of manipulatory skills in infancy leads to the development of the basic mental processes and the ability of the child to develop motor and mental processes are directly related to the parent's participation in promoting mental and motor development through interaction with the child. In early infancy, rapid physical and brain growth occur as the infant develops vision, hearing and a sense of touch. Any

assault to the infant such as injury or illness can affect these developing faculties. Rapid motor development accelerates so that by approximately 8 months of age, the infant can sit alone, soon learns to crawl, and subsequently walks between 12 and 15 months of age. The infant then begins to explore the environment and acquires new experience. The infant at this stage of physical development is labeled a "toddler" because of an unbalanced toddling gait that is the source of many accidents and falls. By 2 years of age, most children have learned to run.

Although there are genetic variations, differences in rate of maturation, and environmental factors to consider, most infants grow in a rapid, predictable manner during the first 2 years of life. This process requires adequate nutrition, consistent love and care, emotional security, and encouragement from parents to reach full developmental potential. Basically, the infant needs freedom to learn about the environment, opportunity to practice newly-developed skills in a safe, unconfined area, and proper play materials to encourage acquisition of both gross motor and fine motor skills. If the infant is not provided these opportunities and experiences, physical (as well as mental) development may be delayed.

The Cognitive Domain (Thought and Language)

Cognitive development begins with birth and occurs rapidly in the first 2 years of life. Cognitive development requires provision of learning opportunities and new experiences. Through curiosity, experimentation and interaction with the environment, the infant learns and develops a sense of self that lays the foundation for future mental development (Piaget, 1963). Although some debate exists about how infants learn to think and develop language skills, researchers tend to agree that certain internal forces (genes, maturation), as well as external forces (family, neighborhood, enriching experiences) combine and are equally important in development of maturation and learning in the young child (Bruner, 1968; Piaget, 1963).

The major developmental tasks of the infants included in the sample were as follows. The 4-8 month old infant must learn to coordinate reflexes and to respond to people and objects in the environment. These behaviors depend on encouragement by caring parents whom the infant learns to trust. In the 12-18 month old stage of cognitive development, the infant becomes more purposeful in response to people and objects and actively experiments through play in the environment. Language also increases as people in the environment respond to the infant's vocalizations.

The phenomenon of "object permanence" emerges at this

stage wherein the infant knows that a person or object exists when out of sight, and is a major milestone of infant cognitive development. Between 18 and 24 months, mental combinations occur and the infant can think before acting, is more experimental and begins creative thinking. Memory also develops and increases at this stage of development. A key variable in cognitive and language development is the quality of parent-infant interaction. The parents' ability to provide adequate stimulation at the infant's level of cognitive growth and to provide language reinforcement in this age group is extremely important. Lack of verbal interaction and reinforcement can hinder language development because language skills cannot be mastered in infancy without communication between infants and adults.

The quality of the home environment in terms of mother-infant interaction, the opportunity for daily stimulation for the infant, and the provision of adequate play materials is also known to be directly related to future cognitive development (Bayley, 1969; Caldwell & Bradley, 1984). It is known that when high levels of stress and upset occur in families, parents may be unable to provide basic physical and emotional needs of the child to promote optimal development. Deficits that result from inadequate parenting behaviors can hinder the infant's progress from one cognitive stage to the next.

This brief overview of infant development illustrates some of the important aspects of development at the stages and ages of infants in the sample and suggests that infants whose parents do not provide basic needs and who do not understand infant development may be unable to fully develop potential for cognitive and psychomotor development. If the mother does not consistently and appropriately respond to or understand the infant's needs, a healthy attachment may not occur between the mother and infant.

A goal of the research was to compare the infant development scores of monitored infants with level of maternal upset to determine if mothers who were more upset had infants with lower development scores. It was anticipated that if the mother experienced a high level of upset, and was unable to offer quality parenting behaviors to her infant, development could be affected. If the mother was fearful of the monitor, or was afraid to take the infant out of the crib to hold and play with the infant, adequate stimulation and opportunities to develop new abilities would be hindered.

Infant Behavior

The field of behavioral pediatrics has developed over the past decade due to significant decreases in physical disease along with current interest in psychological development and promotion of emotional health in infants

and children. Abundant literature exists about the emotional effects of practices such as weaning, toilet training, discipline, and particular behavioral traits displayed by individual children such as shyness, aggressive behaviors, and differences in temperament (Chess & Thomas, 1982).

Other current issues include problems of neglect and abuse, bonding and attachment disorders, faulty parenting practices, and problems of adolescence. Theories of the causes of development of behavioral problems in children include theories about central nervous system dysfunction and social and family factors such as broken homes or single-parent households. More current theorists consider the development of behavioral problems to be related to the complexity of interaction between the characteristics of the child, characteristics of parents and family, and environmental stresses and support (Chamberlain, 1982).

Current ecologic theories of child development suggest that family functioning is an important determinant in development of behavioral problems, and that how a family functions at a particular point in time is directly related to the balance between the stresses experienced and the ability of the family members to cope. Family environments with high levels of stress and low levels of support are characterized most frequently by children who demonstrate behavioral problems (Richmon, 1977). Recent

theories such as those about maternal-infant attachment and promotion of social and cognitive competence in the child are directed toward encouraging these behaviors within the context of a particular family, with consideration of their particular circumstances, levels of stress, coping abilities and available support (Ainsworth et al., 1978; Brooks-Gunn & Hearn, 1983; Chamberlin, 1982; Thomas, Chess & Birch, 1968).

In this study, incidence of behavior problems that were reported by mothers was assessed. Behavior problems were defined as activities that occurred with a frequency or intensity such that the mothers of monitored infants became bothered or distressed. The behavior of the infants was described in the areas of sleep, feeding, emotions, discipline and elimination. The purpose was to determine if mothers with higher levels of upset had infants with more behavioral problems. Information was also sought to determine if infants with lower scores of infant development had more behavioral problems. A consideration to be made by health professionals in the assessment of what are termed "behavioral problems" is an assessment of the parent's knowledge of normal infant growth, development and behavior. What may be normal behavior (crying, or not being toilet trained at 1 or 2 years of age) may be considered a problem for the parent who does not understand that some crying is normal and

that neurological development necessary for bowel and bladder control is usually not present in the young toddler. The mother who does not understand infant growth, development and behavior may not adequately respond to the infants' needs for care, and the infant will respond with behavior (crying, anger) that is interpreted as a problem or as rejection of the mother. Current theory suggests that early interventions by health professionals can alter maladaptive patterns of parent-child interactions that may be developing in early parent-child relationships (Ziegler, Lamb & Child, 1982).

CHAPTER III

CONCEPTUAL FRAMEWORK

The purpose of the research was to describe maternal and infant responses to home infant apnea monitoring. Specifically, the researcher sought to describe: (a) the types of upset experienced by the mothers, (b) parenting behaviors, and (c) infant development and behavior. A major goal was to identify characteristics of maternal upset that may be associated with developmental and behavioral problems in monitored infants.

Introduction to Major Concepts

Home Apnea Monitoring

The process of home infant apnea monitoring in this study concerned healthy infants who developed irregular and sporadic breathing patterns during the first few months of life, and were considered to be at increased risk for Sudden Infant Death Syndrome (SIDS). Such infants are often prescribed a home monitor. Parents of children who require monitoring experience varying degrees of fear concerning their ability to manage apneic episodes and fear that the infant may die. In addition, monitoring at home necessitates a major alteration in lifestyle in order to accommodate the special care required for the

infant. Although the disruptive impact of monitoring on the personal and social lives of parents is significant, mothers (as the major caregivers) are the most profoundly affected (Black et al., 1978; Shannon & Kelly, 1982; Smith, 1984). In addition to stresses experienced during the monitoring process, many mothers experience anxiety and difficulty relinquishing the monitor due to dependency. It is possible that longer periods of monitoring could produce even more maternal upset and detrimental effects upon the infants. The length of time an infant received monitoring was considered to be an important variable and was described to determine if there was a relationship between length of time of monitoring and other variables.

Maternal Upset

Maternal response was conceptualized as maternal upset. Maternal upset refers to reactions in the mother which may diminish or compromise parenting capabilities such as fear, guilt, stress, anxiety, and physical and emotional exhaustion. This variable was considered important because it is the mother who assumes the major responsibility for care of the monitored infant. Although threats to a child's well-being are nearly always upsetting, for some mothers, increased intensity and persistence of upset states occur. If a mother experiences high levels of upset, it is possible that she may be unable to

adequately meet all the demands of her parenting role. Although many factors that contribute to maternal upset are unknown, the variables of social support and stress, as well as certain demographic characteristics (age, education, marital status, religion and occupation of the parents) were described to understand the potential relationship to the type and amount of upset experienced by the mothers.

Stressful Life Events

Stress was an important concept because home apnea monitoring is frequently stressful for parents. In this study, stress concerned reactions of the mothers to events or occurrences that caused her mental and emotional strain or pressure. Events that were considered stressful by the mothers (in addition to monitoring) were described as additional stressors that would likely increase maternal upset. It was a possibility, however, that the stressful life events themselves caused the upset, rather than the monitoring experience.

While recognizing the monitoring might alleviate stress for some parents, the initial adjustment period in the first few weeks was assumed to be stressful for all families. Furthermore, many parents reported that monitoring was stressful for the duration and that stress occurred even for a period after the discontinuation as parents adjust to the absence of the monitor in the home.

Social Support

Social support was defined as emotional support, affiliation or assistance that the mothers received during monitoring from significant others. Social support specifically referred to assistance received from the mother's spouse, relatives, friends and neighbors. Social support was known to be an important determinant of a person's coping ability during times of stress and that absence of social support is itself a stressor. Mothers in the study were in particular need of social support because of the stressful experience of monitoring and the social isolation experienced by most mothers who were confined to the home in order to be in constant attendance to the infant. The presence or absence of social support for mothers of monitored infants was considered to be an important determinant of the type and amount of upset experienced by the mothers.

Parenting

The parenting behaviors of the mothers were described to determine if there was a relationship between level of upset of the mothers and the quality of parenting behaviors. In order to offer quality parenting, the mother must be able to interact satisfactorily with the infant and provide care which satisfies the infant's needs. Her success in establishing a positive and satisfying rela-

tionship with the infant depends on her ability to perform this task. If she is unable to meet the infant's needs, infant development can be delayed or compromised.

Parenting was conceptualized not only in terms of the way the mother felt about and cared for her infant, but the way she felt about and cared for herself. For example, if she exercised regularly, ate nutritious foods, and felt happy and energetic (in contrast to a mother who felt socially isolated and unhappy) it was reasonable to assume that she would be better able to perform her parenting role than the unhappy mother. Thus, the mother's perceptions, emotions, and feelings, as well as her health practices, were included as important factors in her parenting behaviors.

Home Environment

Home environment referred to the living situation of the infant. The home environment of monitored infants was described to determine its adequacy to support and promote infant growth and development. In particular, the researcher sought to assess the quality of the mother's involvement with the child, to determine if the home environment was safe and interesting and if there was adequate stimulation for the infant through the provision of appropriate play materials. Quality parental stimulation and interaction and the provision of a satisfactory home environment are important variables in promotion of

optimal development in infants and children.

Infant Development and Behavior

Measures of infant development were conducted to examine a possible relationship between the level of maternal upset and the developmental outcomes in monitored infants. A mother who experiences high levels of upset may be unable to offer her infant the appropriate stimulation and interaction to promote optimal growth and development. The parents' ability to interact with the infant at the appropriate level of cognitive growth is a powerful determinant of development in infancy. Infant development referred to the status of the infant's mental and motor development. Infant development occurs rapidly in the first year of life as the infant uses senses and motor abilities to gain an understanding of the environment.

Infant behavior referred to a series of predictable, observable responses of the infant that coincided with each stage of infant development. Although infant behavior develops in a patterned and highly predictable manner, as does physical growth, infant behavior is highly influenced by individual differences, the quality of the home environment, and the quality of the parent-infant interaction. The behaviors examined in the infants in the sample were those of feeding, sleep, elimination, emotional behaviors, and discipline.

Modifying Factors

Certain intervening or modifying factors were taken into account that may have had an influence on infant development and behavior. These variables were level of education, occupational level, age, religion and marital status of the parents. These variables were considered important since nearly all of the parents were married (88%), middle income families (85%), and of the Latter-Day Saint (Mormon) faith (81%). It is a possibility that infants who come from intact middle income families may have more advantages than infants who are from lower income, single-parent families in terms of opportunities for enrichment, provision of play materials, and parent interaction. These are qualities that are known to foster infant development. It is also known that the Mormon faith places great value on parenthood and childrearing, which could produce more positive childrearing practices benefitting the infant. In addition, a higher level of education often produces higher incomes and different values that may provide an infant certain advantages described above. Finally, it is possible that older, more experienced parents may provide a more optimal environment, enhancing a young child's mental development. The presence of siblings in these families may also encourage an infant's developmental progress.

Relationship of Study Variables

The investigator proposed that home apnea monitoring was related to maternal upset in a majority of mothers whose infants received monitoring. Factors influencing the level of upset included: (a) the parents' available support systems and (b) additional stresses on the family. The methodology measured level of mother upset, as well as other stressful life events occurring concomitantly with monitoring which might have influenced her upset. Also described were months of monitoring, as a variable that may be have been related to upset and to other variables (Figure 1).

The researcher additionally sought to describe the social support system of the mothers that was available to assist her during the time of monitoring. An assumption was that mothers who experienced multiple stressful events and who lacked support during monitoring would experience high levels of upset.

A major goal was to determine if there was a relationship between levels of maternal upset and parenting behavior. If a mother experiences high levels of upset, it is reasonable to assume that she may have difficulty meeting the infant's needs. She might also have difficulty meeting her own needs. For instance, if she were upset from stress and lack of support, she might feel

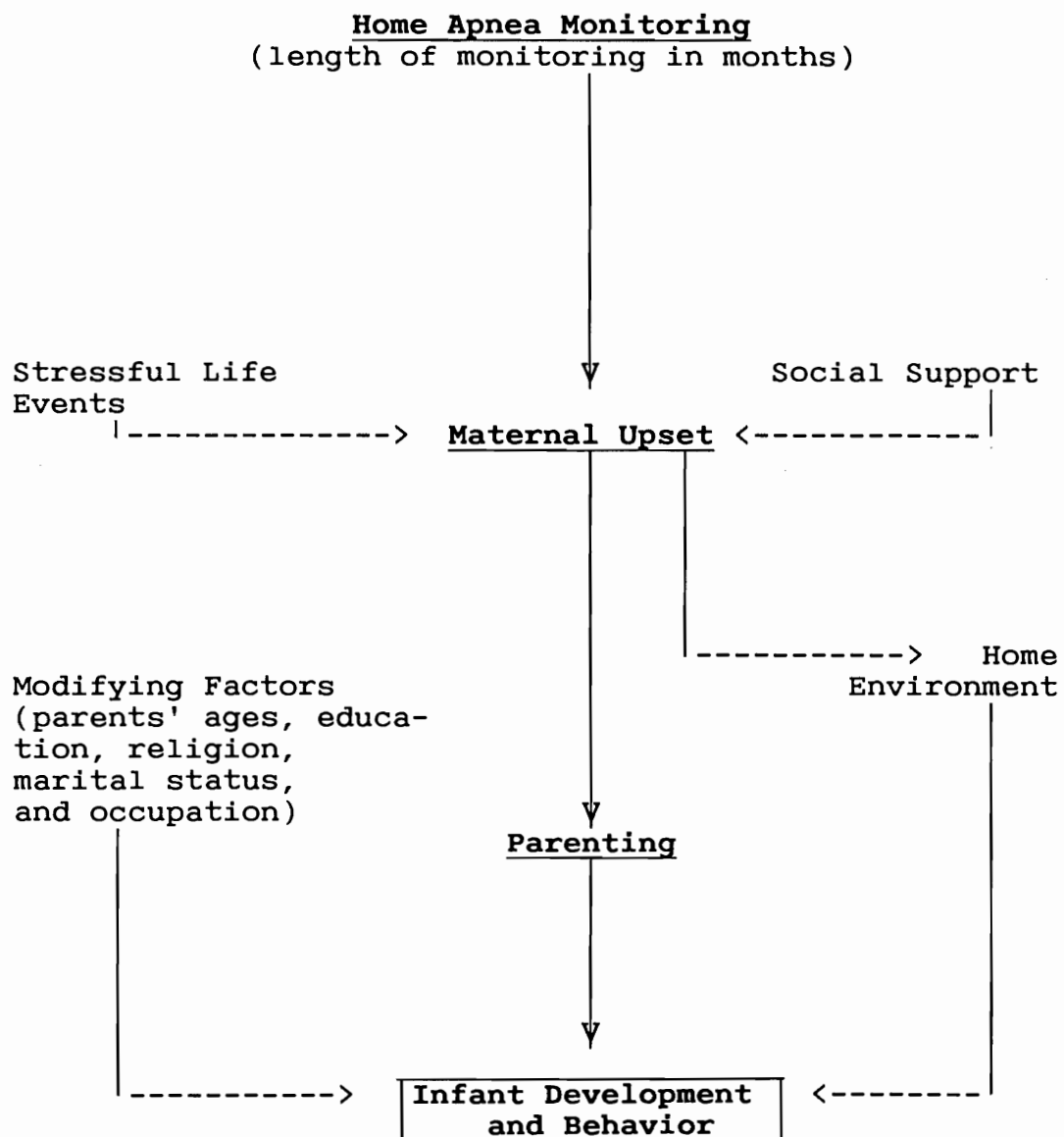


Figure 1. Conceptual model.

overwhelmed. She might be fatigued and lack the opportunity for exercise, recreation or personal activities. An overly tired or overwhelmed mother would have difficulty meeting the 24-hour demands of infant care. Because the first year of life is so important for the infant in terms of acquisition of consistent care and essential needs such as food, warmth and security -- as well as stimulation and satisfaction of emotional needs -- it is important that the mother be able to appropriately respond, or infant development could be affected.

In particular, the mother might not have the energy to offer her infant the verbal stimulation and interaction needed to provide a quality home environment in terms of factors that promote and foster infant development. Aspects of the home environment that were measured included emotional and verbal responsiveness of the mother, acceptance of the infant's behavior, organization of the home environment to facilitate safe play and exploration by the infant, and provision of play materials that offer challenge and encourage developmental advance. Other important factors included involvement of the parent in play activities with the infant and the provision of experiences which offered the infant stimulation on a daily basis.

Certain modifying factors that may be related to the outcome were described in Figure 1. Finally, the investi-

gator included infant development and behavior to determine if maternal upset or parenting behavior during the time of monitoring might have influenced infant development or behavior.

Summary

The specific research questions which originated from the conceptual framework:

Described:

1. Categories and level of maternal upset.
2. Stressful life events coinciding with monitoring.
3. Social support available to the mothers.
4. Characteristics of home environments of monitored infants.
5. Parenting behaviors of the mothers.
6. Modifying factors of age, education, occupation, religion, and marital status of parents.
7. Infant development status.
8. Incidence of infant behavior problems.
9. Length of monitoring in months.

Compared:

1. Scores of infant development with: (a) stressful life events, (b) parenting behaviors, and (c) level of upset of mothers.

Related:

1. Length of time of monitoring to infant development, level of maternal upset, and parenting behaviors.
2. Level of maternal upset and infant behavior, home environment, stressful life events, social support and parenting behaviors.

Research Questions

The following research questions were addressed in this investigation:

1. What are the themes and categories of maternal upset related to monitoring as derived from the Personal Experiences Interview?
2. Will infants who have received apnea monitoring score lower on the Bayley Scales of Infant Mental Development, compared with the Bayley standardized norm?
3. Will infants who have received apnea monitoring score lower on the Bayley Scales of Infant Psychomotor Development compared with the Bayley standardized norm?
4. Will infants who received apnea monitoring score lower on the Home Observation for Measurement of the Environment (HOME) scale

detecting factors in the environment that foster growth and development, compared with the HOME standardized norm?

5. Will infants who scored in the high group of the Bayley Mental and psychomotor scales have homes which received high scores on the HOME scale?
6. Will mothers who experienced higher levels of life stress during the time of monitoring, as measured by the Utah Test Appraising Health (UTAH IVS) have infants who score lower on the Bayley Scales of Infant Development?
7. Is there a difference in incidence of behavior problems, as measured by the Infant Behavior Rating Scale in infants who scored high and low on the Bayley Scales of Infant Development?
8. Are infant development scores on the Bayley Scales associated with mothers who feel less positive about parenting, as measured by the Parenting Inventory?
9. Is there significantly more upset among mothers whose infants scored in the low, as compared with the high, development groups of the Bayley scales?

10. Is there a relationship between length of monitoring and home environment, social support, life stress, upset in the mothers and parenting behaviors?
11. Is there a relationship between level of maternal upset, home environment, social support, life stress, infant behavior and parenting behaviors?

Definition of Terms

The following terminology was utilized in this investigation.

Sudden Infant Death Syndrome (SIDS)

Sudden Infant Death Syndrome (SIDS) is defined as sudden and unexpected death of a previously healthy infant that remains unexplained after careful postmortem studies (Medical Examiner's and Coroner's Handbook on Death Registration, 1978). At autopsy, a diagnosis of SIDS reveals three classic symptoms: (a) pulmonary edema, (b) intrathoracic petechial hemorrhage, and (c) inflammatory changes of the upper airway (Bakke & Dougherty, 1981).

Infantile Apnea

Although infants characteristically exhibit normal pauses in breathing, the term infant apnea is generally used to indicate an abnormal pause in breathing of 20

seconds or longer. Infants with apnea often exhibit irregular and sporadic breathing patterns that may be accompanied by bradycardia (slow heart rate) (Bakke & Dougherty, 1981).

Infant Development

Infant development includes the components of physical, cognitive, language, social and personality development in infants that tends to be rapid, predictable and relatively regular (Horowitz, 1982).

