The Impact of Home Monitoring Apneic Prematures on the Family

by

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Chapter I

Introduction

The purpose of this study is to investigate one aspect of the impact on families of monitoring apnea of prematurity with a mechanical apnea monitor.

Previous studies of families with monitored infants have found little effect on family function (Black & Steineider, 1978; Caine, Kelley, & Shannon, 1980; and Hartsell, 1985). These studies were done primarily on middle-class families, who were monitoring an apneic child for such reasons as a previous sudden infant death (SIDS) in the family or a near SIDS episode. No studies to date have investigated the effects of monitoring on families of premature infants. Yet there are indications that the impact on families with premature infants may be high. This clinician observed greater anxiety, tension and family dysfunction in premature monitoring families than in her nonmonitoring newborn families. In addition, Yount (1986) found families of prematures fail to adhere to the monitoring regimen, inadvertently putting their infant at extremely high risk for SIDS. This study may provide insight into the impact of monitoring on those families, and thus increase understanding as to why families discontinue monitoring.

It is hypothesized that families will be significantly affected by monitoring prematures for apnea. This hypothesis, if substantiated, could provide information to change nursing education, intervention and resource strategies for this group of families monitoring their infants.

Literature Review

The focus of this literature review is the psychosocial impact of home apnea monitoring of premature infants. In order to better understand this area the following subtopics will be discussed:

1. the impact on the family of a chronically ill child.
2. the impact on the family of a premature child.
3. sudden infant death syndrome and its relationship to the premature infant.
4. sudden infant death prevention through home monitoring.
5. what is known about the impact of monitoring on the family in general and on families of prematures in particular.

Impact on the Family of a Chronically Ill Child

Chronic illness is generally defined as those conditions which persist for more than 3 months (Pless and Satterwhite, 1975.) The impact of a chronic illness may have social and psychological consequences that at times may be more serious and debilitating than the physical illness itself (Lavigne and Ryan, 1979).

Of the plethora of studies on chronic illness, most are illness specific. Nevertheless, the areas of impact on the family are striking similar. In general, the research indicates a child who has a chronic illness may have a disproportionate need for family resources leaving fewer resources available for the other members. A highlight of some of the studies on the family and childhood chronic illness follows.

In an early study on the impact of cystic fibrosis on the family, Turk (1964) developed and administered a questionnaire to 25 families with children with cystic fibrosis. She found that families were not deprived of the essentials for living but they were not able to maintain their unusual family relationships. In addition, time and energy spent caring for the chronically ill child precluded parents from carrying on activities with each other and with the other children.

Turk found the mothers tired and occupied with the responsibility of care. In turn, communication broke down on important family issues such as how to handle sibling jealousy and how family members were affected by the prognosis of the disease. Unfortunately there was no comparison group of nonchronically ill families. Also, the study was not subjected to tests for reliability and validity.

Similar communication problems were also found in a more well controlled study by Salk, Hilgartner and Granich, (1972). Their study revealed that parents did talk to one another about the day to day issues of the child's management, but did not discuss the child's illness with their other children or their friends.

In a study of 200 siblings of patients with different chronic illnesses such as heart disease, diabetes and cystic fibrosis, Lavigne and Ryan (1979) found the chronic illness siblings to be more withdrawn and irritable, more fearful and inhibited than the control group. This study was based on the Louisville Behavior Checklist, a 164 item, true/ false adjustment questionnaire which parents fill out. The siblings of the patients ranged in age from 3 to 13 years of age. The hypothesis that younger children would be more affected was not supported. This well designed study also observed for background socioeconomic differences between groups. An analysis of covariance technique was used to minimize the potential effects of the differences on the results.

The constant demands of a chronically ill child put an additional strain on the parent's relationship. A higher rate of marital breakdown was found by Lavigne and Ryan, (1979) and Salk, Hilgartner, and Granich, (1972). Burr (1986) noted that for newlyweds and families that were marginally functioning, the stress of the child's illness could inflict further functioning problems, especially if they did not communicate with each other or their support systems. She did not specify which functioning problems were affected. Although it would appear that the stress on the relationship seems undeniable, Drotor (1984) stated (contradicting the above study) that it was only clinical lore that presumed that the divorce rate was higher. He stated that in well controlled studies like Kooker and O'Malley's (1981), divorce rates of parents with a child with a chronic illness are no higher than those with healthy children.

As one might expect, the functioning of the family appears to affect the adjustment of the chronically ill child as well. In a study of matched chronically ill children and healthy children conducted by Pless, Roghmann and Haggerty (1972), the chronically ill children at greatest risk for psychological problems, based on a battery of tests, were those whose families had lower family functioning scores, using the Family Functioning Index, a tool developed by Pless and Slatterweight. This finding was echoed Grey, Genel and Tambolane (1980) who also found a positive correlation between better adjusted diabetic children and better functioning families, based again on the Family Functioning Index.

The families most impacted by the chronic illness were the families which were already having a difficult time functioning. Stein and Riessman (1980) and Stein and Jessop (1985) studied families with chronically ill children using a tool they were developing, entitled the Impact on the Family Questionnaire. They tested it on 100 families in 1980 and using a refined version of the tool, tested it on 209 families in 1985. They found that the families most negatively affected by the chronic illness were those that were on welfare, lacked social support, had a low income.

Bush, Crawford, and Drotor (1984) in their chapter entitled the Family Contest of Childhood Chronic illness, succinctly summarized the problems that face most parents with a chronically ill child in the following statement:

> "irrespective of greatly varying treatment regimens, amount of visibility, course of disease each an every family must cope with such general problems as (1) allocation of emotional resources to ill versus well members, (2) managing transactions with physicians and health care personnel, (3) coping with hospitalizations and anxieties concerning the child's present and future physical vulnerability, (4) Day to day treatment regimen requiring parents to negotiate parental roles to reconcile career versus family demands (p. 24).

In summary the impact of a chronic illness has social and psychological consequences. It affects numerous aspects of family life, such as time available for other family members, energy, resources and relationships, although it appears to not affect the rate of divorce. As one might expect, the families that are affected the most are the ones who have fewest resources.

The Impact of a Premature Infant on the Family

Parents of prematures face many losses not experienced by the parents of full term infants. Their expectations of a normal, chubby-cheeked newborn; the joy and excitement of the onset of a normal labor and delivery; and the preparation for delivery the physiological and psychological developmental stages of the third trimester affords them are not fulfilled. Furthermore, they lose control over the circumstances present at the birth, and finally they lose the early, unlimited freedom to respond to their infant. They may feel guilty about their part in bringing on the premature labor and stress at the costs in travel time and money of a tertiary care center's neonatal intensive care unit. In addition, Mercer (1977) states that their fear of the death of this infant may interrupt the development of those emotional ties which provide a healthy nurturing environment.

Parents initially come home to an empty house, with no congratulations from family, friends or neighbors for a job well done. Instead, they have a tiny, weak infant attached to machines in a large high-tech institution. Choi (1973) stated that premature delivery poses an additional stress on the mother, she described like a crisis superimposed on the crisis of pregnancy. In her study she found that mothers of premature infants were more depressed and anxious in the early postpartum period than the mothers of full term infants. Gunther (1963) described a similar finding in his early retrospective study of the the family of the premature. Mothers of prematures expressed more fear, inadequacy and nervousness than matched controls using the Cornell Index Form N2, a questionnaire of psychosomatic and neuropsychiatric symptoms. Gunther´s study, although it used a controlled sample and an established tool, had a rather small sample size of 40 mothers.

