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**CARING FOR AT-RISK INFANTS:  
THE EXPERIENCES OF PARENTS WITH INFANTS  
ON HOME APNOEA MONITORS**

**BARBARA LOIS MACLEAN  
1994**

**Caring For At-Risk Infants:  
The Experiences of Parents With Infants  
On Home Apnoea Monitors**

A thesis presented in partial fulfilment  
of the requirements for the degree of Master of Arts  
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**Barbara Lois Maclean**

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## ABSTRACT

Home apnoea monitoring for infants considered to be at risk for sudden infant death syndrome (SIDS) has been available in New Zealand since 1978. In light of the fact that the efficacy of home monitoring is unproven (Krongrad and O'Neill, 1986; Phipps and Drotar, 1990) an understanding of the impact of monitoring on families is essential.

In the present study, descriptive case studies (as described by Yin, 1984) are presented of six New Zealand families undertaking the home apnoea monitoring of their infants. In-depth interviews, conducted over a three month period, prospectively explored the experiences of one or more caregivers. Analysis of the data confirmed many of the reported findings from previous (mainly American) studies. In particular, parents perceived their infants to be "at risk" whilst monitored, and tended to become socially isolated because of their reluctance to leave their infants with other caregivers. The false alarms were a serious problem, causing negative arousal in the parents. When the alarms sounded parents found it very difficult to determine whether or not the infant was, or had been apnoeic. The monitor itself became the best indicator of the child's risk status and parents sometimes relied on the monitor to the detriment of other treatment regimes and of surveillance of the infant's condition for problems other than the risk of apnoea.

The present study used a systemic family nursing perspective to frame the participants' experiences. It was thus considered essential to take into account the family context in which monitoring was undertaken. Parents in the present study who, for example, had previously lost infants to SIDS, spoke of the ongoing grieving processes underpinning their monitoring experiences of

subsequent infants. When the youngest child was no longer monitored, the focus of attention shifted from the risk status of the infant to the prospect of a normal childhood.

Parents increasingly made their own decisions about how and when to use the monitor, based on their perceptions of their own ability to cope without it, rather than on the medical indications for its use or discontinuance. Mothers, especially, expressed strong needs for support from knowledgeable health professionals who could provide an integrated, holistic approach to the care of their infants, for monitoring supervision and for general parenting advice and support. The concept of a community-based nurse case manager is suggested as an appropriate means to meet their needs for a coordinated professional support service.

## PREFACE AND ACKNOWLEDGEMENTS

As a nurse working in a Level II neonatal unit, I became aware that nurses had very differing interpretations of the alarms emitted by apnoea monitors (similar models to those used at home by parents). Without the digital display readouts available on the more sophisticated cardiorespiratory monitors, nurses would respond to apnoea monitor alarms by checking whether or not the sensor pad was appropriately placed. If not, the sensor placement would be adjusted, the alarm reset and no concern was expressed. However, if there was no problem detected with the sensor siting, nurses then made judgements as to whether the infant was apnoeic, or breathing too shallowly or too deeply to register the respirations on the monitor. What one nurse would consider "shallow breathing" another would call "apnoea".

This phenomenon led me to think about what it must be like for parents at home caring for infants on apnoea monitors. How did they cope with alarms in a home setting far removed from the neonatal unit where a second opinion was always available and alternative monitoring equipment on hand for times when apnoea was diagnosed?

From there I widened my field of possible investigation to incorporate a consideration of the effects of home apnoea monitoring on family functioning. Neonatal nurses are increasingly becoming aware of the importance of nursing the whole family, rather than just the infant with parents in attendance.

The result has been the undertaking of the present study where six families' experiences of caring for an infant on a home apnoea monitor have been explored.

My thanks for assistance and support for this study go to firstly, the participants who gave of their time so willingly and shared with me their

experiences and secondly, to the staff of the Department of Nursing Studies, Massey University (now renamed the Department of Nursing and Midwifery), especially to Professor Julie Boddy who supervised and encouraged the writing of this thesis.

