

THE FUNCTIONAL LEVEL OF PARENT WHO EXPERIENCE  
A SUDDEN AND UNEXPECTED INFANT DEATH  
13 TO 18 MONTHS AFTER THE EVENT

by

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## CHAPTER I

## INTRODUCTION

Sudden Infant Death Syndrome (SIDS) or "crib death" claims the lives of 7,000 infants each year in the United States. This represents a rate of 2 per 1,000 live births, with the majority occurring between 2 to 4 months of age. SIDS is the leading cause of death between one week and one year of age.

SIDS is defined as the sudden and unexpected death of an apparently healthy infant, whose death remains unexplained after a thorough postmortem examination (Bergman, Beckwith & Ray, 1970). The use of the words "apparently" and "unexplained" in this definition suggests ignorance, while at the same time the use of the word "syndrome" suggests a definite set of common characteristics in these infants.

The etiology of SIDS is unknown, but researchers are continuing to fit the pieces of the puzzle together. For example, Arnon (1981) found that at least 5% of deaths formerly attributed to SIDS in California, were actually caused by infant botulism.

It has been believed by authors in the past that SIDS parents experience a unique grief reaction and grief resolution process. Various sources in the literature attribute this "uniqueness" to one of three factors: 1) the suddenness of the death, 2) the unexplainedness as to the cause of death, and 3) the extreme guilt feelings the parents experience. It is speculated that the guilt feelings exist for several reasons: the legislated involvement of law enforcement agencies (police, Medical Examiners, etc.), the parents' belief that they could have prevented the death, and the parents' perception of what "others" believe caused their baby's death.



The studies available in the literature report the grief reactions of SIDS parents and the length of time needed for family readjustment and regaining personal happiness. Many articles also report what health care professionals "should do" to lessen the impact of this tragic puzzling event and to help the family adjust to their loss. These "shoulds" include early contact after the death, giving accurate information and reassurance that the death was unpredictable and unpreventable, and intense follow-up with the family for the first year. However, most of these "shoulds" are based on anecdotal information or at best a few small descriptive studies. In addition, the findings are inconsistent as to whether SIDS parents' reactions and grief resolution process needs are different from those of other parents who experience sudden and unexpected death of an infant in the first year of life. Consequently, medical researchers and nurses involved in SIDS counseling are questioning these assumptions that have been the basis for counseling intervention.

#### Review of the Literature

In the review of the literature to follow, four areas will be addressed: the history of SIDS, the epidemiology and etiology of SIDS, parental grief reactions and family adjustment to sudden, unexpected infant deaths, and current theories of the grief process.

#### History of SIDS

Crib death has a history of over two thousand years. It also has been referred to by many names. The British refer to it as "cot death", and in the United States and Canada this disorder has been simply called "sudden death in infants" (Wedgewood & Benditt, 1963), with the official

term Sudden Infant Death Syndrome being coined in 1969 (Bergman, Beckwith & Ray, 1970).

There have been hundreds of theories proposed to explain this phenomenon. The literature of the 1800's discussed the concept of a lethally enlarged thymus. In the early 1900's the role of infection was suspected to be the cause, and by the 1940's suffocation was thought to be the culprit.

#### Epidemiology and Etiology of SIDS

The incidence of SIDS in the United States is approximately 2 per 1,000 live births, with the rate for white babies being the lowest, and the rate for the Native American being the highest (Valdes-Dapena, 1980). There appears to be a significant difference in the rate between countries. Sweden reports the lowest rate of .06/1000 live births (Peterson, 1980) and Canada reports the highest rate of 3/1000 live births (Steele, 1970).

SIDS is more likely to occur in males, low birth weight babies, infants from lower socio-economic groups and infants born to young mothers (Peterson, vanBelle, & Chinn, 1982). Mothers who smoke have a higher rate of SIDS, and there is also a correlation between lack of prenatal care and incidence of SIDS (Naeye, 1980).

There are two patterns that are relatively unique to SIDS--age and seasonal distribution. Most SIDS babies die between 1 and 6 months of age, with the peak occurrence at 2 to 4 months. The majority of deaths occur during the cold winter months in both the northern and southern hemispheres (Beal, 1978).

The recurrence rate in families is well documented. Peterson, Chinn & Fisher (1980) reported a recurrence rate of 21/1000 live births,

approximately a tenfold increase among SIDS siblings as compared to index infants. This high rate is thought to be environmental rather than genetic, but further research is needed to determine how genetic and nongenetic factors might interact, thus resulting in a substantially enhanced risk for death (Merritt & Valdes-Dapena, 1984).

SIDS does not appear to constitute a distinct disease, but reflects an identifiable pathological syndrome of unknown origin. As yet, no system exists for identification of the vulnerable infant, but as each year passes more and more is known. As little as a decade ago, these infants were viewed as healthy normal babies. Naeye, Ladis & Drage, (1976) through their investigations have helped to change that opinion. They found in their prospective study that these babies were subtly physiologically handicapped from birth. Many of their features as neonates suggested abnormalities in respiration, feeding, specific neurologic tests and low Apgar scores. Out of 42 possible risk factors, five have been identified by Naeye (1983) to have an independent relationship to SIDS: a mild infection in the baby at the time of death, preterm delivery, maternal cigarette smoking during pregnancy, abnormal maternal hemoglobin values during pregnancy and a third trimester diastolic blood pressure drop of 20 mm Hg or more to a value <61 mm Hg.

Naeye (1980) has also reported on autopsy, that SIDS babies were found to have evidence of chronic hypoxia. This evidence included abnormal retention of brown fat, increased levels of adrenal hormone cortisol and decreased growth patterns in body organs similar to the pattern observed in mammals maintained experimentally in a low oxygen environment after birth. These abnormalities were found in 66% of the babies studied.

A similar area of growing interest in research is infantile apnea. Steinschneider, Weinstein, & Diamond (1982) observed respiratory activity of 1,311 infants within the first week of life during a feeding and complete daytime nap. Ten of these newborns were subsequently victims of SIDS. The future SIDS victims were found to have a statistically significant greater number of apneic episodes during feeding and a greater number of apneic pauses during sleep than other infants. Other researchers have also reported abnormal regulation of ventilation in infants at risk for SIDS (Shannon, Kelly & O'Connell, 1977; Guilleminault, Ariagno & Korobkin, 1981). The relationship between SIDS and infantile apnea is unclear at the present time. Merritt & Valdes-Dapnea (1984) state that the hypothetical extension of apnea of infancy to SIDS is probably unwarranted judging by current conflicting data (p. 205). Spitzer & Fox (1984) also point out that while all babies dying from SIDS have apnea as a terminal event, the number of children in whom apnea is the primary cause of SIDS is not known.

#### Parental Grief Reaction and Family Adjustment

Bergman, Pomeroy & Beckwith, (1969) reported parents' response to SIDS in the acute phase of grief based on observations from 225 home visits to households of SIDS victims conducted during the first few months after the death. These reactions were reported as disbelief, anger, helplessness and loss of meaning in life. They also reported guilt as "universal", whether or not the parents stated so. The physical symptoms were reported as "whirling around", "losing their minds", "heartache" and "stomach ache". Since that time much of the literature published on the topic has quoted this article (DeFrain & Ernst, 1978; Friedman, 1974; Halpern, 1972; May & Breme, 1982; McElroy, Ruginis, &

Shaefer, 1979; Smialek, 1978). In 1978, Smialek reported her observations of 351 families in whom an infant had died suddenly and unexpectedly. In 75% of the cases, the infants were diagnosed after autopsy as SIDS. The significant findings of Smialek's article was that whatever the final mechanism of death, the immediate expression of loss by the family rarely differed.

Williams and Nikolaisen (1982) reported a nursing research study in the area of SIDS and parents' perception of loss. Their study included a sample of 54 parents (44 married, 10 single or divorced) who lost a baby to SIDS between 1970 and 1976 in King County, Washington. A mailed questionnaire was used to study the parents' perception of the loss of their infant. Results from this study showed that 75% had heard of SIDS prior to the death, that mothers had more difficulty accepting SIDS as the diagnosis, and that mothers and fathers varied in their perceptions of support. The fathers viewed the support they received more positively than the mothers.

Many authors mention the fact that mothers and fathers grieve differently but very little empirical evidence exists to document that belief. Mandell, McAnulty & Reece (1980) studied 28 fathers who lost babies to SIDS and identified four patterns of behavior "peculiar" to men: 1) the necessity to keep busy, 2) feelings of diminished self-worth, 3) self-blame because of lack of care involvement and 4) limited ability to ask for help. DeFrain et al. (1983) found that men stated feelings of anger more and had a stronger desire to keep grieving private. They reported that women expressed more sorrow and were more depressed.

