Maternal Perceptions of Sudden Infant Death Syndrome

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Abstract:
The purpose of the present study was to examine the maternal perceptions of the psychosocial sequelae regarding the loss of an infant to sudden infant death syndrome (SIDS) and the effectiveness of the informal and organized sources of support. Seventy-three mothers experiencing a SIDS death within a 3-year period responded to a questionnaire designed to obtain maternal perceptions of the experience. Results indicate that the death of the infant was viewed as a severe life crisis. However, the majority of the mothers reported increased marital supportiveness, increased emotional closeness to surviving children, and a generally satisfactory adjustment. Perceived emotional support was significantly related to the severity of maternal grief reactions. Although the majority of initial grief symptoms subsided, the data indicate that maternal grief reactions may be more extended than would have been predicted from previous literature. A significant number of mothers reported receiving sufficient informational and emotional support. However, one quarter of the respondents indicated that the support was inadequate. Few mothers contacted mental health professionals and, of those that did, their perception was that this contact was of little or no value. Implications for improved support by mental health professionals as well as directions for future research are discussed.

Article:
The sudden and unexpected death of an apparently healthy and thriving infant represents a tragedy for both the child and the families of the victims. In a recent study examining deaths in infants between the end of the fourth week of life and the end of the first year during a 17-year period from 1962 to 1978, sudden infant death syndrome (SIDS) emerged as the leading reported cause of postneonatal mortality (Khoury, Erickson, & Adams, 1984). The toll from this perplexing syndrome is approximately 8000 deaths a year, or one infant in every 350 live births during the first year of life. The peak incidence of death occurs between 2 and 4 months of age. Almost all deaths from SIDS occur during sleep. Medical autopsies reveal that the deaths appear to occur quietly without any evidence of distress. Although some 75 theories have been postulated as to the cause of SIDS, none has accounted for the disease satisfactorily. As with other forms of sudden and unexpected perinatal death, the parents' grief reaction is usually acute (Mandell & Belk, 1977), and they report this event as the most severe personal tragedy and family crisis they have ever experienced (Defrain & Ernst, 1978).

Of particular concern is the emotional sequelae of the death of a child due to SIDS for the surviving family members. Parental misunderstanding of the unknown causal factors in SIDS-related deaths may result in extreme guilt, and blame may be focused on the other parent, often resulting in subsequent marital difficulties (Cornwell, Murcombe, & Stevens, 1977). Indeed, the death of an infant appears to affect every aspect of family life (Miles, 1975).

The emotional Impact of the infant's death upon parents, particularly mothers, may be particularly devastating. Among the most common grief symptoms experienced by parents who have lost a child to SIDS are the
following fears, loss of appetite, inability to sleep, irritability, anger, preoccupation with thinking about the baby, and guilt (Benfield, Leib, & Vollman, 1978, Smialek, 1978). In one study of 32 families, parents required an average of 16 months to regain the level of personal happiness experienced before the infant's death (Defrain & Ernst, 1978). Because of the intense interdependency between mother and infant during the early postnatal period, mothers, in particular, are at high risk for pathological grief reactions after an infant's death. In one study of 26 mothers who had experienced a perinatal death, 23% were judged to have experienced morbid and prolonged grief reactions 12 to 20 months after the infant's death (Rowe, Clyman, Green, Mikkelsen, & Haight, 1978). Cullberg (1972) found that 19 out of 56 mothers studied 1 to 2 years after the deaths of their newborn infants had developed various psychiatric disorders. Whereas no such empirical data exist regarding the incidence of pathological grief reactions in the fathers of SIDS victims, there are indications that they also experience similar stages of grief (Cornwell et al., 1977).

Depending on the child's age, siblings may be burdened with remorse because of a belief that typical childhood sibling fantasies involving the new infant's death may have caused the event (Mandell & Belk, 1977). Parental response to the surviving children may vary and fluctuate between increased emotional distance and non-availability to intense protectiveness toward the remaining child or children. In addition, the parents' decision to have another child takes on new dimensions after the death of an infant due to SIDS. The subsequent child may be seen as a replacement for the lost infant, a process that has been shown to be associated with delayed resolution of grief and increased psychopathology in mothers (Benfield et al., 1978).

An unexplored area of research for families who experience the death of an infant to SIDS is the effectiveness of various sources of support for these families (e.g., spouse, extended family, friends, support groups of other parents experiencing a SIDS death, and a wide variety of medical, psychological, and social support services) (Rowe et al., 1978, Nicholaisen & Williams 1980). The apparent need for empirical research into this area is highlighted by the findings of Rowe et al., (1978) that mothers of SIDS victims never mentioned medical staff as a source of support. Moreover, they were critical of the lack of contact with their physician after their infant's death.

The present study was designed to obtain evaluative data on families who had experienced a SIDS death at some time during a 3-year period. Maternal perceptions of family adjustment as well as the perceived effectiveness of various sources of formal and informal support were examined.

