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DESENSITIZATION: A PROCESS OF PARENTS' ADJUSTMENT TO THE HOME APNEA MONITORING OF THEIR INFANT

The University of Arizona M.S. 1985

DESENSITIZATION: A PROCESS OF PARENTS' ADJUSTMENT TO THE HOME APNEA MONITORING OF THEIR INFANT

by

Joanne Riley Kilb

A Thesis Submitted to the Faculty of the

DEPARTMENT OF NURSING

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THE UNIVERSITY OF ARIZONA

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STATEMENT BY AUTHOR

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26 November 1985
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DEDICATION

To Emily Anne

who sparked the interest for this thesis

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ABSTRACT

This exploratory study of parents whose infants were home monitored for apnea asked the question: What are parents' perceptions of the effects infant home monitoring has on their lives? Grounded theory (Glaser and Strauss, 1967) was the methodology used for the collection and analysis of the data. The sample consisted of eleven married couples whose infants were presently being home monitored. Data were analyzed for relevant categories and concepts specific to this population. Five main concepts were identified from data these included: Unpredictability, Guardian Angel, Support, Confinement, & Desensitization. A model identifying the relationships between these concepts was proposed.

CHAPTER 1

INTRODUCTION

The purpose of this study was to learn about parents' perceptions of the home apnea monitoring of their infant. This investigator has discharged several infants to home on apnea monitoring and often wondered what are the parents actual perceptions of the apnea monitoring of their infant? Are they frightened? If so, what frightens them: the monitor, the infant, or the possibility of the infant dying? Are they comfortable with the home monitoring of their infant? Do they perceive the home monitor as a savior, a curse, or simply as an inconvenience?

Electronic home monitoring has recently evolved as a widely accepted method of treatment for those infants diagnosed as experiencing "apnea of infancy." Apnea of infancy as defined by Brooks (1982, p. 1012) is "the unexplained and frightening episode of cessation of breathing for 20 seconds or longer, or a shorter respiratory pause associated with bradycardia, cyanosis or pallor." Nurses along with other pulmonary specialists spend considerable time in caring for those infants who have been diagnosed with apnea of infancy. Nurses are usually responsible for the observation and

documentation of apnea episodes as well as for teaching families about the monitoring equipment and counseling families about the possible ways that monitoring affects their lives. Therefore, it is essential that nurses along with other health care providers are aware from the parents' perspective of the effects home apnea monitoring of their infant has on their lives.

Steinschneider (1972) reported the first link of sudden infant death syndrome (SIDS) with infants who had experienced recurrent cyanotic and apneic episodes. His study involved five infants less than two months old who had experienced episodes of apnea, with or without cyanosis, while asleep. The majority of these episodes were short and self-limited, but several of the infants had longer episodes associated with cyanosis and requiring active measures to restore breathing. Two of his original sample of five died during one of these apneic episodes. Steinschneider was the first of many to support the association between prolonged apnea during sleep and the sudden death of infants who may be at some particular physiologic risk.

Several studies reported parents' observations of abnormal respiratory patterns in their infants prior to their infants' death. Mandell (1981) reported in his study that 37% (11 of 30) of trained nurses, whose own infants were victims of SIDS, noted that when these nurses were questioned approximately one month after the infant's death,

most of them reported noticing unusual respiratory events such as apnea, cyanotic episodes, and rapid irregular breathing.

Guilleminault, Ariagno, Korobkin, Nagel, & Baldwin (1979) reported on parents whose infants were labeled as "near miss for SIDS." These infants were discharged in apparently good health from the hospital at birth with no medical indication for the near miss episode. All of the parents reported finding their sleeping infants as pale, blue, limp, and not breathing. Some parents described having to use vigorous measures such as cardiopulmonary resuscitation to stimulate their babies' breathing.

The above scenario is typical of that described by parents in many emergency rooms. The infant is usually evaluated by a physician in the emergency room, in order to identify or rule out specific disease processes that may have caused the apneic episode. If this evaluation strongly suggests that an apneic episode has occurred, the infant is then hospitalized for a 24-48 hour period for direct observation and diagnostic followup. The diagnostic followup consists of chest X rays to rule out pulmonary disease, laboratory work to rule out anemia, infection, or a metabolic disorder, an electrocardiogram to rule out any cardiac abnormalities, and a pnuemocardiogram, a tape recording device that measures heart and respiratory trending with chest wall movement which visually documents

on paper if apnea is occurring. If this evaluation suggests that an apneic event has occurred, a home monitoring device is indicated.

At this point the parents begin a comprehensive learning program which includes cardiopulmonary resuscitation, operation of the home monitoring device, and techniques for accurate documentation of apnea episodes. The teaching is performed by nurses and respiratory technicians until sufficient parental comprehension is obtained. The infant is then discharged to home.

A typical home monitoring device is no wider than 8 1/2 inches, and no longer than 9 1/2 inches. Depth of the monitor is no larger than 3 1/2 inches. These devices are portable, can be run by batteries or by electricity, and have visual blinking displays of respiration and heart rate frequencies. A belt with movable dry electrodes is placed over the infant's chest. A home monitor is considered a non-invasive device.

The use of home monitoring devices is a controversial issue. Proponents of monitor use point out that monitoring saves lives, decreases parental anxiety, and may decrease the need for hospitalization of the infants (Brooks, 1982). However, there is evidence suggesting that monitoring can be viewed as a stressor on the family unit (Black, Hersler, & Steinschenider, 1978; Cain, Kelly, & Shannon, 1980; Wasserman, 1984). Some reported stressors

associated with monitoring are disruptive of family life because of the financial and psychosocial stresses it entails. Some parents have described the monitor as being an isolating experience (Black et al, 1978), one that drastically affected their lives.

This investigator has developed an increasing interest in the effects of monitoring on the family unit. A pilot study by Kilb (1984) had similar findings with Black's wherein parents saw monitoring as confining. Kilb's study suggested that parents may impose this confinement upon themselves. This imposed confinement may have several implications for the nurse taking care of those families with home monitored infants. The goal of the present study is to further explore parents' perceptions of the effects infant home apnea monitoring has on their lives.

Statement of the Problem

The research question identified for this study is: What are parents' perceptions of the effects infant home apnea monitoring has on their lives?

Definitions included in this study are:

Home Monitored Infant- An infant less than twelve months old who is being monitored at home with an apnea and bradycardia electronic monitoring device.

Parents- The mother and father of a home monitored infant

who are either married or have cohabitated in the same household for longer than one year.

Purpose of the Study

This study's intent is to explore and identify, using grounded theory methodology, the process of parents' adjustment to the home apnea monitoring of their infant. Further, it is to identify how parents' experiences with the home apnea monitoring of their infant change over time and what influences those changed perceptions of the monitoring.

Significance of the Study

Nurses can be influential in identifying parents' fears related to the diagnosis of apnea in their infant. These families have to cope with the fear of a possible sudden death of their child, a diagnosis where no potential cause is usually found, and they are the responsible party for resuscitation of their infant if breathing should stop (Black et al, 1979). The home monitor only serves as a warning device for apnea, alarming parents when their infant may require resuscitation. Only a questionable linkage exists between apnea and sudden infant death. Thus home monitoring is not a therapeutic measure to prevent sudden infant death syndrome. This is communicated by the physician and has been documented in several publications

(Southall, 1983; Duffy & Bryan, 1982). Therefore, confused feelings in the parents may result because they realize the home monitoring doesn't control the apnea. Confusion concerning the effectiveness of medical treatment may have parents feeling that no one else can care for their infant but themselves, thereby leading to feelings of isolation or confinement. Nursing care important during this time would be in identifying support resources available to parents.

Studies have suggested different time frames for when the monitoring was perceived as the most stressful by the parents. Black et al (1978) stated the acute phase for monitoring lasted three to four weeks. Parents described how at first they would worry if the machine did not go off, thinking that possibly it was malfunctioning, and how they had lost sleep thinking that they might miss hearing an alarm. This study also suggested that mothers had a longer period of adjustment to the monitoring than the fathers but offered no explanation as to why. Cain et al (1980) described most families as being the most anxious during the first week, with mothers expressing greater anxiety. Mothers told how they were unable to sleep at night fearing they would sleep through an alarm. This study found that fathers minimized the extent of their anxiety and expressed more concerns about monitor failures. Wasserman (1984) stated that after two to four weeks parents felt more comfortable with the monitor. His results were similar to

Cain's in that parents would question the working predictability of the monitor during the early monitoring period. These studies suggest that monitoring is viewed as stressful especially during the early monitoring period but do not explain the process of how parents' perceptions change towards the monitoring and what influences those changed perceptions. Therefore, it would be helpful to understand how parents' perceptions of the monitoring change over time and what influences those changed perceptions of the monitoring.

Summary

To summarize, recent studies have suggested a link between infant apnea and sudden infant death syndrome. Home monitoring signals that an infant is experiencing apnea. Several investigators have suggested that monitoring may be viewed as a source of stress to the family while others suggest that it is an anxiety reducer to these families. The majority of these studies suggest that time influences parents' reactions to the monitoring but do not explain how time influences parents' perceptions of the monitoring.

This study was designed to develop a theoretical description of how parents perceived the home monitoring of their infant. This study did not begin with a preconceived framework for investigation. Rather, this study proposed to

develop a framework of orientation identifying parents' perceptions of the effects of home apnea monitoring of their infant on their lives.

Chapter 2

REVIEW OF THE LITERATURE

This chapter reviews the literature on home monitoring and its effects on the family unit. Specific content relating to parents' views of home monitoring will be examined.

Home Apnea Monitoring Literature

A topic of increased interest appearing in the home monitoring literature during the last seven years has been the impact that monitoring has on the family unit. Black, Hersher, and Steinschnieder's (1978) descriptive study of 32 monitored infants identified the problems experienced by the parents of these infants and how monitoring affected their lives. The majority of families felt the monitor had a significant impact on their lives, and had increased their general anxiety level or tension level. Some parents described themselves as never making a satisfactory adjustment to the monitoring. A majority of families stated that the monitor had a significant or drastic effect on their social life. Parents described life with a monitor as an isolating

experience and they specified that life would have been less affected if competent assistance in the home a few hours each day could be arranged. Some parents saw the monitor as a source of anxiety relating to feeling less confident in caring for their infant. Other parents saw the monitor as a reducer of anxiety, referring to it as "a help or a blessing." Marital discord was described as occurring during this period, stemming from differing attitudes between the spouses regarding the necessity or importance of using the monitor. Different feelings were expressed by parents concerning treatment of the infant during the monitoring period. Some reported that the monitoring made no difference how they interacted with their infant, while others felt they comforted their infants less because of the monitoring. Parents described feeling more attached to their babies because of the monitoring while others resented the intrusion that monitoring caused in their lives.

Black et al's study was the first to look at how parents felt about the monitoring of their infant. Several problems were evident though in the design structure of this study. A questionnaire was developed after several interviews with parents of monitored infants. These interviews were conducted as group sessions with a number of parents. It was unclear as to the number of parents contained in each group session and who actually conducted the interview. No statistics on the reliability or validity of the instrument

were reported by the authors. The authors analysis of the data was reported in percentages and frequencies which is more appropriate for an exploratory design than a descriptive one (Hinshaw, 1979).

Cain, Kelly, and Shannon's (1960) exploratory study of 133 parents' feelings, perceptions, and reactions to the stresses and satisfactions of home monitoring were obtained from structured interviews with each parent and from a self-administered graphic rating scale. The authors' results suggested that mothers expressed greater anxiety than did fathers, fearing to sleep in case they wouldn't hear a monitor alarm. Many parents reported the monitor causing little or no financial problem. Southall (1983) & Wasserman (1984) found an opposing viewpoint where parents saw the monitoring as a financial burden.

Many parents described experiencing restrictions in their social lives because of the monitoring. Many said that they could not find competent or willing babysitters to watch their babies so they could go out. The support systems of these parents were also assessed by Cain et al and it was found that the greatest source of support reported was the other spouse. Positive views of monitoring were also reported by parents; they described feeling more comfortable and relaxed about their children because of the monitoring.

Problems also exist in the data collection technique of the Cain et al study. Interviews were very structured with a five point rating scale given to parents to facilitate objective responses to topics that had been explored in the interviews. The purpose of exploratory work is to obtain a subjective view from the informants of their thoughts, feelings, or perceptions concerning the area of study. One might question the authors' biases concerning the content for questions during the interview and what content based on research the authors obtained for the rating scale.

The effects of angry feelings related to monitoring are empirically described by Klijanowicz, (1984) who found that parents may express guilt, feeling that they are somehow responsible for their baby being on a monitor. The author cited how marital discord can be a problem, referring to opposing attitudes of the necessity of using the monitor. She stated that sexual problems may occur between parents because of the generally tense environment and physical exhaustion of the parents.