The literature does not document adjustment or grief reactions to the sudden and unexpected death of an infant from other causes. Authors

cite the work of Bergman et al. (1969) and state that it "probably" may be generalized to unexpected death from other causes.

Documentation can be found on reactions to the accidental death of a child (Friedman, 1974). The resulting guilt from a preventable accident may be persistent and is not resolved by the grief process. Friedman states that psychological resolution probably is based either upon one's acceptance of his imperfections or denial of responsibility (p. 106).

The Fort Logan grief intervention program studied 105 families following a sudden death of an immediate family member and a control group of 56 families that had not experienced death. The results showed that bereaved individuals and families demonstrate poorer functioning in several areas than nonbereaved groups (Polak, Egan, VandenBergh, & Williams, 1975). Bereaved families show greater pathological emotional expression, restlessness, indecisiveness and greater problems in family interpersonal and social functioning.

There seems to be general agreement among authors that grieving cannot be collapsed in time. Events such as birthdays, anniversaries and holidays must be experienced by the parents before they can "work through" the loss of their infant. Rubin (1981) states that the acute grief reaction lasts 3 to 12 weeks and the mourning period one to two years. In a study of mothers who had babies die from SIDS, Rubin (1981) concluded that the passage of several years "alleviated but did not heal" the sense of loss (p. 108).

DeFrain, Taylor & Ernst (1982) found from the results of their survey of 112 SIDS parents that it took families an average of 12 months to regain the level of family organization they had had previous to the death, and an average of 36 months to regain the level of personal

happiness. DeFrain & Ernst (1978) reporting from a portion of that survey found no significant relationship between recovery time and residency, church activity, number of personal friendships or prior knowledge of SIDS. They did find that higher income was associated with quicker recovery time.

All studies cited mentioned the problem of the difficulty of locating parents after a SIDS death. One study reported 60% of the parents had moved within two and one half years of the death.

Steinschneider (1983) conducted a study on the "Psychological Impact of SIDS on the Family" in 1980 and 1981 in Baltimore, Maryland. The design of the study included interviews with families whose baby died from SIDS between the age of 1 to 6 months and an equal number of families with living infants selected randomly from the hospital where the SIDS victim was born, controlling for socioeconomic status. The families of the SIDS victims were interviewed 13 months after the infant death and the families with living infants were interviewed 13 months after the death of the index case.

The Beck Depression Inventory, the Speilberger State-Anxiety Inventory and the Derogatis Brief Symptom Inventory were used to measure depression, state anxiety, phobic anxiety, psychoticism, somatization, obsessive-compulsive behavior, interpersonal sensitivity, paranoid ideation and hostility. Demographic data were collected and a recent life changes questionnaire was administered. 30 SIDS families participated and 26 families with living infants participated in the study.

The data were statistically analyzed using the t test and chi square. The unpublished results of the study revealed that SIDS mothers

smoked more after their baby died, were pregnant more often, had more health problems, were more depressed, and had more evidence of phobic anxiety, psychoticism, hostility, and somatization.

### Theories of the Grief Process

Many conceptualizations and models have been proposed to help explain human grief reactions. Lindemann (1944) interviewed 101 patients who had a close relative die in hospitals, the armed forces or the Coconut Grove fire. He defined grief as a normal reaction to a "distressing situation". Lindemann's early work described the symptomatology of normal grief as a tightness in the throat, physical exhaustion, shortness of breath, need for sighing and an empty feeling. The duration of a grief reaction, according to Lindemann depends upon the success with which a person becomes "emancipated from the bondage of the deceased". In other words, how quickly new relationships are formed and readjustment is made to the environment from which the deceased is missing.

The most common approach used to describe grief consists of the existence of stages. Kubler-Ross (1969) suggested five stages of "adjustment", including denial, anger, guilt, preparatory grief and the goodbye state. Kavanaugh (1972) outlined seven stages that could be identified in the grief process: shock, disorganization, volatile emotions, guilt, loss and loneliness, relief and reestablishment. Both authors have recognized that their stages are not separate entities but blend with one another. While the stages are well defined and described in the literature, empirical evidence is lacking to sufficiently test the theory. Bugen (1977) proposes that the "existence of a variety of



emotional states is the essential point, and not the need to order them" (p. 197).

Other models have been suggested that do not tie the grief process to a succession of stages. Bugen's model (1977) attributes two dimensions--centrality-peripherality and preventability-nonpreventability --to the intensity and the duration of the grief reaction. Centrality-peripherality refers to the perceived relationship with the deceased. If the relationship with the deceased is seen as central the grief reaction will be more intense. Preventability-nonpreventability refers to whether the mourner believes the cause of death was preventable or unpreventable. Preventability refers to the belief that the mourner themselves could have prevented the death, directly or indirectly, or that others could have prevented the death if contributing factors could have been controlled. If the cause of death is believed to be preventable the grieving process will be prolonged. Even though Bugen (1977) proposes a two dimensional model, he strongly states that the "belief that a death might have been prevented is the single most influential factor contributing to the prolongation of the human grief response" (p. 202).

Applying Bugen's model to survivors of SIDS victims would suggest that the grief reaction of parents would be intense because of the usual centrality of the parent-infant relationship and prolonged because many parents believe the SIDS death was preventable. With other sudden and unexpected infant deaths, with the exception of preventable accidents, the grief reaction would be thought to be intense but somewhat briefer, because the cause of death would be explained and therefore less likely to be believed preventable.

### Theories of the Grief Process as it is Experienced by SIDS Parents

Many descriptive studies exist that describe the immediate grief reactions of parents of SIDS victims. Anecdotal evidence, formal testimony and generalizations from parallel loss groups tell of the anguish and wreckage of lives as a result of a sudden and unexpected infant death. However, few studies have been conducted to substantiate the anecdotal evidence and formal testimony.

Parents whose babies have died of SIDS have been thought to have unique and prolonged grief reactions and yet studies have not been conducted that compare SIDS parents with other parents who lose babies suddenly and unexpectedly.

The SIDS literature suggests two variables that help to explain the uniqueness of SIDS grief resolution. These two concepts are consistently confused in the literature and empirical evidence does not exist to support either concept. Some authors report that the unexplainedness of the death is the cause of the parents' prolonged grief reaction, while others report that it is the guilt the parents experience because they feel they could have prevented the death. Lowman (1979) states that "the primary way in which SIDS deaths differ from other losses is in the extremity of feelings of responsibility that parents report. This responsibility is occasionally projected to another (e.g. physician or relative) but is typically personalized in the form of guilt" (p. 674).

### Conceptual Framework

The conceptual framework for this study consists of three interrelated concepts: grief resolution, unexplainedness, and preventability of the death.

The grief resolution process encompasses a variety of emotional stages that an individual experiences after a loss (Kubler-Ross, 1969). This process is a normal response to loss and the desired outcome is acceptance or resolution within a reasonable time frame, sometimes suggested as one to two years (Rubin, 1981). Anxiety and depression are normal symptoms of grieving; psychotic behavior is usually indicative of an abnormal level of intensity of grief, although psychotic behavior may be normal in certain phases of the grief process.

The second concept involves the unexplainedness of a death. The grief resolution process is said by some authors to be prolonged when the cause of death is unexplained (Rubin, 1981). SIDS by definition states that after an autopsy the cause of death remains unexplained. If the idea that unexplainedness of a death causes prolonged grieving, then one would expect the parents of SIDS infants to grieve longer than parents whose babies die of explainable causes (e.g. infections, car accidents, etc.).

The third concept involves preventability of the death. If the parent believes their baby's death could have been prevented, the grief resolution process will be prolonged (Bugin, 1977). This should be true whether the death was explained (e.g. car accidents, infections or congenital anomalies) or whether it is an unexplained death (SIDS).

This study explored the relationship between grief resolution, unexplainedness and preventability. SIDS parents and nonSIDS parents

were asked if they believed their baby's death was preventable. The scores of these two groups--preventable and unpreventable--were compared to determine the role that perceived preventability plays in the grief resolution process. The unexplained deaths (SIDS) and the explained deaths group scores were also compared to determine the role that unexplainedness plays in the grief resolution process.

#### Statement of the Problem

The specific problem investigated in this study was:

Do parents who lose babies from SIDS have more behavioral sequelae 13 to 18 months after the death than parents who lose babies suddenly and unexpectedly for other reasons?