Barbara Maclean

**Key to Editorial Style Used in Quotations From Transcripts:**

... material omitted

..... pause

(number/number/number) following an excerpt from a transcript refers to Case Study Number/Interview Number/Page Number of transcript.

[ ] Pseudonym used or omission of name to ensure anonymity of participants, or insertion of material not in original transcript to clarify the meaning.

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## INTRODUCTION

In 1988, Dr Shirley Tonkin and Belinda Hutton (from the Cot Death Division of the Child Health Research Foundation) wrote that New Zealand's cot death rate was appallingly high by international standards (5:1000 births in New Zealand compared with less than 1:1000 births in Japan and Sweden). They went on to state that the survival rate of infants past the neonatal period could be achieved by two means. The first is to institute population-based strategies of identification and supervision; and the second is to target very high risk groups of infants and to safeguard them through infancy by such means as the use of home apnoea monitoring.

In New Zealand both these strategies have since been implemented. What is now known as the New Zealand Cot Death Study (Mitchell et al., 1991) has identified major risk factors for cot death, four of them modifiable; prone sleeping position, cigarette smoking, not breast feeding, and bed-sharing with the infant. The study was a three year multicentre case-control design and covered 80% of the country, comparing 485 cotdeaths with 1800 control infants. Commencement date of the study was 1st November, 1987, conclusion was 31st October, 1990. The researchers concluded that the four main risk factors could account for 82% of deaths from SIDS and that the rate of SIDS in New Zealand could fall to less than 0.7:1000 births if all infants in the country were breastfed, were not exposed to cigarette smoke, and were lain supine or on their sides to sleep in their own beds. The subsequent fall in the cot death rate has been attributed to the changes in parenting practices which have been promoted as a result of these findings (e.g. Scragg, Mitchell, Tonkin and Hassall, 1993).

Home apnoea monitoring for infants considered to be at high risk for sudden infant death syndrome (SIDS) has also become increasingly common over the last decade. Monitoring has been available in New Zealand since 1978 and organised programmes for their use have been developed across the country from the early 1980s (Tonkin and Hutton, 1988).

The hypothesis that led to the introduction of apnoea monitors was that babies dying from SIDS have cessation of breathing movements for 30 seconds or longer before death or irreversible brain damage has occurred (Milner, 1985). However, the Taskforce on Prolonged Infantile Apnea for the American Academy of Pediatrics pointed out in 1985, that knowledge regarding the aetiology and optimal management of prolonged infantile apnoea and its relationship to SIDS is only tentative. Five years later, Davies, Milner, Silverman and Simpson (1990) concluded that public awareness of SIDS has increased but the precise mode(s) of death in SIDS remain uncertain and unrecorded. Despite the rise in publicity and parental demands for the use of respiratory monitors at home, the efficacy of home monitoring is unproven. Large-scale controlled studies evaluating the effectiveness of home monitoring in decreasing the mortality and morbidity associated with infantile apnoea would raise serious ethical concerns (Rowland et al., 1987).

Several overseas studies have examined the effects of home apnoea monitoring on families but to date there have been no such studies reported in New Zealand. It is however recognised in New Zealand that for families undertaking home monitoring, the stresses are great and that support from health professionals is necessary, particularly when the time comes for monitoring to be discontinued (Moloney, Norton and White, 1987; Tonkin and Hutton, 1988).