Wasserman's (1984) prospective study of 14 families with home monitored infants aimed to determine the short and long term effects of home monitoring on the family over a five year period. Parents received three psychiatric interviews (some more), and two followup contacts during the five year period. The first followup was at 21 months after

monitor discontinuance; the second followup was two and a half years after the first followup. A process of four distinct phases was described as parents' reactions to the monitoring. The first phase was the doubt/acceptance stage. Parents first doubted their ability to care for the infant. They then slowly began to accept the monitor as a technique that would help their baby. Usually after two to four weeks parents felt more comfortable with the monitor. Dependence/ frustration, the second phase, occurred when parents became irritated with the demands and limitations that monitoring placed on their lives. Discontinuance, the next phase, labeled parents responses to weaning their infants from the monitor. Late effects, the last stage, described the latent effects of monitoring on the marital relationship.

Couples reported being closer or contemplating divorce as a result of the monitoring of their infant. Parents views concerning their children ranged from characterizing them as being "spoiled" to feeling that their children were "special" because they almost died.

One major weakness of this study is that the author never specifies who conducted the psychiatric interviews or who conducted the followup interviews with these families. It is not clear whether one person did both or whether these were done by separate investigators. The majority of the followup interviews were done over the telephone and with

the mothers only. The consistency of the data collection method for this study is a major weakness in its design.

Several references referring to monitoring of an infant as stressful were expressed by authors in a few anecdotal articles. Shannon and Kelly (1982) stated that parents perceived using monitor devices at home as stressful, but also considered other available alternatives such as prolonged hospitalization to be even less acceptable. Bakke and Dougherty (1981) mentioned the psychosocial problems, such as marital difficulties, experienced by parents of monitored infants. They described the concept of "cabin fever" (Bakke and Dougherty 1981, p. 86). This referred to parents feeling confined because babysitters were difficult to find.

Klijanwicx (1984), Duńcan and Webb (1983), and Graber and Balas Stevens (1984), in their teaching guides for nurses, presented strategies for dealing with the psychosocial aspects of reducing stress, or at least maintaining it at a reasonable level for the family with a monitored infant. One main strategy emphasized was the need for followup of these families as a means of support. These articles were written from the authors' own experiences in dealing with these families and were not research based.

Barr (1979) authored a booklet entitled "At Home with a Monitor, A Guild for Parents". Information in this booklet was obtained from a survey, done in 1974, of fifteen

monitored families using a questionnaire and interviews. Barr described three phases of living with a monitor. The initial stage is the "breaking in" stage describing parents reactions of living with the monitor during the first few days at home. Next, the adjustment period described the concessions parents made in order to live with the monitor. The last stage was the time period following the adjustment phase where the monitor has become "part of the family" (pg. 3) This booklet gives excerpts of parents' feelings and perceptions during these phases of monitoring. Parents reported the monitoring as putting added stress and strain on their relationship. Barr stated that almost every parent felt the monitor had brought them closer to their baby and made them appreciate their baby more. Barr's conclusions from this survey were mostly generalized statements from parents' verbalizations. The type of research design and the method for data collection were not specified by the author and no reliability and validity statistics for the questionnaire were reported.

Wilkerson and Feetham (1983), in their descriptive study, compared family functioning of two groups of families; those with normal newborns and those with home monitored infants at six months and twelve months of age. They attempted to discover how a change in pattern and organization of the family following the birth of a child and the presence of an intrusive intervention in the form of

apnea monitoring could affect a family's ability to cope with stress. One variable measured was parental perception of an infants. The authors stated that the parents' perceptions of an infant's behavior patterns could influence their ability to cope with the monitored infant. Study results indicated that at six months, mothers of apnea infants had more positive perceptions of their infants than the mothers of healthy infants. At 12 months there were no significant differences between the two groups of mothers. The authors speculated that the difference in results may suggest that the apnea group mothers are reacting to the presence of a problem in their child by over compensation. The investigators surmised that the birth of a child affects family functioning, and health problems in the child further influences that family functioning.

These authors stated that the relatively small sample they used may have affected the outcome of the study. Their sample number varied significantly at six months (healthy: 50 mother, 50 fathers; and monitored infants: 29 mothers and 17 fathers) but was similar at 12 months (healthy: 30 mothers, 22 father; and monitored infants: 29 mothers and 17 fathers).

Bendell, Culbertson, Shelton, and Carter's (1984) study of 25 monitored and control infants identified the effects of apnea monitoring on maternal stress, infant temperament and early infant development. Several scales

were used and modified by the authors in evaluating the above concepts. One of the scales, the Neonatal Perception Inventory and Degree of Bother Inventory (Broussard and Sturgeon, 1970) were modified with questions added relating to degree of bother associated with the apnea and the apnea monitor. Results suggested that apneic infants were perceived as more active than the control infants. Mothers perceived the care of their apneic infants to be more difficult than did mothers of control infants, with particular emphasis placed on the bother created by the monitor and the apnea itself. Their study also indicated that while the monitor was perceived as mildly stressful, the apnea itself provided the greatest source of stress.

Since one of the instruments were modified, pilot testing of the instrument by the authors prior to use in this study should have been done. This study is limited because it only gives mothers perceptions of their infants and the stress factors involved, the perception of fathers were never identified. Anecdotal evidence from these authors does suggest that mothers of apneic infants impose isolation upon themselves, resulting from reluctance to leave their infants in the care of even close relatives. Other mothers experienced difficulty in securing babysitters who felt comfortable and competent in caring for an apneic infant on a monitor.

Similar findings to Bendell's et al anecdotal findings resulted from a pilot study of seven families with monitored infants done by Kilb (1984). Four main concepts were identified: Guardian Angel, Confinement, Family Support, and Marital Dissension. Figure 1 is a schematic diagram of these concepts and their relationships from the initial pilot work.

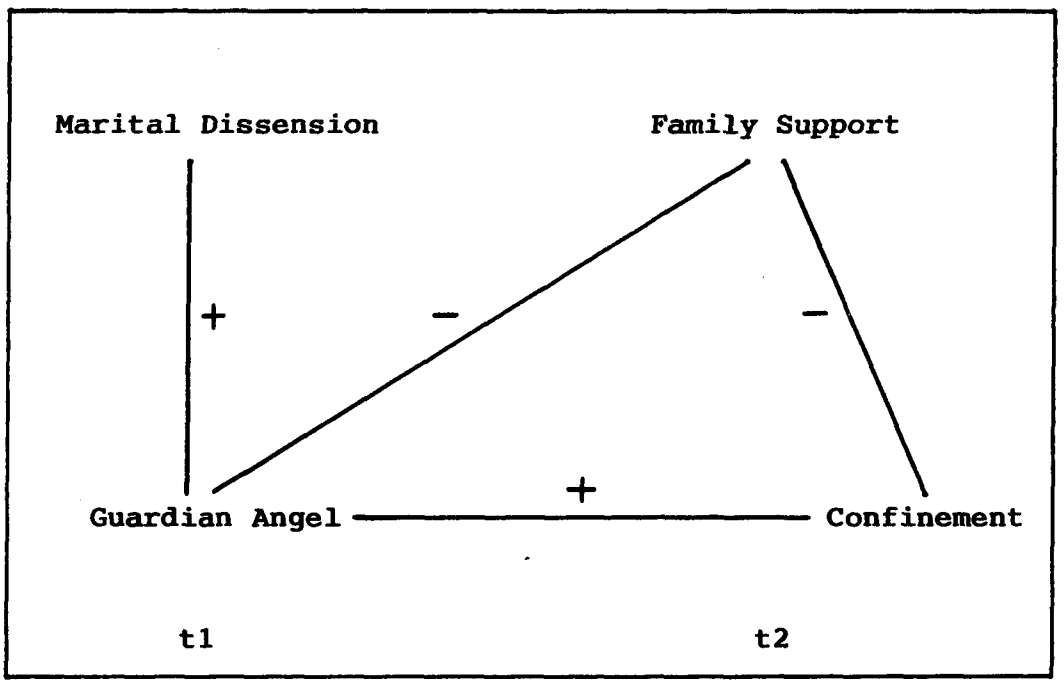

Figure 1. Conceptual Model developed from pilot research

The concept of Guardian Angel contained the idea of the parents being the guardian of the infant and the monitor being an extension of this guardian role. Parents described various vigilant behaviors in making sure their babies were all right. The concept of Confinement expressed the idea that parents didn't go out because of worrying about their infant. The Family Support concept described parents' perceptions of how extended family was helpful or not helpful during the monitoring period. The last concept, Marital Dissension, suggested that a supportive/nonsupportive relationship between spouses influences the Guardian Angel concept.

This investigator found that time was significant in parents' adjustment to the monitoring of their infant. As time goes on, parents begin to trust others and themselves in guarding their infants. Pilot work suggested that during the first four weeks parents refuse to venture out, feeling unable to trust anyone in caring for their infant during their absence. It was still unclear, however, exactly what influenced parents' decisions to finally begin to trust others in caring for their infant, exactly when they felt it was all right to leave their infant with someone else.

Summary

The majority of the research reported on home monitoring utilized questionnaires developed by different investigators. Not one of these studies reported any reliability or validity statistics for any of the questionnaires developed. Major inconsistencies in study designs were noted. Several studies used inappropriate data collection methods and analysis for the type of design reported.

Much of the research data reported was from anecdotal articles with the authors identifying from their own experiences possible ways of helping families cope with a monitored infant. This literature is not research based, but derived from the personal experiences of the authors.

No qualitative research utilizing grounded theory methodology on home monitoring has been reported. A pilot study by this investigator identified the four concepts of Guardian Angel, Confinement, Family Support, and Marital Dissension. It was decided that further investigation would facilitate the development and refinement of these and other concepts related to parents perceptions of the effects of infant home monitoring on their lives.

CHAPTER 3

METHODOLOGY

This chapter will present information on the research design, sample and setting, human subjects, procedure for interview, analysis of data, limitations, assumptions, and reliability and validity.

Research Design

An exploratory design was chosen to identify the effects that home monitoring has on the family unit. The grounded theory method of Glaser and Strauss (1967) was used for data collection to study the processes occurring in families with home monitored infants. The goal of grounded theory is to explain a phenomenon by the linking of hypotheses generated from the researcher's data (Stern, 1980). Grounded theory is one way to look for processes occurring in the social scene being studied (Stern, 1980).

Stern (1980) described five ways that grounded theory differs from other methodologies. First, it offers a conceptual framework that is originated from the data. The investigator considers factors shown in previous studies

influencing the data, but not originating in the data. Second, grounded theory is concerned with the predominant social processes occurring in the phenomenon of interest. Third, every data bit is compared with every other data bit. Fourth, the collection of data may be modified according to the emerging theory and finally, this method utilizes several research processes rather than depending on one structured method of collection. The investigator, from the beginning of her study, is constantly coding, categorizing, and conceptualizing the data.

Sample and Setting

The informants for this study included parents who have an infant less than one year of age at home on an apnea monitoring device. All live in a southwestern city in the United States. Informants were parents whose infants met the following criteria:

1. The monitored infant was no younger than 35 weeks gestation and no older than one year of age.
2. The monitored infant had had minimal oxygen requirements, other than for resuscitative purposes, of 25% or less and for a period of no longer than 24 hours since birth.
3. Parents of the monitored infant were either

married or had cohabitated in the same household for a period of one year.

4. Parents could read and speak English.

For the convenience sample, the names of the informants were obtained from the pulmonary nurse specialist at a nearby university medical center. Informants were first contacted by the pulmonary nurse specialist asking them of their possible interest in participating in the study. Informants were then contacted by telephone by the investigator. This investigator identified herself as a registered nurse and a graduate student in Maternal Newborn Nursing who was interested in talking with families about their experience in living with an infant who was being home monitored. A total of fourteen couples were initially contacted, and eleven of those fourteen couples participated in the study. Those parents willing to participate were given a disclaimer at the time of the interview explaining the study and affirming their anonymity and voluntary participation.

Those infants, whose parents were interviewed, were monitored for varying lengths of time. The minimum time of monitoring reported of an infant was 10 days and the maximum time of monitoring was 5.5 months.

One interview was conducted in each of the informants' homes. The interview took place at the informants' convenience and lasted approximately one to two hours each.

Human Subjects

The human rights of the informants were protected according to the guidelines set by the University of Arizona Human Subjects Committee. The study was explained to all informants by the investigator and included the purpose, procedure, time, risks, benefits, and costs of the study. The voluntary participation of the informants for this study was explained as well as their right to withdraw from the study at any time. The confidentiality of the informants were also assured at this time. All informants were given a written disclaimer form explaining the above information (Appendix A).

Interview Procedure

Informants were contacted by phone and an appointment was made for conduction of the interview in their home at their convenience. Both parents were interviewed together. The interview began with an explanation of the study with the disclaimer form being given. The interview was audio tape recorded and field notes were taken during the interviews. Interviews began with demographic information obtained from the informants in the hopes of making them

feel more at ease, and to begin the interview in a non-threatening manner.

The interview questions were based on information obtained from a previous pilot study of seven families and by the review of the professional literature. The initial questions only served as a guide, and conversation was kept open to allow the informants to direct the flow of discussion. Each informant was interviewed once. Permission to recontact the informants was asked at the end of the interview in case an area of content needed clarification.