Infant Behavior Problems

Behavioral problems were defined as activities that deviate from a discretionary social norm with a frequency or intensity that authoritative adults in the child's environment judge to be too high or too low (Ten Bensel, 1982). In this study, the term specifically referred to infant behaviors that caused the parent bother or distress or that were suggestive of more serious problems.

Maternal Upset

Maternal upset was defined as reactions in the mothers of monitored infants that might diminish or compromise parenting capabilities such as fear, guilt, stress, anxiety, and physical/emotional exhaustion.

Stressful Life Events

Stressful life events were defined as occurrences that caused the mothers stress during monitoring. Stress referred to reactions of the mothers to these events that caused mental and emotional strain or pressure.

Social Support

Social support was defined as emotional support, affiliation, or assistance that the mothers received during monitoring from significant others.

CHAPTER IV

RESEARCH DESIGN AND METHODOLOGY

Introduction

Two methodological approaches (quantitative and qualitative) were utilized in this investigation to answer the research questions. A quantitative approach included use of the Bayley Scales of Infant Development, the Home Observation for Measurement of the Environment (HOME), the Utah Test Appraising Health (UTAH IVS), the Infant Behavior Rating Scale and the Parenting Inventory. A qualitative approach was used to gather data from mothers with the Personal Experiences Interview. This unstructured interview was used to collect data in the mother's own words, including her personal insights and reflections and to allow collection of data which were not anticipated by the researcher. A qualitative approach seeks understanding of the personal meaning and interpretation of an event or experience within the context of the subject's life.

This study was in large part retrospective in that data were collected after monitoring had been terminated. In this type of ex post facto design, a phenomenon in the present is proposed to be linked to some phenomenon in the

past. The goal of retrospective research is to search for and describe relationships between factors which may ultimately lead to association-testing studies (Diers, 1979). The phenomenon occurring in the past was apnea monitoring.

Monitoring took place between 1982 and 1985. Data collection occurred over a 5 month period in 1986. The infants were divided into three groups according to age so that certain age-specific variables could be measured. The age groups were: (a) infants between 6 and 12 months of age (these infants had been off the monitor for several months); (b) infants between 13 and 23 months of age (these infants had been off the monitor for approximately 6 to 18 months); and (c) 24 to 30 months (these infants had been off the monitor for approximately 18 months to 2 years).

The self-reported perceptions of the mothers' experiences during monitoring were assessed through recollection, stressful life events that occurred concomitantly with monitoring according to recollection, the present development and behavior of the infants, the present parenting behaviors of the mothers, and the present quality of the home environment. Use of a retrospective approach allowed the investigator to work with a larger number of subjects in a feasible time frame, to include children of different age groups, and to

determine any short- and long-term effects of monitoring upon infant development and parenting.

Sample

The target population was infants who were referred to the University of Utah Health Sciences Center Pediatric Pulmonary Clinic for primary apnea, who received home monitoring between 1982 and 1985 and whose monitoring had been terminated. Convenience sampling was used to select subjects. In a convenience sample, the researcher employs all sampling units available in the time allotted. The total sample was comprised of:

1. A group of 74 monitored infants and their mothers.
2. Infants who were between 6 and 30 months of age and whose monitoring had been terminated at the time data collection began.
3. Infants who were normal, healthy, and full-term at birth.
4. Infants of English-speaking mothers.
5. Infants and mothers living within 200 miles of Salt Lake City, Utah.

Exclusion

Rationale for exclusion was based on the following consideration:

Non-English speaking: The methodology required

lengthy communications between the researcher and subjects. For this reason, use of an interpreter for non-English speaking families was not feasible.

Setting

The University of Utah Health Sciences Center was utilized to obtain infants with primary apnea who received home apnea monitoring. The Health Sciences Center is a large, teaching hospital in Salt Lake City, Utah which serves clients from all age and socioeconomic groups. The Health Sciences Center also houses an extensive research facility. Data were collected in the subjects' homes.

Design

For this retrospective study, a one-group descriptive design was employed. A combination of standardized measures and several nonstandardized measures were used to answer the research questions. Standardized measures were used to obtain quantifiable data about infant development, home environment and stressful life events. Two rating scales used to measure infant behavior and parenting behavior were constructed by the investigator and an associate, Charles Ralston, M.D., whose area of specialty is behavioral pediatrics. Qualitative data about the mothers' experiences during monitoring were collected in an unstructured interview that was constructed by the investigator. The purpose of the unstructured interview

was to assess the perspective of the person being interviewed and to determine information that could not be directly observed, such as thoughts, feelings, and intentions. The interviewer refrained from projecting preconceived ideas upon the person being interviewed, and considered the person's perspective to be meaningful, knowledgeable, and capable of being made explicit (Patton, 1980). The interview was guided in that all mothers were asked the same broad questions (i.e., "what was the monitoring experience like for you?"), but was unstructured to encourage mothers to describe the experience in their own words, and to express the personal meaning of the monitoring experience as they remembered it.

Instrumentation

The six instruments used to answer the research questions were:

1. Parental Experiences Interview;
2. Bayley Scales of Infant Development (BSID);
3. Home Observation for Measurement of the Environment (HOME);
4. Utah Test Appraising Health (UTAH IVS);
5. Infant Behavior Rating Scale; and
6. The Parenting Inventory.

Parental Experiences Interview

This instrument was constructed by the investigator and an associate and was based upon findings in the literature that the monitoring experience was disruptive and stressful for parents and families (Black et al., 1978; Cain et al., 1980; Dimaggio & Sheetz, 1983; Duncan & Webb, 1983; Geary, 1983; Shannon & Kelly, 1982). One purpose of the interview was to validate the idea that certain mothers cope less well during monitoring than others, and to describe areas of concern and upset. The information gained would be valuable for planning future nursing interventions designed to ameliorate or decrease maternal upset and promote healthier family adaptation during home apnea monitoring.

The Parental Experiences Interview provided a context for the information gathered from standard measures. The interviews were recorded by the investigator. Responses were immediately transcribed at the close of the interview.

Interrater reliability was established through audiotaped interviews of 15 mothers randomly selected by drawing names. This method assures accuracy and agreement in interpreting and coding the data. All interviews were subjected to content analysis by the investigator and another rater. The other rater for the interviews and the audiotapes was an expert in pediatric care. Interrater

reliability was 90%.

Themes emerging from the data were then collapsed or condensed to construct categories of maternal experiences and concerns during monitoring. The major categories emerging from the data were those related to upset of the mothers. The interview questionnaire addressed the general areas of management of the technical aspects of monitoring, effects upon the family, support, stress, feelings about monitoring and suggestions for other parents whose infant requires monitoring.

Interview questions were derived from a review of nursing and behavioral sciences literature, and clinical experience of the investigator. These sources identified a number of factors considered to be upsetting to the mothers during monitoring such as fear, social isolation, lack of support, and disruption of household routine. Questions were asked to elicit information in these and additional areas but were not phrased to elicit either negative or positive responses from the mothers. A pilot questionnaire was administered to 3 mothers to determine readability, clarity and time needed to complete the interview. The decision was made to maintain the questionnaire in its original format.

The interviews were scored through the process of content analysis. This process consisted of three parts. First, the interviews were read several times and examined

for common words, feelings, and experiences expressed by the mothers and notations were made. Second, a summary record was constructed containing major themes which were extrapolated from interview notations. Each of the mother's responses was recorded under a particular theme. Using this method, predominant and less-common themes were identified, as well as unanticipated themes. Each interview was re-read to assure that all major themes were recorded. A third step involved examination of themes for saturation of responses and to determine which themes could be further condensed into major categories.

An example of construction of a major category follows:

In answering a question about response to monitor alarms, mothers used different and personal terminology to express their reactions such as "I panicked every time," "It was frightening," "I lost it completely," and "I freaked out." The terms panicked, frightening, lost it, and freaked out, along with numerous other descriptors utilized by the 74 mothers were noted on a tabulation sheet. These descriptors were then used in Stage 2 to develop emergent themes and themes were used in Stage 3 to construct the major categories of the study. These categories were labeled "Categories of Upset." In Stage 3, the themes which emerged regarding response to a monitor alarm were collapsed into the category of upset entitled Fear. In order to preserve experiential data, subcategories of the 10 major categories of upset which evolved in the study were described and analyzed. For example, the category Fear was collapsed into the six subcategories: (a) fear of death, (b) mentions SIDS, (c) extreme fear in husband, (d) fearful premonitions, (e) fear of inability to perform CPR, and (f) fear of discontinuation of the monitor.

Bayley Scales of Infant Development

The Bayley Scales of Infant Development (BSID) were designed to assess a child's developmental status in the first 2 1/2 years of life (Bayley, 1969). The BSID consists of three complementary parts: (a) the Mental Scale, (b) the Motor Scale and (c) the Infant Behavior Record. The Bayley Scale is considered as one of the most well constructed tests of Infant Development. The Mental Scale tests perception, memory, learning, problem-solving, vocalization, and abstract thinking. The Motor Scale measures gross motor abilities, as well as fine motor coordination. The Infant Behavior Record measures various aspects of the emotional and social response and behavior of the child during the testing period.

The Bayley Scale is often used as a diagnostic tool to identify developmental delays in children, although it has limited predictive validity for determining later cognition (Ruddy & Bornstein, 1982). The Bayley Scales require a training period to ensure that a tester is reliable. The investigator received both didactic and clinical training to administer the Bayley Scales. The mental and motor components of the scales were used.

The Bayley Scales consist of 163 items on the Mental Scale and 81 items on the Motor Scale. Standardized norms were established with 1,262 children of approximate equally distributed ages between 2 and 30 months. The

standardization sample was representative of the United States population in terms of geographic location, race, gender and education of head of household (Anastasi, 1982). The split-half reliability coefficient for the Mental Scale ranges from .81 to .93, with a mean of .88. The Motor Scale (with half as many items) had a reliability coefficient ranging from .68 to .92, with a median value of .948. The standard error of measurement for the Mental Scale ranges from 4.2 to 6.9 and 4.6 to 9.0 for the Motor Scale (Bayley, 1969). Correlations between raw and standard scores for the Mental and Motor Scales decrease as higher levels of child development occur with age. Test/retest reliability for the Mental Scale is high on items dealing with object-oriented behavior, and on social-interpersonal test items (the mean percent of agreement was 89.4). For the Motor Scale, high reliability was demonstrated for items involving independent control of head, trunk and extremities (Werner & Bayley, 1966). All test materials are provided in the Bayley Test Kit. These include such items as cubes, crayons, books, puzzles, toys, and various other items.

The Bayley Scale is scored by the tester on forms provided. The rater checks an item as pass, fail, refused, or report by mother. A child's test performance extends over items placed several months apart, according to age, with increasing levels of difficulty. Two levels

of assessment were ascertained in scoring. The "basal level" is determined, which is the item preceding the earliest failure, and the "ceiling level" which is the item representing the last success (Bayley, 1969). Once the basal and ceiling levels have been established, a raw score for each scale (the total items a child has passed) is recorded. Raw scores are then converted considering the child's age, to the Mental Development Index (MDI) and the Psychomotor Index (PDI), by using conversion tables contained in the Bayley Scales manual.

The Home Observation for Measurement
of the Environment (HOME)

The Home Observation for Measurement of the Environment Scale (HOME) was developed by Caldwell and Bradley (1969) over a 15-year period as a screening instrument to detect factors in a young child's environment that are related to growth and development. The HOME is designed to detect factors which may place a child at risk for developmental delays. The scale includes items that measure important aspects of social, emotional, and cognitive support available to a child in the home environment. The HOME consists of two forms: (a) the HOME for Families of Infants and Toddlers (birth to 3 years) that was used in this study and (b) the HOME for Families of Preschool Children (3 to 6 years). The HOME requires interview, direct observation and administration

by a trained interviewer to the parent or caregiver. The HOME consists of 45 items presented in 6 subscales and takes approximately 1/2 hour to complete. All items on the HOME require responses of "yes" or "no." "Yes" indicates that the home environment meets the criteria being assessed. "Yes" responses are added for each of the 6 subscales and are combined for the total HOME score. The total HOME score is then assessed according to predetermined cutoff points as to whether the raw score falls in the low, middle, or higher percentile. The higher percentile indicates the most favorable environment. The scores are then used to evaluate if a home environment may be considered a factor that could impede development in a young child. The researchers point out that definite cut-off points have not been established below which environments are considered to be a definite risk to the child, and evaluation of the home environment should be considered in conjunction with other determining data (Huber, 1982).

The HOME was constructed through a survey of empirical data, developmental theory, and expert opinion that determined factors to be included in the scale. A criticism of the HOME has been that the standardization data were collected from 174 children who were primarily Black and did not represent a varied cultural group. Despite this limitation, the HOME has been shown to

correlate highly with the Stanford Binet in predicting future mental test performance in infants 6, 12 and 24 months of age. Powell (1981, p. 142) stated that the HOME has emerged as,

... one of the best means of assessing the subtler aspects of the quality and quantity of social, emotional, and cognitive support that is available to a young child within his/her home environment.

Reliability. Internal consistency using the Kuder-Richardson 20 formula ranged from .44 to .89 for the subscales. The estimate of internal consistency for the total score was .89. The stability of the HOME (test-retest reliability) when subjects were 6, 12, and 24 months of age (using Pearson product-moment correlations) for each subscale and the total scale ranged from .24 to .77, indicating moderate stability (Huber, 1982).

Validity. Multiple investigators have demonstrated positive correlations between scores on the HOME subscales and other criteria predicting developmental delay such as socioeconomic status, cognitive development, language development, and achievement (Caldwell & Bradley, 1984; Huber, 1982). According to Huber (1982), HOME scores are positively correlated with infant language development, social interaction and cognitive growth.

Utah Test Appraising Health
(UTAH IVS) (4th Edition)

The Utah Test Appraising Health (UTAH IVS) was developed by Sullivan (Fagley, Miller & Sullivan, 1982). The tool is a standardized instrument used to determine the number of stressful life events experienced by a person within the past year. The UTAH IVS is an adaptation and major extension of the Holmes-Rahe (1967) Schedule of Recent Experiences (SRE). The UTAH IVS consists of six subscales which measure different types of stress: social stress, work stress, lifestyle stress, financial stress, family stress, and personal stress. The UTAH IVS was developed for the purpose of indicating possible future illness or complications in healthy, pregnant women. The UTAH IVS consists of three parts: (a) census data, (b) a set of physical symptoms, and (c) problems confronting normal people. For this research, part (c), common problems, was utilized. The purpose for using the scale was to detect stressful events occurring in the lives of the mothers during monitoring that may have affected level of maternal upset. The tool was not used for the purpose of predicting the onset of future illness (Appendix E). The UTAH IVS was self-administered by the mothers who circled a letter indicating that a type of stress occurred in their lives during monitoring. These raw scores were then added into a total stress index (Fagley et al., 1982).

Reliability. The UTAH IVS reliability coefficients are as follows: Family Stress, .62; Lifestyle Stress, .61; Personal Stress, .77; Work Stress, .83; Social Stress, .67; and Financial Stress, .61. The scale was standardized on a sample of 1,306 pregnant primigravida women participating in prenatal classes or attending clinics in Utah and Arizona and did not represent women of varied ethnic backgrounds.

Infant Behavior Rating Scale

This instrument was constructed by the investigator and an associate, as no instruments evaluating behavior of the three age groups of the sample were available. The scale was used to obtain information about the incidence of behavioral problems of infants. The questions on the rating scale were specific for the three age groups of infants: one part of the scale was administered to mothers of 6-12 month old infants, another to mothers of 13-23 month old infants, and a third part was administered to mothers of 24-30 month old infants. The rating scale was designed using concepts generated from an extensive literature review about infant behavior, the expertise of the investigator gained through caring for children and their families and from professional colleagues.

The questionnaire was self-administered by the mothers and required a Likert-type scaled response in which subjects circled the best answer to questions on a

scale of 1 to 5: 1 = never; 2 = seldom; 3 = sometimes; 4 = frequently; and 5 = always. Questions were asked in such a way that in some cases, choosing a 5 would indicate the most favorable response, and in other cases, answers to questions indicated by circling a 1 would be the most favorable answer. Because the questions were asked in this manner, the scoring of questions was tailored so that the proper points were given for the reversed questions.

The Behavior Rating Scale consists of categories of questions about sleep, feeding, elimination, emotions and discipline. In developing the Infant Behavior Rating Scale, no preitem analysis was performed and the initial use of the questionnaire was considered to be a pilot for further development of the questionnaire. Content validity of the instrument was determined by four pediatric medical residents from the University of Utah Health Sciences Center. A preliminary item analysis for the subscales was computed using coefficient alpha. A second reliability analysis was computed after deleting items which had low correlations with other scale items. The alpha reliability coefficients for the five subscales of the Infant Behavior Rating Scale are presented in Table 1. The Infant Behavior Rating Scale is in need of further refinement and analysis of validity and reliability before further use can be recommended.

Table 1
 Preliminary Reliability Coefficients
 for the Infant Behavior Rating
 Scale

Age Group	Category	<u>n</u>	Alpha
6-12 mos	Sleep Questions 1-11	16	.829
	Feeding Questions 1-6	16	.732
	Elimination Questions 1-4	16	.554
	Emotions Questions 1,2,5	16	.322
13-23 mos	Sleep Questions 1-13	23	.804
	Feeding Questions 1-3,6-11	26	.715
	Elimination Questions 1,2	30	.334
	Emotions Questions 1,3,4,5,8, 10,11-16,18-19	23	.785
24-30 mos	Sleep Questions 1-10	22	.691
	Feeding Questions 1,3,4,5, 8,9	23	.562
	Elimination Questions 1,3	24	.516
	Emotions Questions 1,3,4-24	21	.812

Parenting Inventory

This questionnaire was constructed by the investigator and an associate and was used to obtain information about parenting behaviors of the mothers. Questions included those about infant care, the current physical and emotional status of the mothers and their feelings and perceptions about parenting. A purpose was to determine if there might be residual or ongoing effects for the mothers once the period of monitoring had passed, and to determine if parenting behaviors may be related to infants development status. The questionnaire was designed from a thorough review of the literature of parenting, the expertise of the investigator and consultation with professional colleagues.

The questionnaire was self-scored by the mothers and called for a Likert-type response. Mothers circled answers to questions on a scale of 1 - 5: 1 = never; 2 = seldom; 3 = sometimes; 4 = frequently, and 5 = always. Questions were asked in such a way that in some cases, choosing a 5 would indicate the most favorable parenting response and in other cases, circling a 1 would be the most favorable answer. Because of this type of scoring method, the direction of responses was taken into consideration for scoring purposes. A score of parenting behavior was obtained by adding the raw scores of responses.

The Parenting Inventory contained questions in the categories of emotions and feelings, health and recreation, support, infant care and concerns, and infant health. Content validity was determined by four pediatric residents at the University of Utah Health Sciences Center, and experts in pediatric nursing. A preliminary item analysis for the subscales was computed using coefficient alpha.

A second reliability analysis was computed after deleting items which had low correlations with other scale items. The alpha reliability coefficients for the five subscales of the Parenting Inventory are presented in Table 2. The Parenting Inventory requires further refinement and analysis of validity and reliability before further use can be recommended.

Data Collection

Permission to conduct the investigation was obtained from the University of Utah Institutional Review Board. Subjects were identified by medical records at the University of Utah Pediatric Pulmonary Clinic. A letter concerning the research was sent to mothers of infants meeting the criteria by the medical director of the clinic (Appendix A). Mothers were then contacted by the investigator and were invited to participate. All mothers who were contacted agreed to participate. An appointment was made with mothers who agreed to participate. A home visit

Table 2
 Preliminary Reliability Coefficients
 for the Parenting Inventory

Subscale	<u>n</u>	Alpha
<u>Emotions and Feelings</u>		
Questions 1-14	57	.781
<u>Health and Recreation</u>		
Questions 1-15	65	.759
<u>Support</u>		
Questions 1-6	66	.579
<u>Infant Care and Concerns</u>		
Questions 1-4	73	.762
<u>Infant's Health</u>		
	73	.734

Note. The n varies as all questions were not answered by all of the mothers.

was made by the investigator. Mothers signed a consent form, and randomly selected mothers whose interviews were audiotaped for the purpose of establishing interrater reliability signed an additional consent form. A summary of the measures utilized in data collection is presented in Table 3. The Bayley Scales were completed first so that the infants would not become tired. Second, the mothers were interviewed by the investigator about their experiences during monitoring. While the mothers completed the UTAH IVS, the Parenting Inventory and the Infant Behavior Rating Scale, the investigator completed the HOME scale. The data collection took approximately 1 1/2 hours. The time was dependent on how long the mother took to complete the interview, as many mothers wanted to talk at length about their experiences. In addition, if a child was napping or took longer to become acquainted with the investigator, this affected the length of the interview. Two toddlers refused to be tested with the Bayley Scales.

Table 3
Summary of Measures
(N = 74)

Home Visit	Measures
Completed by Mothers	<ol style="list-style-type: none">1. Utah Test Appraising Health (UTAH IVS)2. Parenting Inventory3. Infant Behavior Rating Scale
Measures Conducted by Investigator	<ol style="list-style-type: none">1. Bayley Scales of Infant Development2. Home Observation for Measurement of the Environment (HOME)3. Parental Experiences Interview

CHAPTER V

RESULTS

Data were collected from 74 infants and mothers who consented to a home visit by the investigator. Two sets of data were analyzed. The first set consisted of scores on the five questionnaires which provided quantitative data about infant development and behavior, life stress, home environment and parenting. The second set consisted of descriptive data obtained from the mothers using the Parental Experiences Interview.

Demographic Information

Age of Mothers

Table 4 presents the ages of the mothers who participated. The average age was 28 years with a range of 18 to 55 years. The youngest mother was a single parent, and the oldest was a grandmother who was the infant's legal guardian and assumed responsibility for parenting.