Numerous studies state that there is an increased rate of separation and divorce among the families of prematures (Gunther,1963; Leifer, 1972, and Mercer, 1977). Mercer describes the parents as feeling scared, angry and guilty and overwhelmed by debts, and feeling out of control. These feelings may affect family communication and could contribute to the higher rate of divorce described.

Premature infants are not easy to care for. They tend to be more fretful and less communicative than their full term peers. They also play less (Crawford, 1982). Crawford´s longitudinal study observed mother-infant behavior using the predetermined check list of behaviors developed by Clarke-Stewart. They were observed at 6, 8, 10 and 14 months. Crawford also found that the mothers of prematures do not spend as much time with these infants compared to mothers of full term infants. He suggested the interaction may depend on mutual behaviors in the mother-infant dyad and that the increased fretfulness and reduced vocalization may affect the amount of time the mother spends with the child, and the quality of their relationship.

Failure to thrive and battering among the premature population has been repeatedly documented as being significantly higher than for the full-term population (Elmer and Gregg, 1967; Kleen and Stern, 1971; Stern, 1973; and Mercer, 1977). Elmer and Gregg (1967) found 5 of the 13 abused caucasian children they studied had been premature. The significance of this number is realized when compared to the expected caucasian premature rate of 1 in 13.There was no increased risk found among black families with a premature. They concluded that prematurity is particularly stressful for caucasian families who may lack the support of a larger extended family to help care for the premature. Crnic (1983) matched 52 premature and 53 full term infant/mother dyads and found using structured interviews, behavior observations and 3 different questionnaires including the Henderson Social Support Scale that the stress from prematurity was positively related to the lack of social support. Where there was adequate social support, there was no significant difference in the stress level of the two groups. His study consisted of primarily two- parent, middle-class families.

In summary, families of prematures are more depressed, anxious, and unlike families with a chronically ill child these families have a higher separation and divorce rate than families with normal newborns. Their infants are more fretful, less likely to give reciprocal regard and have a higher incidence of failure to thrive and battering. Social support appears to have a large impact on how affected a particular family will be.

Sudden Infant Death Syndrome and its relationships to the Premature

Sudden Infant Death Syndrome (SIDS) is the leading cause of death for infants under the age of one year in the United States (Merritt, 1983). It affects approximately 2/1000 infants nationally, and 3/1000 in the northwest region of the United States. Teenage mothers are in one of the highest risk groups for having infants with SIDS; 5/1000 die of SIDS as compared to 1/1000 for mothers over twenty years of age. Their increased rate of premature births may account for this high risk (Babson, Benson. Pernoll & Benda, 1975). Infants with a birthweight under 1.5 kilograms have a reported risk of from 9.6/1000 to 11/1000 (Standfast, 1978,Yount, 1979); statistics of Oregon prematures reveal a risk of 18/1000 (Yount, 1986). The smaller they are, the higher their risk. Others at high risk for SIDS are American Indians, Alaskan Natives, and lower income blacks (Merritt,1983). From a review of the epidemiological data thus far, there appears to be a link between SIDS, prematurity and socioeconomic factors. In Merritt's (1983) review of the causes of SIDS, he concluded the following:

> Factors other than genetics play a greater role in the occurrence of the majority of SIDS case. The data suggest that prenatal, postnatal and environmental factors interacting and together exert substantially more effect than genetic factors in increasing the risk of SIDS. (1983, page 194).

It is interesting to note that factors affecting an increased occurrence of SIDS are similar to the factors affecting the occurrence of prematurity. Noncaucasians have a greater percentage of low birth weight infants as compared to caucasian as shown in Table 1. Differences in socioeconomic opportunities were felt by Babson, Benson, Pernoll and Benda (1975) to explain this difference. The incidence of prematurity and perinatal death is increased with low wage occupational states, less education and age. Two times the number of infants weighing under 1,500 gram are born to teenagers than are born to women 25 to 30 years of age, (Babson, Benson, Pernoll and Benda, 1975). Lack of money and education appear to be important reasons why a pregnant woman and her fetus do not receive adequate health care, diet and rest, inadvertently putting themselves at high risk for prematurity and SIDS.

Table 1

The racial factor in low birth weight fetal and infant mortality

Birth weight under 2,500gm		% of live births
Indian (American)	19,700 births	7.8
Nonwhite	667,462 births	13.0
White	3,606,864 births	6.8

Note. From Management of High-Risk Pregnancy and Intensive Care of the neonate (p.13) by Babson, Benson, Pernoll & Benda, 1975, St. Lois, Mosby.

In summary premature infants are over three times more likely to die of SIDS than are full term infants. Also at high risk are infants from teenage mothers, or families with limited resources. Although genetic factors do effect the incidence of SIDS it appears that prenatal/postnatal and environmental factor exert the strongest influence on the risk of SIDS.

Sudden Infant Death Prevention through Home Monitoring

Prematures are prone to periodic breathing, 90% at 28 to 29 weeks gestation (Rigatto, 1982). At the

University of Manitoba Rigatto also found nearly 25% of all prematures exhibited apnea. Episodes of prolonged apnea (greater than 15 seconds), excessive irregular breathing (periodic breathing), or obstruction characterize breathing patterns of some infants who eventually succumb to SIDS (Ariagno, 1983; Kelly, 1982; Steinscheider, 1977). Rosen (1986) found 13 of the 80 preterm infants on home apnea monitors had persistent apnea or bradycardia that required substantial parental intervention such as mouth to mouth resuscitation. They concluded that "some preterm infants with persistent episodes of apnea, bradycardia and cyanosis beyond 36 weeks of postconceptual age remain at risk for future serious episodes for several months" (p 547). Because of similar earlier findings the American Academy of Pediatrics (AAP) in 1978 took the position that all infants with apnea greater than 20 seconds should have 24 hour surveillance until the prolonged apnea resolves. This greatly increased the number of children on monitors (Cahill, 1982). In 1985 the AAP modified their position from "should have 24 hour surveillance" to "might consider 24 hour surveillance" in response to the growing numbers of families putting their infants on monitors, some without medical advice. Presently the Food and Drug Administration estimates 40,000 to 45,000 apnea monitors are currently in use (NICHD News Notes, 1986). Because of the apnea commonly seen in prematurity a high rate of prematures are given a 24 hour test for apnea prior to discharge and eventually go home on an apnea monitor.

Results of 4 years of monitoring apneic prematures infants at the Oregon Health Sciences University found approximately 1/4 (22) of the families removed their infant from the monitor before they had documented evidence that the apnea had resolved. They did this without consulting their care provider. One third (7) of those infants died of SIDS. Of the 66 families who were compliant in their use of the monitor, only one infant died of SIDS, when his parents slept through the alarm. This data indicates that monitoring may indeed be a hardship for some families, a hardship which is difficult enough to cause them to take their infant off the monitor without seeking medical advice, and thus inadvertently putting their infant at a higher risk for SIDS. It also indicates that monitoring may save lives (Yount, 1986).

There are researchers who question the validity of the increased use of the home monitor (Southall, 1983, Bergman,1975). They cite the limitations of accurately predicting infants at risk, difficulty in intervening in a possible SIDS event and the probable psychological impact on the family. In September, 1986 a conference was held to reach a consensus on the growing use of home monitors. In the official statement from that conference, T. Allen Merritt, president of the Sudden Infant Death Foundation, stated "Foundation Board is convinced that more research is needed in the realm of the psychological and social effects of prolonged use of home monitors". The consensus report published in Pediatrics, February 1987 outlines five area under psychosocial impact that need further research. They are:

1. Research to identify the psychosocial characteristic and apnea program operational procedures that help families adapt, cope with, and use home monitors effectively needs to be undertaken.
2. Short and long-term effects of monitoring on infants, parents, siblings, parent-child interactions, and families should be investigated.
3. The hypothesis of a relationship between monitoring and child abuse needs further study.
4. Studies to establish the rates, causes, and consequences of noncompliance and premature

termination of monitoring should receive high priority.