Collection of data began with interviews with informants experiencing the phenomenon of interest. The interview is the primary method of data collection in grounded theory. The informants were considered the teachers or experts and the investigator the learner. When the informants used terms during the interview that were not familiar to the investigator, clarification of terms was necessary. Assumptions were not made that the informants and the investigators meaning of terms were similar. The investigator continually sought clarification of terms from the informants during the interviews. Initial interviews were highly unstructured and began with very general questions. For example, one of the questions asked in the initial interviews was, "Tell me about your experiences with the monitoring of your infant." Progression was then made from these general questions to questions seeking specific

information (as generated from the data) from the informants such as, "How did you convince yourself that your baby is all right?" Questions were also generated during the interview from what the informants said. These interviews provided the data for analysis. The data were slices of information obtained from informant's verbalizations during the interview.

After each interview the tapes were transcribed and analyzed for content. Anonymity was insured for the informant by numbering the tapes and the field notes. Permission to retain data was granted by the informants. Data information was only available to the investigator.

Analysis of Data

Constant comparative analysis was the method used to generate theory from the units of data. The five stages of data analysis for grounded theory as described by Stern (1980) was used as a blueprint for data analysis in this study. These included: the collection of data, the formulation of concepts, the development of concepts, modification and integration of concepts, and literature support of the emerged concepts.

The first stage of analysis began with the collection of data with transcripts being read line by line and divided into categories, the basic element of grounded

theory methodology. A category was composed of clumps of data which have similar shared meanings or themes. The data were coded after each interview and subdivided into categories. With each new interview data were analyzed on an ongoing basis and reviewed until no new themes were construed from the data. Continual analysis of the data occurred until a point of saturation was met. Saturation refers to no new additional data being found from the informants' interviews.

Concept formation is the next stage of analysis, whereby a conceptual framework was generated using the data as reference. Each of these categories was clumped into similar conceptual elements using the data as reference. The investigator attempted to link the problems as identified by the informants and how they dealt with these problems (Stern, 1980).

The next stage is concept development. This investigator reduced the number of categories, combining those categories that appeared to have similar themes. As linkages between the conceptual elements developed, many of the specific categories collapsed into more general categories. Tentative ideas of relationships between conceptual elements occurred at this time. This led to the formation of hypotheses between these conceptual elements. Selective sampling to obtain additional specific data was then collected in future interviews to further develop the

hypotheses. This process is called theoretical sampling because the data was collected to advance the emerging theory (Stern, 1980). This was a deductive process where data was collected to prove or disprove the emerging hypotheses. Emergence of core variables was the final outcome of this stage. This is a constant ongoing and reciprocal process until data collection was finally controlled by the emergence of a theory (Glaser & Strauss, 1967; Stern, 1980).

The next stage of concept modification and integration, involves the two processes of theoretical coding and memo writing. Theoretical coding is the presentation of data in a schematic diagram. An example of theoretical coding is shown in Figure 1 which schematically presented the conceptual model as developed from the pilot work. Memo writing consists in writing hunches regarding relationships of the data at certain points when data are being coded. It is considered a way of organizing the data and preserving the emerging hypothesis.

The final step in the grounded theory approach was to compare the results obtained from this study with the available literature on the topic. Did the literature support the emerged concepts and hypotheses of the proposed theory? The literature will explain the theory but not be derived from it (Stern, 1980). This final step validates the concepts as being sound.

Limitations

1. Since this investigator has done a pilot study and reviewed the literature, preconceived ideas concerning the area of focus have been made. The challenge for this study was to remain open enough to data that did not appear relevant to previous assumptions made from prior investigation.
2. Time limitations permitted only eleven interviews to be performed. Glaser and Strauss state the investigation ends when the investigator decides when saturation from data is complete. Limited time for this study possibly did not permit complete development of some of the concepts identified.

Assumption

Informants are open and honest in discussing their feelings and perceptions of living with an infant being monitored at home.

Reliability and Validity

Goodwin and Goodwin (1984) suggests that the concepts of validity and reliability should not be irrelevant for qualitative strategies. They stated that, "For qualitative research to produce credible findings, the data should be collected in a consistent reliable way, and must be valid indications of reality" (p. 379). In this study, the investigator was concerned with the reliability and validity categories retained from the data.

To obtain inter-rater reliability, the data was given to a colleague, familiar with grounded theory, to evaluate the emerged categories. The colleague evaluated the categories the investigator had originated from the data. The colleague independently rated the categories, deciding if the categories were present and if the category label implied the category's meaning. The advantage of obtaining inter-rater reliability from another colleague was the input obtained on whether the categories were indeed confirmed or refuted from the data.

Construct validity was obtained by having a set of parents, who are considered the experts, review the categories and the theoretical framework. Evaluation of categories and the conceptual framework by the parents

determined if the investigator described the phenomena from their perspective of the effects from living with a home monitored infant. The parents evaluated the plausibility of the categories and the theoretical framework, as originated from the data, with their own experience.

The issues of reliability and validity are important in deciding if the proposed theory can be applied in practice by health care providers. Glaser and Strauss (1967) described four properties that are necessary to decide the applicability of a theory. First, does the theory have practical applications? Is the theory faithful to the everyday realities of the substantive area as one that has been induced from the diverse data (Glaser and Strauss, p. 239)? This can be related to the construct validity issue when parent evaluators decided if the investigator's categories were similar to their own experiences.

The second property states that the theory should be understood by those who work in the substantive area. Do nurses and physicians who work with these families understand the meaning of the proposed theory? Can it be used in their everyday practice? A colleague, who works with parents of home monitored infants on an ongoing basis, evaluated whether the proposed theory was understandable and if it would be useful in relating to families with a home monitored infant.

Next, does the theory have a general application? Can it be applied to the total experience of all parents who have had a home monitored infant whether they are single, adoptive, or foster parents taking care of a home monitored infant?

Finally, does "the theory enable the person who uses it to have enough control in everyday situations to make its application worth trying (Glaser and Strauss, 1967, p.245)?" Can nurses who work with these families be able to use the theoretical framework in dealing with these families during the monitoring period? Does this theory contribute to their understanding of the effects monitoring has on these families on a daily basis? If all these properties can be met in the proposed theory the issues of reliability and validity would be met.

CHAPTER 4

PRESENTATION AND DISCUSSION OF DATA

This chapter presents characteristics of the total sample, descriptions of initial interviews, categorization and rationale for clustering, procedure for focusing future interviews, category refinement and amalgamation, and emerged concepts as developed from the data.

Characteristics of the Sample

The informants for this research were selected according to the study criteria from the client population of the pediatric pulmonary section of a southwestern hospital. A total of eleven couples were interviewed during the six week period of data collection. All couples were interviewed in their homes at times convenient to them. Table 1 presents information concerning the parents' ages, number of years married, educational background, and their occupation. Table 1 also gives the means for the parents' ages, number of years married and the number of years of education. Table 2 gives information concerning their infants such as their sex; length of time monitored; age of infant when

Table 1
Sample Characteristics of Parents

Couple Number	Mothers Age	Fathers Age	Number of years married	Completed years of education		Occupations	
				Mother	Father	Mother	Father
1	28	33	9	14	17	not working	Foreman
2	26	26	5.5	12	12	Airforce Airman	Airforce Airman
3	30	29	6.5	17	17	Teacher	Forester
4	31	29	3	17	16	Social Worker	Lab Technician
5	27	26	7	14	14	Teacher	Contractor
6	28	42	7.5	12	12	Housewife	Machinest
7	30	29	5	16	16	Engineer	Engineer
8	31	34	8.5	16	18+	Housewife	Student
9	21	21	2.5	14	8	Nurse	Mechanic
10	26	30	2	15	12	Animal Technician	Clerk
11	22	27	3	12	12	Manager	Policeman
	$\bar{x}$=27.3	$\bar{x}$=29.6	$\bar{x}$=5.4	$\bar{x}$=14.6	$\bar{x}$=14		

Table 2
Sample Characteristics of Infants

Infant Number	Sex	Length of time Monitored	Infant's age when first put on monitor	Infant's age at time of interview	Key M=Male F=Female Numerical order of this child in this family
1	M	5 months	at birth	5 months	3
2	F	5 months	1 month	6 months	2
3	M	6 weeks	3 weeks	9 weeks	2
4	M	7 weeks	6 weeks	13 weeks	1
5	F	4 weeks	6 months	7 months	3
6a	M	5 months	at birth	5 months	3
b	M	5 months	at birth	5 months	4
7	M	3 months	at birth	3 months	2
8	F	10 days	6 days	16 days	3
9	M	5.5 months	at birth	5.5 months	2
10	M	2 weeks	2.5 months	3 months	1
11	M	4 weeks	at birth	4 weeks	2

first put on the monitor; present age of infant at time of interview; and finally the numerical order of this child in the family. The vast majority of infants were from singleton births but the sample did include one set of twins. Informants were advised that disclosure of this information was optional.

Initial Interviews

Initial interviews began with very general questions such as, "Tell me about your experiences with the monitoring of your infant", or "Tell me what it is like to have a baby on a monitor." The first interviewed couple described how they felt, "It was very scary at times, especially at first." The father said: "It was really scary at first, that there is something wrong with the child that it can just stop breathing like that and be gone. You just turn around and the next thing you know ....."

The mother went into specific detail describing how, "You can't get away from your baby that much." She elaborated, "You have to have someone who knows CPR you can't just drop them off or have a babysitter come in and watch him like you can with another child. You have to have someone who knows CPR or you won't feel comfortable at all."

These parents began to further describe how they felt very comfortable with the monitor and how they were

glad they had the monitor. They also explained how they have never left their child with anyone but each other. They verbalized this as being their own choice because they didn't feel comfortable with anyone but themselves to watch their child. These parents also seemed interested in trying to find out a reason why the apnea episode had occurred. Did they do anything to contribute to their baby having an apnea episode? They had no answers at this point and found it to be frustrating that there were no easy answers.

Interview of couple number two began with the same general question, "Tell me about your experiences with the monitoring of your infant." These parents described an experience with their infant daughter on the monitor when they had noticed one day that she was real pale, very lethargic, and the monitor was giving frequent alarms. They described how the hospital told them that it was the monitor malfunctioning and not the baby having a true apnea episode. The parents were so frightened that they stayed awake during the entire night because their baby was frequently changing color. They decided early the next morning to go to a different hospital. The baby was diagnosed as having a "virus" that was leading to severe episodes of apnea. This experience led to a discussion of how frightening the monitoring was at times. For example, this mother said, "You don't know if you are going to have to do CPR or not." This mother then elaborated on how it was "rough to go out"

because many people would not babysit for them. This mother stated how she had lost several babysitters because these babysitters felt that they couldn't handle the monitoring, or that she felt the babysitter couldn't handle the monitoring. She verbalized her feelings concerning the time when she needed to return to work and how hard that was because of not feeling comfortable with others watching her baby besides herself. She said,

> "It takes awhile, because I know my mom asked me one day she says, 'Do you mind me watching the kids?', because we had tried everything. The day-care center wouldn't take her because she wasn't six weeks old and they wanted a letter from the Pediatrician on base (airforce) stating that they could watch her and give her the medication she needed. My mom stayed and said, 'Do you feel comfortable with me watching her?' and I said 'Mom at this point I don't feel comfortable with anyone'."

These two interviews had two apparent major themes. The first contained the idea of how scary the monitoring was because these parents had no idea of what to expect, whether their babies would require resuscitation at some future point in time. The second apparent theme was how the mothers had difficulty in finding babysitters because either they couldn't find a babysitter or that they didn't feel comfortable leaving their babies with a babysitter.

In the third interview with couple number three I decided to ask again the experiences of this couple with the monitoring, but I hoped to concentrate more on the two apparent major themes from the previous interviews. The

mother in this interview immediately began to verbalize about how, "You just don't leave your baby with anybody." She said, "I worry a lot. I'm always within earshot. I just can't go out and do what I want to do." She stated that even though they worried a lot there were certain things they wouldn't allow themselves to do such as have the baby sleep in their room. This was different from the couples in prior two interviews because their babies slept in the same room with them. This mother also said how the monitoring was different because, "Instead of waking up to a baby's cry during the night you are awakened by a monitor alarm." The couple further talked about how her mother had taken the CPR training with them before the baby was discharged from the hospital but that they didn't feel comfortable leaving the baby with her even though she had gone through the training. They had gone out only once since the baby was first monitored and only for a few hours. This couple described how they differentiated between the alarms, stating that a false alarm made a different sound than a true alarm. This father said, "The machine tells you that an alarm is false by the beep. A true alarm is beep-beep-beep where a false alarm, say like a loose lead, is one continuous beep." They further stated they still answered all the monitor alarms, even if the monitor signaled a false alarm, because possibly the machine was making a mistake and it was really a true alarm. This mother further talked

about how she would frequently get up during the night to make sure that she had turned the monitor on and that the baby was okay. Both parents described a process of getting use to the monitoring "the sounds the monitor makes, the situation of the monitoring, and how to handle the baby." Father stated how he felt "time was his peace of mind" in adjusting to the monitoring. He felt that since his baby had been gaining weight the apnea episodes had dropped dramatically.

From these interviews I began to organize data of similar meaning into categories. These categories are described in the next section.