The supervision of home apnoea monitoring in New Zealand is typically undertaken by Community Paediatric Nurses who follow up infants whose parents have been issued with monitors after consultation with a paediatrician. A number of parents of their own volition, hire monitors from local branches of the Cot Death Society. Alternatively, some purchase monitors of their own if they fail to meet the criteria for the provision of a rented monitor from an established programme (Moloney, Norton and White, 1987). Guidelines for the recommendation of apnoea monitoring vary according to the region. Auckland hospitals, for example, use a

protocol (written after consultation with Dr Tonkin in 1989 and updated in 1991) which lists the following infants as worthy of consideration of home monitoring; those who have recently been weaned off oxygen therapy, or discharged home on oxygen; infants of drug-abusing mothers; infants who have had an apparently life-threatening event in hospital; infants with respiratory obstruction (for example, from Pierre Robin Syndrome, a congenital condition in which the infant's tongue may fall back and block the airway); those with abnormalities of tone contributing to feeding and swallowing difficulties; apnoea of prematurity persisting beyond 37 weeks gestation; those with apnoea following surgical procedures; infants who are siblings of babies who died from SIDS and who have additional risk factors; and finally, infants of parents who are in an extreme state of anxiety, such as those with a poor obstetric history.

Plunket Nurses<sup>1</sup>, Public Health Nurses<sup>2</sup> and Practice Nurses<sup>3</sup> are all involved to some extent with families with monitors, as are hospital nurses in neonatal units and paediatric wards who may well be part of the after hours support/referral service for parents experiencing problems with monitoring. To increase the understanding of the issues involved, for nurses and other health professionals who seek to provide families of at-risk infants with assistance and support, the current investigation uses the family systems approach as a framework to explore the experiences of parents undertaking home apnoea monitoring.

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1. Registered Nurses who are employed by the Royal New Zealand Society for the Health of Women and Children Incorporated (Plunket Society) which is a voluntary organization receiving considerable financial support from the government in addition to funds raised by its members. They provide parents and children (0 - 5 years) with preventative, supportive, advisory, and educational health services.

2. Nurses who provide predominantly family-centred preventive, supportive, and educational care to at risk groups in the community.

3. Nurses who are employed by doctors in general practice or in health centres. Their salary may be paid by a government subsidy to the doctor. They provide general nursing and delegated medical services in doctors' surgeries, health centres and in clients' homes.

## CHAPTER ONE

### Literature Review

The literature on home apnoea monitoring for infants will be discussed under three broad headings; the identification of those infants considered to be "at risk" and therefore in need of home apnoea monitoring; the technical aspects of the monitoring procedure; and families' responses to monitoring considered in conjunction with the relevant family nursing literature.

#### **The Identification of Infants At Risk of Apnoea**

Sudden Infant Death Syndrome is a poorly understood entity. Krongard and O'Neill (1986) point out that although the use of apnoea monitors to prevent this fatal syndrome is widespread, many questions have been raised regarding the adequacy or efficiency of what they term "this preventive-therapeutic modality"(p. 811). They go on to say that no test is available to indicate with a reasonable predictive value, that any one infant is at risk of sudden infant death and therefore in need of cardiorespiratory monitoring.

Krongrad (1991) comments that the search for infants at high risk for SIDS (candidates for apnoea monitors to safeguard them through infancy) has been based on parental observations and on epidemiologic risk factors. Both of these criteria are problematic. Infants considered to have high risk status (such as siblings subsequent to infants who died of SIDS (subsibs) and infants with reported periods of prolonged apnoea) have failed to demonstrate any specific physiological parameters, consistently and over time, that are different to those of the control group infants. Krongrad points out that parental observation which has been the cornerstone of the current definition of high risk is fraught with considerable error. The data collected by Kelly (1983) for example, which has been used extensively to estimate the incidence of prolonged apnoea in subsibs, relied heavily on

parental reports of apnoea. Davies et al. (1990) providing an update on monitoring and Sudden Infant Death Syndrome, concluded that the currently known epidemiological and physiological risk factors for SIDS are not "significantly sensitive or specific, even in combination, to identify infants for particular intervention" (p.238).