5. Research to identify factors related to and interventions promoting the ability of families to terminate monitoring would be of benefit.

This study, the impact on the family of home monitoring, might shed light on at least two of the above psychosocial research needs, particularly #2, the short-term effect of monitoring and #4, it might assist us understand more about the causes of noncompliance.

In summary, home monitoring is increasingly used to monitor for SIDS through alerting the family when their infant is having an apneic event that may need their intervention. Controversy and concern exists over the volume of monitored patients. Of special concern is the possible unecessary hardship it might place on the families who do not actually need the monitor.

The Impact of Monitoring on the Family

As previously stated by Merritt (1986) there is little information on the psychosocial impact of home monitoring on the family. The results of two major studies carried out in the late 70's and early 80's have been criticized for being conducted by members of the apnea monitoring program and not by an unbiased, outside researcher. (Southall,1983).

The earliest study of impact on the family was a retrospective descriptive study (Black & Steinschnieder, 1978). They used a questionnaire generated from 2 hour interviews with 18 families. No psychometric information was given. The sample of 36 families was a self-selected group from 50 families participating in a home monitoring program conducted by the researchers. They were primarily white and middle-class. There was no control group. The families varied in how long they had been monitored, and some were no longer monitoring their child. The families also varied in the reasons they were monitoring, ranging from the occurrence of a subsequent sibling (an infant born to a family that had already had an infant die of SIDS), infants with apnea, and infants who had had a near-miss episode. The results indicated that families felt that the apnea monitor had a temporary but significant effect on their lives. It negatively affected their sleep, their ability to have a social life and their ability to perform household tasks. The false alarms aggravated the families' problems, but, despite these observations, the researchers concluded that the monitor was not a deterrent to normal parent-child relationships and that most families reported home monitoring an anxiety reducer and worth the trouble.

In 1980, another apnea monitoring program investigated the psychosocial impact of home monitoring (Caine, Kelly & Shannon). Their stated purpose was to determine the most stressful problems with home monitoring and what were the most helpful methods of coping. This was an exploratory study, using an open ended face to face interview with 74 families, 40 of whom were presently using home apnea monitors (HAM) and 34 who had used home apnea monitors in the past. These self-selecting families were again not of the the lower socioeconomic levels; 60% were middle to upper class, with above average financial resources. The results indicate that monitoring is stressful and that it consumes a great deal of time and energy, but that monitoring does not detrimentally affect spousal or other family relationships.

In 1983, Demaggio and Sheetz compared the concerns of mothers with infants on apnea monitors to previously collected data on the concerns of mothers with normal newborns. They found the concerns to be very different. The mothers with normal newborns found physical restoration such as regaining their figure as their primary concern, whereas the primary concern of monitoring mothers was emotional tension and their last concern was regaining their figure. Fifty percent of the monitoring mothers expressed depression in the first weeks home, and 50% emphasized the need for nurses to teach mothers how to relax and reduce tension before they bring their apneic infant home. No corresponding information was given for the non-monitoring mothers. Which is a weakness of their comparison study.

In 1984, Wasserman published the first prospective study on the effects of apnea monitoring. The sample of 14 families was followed for five years, using five periodic open and semi-structured psychiatric interviews. Developmental sequelae were noted in 9 of the 14 children (5 of these had required resuscitation). Twelve of the 16 siblings had short-term psychological problems during monitoring. Many parents reported depression, fatigue and anxiety. However, no mother discontinued the monitor without medical advice.

In 1985 Stengel and Eshevents conducted a limited study of the problems identified by parents who were monitoring their infants for apnea. Over a three month period returning registered nursing students used participant observation to gather data on 25 monitoring families. They found the problems fell into 4 categories: 1) parenting (for example many parents felt resentment rather than satisfaction from their role as a parent); 2) health status factors (for example, many mothers felt continual fatigue); 3) environmental risk factors (the equipment was cumbersome); and 4) general family coping (many felt that it decreased the flexibility in their roles and it decreased the number of external family members who could provide support). Problems were not weighted in terms of severity or frequency. No statistics were presented to validate their conclusions and no demographic data was presented. Yet the study is important for providing initial data to indicate that monitoring was seen as problematic by parents and that further research is warranted.

The most recent study on the psychological effects of home and hospital monitoring was conducted at the University of Alabama in 1985 by Lyman, Wurkle and Wilson. They found, by specifically looking at anxiety and locus of control, that monitoring parents were significantly different than their control families. Both the hospital monitored group (N=20) and the home monitored group (N=20) were significantly more anxious than their control group using the State-Trait Anxiety Inventory. Contrary to previous findings anxiety did not decrease over time but stayed constant, particularly in the home monitored group. Also, contrary to previous findings was the relationship of internal locus of control to anxiety. Usually greater internal control correlates with decreased anxiety, but in the monitoring group their greater internal locus of control appeared to have little correlation with their anxiety scores.

This study also described what it is like to have a child on a monitor. They found that 68% on monitors had false alarms, some in the 1000's. A majority reported negative changes in sleep, social life and sexual habits with symptoms of chronic stress. On the positive side a majority reported improved relationships with their spouse and their other children. They concluded that families must be adequately prepared for the stressful impact of the monitor and special community support services need to be made available to them.

This study did not mention if any of the home, hospital or control children were prematures. They did cite that there was a considerable age difference in the groups, with the control infants being the oldest, the home next and the hospital monitored group the youngest. This uncontrolled variable could have had some effect on locus of control and anxiety results.

The studies that specifically looked at the relationship of home monitoring and family functioning have been published in abstract form only. Using The

Feetham Family function Scale, Wilkerson (1984) concluded that monitoring affected family function negatively. Hartsell (1984), however, using the same scale, found that monitoring did not affect family function. Hartsell stated in a personal communication to this researcher that her self-selected population consisted of white, upper-middle class families.

No study to date has investigated the effect of monitoring on families with premature infants.. Also, no study has reported on the effect of monitoring on predominately lower socioeconomic families, a population one might expect among the families of prematures.

In summary the extent of the impact of monitoring is uncertain. In the few studies that have been done it appears that families experience sleeplessness, stress, depression, and that siblings experience short term psychological problems. Families, in the studies so far, feel monitoring is worth these short term problems. No discontinuation of the monitoring without medical advice was described in the monitoring impact literature.

In conclusion SIDS is a significantly greater problem for premature infants than for the normal newborn population with anywhere from 4 to 8 times the risk of SIDS. Frequently prematures are born to teenagers or those who have little education, money or resources for optimum prenatal and postnatal care.

Home apnea monitoring is increasingly being used with identified premature infants at risk for SIDS. Little research has been done on the affect of the monitoring on the premature infant's family, a family which the above literature has shown will be experiencing more stress, such as divorce, than the average family. Adding the monitor also may add the dimension of chronicity of illness into their lives. Monitors are kept on day and night for up to 6 to 9 months and can false alarm up to 1,000 times. By the large numbers of families with prematures who remove the monitor from their infant before it is determined to be medically safe one could surmise that the monitor is causing some family dysfunction or individual distress.

The research that is available reports on primarily middle class families monitoring for various reasons. The families have found monitoring stressful but worth the trouble and not a deterrent to normal parent child relationships. The results of whether monitoring effects family functioning are inconclusive.

Families monitoring their premature infants need to be studied separately from families who monitor for other reasons such as sibling of a SIDS victim, or having a near miss event.