Seventy-two mothers had no previous experience with monitoring. Of the 2 mothers with experience, 1 had insisted that her child be monitored because a previous child had received monitoring for a number of months for apnea and she was afraid of an occurrence with her new

Table 4
Mothers' Ages in Years

Years	Frequency	Percent
18-20	5	7.0
21-23	12	16.0
24-26	13	18.0
27-29	15	20.0
30-32	12	16.0
33-35	12	16.0
36-38	2	3.0
39+	3	4.0
TOTAL	74	100.0

Note. N=74, Mean = 28.4; Median = 28.5, SD = 6.2;
Range = 18-55.

infant. The other mother had lost a child previously to SIDS, and the twin of that infant (an older sibling of the infant in the sample) was monitored for a number of months. As would be expected with a mean age of 28 years, 60 mothers had 1 or more children prior to the birth of the monitored infant. Fourteen infants were first-born.

Marital Status, Religion and Ethnic Background

Sixty-five mothers were married (88%). Two were separated, 1 was widowed, 5 were divorced and 1 was single. The religious affiliation reported by 81% of the mothers was Mormon (Latter-Day Saint) ($n = 60$). Seven mothers were Catholic, 3 were Protestant and 4 reported no religious affiliation. For the remainder of the data analysis, religion will be reported as LDS/non-LDS.

Ninety-six percent ($n = 71$) of the mothers were Caucasian, 2 were Hispanic and 1 was Black. These statistics are characteristic of the general population in Utah which is predominantly Caucasian and LDS.

Educational Background

Utah generally ranks above the norm in the number of citizens who hold high school diplomas and who have completed 1 or more years of college. The mothers were representative of most Utahns. Table 5 summarizes the educational level of the mothers.

Table 5
Mothers' Educational Background

Grade Completed	Frequency	Percent
8	1	1.0
9	1	1.0
10	1	1.0
11	7	9.0
12	26	35.0
13	9	12.0
14	16	22.0
15	5	7.0
16	8	11.0
TOTAL	74	100.0

Note. N=74; Mean = 13.0; Median = 12.6; SD = 1.70;
Range = 8-16.

Occupational Status

Seventy-four percent of the mothers were homemakers ($n = 54$), while 26% were employed outside the home. Ninety percent of the fathers were employed ($n = 19$). Eighty-five percent ($n = 63$) were employed in nonprofessional occupations and 15% ($n = 11$) were employed in professional occupations.

Social Support

On the demographic questionnaire, 93% of the mothers reported that they had relatives who lived nearby and whom they saw frequently. However, on the Maternal Experiences Interview, only 59% said that their relatives were supportive. Seventy-seven percent reported seeing friends as often as they wanted to, and 95% reported having a person in whom they could confide. The findings revealed, however, that one or two close relatives, particularly the husband provided most of the support during the monitoring period.

Characteristics of Infants

All infants (except 1 with a chronic lung condition) were healthy, full-term infants who developed apneic episodes sometime within the first few months after birth. There were 37 males and 37 females. The sample originally consisted of 75 infants; however, 1 infant died prior to the onset of data collection. The death was apparently

not apnea-related. The ages of the infants ranged from 7 to 30 months. These data are reported in Table 6.

Length of Monitoring in Months

The length of time that the infants were monitored ranged from 1 to 17 months, as illustrated in Table 7. The average length of monitoring was 7.6 months.

Analysis and Findings: Research Questions One through Eleven

Maternal Upset

The first research question sought to describe the concerns and upset experienced by the mothers of the monitored infants. To answer the first research question, a content analysis was performed on the data obtained from the Parental Experiences Interview. These data were utilized to construct the major categories of upset found in the entire sample of mothers (Table 8). Results of the content analysis of the interviews are presented below by Category of Upset and subcategories.

Categories of Upset: Fear

Fear of death (subcategory). Although all mothers expressed fear during the initial episode of apnea, 62% ($n = 46$) described more pronounced, extreme degrees of fear. The fear focused predominantly on death of the infant, and mothers classified in this category tended to perceive their responsibility as maintaining a constant vigil

Table 6
Infants' Ages in Months

Months	Frequency	Percent
7-12	22	30.0
13-18	19	25.0
19-24	13	18.0
25-30	20	27.0
TOTAL	74	100.0

Note. N=74; Mean = 18.3; Median = 17.0; SD = 7.70;
Range = 7-30.

Table 7
Months on Monitor

Months	Frequency	Percent
1	2	3.0
2	5	7.0
3	4	5.0
4	7	9.0
5	8	11.0
6	8	11.0
7	8	11.0
8	4	5.0
9	5	7.0
10	4	5.0
11	4	5.0
12	4	5.0
13	3	4.0
14	3	4.0
15	2	3.0
16	1	1.0
17	2	3.0
TOTAL	74	100.0

Note. $N=74$; Mean = 7.6; Median = 6.8; SD = 4.0; Range = 1-17.

Table 8
Categories of Upset of Mothers

Theme	Subcategories	<u>n</u>	<u>% of Mothers</u>
1. Fear	1. Fear of Death	46	62
	2. Fear of SIDS	24	32
	3. Fear in Husband	18	24
	4. Fearful Premonitions	8	11
	5. Fear of Discontinuing Monitor	13	18
	6. Fear Unable to Perform CPR	34	46
2. Mother Credibility		23	31
3. Problems of Monitoring	1. Technical Problems	48	65
	2. Physical Problems	26	35
	3. Safety Considerations	6	7
4. Disruption of Family Life	1. Marital Problems	21	28
	2. Effects on Siblings	19	26
	3. Isolation	32	43
	4. Sleep Problems	46	62
	5. Financial Hardship	22	30
	6. Time Perspective	10	14
5. Emotional Effects	1. Stress	23	31
	2. Guilt	24	32
	3. Paranoia	15	20
	4. Effect on Decision for Subsequent Child	22	30
	5. Attempts to Control Monitoring Situation	12	16
	6. Denial in Husband	11	15
6. Lack of Support	1. Relatives	44	59
	2. Friends	11	15
	3. Maternal Grandmother	26	35

Table 8 continued

Theme	Subcategories	<u>n</u>	% of Mothers
7. Concerns for Infant	1. Developmental Concerns	17	23
	2. Worried when Infant Sleeps	11	15
	3. Overprotects Infant	9	12
8. Unresolved Problems		28	38
9. Health Professionals Helpful	1. No	36	49
	2. Ambivalent	24	33
	3. Yes	14	18
TOTAL		74	100

over their infants to prevent death. Most discussed the tremendous responsibility they felt to "keep the baby alive." The predominate feeling portrayed by these women was that death was probable. Characteristic statements by these mothers were somewhat morbid. One mother related how she became "fixated on how I would respond if I found him dead." Another mother spoke of the "terror of losing him." One mother explained, "I thought he would die and I was grieving ahead of time." Several of the mothers mentioned the fear of finding their baby dead in the crib and of the inability to go to the crib in the morning in case "he/she was dead." One mother said, "I have experienced death of my baby, even though she lived; the pain, the numbness, the mourning." Another reported, "I felt like I'd already buried her; hooking her up was like inviting death to come in."

Fear of Sudden Infant Death Syndrome (SIDS).

Thirty-two percent of the mothers ($n=24$) initiated a conversation regarding SIDS. Many spoke of experiences with SIDS death of infants of relatives and friends. Although 16 mothers had lost a previous infant to SIDS, not all of the mothers experienced extreme fear during monitoring. Several mothers reported that "it was meant to be," or "It was God's will." Others, however, reported distress and trauma in monitoring a subsequent child. One mother reported that the monitor was a "horrid reminder of

death with lights blinking and flashing; I felt glazed over, and I wanted to die." One mother who had lost a child to SIDS said, "people say that they know what death is; there's a difference between knowing it and feeling it when you hold a cold little body in your arms." A very young mother said, "I can't stand crib death; I'm paranoid about it."

Fear in husbands. Twenty-four percent ($n=18$) of the mothers reported a heightened degree of fear in their husbands. One mother remarked, "He started drinking; he couldn't deal with the constant reminder that he (the infant) might die." Another said, "my husband was so scared when the first spell happened at home; he just stood and stared; he froze." Another reported,

The alarm went off and my husband just started shaking her, and she was limp, and he was so scared that he just panicked and threw her on the floor. From that day on, he never touched her again until she was nearly 2 years old.

Fearful premonitions. Eleven percent ($n=8$) of the mothers reported experiencing frightening premonitions that the infant was in danger. One said, "I was sleeping, and something woke me up. I looked over and she was black and her eyes were bulging. I didn't know CPR; I called the paramedics." Another said, "I had a premonition to go in the room; the baby had been sleeping too long; I went in and he was limp and pale." Other mothers commented that they had "a funny feeling," "an eerie feeling." One

mother remarked, "I had a dreadful feeling that I should go to the crib. I put down my dishtowel and went in; he was turning blue." A mother who had lost a previous child to SIDS told of having a premonition to look down at her child at her feet in a basket. She said, "I just knew. I looked down, and she was dead." One mother said, "I received a 'spiritual slap' to go put the monitor on."

Fear of discontinuing the monitor. Families varied in their responses to the recommendation that monitoring be discontinued. Many mothers reported discontinuing the monitor immediately, while 18% (n=13) reported extreme fear. Several mothers said they "weaned themselves from the monitor slowly." Many spoke of keeping the monitor for awhile "just to be on the safe side;" "just in case." As one mother related when she had to take the monitor back, "I was so scared, I cried; I was afraid she would die, so I let her sleep on my chest so I could feel her breathing. Now she's 2 years old and she still won't sleep alone, but I don't care." Four mothers reported that they had to return the monitor because they could not afford it: "It was awful, we couldn't afford it, and we had to give it back." One mother was uncomfortable about returning the monitor but she did so because "I don't want them to think I'm a [hang onto the monitor mom]."

Fear of inability to perform CPR. Forty-six percent (n=34) of the mothers expressed the fear that they would

be unable to perform CPR if required to do so. The fear was related to the severe emotional reaction that would occur and the inability to maintain the control needed to resuscitate the child. Many mothers felt that they needed more CPR classes. One mother said, "when you learn CPR, you're really upset anyway, and you don't remember much of it; you only remember a part of it. The nurse was really good. I wish we could have had a refresher class from her." Several mothers said that they did not believe extra classes would help them. As one mother remarked, "We had a plan; I would shake him, and my husband would call the paramedics." Another mother said, "My husband went to a CPR class; if he hadn't, the baby would have died."

Categories of Upset:
Mother Credibility

This category of upset refers to instances in which mothers had observed apneic spells and/or cyanosis and were unable to convince health professionals that the event occurred. Thirty-one percent ($n=23$) of the mothers reported this experience. The category also included attempts by health professionals to minimize the event, by offering reassurances such as "you are just a new mom," "let's change the formula;" "he/she will be fine," and the use of "mom" and "mommy labels" when talking to mothers in place of their names. One mother reported that she ob-

served her infant stop breathing several times and turn blue. She took the infant to the emergency room of a hospital where the physician could not find anything wrong with the baby. "I was upset, so I just sat in the emergency waiting room until she did it again and then I yelled. When they saw her, they admitted her to the intensive care unit." One mother said she felt humiliated when the physician told her he would "order a monitor if it would make her feel better." Another mother said, "I was so tired and frightened, I started to cry. I could tell by the nurse's expression that "she thought I was going off the deep end." Other remarks made by mothers included, "unless they see it, they won't believe it," "I couldn't get their attention," "I felt patronized, as if they were humoring me, but were probably thinking, 'let's not make paranoid parents.'" One mother said,

I had already lost one child to SIDS, so when they didn't believe me, I became very angry. They looked at me like "Is she altogether?" I said, "Look, I'm not your typical ignorant first-time mother. I've already lost one child; I'm not about to lose another". . . Then they believed me and gave me a monitor. I feel sorry for mothers who aren't as strong as I am.

Categories of Upset: Problems With Monitoring

Technical problems. A large number of mothers reported problems with monitoring. Sixty-five percent (n=48) reported technical problems with the monitor such as false alarms, loose leads, tangled wires, and the

monitor becoming disconnected as the infant became older and more active. All mothers reported false alarms as "frightening," "maddening," or "annoying." The monitor was bulky and mothers complained of not being able to move the monitor and the baby at the same time. Also, chest belts slipped or wore out, and electrodes cracked. By far, the greatest annoyance was the number of false alarms which occurred, according to several mothers. These alarms were especially frightening at night. A few mothers worried about the wires shocking the baby, and about wires becoming entangled around the infant.

Physical problems. Physical problems included rashes and chafing of the infant's skin. These problems were reported by 35% ($n=26$) of the mothers. Two mothers reported cases of monilia occurring under the monitor pads.

Safety problems. Safety problems were experienced and described by 7% ($n=5$) of the mothers. These included two instances where older children disconnected the monitor. In one case, a child disconnected an adapter and plugged it into an electrical outlet, sustaining a serious burn to the hand. In another similar incident, a toddler plugged a cord into a socket and sustained an electrical shock. In two other cases, infants were found with wires wrapped around their necks, and in one case, the child "was a purple color" when discovered by the mother.

Similar situations related to monitor safety are

reported in current literature. In one instance, an infant was left in the crib wearing electrodes which had been disconnected from the apnea monitor. A sibling plugged the loose-end leads into the live power cord and electrocuted the infant (American Journal of Nursing, 1985; FDA Drug Bulletin, 1985). In another situation, a sibling received burns when he tried to place the leads into the power cord. In another incident, an infant crawled over and plugged his leads into a wall socket and suffered third-degree burns. In response to concerns about safety issues, the first meeting of the Apnea Monitoring Committee of the Association for the Advancement of Medical Instrumentation was held in 1985 to set monitor standards for the industry. It is acknowledged that monitors in current use were designed for use with infants and not for use with the more active, older infant and toddler.

Categories of Upset: Disruption of Family Life

Marital problems. Emotional effects are known to occur in families of monitored infants, and imposed stress is one of the most serious criticisms of apnea monitoring. The emotional impact is attributable to a multitude of factors including stress, fear, change in household routine, burden of constant care, lack of sleep, and others. The study mothers reported assuming the major burden of

infant care. Twenty-eight percent ($n=21$) of the mothers reported marital problems which occurred during the period of monitoring. These related to such problems as the inability to spend time together away from the baby and resentment that the husband could "get a break and go to work and see people." Three mothers reported more arguments due to constant stress. One family attributed their divorce to monitoring, and one separated mother said that her husband "couldn't handle the experience along with losing his job at the Kennecott mine." One mother admitted, "I wasn't taking care of my husband like I should." Another said that her family life had changed completely. "My husband slept; I didn't. I was irritable and he 'tuned me out.'" One family said they went to a marriage counselor for "help in adjusting during monitoring." One mother revealed, "We couldn't get a babysitter. I used to have a drinking problem, and I could feel the pressure building up. I became a junk food-a-holic, and a compulsive eater; that's how I handled the stress of it."

Effects on siblings. Twenty-six percent ($n=19$) of the mothers reported negative effects upon siblings and 11 reported high degrees of upset. One mother described "anxiety attacks in her school-aged daughter, especially when the alarms went off." Several children feared death of the baby. One child would cry, according to his mother

and "beg me not to put the monitor on the baby." Several mothers reported incidences of poor performance in school and behavioral problems. They all believed that the siblings felt "pushed into the background," and that the problems resulted from a change in the child's routine, and the inability of the mothers to spend as much time with the siblings and take their places as they had done before the baby was born. One mother stated that the child's "lifestyle had to change too much."

Mothers handled siblings' needs and problems in different ways. Several mothers arranged for grandparents to take siblings on outings. One mother took the monitor to school for "show and tell." Another mother seemed pleased that "all the children in the neighborhood can work a monitor." Several mothers stated that children should be prepared before the baby comes home with a monitor so that they will not be frightened.

Isolation. Forty-three percent ($n=32$) of the mothers reported feeling socially isolated and confined to the house. It was mentioned consistently that lack of responsible babysitters was a problem. One mother mentioned, "We never went out once in 11 months." Twenty mothers reported that they never left their infants during the monitoring period. "If I did go out, I took the monitor and the baby with me, and people stared. It was embarrassing." Several mothers remarked that friends and

relatives "shied away and never came to visit."

Sleep problems. Sleep problems were reported by 62% ($n=46$) of the mothers. Characteristically, infants slept in parents' rooms where blinking lights and false alarms interrupted sleep. Many mothers reported that the monitor was "a blessing," because without it they would never have slept. Several reported fear of sleeping through an alarm. Some mothers reported sleeping an average of 2 hours per night and of taking shifts with their husbands to watch the baby. Thirty-eight percent of parents reported that the infants slept in their room during monitoring and 10 reported that the infant slept in the parent's bed. Of those who slept in their parent's room, 3 were still in the parents room at the time of data collection, 1 had remained for 9 months, 1 for 17 months and 1 for 2 years. One mother slept on the floor of her infant's room for 2 years. Of those who slept in their parent's bed, 1 infant did so for 6 months, 1 for 9 months, 2 for 12 months, and 1 for 15 months. One mother said she let her infant sleep with her so that she could "watch him breathing." Another said she did so in order to "see him all through the night." Generally, sleep problems of the parents continued until monitoring was terminated.

Financial hardship. The problem of financial stress was reported in 30% ($n=22$) of families. One group did not

have insurance coverage and experienced hardship in paying the monthly fee of approximately \$200 for the monitor. Although insurance coverage pays 80% of the costs in most cases, many families reported difficulty in paying the balance. Several families had to return the monitor prematurely because their particular company only covered monitoring for a period of several months. Although the pediatric pulmonary clinic did have several monitors which could be loaned to families at no charge, the demand oftentimes exceeds the supply.

Time perspectives. Fourteen percent ($n=10$) of families reported that "time stood still" during the monitoring. As one mother commented, we had to "put our lives on hold." Comments from other mothers included, "It hangs you up; I wanted my life to be normal;" "I had no control over my life; I existed day to day." Other problems included inconveniences such as not being to work in the yard, take a shower, play the piano, listen to the radio, or even vacuum the carpet for fear of missing an alarm.

Categories of Upset:
Emotional Effects

Stress. Thirty-one percent of the mothers ($n=23$) reported high levels of stress and anxiety during monitoring. Having the infant stop breathing was stressful for all mothers and many mentioned lack of control during apneic episodes. The mothers verbalized their fear and

stress using terms such as "I was a basket case;" "it was stressful;" "I was drug through the ringer;" "Anxiety was my middle name;" "It was traumatic, I cried all the time;" "I lost all my friends;" "I panicked, I was afraid to be home alone;" "I became obsessed with it. I kept going in and poking her when she was asleep;" "I retreated into myself for 3 months;" "At first, I was so scared I slept on the couch with the crib next to me. I would lay there and count the seconds of apnea and wait for the alarm to go off."

Guilt. Thirty-two percent ($n=24$) of the mothers reported feelings of guilt. Many said they wondered, "why me?" Two mothers said that if they had watched the baby closer, "it might not have happened." Other remarks included: "I blamed myself for having a few drinks or a beer when I was pregnant"; "I dieted during my pregnancy. That may have had something to do with it"; "I smoke." Some of the mother's guilt reactions were prompted by remarks made by their husbands. As one mother stated, "We're LDS and I smoke, and my husband said "if you hadn't been smoking, this would never have happened." One mother whose husband was Iranian said that her husband believed the apnea was caused by a weakness in the infant caused by her loss of amniotic fluid near the end of her pregnancy. Another said she thought of all the things she had done when she was pregnant, "the partying, the booze, smoking pot."

Paranoia. An interesting and recurring theme in the study was the use of the word "paranoid" by 20% ($n=15$) of the mothers, in referring to themselves. The term covered a broad range of usage and was not used in a clinical sense; rather, it seemed to be a descriptor of self-image. For example, it was repeatedly used as "I was paranoid," "I felt paranoid," "I'm still paranoid." As one mother said, "I was paranoid; maybe I am a rotten mother."

Effect on the decision to have a subsequent child. Thirty percent ($n=22$) of the mothers reported that monitoring had a negative effect on their decision to have another child. Two mothers had tubal ligations and 1 father had a vasectomy. Several decided initially not to have more children but later changed their minds. Many said they wanted to have more children but were afraid. One mother said, "we now realize how fragile life is." At the time of data collection, 9 of the mothers were pregnant. Twenty-six mothers reported that if they did have another child, they would definitely monitor the infant whether or not apnea was diagnosed. Nine mothers stated that every newborn should be monitored for a period of several months, and 12 parents wanted to buy a monitor for personal use. Four families were annoyed because insurance companies would not allow them to purchase the monitors.

Attempts to control the monitoring situation.

Sixteen percent ($n=12$) of the mothers demonstrated certain behaviors which seemed to indicate a need to gain more control over the monitoring situation. For example, 7 mothers reported they were using the Fisher Price Nursery Monitor at all times as a backup to the apnea monitor. They called the monitors a "Godsend, 'absolutely wonderful,'" "something every mother should have." A large number of mothers were aware of Fisher Price monitors but had not purchased one. The Fisher Price monitor consists of a receiver placed at the infant's bedside and a portable unit carried by the mother. The receiver transmits sounds to the portable unit which frees mothers to go out in the yard, or down in the basement, or to be further away from the infant than would be possible without it. One mother called it, "a false sense of security," because one needed to be "within 10 seconds of the infant for CPR which they may not be if they are out in the front yard."

In two instances, mothers did not "trust" the monitor initially. One mother said that she went home and attached the monitor to her chest and held her breath to see if the alarm would ring. In the other instance, the husband tested the monitor in a similar fashion and then took it apart to see how it worked. One mother told the investigator that she had moved to a small town 300 miles from Salt Lake City and that the church in her town had its own monitor and "let anyone who wanted to, use it."