The uncertainty about the efficacy of home apnoea monitoring is demonstrated in the following advice given in 1985 to medical practitioners by the Task Force on Prolonged Infantile Apnea (p.129);

Physicians must evaluate and treat each case individually. Those who believe there is a relationship between prolonged apnea and SIDS and/or that home monitoring may be helpful should prescribe monitoring; those who do not are not obligated to prescribe monitoring and should not feel pressured to do so. All should recognize and communicate that monitoring cannot guarantee against SIDS.

### **Technical Aspects of Monitoring**

The most commonly used model in New Zealand is the Graseby MR10 Respiration Monitor which is activated by abdominal movements detected by a sensor pad taped to the infant's abdomen. Davies et al. (1990) reiterate the shortcomings of this model - no data storage facilities are incorporated for event analysis, false alarms occur if the sensor pad is dislodged from the abdomen and more importantly, there is an inability to identify apnoea due to airway obstruction. Because no cardiac monitoring is incorporated, when an infant struggles against an obstructed airway, the body movements or bradycardic heartbeats may be picked up by the monitor as breaths. Caregivers may thus have unrealistic expectations that the monitor will always alarm if the infant suffers an episode of prolonged apnoea.

The false-negative problem, or failure to alarm is a major consideration with the MR10 monitor because as Davies et al. (op cit) point out, apnoea during apparent life-threatening events may be central (caused by failure of the central respiratory drive); obstructive (where there is some impedence to the flow of air from the nares to the alveolae) or a mixture of the two. Tonkin (1985) does however report that central events often become obstructive before normal respiration is re-established and that obstructive events can soon lead to central apnoea.

Recent suggestions for the improvement of home monitoring devices have included the use of oxygen saturation monitors to detect hypoxia (Davies et al., 1990) and the addition of an auditory stimulus to the alarm function to normalize the breathing pattern of the infant and thereby reduce the incidence of SIDS (Stewart and Stewart, 1991). Peeke and Levett (1992) write of the benefits of the use of event recorders incorporated into home cardiorespiratory monitors (these were not respiration detection only monitors such as the Graseby MR10 model). Event recorders enable computerized printouts to be made of heartrate and respiration patterns when an alarm is triggered. They also document caregiver compliance with instructions for the use of the monitor.

A number of studies have demonstrated that there is very little correlation between parents' reports of apnoea episodes and hard data obtained of cardiorespiratory activity from event recorders attached to the monitor. A recent study by Steinschneider and Santos (1991) confirmed the earlier findings by Krongrad and O'Neil (1986) and Weese-Mayer et al. (1989) that true biologic events were not reflected by parental reports of apnoea in the vast majority of recorded instances. Steinschneider and Santos monitored 155 "at risk" subsibs and with an attached event recorder, found that of the reported 1051 "true" apnoea episodes and 422 bradycardia episodes, none had a confirmed cardiopulmonary event that could be considered life-threatening. Anxious parents had made hundreds of attempts at stimulation or cardiopulmonary resuscitation (CPR) apparently needlessly.

Occasional reports have been documented of what appear to health professionals to be deliberately falsified apnoea histories. Rowland et al. (1987) encountered three such cases in a five year period of monitoring 211 infants, from 1981-1986 in Massachusetts. Light and Sheridan (1990) surveyed 127 apnoea monitoring programmes and found an incidence of this phenomenon, known as Munchausen Syndrome by Proxy and Apnoea (MBPA) of 0.27%. In such instances, management involves verification of symptoms with event recordings and therapy for families to break the link between the reporting of symptoms and receiving help. Light and Sheridan (op cit) appreciate the difficulties for clinicians presented with an infant who supposedly suffered apnoea, to tread the fine line between too much and too little suspicion of parents' reports.

Several issues arise from this literature review. Firstly, the value of monitors which alarm but provide no event recordings for the parents to compare, must be questioned.

Secondly, parents may be putting their infants at risk by relying on the monitor to detect any of the three types of apnoea, in time for the infant to be successfully resuscitated. Concern has also been expressed (McIntosh, 1990) that parents could regard the monitor as a safety net and rely on it inappropriately, sometimes unintentionally neglecting other physical aspects of their child's care.