The conceptual framework

The conceptual framework consists of three concepts and the relationship between them. The first concept is infant stimulated parental activity, defined as the amount of infant initiated behavior that requires action on the part of the parent. The second concept is role transition to parenthood, a social role modification requiring a change in behaviors creating an impact on the individual(Burr, 1973). The third concept is family functioning, defined as how family members relate to one another and to the environment, individually and as a whole as they fulfill basic needs. These concepts are theoretically related to each other in the following manner; the amount of infant behavior that requires action on the part of the parent will effect both the ease of role transition and degree of family function in an inverse direction. Thus, higher activity demands, such as monitor false alarms, will result in a more difficult role transition and a lower level of family functioning. See appendix A for the a partial diagram of the conceptual framework.

This conceptual framework is drawn in part from the work of Florence Roberts (1983) on ease of role transition into parenthood. She found that increased needs on the part of the infant negatively effected parenthood role transition and the parent's perception of the infant.

The Hypotheses

Two hypotheses are based on the premise that infants attached to an apnea monitor will require greater parent time and energy (Black,1978, Caine,1982, and Wasserman, 1984).

Hypothesis one: Prior to discharge parents with prematures in the monitored or control group and nonmonitored or experimental group will not be significantly different in scores of disruption of social relationships, financial impact, coping, general and total impact as measured by the Impact on the Family Scale.

Hypothesis two: One month after discharge parents who have a premature baby at home on an apnea monitor will have higher subscale scores on the Impact on the Family Scale than those who are not monitored.

Chapter II

THE METHODS

Introduction

A quasi experimental pretest post test design was used to investigate the impact of monitoring on families with premature infants. See below:

A symbolic representation of this pretest-post-test quasi-experimental design:

		monitored	
group 1	0	X	0
group 2	0		0

Instruments

The impact of monitoring on the family was measured by the Impact on the Family Scale (IOF). This scale, designed by Dr. R.E. Stein, was developed to quantify the impact of childhood chronic illness on a family. It uses a four point Likert scale, scored from 1 equals strongly disagree to 4 equals strongly agree. The reliability stated as a Cronbachs alpha is .88 for the entire scale. Through psychometric analysis used to refine the scale, the 27 retained items fell into 5 dimensions, or subscales. The five subscales are: Total Impact (Total), General Impact (Gen), Disruption of Social Relationships (DOSR), Coping (Cope) and Financial Impact (FIN). Their corresponding reliabilities are .88, .83, .82, .56, and .59 repectively. The subscale 'Total Impact' is a composite of all the negative impact items; positive impact, such " My family is closer because of my childs' illness," were not included in the 'Total' subscale but would be found in the positive worded 'Coping' subscale. 'Gen' contains only negative worded items, many are related to the burden experienced by the primary caretaker. 'DOSR' is the quality and quantity of interaction with others, outside and within the family unit. 'Fin' describes changes in financial status. See appendix B for Impact of the Family Scale.

The construct validity for families with ill children was determined through expert review and pilot testing 209 families within the target population. It was found to be tapping the construct it was designed to measure. Higher total impact scores were associated with lower education, and lower income; with the mother's perception of her child as difficult to care for, increased hospitalizations of that child and lack of social support. The target population was predominantly urban poor families with chronically ill children. The authors stated that this population was able to understand and complete this test without undo difficulty.

The scale was administered to this sample population of families with prematures with one item of the 27 items missing. This item was inadvertently omitted. It was included in both the Total and General subscale totals. The mean subscale score for the subscales Total and General was inserted for that item to minimize the effect of the missing data.

Demographic data including income, education, living situation and age were collected through a questionnaire designed by the researcher. See appendix C for Demographic Information.

Setting

The sample was selected from the population of infants scheduled for apnea testing and considered for discharge. The prematures were in one of three units, the Neonatal Intensive Care Unit (NICU), the Intermediate Neonatal Care Unit (INC) and the overflow beds for stable prematures on a pediatric unit at an urban, university based hospital.

These units serve infants with critical health problems from all over the state of Oregon. Many were transported in at birth by the transport team, but the majority were born at the OHSU, a tertiary care center that serves many medically financially indigent families.

The prematures in this study were primarily from INC, a level two nursery that serves preterm and full term infants. Infants who graduate from the NICU because of improving health stay at the INC for observation prior to discharge. Prematures under consideration for discharge are tested for prolonged apnea immediately prior to discharge using a 24 hour sleep apnea monitor. If their apnea is found to be severe, they continue to stay at the INC and are retested in approximately one week. If they show no prolonged apnea on the apnea test, they are discharged without an apnea monitor. If they show a moderate amount of apnea, they are usually discharged with the recommendation that they use the heart and respiration home apnea monitor. They continue to use the monitor for 3 to 9 months or until they pass a number a tests which indicate they have matured out of their apneic episodes.

The Sample

All families of prematures scheduled to have the 24 hour polygraph test for prolonged apnea, prior to discharge were eligible to participate in the study. The enrollment was concluded when 21 families had agreed to participate. The prematures who had prolonged apnea warranting a home monitor, worn while sleeping or not actively being observed, became the experimental group and those that did not require a monitor became the control group. The groups were approximately equal in size, with 10 in the monitoring and 11 in the nonmonitoring group.

Families could not be randomized into the control or experimental groups. Their group placement ultimately depended on the results of a 24 hour apnea test and the advice of the neonatologist. Families for whom the monitor was recommended, but who declined its use, and families who insisted on a monitor, lacking evidence of prolonged apnea, were not included in the study. The study entrance qualifications excluded any child who needed complex care other than monitoring and oral medication.

Procedure for Sample Collection

Prior to administering the tool to families, the study, including the sample, procedure and instruments, was presented and approved by the OHSU Human Subjects Review Board.

After receiving Review Board approval, the parents of the infants who met study criteria were contacted by the researcher or their unit nurse. This was done before they knew whether their child would need the home apnea monitor. The contact was made by phone, note or in person. They were asked to participate in the study which would take 25 minutes now and 15 minutes in one month.

An informed consent form was obtained from those that agreed to take part in the study. (See appendix D) Parents were also asked fill out the demographic questionnaire in addition to the Impact on the Family (IOF) questionnaire. The parents were assured of data anonymity by assignment of code numbers to all questionnaires. They were told that they would receive a second, identical IOF questionnaire in approximately one month. Participants were also told that they would receive $5 for filling out the pre and post-test. Nineteen families completed and returned the pre and post-test.

Initially the pediatric nurses on all three units (NICU, INC, and 13a) were to invite families to participate and give out the initial questionnaires. After 2 months and only 3 subjects, the researcher changed the sampling procedure. She assisted the nurses in recruitment by visiting the wards one to two evenings per week and personally invited qualifying families to join the study.

After receiving only 2 of the first four post-tests the researcher also took a more active role in follow-up questionnaire collection. At one month post discharge the parents were called to inform them that the second questionnaire would be arriving soon. If the second questionnaire was not returned within a week, a reminder letter with a another post-test was sent. Initially there had been no phone call or one week reminder. After initiating this procedure, 100% of the parents completed and returned the post-tests.

Analysis

Differences in impact on the family between the experimental and control groups was determined using mean subscale scores. The difference between the two groups were analyzed by computing T statistics both prior to discharge and one month post discharge. The resulting difference in scores were evaluated for statistical significance. To support hypothesis I, prior to discharge the control and experimental group need to have no significant difference between the subscale score. To support hypothesis II, one month post discharge families with prematures on monitors must have a significantly higher subscale scores on the Impact on Family Scale than families whose prematures are not monitored.