Categorization and Rationale for Clustering

Two initial categories labeled Worry and Scared contained the verbalizations of several parents describing themselves as either being worried or scared about what could happen with the monitoring. The Worry category expressed the anxiety and the concern parents felt. Parents were worried that their babies weren't okay. "The biggest worry is her breathing." "You have a lot of nights where you don't get much sleep because you are really worried", are two examples of data contained in this category. The Scared category expresses parents thoughts relating to a fear that their baby could die at any moment. Data such as

"Scared that I might lose her" or "When they first came home I was scared to death I would lose them", are examples of data in the scared category.

The Restrictions category represented parents' feeling that the monitoring causes certain restrictions. "You have to have someone who knows CPR to watch your baby." "You just can't leave them with anybody." This datum emphasized the feeling that the monitoring prevented these parents from doing certain things because of special considerations required by the monitoring. For example, parents needed to have babysitters who knew CPR to take care of their babies in their absence. Parents couldn't take the risk of leaving their babies with someone who did not know CPR.

Several categories with the labels of Listening, Checking, and Watching were developed from data regarding behaviors of what parents would do in order to hear or see their baby better. The Listening category considered parents' behaviors of what they did so they could better hear their baby's breathing. For example, some data referred to parents setting up intercoms in their baby's room, "We could hear her breathe and she could hear us." "I'm always within earshot." "When you go to bed at night it is usually on always on." Checking were those behaviors where parents actually walked in the room to make sure their baby was ok. Examples of data in this category are, "I go

in to make sure she is breathing." "Walk in and peek in while walking by his room." The Watching category referred to parents watching their babies to make sure they were breathing or measures undertaken by parents to further enhance observation of their babies. "We keep the baby in our room", "We just sat there and watched her breathe" are examples of data contained in this category.

The category of Security contained parents' verbalizations of feeling secure with the monitor. The monitor was perceived as being especially helpful during those times when parents' could not watch their baby such as when they were sleeping. "You feel competent the machine will let you know when something is wrong", "Knowing that if he slows down to a certain point we will know about it", and "It lets you know something is happening" are examples of data contained in this category.

The category of Confinement developed from data such as, "You can't get away from them very much", and "We have never left him." This category suggests parents' feeling unable to leave their infant either because they choose not to or because of their inability to find someone to care for their infant.

The category of Getting Used To contains data describing parents adjustment to the monitoring. Examples of data in this category include: "You don't think about it anymore because it's natural to do it this way", "You adjust

at your own speed", and "Getting used to the sounds, the situation, and how to handle him."

The category of Support contained data describing supportive or nonsupportive measures from others, usually in the form of babysitting, that led to parents' feeling that others were either concerned or indifferent towards their situation. Examples of data bits of supportive measures included: "The people at the chest clinic have called every month to see how he is doing and if he has any problems", and "My mom would watch her and let us go out." At the opposite end of this category are parents' perceptions of nonsupport from others, usually related to lack of understanding about apnea and the monitoring. Examples of data include: "People have told us, 'don't ask us to babysit'", and "My mother she's really afraid, she doesn't even want to watch her when she's not sleeping."

After developing these categories further interviewing was indicated to determine if the categories would be validated or refuted from future data. A more abstract level of thought was needed in identifying and developing conceptual themes from the data.

Procedure for Focusing Interviews

During the next 6 interviews I was interested in further refining or redefining my categories, identifying

conceptual themes with the different categories, and finally identifying and defining relationships between the identified concepts. In interviewing couple number four I was interested in the parents' perceptions of how they felt monitoring had affected their life. This couple proceeded to describe to me how "life itself is so fragile", "how you cannot predict what will happen." The father described these feelings very well when he said, "One moment you can be here and the next moment be gone. There is nothing that can stop him from breathing in the middle of the night." The mother also expressed similar feelings when she said, "Just being the most responsible parent in the world doesn't guarantee that you will have a healthy child." The most significant development from this interview is that even though these parents felt that nothing was predictable, they verbalized how they had become lax with the monitoring. The father stated how he didn't answer all the alarms because he could tell which were false alarms and which were not. He said he felt confident that nothing would happen to the baby because the baby hadn't had any true alarms. The mother said that she would answer every alarm and not assume whether it was false or not. A memo written from this interview stated, "It seems the alarm frequency or whether an alarm was real affected these parents' perception of whether to be scared about the monitoring." This interview provided a focus because it was the first time that parents

described a period of becoming very comfortable with the monitoring and linking that to the fact the baby had no significant alarms.

After discussing the data with a colleague I decided to focus the next three interviews in finding out how parents dealt with the unpredictability associated with the monitoring and how parents rationalized those feelings to the point that they didn't watch their babies as closely as they used to. An overall finding from these interviews suggested that many parents felt the apnea episode was an isolated event. They expressed strong feelings that it would not happen again and they related these feelings to the fact that none of their babies had an alarm or ever needed to be resuscitated. The more strongly they felt their baby wouldn't have an apneic episode the more they would begin not to be worried about hooking their babies up to the monitor, especially during the day. Some mothers would take the role of checking the babies "every once in a while" to make sure everything was okay but knew somehow everything would be okay. The mother in interview #7 described how her baby "wasn't that bad of a case." She described how she would vacuum or do the laundry knowing that she possibly would not hear the monitor alarm, but felt assured that nothing would happen. These interviews led to the development of two new categories: one was labeled Unpredictability and the other was labeled

Confidence. The category of Unpredictability described parents not being able to predict whether an event would happen or when it would happen. The apnea episode was seen as a random event with no set time of predicting when it would happen again. One mother said, "I've told her, mom if it's gonna happen, it's gonna happen in the car here, if it's gonna happen there's not much you can do about it." Parents also described how the monitors did not necessarily predict if an event would not happen again. One father stated, "I don't know if the monitors were really necessary but I wouldn't want to take the chance to find out." Even though Unpredictability was labeled as a category at this time I decided it had the potential to be a concept and looked to see from future interviews to develop this as a concept.

The category of Confidence described parents' feeling real confident that the baby would not have an apneic event. Parents would start to leave the monitor off during the day or else they would run the vacuum cleaner, while the baby was monitored, knowing that they could not hear the monitor alarm if it went off. One mother stated, "I have pretty much faith in him, he's healthy, and he seems to be breathing fine and I haven't had any problems, the monitor hasn't gone off. I don't think he needs it."

The last several interviews then dealt with further refining these categories and to further develop the

emerging concepts and their relationships until the point of saturation was met by the investigator. The categories and concepts as identified from this data are in the following two sections.

Category Refinement and Amalgamation

Several categories collapsed into other categories because their meanings were very similar. Appendix C contains the labeled categories and the data bits comprised in each category.

The category of Chance had been previously labeled unpredictability. Unpredictability seemed to be a more suitable conceptual label than a category label. This category of Chance describes parents' perceptions related to the unexpectedness and randomness of the apnea episodes and the inability to predict whether it would occur again. Statements such as, "One moment you can be here the next moment be gone", or "He's a gift to me he could be taken away", describes the unpredictable nature of the apnea or of life itself. It seems that life itself is unpredictable and so is the apnea. One father stated, "Not really much you can do to predict whether you will have an apneic child or not." Apnea is seen as some uncontrollable event that just happened to this baby for whatever reason. A father stated, "It's so random. How do you know which kids are the ones

who will get apneic?" Parents perceived the apnea episode as a random event of nature one over which they had no control.

The category of Afraid resulted from combining the categories of worry and scared. This category expresses parents' feeling scared, especially about what a monitor alarm could mean. Does an alarm mean the baby is all right or does the alarm mean I might have to do CPR? One mother stated, "You never know when the alarms go off, that it won't be the one you can't pull him out of." Another mother best described the frightened feelings parents experience when an alarm goes off when she said, "There is a feeling of panic when the alarms go off, is he breathing?, is he okay?, am I gonna have to get him up and start shaking him to make him start breathing?"

The category of Fallible expresses the idea that the monitor may error and that you can't totally rely on the monitor. Several statements such as, "It was comfortable until a doctor told me you can't rely on these 100 percent", or "Even though there is a machine to pick up the sound, you wonder if it will make the sound", are examples of data in this category.

The categories of watching, listening, and checking were combined to form the category of Vigilance. This category includes those behaviors that parents' exhibit in making sure that their babies were all right. "We just keep

an eye on them", "Many times I'd go in and put my hand on his back and make sure he was breathing", and "I answer every alarm" are a few examples of data bits included in this category.

The category of Security portrays the monitor as being "a security blanket." It will let parents' know when something is wrong. One mother stated, "Knowing that if he slows down to a certain point we will know about it." The monitor allows parents the flexibility to do other things so that they don't have to continually watch their babies. A father stated, "It allows you the flexibility of doing other things and still have the protection that if something did go wrong you would be notified and could take protective action." The monitor is also perceived as an extension of the parents. When parents can't watch their babies the monitor can. One father stated, "When you are not in the room something is there."

The Nobody Else But Me category describes parents' feeling very protective of their infants to the point where they would rather have one of themselves stay with the baby than have someone who they don't completely trust watch their baby. One mother stated, "If something does happen there is nobody else who knows how to take care of it." Parents felt they were the most competent person to take care of their baby. One mother stated, "It would be more traumatic for me to go out somewhere and leave him with

someone for a long time than for me to take him with me." Some parents feel so strongly that they only are capable of taking care of their infant that they choose not to have others watch their baby. For example, one mother said, "It's just your personal decision and how comfortable you are."

The category labeled Captive which previously was labeled confinement expresses the idea of parents being held captive because of their own emotions. For example, if the parents decide they don't trust anyone else to watch their baby they are holding themselves captive. They can do this in several ways: 1. By not going out at all, or 2. By taking the baby with them when they do go out, even though they entrust their other children to a sitter. Examples of data expressing these ideas are, "We have never left him", "We're always home with the kids because of him on the monitor", or "We just take her with us."

The category of Restrictions suggests that parents' feel confined because of the extra considerations they have to make in order to find someone to take care of their infant. For example several parents stated, "You have to have someone who knows CPR", "You just can't leave him with anybody." If parents can't find someone who fulfills these considerations, they are "stuck". Parents also have other considerations to make with the monitoring, for example, if a set of parents decided to take a camping trip would there

be a medical facility nearby that could handle their child in the case something would happen? As one father stated, "You don't want to get too far away from a medical center in case something would go wrong." In some cases parents described not being able to take showers because they might not be able to hear an alarm. One mother said, "Sometimes I want to take a shower and nobody is here and I have to wait until my husband is here and it is bothersome."

The category label of Relief Pitcher replaced the category of support. This category mostly describes parents' perceptions of having someone available to relieve them of their vigilant role. It could be family, friends, doctors, nurses, or the monitor supplier who may come out early in the morning to figure out what's wrong with the monitor. One mother stated, "One time the medical supplier came out at 3:00 in the morning when we were having problems with the machine." This category further expresses the idea of having someone available to give the parents emotional support, telling them that they are doing okay and hang in there. One father said, "It's nice to have someone to know that you are having problems and you don't have to really bear the burden alone." This category also describes parents' perceptions of feeling nonsupport from others. Parents expressed being upset at not receiving the support they thought they should get from others, especially from family and friends. This can be in terms of babysitting

support as well as emotional support for the parents. For example one mother stated, "My mother, she's really afraid. She doesn't even want to watch her when she's not sleeping." Many parents felt that others just did not want to take the responsibility of caring for an infant on a monitor. Many parents attributed this to the lack of understanding about apnea and home monitoring. One mother expressed these feelings best when she said, "They don't understand what it is for and how it is used, that it's a benefit for them but they think so he's got this thing so he's obviously had a problem and he's probably going to have more."

The category labeled Partnership describes parents feeling supportive of each other and knowing that they could count on their spouse for support. One mother stated, "You have to have a couple that really cooperate with each other." This also means that if one spouse has the responsibility of caring for the baby, he or she doesn't resent the other spouse because he or she seems to be less involved with the baby.

The category of Getting Used To portrays parents' adjustments to the monitoring of their infant. It describes how initially parents were tense and eventually some point later became more relaxed with the idea of monitoring. A few examples of data in this category are: "It was acquired, a process of having lived with the machine", "It sorta becomes like a routine", and "It's time and adjustment."

This category suggests that the passage of time appears to be a factor in parents' adjustment to the monitoring.

The category of Confidence labels parents' feeling very confident that the apnea episode will never happen again. Parents' relate this confidence to the fact their baby has never had an alarm or never had a true alarm. Some just describe it as a feeling of knowing nothing is going to happen to the baby. They begin to feel in control of the monitoring situation and of feeling very sure nothing is going to happen. A mother stated, "I don't see the significance of a monitor when for a long period (at this point 2 weeks) nothing has happened." A father stated, "We have a high degree of confidence that he is not going to experience any type of episode that we would really need to be really worried about."

The category of Weaning consisted of those behaviors where parents began to rely less on the monitor. A father stated, "It was more convenient for us to put them in the playpen than in their crib on the monitor. The first day was about 15-20 minutes, the next longer, and the next day longer." This category suggests that parents actually go through a testing period of taking their babies off the monitors for varying lengths of time. If the infant passes the test that nothing has happened while off the monitor, parents will gradually lengthen the time of their infant off the monitor but will still depend on the monitor for those

vulnerable periods of time such as when the parents are asleep.