Thirdly, there is risk to the monitored infants who are resuscitated unnecessarily. Rowland et al. (1987) warned that administered CPR does not necessarily mean required CPR. Clearly, the reported extent of the initial resuscitation of an apnoeic infant is not a reliable indicator of the event.

Fourthly, the reactions of the parents to the monitor alarms should be seriously considered. False positive alarms which are interpreted as real events are a potent source of stress for parents. Mothers have told of feeling threatened and upset when health professionals have questioned them about apnoeic episodes in a non-supportive, insensitive manner (Nuttall,

1988). Steinschneider and Santos (1991) observe that there are no published studies examining the influences of experiential and psychological factors on parental responses to monitor alarms.

### **Family Responses to Monitors**

Families with home apnoea monitors are a specific population but share many of the attributes of other families experiencing the stress of having a child with a chronic illness (Geary, 1989; Sweeney, 1988; Wasserman, 1984).

#### *Risk Perception of the Child*

Wasserman (1984) in comparing and contrasting monitoring with the experience of living with a chronically ill child, states that although home monitoring is a time-limited experience (unlike truly chronic illnesses) its constant presence does not allow the family any denial of the fact that the child may die at any time. Constant vigilance required by the electronic surveillance programme thus leads to stress and emotional and adjustment problems similar to those reported in parents of children with chronic illnesses.

Shapiro (1983) in a review article of family reactions and coping strategies in response to the physically ill or handicapped child, describes the effects of a chronic or life-threatening illness on the family as profound, with the depth of the family response being directly related to the parents' perceptions of the severity of the risk to the child. She reports that if parents mistakenly identify their children as being at risk from, or suffering from some serious physical condition, then dysfunctional family responses such as overprotection of the child which occurs in the "vulnerable child syndrome" may result. The vulnerable child syndrome was first described by Green and Solnit (1964) who identified parents' reactions to the threatened loss of a child. Shapiro (1983) cites a follow-up study of misdiagnosed infants (Carey, 1969) which found that years afterwards, the

misdiagnosed children were still perceived differently and treated differently by the mother. Phipps and Drotar (1990) emphasise the importance of understanding the impact of the monitor on the parent-child relationship considering the undocumented nature of the preventive value of home monitoring.

In light of the recent findings by Krongrad (1991) and Steinschneider and Santos (1991) the question arises - are parents of monitored infants suffering needless anxiety because of a mistaken perception of the risk status of their infants? Certainly, Black, Hersher and Steinschneider (1978) point out that the alarm rates of monitors became important determinants of parents' convictions about the severity of risk to their infant.

#### *Family as Context and Recipient of Care*

The reciprocal relationship between the family and chronic illness is recognised by nurses and other health professionals who adopt a family systems approach as a framework for clinical practice. In the family nursing literature, authors such as Wright and Leahey (1984); Leahey and Wright (1987); Gillis (1991); and Shaw and Halliday (1992) emphasise interventions deliberately and consistently designed for the family unit, rather than for individuals in the context of the family. According to Woods, Yates and Primomo (1989) the entire family experiences the effects of demands generated by the disease and its treatment. Wright and Leahey (1990) advocate family systems nursing which concentrates on the interconnections between illness, the individual and the family; as life threatening illness affects the individual and family, the behaviour of family members, in turn, influences the course of the illness.