Alpha Reliabilities

Internal consistencies (Cronbachs Coefficient alpha) were computed for the total and subscales to test for inter-item correlation for this sample. They were found to be comparable to or higher than the original alphas reported by Stein and Jessop (1981) except in the coping subscale. (Note:the reliabilities for the Total and General subscale were run with one of the items missing). Coping had an unacceptably low alpha of 0.56 in Stein and Jessop's original report, but with this sample population the alpha was even lower at r= 0.18. Therefore, comparisons on this subscale were not calculated. Without the item "My partner and I discuss my child's problems together" the alpha would have been 0.71. It is conceivable that the high number of single parents in this study contributed to the variability on this question and the lower score overall. Fifty percent of the sample population were not living with the father of the infant at the time of the study.

The financial subscale also had a low alpha of 0.54 for the sample population. But this is consistent with the findings of the authors Stein and Jessop who reported an alpha of 0.59 for that subscale. (See table 2 for summary of the IOF reliabilities.

Table 2

Alpha Reliabilities for IOF Subscales on Families With Prematures

	Total	Gen	DOSR	FINA	COPE
Alpha	0.91	0.75	0.87	0.54	0.18
Standardized alpha	0.92	0.72	0.86	0.55	0.47
Inter-item correlation	0.39	0.24	0.40	0.29	0.18
Number of items	18	8	9	3	4
N	21	21	21	21	21

Chapter III

THE RESULTS

Description of the Study Sample

Collection of the data took place from January 1987 to February 1988. Approximately 40 parents of premature infants meeting the criteria for the study were contacted by the unit nurse or the researcher. Of these 40, approximately 25 agreed to participate in the study. The consent form, the Impact on the Family Scale (IOF) pre-test and the demographic questionnaire were given to the parents at the time of acceptance.

Twenty one families completed the initial questionnaire. Nineteen of those 21 completed and sent in the final post IOF questionnaire.

Demographic Characteristics

Family characteristics were obtained by data gathered from the Demographic Information Form. Information about parental age, prematurity, level of education and income, living situation and race were obtained.

The parents ranged in age from 16 to 36 years of age. The mean age was 21 years in the monitoring group. The mean age in the non monitoring group was 25 years.

The preterm infants ranged in gestational age at birth from 28 to 35 weeks. The mean gestational age was 31 weeks for the monitoring group and 33 for the non monitoring group.

A majority of the mothers of the infants in both groups did not work, whereas a majority of the fathers did work in both groups.

The educational background for the parents ranged from some high school to some college credits. A greater number of parents in the monitoring group had not completed high school, 6 as compared to 2 in the non-monitoring group. None of the parents had completed college.

The incomes ranged from less than 6,000 a year to greater than 30,000 a year. Parents primarily fell within the 6,000 to 10,000 a year range in both groups.

Four of the 10 monitored families and 4 of the 11 non monitored were receiving welfare. Also four in each group did not have any medical insurance at the time of the pretest.

Approximately 1/2 of each group were single, and living alone or with their parents. Two more in the non-monitored group (6 parents as compared to 4) were married and living with their partner.

Both groups were primarily caucasian. There were 8 caucasian and 2 hispanics in the monitored group and 10 caucasians and 1 black in the nonmonitored group.

The families primarily lived in Portland, Oregon or in the Metropolitan Tri-county area surrounding Portland.

Three lived at the coast and five lived in small rural areas such as Shedd and Broadbent, Oregon. The monitored and nonmonitored group's demographics are compared in Table 3.

Table 3

Comparison of demographic information between families of monitored and non-monitored preterms.

Demography	monitored	non-monitored
mean parental age	21.8 years	25.4 years
mean gestational age of infant	31.3 weeks	33.0 weeks
employed parent		
yes	6	7
no	3	1
unknown	1	3
Highest education		
some HS	6	2
completed HS	4	5
some college	0	4
completed college	0	0
Marital status		
single	6	2
married	4	6
divorced	0	1
separated	1	0

Table 3 Continued

Demography	monitored	non-monitored
Living Situation of Respondent		
with parents	4	4
with infant's father	4	6
alone	2	1
Income		
<6,000	6	5
6,001 to 10,000	2	1
10,001 to 15,000	0	2
15,001 to 20,000	0	0
20,001 to 30,000	2	1
> 30,000	0	2
welfare		
yes	4	4
no	6	7
medical insurance		
yes	6	7
no	4	4

IOF Results

Analysis was performed on data obtained from the 4 subscales on the Impact on the Family instrument. The mean of each subscale was substituted for missing data in that subscale, including the one item inadvertently left out of the General and Total subscale. T-tests were used to compare the means of IOF totals and subscale score between the families with infants on monitors at home and those families with prematures not prescribed home monitors.

Hypothesis I results

The scores of the monitored and nonmonitored groups on the subscales were evaluated for differences using the T test for independent groups with pooled variance. No significant differences at the $p<0.o5$ level were found. The p values ranged from $p=0.18$ to $p=0.39$. Thus the results support Hypothesis I, that prior to discharge the scores on the IOF for control and experimental group were not significantly different. See Table 4.

Table 4

Comparison between monitored and non-monitored group means on IOF pretest

Subscales		monitored	nonmonitored	T-test
Total		2.922	2.556	1.37 (n.s.)
	sd	0.476	0.723	
DOSR		3.144	2.818	1.27 (n.s.)
	sd	0.508	0.654	
GEN		2.650	2.364	1.19 (n.s.)
	sd	0.457	0.627	
FIN		2.764	2.485	0.87 (n.s.)
	sd	0.668	0.808	

Hypothesis II results

Hypothesis II that one month post discharge families with prematures on monitors will have significantly higher scores on the IOF scale than families whose prematures are not on monitors, was not supported. Using a T-test with pooled variances and an analysis of variance the differences were less than the predetermined significance level of $p < 0.05$.

In general the monitored group did have higher impact scores on all the negative subscales (Total, General, Disruption of Social Relationships) but Financial. "Higher impact" meaning the negative affect on their family was greater. Thus the direction of change was in the direction hypothesized for all the subscales but Financial. In addition, the range of the post test subscale scores were less wide in the monitoring group demonstrating less variability in the answers. This could indicate the monitoring had a similar effect on hte families.

The alpha correlations for this sample population demonstrated higher correlations between pre- and post-test subscales score in the non-monitored group than in the monitored group. Three of the 4 subscale correlations were in the $r=0.80$ or greater in the non-monitored group but in the monitored group none of the correlations were as high as r=80. They ranged between r= 0.37 to r= 0.78. This represents a second indication that the monitored group may have more of a change toward negative impact than did the non-monitored group, however slight. See table 5.

Table 5

Comparison of Alpha Correlations for IOF between pre and post-test for both monitored and nonmonitored groups

Pretest	Post-test	Monitored		Nonmonitored	
		r	p value	r	p value
Total	Total2	0.68	0.027	0.91	0.000
FIN	FIN2	0.37	0.281	0.87	0.001
DOSR	DOSR2	0.71	0.019	0.84	0.004
GEN	GEN2	0.78	0.007	0.88	0.001

The individual subscales

Total

This is a composite of all the 18 negative impact qestions. The mean of the total impact score was higher for the post test monitoring group indicating greater overall negative impact in this group (mean=2.92) than for the post-test non-monitored group (mean= 2.28).

Using a t-test with separate variances, the difference was not statistically significant, p=0.69 for separate variances. (Separate variance was used in the total subscale because of the great variability in the answers). See Figure I and Table 6.