One mother stated that the use of a Womb Bear was very helpful. A Womb Bear placed in the crib simulates the sound of a heartbeat, which according to this particular mother, "keeps the infant in a lighter state of sleep and prevents apnea." Another mother had come to the same conclusion about the benefits of a slight noise level in preventing apnea. She reported going to University Hospital and recording sounds of nurses talking, doors slamming, babies crying, etc. and played the tape whenever the infant was sleeping to "keep her more alert." She stated that fewer alarms occurred when the tape was playing. Many mothers played radios at home to provide music for the baby, but did not explicitly offer a reason.

Attempting to control the monitoring situation was also apparent in several mothers. For example, one mother reported leaving the monitor on the baby for several months longer than recommended because, as she stated,

This is our baby and we wanted to decide for ourselves when he was ready to come off. We had come to an agreement that we would keep the monitor until the day after the anniversary of his first birthday.

The belief in the importance of an anniversary date was described by several mothers and referred to a situation where the parents believed that a baby was safe from SIDS if he/she lived to the first birthday.

Denial in husbands. Fifteen percent ($n=11$) of the mothers provided evidence of denial in their husbands

which occurred during the monitoring period. One mother said,

He didn't believe there was anything wrong with the baby until he actually saw it, and then he became "stringent." He would never leave her after that except to go to work. He never allowed me to leave her and we never went anywhere. Two years later, he's still overprotecting her and puts her before me.

Others said, "He denied the problem. I didn't get any support from him." "He denied everything; he spent a lot of time away from home." One mother said her husband remarked, "No way is my kid going to be hooked up to that thing," but "I insisted and it hurt our marriage." One mother said, "he was too cheerful, too hyper, too relaxed about the whole thing." Distancing was common in fathers practicing denial behaviors, according to the mothers.

Categories of Upset: Lack of Support

Only 7% ($n=5$) of the mothers reported lack of support from their husbands, and most reported that their husbands were their only source of real support. Fifty-nine percent ($n=44$) of the mothers reported lack of support of relatives, and 15% ($n=11$) reported lack of support in friends and neighbors. The literature suggests that relatives and friends tend to distance themselves from families with a monitored infant. The reasons are primarily attributed to fear that something might happen to the baby; fear of the monitor; and fear of CPR. An unexpected

finding of this research was that 35% ($n=26$) of the women reported a lack of support from their own mothers. Reactions of maternal grandmothers ranged (according to the mothers) from "worried" to "completely unglued." A theme that consistently emerged was that grandmothers felt frightened, depressed, and incompetent to care for their grandchildren. As one mother explained, "She felt helpless, worthless. . . She couldn't help her own daughter; she couldn't answer my questions." Other mothers confirmed this feeling in their mothers. They stated, "She couldn't handle it. She worried as much or more than I did." "She was upset, afraid, shocked at all the wires." Seventeen of the mothers said that the maternal grandmothers would not "tend" the baby. As one mother summarized, "She was the only one I dared ask, and there was fear there; I saw the nerves in her face; her self-esteem was gone." Another mother reported,

My mother had nine children; she was a very strong person. I didn't realize how afraid she was until I asked her to watch the baby and she refused. My strong mother was afraid! It changed our relationship. I saw her as more vulnerable, more human. I know she couldn't have taken the blame if something had happened. The guilt would be devastating.

Paternal relatives were consistently unhelpful according to the majority of mothers.

Categories of Upset: Concerns
for the Infant

Twenty-three ($n=17$) percent of the mothers reported concern about their infant's development and about possible learning disabilities. Most of the concerns which were expressed related to the infant's having been deprived of oxygen during apneic episodes and the fear that the child might be retarded. Fifteen percent ($n=11$) worried constantly when the infant slept. Twelve percent ($n = 9$) felt that they overprotected their infants. As one mother stated,

He's still overprotected, hovered over. The grandparents dote on him and call him a "miracle baby." I feel he's delicate; special. I definitely overprotect him. For 2 years, I thought he might have cerebral palsy because he didn't get enough oxygen. I kept it inside. I didn't want to worry my husband. I know we've spoiled him.

One mother stated, "to this day I have never left him. I never let him out of my sight."

Categories of Upset: Unresolved
Problems

This category of upset refers to unresolved effects or late effects related to the monitoring experience. Specifically, this category refers to upset which continues to be present with certain mothers, although the period of monitoring is over. This phenomenon was reported by 38% ($n=28$) of the mothers. As one mother said, "To this day I'm upset. I'm just beginning to

recover." Others said, "I was a basket case for 6 months." "Even now my husband is overprotective two years later." "He couldn't deal with it." "I lost every friend I had," I still check on him at night." "I'm still afraid. Last week, my older child ran in and said the baby was in the toilet head first. I froze; I panicked; I couldn't deal with it, so my son got him out." Another said, "I kept reliving the incident. I'd stay busy so I wouldn't remember her face; blue lips and blue around her mouth." Several mothers reported feeling depressed for several months after discontinuing the monitor, until their lives became normal.

Categories of Upset: How Health Professionals Could Be More Helpful

In response to the question, "How helpful were health professionals?," 33% ($n=24$) of mothers reported feelings of ambivalence and 49% ($n=36$) reported that health professionals were not as helpful as they might have been. The mothers conveyed the belief that their child was in imminent danger of death and health professionals were not in tune with their anxiety. As one mother explained,

If a doctor thinks a baby is going to die, it is usually admitted to the hospital and a lot of times it goes to intensive care, but when they quit breathing and you take them to the doctor, they don't act right away. They refer you to a special clinic. I had to wait for 2 days for an appointment. I stayed awake for 2 nights watching her until I could get in. They didn't admit her to the hospital, but they showed me

CPR. I was getting two different messages -- she's okay, but she might die.

One mother said,

I didn't understand the medical words. That night the heart alarm went off, and I panicked. I asked my husband, "what's the heart alarm?" I didn't know who to call so I just sat up and watched her all night.

The ambivalent mothers were grateful for the care they received, but some of their expectations were not met. One mother said, "Skillwise, they were very good and very nice, but the support I needed just wasn't there. I needed someone to talk to."

Seventy-eight percent ($n=58$) of the mothers felt the need for emotional support by the staff, and the need for more support by health professionals once they went home, especially in the first few days. They felt that home visits by health professionals in the first week would be very helpful. Forty-nine percent ($n=36$) believed telephone availability of health professionals to answer questions on a 24-hour a day basis should be provided to parents. Twenty-six percent ($n=19$) mothers mentioned the nurse at the pediatric pulmonary clinic as being extremely helpful to them, but they disliked waiting for her to return their calls, even though they knew she had a very busy clinic schedule during the day. Several mothers suggested that coordination between their private physicians, the pediatric pulmonary clinic and a liaison person to interpret information to them would be very helpful.

Fifty-nine ($n=44$) percent of the mothers felt that being able to call "another mother who is going through the same thing, to share experiences with" would be very helpful. These and other parental suggestions are summarized in Table 9.

Infant Development

Research questions two and three addressed infant mental and motor development. Research question two concerned mental development scores of infants who had received home apnea monitoring, while question three related to psychomotor development scores of infants who received home apnea monitoring. To answer these questions, the standardized Bayley Scales of Infant Development were used to assess and compute scores for two components:

1. The Mental Development Index (MDI); and
2. The Psychomotor Development Index (PDI).

The MDI and PDI scores for the infants were:

Mental Development Group:

(MDI): Mean = 102.1; median = 106.3; SD = 27.4; range = 68-150.

Psychomotor Development Group:

(PDI): Mean = 108.5; median = 116.3; SD = 28.2; range = 64-150.

A 1-sample t test compared the sample mean of each index of the infants with that of the standard Bayley mean score of 100 for each index. Results were:

Table 9
How Health Professionals Might Have Been
More Helpful

Suggestions Offered by Mothers	Frequency	Percent
1. Plan parent-to-parent telephone support groups	44	59.0
2. Form parent support groups	41	55.0
3. Offer additional education	33	45.0
4. Offer additional CPR classes	22	30.0
5. Offer a class for grandparents	33	45.0
6. 24-hour telephone availability of staff to answer questions (at least first week)	36	49.0
7. Offer emotional support to mothers	58	78.0
8. Provide mothers with names of qualified babysitters	58	78.0
TOTAL	74	110.0

Group MDI (Mean = 102.1)	
Bayley MDI (Mean = 100.0)	$\underline{t}=.66; p=.506$
Group PDI (Mean = 108.5)	
Bayley PDI (Mean = 100)	$\underline{t}=2.58; p=.012.$

Results indicate that there was insufficient evidence in the sample of mental development scores to demonstrate significant difference between that group and a nonmonitored population of infants. The psychomotor scores of monitored infants was significantly higher than in Bayley's population of infants ($p = .012$)

To be able to understand what factors were related to scores of infant development, two groups were formed for comparison analyses. If the infant's score on the Mental Development Index (MDI) was below the Bayley mean of 100, the infant was ranked in the "low mental development" group. If the infant's score was 100 or above, the infant was ranked in the "high mental development" group. Accordingly, the infant's score on the Psychomotor Development Index (PDI) determined its placement in either the high or low psychomotor development group, according to the normative Bayley Mean of 100. The number of subjects scoring above and below 100 on the MDI and PDI are presented in Table 10.

Seventy-seven percent of the infants ranked in the same group of the MDI and the PDI, either ranking in the low development group on both indices or in the high development group on both indices. For subjects not

Table 10
 Number of Subjects Scoring Above and Below 100
 on the Bayley MDI and PDI
 (n=71)

Group	MDI		PDI	
	<u>n</u>	%	<u>n</u>	%
I (less than 100)	26	37.0	17	24.0
II (greater than 100)	45	63.0	54	76.0
TOTAL		100.0		100.0

Note. Bayley mean = 100; Three infants refused to participate in the Bayley testing session; MDI = Bayley Mental Development Index; PDI = Bayley Psychomotor Development Index.

ranking in the same group of high or low on both indices, all had scores close to the Bayley mean of 100, which suggests that no subjects who scored high or low were placed in the wrong groups. Restated, a subject who scored low was not likely placed in the high group and a subject who scored high was not likely placed in the low group. Findings suggest that within the constraints of this retrospective design, apnea monitoring was not associated with sufficient family disruption, upset or problems in parenting to significantly affect infant mental development.

The psychomotor index of the Bayley (PDI) scales was significantly higher in the infants as compared to the Bayley Mean scores ($p=.012$), although differences were not extreme. The same conclusion can be drawn that apnea monitoring did not contribute to lower scores of infant psychomotor development in the infants.

Home Environment

The fourth research question concerned the quality of the home environment of infants who received home apnea monitoring. To answer this question, differences between the infant's scores on the Home Observation for Measurement of the Environment scale (HOME) were analyzed by a 1-sample t test to determine if the sample mean of infants was the same or different from the HOME norm. The HOME assessment consists of six subscales which were standard-

ized on three separate age groups: infants 6 months of age, 12 months of age, and 24 months of age. For comparison of the mean score of the infants with the mean of the HOME norm scores, the sample was grouped into the same three age categories. Table 11 presents mean comparisons of the HOME norm scores and scores of infants participating in the study.

In the 6 to 9 month age group, scores were significantly higher on two of the subscales, and in both the 10 to 18 month group and the 19 to 30 month group, scores were higher than the HOME norm on nearly all of the subscales. Results suggest that the infants in the sample had more enriched environments which are known to encourage infant development.

Home Environment and Infant Development

The fifth research question sought to determine if infants who scored in the high groups of mental and psychomotor development received high scores on the HOME scale measuring quality of the home environment. Differences between these developmental groups on the HOME categorical scales were compared and analyzed by the Mann-Whitney U-Test. Variables demonstrating significance are presented in Table 12. Significant differences on the HOME scales between development groups of the sample were as follows: the higher mental development group of

Table 11
 Mean Comparisons of the HOME Norm and HOME
 Scores of Infants in the Sample

Home Subscale	Home \bar{X}	Study \bar{X}	t	p
<u>Ages 6-9 Months (n=12)</u>				
I. Responsivity of Mother	7.60	8.50	1.039	.321
II. Avoidance and Restriction of Punishment	5.91	6.50	1.355	.202
III. Organization of Environment	4.62	5.50	3.040	.011
IV. Appropriate Play Materials	5.04	6.33	1.670	.122
V. Maternal Involvement Score	3.01	3.58	.873	.401
VI. Variety in Daily Stimulation	2.25	3.25	2.240	.046
VII. Total Score	28.49	33.66	1.612	.135
<u>Ages 10-18 Months (n=29)</u>				
I. Responsivity of Mother	8.02	8.82	2.430	.022
II. Avoidance and Restriction of Punishment	5.29	6.79	6.550	<.001
III. Organization of Environment	4.89	5.75	8.110	<.001
IV. Appropriate Play Materials	6.36	7.75	5.350	<.001

Table 11 Continued

Home Subscale	Home \bar{X}	Study \bar{X}	t	p
V. Maternal Involvement	3.32	3.96	2.010	.053
VI. Variety in Daily Stimulation	2.97	4.03	4.620	<.001
VII. TOTAL SCORE	30.85	37.13	5.160	<.001
<u>Ages 19-30 Months (n=33)</u>				
I. Responsivity of Mother	8.57	8.75	.511	.612
II. Avoidance and Restriction of Punishment	5.24	6.36	3.990	<.001
III. Organization of Environment	4.93	5.18	1.120	.268
IV. Appropriate Play Materials	6.36	7.39	3.260	.002
V. Maternal Involvement	3.54	4.54	3.640	<.001
VI. Variety in Daily Stimulation	3.03	4.21	5.820	<.001
VII. TOTAL SCORE	31.69	36.48	3.300	<.002

Table 12
Differences Between High and Low
Development Groups on HOME
Scale

HOME Subscale Category	Group	Median	p
<u>Mental Development Group</u>			
Responsivity of Mother	Low	2.07	.04
	High	2.51	
Avoidance and Restriction of Punishment	Low	2.14	.001
	High	2.80	
Organization of Environment	Low	2.57	.006
	High	2.91	
Provision of Play Materials	Low	2.26	.013
	High	2.82	
Maternal Involvement	Low	1.60	.0001
	High	2.71	
Variety in Daily Stimulation	Low	2.50	.006
	High	2.88	
Total Score	Low	2.16	.0023
	High	2.78	
<u>Psychomotor Development Group</u>			
Variety in Daily Stimulation	Low	2.50	.03
	High	2.84	

infants scored higher on all of the HOME subscales including the total score. The HOME scales assess maternal involvement with the infants, characteristics of the environment, and types of stimulation offered to the child. The higher psychomotor development group scored higher on the HOME subscale: variety in daily stimulation. Results suggest that infants benefit from homes which provide important aspects of social, emotional, and cognitive support to infants in their early environments.

Stressful Life Events

The sixth research question sought to determine the relationship between higher incidence of stressful life events experienced by the mothers during the monitoring period and lower scores of infant development. The data were analyzed by independent t -test. No significant differences were found between groups of mothers who reported higher incidence of stressful life events during monitoring and scores of lower infant development (Table 13).

Infant Behavior and Infant Development Scores

The seventh research question sought to determine if there was a significant incidence of behavioral problems according to high and low scores of infant development. To answer the question, the mothers' responses on the Infant Behavior Rating Scale were analyzed by the Mann-

Table 13
 Comparison of Scores of Utah Test Appraising
 Health (UTAH IVS) and Development Group
 Scores (Nonsignificant Findings)

Variable	Development Group	\bar{x}	t	df	p	
<u>Mental Development Group</u>						
1	Family Stress	Low High	1.79 1.48	.74	54.3	.465
2	Lifestyle Stress	Low High	3.08 2.97	.22	41.9	.826
3	Personal Stress	Low High	5.00 4.51	.80	46.2	.426
4	Work Stress	Low High	.916 .787	.35	45.3	.730
5	Social Stress	Low High	1.00 .446	1.58	30.8	.124
6	Financial Stress	Low High	2.00 1.85	.37	48.9	.711
<u>Psychomotor Development Group</u>						
1	Family Stress	Low High	2.31 1.38	1.79	22.0	.088
2	Lifestyle Stress	Low High	3.25 2.94	.55	22.3	.585
3	Personal Stress	Low High	5.37 4.47	1.37	25.9	.182
4	Work Stress	Low High	1.00 7.81	.45	20.4	.657
5	Social Stress	Low High	.687 .618	.24	32.3	.814
6	Financial Stress	Low High	.237 1.760	1.22	21.6	.235

Whitney U-test. Statistically significant differences on the Infant Behavior Rating Scale for the two mental and psychomotor groups of high and low development (according to age) are presented in Table 14.

Significant differences were demonstrated in infant behavior in both the low and high development groups. Infants in the lower psychomotor development group (age 6-12 months) slept in their parents' beds more frequently and required spanking more often than did infants in the high psychomotor development group. A behavior such as regularly sleeping in the parent's bed may be evidence of the parents' inability to set limits on the infant's demands, or parental fear of being away from the child during sleep that may be an effect of the monitoring. Frequent spanking of a 6-12 month old infant is rarely indicated and suggests certain problems (i.e., lack of parental knowledge about child development and normal behavior of young infants and parenting techniques).

In the 13-23 month age group, infants in the higher development group generally awakened once at night (which is the desired response as opposed to waking frequently at night) more often than did infants in the low development group. Mothers of infants in the high mental development group tended to ignore problem behavior as a method of discipline more often than did mothers of infants in the low mental development group. Other infant behavior

Table 14
Differences in Incidence of Infant Behavioral
Problems

Variable Description	Develop- mental Group	Median	p
<u>6-12 Month Age Group</u>			
<u>Psychomotor Development</u>			
11 Sleep Parents' Bed	Low High	2.00 1.07	.04
38 Requires Spank- ing to Disci- pline	Low High	1.50 1.00	.008
<u>13-23 Months Age Group</u>			
<u>Mental Development</u>			
2 Awaken Once at Night	Low High	2.00 3.00	.04
17 Drink Milk from Bottle	Low High	4.64 3.50	.05
24 Spit Out Food	Low High	3.40 2.33	.03
35 Whine/Cry Excessively	Low High	2.62 1.85	.03
44 Requires Discipline	Low High	3.30 2.28	.01
45 Discipline Verbal	Low High	4.70 3.85	.005
47 Requires Hand Spanked to Discipline	Low High	3.33 2.83	.05 .05

Table 14 continued

Variable	Description	Develop- mental Group	Median	p
49	Ignore to Discipline	Low High	1.11 2.58	.01
<u>13-23 Months Age Group Psychomotor Development</u>				
44	Requires Discipline	Low High	3.33 2.50	.05
45	Discipline Verbal	Low High	4.83 3.90	.005
47	Hand Spank to Discipline	Low High	3.50 2.86	.02
<u>24-30 Months Age Group Mental Development</u>				
4	Takes a Good Nap	Low High	4.90 4.07	.03
18	Spits Out Food	Low High	2.83 1.68	.04
20	Eats Things That Are Not Food	Low High	2.83 1.38	.01
38	Loses Control in Play	Low High	3.50 2.50	.03
41	Holds Breath When Upset	Low High	1.83 1.15	.03
43	Plays Alone Well	Low High	4.90 4.05	.01
45	Moves From Toy to to Toy	Low High	4.00 2.78	.02

Table 14 continued

Variable	Description	Develop- mental Group	Median	p
24-30 Months Age Group				
Psychomotor Development				
14	Drinks Milk From Bottle	Low High	3.66 1.44	.02
15	Eats With Family	Low High	3.87 4.84	.004
19	Throws Up When Not Ill	Low High	2.12 1.15	.001
27	Seems Healthy and Strong	Low High	3.75 4.79	.01
28	Becomes Easily Frustrated	Low High	2.75 1.68	.02
37	Seems Clingy and Dependent	Low High	3.75 2.56	.05
48	Acts Overly Shy	Low High	2.75 1.85	.03
53	Spank for Discipline	Low High	2.00 3.00	.05
54	Ignore for Discipline	Low High	1.25 2.75	.01

problems demonstrating significance in this age group of infants were as follows: in the lower mental development group, more infants drank milk from a bottle, spit out food, and whined and cried excessively. Mothers reported that these infants required discipline often, including more verbal discipline and spanking with the hand than did infants in the high mental development group.

In the 24-30 month age group, significant differences in infant behavior were reported for the lower mental development group. Mothers reported that these infants napped less often, spit out food, and ate things that were not food more often. Although they played alone well, they often moved from toy to toy and lost control in play. In the higher psychomotor development group, four significant differences were noted. Mothers in this group reported that their infants seemed healthy and strong more often than did mothers of infants in the lower psychomotor group (but this group also reported ignoring and spanking their infants more often for discipline). Mothers of infants in the low psychomotor group reported the following problems: infants drank milk from a bottle more often, vomited when not ill, became easily frustrated, seemed clingy and dependent and acted overly shy more often than did infants in the higher psychomotor group.

Parenting and Infant Development

The eighth research question sought to determine if mothers who felt less positive about parenting had infants who scored lower on measures of infant development. To answer the question, the mothers' responses on the Parenting Inventory were analyzed by the Mann-Whitney U-test. The variables presented in Table 15 are those demonstrating significance. Significant differences between the psychomotor development groups were: mothers of infants in the low psychomotor development groups were more tired, felt more locked in the house, and enjoyed their infants less than did mothers of infants in the high psychomotor group. These mothers also felt that the infants' demands were overwhelming, and felt more anxious, bored, and less energetic than did mothers of infants in the high psychomotor development group. In addition, they reported having less help with baby care, and worried more about their infants' development than did mothers of infants in the high psychomotor development group.