These categories were reviewed and evaluated by a colleague familiar with grounded theory methodology. This colleague evaluated the categories for plausibility and if the data were consistent with the meaning represented by the category label. Two minor changes concerning data bits were suggested by this colleague. The next section links these categories to those concepts which emerged from the data.

Emerged Concepts

Five major concepts emerged from the data in these interviews. These included the concepts of Unpredictability, Guardian Angel, Confinement, Support, and Desensitization. Appendix C contains the labeled concepts and their categories. This section will explain the meaning of each concept.

Unpredictability is the first concept. This concept is defined as the unexpectedness and randomness associated with an apnea episode and the inability to predict the possibility of future apneic episodes. Parents cannot predict the onset of an apnea episode, therefore, it is unpredictable. No one can guarantee that whether the baby who is monitored will have a future apneic event or not. No one guarantees that home apnea monitoring will prevent apnea

episodes from reoccurring. In a sense monitoring increases the unpredictability. A baby who is monitored is a baby whom we do not know for sure will have another apneic episode.

The categories of Chance, Afraid and Fallible are contained under the concept of Unpredictability. The category of Chance explains the unpredictability associated with the apnea episode. Apnea is an event which parents have no control over. Parents cannot predict if another apnea episode will occur again. Parents can only conclude that if an apnea episode happened once, it may happen again. The monitor is seen as something which decreases the chance of another apnea episode from occurring because it alerts parents to when a problem may be occurring. The category of Afraid explains the unpredictability associated with the monitor alarm. When the monitor alarm goes off does that mean the baby is really all right or does it mean the baby is having another apneic episode? Parents question and interpret the meaning of an apnea alarm. The initial meaning of an apnea alarm is unknown to parents and until they have learned to discriminate the different alarm sounds parents are frightened by what that sound may mean. The category of Fallible explains the unpredictability associated with the monitor itself. The monitor is not a predictor of apnea. The possibility exists that a baby could still have an apneic event and the monitor would not

register it. The monitor is capable of making an error and therefore, is unpredictable.

The **Guardian Angel** concept explains the guardian role, assumed by the parents or the monitor, for the purpose of keeping a constant surveillance of the baby. If the parents are not guarding the baby the monitor is. This concept describes behaviors of parents such as always keeping a watchful eye or ear out for the baby. This concept also describes the monitor as being a watchdog of sorts. It will bark, in this case alarm, when a problem is occurring. This concept also expresses parents feeling totally responsible for their infant. They feel better when they are watching their infant.

The categories of Vigilance, Security, and Nobody Else but Me are contained under the Guardian Angel concept. The category of Vigilance suggests that parents' continually keep a vigilant eye or ear out for their baby. Parents exhibit certain behaviors to enhance surveillance of their infants. Parents may use an intercom to make sure they know their baby is breathing or to enhance the sound of the monitor alarm. Parents assume the guardian angel role by exhibiting certain vigilant behaviors. The category of Security expresses the idea of the monitor being the guardian angel, especially during those times when the parents cannot survey their baby such as when they are asleep. The monitor assumes the guardian angel role when

the parents cannot assume the guardian role. The Nobody Else but Me category expresses the idea of parents' feeling they are the only person capable of keeping a continual watchful eye on their infant. Parents' won't leave their infant with someone else because of their lack of trust concerning others capabilities in caring for a baby with an apnea problem. These parents solely assume the guardian angel role. Parents view themselves as the guardian angel of their infant from feeling they are the most competent person to take care of their infant.

Confinement is the next concept, subsuming parents' feelings of being restricted. Parents see themselves as being physically restricted and emotionally restricted. For example, they are physically restricted if they can't find a babysitter. They want to go out but they can not find someone who can perform CPR. Emotionally they are confined because some choose to confine themselves. They ask themselves, "What if something would happen while we were out? We'd better stay home."

The two categories of Captive and Restrictions are included in this concept. The category of Captive suggests that parents' are emotionally binding themselves to their baby. Parents' stay at home because they don't feel comfortable with someone else watching their infant. Parents' confine themselves until they choose not to confine themselves usually by taking the initiative of finding a

babysitter to watch their infant. The category of Restrictions suggests that confinement is caused by all the extra considerations parents need to make with a monitored infant. Parents need to find babysitters who are trained in the use of the monitor and in CPR. If parents cannot find someone who meet these criteria they stay at home with their infant or take their infant with them.

The next concept of **Support** explains the idea of parents receiving relief from each other or from an outside resource such as family or friends. These resources may provide either physical support such as offering to babysit or they may provide emotional support to these parents. This concept also includes the idea of having no support which usually results from others lacking understanding of what home apnea monitoring means.

The categories of Relief Pitcher and Partnership are contained under the concept of Support. The category of Relief Pitcher suggests that having someone else who is capable of assuming the parents' vigilant role is seen as a source of support to the parents. Others are seen as a source of nonsupport usually resulting from a lack of understanding about the meaning of apnea and home monitoring. The category of Partnership suggests the spouse as being the most important means of support. Husbands and wives need the understanding and the support of each other in order to adjust optimally to the monitoring of their infant.

The last concept which emerged is **Desensitization.** Seligman (1975) used this term in describing how subjects finally feel they have control of an imagined fear. He described this as a cognitive process where the subjects felt they had control of the situation. This applies to parents whose infant is being monitored. Parents are convinced cognitively that this apneic episode will never happen again. They then exhibit this attitude in their behavior by becoming more lenient in their normal routine of monitoring.

The categories of Getting Used To, Confidence, and Weaning are contained under the concept of Desensitization. The category of Getting Used To suggests that parents reach a point where they finally accept the monitoring of their infant. Parents stop perceiving the monitor as being a threat. Parents begin to feel comfortable with the idea of monitoring. The category of Confidence suggests that parents perceive themselves as beginning to have some control over the threat of apnea. Parents through a gradual cognitive process reach a point where they are certain their baby will not again experience an apnea episode. Parents' begin to think that since their infant has not experienced a true alarm since being monitored, the possibility of another apnea episode occurring is almost nonexistent. The category of Weaning represents the behavioral outcomes resulting from parents' thoughts of the

low probability of another apnea episode as occurring. If parents begin to feel that the chances of another apnea episode occurring are remote, their behavior will exhibit these same thoughts. Parents gradually wean themselves from being completely dependent on the monitor. Parents will start to take risks by instituting test time trials of leaving their babies off the monitor.

To conclude, this chapter has described characteristics of the sample used for this research, the processes used by this investigator to obtain the categories and concepts, and the categories and concepts which emerged from the data. The next chapter will identify the relationships between these concepts.

CHAPTER 5

CONCLUSIONS

This chapter will present the conclusions of this research by presenting the conceptual model and identifying the relationships between the major concepts. This chapter will end by giving implications for nursing practice and recommendations for future study.

Conceptual Model and Identified Relationships

This section will present the conceptual model as developed from the theoretical coding of the data. This section also uses the available literature to support the emerged concepts and the linkages (hypotheses) proposed between the identified concepts in this research study.

Figure 2 portrays the conceptual model developed from the data. This model diagrams the process of parents' adjustment to the home monitoring of their infant as interpreted by this investigator from the data obtained in this study.

The concept of Unpredictability is the first concept indicated on the left side of the model. The model reveals

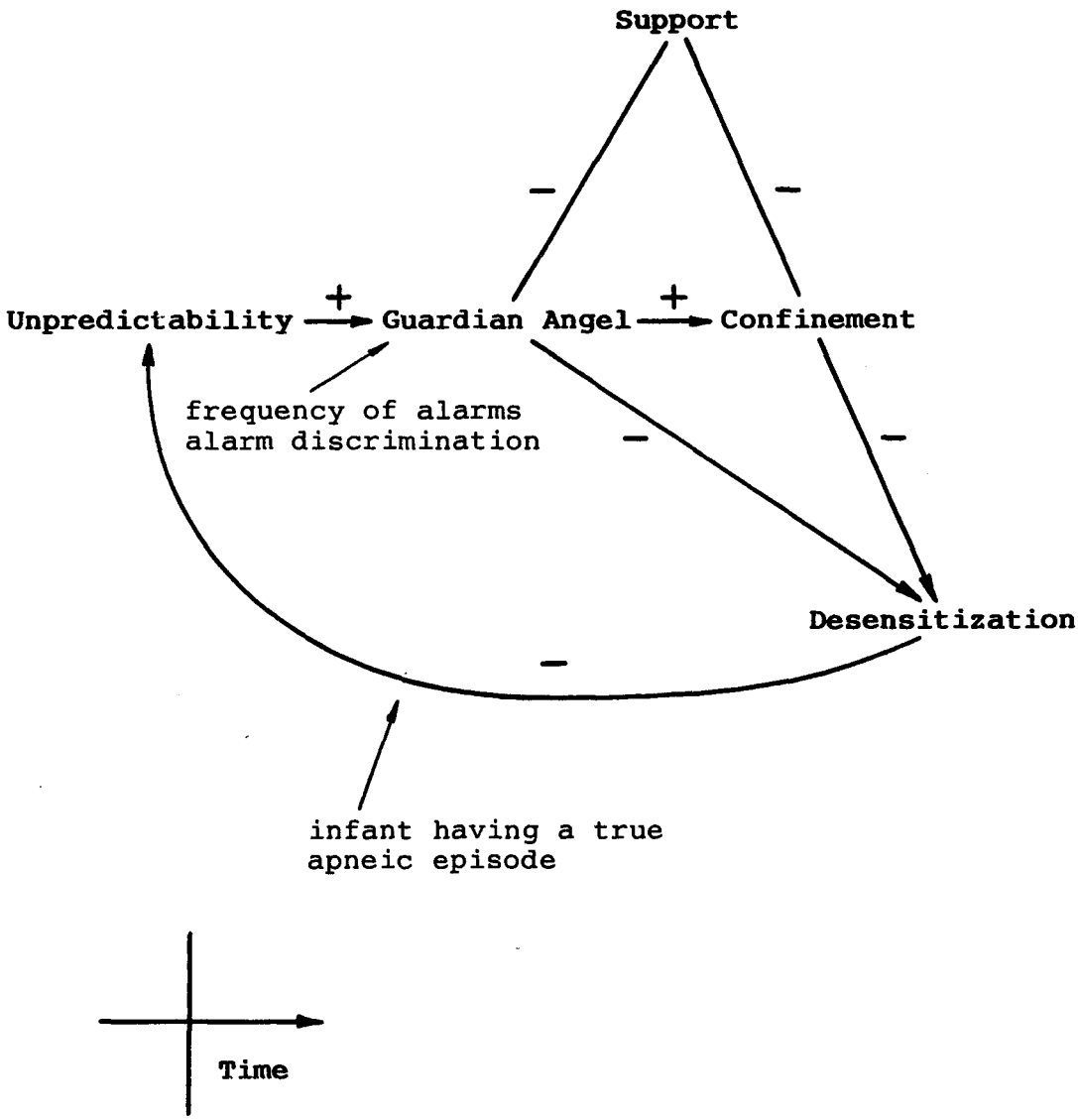

Figure 2. Conceptual Model of the process of parents' adjustment to the home monitoring of their infant.

the concept of Unpredictability as having a causal relationship with the Guardian Angel concept. The Unpredictability associated with the monitoring of an infant leads to parents' feeling their infants are very vulnerable, and as a result, these parents show vigilant behavior towards their infants. The more the parents see the monitoring as unpredictable, the more likely they are going to exhibit guardian angel behaviors. Seligman (1975, p. 113) described people as being safety seekers. They search out for predictors of unavoidable danger because such knowledge also gives them knowledge of safety. If parents of a monitored infant perceive the monitor as being a safety signal, a predictor of when danger will occur, these parents will exhibit fewer guardian angel behaviors. They feel the monitor is a predictor of when an apneic episode will occur. But if the parents feel the monitor is an unreliable indicator of when danger will occur, they will increase their vigilant behavior. Initially, parents will be more watchful of their baby because they have not yet learned to trust the monitor. A data bit which supports this relationship is one father's statement, "That's one of the reasons why I kept walking by a lot. It's a comfortable feeling to know that we had it, but it's still a machine."

The next linkage identified in the model is the causal relationship between the Guardian Angel concept and

the Confinement concept. The Guardian Angel leads to Confinement because parents feel uncomfortable leaving their baby with someone else. One mother expressed this relationship between these two concepts when she said, "We don't have as many times together but it might be due to me because I don't feel comfortable yet with leaving him." The more parents perceive themselves as the Guardian Angels, the more they will confine themselves. Many parents described how they would always take their baby with them if they went out. This investigator sees this as being an emotional confinement where parents won't let themselves trust anyone besides themselves to care for their infant. The frequency of monitor alarms and if they are real or false can have an impact on this relationship. If the baby is having real episodes of apnea, setting off true alarms, the parents will increase their vigilant behavior. They will not leave their baby until they feel that the baby is all right. One mother stated, "I'd find myself after an alarm sitting there to make sure the alarm would not go off again especially when we first had it."