This study is a partial replication of "The Psychological Effects of SIDS on the Family" conducted in Baltimore, Maryland by Dr. Alfred Steinschneider to assess the behavioral sequelae of parents 13 months after the death of their infant. However, this study compares the behavioral sequelae of parents whose baby died from SIDS 13 to 18 months after the death with the behavioral sequelae of parents whose baby died unexpectedly for other reasons.

#### Hypothesis

The following hypotheses will be tested in this study:

1. Parents who believe their baby's death was preventable will exhibit more anxiety, depression, hostility, psychotic behavior and life changes than parents who believe their baby's death was not preventable.
2. SIDS parents will experience higher levels of anxiety, depression, psychotic behavior and life changes than parents who experience non-SIDS infant deaths.

3. The cause of the infant's death will have less effect on the dependent variables than the parent's perception of whether or not the death was preventable.

#### Operational Definitions

The following operational definitions were used for the purposes of this study:

1. SIDS deaths: Infants who died between one week and one year of age with Sudden Infant Death Syndrome stated as the cause of death on the death certificate. These were considered unexplained deaths.
2. Other sudden and unexpected deaths: Infants who died between one week and one year of age who were healthy, normal infants.
3. Preventable deaths: Deaths of infants whose parents believe their baby's death was preventable and respond accordingly on the questionnaire.

## CHAPTER II

### METHODS

#### Setting and Sample

Oregon is a rural state with a population of 2.7 million and has an average of 42,000 live births per year. There are approximately 110 SIDS cases each year in Oregon and approximately 67 other infant deaths over 7 days of age in Oregon yearly. Of the 67 other infant deaths, approximately 45 are sudden and unexpected based on the reported cause of death.

The population for this study were parents who experienced a sudden and unexpected death of an infant in the State of Oregon. There were two groups of subjects studied: parents whose infant, age one week to one year, died of Sudden Infant Death Syndrome between November 1, 1982 and May 31, 1983; and parents whose infant, age one week to one year died unexpectedly from other causes between March 1, 1983 and August 31, 1983. During these time periods there were 58 SIDS cases and 27 other unexpected infant deaths.

#### Description of Subjects

Of the 58 SIDS cases, 25 families agreed to participate and of the 27 other infant deaths, 9 families agreed to participate. The demographics of the two groups are outlined in Table 1 and 2. The non-participants in the study were younger in age and less educated than the participants. Twelve (48%) of the SIDS parents attended a parent support group and two (22%) of the parents whose infants died of other causes reported attending a support group. Twenty-four (96%) of the SIDS families stated they were contacted by the Oregon SIDS Center or a public health nurse.

Of the 25 SIDS cases studied 17 fathers agreed to participate and 4 non-SIDS fathers participated in the study. Geographically the families were distributed across the state as would be expected by the population in a given area. The SIDS parents were located as follows: Portland areas (n=12), midWillamette Valley (n=9), Eastern Oregon (n=4). The non-SIDS parents were located in the Portland area (n=4), Eugene (n=1) and Southern Oregon (n=4).

The cause of death for the non-SIDS victims was varied. Congenital heart defect was the leading cause of death (n=5) with most of the parents reporting that their baby died during or shortly after open heart surgery. Other causes of death included meningitis (1), complications of pneumonia (2) and an accidental fall from a bed (1). One of the non-SIDS victims was with a baby-sitter at the time of death. At the time of the home visit and data collection four families had a subsequent child, one family was pregnant and one family had recently had a miscarriage.

The SIDS infants ranged in age from 20 days to 6 months with the average age being 3 months. There were 14 male infants and 11 female infants. Six of the SIDS infants died while with a baby-sitter. At the time of the home visit and data collection 10 families had a subsequent child and an additional 2 families were pregnant.

Table 1

Demographics of Subjects

<u>Mean</u>	<u>SIDS CASES</u> N=58		<u>OTHER DEATHS</u> N=27	
	<u>Participants</u> N=25	<u>Nonparticipants</u> N=33	<u>Participants</u> N=9	<u>Nonparticipants</u> N=18
Age of Parents:				
Mother	25.4	22.39	30.22	24.38
Father	33.24	27.00	32.20	30.28
Education:				
Mother	12.76	10.60	15.22	12.33
Father	16.92	11.37	14.25	12.92
Income:	\$18,000	not available	\$17,500	not available
Age of infant at death	2.8 mos.	3.4 mos.	3 mos.	3.4 mos.
Length of time since death	15.12	15.50	15.55	15.0



Table 2

Demographics of SubjectsSIDS CASE                      OTHER DEATHS

N=58

N=27

	<u>Participants</u>	<u>Nonparticipants</u>	<u>Participants</u>	<u>Nonparticipants</u>
	N=25	N=33	N=9	N=18
Subsequent child	10	not available	4	not available
Pregnant at time of data collection	2	"	1	"
Died at babysitters	6	"	1	"
Number who attended a parent support group	12	"	2	"

### Design

The design of this study was ex post facto. The cause of death and whether the parents perceived the death as preventable or not were treated as independent variables. Standardized test scores of depression, state anxiety, interpersonal sensitivity, somatization, obsessive-compulsive behavior, phobic anxiety, paranoid ideation, psychoticism and hostility were treated as dependent variables.

This study compared the functional relationships between each independent variable and the dependent variable as well as the relative influence of each independent variable on the dependent variables.

The study was approved by The Oregon Health Sciences University Human Subjects Review Committee and by The Oregon State Health Division's Human Subjects Review Committee. Human subjects were informed of their rights by use of a written consent form which they signed before participating in the study (Appendix A).

### Procedure

Because the SIDS and non-SIDS samples were obtained from different sources, different procedures were used for contacting each group. The names of the SIDS cases which occurred in Oregon between November 1, 1982 and May 31, 1983 were obtained from the Oregon SIDS Center. The Center's function is to provide information and counseling to SIDS parents and professionals. It is routinely notified of all SIDS cases by the Medical Examiners Office. Letters were mailed to 57 of the 58 parents whose infant's had died during the specified time period asking them to participate in the study (Appendix B). One family was not included in the study because they had just lost their second child to SIDS at the time of the mailing. There were 7 letters (12%) returned because the

family had moved and left no forwarding address. One week after the mailing, the families were contacted by telephone; if they agreed to participate in the study an appointment was made for a home visit. Only 29 families could be reached by telephone and 25 of these (86%) agreed to participate. The 21 families who could not be reached by telephone were mailed stamped post cards to return indicating whether or not they wished to participate. None of these 21 families responded.

A different procedure was necessary for contacting the non-SIDS cases since they were only accessible through the vital statistics office of the Oregon State Health Division which would not release names because of confidentiality. An employee of the vital statistics office mailed letters to these families, but no telephone follow-up was possible because the researcher was not allowed access to the names until the families agreed to participate. Letters were mailed to the 27 families in Oregon whose babies had died from reasons other than SIDS between March 1, 1983 and August 31, 1983 (Appendix C). These parents were asked to return a form if they wished to participate (Appendix D) and the returned forms were then given to the researcher. A telephone call was then made and an appointment set up for a home visit to collect data. Of the 27 letters sent, 6 (22%) were returned with no forwarding address and 9 (33%) were returned indicating agreement to participate.

#### Measurement Tools

Data for this investigation was collected through a series of questionnaires which the subjects completed in the researchers presence in their homes. The questionnaires administered included the Beck Depression scale, the Derogotis Brief Symptom Inventory, the Spielberger

State Anxiety Scale and a Recent Life Changes Questionnaire (Appendices E,F,G,H & I).

#### Measurement of the Independent Variable

The independent variables in this study were 1) the cause of death and 2) whether the parents perceived the infants' death as preventable or not. The cause of death was determined from the death certificate (Appendix J). In Oregon, state law requires that all infants believed to have died from SIDS be autopsied and requires the use of the term "Sudden Infant Death Syndrome" on the death certificate when after autopsy no other cause of death can be determined. The question of whether parents perceived the death as preventable or not was determined by their response to a specific question regarding this on the questionnaire.

Other sudden and unexpected deaths were determined by the cause of death listed on the death certificate. The death was considered sudden and unexpected for the purposes of this study if the infant was over one week of age at the time of death and the cause was the result of an accident, a sudden overwhelming illness, or a previously undiagnosed congenital anomaly.

#### Measurement of the Dependent Variables

This study measured nine dependent variables: depression, state anxiety, phobic anxiety, psychoticism, hostility, obsessive-compulsive behavior, somatization, personal sensitivity and paranoid ideation. The parents were asked to complete the three standardized questionnaires used in the Baltimore study: (Appendices E,F & G).