A recurrent theme characterizing mothers of infants in the low psychomotor development group was a combination of discontent and lack of support. A frequent need reported by nearly all mothers was the availability of qualified persons who are willing to babysit for monitored infants. The mothers consistently reported that relatives, friends and neighbors were too frightened of the

Table 15
 Mothers' Responses to the Parenting Inventory

Variable Description	Develop- mental Group	Median	p	
<u>Mental Development Group</u>				
4	Feel Tired	Low High	3.96 3.33	.023
10	Feel Locked in House	Low High	3.22 2.50	.02
14	Feel Bored or Anxious	Low High	3.04 2.40	.04
45	Pray for Baby's Safety	Low High	3.50 4.21	.01
<u>Psychomotor Development Group</u>				
4	Feel Tired	Low High	4.12 3.39	.007
10	Feel Locked in House	Low High	3.35 2.61	.01
12	Enjoy Baby	Low High	4.61 4.89	.02
13	Baby's Demands Overwhelming	Low High	3.37 2.80	.04
14	Feel Bored or Anxious	Low High	3.07 2.50	.04
16	Feel Well, Energetic	Low High	3.10 3.84	.01

Table 15 continued

Variable	Description	Develop- mental Group	Median	p
19	Get Exercise	Low High	2.35 3.56	.005
28	Feel Too Tired To Do Anything	Low High	3.25 2.52	.01
31	Have Help With Baby Care	Low High	2.07 2.89	.01
39	Worry About Baby's Development	Low High	2.83 2.04	.02

monitor and the responsibility of caring for a monitored infant to offer help.

Maternal Upset and Infant Development

The ninth research question was designed to determine whether higher levels of upset were reported by mothers whose infants ranked in the low versus the high development groups. To answer the question, infants in the high and low mental and psychomotor development groups were compared to high and low levels of upset reported by the mothers. Significant differences between groups were found on the following variables:

Category of upset: Emotional effects.

1. Attempts to control monitoring situation: Low mental development group (4.2%); High mental development group (23.4%); chi-square = 4.1; $p = .040$.

2. Concerns for infant (overprotects infant): Low mental development group (4.2%); High mental development group (23.4%), chi-square = 4.1; $p = .040$.

Results indicate that mothers of infants in the high mental development group attempted to control the monitoring situation more often than did mothers of infants in the lower mental development group. These mothers also tended to overprotect their infants more than any other group. Attempting to control the monitoring situation refers to situations in which mothers embellished the use

of the monitor with objects or techniques that made them feel more secure. For example, several mothers used the Fisher Price Nursery Monitor which is sensitive to breathing sounds that can be heard by the mother when she is in a different part of the house. In one instance, a mother placed a Womb Bear in the crib. Other methods used by mothers included tape recordings of hospital noise played continually in the infant's room to keep the infant partially aroused during sleep.

Overprotection of the infant referred to situations where the mother would not leave the child with a babysitter, was overly concerned with the child's health, restricted the child's play, or worried when the child was out of sight.

Relationship of Duration of Monitoring to Other Variables

The tenth research question examined the relationship between duration of monitoring (in months) and other variables. To answer the question, Pearson Product Moment and Spearman Rho correlation coefficients were computed. Table 16 presents significant correlations. Results indicate that mothers of infants who received monitoring for significantly longer periods of time lacked support from their spouses and significant others, and were often lonely, bored and anxious. Fear of SIDS in the mothers was also significantly related to longer duration of

Table 16
 Correlates of Months of Monitoring
 and Other Variables ($N = 74$)

Type	No.	Variable Description	Correlation Coefficient	
			Pearson	Spearman
Demo- graphic	16	Feeling Lonely		.32**
Parenting	5	Share Feelings with Friend		-.31*
	14	Feel Bored, Anxious		.33*
	20	Get Enough Sleep		-.29*
	34	Relatives Available		-.33**
	48	Infant Has Frequent Colds		.22*
Maternal Upset				
Fear of Death	1	Fear of SIDS	.23*	
Concerns for Infant	1	Developmental	.22*	
	3	Overprotect	.22*	
Lack of Support	4	Husband	.24*	
Health Profes- sionals Helpful	7	Emotional Support from Health Profes- sionals (No)	-.23*	
	2	Parent Support Group Needed (Yes)	.28*	

Note. * $p < .05$; ** $p < .01$.

monitoring. The infants who received monitoring for a longer period had frequent colds and mothers reported that they overprotected their infants and worried more about infant development than did mothers who did not monitor their infants for as long a period of time. Mothers of infants in the 13-23 month age group reported that their infants awakened frequently at night and slept in their parents' room. These mothers reported that they themselves seldom got enough sleep. The mothers of infants who received significantly longer durations of monitoring also reported that health professionals did not offer sufficient emotional support to them, and the mothers stated that a parent support group would have been very helpful.

Maternal Upset in Relation to Other Variables

The eleventh research question assessed the relationship between upset in the mothers and the other variables. In order to answer the question, Pearson Product Moment correlation coefficients were computed between level of upset in the mother and the other variables. This question did not specifically involve infant development, and was mainly concerned with environmental aspects of monitoring. Therefore, infants were considered as one group of 74 infants and were not divided into groups of higher and lower development. In order to simplify the

analysis, the 10 separate categories of maternal upset were condensed into one variable, "Maternal Upset." The Infant Behavior Rating Scale was also condensed into five categories: sleep, feeding, elimination, emotions, and discipline for each age group. Similarly, the Parenting Inventory was combined into five categories: emotions, health of mother, support, concerns for the infant, and concerns for self. The five categories of stress were also combined into a total score. Pearson Product moment correlation coefficients are presented in Table 17.

Variables demonstrating significance that were related to maternal upset were the infant's age in months when monitored and number of months that the infant was monitored (that is, the higher the level of maternal upset, the older the infants were and the longer the infants received apnea monitoring). Also, results indicated that the higher the mother's level of upset, the less healthy she said she was, the less support she received, and the more stress she experienced. The two infant behaviors demonstrating significance were the following: the higher the mother's level of upset, the less the infant in the 6-12 month age group demonstrated normal sleep patterns, and the less the infants in the 24-30 month age group demonstrated normal elimination patterns.

Table 17
 Significant Correlations of Maternal Upset with
 Demographic Factors, Home Environment, Stress,
 Infant Behavior and Parenting Variables

Type	Variable Description	Pearson Product Moment Correla- tion Coefficient
Demographic	2 Infant's Age	.38**
	19 Months on Monitor	.24*
Parenting	Mother's Health	-.30*
	Support	-.29*
Stress		.32**
Infant Behavior 6-12 mos	Normal Sleep Pattern	-.68**
Infant Behavior 24-30 mos	Normal Elimination Pattern	-.45*
		Spearman Rho Corr. Coeff.
Infant Behavior Variables	<u>6-12 months</u>	
	7 Nap in Afternoon	-.47*
	<u>13-23 months</u>	
	2 Wake Once at Night	.62**
	3 Wakes Twice at Night	.56**
	4 Requires Attention When Awakens at Night	.41*
	10 Sleeps in Parent's Room	.52**
	32 Seems Healthy, Strong	-.51*

Note. * $p < .05$; ** $p < .01$.

Additional Analysis

The data reported in this section are additional findings for which no specific research questions were formulated. These include: (a) demographic data, and (b) information about infants who were siblings of victims of Sudden Infant Death Syndrome.

Significant Demographic Variables in the Study

Differences between the high and low infant development groups on demographic variables were analyzed by independent t test. Significant differences between groups were found on several variables.

1. Infants with higher mental development scores had older mothers (Mean = 29.4), compared with mothers of the infants with lower mental development scores (Mean = 25.2; t [51.7 df] = 3.18, p = .003).

2. Infants with higher psychomotor development scores had older fathers (mean = 31.7) compared with infants with lower psychomotor development scores (Mean = -27.4; t [33.3 df] = -2.72; p = .010).

The following demographic variables were significant and were analyzed by chi-square:

1. Professional occupation of the father in the high mental development group: Low mental development group (0%); High mental development group (21.3%); chi-square = 5.943; p = .01.

2. Infant was a sibling of a victim of SIDS: Low mental development group (4.2%); High mental development group: 31.9%); chi-square = 7.007; $p = .008$.

3. Mother has a confidant: Low psychomotor development group (81.3%); High psychomotor development group (98.2%); Fisher's Exact test; $p = .034$.

Siblings of Victims of Sudden
Infant Death Syndrome:
Significant Variables

Data were also obtained for 16 infants who were siblings of an infant who had died from Sudden Infant Death Syndrome (SIDS). It was assumed that mothers who had lost a previous child to SIDS might be more fearful and react differently to monitoring than mothers who had not. Significant differences between groups of infants who were and were not siblings of victims of SIDS were found on the following variables.

Infant development. Infants who were siblings of victims of SIDS scored higher (Mean = 113.6) on the Bayley Mental Development Scale than infants who were not siblings of victims of SIDS (Mean = 104.3; t [35.2 df] = 2.28; $p = .029$).

Infants who were siblings of SIDS victims also scored higher on the psychomotor development scale (119.9) than did infants who were not siblings of victims of SIDS (Mean = 111.1; t [33.5 df] = 2.16; $p = .038$).

Health professionals helpful. Significant differ-

ences between groups were found on the variable "Telephone support group a good idea:" Mothers of siblings of SIDS victims reported yes 81% of the time; and mothers of infants who were not siblings of SIDS victims responded yes 53.4% of the time (Chi-square = 4.02; $p = .044$).

Demographic variables. Differences between infants who were siblings of victims of SIDS and infants who were not for demographic variables were analyzed by independent t test. Significant differences between groups were found on the variable "Infant's birthweight in ounces:" Siblings of SIDS victims (mean birthweight = 122.9); and Infants who were not siblings of victims of SIDS (Mean = 108.7; t [30.4 df] = 2.78; $p = .009$). There were no significant differences between the infants who were siblings of victims of SIDS and those who were not on the other study variables (Mother upset, HOME scores, stressful life events during monitoring, parenting, and the incidence of infant behavior problems).

CHAPTER VI

DISCUSSION AND IMPLICATIONS

The purpose of this investigation was to describe maternal and infant responses to home apnea monitoring. Maternal response referred to levels of upset experienced by the mothers during monitoring. Infant responses referred to scores of mental and psychomotor development and incidence of behavioral problems.

The specific intent was to describe how levels of maternal upset during home apnea monitoring may be related to parenting behaviors of the mother and to infant development and behavior. A major assumption was that the mothers who experienced higher levels of upset during monitoring might be unable to adequately meet the infant's needs and infant development could be compromised.

Important concepts that formed the conceptual framework were: (a) the process of apnea monitoring; (b) stressful life events; (c) social support; (d) parenting behaviors of the mothers; (e) infant development and behavior, and (f) modifying factors (parents' age, occupation, educational level, religion and marital status).

Major Findings

Results described, compared and related the data obtained and are discussed according to the four major findings:

1. Nine specific categories of upset experienced by mothers of monitored infants emerged.
2. Mothers who felt less positive about parenting had infants with significantly lower scores of infant mental and psychomotor development and more behavioral problems.
3. Longer duration of monitoring was significantly related to lack of support, fear of Sudden Infant Death Syndrome and developmental concerns for the infant.
4. Lack of support was significantly related to high levels of maternal upset, longer duration of monitoring, mothers who felt less positive about parenting, lower scores of infant development, and higher incidence of infant behavior problems.

Major Categories of Maternal Upset

Results indicated that the majority of mothers were upset during home apnea monitoring. This finding was consistent with previous research in which monitoring was described as stressful and anxiety-producing for families

(Black et al., 1978; Cain et al., 1980; Dimaggio & Sheetz, 1983; Duncan & Webb, 1983; Shannon & Kelly, 1982; Smith, 1984; Wasserman, 1984). These authors described general types of distress experienced by mothers during monitoring such as fatigue, stress, anxiety, and lack of support. The researcher sought to validate these findings but also to more specifically describe what, in particular, upset the mothers so that nurses could be more helpful to mothers of monitored infants.

A content analysis of the Personal Experiences Interviews of the mothers led to a description of 9 specific areas of upset: (a) fear; (b) mother credibility (referring to skepticism of health professionals that apnea was real); (c) problems with the monitor; (d) disruption of family life; (e) emotional effects; (f) lack of support; (g) concerns for the infant; (h) unresolved problems; and (i) nonhelpfulness of health professionals. Each of these areas will be briefly discussed and will include suggestions that could guide nurses to develop interventions to assist families of monitored infants.

Fear

Fear is a universal experience for mothers of monitored infants (Black et al., 1978; Cain et al., 1980; Dimaggio & Sheetz, 1983; Duncan & Webb, 1983; Shannon & Kelly, 1982; Smith, 1984; Swanson, 1982; Wasserman, 1984). In this sample, all mothers experienced fear during the

initial apneic episode, although many expressed more pronounced, extreme degrees of fear. The fears described were focused in four areas: (a) fear of death of the infant (62%); (b) fear of Sudden Infant Death Syndrome (32%); (c) fear of not being able to perform cardiopulmonary resuscitation (46%); and (d) fear of discontinuing the monitor (18%).

Fear of death. In contrast to mothers in this sample, Bakke and Dougherty (1981) reported that mothers of monitored infants seldom directly identified fear of death as a source of anxiety or upset, and instead expressed fear in terms of monitor problems, false alarms, and monitor failure. In this sample, however, the mothers were quite open and communicative about their fears. One possible explanation for this finding is that the mothers shared information about their fears more openly because they were interviewed at length in their homes after monitoring had been discontinued. In the Bakke and Dougherty investigation, the mothers were interviewed in apnea centers during the time that the infant was being diagnosed for apnea and when monitoring was just beginning. Lengthy relaxed interviews were likely not possible under these circumstances.

Mothers in this sample reported that because of high levels of fear of death of the infant, they were not able to absorb much of the information given to them by health

professionals. They stated that during this frightening time, they especially needed emotional support from health professionals and someone to talk to. Some mothers reported that they continued to be fearful during the duration of monitoring while others became more relaxed as they learned to trust the monitor. Similar findings were reported by Cain et al. (1980). Eleven percent of the mothers stated that they had fearful premonitions that the baby would die.

Many studies confirm that the initial weeks at home are the most frightening for parents (Black et al., 1978; Cain et al., 1980; Duncan & Webb, 1983) and mothers who had high levels of fear seemed to perceive their responsibility as one of maintaining a constant vigil over their infants at home to prevent death. Several mothers described the fear of "finding the baby dead in the crib."

Previous researchers have not reported fear as vividly as described by the mothers in this sample. The information shared by these mothers is extremely valuable for nurses who care for families of monitored infants. This information needs to be verified and explored through other research about maternal response and adaptation during home monitoring. The data suggest that nurses could assist mothers whose infant has experienced apneic episodes by offering emotional support and by empathically listening to the mother so that she will feel comfortable

CPR, but would call the paramedics, although they expressed guilt and anxiety about not wanting to try CPR on their infant. Many mothers stated that a "refresher" class after a few weeks at home would be very helpful. Some suggested that grandparents be included in the classes so that they would feel more relaxed around the infant. In the majority of families, the husband accompanied his wife to the CPR class, but the grandparents did not.

It is probable that much of the fear and lack of knowledge about CPR could be ameliorated by nurses. It seems that CPR classes might be more appropriately offered to parents after they have received a thorough explanation of the infant's condition, and the reasons why apnea monitoring is indicated. Families could be instructed in what an apnea monitor looks like, how it works and sounds, and why it is used. After families receive classroom instruction about monitoring, they might participate in some practical instruction on monitor use. Once families understand the nature of apnea, and how to use the monitor, they would be more emotionally prepared to learn the principles of CPR.

Some families might feel comfortable after one or two CPR classes, while others might require additional classes and practice. There may be an occasional family that will not be able to learn CPR and in these cases, the infant

may need to remain in the hospital or in some type of surrogate care situation until the apnea resolves.

Most importantly, families need to be assured that nearly everyone is capable of learning CPR and that it is a relatively uncomplicated intervention to be used until help arrives. It is important that health professionals systematically assess the family's competence to perform CPR and that they are emotionally capable of performing it correctly. Health professionals could then offer support and encouragement and additional education as indicated. Reinforcement and periodic assessment of CPR ability should continue throughout the duration of monitoring. It is imperative that at least two adults who will care for the infant be instructed in operation of the monitor and in CPR. Most importantly, families need ongoing emotional support and communication from health professionals to help them adapt to the process of home monitoring.

Fear in husbands. Twenty-four percent of the mothers reported high levels of fear in their husbands. It is possible that this problem might be avoided if health professionals systematically included spouses in educational sessions, assured them of the importance of participating in care of the infant, and encouraged them to ask questions and express their fears and concerns. Since husbands were the major source of support for mothers, it is imperative that nurses include them in

counseling sessions and help them to feel comfortable in caring for the infant. It may be important for nurses to arrange for these families to meet with other families to share common concerns and ways to deal with fears. Nurses might also want to organize a "husbands only" support group to assist husbands in obtaining advice and support from one another.

Fear of sudden infant death syndrome. Thirty-two percent of the mothers initiated a conversation about SIDS and its relationship to apnea. Mothers were very aware of the nature and incidence of SIDS through various media. Many had friends or relatives who had lost an infant to SIDS and a few were aware of apnea monitoring. Sixteen had lost a previous infant to SIDS, although not all of these mothers expressed an extreme fear of SIDS. (The 16 mothers and siblings of SIDS victims are discussed in the Additional Analyses section).

Some mothers had misconceptions about SIDS, and believed that every infant should be monitored in order to "prevent" SIDS. Most mothers were aware of some connection between apnea and SIDS although they did not have information about the specific relationship. Most knew apnea meant that the infant stopped breathing periodically, believed that these breathing pauses could "lead to SIDS," and wanted to discuss this in more detail with health professionals. However, health professionals (as

reported by the mothers), gave the impression that discussion of SIDS may cause undue alarm for families and tended to bypass these questions which further compounded the mothers' fears. Health professionals could help families by directly answering questions and explaining that the cause of SIDS is not known, but that apnea monitoring is usually recommended for infants with apnea as a reliable safety precaution for a period of months until the apnea resolves, although it is not a guarantee that the infant will survive.

Fear of discontinuing the monitor. Extreme fear of discontinuing the monitor was reported by 18% of the mothers and is confirmed as a problem in other studies cited previously. These mothers seemed overly dependent on the monitor. Although most admitted some apprehension when it was time to discontinue the monitor, families varied markedly in their response to the recommendation that the monitor be discontinued. Some mothers reported that they discontinued the monitor immediately and others decided to "wean" the infant slowly, starting first during naps, and then gradually leaving the monitor off at night.

Discontinuation of monitoring is medically indicated when the infant has been free of apnea and monitor alarms for 6 weeks to 2 months. At this time, the infant is usually scheduled for a physical examination and may receive an overnight sleep study, or pneumogram. If no

apnea occurs, the monitor is then discontinued. Most of the fearful mothers reported that they were afraid the infant would have another apneic spell and die without the monitor. Health professionals could help these parents by making periodic home visits to assess the status of the infant and to offer support to the mother. Nurses could let parents know that by 6 months of age, most apnea resolves because of the maturity of the respiratory system (although there may be other reasons for apnea).

While in the past it has been fairly easy for families to keep the monitor until they feel comfortable relinquishing it, more current insurance policies require that physicians validate that the monitoring is necessary. Many companies will no longer cover extended periods of unauthorized monitoring. Nurses need to assess families' feelings about eventual discontinuation of the monitor, as well as reasons for keeping the monitor longer periods of time.

These families would benefit from consistent support and periodic evaluations of the infant's growth and development to validate normal findings with the mother. Mothers may need reassurance from the physician that the infant is ready to be taken off the monitor. Also, these families may need the nurse to be physically present during times when the monitor is discontinued so that they have support and are less fearful. It may be helpful for

mothers who are fearful of discontinuing the monitor to talk to other mothers who have terminated monitoring. Timely discontinuation is important so that the mother can resume a normal life, but is equally important for the infant. Monitoring does hinder and restrain the infant because of wires and leads, in addition to noise and blinking lights. It is important that the infant be free of these encumbrances as soon as possible in order to move freely and explore the environment and facilitate mental and psychomotor development.

It is suggested that nurses conduct postmonitoring interviews with mothers to find out ways that they managed during monitoring and to elicit information about how they managed during the period of discontinuation. The knowledge gained could be used by nurses to assist similar families. Finally, it is suggested that physicians refer families to accountable monitor vendors who offer comprehensive 24-hour services to families so that they feel less fearful about the monitor and have a source of communication as problems or questions arise.

Mother Credibility

This category of upset referred to instances in which health professionals appeared skeptical of mothers' reports that apnea occurred in their infants. This concern has not been previously described in the literature, but was a problem for 31% of the mothers in this

sample. The skepticism referred not only to what the mothers interpreted as disbelief, but an attitude conveyed to them that they were not qualified to make a judgment or assessment of the infant's condition. It seemed clear in the interviews that the mothers believed that the apneic event was real and life-threatening, aside from the opinion of health professionals and that their distress was caused by that belief.

In the initial interview with health professionals, mothers reported that they often interpreted health professionals' questions such as "what do you mean by blue?" (referring to the infant's color) to mean that the mother was unable to assess her infant's skin color or status. The mothers seemed threatened by these types of questions, although they were usually necessary, since the physician did not often witness the initial apneic episode and had to make a diagnosis based on the mother's report. The physician is also concerned that placing an infant on a monitor labels the child "at risk," which can have ongoing harmful implications, particularly for the overly-anxious mother. Care does need to be exercised by the health professional against hastily deciding that a mother is incorrect in her assessment, however. Even though a large number of mothers perceived skepticism and lack of credibility from health professionals, 44 reported that their infants experienced one or more apneic events that

they considered serious once they were home with the monitor. Most of these events self-corrected when the alarm startled the infant to breathe, but intervention was needed with a few infants, ranging from slight to vigorous stimulation and CPR by paramedics.

A second cause of upset in the mothers was the experience of being called "mom" or "mommy" by health professionals. Mothers were also upset by health professionals who minimized their distress with remarks such as "You are just a new mom. The baby will be fine."