The next concept of Support has an associational relationship to the Guardian Angel and Confinement concepts. In other words, the concept of Support impacts or influences the concepts of Guardian Angel and Confinement. The amount of support given by families or friends to parents will directly affect these two concepts. For example, if a

family member provides babysitting support, he or she acts as the guardian angel for a while thus letting the parents go out. This decreases the parents' confinement because of the opportunity to be freed from the responsibility of being the Guardian Angel. The following data bits substantiate this relationship between Support, the Guardian Angel, and Confinement concepts, "My mom would watch her and let us go out," "I have another girlfriend. She's not afraid, she'll watch her," and "She (mother in law) didn't offer that much before to babysit but now she realizes we are more comfortable with her watching than anyone else." If no support is available to these parents, the confinement is increased because they have no options to decrease their confinement. One mother stated, "I explained to her (babysitter) it's for when he's sleeping so you don't have to watch him as close or whatever. She heard the word monitor and she said no. No, I don't want to sit for him." This type of confinement is not by choice and the parents remain the guardian angel unwillingly for long periods of time.

The model also portrays the Guardian Angel concept and the Confinement concepts as having a directional relationship with the Desensitization concept. In other words, the Guardian Angel and Confinement concepts eventually lead to the Desensitization. If parents feel confident that no future apnea episodes will occur they will slowly begin to decrease their Guardian Angel behaviors and thus decrease

their confinement. In other words, the greater the Desensitization of the parents the less the Guardian Angel behavior. It seems that parents reach a point where their vigilant behaviors towards their infants begin to decrease. If their child has not had a true apnea episode since being monitored, the threat of an apnea episode is reduced cognitively in the parents' minds. Parents begin at this time to analyze what constitutes an apnea threat by discriminating between the monitor alarms. Several parents stated, "When the leads are out, it's a constant alarm but when it's a heart rate or apnea every second is a broken beep," and "It was about three seconds long; beep, beep, beep, and I knew the difference." Parents discriminate between alarms so well that they eventually won't answer all the alarms if they perceive the alarm was false. One mother stated, "Not lately have I been answering all the alarms." Breznitz (1976) discussed how false alarms can affect one's behavior so that they terminate whatever behavior the subject was engaged in, in order not to waste energy, time, or money to prepare themselves against something that will not materialize. Many guardian angel behaviors begin to decrease during this period of desensitization because parents feel confident that the apneic episode will never materialize.

Desensitization may also be seen as a cognitive form of control. In Taylor's (1983) theory of cognitive adaptation to threatening events, one of the three themes proposed

is how subjects may attempt to gain a sense of mastery over the threatening event. This theme of mastery centers around gaining control over the event and one's life (p. 1161). Taylor (1983, p. 1163) stated that, "this theme of mastery is exemplified by beliefs about personal control." The parents with a monitored infant eventually perceive themselves as having control over the situation. The parents feel they can predict with confidence that an event will not occur. Taylor (1983) proposed that a positive attitude is one way of subjects efforts at gaining mental control of a situation. Several parents in this study related how a positive attitude possibly would prevent an apnea episode from occurring, they stated, "I sorta have this thing that if people dwell on something bad it's going to happen. You're liable to draw it to you somehow," and "You have to think positive and believe it."

The last relationship portrayed in this model is the feedback relationship between Desensitization and Unpredictability. This relationship suggests that as the unpredictability lessens, the more desensitized parents become because they feel the event of the baby not having an apnea episode is more predictable. If an infant were to have a true apneic episode requiring vigorous stimulation this affects the relationship of Unpredictability and Desensitization. Parents would again experience those feelings of unpredictability thus going through the whole

process of guardian angel, confinement, and support before getting back to desensitization. Several data bits from parents support this relationship. These include: "If I brought him home and the monitor went off and I ran in there and we resuscitated him maybe that would be a different story maybe I wouldn't feel this way," "If it started to take off continuously of some duration there would be more reason to be alarmed," and "If it went off a couple of times when he was first born or the first month, something like that, and we got up and he wasn't breathing then I'm sure we would have wanted to have it on all the time, but he hasn't seemed to have any problems with it."

This model does suggest that parents' perceptions of the home monitoring of their infant change over time. Initially, parents experience feelings of unpredictability associated with the diagnosis of apnea and with the monitoring. These feelings of unpredictability lead to parents assuming the guardian angel role, which then leads to confinement. After a period of time parents proceed to the desensitization period whereby they feel confident that the threat of apnea is almost nonexistent. If an infant experiences another true apnea episode, parents would again reexperience those feelings of unpredictability and progress once again through this whole process. This study does indicate that parents do vary in times of adjustment to the monitoring. Parents' seem to have their own pace of

adjustment. Some parents go through this process more quickly than others. This seems to be based on when parents feel more confident with themselves and confident that another apnea episode will not be repeated.

The model, portrayed in Figure 2, was reviewed by my last set of informants to confirm whether the model described their experiences of the monitoring. The couple who reviewed the model felt the model portrayed their experience of living with their home monitored infant. This model was also confirmed by the pediatric pulmonary nurse specialist, who works with families of monitored infants on an ongoing basis, as portraying the perceptions of parents whose infants are monitored at home.

Implications for Nursing Practice

This section will reiterate the four properties as described by Glaser and Strauss (1967) to attest that this proposed theory can be applied in practice by health care providers. The first property asks, is the theory faithful to the everyday realities of the substantive area as one that has been induced from the diverse data? This proposed theory represents those perceptions from parents describing their experiences with home monitoring. The data contained in this theory has been induced from those verbalizations of parents concerning the monitoring of their infants.

Therefore, we can assume that these comments represent perceptions of some parents with monitored infants.

The second property states the theory should be understood by those who work in the substantive area and that the theory can be used in everyday practice. The knowledge of parents descriptions of their experiences with monitoring would help nurses and physicians in counseling families whose infants are being discharged from the hospital to home on a monitoring device. Nurses could counsel parents about the different periods of feelings they might encounter in the forthcoming weeks or months. Nurses could explain about the initial period of unpredictability describing it as a period of when parents are unsure of themselves and unsure about the monitoring of their infant with the diagnosis of apnea. An important consideration for parents at this time may be to have a nurse sit with them and discuss with them how they might deal with certain situations related to the monitoring, if they appeared. How would parents react if they heard an alarm? Nurses could reassure parents that it is normal if they feel protective of their infants, that many parents have described these protective feelings before. This theory also suggests the importance of a support system for these families. Parents who have supportive family and friends will be able to get out and away from the situation for a short time because of the availability of these support systems. A big

concern of parents was the lack of available competent baby-sitters. It would be helpful to these families if nurses were aware of babysitting resources available to these families. This model also suggests that nurses could have a great impact in providing outreach education to different facilities in teaching about apnea and the home monitoring of infants. Data from this study suggests that parents were appalled at the lack of information and understanding that the general population has about apnea and home monitoring. Nurses could find themselves involved in teaching baby-sitting co-ops about these infants who are being monitored. Nursing could emphasize monitoring as not something to be feared but as something that should be considered as an aid when babysitting a child with an apnea problem. Another source of support to parents would be other parents with monitored infants. Nurses should be instrumental in introducing these new parents with a monitored infant to someone who is already experiencing the ins and outs of monitoring.

The third property asks if the theory has general application? This theory possibly has implications for all those parents with monitored infants whether they are single, adoptive, or foster parents. Although subjects in this study were couples, it is possible that other different groups of parents would experience this same process. Only by further investigation of other groups of parents would general applicability of this theory be proven.

And lastly, can those nurses who work with these families use the theoretical framework in caring for these families during the monitoring period? Nurses who work with these families can use this model to continually assess where the parents are in this process and how they are currently dealing with the monitoring situation. Thus allowing the nurse to anticipate problems and begin the problem solving process immediately when troubles first appear. An example would be a set of parents whose infant has been monitored for a considerable length of time without any problems, and then all of the sudden has a true apnea episode. These parents' would again experience those feelings of unpredictability, guardian angel, etc. Nursing care important during this time would be close followup of these parents in alleviating their renewed concerns about apnea in their infant.

Recommendations for Future Study

Recommendations for future study include:

1. Replication of this study following several families during the same period of monitoring. This would provide the opportunity to validate these proposed concepts and their sequencing. This also would provide the opportunity for continued exploration of these concepts and their relationships.

2. Replication of this study following several families after the discontinuance of the monitoring device. This investigator proposes that parents reexperience those feelings of Unpredictability, Guardian Angel, etc. after discontinuance of the monitoring device. Replication of the study would confirm if the model upholds during this period.

Summary

To summarize, this researcher organized and categorized parents' perceptions concerning the home monitoring of their infant. Only by clearly understanding parents' feelings and attitudes towards the monitoring of their infant will we begin to understand the process of parent's adjustment to the monitoring situation. Further research in this area would assist nurses in providing optimal care to these families.

APPENDIX A

Subject Disclaimer Form

Dear Parent,

You are being asked to voluntarily take part in a study designed to learn about parents views and feelings of what it is like to live with an infant who is being monitored at home. The purpose of this study is to identify and describe the effects monitoring has on the family and to identify how parents views of infant home monitoring change over time.

You will be interviewed, on one occasion, for one to two hours. If necessary, I may call you on the telephone after the interview if I have any other questions. This telephone followup will not last longer than 30 minutes. The interview will be audiotaped. You will decide the time and place of the interview.

There are no potential known physical or emotional risks associated with this study. Your identity will remain anonymous. Interviews will be numbered with no names collected. You will not be given money to take part in this study. This study will have no probable benefit for you. However, it may help health care providers understand the effects of home monitoring from the parents' point of view. This study may also help in identifying supportive care by health care providers that is beneficial to families with a home monitored infant.

The written and taped information from the interview will be used for a Master's thesis and possibly for publication. Information from this study will be reviewed by members of my thesis committee only. Your participation is completely voluntary and you are free to withdraw at any time. If you do decide to withdraw, your infant's care will not be jeopardized. I will answer any of your questions, at any time, during the study. Copies of this thesis will be placed in the Medical and Main Libraries of the University of Arizona in Tucson when completed. Segments of this

thesis may be published in nursing journals. Thank you for your time in taking part in this study.

Joanne Riley Kilb

Appendix B

HUMAN SUBJECTS APPROVAL

THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85721

COLLEGE OF NURSING

MEMORANDUM

TO: Joanne Riley Kilb, BSN
Graduate Student
College of Nursing

FROM: Ada Sue Hinshaw, PhD, RN
Director of Research

Katherine Young, PhD, RN
Chairman, Research Committee

DATE: June 17, 1985

RE: Human Subjects Review: Parents' Perceptions of the Home Monitoring of Their Infant

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

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

ASH/fp

Appendix C

Labeled Concepts and Categories

Unpredictability

Chance

M: She said you're crazy this was just a course of events. (sister telling mother.)
F: That life itself is so fragile.
F: One moment you can be here the next moment be gone.
F: There is nothing that can stop him from breathing in the middle of the night.
M: Just being the most responsible parent in the world doesn't guarantee that you will have a healthy child who lives to be an adult.
M: They said how can you have him down the hall what if he stops breathing.
F: You brought the monitor home you are expecting something to happen. It's going to happen because you got the monitor because it happened the first time.
M: He's a gift to me he could be taken away. He could have an accident in a car, somebody could kidnap him.
F: It will never happen again but to be on the safe side they want us to use the monitor till he is about 6 months old.
F: I accepted all the things that happened that's the way it's going to be, it was his destiny.
M: Once I realized that it was going to happen wherever....
F: I don't know if the monitors were really necessary I wouldn't want to take the chance to find out.
F: For myself it was just one of those isolated type of situations.
M: There is a possibility she may be a crib death but the same possibility exists that she could have a problem like leukemia or whatever.
F: How many thousands of children are born every year? How many of them are probably apneic who never get

monitored? How many do get monitored and are mildly apneic borderline and probably it wouldn't have made any difference if they were monitored or not?

F: Who knows if we didn't have him on the monitor. I'm sure all children, where they stopped breathing longer than normal they are not on the monitor. They wake up the next morning ready to eat again but you never know.

F: Not really much that you can do to predict whether you will have an apneic child or not.

F: It's so random how do you know which kids are the ones who will get apneic?

F: It's real tough all of a sudden they tell you your kid has apnea. They say we don't know what it is either but we are going to send you home on a monitor and we are going to give you infant CPR. Ask why do I need that? You go in there and start doing chest compressions counting them off and you start making correlations that this is some life threatening event.

M: You've got all this pressure you don't know what you've got.

F: We cannot predict what is going to happen to her in the future but the Lord knows.

F: Nobody knows, thats the problem. Nobody knows, not the technicians or the pediatrician.

M: This kind of thing could happen to anybody.

F: We asked how long? They said 6 months to a year. We said we want a definite time.

M: Having the test they realized he had apnea, like my other little boy he could have had it and we never would have known about it. There could be a lot of babies born with it that they just....

M: I always say it doesn't matter if the kids a B (family name) or not the kids got apnea, I mean nobody can do anything about it.