1. The Beck Depression Inventory (BDI) short form.

The variable measured with this tool is depression. The DBI consists of 13 items with the response alternatives defined by a 4-point

(0 to 3) ordered scale. The items each correspond to a specific manifestation of depression. The BDI takes approximately five minutes to complete and is scored by summing the individual responses. Higher scores indicate higher levels of depression. Split-half reliability (n=97) and the Spearman-Brown reliability coefficient of 0.93 have been obtained in standardization studies (Beck & Beck, 1972).

Validity of the BDI has been supported by comparing clinicians' ratings of patients with BDI scores. The BDI score correlated significantly with the clinicians ratings of depression--0.65, 0.61, and 0.66 (Beck & Beck, 1972).

Internal consistency has been evaluated by comparing item scores and total scores for each patient (n=200). Using the Kruskal-Wallis nonparametric Analysis of Variance of Ranks, all items were found to have a significant correlation with the total score (Beck & Beck, 1972).

## 2. The State-Trait Anxiety Inventory (STAI).

This tool is designed to measure the variable of anxiety. Two dimensions of anxiety can be measured: 1) State anxiety which examines the amount of anxiety an individual is experiencing at the time the STAI is administered and 2) Trait anxiety which examines the amount of anxiety an individual generally experiences. Only the A-state scale of this tool was used to measure the amount of anxiety the individual was experiencing at the time it was administered. The A-state scale takes approximately seven minutes to complete and consists of 20 statements with the response alternatives defined by a four point (1 to 4) scale. The STAI is scored by summing the response values printed on the scoring key for each item. Higher scores indicate higher levels of anxiety. In the original standardization procedure, Alpha coefficients were computed for the STAI

scales using K-R 20 as modified by Cronbach. These reliability coefficients ranged from .83 to .92 for A-state (Spielberger, Gorsuch, & Lushene, 1970).

### 3. Derogatis Brief Symptom Inventory (BSI)

Brief Symptom Inventory (BSI) is the brief form of the SCL-90-R (Derogatis, 1977). It is a 53-item self-report symptom inventory designed to measure current, psychological status along nine primary dimensions: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. There are an additional four items that are not subsumed under the primary dimensions, but are included because of their clinical importance. They are intended to be used descriptively (Derogatis & Melisaratos, 1983). Each item of the BSI is rated on a five point scale ranging from "not at all" to "extremely"; it takes approximately 10 minutes to complete. Higher scores indicate higher levels of the nine primary dimensions.

Correlations between the BSI and the SCL-90 have been calculated on a sample of 565 psychiatric patients; they range from .92 to .99 and support the validity of the BSI.

Validity of the Derogatis has also been supported by other studies. Concurrent validity has been demonstrated by contrasting dimension scores of the BSI with scores from the MMPI on a sample of 209 symptomatic volunteers. A principal component analysis was also done on a sample of 1,002 outpatient subjects. Only the 49 items comprising the nine symptom dimensions were used in the analysis. Seven of the nine hypothesized symptom constructs were reproduced with little or no disjuncture of items. The interpersonal sensitivity dimension, which contains only 4

items, did not stay together as a linear combination (Derogatis & Spencer, 1982).

Two types of reliability have been studied: internal consistency and test-retest. Internal consistency was established on a sample of 1,002 outpatients by using Cronbach's coefficient alpha. Alpha coefficients for all 9 dimensions ranged from a low of 0.71 to a high of 0.85. The stability coefficient on the test-retest ranged from a low of 0.68 to a high of 0.91 (Derogatis & Spencer, 1982).

Scoring is done by adding the raw scores of each item and dividing by the number of items in that dimension; this results in an average score for each dimension. The score is then converted to a standardized T-score using the normative scale.

#### Additional Data

During the home visit when the questionnaires were administered the researcher also collected demographic data to compare the characteristics of the samples with the characteristics of the target populations and the characteristics of the other samples reported in the literature and the Baltimore study. These data included parents' dates of birth, marital status, race, employment status, highest grade completed, and household composition (Appendix I).

Information was also collected regarding recent life changes. The major topics on this questionnaire included: health, work, home-life, personal and social and moves (Appendix E). The records from the SIDS office and vital statistics provided cause of death, date of death and age of child at death.

### Data Analysis

The demographic data was analyzed using both descriptive and inferential statistics. The two sample populations - SIDS parents and non-SIDS parents -- were compared by the t-test and chi square on their income, age, educational level, length of time since death and whether or not there was a subsequent child.

The t-test was also used to compare the mothers' mean scores on the psychometric measures with the fathers' mean scores on the same.

Each hypothesis was analyzed using the appropriate statistics:

1. Parents who believe their baby's death was preventable will exhibit more anxiety, depression, hostility, psychotic behavior and life changes than parents who believe their baby's death was not preventable.

In the analysis of hypothesis #1, a one-way analyses of variance was used in which perceived preventability was treated as the independent variable and the nine psychometric measures -- depression, state anxiety, phobic anxiety, somatization, interpersonal sensitivity, psychoticism, hostility, obsessive-compulsive behavior and paranoid ideation -- were treated as dependent variables. The non-SIDS fathers were excluded from this analysis because of the small number who participated (N=4).

2. SIDS parents will experience higher levels of anxiety, depression, psychotic behavior and life changes than parents who experience non-SIDS infant deaths.

In the analysis of hypothesis #2, the t-test was used to compare SIDS and non-SIDS parents' scores on the psychometric measures of the dependent variables listed above.

3. The cause of the infant's death will have less effect on the dependent variables than the parents' perception of whether or not the death was preventable.



In the analysis of hypotheses #3, the researcher intended to use an analysis of variance in which cause of death and perceived preventability were treated as independent variables and the nine psychometric measures were treated as dependent variables. If main effects of the independent variables were obtained, appropriate post hoc tests would have been employed after which the relative influence of each independent variable on the dependent variable would have been assessed.

## CHAPTER III

## Results and Discussion

This chapter is divided into four sections. The first three sections contain a description of the analysis and findings related to each hypothesis and the fourth section reports the additional data analysis.

Perceived Preventability

The first hypothesis was tested by a one-way analysis of variance. It was hypothesized that parents who perceived the infants' death as preventable would score higher on the dependent variables than those who did not. The one-way ANOVA did not support the hypothesis and did not reveal a statistically significant difference between the groups of parents. Table 3 describes how the parents answered the perceived preventability question. Some of the comments from the parents who did not know if it was preventable were: "I wasn't there", "maybe", and "I don't know, monitoring might have helped".

Table 4 describes the SIDS mothers' mean scores on the measurements of the dependent variables according to their perceived preventability. While the one-way ANOVA did not show a statistical difference between the three groups ( $p < .05$ ), Table 4 depicts a clear pattern of scores. The mothers who believed their baby's death was not preventable consistently scored lower than the other two groups on all nine dependent variables. The group of mothers that consistently scored highest were those who "didn't know" if their baby's death was preventable.

Table 3

## Parents Perceived Preventability of Their Infant's Death

Perceived Preventability	Cause of Death				Total
	<u>SIDS</u>		<u>NON-SIDS</u>		
	<u>Mothers</u>	<u>Fathers</u>	<u>Mothers</u>	<u>Fathers</u>	
No	11 (44%)	6 (35%)	6 (66%)	3 (75%)	26 (47%)
Yes	6 (24%)	4 (24%)	3 (34%)	1 (25%)	14 (25%)
Don't Know	8 (32%)	7 (41%)	0	0	15 (28%)
Total	25	17	9	4	55

Table 4

The Effect of SIDS Mothers' Perceived Preventability on the Dependent Variables (N=25)

Dependent Variables Measurement Tools	Perceived Preventability					
	No (N=11)		Yes (N=6)		Don't Know (N=8)	
	X	SD	X	SD	X	SD
1. Beck Depression Score	4.72	3.25	6.00	2.75	9.50	8.15
2. Speilberger State-Trait Anxiety Score	41.36	10.93	42.5	9.13	46.12	16.53
3. BSI Subscales						
Somatization	.33	.37	.76	.80	.57	.51
Obsessive-Compulsive	1.00	.52	1.30	.62	1.39	1.23
Interpersonal Sensitivity	.93	.80	1.04	.42	1.07	1.27
Depression	.67	.54	1.17	1.03	1.03	1.18
Anxiety	.76	.58	1.10	1.00	1.30	1.24
Hostility	.68	.67	1.08	.69	.92	.92
Phobic Anxiety	.39	.44	.60	.63	.58	.88
Paranoid Ideation	.57	.51	.56	.45	.92	1.20
Psychoticism	.57	.55	.77	.52	.92	1.10

\* No statistical difference ( $p < .05$ ) between the three groups.