General Impact (GEN)

This represents general negative impact. It is made up of 10 questions. The monitored group reported a slightly higher negative impact than the nonmonitored group in this subscale. The mean of the monitored group was 2.778 as compared to the non-monitored group mean of 2.667. The T- test of 0.33 for separate variances indicated that this difference was not statistically significant; P=0.7442. Both monitored and nonmonitored groups tended to agree with the general negative impact items, and both had higher impact scores on the post-test. See Figure I and Table 6.

Disruption of Social Relationships (DOSR)

This subscale combines the quality and quantity of interaction with others in and outside of the family unit. On the post-test the mean of the non-monitoring and monitoring groups were 2.98 and 3.333 respectively. The T-test indicates that this difference is not statistically significant. The P= 0.2276. The item raw scores do indicate the monitored families feel more negative impact in this area. Where 4=strongly agree and 3=agree the monitored mean of 3.333 indicates that they more than agree with this disruption on relationship subscale. See Figure I and Table 6.

Financial (FIN)

There was slightly less financial impact of the monitored group (mean=2.60) than on the non monitored group (2.630). This was again not statistically significant using the t=test, p=0.946.

Coping (COPE)

Because of the low reliability for this sample population the positive subscale coping (alpha = 0.18) is not reported in these results.

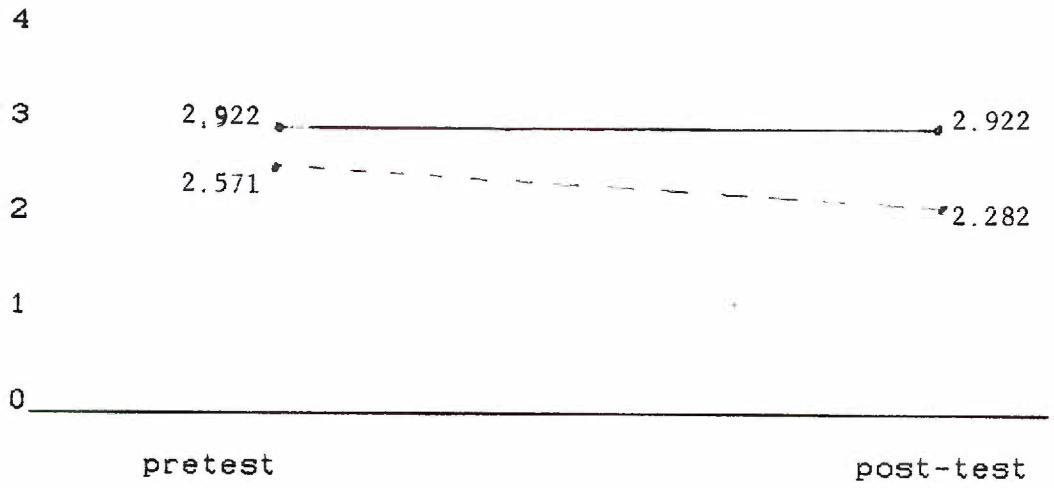
Table 6

Comparison between monitored and nonmonitored groups means on post-test

IOF Subscales		monitored mean	nonmonitored mean	T-test
Total2		2.922	2.283	1.43 (n.s.)
	sd	0.476	0.723	
DOSR2		3.333	2.988	1.29 (n.s.)
	sd	0.471	0.892	
GEN2		2.778	2.667	0.33 (n.s.)
	sd	0.448	0.892	
FIN2		2.600	2.630	-0.07 (n.s.)
	sd	0.798	1.086	

Figure I

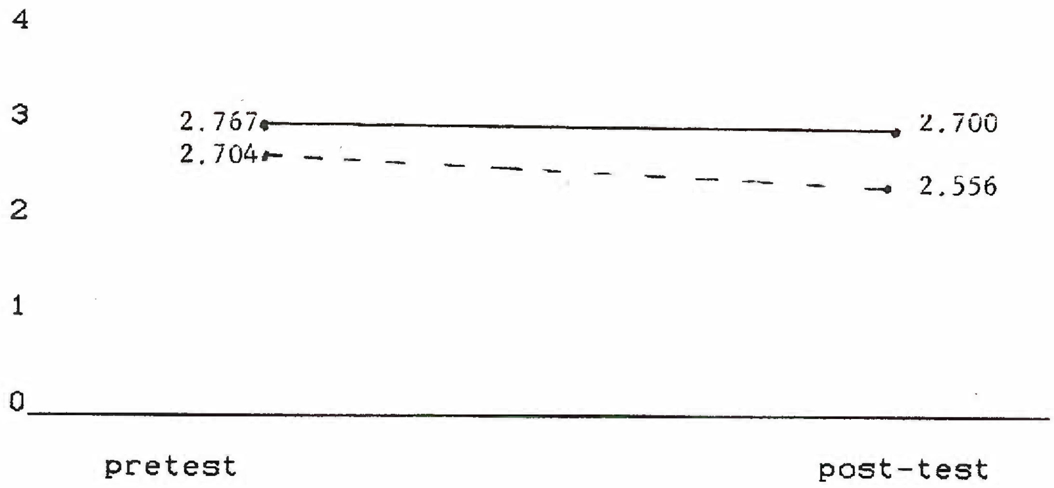
Comparison of mean IOF subscales scores between monitored and non-monitored on pre- and post-tests



Total Impact Subscale means

monit ——————

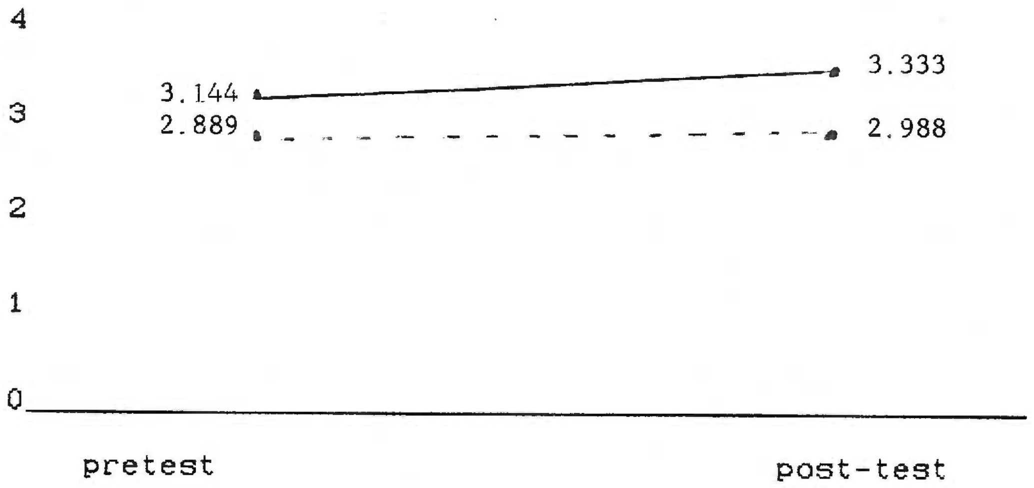
nonmonit – – – – –



Financial Impact Subscale means

Figure I cont.