Rankin (1989) developed a framework to assist nurses and other health professionals to appreciate the diversity, complexity and plasticity (the capability of considerable alteration over time) of families. The framework melds two traditions, that of psychosocial transitions (based on the work of Parkes, 1971) and family development theory (Duvall, 1977). Rankin

emphasises that although consideration of common psychosocial transitions helps to reveal important tasks of families during certain phases in their histories, the unique context and perspective of each family must be taken into account. Developmental theory has been synthesized by Stainton (1989) a nurse advocate of the family as the unit of care. She emphasises the importance of a new mother's relationships with her "significant others" and her mate (p 201) and lists a set of four developmental tasks for her to accomplish within the family context. Families experience transitions in different ways and their resources and their abilities to cope must be taken into account when the needs for intervention are assessed. Family situations in which home apnoea monitoring is undertaken would thus both affect and be affected by the monitoring experiences.

The indications for the use of the monitor have been found to influence parents' reported levels of stress. Black, Hersher and Steinschneider (1978) found for example, that anxiety levels in their study's participants were higher in parents whose child had a diagnosis of sleep apnoea and in those who had had a previous child die from SIDS.

An understanding of the long-term effects of the loss of a child, is necessary to put into context the experiences of monitoring a subsequent child. Weinstein (1978) writing specifically about the responses of families to the loss of a child from SIDS, points out that the parents of the dead infant are left with the knowledge that their child died inexplicably, perhaps because of something they unwittingly had done or failed to do. They look for a reason to explain the death, partly to expunge the sense of guilt and feeling that others may consider that some neglectful action on their part caused the child to die. Bugen (1977) recognizes that the intensity of the grieving reaction is related to the preventability of the death. However, with cotdeath, the parents do not know what could have been done to prevent it. Family nursing authors, McClowry, Gillis and Martinson (1989) reject the traditional model of bereavement and instead describe how the pain of grief is ongoing and becomes integrated into the person the bereaved person has become. Monitoring parents who have lost a child thus cannot be assumed

to have passed through a series of predictable stages in the grief process and have successfully or unsuccessfully "resolved" their grief. McClowry et al. (1989) advise that bereavement is difficult and mourners are subject to a variety of ongoing emotional sequelae.

#### *Demands of Monitoring: Anxiety and Social Support*

Vohr, Chen, Coll and Oh (1988) used standardised questionnaires to compare the maternal stress perceptions and social support levels of ten mothers of preterm infants on apnoea monitors; ten mothers of full-term infants on home monitors; and ten mothers of non-monitored term infants. Monitored infants' mothers experienced significantly more stress than those whose infants were not monitored. Preterm infants' mothers reported more favourable responses to monitoring, however, than did the mothers of their full-term counterparts. The authors comment that parents of preterm infants are exposed to apnoea monitors in the neonatal care of their infants before hospital discharge. They postulate that the increased levels of pre-existing stress in mothers of preterm infants, because of the effects of the premature birth and its sequelae, contribute to the lower stress levels reported when monitoring at home.

The adjustments in family lifestyle necessitated by the birth of a premature infant were investigated by McHaffie (1990). Although McHaffie did not look at the monitoring experiences of parents of premature infants, her study is reviewed here because it provides an insightful exploration of the parenting of one group of 'at risk' infants who often are monitored at home for apnoea. McHaffie (1990) prospectively studied the perceptions of 21 mothers of very low birth weight infants, conducting six in-depth interviews with each mother from one week after delivery to three months after the baby's discharge from hospital. Extra data were supplied by diaries kept by the participants and by the administration of the standardised Neonatal Perception Inventory. She identified six phases in their experiences of the premature birth and subsequent home-coming, each characterized by certain critical factors related to the mother's emotional

state, her perceptions of the baby and family responses. The mothers who felt ready to take the infant home from hospital coped with the baby's ongoing care more effectively than those who felt unprepared for discharge. Both studies (Vohr et al. 1988; and McHaffie, 1990) conclude that strong levels of support for mothers diminish stress. McHaffie adds that professionals can help mothers to overcome their feelings of inadequacy by giving them the opportunity to talk frankly about their concerns without fear of censure or advice.