Table 5 describes the SIDS fathers' mean scores and perceived preventability. In this case the fathers who believed the death was preventable scored consistently higher than the fathers who did not think the death was preventable or who did not know.

Table 6 describes the non-SIDS mothers' mean scores on the measurements of the dependent variables according to their perceived preventability. The non-SIDS mothers did not score lower when they felt the death was not preventable. The pattern described in the SIDS mothers was not present in the non-SIDS mothers. The small number (9) could certainly account for the difference in the two groups.

#### Cause of Death

The second hypothesis was tested by a t-test to investigate the difference between SIDS and non-SIDS parents. [Only the mothers' responses were used in the analysis since only 62% of the fathers chose to participate]. It was hypothesized that the SIDS mothers would score higher on the measures of the dependent variables than the non-SIDS mothers because the SIDS deaths were unexplained. The t-test did not reveal a statistically significant difference between the two groups of mothers; the hypothesis was not supported.

Table 7 outlines the mean scores and standard deviations of the two groups -- SIDS mothers and non-SIDS mothers.

#### Parents Response by Cause of Death and Perceived Preventability

To test the third hypothesis the ANOVA was used. It was hypothesized that perceived preventability would account for the greatest variance in the dependent variables. However, the obtained sample size was too small to use inferential statistics appropriately.

Table 5

The Effect of SIDS Fathers' Perceived Preventability on the Dependent Variables (N=17)

Dependent Variables	Perceived Preventability					
	No (N=6)		Yes (N=4)		Don't Know (N=7)	
	<u>X</u>	<u>SD</u>	<u>X</u>	<u>SD</u>	<u>X</u>	<u>SD</u>
1. Beck Depression Score	3.5	5.0	3.50	4.72	2.28	2.36
2. Speilberger State-Trait Anxiety Score	39	13.5	46	20	34	8.4
3. BSI Subscales						
Somatization	.14	.34	.61	.55	.05	.11
Obsessive-Compulsive	.62	.93	.95	.73	.74	.72
Interpersonal Sensitivity	.63	.72	.31	.35	.51	.55
Depression	.34	.54	.43	.47	.50	.82
Anxiety	.67	.91	.78	1.09	.30	.35
Hostility	.72	.89	.99	.90	.25	.19
Phobic Anxiety	.20	.41	.34	.65	.32	.30
Paranoid Ideation	.32	.53	.47	.83	.44	.45
Psychoticism	.08	.17	.41	.50	.49	.52

\* No statistical difference ( $p < .05$ ) between the three groups.

Table 6

The Effect of SIDS Mothers' Perceived Preventability on the Dependent Variables (N=9)

Dependent Variables	Perceived Preventability			
	No (N=6)		Yes (N=3)	
	X	SD	X	SD
1. Beck Depression Score	7.0	4.1	6.6	6.4
2. Speilberger State-Trait Anxiety Score	48.16	15.23	43.33	6.22
3. BSI Subscales				
Somatization	0.46	.57	0.84	.68
Obsessive-Compulsive	1.31	.53	1.56	.90
Interpersonal Sensitivity	1.07	.66	.85	1.03
Depression	1.67	.98	1.31	.67
Anxiety	1.56	1.11	1.62	1.61
Hostility	1.20	.66	1.40	1.52
Phobic Anxiety	0.65	.54	0.58	1.01
Paranoid Ideation	0.62	.50	0.70	.74
Psychoticism	0.87	.56	0.97	1.16

\* No statistical difference ( $p < .05$ ) between the three groups.

Table 7

Mean and Standard Deviation of SIDS and Non-SIDS Mothers on Measures of the Dependent Variables

Dependent Variables	SIDS Mothers (N=25)		Non-SIDS Mothers (N=9)		t Value	Significance of t
	X	SD	X	SD		
1. Beck Depression Score	6.56	5.47	6.88	4.59	-0.16	NS
2. Speilberger State-Trait Anxiety Scale	43.16	12.31	46.55	13.91	-0.69	NS
3. Derogatis					-0.35	NS
Somatization	.51	.55	.58	.59	-0.63	NS
Obsessive-Compulsive	1.20	.70	1.19	.54	.01	NS
Interpersonal Sensitivity	1.00	.88	1.00	.74	-1.86	.07
Depression	.91	.89	1.55	.85	-1.45	.15
Anxiety	1.02	.93	1.58	1.19	-1.33	NS
Hostility	.85	.75	1.26	.93	-0.48	NS
Phobic Anxiety	.51	.53	.63	.67	-0.11	NS
Paranoid Ideation	.68	.77	.65	.55	-0.58	NS
Psychotocism	.73	.75	.90	.74		



The F significance levels ranged from 0.07 to 0.96. While none of the findings were of statistical significance there was a trend for perceived preventability to be associated with higher scores on the Beck Depression scale and the somatization and paranoid ideation subscales of the BSI. The cause of death was significant at the  $p < .07$  level on the BSI depression subscale. Because of the violation of the law of homogeneity of variance and the small sample size of non-SIDS deaths, no further analyses were performed.

#### Additional Analysis

##### Recent Life Changes

The Recent Life Changes questionnaire was examined by frequencies to determine if the two groups experienced similar changes after the death. It was observed that the changes were very similar in the two groups. Some of the more common changes were:

	<u>SIDS FAMILIES</u>	<u>NON-SIDS FAMILIES</u>
Fewer family get-togethers	44%	24%
More arguments with spouse	25%	52%
More problems on the job	37%	36%
Experienced pregnancy	50%	88%
Fewer social activities	52%	52%
Increased smoking	40%	56%
Moved	64%	55%

The above reported changes are consistent with the literature on SIDS that describes what bereaved parents experience. The literature also mentions that many families divorce after a major crisis. The two couples in this study that did divorce after the death both stated that they would have divorced anyway. There were 3 other couples in the study

who were separated and directly attributed their marital problems to the death of their infant.

#### BSI Additional Items

The 4 additional items not subsumed in the 9 subscales of the BSI were examined descriptively. The four items were poor appetite, trouble falling asleep, thoughts of death or dying, and feelings of guilt. The mothers in both groups scored higher than the fathers (Table 8). Feelings of guilt, as the literature suggests would be "universal", were not an overwhelmingly reported symptom. The mean of both groups of mothers was the same.

#### General Discussion of Findings

When considered as a whole, some general themes and trends emerge from the data. First, the two groups of parents' scores were similar and the SIDS parents did not score consistently higher. In fact, the non-SIDS mothers scored slightly higher on 9 of the 11 dimensions.

The mothers scored consistently higher than the fathers supporting the literature's view that men and women grieve differently. However, women in our culture consistently report significantly greater numbers of psychological symptoms than do men (Derogatis & Spencer, 1982).

The parents perceived preventability may have played a role in the grief process. The parents who thought it was preventable and the parents who "didn't know" scored consistently higher than parents who reported it was not preventable. While it was not statistically significant, the pattern and trend that emerged should be of interest to clinician and future researchers.

Table 8

## BSI Additional Items Mean Scores of Parents

BSI Additional Items	SIDS Group				Non-SIDS Group			
	Mothers (N=25)		Fathers (N=17)		Mothers (n=9)		Fathers (N=4)	
	<u>X</u>	<u>SD</u>	<u>X</u>	<u>SD</u>	<u>X</u>	<u>SD</u>	<u>X</u>	<u>SD</u>
11. Poor Appetite	.80	1.18	.29	.77	1.11	1.69	.50	.57
12. Trouble Falling Asleep	1.08	1.28	.58	1.00	1.44	1.65	1.25	1.0
13. Thoughts of Death or Dying	1.16	1.31	.82	1.01	1.22	1.30	1.75	2.06
14. Feelings of Guilt	1.12	1.30	.52	.87	1.00	1.50	1.00	1.41

The SIDS parents participated in parent support groups more than the non-SIDS parents. The SIDS parents were also contacted by the SIDS center and/or a public health nurse shortly after the death. Perhaps if the non-SIDS parents had also been involved in parent support groups or had early intervention their scores would have been lower than reported. During the home visits the non-SIDS parents more often expressed concern about the normalcy of their grief process than the SIDS parents. Many of the non-SIDS parents also expressed a desire to be involved in a support group.

#### Limitation of the Study

Many limitations of this study have already been discussed in earlier sections. They include the small and unequal sample size, the volunteer-nonrandom sample of subjects and the difference in the use of support groups by the subjects.