M: I've told her mom if it's gonna happen there's not much you can do about it.

<u>Afraid</u>

F: The more you know about apnea spells and what could happen, the more you worry about it, especially if it's your own kid.

M: Scary at times especially when the alarms go off.

M: Scared that I might lose her.

M: But when they first came home I was scared that I would lose them.

F: When they first came home I was scared a little bit that something could happen to them.
M: A couple of times when they first came home and started making noises I got scared walking into the bedroom.
F: Something's wrong with the child, it can just stop breathing and be gone.
M: You never know when the alarms go off, that it won't be the one you can't pull him out of.
M: Or that you will have to start CPR and take him to the hospital.
M: It's an uneasy feeling.
F: That he can just drop off and die any minute.
M: It's the unknown that scares you.
M: It's not the known, the known you can absorb and handle.
M: I am always afraid that I will have to do it (CPR).
M: Instead of being awakened by a cry you are awakened by an alarm.
M: Fearing the worst would happen.
M: There is a feeling of panic when the alarms go off is he breathing?, is he okay?, am I gonna have to get him up and start shaking him to make him start breathing.

Fallible

M: I'd rather have false alarms than no alarms.
F: Even when he has been in my arms he would have breathed 3 times and the machine has only picked it up once.
M: Even though there is a machine there to pick up the sound you wonder if it will make the sound.
M: You always hope machines aren't infallible you just hope this one isn't.
M: Sometimes the monitor would go off and everything was okay.
M: My girlfriend says rely on the machine but I think what if the machine is malfunctioning? I have to go in and see.
M: It was comfortable until a doctor told me you can't rely on these 100%.
F: That's one of the reasons why I kept walking by a lot its a comfortable feeling to know that we had it but its still a machine.
M: I'm sure the machine could foul up minimum chance but it could.
F: Because of this little machine here you wonder if its really gonna do the job.
M: One of the doctors told me they could have a problem sometimes it doesn't work all the time.

M: I'm sure a baby can die on a monitor. Life is not depending on a monitor.
M: Possible if he's not suppose to be here it could happen with him on the monitor.
M: How do you know its a loose lead?

Guardian Angel

Vigilance

M: If he has a cold I will watch him more because it is harder for him to breathe.
M: We keep the baby in our room.
M: I'm sure the baby will stay in our room until the monitoring is done.
M: Every once in a while I find myself looking at the monitor lights to make sure they are blinking.
M: We got to the point where we watched her constantly.
M: We just sat there and watched her breathe.
F: She was in our room a lot of sleepless nights.
M: We kept her in our room.
M: I'll watch as he lays there and breathes.
F: We still do it. I'll go in and look at him and if its dark we have to really look close and see if he's going up and down. He breathes real shallow.
M: Even when we first came home and the alarm didn't go off I'd have to go in and see that he was breathing.
M: The light, I mainly look at the lights to see if they are still beating on the monitor.
F: To see if she's breathing to make sure her stomach is moving.
M: J(oldest daughter age 6) will watch the kids while I put clothes on the line. She'll sit in here.
F: We just keep an eye on them.
F: These guys I don't make a point to look at them but if I am going by the playpen and they're sleeping I would look to see if their chest was breathing.
M: I told the doctors either put them on the monitor or I am going to be sitting in there 24 hours a day because of what happened to M.
M: We had to change his bedroom. I planned on having a nursery but when I found he was going to be on a monitor I had to move him up into the den.
M: When she's awake she is with me and I can watch her.
M: The baby has to be watched while I'm doing something far from the house, or if I have a vacuum cleaner on or something noisy.

M: Every night it's on but during the day then I'm going in there and I'm cleaning and I'm back and forth I keep looking at him and making sure he's okay.
M: I go in to make sure she is breathing.
M: I had a doctors appt. today and it ended up being longer I called and asked "Is everything okay?"
F: Walk in and peek in while walking by his room.
M: I don't know how long it has been and I'll run in there- race in there- and look at him.
M: I can say for the last three nights I have gotten up and made sure the alarms were on after I laid there for three minutes and thought I'm going to check.
M: Many times I'd go in and put my hand on his back and make sure he was breathing.
M: I'd find myself after an alarm sitting there to make sure the alarm would not go off again especially when we first had it.
F: That's kind of a morbid thought to go in and check on the baby to see if he is breathing but we do it.
M: Whenever I get the urge now even if I'm real comfortable I'll hop right up and get right in there.
M&F: We always check on her a lot and I'm glad we do because that one time it paid off.
M: At church we put her in the nursery I go back and check on her. I really check on her and look through the window a lot to see if she's okay.
F: I wasn't worried about it. I got up several times and checked her.
M: I think gee, I don't want to run in there because I'll wake him up if I do but you have to.
F: Walk in turn on the light on or hall light to see her breathing.
F: They say the first thing you are suppose to do is look at the baby and check his color, never had an incident so I just looked to see what it is because I figured it was a heart rate.
F: The light on it was an apnea light so I looked at her and she was fine-breathing fine.
M: Before I wouldn't dare go by her room fearing that I would wake her up not the case anymore.
M: During her nap time I am always at the door it seems, not like before.
M: I answer every alarm.
F: Check the color mainly.
F: I still go in and check him even when the monitor was on.
F: We found ourselves every move she made or sound we were up checking on her.
M: We were running out of the room a lot.

F: There were a couple times when they were in sleeping in the playpens I would look over to see if he was breathin and check his color.
F: I'll just look to see if 2 green lights are on, if the monitors are working.
F: You just stop everything else and go and see what the problem is.
M: Before going to bed I'll look at them even when the monitor is on I'll look at them.
M: If he's awake I'd go like out into the kitchen and get a drink something like that and come back and check on him every few minutes but if he's asleep I won't do it.
M: Somebody has to be close to the baby.
M: I go occasionally in the middle of the night and check on him. I'm a very light sleeper a lot of things can happen.
M: I kept checking him every once in awhile making sure he was ok.
M: Even now when I leave them at night with my sister, she'll come over and watch him, I keep calling cause you are worried and can't go out and have a good time.
F: An hour or 1/2 hour after we put him to sleep we'll check on him. If we happen to be sitting here and watching TV or we'll go to the bathroom and just check on him. Then we check on him right before we go to bed.
M: We could hear her breathe and she could hear us.
M: We'd listen for it.
M: I go in listen to hear regular movement.
M: I just listen to make sure she is okay.
M: I'm always within earshot.
M: If she's sleepy and wakes up I'm right there, whereas before I would let her fuss to see if she would go back to sleep and I just can't do that now.
M: When you go to bed at night it is usually on always on. (the intercom).
F: It's (intercom) kind of comforting you don't have to get up in the middle of the night and go check on her as much, you can hear her breathing.
F: We can hear the alarm in our bedroom even without the intercom but its just very sensitive you can hear every single move, breath and everything.
M: You sit and listen to every alarm.
M: I run to her with every noise and every cry she makes.
M: We have an intercom we can hear every breath that she takes.
F: There was never anybody out of earshot of the alarms the entire month of April and March for about 6 weeks.
F: We are right across the hall where he sleeps. We take the intercom when we go outside.
M: You have to remember not to fall asleep with your son on a monitor.

M: We did a lot of calling.
M: I still check on him a lot.
M: We usually are right here. We don't leave a lot usually he's here (the baby), right here with us.

Security

M: Knowing that he is on the monitor is a secure feeling.
M: Knowing that if he slows down to a certain point we will know about it.
M: You don't have to be constantly hovering over them.
M: It's a comfortable feeling to know the monitor is there.
F: The machine lets you know when that (apnea) happens.
F: The machine tells you an episode is occurring.
F: You know the machine is going to react every time.
M: I can tell you right now I have relied a lot on it.
F: You feel competent the machine will let you know when something is wrong.
M: It's like a crutch.
F: There is a lot of information there that I wouldn't normally have.
M: It will go off when it is suppose to and once you get that set in your mind you can rely on the machine.
F: Without it we would have been on pins and needles all the time especially after we brought her home.
M: I knew that if we didn't have it we would be sleeping with her.
F: It was a big relief to have it.
F: As soon as the monitors came in the house I felt real good because there is no way in the world we could have watched both of them without the monitors.
F: Its like the boy who lives in the bubble as long as he is in the bubble he's allright. The monitors are their bubbles.
F: The monitors have been our security blanket.
F: It gives you more security.
F: When you are not in the room something is there.
F: They are really an electronic babysitter.
F: I don't even give it a second thought when they are on the monitor because if something happens the alarm is going to go off and we have gotten to be pretty responsive to the alarm.
F: It allows you the flexibility of doing other things and still have the protection that if something did go wrong you would be notified and could take protective action.

F: It allows you the flexibility and mobility to move around to do other things but yet the security of knowing of some life threatening problem you would be able to respond in a timely manner.

F: It allows you a lot more freedom and flexibility. If you had to stay and constantly watch, it would be very time consuming and cumbersome to do that day after day hour after hour.

M: I wouldn't leave and go into the other room without putting him on the monitor.

F: It's easier for peace of mind to put him on the monitor when out of the room otherwise we both are glancing over. It's one of those things when he's on the monitor you're kinda watching his respirations.

M: I feel now that the monitor helps us just to see if the baby is still breathing.

F: He suggested one of these monitors for the baby might not be bad, since its unlikely somebody will be able to watch her continuously.

M: She has it on all the time because she sleeps a lot.

M: She has the belt on most of the time I take it off when I give her a bath.

F: Our decision to put him on the monitor whether he needed or not was more for mere safety and peace of mind with the monitor.

F: For my wife that's insurance for her.

M: The monitor was something to make us feel more relaxed with him then he was going to be napping so we wouldn't have to be watching him every second.

M: I always respond to the alarm. I always go look to make sure he's allright but it hasn't gone off since he was 3 or 4 weeks old.

M: I know that if he stops breathing this monitor is gonna tell me if I'm asleep.

F: I have a lot of confidence in the monitor, it is sensitive enough to go off at the least little thing and for that I am grateful for.

M: I mean it was better than maybe waking up and thinking he was dead.

M: We knew it could happen and we wanted something to protect us just in case it did, that's why we got the monitor.

M: Our little watchdog.

Nobody Else But Me

M: Even if you leave them with someone else who knows CPR you have this funny feeling in your gut.
M: What if they don't do it right? (CPR)
M: What if they can't do it (CPR) as good as I can.
M: We have someone come over and watch the other boys, but we have taken him (the baby) with us.
M: It's just your personal decision and how comfortable you are.
M: It would be more traumatic for me to go out somewhere and leave him with someone for a long time than for me to take him with me.
M: Mom I said at this point I don't feel comfortable with anyone.
F: I can hear the intercom out in the garage, her (mother in law) awareness level isn't the same as ours.
M: He (father) would leave him with someone I wouldn't.
M: If something does happen there is nobody else who knows how to take care of it.
M: I am not going to leave him overnight alone even with my mother.
M: She (grandmother) doesn't hear the monitor alarms and that worries me.
F: You just can't go and leave him with anybody.
F: He needs special attention.
M: I'm just not going to leave him with anybody.
F: It depends if you can find someone experienced and who knows what's going on.
M: We use to drop the older son when he was a baby in the church nursery not the case anymore. I'm not going to leave him (baby on monitor) in the church nursery.
M: My sister would watch him but I don't know if I would feel comfortable.
F: One of us has to be available in case something happens, for example, in the case if one of us is taking a shower.
M: I think you become a lot more aware of who takes care of your baby.
M: He (father) is worried about it too because he would never have taken the other girls to a restaurant.

Confinement

Captive

M: You can't get away from them very much.
M: We have never left him.
M: We didn't go anywhere the whole weekend.
M: We don't go out very often, can't really find anyone to watch her.
F: It's put on a lot of stress, we can't go anywhere.
M: Having a baby limits your social life but having a baby on the monitor cuts it almost to nil.
M: It is difficult it really limits your social life.
M: We sorts think we would have had more times to ourselves if he hadn't been on the monitor.
F: We went out to lunch together and to a movie that's the most fun we have had since.
M: I jogged went to the movies had people over. We were real social butterflies, not anymore.
M: The only time I have away from that kid is when I am sleeping.
M: We don't have as many times together but it might be due to me because I don't think I am comfortable yet with leaving him.
M: We don't have as many special times as we use to.
F: Now we are watching the evening news that kind of stuff.
M: The first time we went out I didn't want to go at all.
F: We've only gone out twice in 5 months because we haven't been able to find sitters.
M: We're always home with the kids because of him on the monitor.
F: It makes it a little rough to go out and just have a good time, to get out and enjoy yourself.
M: We were paranoid at first, everyone knew what they were suppose to do but we were kinda reluctant to leave him.
M: We were hesitant at first even though he was real little they would call you and say "you guys go out." No we'll just stay home.
M: Seems complicated with 2 kids. Seems like a burden putting it on someone. We just haven't gone out yet.
M: If I feel like I don't want to leave her somewhere he's real supportive let's just take her with us. Let's go whereas we might have ended up staying here.