A number of studies have examined the relationship between home apnoea monitoring and emotional stress for families. Whilst there is general consensus that monitoring makes demands upon parents, there is considerable controversy as to whether monitoring significantly increases or decreases parental anxiety levels (Andrews, Nuttall, and Neilson, 1987). Initial studies were retrospective and descriptive in nature (Black, Hersher and Steinschneider, 1978; Cain, Kelly and Shannon, 1980) and presented generally positive pictures of the monitor as anxiety-reducing. Black, Hersher and Steinschneider (1978) obtained descriptive data from 31 monitoring families, through questionnaires designed after intensive interviews were conducted with 18 mothers and 15 fathers. They concluded that monitoring had a significant but temporary impact on family life. Many patterns of daily living were altered to accommodate the demands of monitoring and the technical limitations of the machine severely aggravated parents' problems. Most parents believed the monitor was ultimately an anxiety reducer and worth the inconvenience.

Wasserman's (1984) study used a prospective design to follow up 14 families of monitored infants for a period of five years from the time of initial contact. Each family received at least three "psychiatric" interviews and two other follow-up contacts. Wasserman reported that monitoring caused substantial distress manifested in depression, fatigue and anxiety in many parents, especially mothers, who had the largest burden of care. Cain, Kelly and Shannon (1980) conducted an exploratory study of 133 parents' perceptions of monitoring (74 families). Each parent was interviewed once

only in a structured interview lasting one hour. A self-administered graphic rating scale was used to supplement the data. The researchers found that fathers and mothers did not necessarily share the same perspective of the seriousness of the monitoring and that mothers tended to report higher levels of anxiety and insomnia, especially in the first month of monitoring.

A controlled prospective study of the impact of monitoring on mothers was undertaken by McElroy, Steinschneider and Weinstein (1986). Fifty-six mothers of monitored infants were studied at several periods following the infants' births; at 6 weeks, 12 weeks and one year. A battery of questionnaires was administered to these mothers and to 56 mothers of non-monitored infants in the control group. Very few statistically significant differences were found between the two groups and the authors conclude that a home monitoring programme, which includes an 'aggressive and readily available support system, does not impose a marked health hazard to mothers' (p.780).

Phipps and Drotar (1990) conducted a comparative study of three groups each of 30 mothers; mothers of infants who had suffered an apnoeic episode and who were being home monitored; mothers of infants with mild congenital heart lesions; and mothers of normal healthy infants. Measures were made of parenting stress, family resources and support, family coping activities, health locus of control, and maternal coping style. Mothers of monitored infants reported slightly increased levels of stress, their infants were perceived as more demanding, and the mothers reported less attachment to the child. Acute distress was engendered by monitoring in the first month but these effects were transient. Their findings were in line with those of Cain et al. (1980) but contrary to those of Nuttall (1988) and Williams and Williams (1990) who found no evidence with the passage of time, of an attenuated effect on mothers, particularly in families lacking cohesion and where low self-esteem of the mother hampered help-seeking behaviours. Phipps and Drotar (1990) suggested that family resources, including the availability of social/emotional support appear to be the crucial determinants of parenting stress. The study by Williams and

Williams (op cit) was of 25 mother/child pairs who were discharged home from hospital with apnoea monitors. Data were collected retrospectively from mothers using standardised instruments, including the Receptive-Expressive Emergent Language Scale; Home Observation for Measurement of the Environment; Family Coping Strategy questionnaire; Family Adaptability and Cohesion Evaluation Scales; and the Functional Social Support Questionnaire.

Another retrospective comparative study was conducted by DiMaggio and Sheetz (1983). Twenty-nine mothers of monitored infants were compared to mothers of normal infants. Monitoring mothers in this study felt socially isolated because of a lack of people who were willing or able to babysit and they experienced resultant emotional tension. They tried to maintain usual household routines despite the additional demands imposed by monitoring. These mothers expressed the need for networking with other monitoring parents as well as support from professionals.