Health professionals could be more supportive and helpful to families by being aware of the vulnerability of the mother and her interpretation of some types of questions asked during the initial visit to the health care facility. Health professionals need to explain that certain questions must be asked, but that they are not meant to discredit or discount what the mother has observed, and are asked merely to clarify details of the apneic episode. As stated previously, the health professional needs to be aware that the mother almost always believes that the apneic event was life threatening, and is frightened and anxious about the infant's condition. If the health professional is cognizant of the mother's distress, phrases questions in a careful, nonthreatening manner (in terminology that the mother understands), and addresses her by name, a much more supportive and thera-

peutic relationship can be established.

It is hoped that this approach will combat feelings of distress in the mother or feelings of incompetence in her mothering abilities. Raising the problem of perceived skepticism by health professionals through educational offerings or publications in professional journals would be an important goal for nurses.

Technical Problems with Apnea Monitoring

Sixty-five percent of the mothers reported that they experienced technical problems with the monitor. This finding is confirmed by other studies (Dimaggio & Sheetz, 1983; Wasserman, 1984). The highest percent of problems were attributed to false alarms that were frightening to parents. Although this problem is becoming less common due to continued refinement of monitors on the market, parents need proper instruction by health professionals about the correct application of monitor leads and electrodes so that false alarms can be minimized. Most parents experienced false alarms during the night that sent them rushing to the infant's crib in a panicked state. Parents need thorough instruction about all aspects of monitoring before being sent home to operate the monitor. Parents also need to know that strict safety standards insure monitor safety, so that their fears may be lessened.

Physical problems. Physical problems referred to rashes and chafing of the infant's skin that occurred under the electrode pads or chest belt. These problems can usually be prevented if the infant's skin is kept clean and dry and if the belt or pads are left off periodically during the day and exposed to air.

Safety problems. Six infants in this sample sustained a potentially serious injury during monitoring. This apparently was related to the length of monitoring as some of the infants in the study were monitored longer than is currently recommended. Because monitors were initially designed for use with very young infants, apnea monitors are potentially more dangerous when used with toddlers. In two instances, toddlers plugged the monitor adaptor into an electrical socket. One suffered a serious burn to the hand and the other sustained an electrical shock. Two infants had their monitors unplugged by siblings and 2 infants were found in their cribs with wires wrapped around their necks. Although similar incidents were reported in the literature, a safety alert to healthy professionals who care for monitored infants was recently issued by the Federal Drug Administration (1985). Safety for families during monitoring is a crucial area to be addressed by nurses and other health professionals caring for monitored infants.

This is especially important as medical technology is

being used at an accelerated rate in home care. Parents and siblings need education about safe monitor use and parents need to be aware that toddlers are often fascinated by the monitor and that injury can occur if they are allowed to play unsupervised around the monitor. Safety education for families of monitored infants needs to be presented in the hospital setting. The nurse also needs to make a home visit to assess the feasibility for safe home monitoring, although most homes can safely accommodate a monitor. The nurse could assess whether the home has proper electrical outlets, a telephone to call for assistance if problems arise, and the reliability of the caregiver who will assume the major responsibility for care of the monitored infant.

Siblings could be prepared at this time for the arrival of the infant, and need explanations about what the monitor is and what it does (i.e., it helps the baby to breathe). Depending on the age of the siblings, this would be a good time for the nurse to introduce the principles of monitor safety to the other family members. The nurse might explain to siblings that it is dangerous to touch the monitor or to plug in or unplug the monitor. Parents and siblings also need to be adequately prepared through anticipatory guidance for the change in household routine that will occur. An additional goal of nurses, as discussed earlier, would be to assist families in discon-

tinuing the monitor as soon as indicated as this will minimize the potential for accidents and injury.

Disruption of Family Life

Home apnea monitoring was disruptive for the majority of families. Similar results were reported in other research (Bakke & Dougherty, 1982; Black et al., 1978; Brooks, 1982; Duncan & Webb, 1983). The problems described focused on six areas: (a) marital difficulties, (b) effects on siblings, (c) isolation, (d) sleep problems, (e) financial hardship and (f) time perspectives.

Marital problems. Marital problems were reported by 28% of the mothers. Difficulties were attributed to such factors as constant stress, lack of sleep, isolation and the burden and responsibility for care of the infant. Two major concerns reported by mothers of monitored infants were that they were unable to spend time with their husbands and they became irritable from lack of sleep. Dimaggio and Sheetz (1983) found that emotional tension was the greatest concern of 29 mothers of monitored infants. Several mothers in this sample reported that they were resentful that their husbands could sleep at night and see people at work during the day, while they were confined to the house. Nearly all mothers reported that they lacked qualified babysitters, and that relatives and friends were reluctant to help. Several reported more arguments with family members due to the stress of never

being able to rest or relax. One couple was divorced because they "couldn't take the strain of monitoring."

It is possible that the assumption by health professionals that most families are able to manage the 24-hour burden of care of monitored infants is an unrealistic expectation. It may be advisable that health professionals systematically assess each particular family for the ability to cope during monitoring. Further research is needed to determine the costs in terms of the emotional effects and family disruptions that occur during monitoring and the risks that accompany the process.

It seems that nurses could help families by actually organizing support groups and babysitting services. Many mothers indicated that they were willing to babysit for monitored infants, and some said that they would like to trade babysitting services. If parents were able to support and babysit for one another, the problems of social isolation, lack of rest and recreation, and lack of communication might be preventable. Nurses might help mothers with marital difficulties by listening and offering support, counseling with husbands and by referring these couples for marital counseling.

Effects on siblings. Although some studies suggest that siblings may be negatively affected by monitoring, no specific data were available about the types or incidence of problems with siblings. In this sample, 26% of the

mothers reported negative effects in their other children during monitoring and 11 mothers reported high degrees of upset. Problems with siblings related to fear that something would happen to the baby, anxiety attacks, and problems in school.

Wasserman (1984) noted that generalized anxiety was the most common symptom in siblings of monitored infants. The mothers in this sample also reported that siblings felt "pushed into the background," that their routines changed dramatically, and that the mothers were unable to spend as much time with the child as they did previously. Several suggested that siblings be prepared before the baby goes home with a monitor so that they know what to expect. This could be a necessary inclusion in educational programs that nurses could plan for siblings of infants who are monitored, in addition to safety aspects. Nurses could also suggest that relatives and grandparents take siblings on periodic outings, and communicate with parents about the special needs of siblings and the need to spend time with them.

Isolation. Forty-three percent of the mothers reported that they felt socially isolated and confined to the house during monitoring. This was due to fear of leaving home with the baby, the reluctance of friends or relatives to visit or help, and the lack of qualified babysitters. Twenty mothers reported that they never once

left their infants during monitoring. Four reported that they were upset because they were unable to return to work after the baby was born as they had expected. Several reported that they were able to obtain battery-operated monitors that they used for outings which were very helpful. As a whole, mothers felt that their social lives were severely limited and reported that it would be extremely helpful if they could meet other mothers "who were going through the same thing." Nurses could facilitate contact between parents of monitored infants, and could actively contact relatives and friends regarding the mother's need for help and support. The nurse could provide education to supportive others about the monitor, care of the monitored infant and the principles of CPR. In this way, mothers could obtain mutual support and share ideas about managing the monitoring experience. Also, less experienced mothers might be able to receive assistance from those with more experience, as suggested by other authors (Dimaggio & Sheetz, 1983).

Sleep problems. The process of monitoring interfered with the mothers' sleep, not only because of flashing monitor lights and false alarms but because of fear of sleeping through an alarm. They stated that it is was difficult to sleep or truly relax and rest during monitoring. Once the alarm sounded, mothers were usually unable to go back to sleep for the remainder of the night.

Thirty-eight percent reported that their infants slept in their rooms and that the noise and lights from the monitor were disturbing. Ten mothers reported that their infants slept in their bed until monitoring was discontinued. Since sleep problems occurred in 62% of the sample, this is an important area of intervention for nurses. Nurses could assess the particular problems of the mother. If she lacks sleep because she is unable to relax, the nurse might be able to recruit neighbors or relatives to stay with the infant so the mother could sleep during the day. The nurse could also encourage parents to put the infant's crib a short distance from their bed where the alarm could be heard, but where noise from the monitor and infant would not be disturbing. Nurses could also counsel families about the mother's need to sleep, and suggest that husbands take turns sleeping near the infant while the mother is in another room.

Sleeping in the parents' bed should be discouraged as the infant could be injured and the parents' sleep will be disturbed. This practice can also lead to behavior problems when monitoring is discontinued and the infant refuses to sleep alone. If mothers are rested, the pressures of infant care during monitoring will be easier to bear. It is possible that some may have deeper fears such as being away from the infant during sleep, and these mothers may need to be referred to a professional coun-

selor for help.

Financial hardship. The problem of financial strain during monitoring was reported by 30% of the mothers. Although insurance traditionally covers 80% of the costs of apnea monitoring, the remainder must be paid by parents and this can be a hardship for some families. Parents without insurance are particularly burdened, as a monitor typically costs between \$1200 and \$1500 to purchase or approximately \$200 per month to rent. Additional costs include physician visits, medications, pneumograms, household help, transportation, motels near the hospital for some families, and long-distance telephone calls. Wasserman (1984) found that most families were in debt for 1 to 3 years after monitoring was terminated. In this sample, many families reported that the cost of monitoring needed to be supplemented by relatives. One mother reported that she was "terrified" because she ran out of money and had to give the monitor back. Nurses could assist families by possibly arranging for monitors to be donated by businesses or organizations that could be loaned to families who could not absorb the cost of monitoring. Nurses could also refer families who are unable to pay for the monitor or to social workers who might be able to arrange for a monitor.

Time perspective. This category of upset referred to a problem described by 14 mothers who said they were

unable to lead normal lives during monitoring. These mothers said that they perceived time as "standing still" during monitoring. They felt that their lives were "on hold" and that everything revolved around the monitor. They essentially decided to wait out the monitoring period and felt that they had no control over their lives. These mothers seemed to be in particular need of support and encouragement to assume normal activities of daily living. They were afraid to vacuum, play the piano, watch television, or take a shower in fear of missing an alarm.

Nurses might assist by arranging contact with other mothers who managed well during monitoring to share ideas. Nurses could also arrange support from relatives and friends who might be willing to stay with the infant so that the mother could have some personal time to herself. These mothers need to be encouraged to live normal and less-restricted lives.

Emotional Effects

Emotional effects in this study referred to upset experienced by mothers in terms of stress, guilt, feelings of "paranoia," indecision about having a subsequent child and the need to control the monitoring situation.

Stress. Stress was common among mothers. Thirty-one percent reported high levels of stress during monitoring. Stress generally referred to reactions of mothers to events or occurrences that caused them mental or emotional

strain or pressure. They reported that the initial adjustment period in the first few weeks at home was particularly stressful. They were fearful that something would happen to the infant, unsure of monitoring equipment, fatigued, and overwhelmed by the reorganization of their home environment to accommodate monitoring. As discussed previously, health professionals could alleviate much of the mother's stress by addressing its particular causes. This would be helpful in assisting nurses to plan education aimed at reducing stress. Nurses could offer mothers support at home, or could contact family and friends or babysitters to assist and relieve the mother. Nurses could contact other mothers of monitored infants who would be willing to help this group of mothers adjust during monitoring. Mothers need to be encouraged to maintain normal lifestyles and pursue outside interests during monitoring.

Guilt. Twenty-four mothers reported feelings of guilt that they were responsible for the infant's apnea. Nurses could help these mothers by explaining that the cause of apnea is not known and by correcting misconceptions that something during their pregnancy caused the infant to develop apnea. Health professionals need to be aware that insensitive remarks or threatening questions may lead to the development of guilt.

Paranoia. Paranoid was a recurring word used by 15

of the mothers. This self-descriptor seemed to indicate that the mothers might feel that they themselves were overly concerned, and worried excessively. In some cases, they seemed insecure in their mothering abilities. They used the word "paranoid" to describe themselves, such as "I felt paranoid," "I'm still paranoid," and "I was paranoid, maybe I'm a rotten mother." Perhaps these feelings were inadvertently caused by health professionals or relatives who appeared to doubt the mother's credibility concerning apneic episodes, or perhaps the mothers felt guilty or embarrassed by their fears for the infant. The use of the word paranoid may also indicate lingering fears, or distrust of the monitor. Health professionals need to explore in greater depth the meaning of the word paranoid with mothers of monitored infants.

Decision to have a subsequent child. Thirty percent of the mothers said that monitoring negatively affected their decision to have another child because of the frightening experience of monitoring. Although most of the mothers changed their minds and became pregnant, 2 had tubal ligations and 1 husband had a vasectomy to prevent future pregnancies. Twenty-six mothers reported that they would definitely monitor a second child and 9 felt that every new baby should be monitored. Twelve mothers wanted to buy a monitor for a subsequent child, if needed.

One criticism of apnea monitoring is that many

parents perceive the monitor as a cure for Sudden Infant Death Syndrome (SIDS). Parents need to be given valid information about apnea monitoring, apnea and SIDS, and need to know that the monitor is not a "cure" for SIDS. Parents also should be told that physicians cannot guarantee that the apnea monitor will prevent SIDS, as a very small percentage of the infants who were monitored died, although no valid statistics can attribute the cause of death to a specific cause (monitor failure, negligence of the parent to use the monitor properly, or severity of the apneic episode). Lastly, parents need to know that no assurances can be made as to which infants will die of SIDS, whether or not they have a monitor. The monitor needs to be realistically evaluated as a mechanism that can help prevent prolonged apneic episodes, but is not an absolute guarantee against infant death.

Attempt to control the monitoring situation. This category of upset referred to a situation where mothers felt more comfortable using other devices or methods that they believed added to the monitor's function or reliability. For example, 7 mothers used the Fisher Price Nursery Monitor during monitoring. These mothers seemed compelled to use the devices and to recommend them to all mothers. The use of extra devices may possibly indicate high levels of fear in the mothers, but they may also be harmless reassurances to the mothers. Nurses need to be

aware that mothers who use these methods may be more upset than they admit, although this was not demonstrated in this study. Mothers who are highly upset may need more support and counseling to help them dispel or deal with their fears.

Denial in husbands. Fifteen percent of the mothers reported that their husbands appeared to deny the importance or seriousness of the monitoring situation by acting too "happy or carefree." Some husbands distanced themselves from the mother and infant and "escaped into their work or hobbies." These mothers felt resentful, and were unable to resolve the problem in attempts to communicate with their husbands. With these families, the nurse could meet with the husband and try to determine the cause of his denial and to encourage him to support and assist his wife. The nurse may be able to determine specific fears of the husband and to answer questions and clarify misconceptions that he may have. The father may have questions that he may not be willing to ask in the more threatening hospital environment. These fathers may benefit by meeting other fathers or other parents of monitored infants and discussing similar concerns.

Lack of Support

In the personal experiences interview, lack of support was described as a major cause of upset for the mothers (90%). They reported lack of support from

relatives (59%) who were afraid to care for the infant, lack of support from friends (15%), and lack of support from the maternal grandmother (35%) that was attributed to the grandmothers' fear of responsibility for care of the infant, and fear of operating the monitor. This finding was particularly stressful for mothers who looked to their own mothers for support and assistance as they had done in the past.

The reported lack of support described by mothers on the Personal Experiences Interview appeared to be inconsistent with statistics given on the demographic questionnaire when 95% of the mothers reported that they had relatives and friends nearby with whom they visited and saw as often as they wanted. However, the demographic questionnaire inquired about the present situation of the mothers now that monitoring had ended, whereas the Personal Experiences Interview inquired about support available during monitoring. It is possible that the proximity of relatives and friends is not perceived by the mothers as necessarily supportive. Lack of support was confirmed as a concern of mothers in other research (Bakke & Dougherty, 1981; Cain et al., 1980). Lack of support will be addressed in greater detail under the fourth major finding of the study.

Concerns for the Infant

Infant development. Twenty-three percent of the mothers worried about their infant's development. They were particularly concerned that the infant might have experienced a lack of oxygen during apneic episodes that might have affected mental and motor development. Mothers also worried when the infant slept, and would frequently go to the infant to see if the infant was breathing, or would shake the infant to make the child move. Some mothers worried because they felt overprotective. Each of these concerns could be addressed by nurses. Parents usually need information about normal growth and development, especially when the infant has suffered either a real or perceived threat to health and development. This concern was anticipated by the American Academy of Pediatrics (1978) recommendation that health professionals address parental concerns, systematically support families of monitored infants, and periodically assess and validate normal growth and development in these infants.

Worry during sleep. It is understandable that parents of monitored infants might worry when the infant with apnea is sleeping. Nurses can help parents by assisting them to apply the monitor correctly and by encouraging them to rely on the monitor as an aid to help them relax. Monitor standards require that monitors be reliable, safe, and trustworthy; a malfunction would be

extremely rare. No statistics are reported in the literature about the incidence of monitor failure (except in the instance of too many false alarms).

Overprotecting the infant. Mothers who are upset by the tendency to overprotect the monitored infant would benefit from counseling with nurses to determine the reasons and to encourage the mothers to provide a safe environment where the infant could play and explore in a nonrestricted way. This is a necessary task that the infant must accomplish for normal infant development to occur. The nurse needs to assure the mother that all toddlers fall or have occasional minor accidents, but that these incidents are a necessary part of certain developmental tasks such as learning to walk, run, ride a tricycle and others.

Unresolved Problems

Twenty-eight mothers reported that they had various unresolved problems after monitoring was discontinued. One described her problem as a "psychic letdown" from the monitoring experience. Other mothers reported that they continued to be upset or depressed for a number of weeks or months after monitoring was over. Some said that they often relived the memories of apneic events or had continued fears for the infant. These mothers could be assisted by counseling with the nurse or by referral to a professional counselor, as indicated. There may also be a

medical reason for her symptoms and the nurse could refer the mother for a medical examination.

How Health Professionals Could Be More Helpful

Forty-nine percent of the mothers believed that health professionals were not as helpful as they might have been and 33% were ambivalent. A large majority (78%) felt that the need for emotional support was not met. They conveyed that they believed that their infant was in danger and that health professionals were not in tune with their anxiety. Seventy-eight percent believed that home visits by health professionals in the first week would be extremely helpful. Other suggestions about helpful measures included: (a) parent-to-parent telephone support groups (59%); (b) parent support groups (55%); (c) additional education sessions (45%); (d) additional CPR classes (30%); (e) classes for grandparents (45%); (f) 24-hour telephone availability of health professionals the first week or so at home (49%); and (g) qualified babysitters (78%). Nearly all of these needs were confirmed in other studies previously cited.

The overwhelming indication of unmet needs of families in this sample illustrates that families of monitored infants are not always given the necessary component of follow-through and assistance that they need. Families reported that adequate education and emotional

support were lacking in both the health care setting and at home. Health professionals may need to examine critically the safety and practicality of sending medical equipment into the home to be managed solely by unprepared and apprehensive families. Adequate support and weekly follow-through by health professionals seems critical if a safe and high quality of care is to be provided to clients whose infants require home apnea monitoring.

Summary

The overall description of the types of upset experienced by mothers in the sample could guide nurses in developing interventions that would be helpful to families of monitored infants. The assistance needed by families focused on four areas:

1. Mothers described the need for emotional support from health professionals.
2. Mothers needed more education about the management of home apnea monitoring and CPR in order to deal more competently with the demanding period of home monitoring.
3. Mothers universally requested contact with other parents of monitored infants to share experiences and concerns.
4. Mothers needed qualified babysitters to relieve them of the constant care of the infant.

Relationship Between Parenting
Behaviors and Infant
Development and
Behavior

Mothers who felt less positive about parenting had infants who scored lower on the Bayley Scales of Mental and Psychomotor Development. These mothers were significantly more tired, anxious, bored, and had less support than mothers of infants who scored higher on the Bayley Scales.

These findings suggest a positive relationship between the quality of parenting and level of infant development. The infants with lower development scores also had significantly more behavioral problems in all of the three age groups of infants in the study. A major concern of mothers who felt less positive about parenting was the lack of emotional support from health professionals received during the period of monitoring and the lack of available babysitters.

These findings have important implications for nurses who work with families of monitored infants. Nurses could help mothers by offering assistance and emotional support during the first visit to the health care facility. This could be accomplished by spending time with the mothers to answer questions, clarify information, and help assuage fears.

After infants are sent home with the monitor, nurses could make periodic home visits to maintain continuity of

care and support, to help mothers learn to care for monitored infants, and to assess the quality of family relationships in the home environment. For example, nurses might assess certain important factors: (a) Does the mother seem happy and able to manage the care of the monitored infant, or does she seem preoccupied, depressed, or disorganized? (b) Does the mother seem to enjoy the infant or does she seem reluctant or fearful? (c) Does the home provide opportunity for the infant to play and explore in a safe and interesting surrounding? (d) Is the interaction between the mother and infant warm and positive, or does the mother tend to ignore her infant? (e) Does the mother have neighbors or relatives available to support and assist her? and (f) Are the needs of siblings being met?

These are examples of observations that the nurse might make to determine the ability of the mother to adjust to home monitoring. Nurses might assist mothers by organizing contact with other mothers of monitored infants, as well as babysitting services so that the mother could have time for rest and relaxation. The nurse could offer the mother encouragement and positive reinforcement of her parenting abilities.

Importantly, the nurse could teach the mother principles of normal growth and development to help her learn the expected behavior within the physical, cogni-

tive, and psychological domains of her child. Through anticipatory guidance, the nurse could help the mother set realistic limits on the infant's behavior to help prevent the development of behavioral problems.

Development of positive parenting abilities is especially important in infancy because of the developing personality of the infant and need for positive reinforcement from a receptive, responsive parent. If the parent does not interact with the child in a warm and positive way, the child will often respond with insecure behavior such as clinging, crying and unhappiness.