M: We just take her with us - she's easy to take with us. She's easy to take along.
M: We have always just taken her. This has affected us more than we realize, we had never taken her to the movies before and now we take her to the movies.
M: We have been taking her along with us a lot.
M: We have taken her to dinner with us - made a lot of excuses. We have to bring this baby because we don't have a babysitter.
M: I was just nervous if something happened and we weren't home.
F: I'd just rather stay with the boys than have someone else do it, not that I don't think anyone is anymore capable than us to take care of them.
F: Once the alarm goes off then it's up to us to give the baby the attention it needs.
M: I wouldn't like to leave her to long. Not feeling secure, wouldn't want to leave her with someone who doesn't know how to handle a difficult situation.
M: We usually go out all together all the children.
M: She (talking to her mother) went through the course and yet I don't feel she could give it (CPR) and thats really a worry.
F: I don't really feel that comfortable. She's (mother in law) not a crisis oriented person.

Restrictions

M: You have to have someone who knows CPR.
M: You can't just drop them off somewhere or have a baby-sitter come in and watch them like with another child.
M: You have to have someone who knows CPR or you don't feel comfortable at all.
M: Reason not working now is because he is on the monitor.
M: It's rough if you want to go out, cause a lot of people won't babysit for us.
M: You just don't leave him with anybody.
M: I just can't go out and do what I want to do.
M: I had wanted to teach in the fall but who am I going to leave him with?
M: The monitoring has prevented us from going to church.
M: We wanted to go camping I wondered how do we recharge that battery if we wanted to go longer than 5 days.
F: You don't want to get too far away from a medical center in case something would go wrong.

M: If they said he could go we would get additional poundage for his furniture but since they said he can't go we don't get the additional poundage.
M: If I want to go to the grocery I just can't get the neighbor girl to come over and sit and watch him for an hour while I do that.
M: We have had a real hard time with babysitting. We only have one person who will babysit for us that's the person who came and learned how to use the monitor and went through the CPR.
M: At the beginning I wouldn't hang up clothes.
M: I cannot take a shower.
F: Its difficult getting babysitters and to have the time to do other things. Plus going anywhere, its cumbersome you have to drag all the equipment.
M: I cannot go to the laundry if she is alone. My husband needs to be here, or somebody.
M: Sometimes I want to take a shower and nobody is here and I have to wait until my husband is here and it is bothersome.
M: We can leave her with somebody who is trained with the monitor and with CPR.
F: I'll say, "Let's go out and do something." She'll say, "No we have to have a babysitter." There is only a few select people to watch him for us and make sure everything is fine.
M: With him you have gotta leave him with someone, a person, you would trust, someone who knows what they are doing in case something would happen.
F: Your average 15 or 16 year old babysitter would be no problem to me. As it is we only have a few people that are babysitters and it's her side of the family who are suppose to know CPR and they know how to handle things.
M: You can't come and go as you please you can't leave him with certain people.

Support

Relief Pitcher

M: If I had to get away they would understand. If I just wanted to come over and sit by myself.
M: If I just wanted to get away.
M: If I just wanted to lay down or something.
M: One time the medical supplier came out at 3:00 in the morning we were having problems with the machine.
M: The people at the chest clinic have called every month to see how he is doing, if he has had any problems.
M: Just to know that someone else out there cares, that's nice.
F: Its a lot better now so many professional groups are getting more involved in this right now.
M: The rescue squads are aware there is a baby in their area with a apnea monitor.
M: All the monitor babies are on special lists (electric, telephone).
M: I did a lot of reading in a lot of periodicals.
M: My mom would watch her and let us go out.
M: I have another girlfriend she's not afraid, she'll watch her.
M: The only one I feel comfortable with is my mom.
F: They are all very interested and concerned (their friends).
F: It's nice to have someone to know that you are having problems and you don't have to really bear the burden alone.
F: Someone to let you know they were there and if you need this or that, someone just to talk to.
M: They (grandparents) called when the baby was in the hospital, they offered to come out but there wasn't anything they could do.
F: Moral support was the most helpful.
M: My girlfriend is a nurse practitioner in the pediatric clinic and she came to visit us everyday.
M: She's a great sitter.
M: I feel comfortable taking him over there (to the sitters).

M: She (mother in law) didn't offer that much before to babysit but now she realizes we are more comfortable with her watching than anyone else.
M: Most of the time my mother will watch (went through the CPR training) her anyway.
M: We have nurses come into our house we had one come in and watch D one night.
M: My sitter knows CPR I taught them about the monitor and stuff.
F: She (grandmother) said if we needed to get away for awhile she would even take him and watch him for us.
M: My grandma took the classes with us and learned about the monitor.
M: We had a lot of cooperation from our family and friends- a lot of help.
F: I really wasn't worried about leaving him with anybody because they went through the training.
M: After J came home they (grandparents) were always giving us a hard time having the baby in his own room and after he stopped breathing putting him back in that room meant God you don't even love this kid.
M: People have told us don't ask us to babysit.
M: My mother she's really afraid. She doesn't even want to watch her when she's not sleeping.
M: I think geez there is nothing really wrong with her but then I can't blame them because I might have felt the same way.
M: They're afraid that it's going to happen again.
M: If we have to go out of town, people have told us don't ask us to babysit even after she goes off the monitor.
M: They'll babysit the two other ones but not the baby.
M: I'm not going to watch the baby, what if she does that, so they're afraid.
F: I don't think its trust on or part, people don't want to take the responsibility.
M: The other thing that really falls back is babysitters.
F: Her parents were down just a little while ago and they said they didn't want to babysit or do anything.
M: We got retrained with D but nobody else did.
M: You're not sure of your friends and relatives they don't know what's going on they're asking all these questions and are inferring that you've got a baby that's going to be a SIDS baby.
F: They don't want to be involved and they don't want to come into a situation like that.
F: It's like, "So what you have an apnea baby you've got a monitor what more could you want."
M: They gave us a list of people you could talk to that formed an organization of parents of kids who are on monitor. I called them they said we dissolved that about 6 months ago.

M: They don't understand what it is for and how it is used. That it's a benefit for them but they think so he's got his thing so he's obviously had a problem and he's probably going to have more.
M: Every babysitter being deathly afraid when you mention the word monitor.
M: Her (babysitter) rationale was that if he is such a bad risk that they feel he needs to be on a monitor then I don't want him.
M: I explained to her (babysitter) it's for when he's sleeping so you don't have to watch him as close or whatever. She heard the word monitor and she said no. No I don't want to sit for him.
M: She (babysitter) did not refuse him until the monitor situation.
F: The babysitter, the one we lost, is a nurse but she was scared because it happened to her and she just didn't want the responsibility anymore.

Partnership

M: With M (first child) we shared a lot more. B (husband) stayed home a lot more than he has with this baby.
M: You have to have a couple that really cooperate with each other.
M: I know if I need him he will be right there.
M: Just to have someone sharing with you.
F: She gets up most of the time.
M: He was there if I needed him sometimes it was like pulling teeth but you were there.
M: I trust him (husband). I would rather have him home if anything happened than me home because I'd go hysterical.
M: He gets up a lot during the night.

Desensitization

Getting Used To

F: It was acquired, a process of having lived with the machine.
F: It's like anything else in your life once you do it often enough it becomes habit.
F: You don't think anymore about it because it's natural you do it this way.
F: It sorta becomes like a routine.
F: You take one day at a time and you take that day for whatever it gives you.
M: Getting use to the sounds, the situation, & how to handle him.
M: It's time and adjustment.
F: It's part of our routine now, we bring him home, we bring the monitor, we put him to bed at night and start the monitor.
F: After awhile it was no big deal, no big worry.
F: After we had been home with J and had the monitor for awhile things got sorta back into a routine. I was less and less concerned with the thing blinking on and off. Started paying more attention to my son.
F: The first few nights the monitor was the big blue monster. That's the way I pictured it.
M: I felt moving him in our room would have handicapped us and the baby.
F: Its something that he's going to get over with it's just a matter of time.
M: We had a period of adjustment during the first few days.
M: You just can't sit there and keep thinking in your mind every second, day and night, oh my gosh I gotta watch him.
M: At first I thought it might be nice for just a night so we wouldn't have to be worried about jumping up and running in there and checking on him all the time. But after awhile I became a little more relaxed with him.
M: When we first brought her home I would never have done it (baby sleeping without the monitor) she slept in my arms.

Confidence

F: He's never had a true alarm.
M: I thought I'm not going to start to take that thing everywhere. I am going to have to learn.
M: I'm getting more and more comfortable without putting the baby on the monitor all the time.
M: Lead alarms drive you nuts. Sometimes I think do I really need to go in there?
F: The apnea alarm has only come on one time.
M: When I hear an alarm now I just think it's the baby moving or just a loose lead. They do it all the time to me.
M: I pretty much have faith in him he's healthy and he seems to be breathing fine and I haven't had any problems, the monitor hasn't gone off. I don't think he needs it.
F: It if started to take off continuously of some duration there would be more reason to be alarmed.
F: I'd be a little more concerned if it happened again.
M: If I brought him home and the monitor went off and I ran in there and we resuscitated him maybe that would be a different story maybe I wouldn't feel this way (of baby not needing monitor).
M: I sorta have this thing that if people dwell on something bad its going to happen. You're liable to draw it to you somehow.
F: I just know it's one of those things it's a feeling that I have. I just know it just happened one time.
F: About when he was a month old I started to feel comfortable because it didn't seem to be going off.
M: I don't see the significance of a monitor where for a long period (at this point 2 weeks) nothing has happened.
F: Just the other night we said we aren't going to mess with hooking it up anymore because I feel that its just not going to happen anymore (not hooking up the last 2 nights.)
F: It has been so easy, uneventful.
M: He's never had one incident not one.
M: It was allright at first, I'm getting to the point now where I think it's not worth going through this every night putting it on.

F: I feel the likelihood of him having an apneic period where he would not self correct is very slight.
M: It has never gone off during the day only at night in his deep sleep. I don't really listen as much as I should.
M: After he was a couple months old the monitor hadn't gone off and he seemed to be breathing fine and not having any problems, and progressing well eating fine.
F: I don't think he needs it - its a nice precautionary measure.
M: The doctors said we could have a normal babysitter now that he isn't that bad of a case.
M: I kind of have faith that nothing is going to happen he seems to be breathing and he doesn't need it.
F: I'm real comfortable with him now. We are almost confident that nothing is going to take place.
M: We haven't had any problems with them so I'm relaxed.
F: The thought just never entered my mind anything serious enough would happen where I would have to do it.
M: We've had no trouble.
F: I don't think we need the monitor lately.
M: He always tell me the kid is a B (family name) the kid is gonna be ok.
F: You have to think positive and believe it.
F: He's never really stopped breathing where he can't self start or self correct. He hasn't required any outside intervention.
F: I think as far as having apnea again as far as slipping into another apnea spell where he would not self recover or self start I think the likelihood of that is slim.
M: I don't think he needs it anymore it hasn't gone off, it's gone off with a lose lead but that's it - no apnea or bradycardia.
F: I had feelings everything would be allright because my family tree never had any problems like that. For some reason I believe the kid is fine.
F: We have a high degree of confidence that he is not going to experience any type of episode that we would really need to be really worried about.
F: Secure, I think that the baby is doing allright.
F: Caution wasn't a real big thing with me of course with V (his wife) it was.
M: I really feel that the monitor can be of use for a couple of months and to see if the baby doesn't have any problems.
M: I'm not all the time thinking the alarm is going to sound. I'm not thinking what if the alarm sounds.

F: If it went off a couple of times when he was first born or the first month something like that and we got up and he wasn't breathing then I'm sure we would have wanted to have it on all the time but he hasn't seemed to have any problems with it.
F: Our philosophy is it would be a lot different, if they had serious problems.
M: He's never set anything off and we're just confident I guess maybe over confident.
M: You are sitting in bed the first couple seconds I know that it's a false alarm should I get up or should I stay in bed?
M: C hasn't done anything so its kinda we'll see what happens. So we pretty much felt comfortable right away.

Weaning

M: Now I don't generally put on the monitor during the day for naps but at night I always try to put him on it.
M: In the daytime if he's sleeping I'll lay him down, without the monitor.
M: We have gotten lax.
M: I am pretty sure it's never going to happen again so I am comfortable just sleeping her on the floor when I'm in another room without the monitor.
M: I give it the amount of time that if she did stop breathing she'd be okay. (Letting baby sleep without the monitor) Every 2 or 3 minutes I'm running back and forth.
M: We had him tested we know how bad he is and he is slightly abnormal. So I run the vacuum, I go in the laundry room when the wash is running I can't really hear the monitor but I know he isn't that bad.
F: There's been a couple times in the morning when R gets them up takes their belts off and leaves the belts in the crib, they don't get belts back on until they go to bed at night.
M: On the monitor when asleep and taking naps. I am in the kitchen I'll put them in the playpen, they are not on it.
M: Not lately have I been answering all the alarms.
F: It was more convenient for us to put them in the playpen than in their crib on the monitor. The first day about 15-20 minutes, the next longer, and the next day longer.
M: About a month ago they started to stay awake longer and be more active I put them in the playpen without the monitor.

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