In discussing the potential costs of home monitoring on families, McIntosh (1990) cautions that parents may react to the stresses of monitoring by becoming very demanding or withdrawn. The cumulative effects of the strains of monitoring can lead to social isolation and loss of social support as friends and family distance themselves.

Geary (1989) a clinical nurse specialist, emphasised the intensity of mothers' concerns arising from the impact of monitoring on a lifestyle that has already changed to accommodate a new baby. Discussing the findings of her qualitative study of 20 monitoring mothers, Geary warns that nurses must not overlook mothers' needs which become submerged in the process of caring for the baby. The prolonged stresses of monitoring may limit the amount of energy available to mobilise support. She identified frequently-used coping strategies such as denial or minimising the negative and emphasising the positive aspects of monitoring.

Selected findings from Geary's study were previously reported in 1986 by the same author (published under the name Dean). Dean categorized the stresses experienced by mothers as the need for constant watchfulness; feelings of confinement; lack of personal time; and limited time with other children in the family.

Maternal responses to home monitoring were described by Nuttall (1988) in a retrospective study of 74 mothers. Using semi-structured interviews, Nuttall found mothers reported family disruptions from the monitoring and a distressing lack of support from friends and relatives who were reluctant to assume any responsibility for the monitored infant. Monitoring also seemed to have precipitated fears in the mothers about the vulnerability of their babies. Nuttall describes home monitoring as a prototype for other medical technologies now being used in the home. The responsibility for 24-hour technological care is undertaken by the parents. Andrews et al. (1987) assert that education of families and supportive care by collaborative multidisciplinary health teams are vital for home monitoring to be an acceptable alternative to hospital care.

#### *Compliance With Monitoring Protocols*

Wilson, Stevens, Becker and Klinghagen (1990) point out that studies of family responses to monitoring have not provided data regarding how the parents used the monitor. In an investigation of 35 families in the South Dakota area, they interviewed caregivers in a home apnoea monitoring programme and found that only 8% of respondents followed the monitoring protocol advocated by the programme. Non-compliance and premature termination of monitoring were common with the result that many babies in the sample would not have received prompt attention if apnoea had occurred. The authors conclude that a mother's compliance with procedures is an indication of how vulnerable she perceives the child to be.

### *Cultural Considerations*

Cultural considerations in the use of home monitors have been largely ignored. Bushy and Rohr (1990) emphasised the importance of providing meaningful and efficacious care to ethnic populations. Their work with the Plains Indians also revealed "non-compliance" of families with the monitoring protocols, which they attributed to cultural influences such as the role of the extended family in caring for the infant and the incongruity of technological monitoring with traditional health beliefs. Light and Sheridan (1989) reported that Hawaiian families who failed to use monitors were often from minority ethnic groups such as the Vietnamese, Koreans, Samoans or Blacks, suggesting cultural factors are involved in the acceptance or rejection of monitors. No New Zealand studies of Maori people's responses to monitoring have been published.

### **Summary**

The role of apnoea monitors in preventing SIDS is unproven, but there was no dramatic decline in the incidence of SIDS victims reported when monitors were introduced over a decade ago. The apparent inability of parents to distinguish which alarms are associated with genuine apnoea and bradycardia episodes, is a major concern, as is the unrealistic expectation of parents that monitors will always alarm if the infant suffers a life-threatening episode.

Understanding the impact of home monitoring on families is considered essential when evaluating the costs versus the benefits of monitoring (Phipps and Drotar, 1990). It is noteworthy that several of the studies reviewed above have investigated only the mothers' perceptions of the stresses involved in monitoring. Most authors agree that monitoring represents a significant stressor for the family but there is a lack of consensus of opinion regarding the severity and temporal effects of monitor-related distress. Further study of the impact of monitoring is recommended. No such studies have been reported in New Zealand to date and the present

study was undertaken with the intention of providing insight into the experiences of home apnoea monitoring parents (both mothers and fathers) in a New Zealand context.