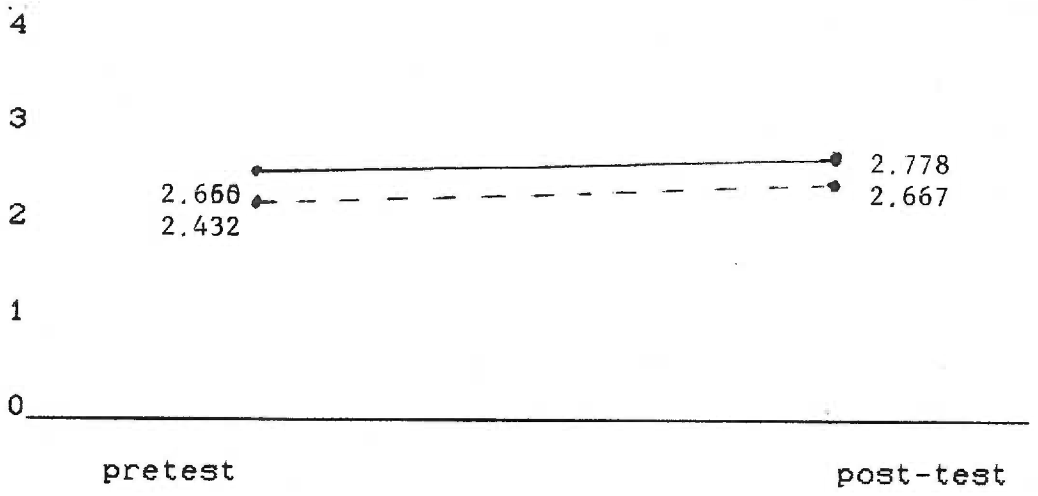
Comparison of mean IOF subscales scores between monitored and non-monitored on pre- and post-tests



Disruption of Social Relationships Subscale means

monit____________

nonmonit_ _ _ _ _



General Impact Subscale means

Chapter IV

THE DISCUSSION, CONCLUSION AND LIMITATIONS

The purpose of this study was to examine the effect of home apnea monitoring on the family of a premature infant. This chapter discusses the findings and influences affecting the outcome of this study. First, a discussion of the findings for each research question is presented. Then the limitations of the study are described. The summary and conclusion section precedes the implication for nursing and recommendations for further research.

The Discussion

The demographic data indicated no significant statistical difference between the two groups in gestational age of the infant and age of the parents.The monitored groups were gestationally younger, which is consistent with the literature which indicates that younger prematures are more likely to have apnea (Rigatti, 1982). The raw mean age of the monitored parents was also younger, 21 years old as compared to 25 years old for the non- monitored group. This is consistent with the findings of Pernoll and Benda (1975), that premature infants are born more frequently to adolescent parents, and that the more premature the infants are the more likely the parents are young. The nonmonitored group also reached a higher level of academic achievement than the monitoring group, although no parent in either group completed college.

Hypothesis I

The hypothesis that there was no difference between families monitoring and those not monitoring their premature prior to discharge was concerned with establishing and validating a control and experimental group for hypothesis II. The results of the data analysis on the Impact of the Family Scale (IOF) pre-test support this hypothesis.

Discussion of Hypothesis II

Hypothesis II was concerned with the effect on the family of having a premature infant on a home apnea monitor. The results of the data analysis provided no statistically significant support for this hypothesis: that one month post discharge families with prematures on monitors will have significantly higher total and subscale scores on the IOF Scale than families whose prematures are not monitored.

However, the raw data for all subscales but one did show higher mean scores for the monitored group. This indicates an increased negative family impact with apnea monitoring, although statistically insignificant.

The only subscale which had a higher negative impact mean score for the non-monitored group was FINA or the Financial Impact. This contradicts the literature which cites the increased financial burden as a problem for monitoring families (Consensus Statement, 1987). Although monitors do cost approximately $200 per month, it is possible that the financial assistance provided by welfare and medical insurance could off-set this difference for a majority of families.

The subscale which indicated the greatest impact, although still statistically insignificant, was the DOSR or Disruption of Social Relationships both within and outside of the family. If the sample size had been 100 in each group rather than the 10 in each group found in this study, and the means had remained the same, the t-test would have been $t=4.157$ which is significant at the $p= .001$ level. This indicates that small sample size may be exerting a large affect on the significance of these findings.

This greater effect on social relationships is consistent with literature on the psychosocial effects of apnea monitoring. For example, Wilkerson (1981) using Feethan Family Function Scale found that monitoring was disrupting to family function. Demaggio and Sheetz (1983) found it decreased role flexibility and external members who could provide support. Lyman, Warble & Wilson (1986) found it was difficult to have a social life. The disruptions were explained by the increased demands of time and emotional energy caring for the child's needs.

The insignificant findings related to all the subscale scores could be greatly affected by the small sample size as seen above. In addition, the lack of a significant difference between the monitored and non-monitored group could be related to the tool that was used, the IOF or Impact on the Family Scale. Many parents did not see prematurity as an illness when asked if the illness of their child affected different facets of their life. Also, parents may be reluctant to answer questions about the negative impact the infant has on their life when they have not yet had time to develop self confidence as a parent. This could be especially true in teen parents whom this clinician has found to be frequently in denial about the negative effect a child has on their life until the child is older (a greater number of the monitored group were teen parents.)

Limitations

This study was limited by the small sample size. It is possible that the differences that did exist between monitoring and non-monitoring might have been statistically significant if a larger sample, such as 100 families, was used.

This study was also limited in the length of time it observed the monitoring families. One month may have been too short a time to observe a difference between the two groups. The impact of chronicity of monitor use may not be felt until later.

One of the items on the IOF scale was inadvertently left out of all questionnaires. This affected the Total and DOSR subscales only. A mean score for that subscale was inserted to minimize the affect of the missing data. The reliability of these two subscales might have been slightly reduced because of this.

The IOF scale may be inappropriate for single parent families, families with prematures and those that are not employed since some of the items, particularly the financial subscale assume there is a partner in the family and one is employed. Some parents did not think of their child's prematurity as an illness when the term illness was used in the tool, even though they were couched to do so in the cover letter to the questionnaire.

These limitations prevent generalizing the findings of this study to the population of families with prematures on monitors, in general. The lack of significant findings for Hypothesis II that families with prematures on monitors will experience greater impact should not be used to change clinical nursing practice in a way that would decrease intervention available to these families. The services that are available currently may contribute to the lack of differences between groups.

Summary

It was the intent of this study to examine the impact apnea monitoring has on the family with a premature infant. Specifically, the study's purpose was to measure and compare the impact on the family of a premature not being monitored at home to one who is being monitored.

The review of the literature supported the concept that some families with infants on long term monitoring at home may experience a negative impact. No information was available on families of home monitored prematures. Apnea monitoring has become a popular way in

America to attempt to prevent SIDS in certain prematures. Yet there is a consensus among pediatrics disciplines that are involved with premature apnea that more information on the impact on the family must be known to continue to embrace this preventive modality.

The sample population studied was an experimental group of 10 families of preterm infants prescribed home monitors and a control group of 11 families of preterm infants who were not prescribed home monitors. The families were similar in age, living situation and income. The nonmonitored parent group had a higher level of achieved education and were slightly older. The Impact on the Family Scale was administered prior to discharge and again after they had been home approximately one month. The scores obtained from this scale were compared and analyzed using paired and independent t-tests.

The results of the Impact on the Family pre-test indicate that there was no significant difference between the two groups. The results of the one month post-discharge IOF test indicate that there was a slight, although insignificant tendency toward the direction hypothesized. The monitoring group did have a slightly greater negative family impact than the non-monitoring group. This difference was not statistically significantly greater. The conceptual framework that greater infant initiated behavior, and greater parental role transition, negatively impacts how members relate to each other and to their environment was given some supported by the direction of change in IOF scores. However, the lack of significant findings suggests that further evaluation of this framework is needed.

Conclusion

The following conclusions can be drawn from this study: using a small study sample and the IOF scale there appears to be no significant difference on the impact on the family between the families who are monitoring their premature infants for apnea and those who are not.