Nurses could also help mothers to differentiate normal infant behavior from misbehavior. For example, mothers who do not understand that some crying is normal in young infants, may perceive this behavior as dissatisfaction or rejection by the infant. These mothers would benefit from education, anticipatory guidance, and encouragement in their mothering abilities and parenting skills so that the formation of a maladaptive relationship between the mother and infant can be prevented. According to Berger (1983), parents who are under stress and who lack support are less able to respond affectionately to their children and are much more likely to take out their problems on their children.

Finally, the nurse could help the mother to organize activities that she and the infant can enjoy together and

that can include other siblings and family members, as well. For instance, the nurse could recommend that the family obtain a battery-operated monitor so that the family could take the infant on outings with them. It is equally important that nurses encourage mothers to obtain some assistance with child care so that they are free to spend time away from the infant with their other children and husbands.

Mothers who felt less positive about parenting had infants with lower scores of infant development and more behavioral problems. These findings have critical importance for nurses working with families of monitored infants. Suggestions for nursing interventions to help families to encourage developmental advance and to ameliorate behavioral problems have been previously discussed. It is important that nurses develop systematic means of addressing the needs suggested by mothers in this study, in both the health care setting and during the months of home monitoring.

Relationship of Duration of Monitoring to Other Study Variables

In this investigation, longer duration of home apnea monitoring was significantly related to certain types of upset in the mother. These were: (a) fear of Sudden Infant Death Syndrome (SIDS); (b) concerns about infant development; (c) boredom and anxiety; (d) lack of support;

and (e) lack of emotional support from health professionals. In addition, the infants who were 13-23 months old and received longer periods of monitoring had significantly more behavioral problems related to sleep.

It seems reasonable that mothers who had high levels of fear of SIDS would have difficulty relinquishing the monitor, especially if the anxiety remained high or worsened during monitoring. Some mothers may also have difficulty discontinuing the monitor if they tend to view the monitor as a preventative measure against SIDS. One explanation for longer duration of monitoring may be that some mothers who have increased anxiety levels about SIDS may convince the physician to order a monitor for their infant even though the diagnosis of apnea is questionable, and then keep the monitor because of fear.

The finding that mothers who monitor longer are bored and anxious was not unexpected as these symptoms are present in most mothers who monitor their infants for shorter periods of time, and it is understandable that these problems might increase if monitoring continued over an extended period of time. It is also a reasonable expectation that mothers who monitor longer might have developmental concerns for their infant since they are generally anxious and fearful that their child's life is in danger from apnea and SIDS.

The development of sleep problems in these infants is

also not surprising. Sleep problems of infants who received monitoring for longer periods of time related to infants' awakening often during the night, sleeping in their parents rooms, and/or sleeping in parents' beds (both during monitoring and in some cases, after monitoring was discontinued). It appears that this group of mothers probably fears separation from the infant even during sleep.

Longer duration of monitoring was also related to maternal lack of support, and lack of emotional support from health professionals. The combination of social and emotional support, together with intense fear suggests that these mothers are at particularly high risk for development of multiple problems, and raises an important question for health professionals. Specifically, did the reported lack of emotional support, education, and communication by health professionals at the health care facility and in the home contribute in part to the mothers' fears and to longer duration of monitoring?

It seems that mothers who keep the monitor for longer periods of time might benefit from more directed support and counseling at the health care facility by nurses to identify particular fears and concerns, particularly with regard to SIDS. At this time, nurses could clarify misconceptions that the mothers may have about SIDS through direct and honest response to questions and by

allowing the mother to talk about SIDS. Additionally, the nurse could make frequent home visits to assess the mother's adjustment to monitoring and to offer ongoing support. The nurse could also help the mother to prepare for discontinuation of the monitor. Families could be offered information in advance of discontinuing the monitor so that they would know what to expect. For example, nurses could advise families that by 6 months of age, most apnea of infancy is resolved, and that if the infant has been free of apneic episodes for 6 to 8 weeks, most physicians agree that monitoring can be safely discontinued.

Families should know that they have a choice to discontinue the monitor abruptly, or that monitoring can be slowly discontinued by first leaving it off for naps and eventually at night. If nurses perceive that certain mothers are fearful of relinquishing the monitor, they would need to assess the nature of the fear and concerns in order to plan supportive interventions to facilitate the discontinuation process. Some mothers might feel more comfortable if the infant has a medical examination and an overnight sleep study (pneumogram) to validate that the child is free of apnea. It might also be helpful to introduce the mother to other mothers who have been through the experience of discontinuing the monitor in order to learn how they coped during the process and to

find out what was helpful to them. In addition, these mothers may feel more comfortable if the nurse is present as they discontinue the monitor. If these measures do not resolve the mother's fears and conflict about discontinuing the monitor, the mother may need to be referred to a professional counselor for assistance.

Relationship of Lack of Support to Other Study Variables

Lack of support during monitoring was found to be significantly related to the following variables: (a) high level of maternal upset; (b) longer duration of monitoring; (c) mothers who felt less positive about parenting; (d) lower scores of infant development; and (e) incidence of infant behavioral problems. Support was defined as affiliation, help, or assistance that the mothers received from significant others during home monitoring.

Nearly all mothers (90%) initially reported on the demographic questionnaire that they had friends and relatives nearby whom they saw or could see as often as they wished. During the Personal Experiences Interview, however, mothers stated that they did not perceive relatives and friends as helpful during monitoring and that it was predominantly the spouse who offered the majority of support during monitoring. The finding that the spouse was the most supportive person during monitor-

ing was confirmed by Geary (1983).

Thirty-five percent of the mothers reported that their own mothers were not as helpful as they had expected them to be. The grandmothers were reported to be reluctant to help with infant care and were fearful of the monitor. Some mothers reported that this had a detrimental effect on their previously close relationship with their mothers whom they had always relied on for support and help. The grandmothers' fears (as reported by the mothers) related to fear that something would happen to the infant while in their care, and fear of operating the monitor. Only two grandmothers had accompanied their daughters to the CPR class and none had received education about the monitor. One mother commented that her mother's apprehension was related to changes in health care and the new technology that her mother had not experienced when raising her family. As suggested previously, it would be helpful to include grandparents and other family members in education classes about the monitor and CPR training classes so that they would be prepared to care for the infant and would feel more comfortable in assisting the mother with the monitored infant.

A large number of mothers (59%) reported that relatives were also nonhelpful and tended to "stay away" during monitoring, as did friends (15%). These findings are similar to those reported by Geary (1983). Results

indicate that mothers who demonstrated a more positive response during monitoring had more social support, particularly from their husbands.

Social support appears to be a very important variable affecting the mother's level of upset, her parenting behaviors, and infant development and behavior. The relationship of social support to each of these variables (including suggestions for nursing interventions) have been discussed previously.

It was not anticipated that the variable social support would have such an important impact upon maternal and infant response to home monitoring. This finding suggests that further research is needed to evaluate systematically the relationship and importance of social support to healthier responses of mothers and infants during home monitoring. Data from this investigation suggest that social support may have decreased some of the deleterious effects of home apnea monitoring.

It is notable that the qualitative data obtained from mothers on the Personal Experiences Interview concerning the importance of social support and its relationship to other variables validates both the utility and complementarity of qualitative and quantitative research approaches. The mothers' responses to the Personal Experiences interview added an important context to the quantitative data obtained and enabled social support to

more clearly emerge as a critical variable affecting maternal response to monitoring.

Other Findings of Clinical Interest

Infant Development Scores Compared with Home Environment Scores

Infants scored significantly higher on the Bayley Scales of Infant Development than the Bayley norm, and scored higher on most subscales of the Home Observation for Measurement of the Environment (HOME) than the HOME norm. A possible explanation for this finding is that nearly all infants in the sample belonged to two-parent, middle class families of the same religious denomination. Since the HOME scores demonstrated that the infants had higher scores of opportunities for daily stimulation, mother-infant interaction, and other qualities promoting developmental advance, this may in large part, explain their higher infant development scores. A second factor that may have contributed to higher infant development scores is that nearly all families were of the Mormon faith which places a high value on childrearing. Nearly all homes had adequate provision of toys and play things to encourage infant development.

Incidence of Behavioral Problems

There were significantly more behavior problems reported by mothers of infants who had low mental and

psychomotor development scores in all three age groups. This may, in part, be attributed to the fact that infants who had higher development scores, had older mothers and fathers. In addition, more fathers of these infants were employed in professional occupations. It is possible that older, more experienced parents and those with a professional background somehow provided a more optimal environment than the younger mothers were able to provide. It is a possibility that some young mothers who have not had experience with parenting may lack parenting skills and do not understand how to care for a young infant, or what normal infant behavior consists of.

It is possible that in these cases, the mother might become frustrated with the infant and may not be able to meet the infant's needs in an appropriate way. For instance, she may not know which play things to select for her infant. She may interpret the infant's crying or unhappiness as a rejection of her mothering abilities which may interfere with establishment of a healthy mother-infant relationship. These families need sensitive and caring guidance by nurses and health professionals to correct maladaptive parenting behaviors. Behavior problems in infants between 7 months and 2 1/2 years of age are often manifested by excessive crying, feeding problems, sleeping problems, elimination problems, and problems requiring appropriate discipline. Nurses could

help young and inexperienced mothers by offering anticipatory guidance for behaviors of the infant's appropriate age, and assist with parenting skills. Mothers would benefit from education about infant growth and development and ways that the mother can offer enjoyable experiences to the child that will encourage development and happier behavior. The nurse might refer the mother to a young parents' class offered by many community centers, as well as recommend that the mother meet with other mothers of monitored infants in order to share experiences of parenting the monitored infant. The nurse could make periodic home visits to the mother and infant to assess their relationship, to correct maladaptive parenting behaviors, and to encourage the mother in her mothering practices. The nurse might have to arrange support for these mothers and provide them with names of qualified babysitters so that she can have some time for herself away from the infant.

Maternal Upset: Significant
Correlation With Other
Variables

In addition to social support and duration of monitoring, maternal upset was significantly correlated with: (a) infants who were older at the time of monitoring, (b) mothers who felt less healthy, (c) mothers who reported sleep problems in infants 7-12 months of age, and (d) infants who had elimination problems in the 24-30

month age group. Sleep problems referred to infants who awakened several times or more during the night and would not take naps, or those who had difficulty going to sleep at night. Elimination problems referred to constipation or diarrhea that sometimes can indicate illness or emotional upset in children.

Each of these problems may be related to parenting behaviors by a mother who is very upset and does not perform her parenting role in a satisfactory way, or who is consistently unable to meet her infant's needs. These mothers would benefit by assessment of problems and education by nurses to correct faulty parenting behaviors. Nurses could assist mothers to help the infant feel happy and relaxed through play or outings prior to going to sleep, and to offer the infant interesting and stimulating activities during the day so that the infant feels tired and wants to sleep at night. The nurse could also assess the nutritional and health status of infants that may be related to elimination problems, and help the mother provide a more suitable diet. The nurse could refer the infant for a physical examination if health problems are detected. If the mother is attempting to toilet train a child who is not neurologically ready, elimination problems can also occur. This often causes a mother frustration if she thinks that the child is misbehaving by not using the toilet. The nurse could help the mother set

more realistic goals for the time when the child is ready to be toilet trained.

Finally, the nurse could encourage her to spend time away from the infant in activities that she enjoys. This will help to improve her relationship with the infant because she will feel more happy and relaxed if she has time to pursue her own interests and is not continually confined to the house with the infant.

Discussion of Additional Analyses

Demographic Data

The older age of mothers whose infants had high mental development scores and the older age of fathers whose infants had higher psychomotor scores on the Bayley Scales of Infant Development suggest that experience in parenting may possibly be a factor that enhances a young child's mental development. In addition, the presence of siblings in these families may encourage an infant's developmental progress.

Professional occupation of the father was a significant variable related to high mental development. Since professional education is usually attained by a college education that sometimes leads to higher salaries, these families may have more enriched lifestyles that could benefit the infants.

Mothers who reported that they had a confidant had

significantly more infants who scored in the high psychomotor development group. Possibly, this is related to the supportive relationship that the mother had with a friend since support was demonstrated to be extremely important in maternal response to home apnea monitoring.

Siblings of Victims of Sudden Infant Death Syndrome

Infants who were siblings of victims of SIDS had significantly higher mental and psychomotor development scores. This was an unexpected finding as it was assumed that parents who had lost a child previously to SIDS would be more upset or anxious that might compromise infant development. However, opposite results were found. Perhaps these parents were more attentive or devoted to the subsequent infant which encouraged infant development. These infants also had significantly higher birthweight which may reflect more careful, or better prenatal care.

Limitations of the Research

Although efforts were made to minimize the limitations of this investigation, the following are recognized. The retrospective design was a major limitation, as subjects were required to report data based on recall and may have perceived the monitoring experience as a singular, global event, rather than as a continuum of life events.

A second limitation is that the sample accessible to

the researcher consisted primarily of middle class, traditional, nuclear families who were Caucasian and of the Mormon faith. Therefore, results cannot be generalized to families of lower economic and educational levels, those of differing ethnic groups and cultures, alternative families or noncohesive families. Because of these design and sample limitations, it is not possible to state that the relationships found in the sample would be the same as the relationships in any other group of mothers and infants. Finally, two pilot instruments constructed by the researcher and an associate were used and must be refined before reliability can be demonstrated.

Implications for Nursing Education and Research

Nursing Education

Nursing education provides theoretical content and clinical experience to teach the art and science of nursing. Because apnea monitoring is one of multiple medical technologies now being introduced into home care, nursing students need education about the safe and appropriate use of this equipment in the home in order to offer safe, quality care to clients. It is indicated that nursing curricula include courses on home care at both the baccalaureate and master's level in order to meet this educational need. Pediatric and community health students also need the clinical opportunity to care for techno-

logically-dependent children in the home setting, to assist families in the management and care of monitored infants, and to apply skills learned in psychosocial nursing. Registered nurses who practice in hospitals will then be knowledgeable of the special problems of home care that can assist them in appropriate discharge planning for clients.

Nursing Research

The process of infant apnea monitoring is a prototype for other medical technology now being used in the home including dialysis, hyperalimentation and mechanical ventilation. These technologies are being increasingly prescribed to parents who are being asked to assume the burden and responsibility for highly technological care of their children on a 24-hour basis. The population of parents to whom these technologies are being prescribed is, at this point in time, an essentially unstudied population. Researchers need to focus on the specific needs of these families and the safe delivery of quality home care. Importantly, nurses need to conduct research to bring a nursing perspective to delivery of highly technological care in the home, to complement those of psychologists, pediatricians and related disciplines.

Recommendations for Future Research

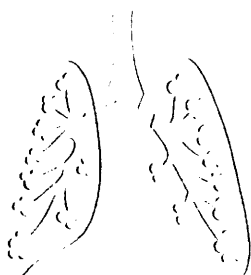
This descriptive research provides a starting point on which other research can be based. Recommendations for future studies include, but are not limited to, the following areas. Nurses could conduct studies to determine the effects of nursing support on maternal adjustment to home apnea monitoring, as support was a critical variable affecting the mothers' level of upset in this sample.

It is also important that future research address the effect of parent education on the duration of monitoring. Research needs to be conducted to determine the effects of parent education, emotional support, and home follow-up services on adjustment during monitoring and it would be equally important to determine the effect of education on adjustment of grandparents and relatives during monitoring. Another important question to be addressed by research is whether planned emotional support decreases maternal feelings of fear, isolation and upset. Investigators could address the participation of fathers upon developmental outcomes of monitored infants and the effect of systematic anticipatory guidance upon incidence of behavioral problems of monitored infants. A goal of future studies is to identify ways that families can have more control over their own care during apnea monitoring

and become more autonomous participants in the health care delivery system.

APPENDIX A

LETTER OF INTRODUCTION AND CONSENT FORMS



DIVISION OF PEDIATRIC PULMONOLOGY

Department of Pediatrics • University of Utah Medical Center
50 North Medical Drive • Salt Lake City, Utah 84132 • (801) 581-2410

Dear :

In 1982 we saw your child #F3# in our program at the University of Utah and because of the history and our findings we recommended using a home monitor for a few months. We are very interested in the continued health of our previous patients and in following their progress.

We are writing to you because a study will begin shortly in which families whose children have been on home apnea monitors will be contacted and invited to participate. This will involve one meeting with you and #F3# during which you will be asked a number of questions and your child's response to his/her environment observed. The information we are seeking concerns child development and behavior and your experiences with home monitoring. The information gained will assist us and other health care professionals to help other children and their families who require apnea monitoring and will assist us in learning more about #F4# progress. We believe that this is an important study and would appreciate very much your help. Again, only one meeting lasting one to two hours is required.

The person conducting the study is Pat Nuttall, R.N., of the University of Utah College of Nursing. She will call you within the next week to arrange an appointment with you in your home. Your participation is strictly voluntary. You may call her at 364-4203 if you have questions or would like more information. Thank you for your consideration.

Sincerely,

Dennis W. Nielson, M.D., Ph.D.
Assistant Professor of Pediatrics

DWN:md

Informed Consent Form

This study concerns home apnea monitoring. Since you are the parents of an infant who received apnea monitoring, I would like to invite you to participate in the study. The purpose of this research is to learn more about home apnea monitoring and its effect upon infants and their families. The information gained will assist child care professionals to offer helpful information and guidance to other families whose child requires monitoring. If you decide to participate in the study, you and your infant will meet with the investigator on one occasion in your home. The visit will last approximately 1 1/2 hours.

Mothers who participate in the study will fill out several brief questionnaires and be interviewed by the investigator at the home visit. This will include information about your baby's personality characteristics and behavior and about your experiences during the period of apnea monitoring. The investigator will also perform an examination of your baby's development and observe you and your baby in your home environment. If your child should become upset or tired, the examination will be terminated. You may choose not to respond to a particular topic or questionnaire or interview question and you may decline to have your baby receive the examination.

All information will be kept confidential and you will remain anonymous through the use of a code number rather than your name (The Food and Drug Administration may inspect the research but information will be kept confidential). There will be no cost to participants. Mothers may withdraw from the study at any time and this will not influence any future care which the mother or child may receive at the University of Utah Medical Center.

If you have questions or need clarification or further information about the study, please feel free to contact the investigator of this research:

Patricia Nuttall
College of Nursing, University of Utah
25 South Medical Drive
Salt Lake City, UT 84112
(801) 581-8214

You may also call the Institutional Review Board office (581-3655) if you have further questions.

I have read and understand this informed consent form and agree to participate with my infant in the research described above. I understand that I am to retain a copy of this consent form.

Name of Infant _____

Signature of Approving Person

Legal Position of Approving Person

Date _____

Informed Consent for Audiotaping

A number of mothers who agree to participate in the study will be randomly selected and asked if they would be willing to have the interview portion of the study audiotaped. The content of the tape will be kept confidential and your identity will remain anonymous through the use of a code number. The audiotapes will be destroyed at the conclusion of the study. Your participation in the audiotaping is voluntary and you are free to decline if you wish.

For comments, clarifications, questions, or further information, please feel free to contact the principal investigator of this research:

Patricia R. Nuttall
College of Nursing
University of Utah
25 South Medical Drive
Salt Lake City, UT 84112
(801) 581-8214

You may also call the Institutional Review Board office (581-3655) if you have further questions.

* * * * *

I have read and understand this informed consent and agree to have my interview with the investigator audiotaped. I understand that I am to retain a copy of this consent form.

Name _____ Signature _____

Date _____

APPENDIX B

INFANT BEHAVIOR RATING SCALE

Infants 6-12 Months

The following questions are meant to describe the patterns of your child's life. You are asked whether a specific behavior occurs and how frequently it is seen (1 = never, 5 = always). If you feel a particular question does not apply to your child, you may simply write NA.

Child's name _____ Birthdate _____

How often does your child do the following?

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
<u>Sleep</u>					
1. Have a regular sleep pattern	1	2	3	4	5
2. Waken at night?	1	2	3	4	5
3. Require comfort- ing when awakens at night?	1	2	3	4	5
4. Need feeding once awakened at night?	1	2	3	4	5
5. Up for longer than 1/2 hour at night?	1	2	3	4	5
6. Nap in the morning?	1	2	3	4	5
7. Nap in the afternoon?	1	2	3	4	5
8. Seem restless in sleep?	1	2	3	4	5
9. Have difficulty settling down to sleep?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
10. Sleep in parents' room?	1	2	3	4	5
11. Sleep in parents' bed?	1	2	3	4	5
<u>Feeding</u>					
1. Eat well?	1	2	3	4	5
2. Spit up/vomit feedings?	1	2	3	4	5
3. Enjoy finger feeding?	1	2	3	4	5
4. Drink from a cup?	1	2	3	4	5
5. Seem satisfied after feeding?	1	2	3	4	5
6. Appear distressed or have gas after eating?	1	2	3	4	5
7. Dump food from table in play?	1	2	3	4	5
<u>Elimination</u>					
1. Have regular bowel movements?	1	2	3	4	5
2. Have diarrhea	1	2	3	4	5
3. Have constipation or straining for stools?	1	2	3	4	5
4. Require an enema for BM?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
<u>Fussing/Crying</u>					
1. Cry or seem miserable or unhappy?	1	2	3	4	5
2. Soothe easily when picked up while crying?	1	2	3	4	5
3. Cry when you leave the room?	1	2	3	4	5
4. Seem happy, smile or laugh?	1	2	3	4	5
5. Remain happy when alone on the floor or in a playpen?	1	2	3	4	5
6. Cry when a stranger approaches?	1	2	3	4	5
7. Seem to cry to get his/her way?	1	2	3	4	5
8. Hold breath or turn blue with crying?	1	2	3	4	5
<u>Discipline/Behavior Control</u>					
1. Understand the meaning of "no!"?	1	2	3	4	5
2. Willfully disobey your commands?	1	2	3	4	5
3. Need to be disciplined?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
4. When disciplined, what techniques are used?					
(a) spoken command ("No," "Don't")?	1	2	3	4	5
(b) distraction (playing with child to keep from doing something else?)	1	2	3	4	5
(c) remove from undesirable situation -- "time out" (e.g., putting in playpen or crib?)	1	2	3	4	5
(d) spanking of the hand?	1	2	3	4	5
(e) other spanking?	1	2	3	4	5

Infant 13-23 Months

Child's Name _____ Birthdate _____

The following questions are meant to describe the patterns of your child's life. You are asked how often your child shows a certain type of behavior (1 = never, 5 = always). If a particular question does not apply to your child, you may simply write NA.