The sample size was limited by many factors. First of all, the number of SIDS cases each year is almost three times the number of other sudden infant deaths in Oregon. Since the families were not contacted until at least one year after the infant death, many of them had moved, further limiting the available population. This study illustrates that telephoning nonrespondents increases the sample size; unfortunately this could be done for only the SIDS group.

It is not possible to generalize the results of this study to the general population because of the self-selection of volunteers and the limited sample size.

## CHAPTER IV

## Summary, Conclusions and Recommendations and Implications for Nursing

Summary

The immediate devastation a family experiences after an infant death is clearly documented in the literature and an infant death from SIDS is described as the most devastating because a "normal, healthy infant" dies unexplainedly. Federal funding earmarked for providing information and counseling for SIDS families has resulted in a network of support groups and bereavement follow up that is not in place for parents who lose babies for other reasons. The purpose of this study was to describe the differences between SIDS and non-SIDS parents and to examine the role perceived preventability plays in the grief process.

This study was a partial replication of an unpublished study conducted in Baltimore, Maryland on "The Psychological Effects of SIDS on the Family". The same standardized tools were used, as well as the same method of data collection. However, the Baltimore study compared SIDS parents with parents with living babies and this study compared two groups of parents who had lost infants -- SIDS and other unexplained deaths.

The sample sizes were small with 25 SIDS families participating and 9 non-SIDS families. Data were collected from the parents by means of a structured home visit and the completion of standardized questionnaire. The home visits were conducted 13 to 18 months after the infant's death. The following hypotheses were tested in the study.

1. Parents who believe their baby's death was preventable will exhibit more anxiety, depression, hostility, psychotic behavior and life changes than parents who believe their baby's death was not preventable.
2. SIDS parents will experience higher levels of anxiety, depression, psychotic behavior and life changes than parents who experience non-SIDS infant deaths.
3. The difference between the functional levels of parents whose babies die from SIDS and non-SIDS will be less than the difference between the functional levels of those parents who believe they could have prevented their baby's death and those who do not believe they could have prevented their baby's death.

The first hypothesis could not accurately be tested because of the small and unequal cell sizes. The second hypothesis was rejected because the parents who perceived the death as preventable did not score significantly higher than the parents who thought it was not preventable or did not know. However, the parents who perceived the death as preventable scored consistently higher on 9 of the 11 psychometric dimensions. The third hypothesis was also rejected because SIDS mothers did not score significantly higher than the non-SIDS mothers leaving one to believe that the explainedness of the death does not dictate the grief resolution process.

In general, the two groups of parents scored similarly on the dependent variables and were similar in demographic characteristics except for attending parents support groups. Women scored consistently higher than men on all of the psychometric dimensions tested.

### Conclusions

The following general conclusions can be drawn from this study. Parents who experience an infant death are still working toward grief resolution 13 to 18 months after the event. It appears that the cause of death does not significantly influence the grief process 13 to 18 months after the death. Parents who believe their baby's death was preventable will exhibit more behavioral sequelae than parents who believe the death was unpreventable. Also parents who "don't know" if the death was preventable will exhibit more anxiety and depression than parents who believe the death was unpreventable.

### Nursing Implications

The results of this study contribute to a broader knowledge base regarding the grief resolution process. While perceived preventability was not statistically significant, the trend was well documented that parents who perceived the death as preventable experienced more anxiety, depression, hostility, etc. Nurses can use the preventability variable as part of their assessment when working with a bereaved parent. This information may help nurses target families who need additional support and specific services.

While the results of this study cannot be generalized, decision makers should consider broadening resources to provide intervention for all families that lose a baby suddenly and unexpectedly.

### Recommendations

The findings and content of this study suggest a number of recommendations for further research:

- 1) The study should be replicated with larger and equal sample sizes in order to generalize the findings to other populations.

- 2) A longitudinal replication needs to be conducted with the instruments administered at several different times during the grief process to establish trends.
- 3) The difference between the grief process of mothers and fathers needs to be further explored to identify factors that may contribute to the difference in the grief process.
- 4) There is a need for research that would measure the effect of parents' involvement in formal support groups.
- 5) Further research needs to be conducted that would explore not only the parents beliefs about preventability but who the parents felt could have prevented the death. Perhaps a tool that measured perceived preventability would establish a more accurate description.



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APPENDICES

Appendix A  
Informed Consent

# THE OREGON HEALTH SCIENCES UNIVERSITY

School of Nursing  
Department of  
Family Nursing

3181 S.W. Sam Jackson Park Road Portland Oregon 97201 (503) 225-8382

## Informed Consent Form

I, \_\_\_\_\_  
(First Name) (Middle Name) (Last Name)

agree to serve as a subject in the investigation named, The Functional Level of Parents Who Experience a Sudden and Unexpected Infant Death 13 to 16 Months After the Event, by JoAline Olson, R.N.,P.N.P. under the direction of Marie Brown, Ph.D. The purpose of this investigation is to determine the functional level of parents 13 to 16 months after the death of their infant.

I understand that I will be visited by JoAline Olson, R.N.,P.N.P. in my home and that I will be asked to complete 4 short questionnaires which will take approximately one hour. I understand that all information obtained will be kept confidential and that a code system will be established to maintain my anonymity. Information will be reported in ways that will not identify me with my specific answers.

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 parents who lose babies suddenly and unexpectedly so that future intervention with families will be more effective.

JoAline Olson, 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) 259-1544.

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.

"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 occurred 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."

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

Date: \_\_\_\_\_ Signature: \_\_\_\_\_

Witness: \_\_\_\_\_



Appendix B  
Letter to SIDS Parents



## THE OREGON HEALTH SCIENCES UNIVERSITY

School of Nursing  
Department of  
Family Nursing

3181 S.W. Sam Jackson Park Road Portland, Oregon 97201 (503) 225-6382

## LETTER TO SIDS PARENTS

March 12, 1984

Dear

For the past 7 years, I have been working as a nurse with families who have had a baby die from Sudden Infant Death Syndrome. I have been concerned about how little we as health professionals know about how to help these families. Because of these concerns I have decided to choose this topic as a research project for my thesis. This thesis is the last requirement for my Masters Degree in Nursing, and I am glad to have the opportunity to investigate this problem as part of my education.

Because of your experience with the loss of (name of infant), I am hoping you will be willing to help me in this study. I feel that we as nurses will be able to work more effectively to help families of babies who have died from Sudden Infant Death if we can find out more about this experience directly from the families themselves.

I will be calling you in the next week or so to see whether you feel you would be willing to help in this project. If you are, I will be asking you to spend about an hour filling out a set of questionnaires about your experiences and feelings since the death of (name of baby). I would be grateful for any information you are willing to share and can assure you that this information will remain anonymous. You will never be identified by name in any publication or in any other way.

I will be calling you soon, and hope you will decide to help me in this study. Thank you for your time.

With Best Regards,

JoAline Olson, R.N., P.N.P.



Appendix C

Letter to Families non-SIDS Deaths

*Department of Human Resources*  
**HEALTH DIVISION**

1400 S.W. 5th AVENUE, PORTLAND, OREGON 97201 PHONE

July 30, 1984

Dear Parents:

We have received a request from a nurse conducting a research study for names of parents who have lost babies suddenly and unexpectedly. This nurse has had years of experience working with parents and families who have lost babies and is concerned with how little health professionals know about what families experience after such a tragedy.

The Oregon State Health Division feels that this research is important. The results will enable health professionals to work more effectively with other parents in the future. The study involves filling out a set of questionnaires about your experiences and feelings since your baby died. It would take about an hour of your time and all information would remain confidential.

If you would be interested in participating in the study please fill out the attached letter and return in the enclosed envelope. The nurse researcher will contact you after you return this letter. The files and names in the Vital Statistics records are confidential. If we do not hear from you your name will not be released to the researcher.

Please feel free to call us if you have any concerns before releasing your name to the researcher. Call Joyce Grant-Worley, 229-6123. Ms. Worley is the chief research analyst for the Oregon Vital Statistics Section and will be responsible for release of names of voluntary participants.