The reading of current literature as well as previous clinical experience with families of preterm infants on monitors originally led the investigator to believe that parents of premature infants using home apnea monitors would have more family problems due to limitations in time, money and increased levels of anxiety and intrusion. It appears that either the sample population was not affected adversely by monitoring, that the sample poplulation was too small, that one month was not long enough to illuminate the problem, or that the tool was not sensitive enough to pick up the difference.

Implications for Nursing Practice

These results to a limited degree are encouraging to pediatric and community health nursing. The implications are that the anticipatory guidance and practical education on monitoring and resuscitation may be adequately meeting the family needs. Because of the trend for the findings of this small sample to be in the direction of the hypothesis no action should be taken to limit nursing intervention or to lessen caution with monitoring families until further research has been done.

Recommendations for further nursing research

The recommendation for further research derived from this study are aimed at obtaining a better understanding of the impact apnea monitoring has on the family. The following activities are suggested.

1) Replicate this study using a larger sample size.
2) Replicate this study testing the impact at 3 to 6 months after discharge.
3) Perform studies using more than one family impact or family function tool.

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APPENDIX A

Conceptual Framework Diagram

↑ INFANT STIMULATED BEHAVIOR =

↓ EASE OF ROLE TRANSITION =
TO PARENTHOOD

↑ INCREASED NEGATIVE IMPACT ON THE FAMILY

APPENDIX B

Impact on the Family Scale

Subject #___

Impact of the Family

For each of the statements below please indicate, by circling, whether at present time you strongly agree, disagree, or strongly disagree with the statement.

	Strongly Agree	Agree	Disagree	Stronly Disagree
1. The illness is causing financial problems for the family	4	3	2	1
2. Time is lost from work because of hospital appointments	4	3	2	1
3. I am cutting down the hours I work to care for my child	4	3	2	1
4. Additional income is needed in order to cover medical expenses	4	3	2	1
5. I stopped working because of my child's illness	4	3	2	1
6. Because of the illness, we are not able to travel out of the city	4	3	2	1
7. People in the neighborhood treat us specially because of my child's illness.	4	3	2	1
8. We have little desire to go out because of my child's illness	4	3	2	1
9. It is hard to find a reliable person to take care of my child	4	3	2	1
10. Sometimes we have to change plans about going out at the last minute because of my child's state	4	3	2	1
11. We see family and friends less because of the illness	4	3	2	1
12. Because of what we have shared we are a closer family	4	3	2	1
13. Sometimes I wonder whether my child should be treated "specially" or the same as a normal child	4	3	2	1

14. My relatives have been understanding and helpful with my child	4	3	2	1
15. I think about not having more children because of the illness	4	3	2	1
16. My partner and I discuss my child's problems together	4	3	2	1
17. We try to treat my child as if he/she were a normal child	4	3	2	1
18. I don't have much time left over for other family members after caring for my child	4	3	2	1
19. Relatives interfere and think they know what's best for my child	4	3	2	1
20. Our family gives up things because of my child's illnes	4	3	2	1
21. Fatique is a problem for me because of my child's illness	4	3	2	1
22. I live from day to day and don't plan for the future	4	3	2	1
23. Traveling to the hospital is a strain on me	4	3	2	1
24. Learning to manage my child's illness has made me feel better about myself	4	3	2	1
25. I worry about what will happen to my child in the future (when he/she grow ups, when I am not around)	4	3	2	1
26. Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, ok when things are stable	4	3	2	1

27. Do you expect to be the primary caretaker for this infant? yes__ no___ If no, please specify who will be________________

28. Is there anything else you would like to tell me about living with your infant____

APPENDIX C

Demographic Tool

Subject #___
date_________

Demographic Information

Infant's name	birth date	sex

Your name	age	sex	# weeks pregnant at birth

address	city	zip	phone #

your occupation____________________ currently employed? yes___ no___

spouse's occupation_________________ currently employed? yes___ no___

To complete the following questionnaire just ___ the appropriate slot.

1. What is the highest level of school you completed?
   - _____some high school
   - _____completed high school
   - _____some college
   - _____completed college
   - _____post college credits

2. What is your marital status? ____ single _____ divorced _____widowed
____ separated ___married

3. What is your and your infants living situation?
   - a.___ live with your parents
   - b.___ live with other relatives
   - c.___ live with father of baby
   - d.___ live with foster parents
   - e.___ live alone
   - f.___ other_______________________
     please indicate

4. What is your race? white__ black__ hispanic__ asian___ other___

5. What is your yearly income?
   - a.___ less than 6,000
   - b.___ 6,001 to 10,000
   - c.___ 10,001 to 15,000
   - d.___ 15,001 to 20,000
   - e.___ 20,001 to 30,000
   - f.___ greater than 30,000

6. Are you receiving any public assistance (welfare)? yes____ no___
If yes please specify______________________________

7. Do you have medical insurance? yes____ no_____

APPENDIX D

Informed Consent Form

Informed Consent Form

I, ____

(Frist Name) (Middle Name) (Last Name)

agree to serve as a subject in an investigation of the impact on the family of the birth of a premature infant. This study is conducted by Marilee Dea, R.N.,P,N.P. under the direction of Pam Hellings, R.N., Ph.D.

I understand that I will be contacted by Marilee Dea, R.N., P.N.P. or her designee in the hospital, near the time of discharge and again, at home, one month after discharge, that I will be asked to complete a questionnaire which will take approximately twenty minutes each time. I understand that all information obtained will be kept confidential and that a code system will be establised to maintain my anonymity. Information will be reported in ways that will not identify me with my specific answers.

It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occured through the fault of the Center, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D., at (503) 225-8014.

Marilee Dea, R.N.,P.N.P. has offered to answer any questions I might have about my participation in this study. I can contact her at (503) 648-9528.

I understand that I may refuse to participate or withdraw from this study at any time without affecting my relationship with or treatment at, the Oregon Health Sciences University hospital.

While I may not benefit directly from participation in this study, others may be helped by the results of this study. However, health professionals may gain valuable information about families who have premature infants so that future intervention with families will be more effective.

I have read the above explanation and agree to participate in the study as described.

Date:____________________ Signature:______________________

Witness:________________________

AN ABSTRACT OF THE THESIS OF
MARILEE DEA

For the MASTER OF SCIENCE

Title: The Impact of Home Monitoring Apneic Premature [redacted] on the Family

Approved:____________________________________

Pam Hellings, R. N., Ph.D., Thesis Advisor

The purpose of this study is to investigate the impact of apnea monitoring on families with premature infants.

The design was quasi-experimental. A convenience sample of families of prematures undergoing apnea testing was used. Parents of premature infants requiring monitoring at home were the experimental group and parents of prematures who did not require monitoring were the control group. There were twenty one families in all, 11 families in the control group and 10 in the experimental group. The demographic data indicated that there was no statistically significant difference between the two groups, although the monitoring group was slightly younger, and had less formal education.

Families were studied using the Impact of The Family Scale. It measures five areas of impact: *Financial*, *Disruption of Social Relationships*, *Coping* or Mastery, *General Impact* and the *Total Impact*, which is a composite of all the negative impact questions. The scale was administered prior to discharge, and again one month after discharge. The scores in the five areas were compared using

a T test. It was hyposthezed that the monitoring families would have higher impact scores. The pretest results indicate that there was no statisically significant difference between the two groups. The post test results show a trend toward the direction hypothesized but the difference was not statistically significant. The small sample size may have effected the significance of the results. The area of greatest impact for the monitoring group was the Disruption of Social Relationships.

The lack of significance should not be used to decrease intervention available to these families. The services that are available currently may contribute to the lack of difference. The trend toward higher impact in the monitoring group warrents further investigation with a larger sample population.