How often does your child do the following?

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
<u>Sleep</u>					
1. Have a regular sleep pattern?	1	2	3	4	5
2. Wake once at night?	1	2	3	4	5
3. Wake 2 or more times/night?	1	2	3	4	5
4. Require attention when awakens at night?	1	2	3	4	5
5. Seem to have nightmares?	1	2	3	4	5
6. Take an afternoon nap?	1	2	3	4	5
7. Take a morning nap?	1	2	3	4	5
8. Awaken at the slightest sound?	1	2	3	4	5
9. Have difficulty settling down to sleep?	1	2	3	4	5
10. Sleep in parents' room?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
11. Sleep in parents' bed?	1	2	3	4	5
12. Go to bed by 8:30 pm?	1	2	3	4	5
13. Go to bed at a regular time?	1	2	3	4	5
If so, what time?					

Feeding

1. Have regular meals?	1	2	3	4	5
2. Have a good appetite?	1	2	3	4	5
3. Try new foods and enjoy them?	1	2	3	4	5
4. Drink milk from a bottle?	1	2	3	4	5
5. Eat with a spoon?	1	2	3	4	5
6. Eat at the table with the family?	1	2	3	4	5
7. Eat vegetables when offered?	1	2	3	4	5
8. Eat meat when offered?	1	2	3	4	5
9. Eat fruit when offered?	1	2	3	4	5
10. Prefer to eat sweets?	1	2	3	4	5
11. Spit out food?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
12. Prefer to feed himself/herself?	1	2	3	4	5
<u>Toileting</u>					
1. Have regular bowel movements?	1	2	3	4	5
2. Have loose stools or diarrhea?	1	2	3	4	5
3. Fight having diaper changed?	1	2	3	4	5
4. Cry or tell you when he/she needs a diaper change?	1	2	3	4	5
5. Have constipation or straining for stools?	1	2	3	4	5
<u>Emotions and Play</u>					
1. Seem happy and playful?	1	2	3	4	5
2. Seem healthy and strong?	1	2	3	4	5
3. Become easily frustrated?	1	2	3	4	5
4. Have temper tantrums?	1	2	3	4	5
5. Whine and cry excessively?	1	2	3	4	5
6. Seem overly active?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
7. Become upset by strangers?	1	2	3	4	5
8. Cry when you leave?	1	2	3	4	5
9. Like to be held and cuddled?	1	2	3	4	5
10. Seem to be clingy and dependent on you?	1	2	3	4	5
11. Seem fearful of noises, objects or animals?	1	2	3	4	5
12. Seem willful or defiant?	1	2	3	4	5
13. Get hurt accidentally (accident-prone)?	1	2	3	4	5
14. Require discipline for problem behavior?	1	2	3	4	5
15. For discipline, how often do you use:					
(a) verbal demands (No!, Stop!)?	1	2	3	4	5
(b) redirection to another activity (getting child to play a game with you instead of playing with the TV?)	1	2	3	4	5
(c) spanking of hand?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
(d) other spanking?	1	2	3	4	5
(e) ignoring (not giving attention to bad behavior)?	1	2	3	4	5
(f) "time out" (placed in playpen, crib or corner when disobeys)?	1	2	3	4	5
16. Lose control in play (bite, throw toys, pull hair, etc.)?	1	2	3	4	5
17. Enjoy playing when you and other family members are not nearby?	1	2	3	4	5
18. Enjoy playing with other children?	1	2	3	4	5
19. Move from one toy to another, spending little time with one?	1	2	3	4	5

Child Age 24-30 Months

The following questions are meant to describe the patterns of your child's life. You are asked how frequently certain behaviors are seen (1 = never, 5 = always). If you feel a specific question does not apply to your child, you may simply write NA.

Child's Name _____ Birthdate _____

How often does your child do the following?

Never	Seldom	Some- times	Often	Always
1	2	3	4	5

Sleep

1. Wake up at night?	1	2	3	4	5
2. Require your attention when wakes at night?	1	2	3	4	5
3. Have nightmares (bad dreams)?	1	2	3	4	5
4. Take a good nap?	1	2	3	4	5
5. Need a nap but not take one?	1	2	3	4	5
6. Awaken at the slightest sound?	1	2	3	4	5
7. Have difficulty settling down to sleep?	1	2	3	4	5
8. Sleep in parents' bed?	1	2	3	4	5
9. Have a regular bedtime?	1	2	3	4	5
10. Get enough sleep?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
<u>Feeding</u>					
1. Have a good appetite?	1	2	3	4	5
2. Try new foods easily?	1	2	3	4	5
3. Use a spoon without spilling much?	1	2	3	4	5
4. Drink milk from a bottle?	1	2	3	4	5
5. Eat at table with family?	1	2	3	4	5
6. Have stomach cramps, gas or "colic"?	1	2	3	4	5
7. Prefer to eat sweets?	1	2	3	4	5
8. Spit out food when not wanted?	1	2	3	4	5
9. Throw-up when not ill?	1	2	3	4	5
10. Eat things that are not food?	1	2	3	4	5
<u>Elimination</u>					
1. Cry with bowel movements?	1	2	3	4	5
2. Have diarrhea or loose stools when not ill?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
3. Have constipation or straining for stools?	1	2	3	4	5
4. Play with (or smear) bowel movements?	1	2	3	4	5
5. Require the use of an enema?	1	2	3	4	5

Emotions and Play

1. Seem happy and playful?	1	2	3	4	5
2. Seem healthy and strong?	1	2	3	4	5
3. Become easily frustrated?	1	2	3	4	5
4. Have temper tantrums?	1	2	3	4	5
5. Seem overly stubborn?	1	2	3	4	5
6. Whine or cry excessively?	1	2	3	4	5
7. Appear overly active?	1	2	3	4	5
8. Become upset by strangers?	1	2	3	4	5
9. Cry when you leave?	1	2	3	4	5
10. Show fear of noises, animals or objects?	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
11. Sneak out of the house?	1	2	3	4	5
12. Seem clingy or dependent on you?	1	2	3	4	5
13. Lose control in play (bite, throw toys, pull hair, etc.)?	1	2	3	4	5
14. Seem willful or defiant?	1	2	3	4	5
15. Get hurt accidentally (accident-prone)?	1	2	3	4	5
16. Hold breath when upset?	1	2	3	4	5
17. Show destructive behavior?	1	2	3	4	5
18. Enjoy playing when you or other family members are not nearby?	1	2	3	4	5
19. Enjoy playing with other children?	1	2	3	4	5
20. Move from one toy to another spending little time with one?	1	2	3	4	5
21. Play with genitals (sex parts)?	1	2	3	4	5
22. Have nervous habits (nail biting, hair pulling, rocking, etc.).	1	2	3	4	5

	Never	Seldom	Some- times	Often	Always
	1	2	3	4	5
23. Act overly shy?	1	2	3	4	5
24. Require discipline (punishment) for problem behavior?	1	2	3	4	5
25. For discipline, how often do you use:					
(a) verbal demands (No!, Stop!)?	1	2	3	4	5
(b) redirection to another activity (getting child to play a game with you instead of playing with the TV?)	1	2	3	4	5
(c) spanking of hand?	1	2	3	4	5
(d) other spanking?	1	2	3	4	5
(e) ignoring (not giving attention to bad behavior)?	1	2	3	4	5
(f) "time out" (placed in playpen, crib or corner when disobeys)?	1	2	3	4	5

APPENDIX C

PARENTING INVENTORY

Never	Seldom	Some- times	Fre- quent- ly	Always
1	2	3	4	5

Emotions and Feelings

How often do you?

1. Enjoy being a mother?	1	2	3	4	5
2. Feel close to your baby?	1	2	3	4	5
3. Wish you could lose weight?	1	2	3	4	5
4. Feel tired?	1	2	3	4	5
5. Share your feelings with a friend?	1	2	3	4	5
6. Feel that the baby's demands are overwhelming?	1	2	3	4	5
7. Feel generally happy and content?	1	2	3	4	5
8. Feel upset if the housework is not done?	1	2	3	4	5
9. Feel that the baby is spoiled?	1	2	3	4	5
10. Feel locked in the house?	1	2	3	4	5
11. Feel you may not be meeting all of your baby's needs?	1	2	3	4	5
12. Enjoy your baby?	1	2	3	4	5

	Never	Seldom	Some- times	Fre- quent- ly	Always
	1	2	3	4	5
13. Feel that the baby's demands on your time are overwhelming?	1	2	3	4	5
14. Feel bored and anxious?	1	2	3	4	5
15. Feel that your relationship with your husband is happy and satisfying?	1	2	3	4	5

Health and Recreation

How often do you?

16. Feel well and energetic?	1	2	3	4	5
17. Eat nutritious foods?	1	2	3	4	5
18. See the doctor?	1	2	3	4	5
19. Get exercise?	1	2	3	4	5
20. Get enough sleep?	1	2	3	4	5
21. Spend an evening out with your husband or a friend?	1	2	3	4	5
22. Have friends in to visit?	1	2	3	4	5
23. Visit friends in their homes?	1	2	3	4	5
24. Pursue a hobby or interest?	1	2	3	4	5

	Never	Seldom	Some- times	Fre- quent- ly	Always
	1	2	3	4	5
25. Work at a job outside the home?	1	2	3	4	5
26. Go to church?	1	2	3	4	5
27. Work in the yard?	1	2	3	4	5
28. Feel too tired to do much of anything?	1	2	3	4	5
29. Feel slightly tired at the end of the day?	1	2	3	4	5
30. Go on a short vacation?	1	2	3	4	5

Support from Others

How Often Do You?

31. Have help with baby care?	1	2	3	4	5
32. Have help with housework?	1	2	3	4	5
33. Have a baby-sitter?	1	2	3	4	5
34. Have relatives available to help you if you need support and help?	1	2	3	4	5
35. Spend time with a close relative?	1	2	3	4	5

	Never	Seldom	Some- times	Fre- quent- ly	Always
	1	2	3	4	5
36. Receive cooperation and assistance from your husband with housework and baby care?	1	2	3	4	5
37. Receive contact and help from your church group?	1	2	3	4	5

Concerns about Infant Care

How often do you?

38. Worry about your baby's health?	1	2	3	4	5
39. Worry about your baby's development?	1	2	3	4	5
40. Wish you could spend more time with your baby?	1	2	3	4	5
41. Feel satisfied that your baby is content and happy with the care you provide?	1	2	3	4	5
42. Worry that something might happen to your baby?	1	2	3	4	5
43. Pray for your baby's safety?	1	2	3	4	5
44. Feel uneasy when you have left your baby with a baby-sitter?	1	2	3	4	5

Never	Seldom	Some- times	Fre- quent- ly	Always
1	2	3	4	5

Infant Health

How often does your baby?

45. Have a health problem?	1	2	3	4	5
46. See a doctor?	1	2	3	4	5
47. Have an ear infection?	1	2	3	4	5
48. Have a cold?	1	2	3	4	5

APPENDIX D

HOME INVENTORY FOR FAMILIES OF INFANTS
AND TODDLERS

by Bettye M. Caldwell and Robert H. Bradley¹

Family Name _____ Date _____ Visitor _____

Child's Name _____ Birthdate _____

Age _____ Sex _____ Caregiver for visit _____

Relationship to child _____

Family Composition _____
(persons living in household including
sex and age of children)

Family Ethnicity _____ Language Spoken _____

Maternal Education _____ Paternal Education _____

Is Mother Employed? _____ Type of Work When Employed _____

Is Father Employed? _____ Type of Work When Employed _____

Address _____ Phone _____

Current child care arrangements _____

Summarize past year's
arrangements? _____

Caregiver for visit _____

Other persons present _____

Comments _____

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Summary

Subscale	Score	Lowest Middle	Middle Half	Upper Fourth
I. Emotional and Verbal RESPONSIVITY of parent		0-6	7-9	10-11
II. ACCEPTANCE of Child's Behavior		0-4	5-6	7-8
III. ORGANIZATION of Physical and Temporal Environment		0-3	4-5	6
IV. Provision of Appropriate PLAY MATERIALS		0-4	5-7	8-9
V. Opportunities for VARIETY in Daily Stimulation				
TOTAL SCORE		0-25	26-36	37-45

For rapid profiling of family, place an X in the box that corresponds to the raw score on each subscale and the total score.

Home Inventory²

Place a plus (+) or minus (-) in the box alongside each item if the behavior is observed during the visit or if the parent reports that the conditions or events are characteristic of the home environment. Enter the subtotal and total in the summary section of the record sheet.

I. Emotional and Verbal RESPONSIVITY

1. Parent spontaneously vocalized to child twice	
2. Parent responds verbally to child's verbalizations	
3. Parent tells child name of object or person during visit	
4. Parent's speech is distinct and audible.	
5. Parent initiates verbal exchanges with visitor	
6. Parent converses freely and easily.	
7. Parent permits child to engage in "messy" play.	
8. Parent spontaneously praises child at least twice.	
9. Parent's voice conveys positive feelings toward child.	
10. Parent caresses or kisses child at least once.	
11. Parent responds positively to praise of child offered by visitor.	
Subtotal	

²For complete wording of items, please refer to the Administration Manual.

II. ACCEPTANCE of Child's Behavior

12. Parent does not shout at child	
13. Parent does not express annoyance with or hostility to child	
14. Parent neither slaps nor spansks child during visit.	
15. No more than one instance of physical punishment during last week.	
16. Parent does not scold or criticize child during visit.	
17. Parent does not interfere or restrict child more than 3 times	
18. At least 10 books are present and visible.	
19. Family has a pet	
SUBTOTAL	

III. ORGANIZATION of Environment

20. Substitute care is provided by one to three regular substitutes	
21. Child is taken to grocery store at least once/week	
22. Child gets out of house at least four times/week	
23. Child is taken regularly to the doctor's office or clinic	
24. Child's has a special place for toys and treasures	
25. Child's play environment is safe	
SUBTOTAL	

IV. Provision of PLAY MATERIALS

26. Muscle activity toys or equipment	
27. Push or pull toy	
28. Stroller or walker, kiddie car, scooter, or tricycle	
29. Parent provides toys for child during visit	
30. Learning equipment appropriate to age -- cuddly toys or role-playing toys	
31. Learning facilitators -- mobile, table and chairs, high chair, playpen	
32. Simple eye-hand coordination toys	
33. Complex eye-hand coordination toys (those permitting combination)	
34. Toys for literature and music	
SUBTOTAL	

V. Parent INVOLVEMENT With Child

35. Parent keeps child in visual range, looks at often	
36. Parent talks to child while doing household work	
37. Parent consciously encourages developmental advance	
38. Parent invests maturing toys with value via personal attention	
39. Parent structures child's play periods.	

40. Parent provides toys that challenge child to develop new skills	
SUBTOTAL	

VI. Opportunities for VARIETY

41. Father provides some care daily	
42. Parent reads stories to child at least three times weekly	
43. Child eats at least one meal per day with mother or father	
44. Family visits relatives or receives visits once a month or so	
45. Child has three or more books of his/her own	
SUBTOTAL	
TOTAL SCORE	

APPENDIX E

UTAH TEST APPRAISING HEALTH: UTAH IVS

Instructions¹

The following questions relate to situations which may have occurred in your life during the time your child received monitoring for apnea. Please respond by circling the letter in the column if the event or situation occurred. If the event did not occur, do not respond at all.

During the time your child received apnea monitoring, did you?

- | | |
|--|---|
| 1. Have a change in your role as wife or mother? | A |
| 2. Have a change in living conditions? | B |
| 3. Change some of your personal habits? | C |
| 4. Have a change in responsibilities in work? | D |
| 5. Experience a marital reconciliation? | A |
| 6. Have a change in residence? | B |
| 7. Change some of your eating habits? | C |
| 8. Have a fight with a close friend? | E |
| 9. Have monthly car payments | F |
| 10. Begin or finish school? | B |
| 11. Change some of your sleeping habits? | C |
| 12. Become drunk or disorderly? | E |
| 13. Have a change in attitude toward your job? | D |
| 14. Get married? | A |
| 15. Have a bank loan (other than education, house, or car loan)? | F |
| 16. Have a change in your usual social activities? | B |
| 17. Change some of your exercise habits? | C |
| 18. Leave home for a period of hours or longer because of a dispute? | E |

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19. Have a change in your boss? D
20. Have trouble with your inlaws? A
21. Change your recreational activities? C
22. Have a change in your co-workers? D
23. Have more or fewer arguments with your spouse? A
24. Have a change in your physical conditions at work? D
25. Have an increase in family income? F
26. Run away from home? E
27. Discuss a possible separation from your spouse? A
28. Have a change in your financial state? F
29. Change the time you woke up or went to bed? C
30. Have a close friend who was arrested or killed? E
31. Have a temporary change in the kind of work you do? D
32. Have religious conflicts within your household? A
33. Make a major purchase (house, furniture, car etc.)? F
34. Have a change in the time (more or less) you spend by yourself? B
35. Occasionally use social drugs (marijuana, alcohol)? E
36. Because of inflation, change your eating habits? F
37. Think of suicide? E
38. Overdraw your checking account? F
39. Spend less time in outdoor activities? B
40. Increase or decrease social contacts? C

41. Experience a change of attitude toward your family? A
42. Change your work hours or work conditions? D
43. Experience considerable mood changes? C
44. Become fearful of being alone while at home? E
45. Strongly dislike your work? D
46. Have arguments about family finances? A
47. Buy major purchases on credit? F
48. Have a change in your financial state? F
49. Change your style of dressing? B
50. Exceed the speed limit by more than 10 miles per hour? E
51. Want to quit your present job (if you could afford not to work)? D
52. Have a change in your daily activities? C

APPENDIX F

PARENTAL EXPERIENCES INTERVIEW

Date Monitoring Began _____

Date Terminated _____

1. How is _____ getting along? (refers to baby).
2. How are you doing (refers to mother)?
3. What happened to the baby that caused the doctor to recommend monitoring?
 - (a) who was with you?
 - (b) what did you do?
 - (c) who was called for help?
4. How did you feel when this happened?
5. How did your husband feel?
6. What was it like at home with the monitor?
7. Did the baby have any nonbreathing spells at home?
If yes, (a) what did you do?
(b) how did it feel?
8. Did you use the monitor at all times or only when the baby was asleep?
9. Did you experience any false alarms?
10. Who usually responded when the alarm went off?
11. How did you feel when this happened?
12. What was monitoring like for the other members of your family (husband, children, grandparents)?
13. Was your husband able to share responsibility for the care of the baby?
14. Were you hesitant to ask relatives for help?
15. Did you have friends who offered support during this time?
16. How did you feel about the monitor?
17. What changes did it cause in your life?
18. Did you experience any problems with the monitor?

19. Why did you stop monitoring?
20. Did you stop abruptly or slowly?
21. Do you feel you were prepared to perform CPR?
22. How would you define the word "apnea"?
23. Was monitoring a financial hardship?
24. How helpful were health professionals to you?
25. Do you have any suggestions for ways in which they may be more helpful to parents?
26. What suggestions would you offer other parents about monitoring?
27. Did monitoring affect your decision to have another baby?
28. Do you think contact with other parents who have monitored an infant would be helpful?
 - (a) What type of contact do you think would be most helpful (i.e., groups, meetings, telephone contact)?
29. Would you babysit for a monitored child?
30. Did you feel anxious during the time of monitoring?
31. Did you experience sleep problems?
32. What were your concerns about the baby?
33. What were your concerns for yourself?
34. Did your relationship with your husband change in any way?
35. Have you experienced guilt about your baby's problem?
36. During the period of monitoring, where did your baby sleep?
37. Were you and your husband able to go out together and did you see friends and relatives on a regular basis?
38. Do you have other comments about monitoring which you would like to offer?

APPENDIX G

DEMOGRAPHIC QUESTIONNAIRE

Your name _____

Your birthdate _____ Birthplace _____

Your baby's name _____

Baby's birthdate _____ Birthplace _____

Address _____

Marital Status:

Single _____ Married _____ Widowed _____

Divorced _____ Separated _____

If married, husband's name _____

Birthdate _____

Ethnic background:

_____ Asian
 _____ Caucasian
 _____ Hispanic
 _____ Black
 _____ Other _____ (specify)

Religious affiliation:

_____ LDS
 _____ Catholic
 _____ Protestant
 _____ Jewish
 _____ Other _____ (specify)
 _____ None

What is the highest grade of school you have completed
 (circle answer):

Grade School	5	6	7	8		
High School	9	10	11	12		
College	13	14	15	16		
Graduate School	17	18	19	20	21	22

Baby's birthweight _____

Occupation of father _____

Your occupation _____

Other children:

Name

Age

Adult relatives living nearby whom you see frequently:

Paternal (Father's relatives)

Name

Relationship

Maternal (Mother's relatives)

Name

Relationship

1. Do you see your relatives and friends as often as you want to or are you somewhat unhappy about how little you see them (Please circle).

2. As often as wants to

1. Somewhat unhappy about how little

2. Do you have someone you can trust and confide in?

2. Yes

1. No

3. How many times during the past week did you spent some time with someone who does not live with you, that is you went to see them or they came to visit you, or you went out to do things together?

- 3. Once a day or more
- 2. 2-6 times
- 3. Once
- 1. Not at all.

4. Do you find yourself feeling lonely quite often, sometimes or almost never?

- 0 Quite often
- 1 Sometimes
- 2 Almost never

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