Sincerely yours,

Joseph D. Carney, Manager  
 Oregon Center for Health Statistics

JDC:mh

AN EQUAL OPPORTUNITY EMPLOYER

Mailing Address: P.O. Box 231, Portland, Oregon 97207  
 EMERGENCY PHONE (503) 229-5599

Appendix D

Return Form Acceptance of Participation



VICTOR ATIYEH  
GOVERNOR

*Department of Human Resources*

## HEALTH DIVISION

1400 S.W. 5th AVENUE, PORTLAND, OREGON 97201 PHONE

### VOLUNTARY RELEASE OF NAME

I would like to participate in the nursing research study.  
The nurse may contact me at the address and phone number  
below:

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY, STATE \_\_\_\_\_

CURRENT PHONE # \_\_\_\_\_

SIGNATURES \_\_\_\_\_

\_\_\_\_\_

DATE \_\_\_\_\_

AN EQUAL OPPORTUNITY EMPLOYER

Mailing Address: P.O. Box 231, Portland, Oregon 97207  
EMERGENCY PHONE (503) 229-5599

Appendix E

Beck

Date:                 
Mo. Day Yr.

ID# \_\_\_\_\_

Phase:  $\frac{1}{A}$   $\frac{2}{C}$   $\frac{3}{F}$

Respondent  $\frac{1}{Mo.}$   $\frac{2}{Fa.}$

INSTRUCTIONS

This is a questionnaire. On the questionnaire are groups of statements. Please read the entire group of statements in each category. Then pick out the one statement in that group which best describes the way you feel today, that is, right now! Circle the number beside the statement you have chosen. If several statements in the group seem to apply equally well, circle each one.

- 1. 0 I do not feel sad  
1 I feel sad or blue  
2 I am blue or sad all the time and I can't snap out of it  
3 I am so sad or unhappy that I can't stand it
  
- 2. 0 I am not particularly pessimistic or discouraged about the future  
1 I feel discouraged about the future  
2 I feel I have nothing to look forward to  
3 I feel that the future is hopeless and that things cannot improve
  
- 3. 0 I do not feel like a failure  
1 I feel I have failed more than the average person  
2 As I look back on my life, all I can see is a lot of failures  
3 I feel I am a complete failure as a person (parent, husband, wife)
  
- 4. 0 I am not particularly dissatisfied  
1 I don't enjoy things the way I used to  
2 I don't get satisfaction out of anything anymore  
3 I am dissatisfied with everything
  
- 5. 0 I don't feel particularly guilty  
1 I feel bad or unworthy a good part of the time  
2 I feel quite guilty  
3 I feel as though I am very bad or worthless
  
- 6. 0 I don't feel disappointed in myself  
1 I am disappointed in myself  
2 I am disgusted with myself  
3 I hate myself
  
- 7. 0 I don't have any thoughts of harming myself  
1 I feel I would be better off dead  
2 I have definite plans about committing suicide  
3 I would kill myself if I had the chance
  
- 8. 0 I have not lost interest in other people  
1 I am less interested in other people than I used to be  
2 I have lost most of my interest in other people and have little feeling for them  
3 I have lost all of my interest in other people and don't care about them at all





Appendix F  
Stait-Trait Anxiety

# SELF-EVALUATION QUESTIONNAIRE

Phase:  $\frac{1}{\text{A}}$   $\frac{2}{\text{C}}$   $\frac{3}{\text{F}}$

Developed by C. D. Spielberger, R. L. Gorsuch and R. Lushene

## STAI FORM X-1

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *feel* right now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO	
1. I feel calm .....	①	②	③	④	_____
2. I feel secure .....	①	②	③	④	_____
3. I am tense .....	①	②	③	④	_____
4. I am regretful .....	①	②	③	④	_____
5. I feel at ease .....	①	②	③	④	_____
6. I feel upset .....	①	②	③	④	_____
7. I am presently worrying over possible misfortunes .....	①	②	③	④	_____
8. I feel rested .....	①	②	③	④	_____
9. I feel anxious .....	①	②	③	④	_____
10. I feel comfortable .....	①	②	③	④	_____
11. I feel self-confident .....	①	②	③	④	_____
12. I feel nervous .....	①	②	③	④	_____
13. I am jittery .....	①	②	③	④	_____
14. I feel "high strung" .....	①	②	③	④	_____
15. I am relaxed .....	①	②	③	④	_____
16. I feel content .....	①	②	③	④	_____
17. I am worried .....	①	②	③	④	_____
18. I feel over-excited and "rattled" .....	①	②	③	④	_____
19. I feel joyful .....	①	②	③	④	_____
20. I feel pleasant .....	①	②	③	④	_____



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577 College Avenue, Palo Alto, California 94306

Appendix G

Derogatis

**INSTRUCTIONS:**

Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please fill in one of the numbered circles to the right that best describes HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST WEEK INCLUDING TODAY. Mark only one numbered circle for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask the technician.

**SEX**

MALE

FEMALE

NAME: \_\_\_\_\_

LOCATION: \_\_\_\_\_

EDUCATION: \_\_\_\_\_

MARITAL STATUS: MAR. \_\_\_ SEP. \_\_\_ DIV. \_\_\_ WID. \_\_\_ SING. \_\_\_

DATE		
MO	DAY	YEAR

ID. NUMBER

AGE

**EXAMPLE**

HOW MUCH WERE YOU DISTRESSED BY:

NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY

1. Bodyaches

0	1	2	3	4
---	---	---	---	---

VISIT NUMBER: \_\_\_\_\_

**HOW MUCH WERE YOU DISTRESSED BY:**

NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
------------	--------------	------------	-------------	-----------

1. Nervousness or shakiness inside	1	0	1	2	3	4
2. Faintness or dizziness	2	0	1	2	3	4
3. The idea that someone else can control your thoughts	3	0	1	2	3	4
4. Feeling others are to blame for most of your troubles	4	0	1	2	3	4
5. Trouble remembering things	5	0	1	2	3	4
6. Feeling easily annoyed or irritated	6	0	1	2	3	4
7. Pains in heart or chest	7	0	1	2	3	4
8. Feeling afraid in open spaces	8	0	1	2	3	4
9. Thoughts of ending your life	9	0	1	2	3	4
10. Feeling that most people cannot be trusted	10	0	1	2	3	4
11. Poor appetite	11	0	1	2	3	4
12. Suddenly scared for no reason	12	0	1	2	3	4
13. Temper outbursts that you could not control	13	0	1	2	3	4
14. Feeling lonely even when you are with people	14	0	1	2	3	4
15. Feeling blocked in getting things done	15	0	1	2	3	4
16. Feeling lonely	16	0	1	2	3	4
17. Feeling blue	17	0	1	2	3	4
18. Feeling no interest in things	18	0	1	2	3	4
19. Feeling fearful	19	0	1	2	3	4
20. Your feelings being easily hurt	20	0	1	2	3	4
21. Feeling that people are unfriendly or dislike you	21	0	1	2	3	4
22. Feeling inferior to others	22	0	1	2	3	4
23. Nausea or upset stomach	23	0	1	2	3	4
24. Feeling that you are watched or talked about by others	24	0	1	2	3	4
25. Trouble falling asleep	25	0	1	2	3	4
26. Having to check and double check what you do	26	0	1	2	3	4
27. Difficulty making decisions	27	0	1	2	3	4
28. Feeling afraid to travel on buses, subways, or trains	28	0	1	2	3	4
29. Trouble getting your breath	29	0	1	2	3	4
30. Hot or cold spells	30	0	1	2	3	4
31. Having to avoid certain things, places, or activities because they frighten you	31	0	1	2	3	4
32. Your mind going blank	32	0	1	2	3	4
33. Numbness or tingling in parts of your body	33	0	1	2	3	4
34. The idea that you should be punished for your sins	34	0	1	2	3	4
35. Feeling hopeless about the future	35	0	1	2	3	4

Appendix H  
Recent Life Changes



D. Personal and Social

Since the death of your baby have experienced:

- |   |    |     |
|---|----|-----|
| 16. becoming pregnant?  | No | Yes |
| 17. having a miscarriage or abortion?   | No | Yes |
| 18. problems with sex?  | No | Yes |
| 19. quitting school or college?   | No | Yes |
| 20. adopting any children or taking in foster care children?                        | No | Yes |
| 21. a minor violation of the law?   | No | Yes |
| 22. fewer social activities (clubs, movies, visiting)?                              | No | Yes |
| 23. legal trouble resulting in your being held in jail?                             | No | Yes |
| 24. girlfriend or boyfriend problems?   | No | Yes |
| 25. a "falling out" of a close personal relationship (other than a sexual partner)? | No | Yes |
| 26. family problems?  | No | Yes |
| 27. more use of alcohol?  | No | Yes |
| 28. more use of drugs?  | No | Yes |
| 29. more smoking?   | No | Yes |
| 30. a major change in finances?   | No | Yes |

E. Moves

Since the death of your baby how many moves have you made:

- |  |       |
|--|-------|
| 31. within the same city or town?        | _____ |
| 32. to a different city, town, or state? | _____ |

This last question involves feelings about the cause of your baby's death. Any information you can share will be helpful.

- |  |    |     |
|--|----|-----|
| 33. Do you feel your baby's death could have been prevented? | No | Yes |
|--|----|-----|

Please explain:

Appendix I  
Demographic Data Collection



DEMOGRAPHIC

Race: \_\_\_\_\_

Date:              
 mo dy yr

Group: \_\_\_\_\_

ID# \_\_\_\_\_

1. Interviewee: 1 2 3  
 Mo. Fa. Both

2. Date of Birth:              
 Mo. Day Yr.

3. Working:          
 no yes

4. Hours per week \_\_\_\_\_

5. Highest grade completed in school \_\_\_\_\_

6. Student now          
 No Yes

7. Part time or Full Time          
 Pt Ft

8. House Composition

<u>Name</u>	<u>Age (yrs)</u>	<u>Sex (1=F, 2=M)</u>	<u>Relationship to infant</u>
(Interviewee)	— —	—	—
_____	— —	—	—
_____	— —	—	—
_____	— —	—	—
_____	— —	—	—
_____	— —	—	—

9. Yearly household income: Less than \$10,000 \_\_\_\_\_  
 10,000 to \$15,000 \_\_\_\_\_  
 15,000 to \$20,000 \_\_\_\_\_  
 20,000 to \$25,000 \_\_\_\_\_  
 25,000 to \$30,000 \_\_\_\_\_  
 30,000 to \$35,000 \_\_\_\_\_  
 35,000 to \$40,000 \_\_\_\_\_  
 40,000 to \$50,000 \_\_\_\_\_  
 50,000 plus \_\_\_\_\_

10. Average sleep pre-pregnancy (hrs) \_\_\_\_\_

OTHER PARENT

ID# \_\_\_\_\_

11. Date of Birth:              
 Mo. Day Yr.

12. Working:              
 No yes dk



Appendix J

Copy of Death Certificate

STATE OF OREGON  
 OREGON STATE HEALTH DIVISION  
 DEPARTMENT OF HUMAN RESOURCES  
**Vital Records Unit**  
**CERTIFICATE OF DEATH**

**SAMPLE**

TYPE OR PRINT IN PERMANENT BLACK INK FOR NOTATIONS & HANDBOOK

**DECEDENT**

IF DEATH OCCURRED IN INSTITUTION SEE HANDBOOK REGARDING COMPLETION OF RESIDENCE ITEMS

**DISPOSITION**

**CERTIFIER**

CONDITIONS IF ANY WHICH GAVE RISE TO IMMEDIATE CAUSE STATING THE UNDERLYING CAUSE LAST

**CAUSE OF DEATH**

Local File Number			State File Number		
DECEASED—NAME First Middle Last					DATE OF DEATH (month, day, year)
1 RACE (White, Black, American Indian, etc. (specify))	2 SEX	3 AGE—Last birthday (years)	4 Under 1 year (mos, days)	5 Under 1 day (hours, min)	6 DATE OF BIRTH (month, day, year)
7a CITY, TOWN OR LOCATION OF DEATH	7b HOSPITAL OR OTHER INSTITUTION—NAME (If not in either, give street and number)			7c IF HOSP OR INST indicate DOA OP, Emer, Rm, Inpatient (Specify)	7d COUNTY OF DEATH
8 STATE OF BIRTH (If not in U.S.A. name country)	9 CITIZEN OF WHAT COUNTRY	10 MARRIED, NEVER MARRIED, WIDOWED, DIVORCED (specify)	11 SPOUSE (IF MARRIED, WIDOWED)	12 WAS DECEDENT EVER IN U.S. ARMED FORCES? (Specify Yes or No)	
13 SOCIAL SECURITY NUMBER		14a USUAL OCCUPATION (give kind of work done during most of working life, even if retired)		14b KIND OF BUSINESS OR INDUSTRY	
15a RESIDENCE—STATE	15b COUNTY	15c CITY, TOWN, OR LOCATION	15d STREET AND NUMBER OR R.F.D., ZIP		15e Inside City Limits (specify yes or no)
16a FATHER—NAME (first, middle, last)		16b MOTHER—NAME (first, middle, last (Maiden Name))		16c INFORMANT—NAME and relationship to decedent	
17a BURIAL, CREMATION, REMOVAL, MAUS. (specify)		17b CEMETERY OR CREMATORY—NAME		17c LOCATION (city or town, state)	
18a FUNERAL SERVICE LICENSEE (Or Person Acting As Such (Signature))		18b NAME AND ADDRESS OF FACILITY			
19a To the best of my knowledge, death occurred at the time, date and place and due to the cause(s) stated		19b DATE SIGNED (Mo., Day, Yr.)		19c HOUR OF DEATH	
20a 21a (Signature) NAME AND ADDRESS OF CERTIFIER (Type or Print)		20b		20c M	
21d NAME OF ATTENDING PHYSICIAN IF OTHER THAN CERTIFIER (Type or Print)		21e			
22a DATE RECEIVED BY REGISTRAR (Mo., Day, Yr.)		22b REGISTRAR (Signature)			
23 IMMEDIATE CAUSE (ENTER ONLY ONE CAUSE PER LINE FOR (a), (b), AND (c).)					Interval between onset and death
PART I (a) DUE TO, OR AS A CONSEQUENCE OF:					Interval between onset and death
(b) DUE TO, OR AS A CONSEQUENCE OF:					Interval between onset and death
(c) DUE TO, OR AS A CONSEQUENCE OF:					Interval between onset and death
PART II OTHER SIGNIFICANT CONDITIONS—Conditions contributing to death but not related to cause given in PART I (a)			24 AUTOPSY (Specify Yes or No)	25 WAS MEDICAL EXAMINER NOTIFIED (Specify Yes or No)	
26a ACCIDENT (Specify Yes or No)	26b DATE OF INJURY (Mo., Day, Yr.)	26c HOUR OF INJURY	26d DESCRIBE HOW INJURY OCCURRED		
26e INJURY AT WORK (Specify Yes or No)	26f PLACE OF INJURY—At home, farm, street, factory, office building, etc. (Specify)		26g LOCATION	26h STREET OR R.F.D. NO.	26i CITY OR TOWN STATE
RESERVED FOR REGISTRAR'S USE					

ORIGINAL - VITAL STATISTICS COPY

AN ABSTRACT OF THE THESIS OF  
JOALINE GRUZENSKY OLSON, B.S.N., P.N.P.  
FOR THE MASTER OF NURSING

DATE RECEIVING THIS DEGREE: June, 1985

TITLE: THE FUNCTIONAL LEVEL OF PARENTS WHO EXPERIENCE A SUDDEN AND  
UNEXPLAINED INFANT DEATH 13 TO 18 MONTHS AFTER THE EVENT

APPROVED:

Marie Scott Brown, R.N., Ph.D.

THESIS ADVISOR

This ex post facto study explored the grief process of forty-two parents whose baby's died of Sudden Infant Death Syndrome with thirteen parents whose baby's died for other reasons to determine the relationship between cause of death, perceived preventability and grief resolution.

The cause of death and whether the parents perceived the death as preventable or not were treated as independent variables. Standardized test scores of depression, state anxiety, interpersonal sensitivity, somatization, obsessive-compulsive behavior, phobic anxiety, paranoid ideation, psychoticism and hostility were treated as dependent variables.

The SIDS parent sample size consisted of twenty-five mothers and seventeen fathers; the non-SIDS parent sample size consisted of nine mothers and four fathers. The families were geographically located in the State of Oregon and had experienced an infant death between November 1, 1982 and August 31, 1983. There were fifty-seven SIDS parents asked to participate and twenty-seven non-SIDS parents.

The data were collected by administering standardized psychological tests in the homes and having the parents complete a recent life changes questionnaire. The data took six months to collect.

The study revealed the following findings: the difference between the SIDS and non-SIDS parents' scores were not statistically significant and the SIDS parents did not score higher as expected; the mothers scored consistently higher than the fathers; the parents who thought the death was preventable and the parents who "didn't know" scored consistently higher than parents who reported the death as not preventable but the difference was not statistically significant.

It is not possible to generalize the results of this study to the general population because of self-selection of volunteers and a limited sample size. Other limiting factors include the unequal sample size and the difference in the use of support groups by subjects.

Implications for practice include: using the preventability variable as part of the assessment of the bereaved parent and broadening resources to provide intervention for all families that lose a baby suddenly and unexpectedly.