**METHOD**

**Subjects**

An attempt was made to contact by mail each parent of a child whose death was attributed to SIDS in Oklahoma during the period of the study. All 317 families experiencing a neonatal death due to SIDS from January 1980 through December 1982 were mailed a questionnaire. With the inception of a federally sponsored information and counseling project and a prior 1974 commitment from the Office of the Chief Medical Examiner of the State of Oklahoma to identify and diagnose all SIDS cases, few if any SIDS deaths were undetected during this period. Of the 317 families, at least 75 were known not to have received the questionnaire as they had moved without a forwarding address. Of the remaining 242 families, 73 (or 31%) of the mothers completed and returned the questionnaire. A significantly smaller number of fathers ($n = 41$) returned the questionnaires and, of those that did, the questionnaires were often incomplete. Therefore, the data reported in the study are based entirely on maternal responses. Although it is unclear as to the reason the remaining families did not respond, there were no significant differences between responders and nonresponders on demographic variables based on SIDS project data. In addition, demographic data obtained on the present sample were similar to that reported in other studies investigating familial adjustment to SIDS (Defrain & Ernst, 1978, Rowe et al., 1978). Thus, given demographic similarities and the extreme mobility of this population that has been documented previously (Bergman, 1974, Rowe et al., 1978), it is felt that the present sample, though a small percentage, is representative of the total group.
The majority of the mothers (87%) were married at the time of the delivery of the baby, with 3% divorced and 10% single. Seventy percent of the married mothers had been married 2 or more years. The majority of the mothers (80%) were in the 21- to 30-year age group, with 9% in the 17- to 20-year age range and 11% in the 31- to 40-year age range. The majority of the mothers were white (75%), with 16% black, 3% American Indian, and 4% of Hispanic origin. Of the mothers responding, 35% were not employed outside of the home, while the remainder were generally evenly divided as to occupational status (blue collar, white collar, professional), educational level, and income. Similar socioeconomic status was reported for fathers who also responded to the question \( n = 41 \), with the exception of a slightly greater representation of blue collar occupations (66%).

Geographically, most of the families were evenly distributed among large towns (over 50,000), small towns (under 1,000), or moderately sized towns, with fewer families residing in rural areas.

Slightly more mothers smoked during their pregnancy than not (i.e., 52% versus 48%), and this increased somewhat after the baby's delivery (i.e., 57% versus 43%). Among the 39 fathers responding to this item, 59% smoked after the baby's birth. These figures are higher than the estimate reported by the U.S. Public Health Service that 40% of the general population smoked during the 10-year period from 1964 to 1975 (U.S. Public Health Service, 1979). Reports of alcohol consumption indicated that 58% of the mothers consumed no alcohol during their pregnancy, whereas 6% admitted to weekly alcohol consumption. Twenty-six percent of the mothers indicated that they took some type of medication during their pregnancy whereas 74% reported taking no medication.

Fifty-four percent of the infants who died from SIDS were male. The majority (84%) died within the first 6 months of life with the most frequent ages of death being 2 months (27%) and 4 months (23%). Approximately 80% of the infants weighed more than 88 ounces at birth. Sixty-eight percent had a gestational age of 38 to 42 weeks, with 23% less than 38 weeks. Only one infant was the result of a multiple (twin) birth. Thirty-three percent of the SIDS infants were the first born in their family, another 33% second born, 14% third born, and 14% fourth born. Length of hospital stay after delivery was generally short (e.g., 3 days or less) for 70% of the infants, with only 45% requiring hospitalization for greater than 2 weeks. Consistent with previous research, the majority of mothers did not perceive their infant as abnormal before the SIDS death. This was indicated by the fact that relatively few of the respondents noted abnormalities related to the baby's cry (16%), movements (13%), or breathing (18%) or the necessity of resuscitative efforts (4%).

Materials
The data used in this study were obtained from a 113-item questionnaire mailed to parents who had lost an infant to SIDS 6 months to 25 years previously. This questionnaire was modeled after questionnaires used in previous studies that were found to be a satisfactory instrument in measuring parental and family grief reactions with this population (Benfield et al., 1978, Defrain & Ernst, 1978). The majority of the items utilized a 5-point Liken scale format. In addition, several open-ended and multiple choice items were included where this was the most appropriate response format. The questionnaire was designed to obtain parental perceptions in the following areas marital and family stress, mobility, relationship with surviving children, perceptions of siblings' grief reactions, maternal emotional and physical symptoms (both initially and during the more extended adjustment period), and the effect of the death on decision to have subsequent children. Also evaluated were maternal perceptions and satisfaction with social support services received from professionals, other SIDS parents, families, and friends. Mothers were asked to reflect on their subjective experiences during the first few days after the death as well as their current perceptions at least 6 months after the death.

RESULTS
Maternal Evaluation of Social Support
Perceived emotional support or lack of it was related to the reported severity of mothers' grief symptoms initially and several months later. For the purposes of the present study, social support was defined as the respondents' ratings on a Liken-type scale of the degree of helpfulness and satisfaction experienced from the contacts provided to the mothers through the Oklahoma SIDS project. A significant number (78%) of the families in the present study indicated that they received sufficient emotional support \[ \chi^2, df(1) = 12.87, p \leq \]
Univariate analyses of variance indicated that mothers who reported receiving adequate emotional support also reported initial and follow-up grief symptoms that were significantly less than those reported by mothers experiencing inadequate emotional support \( F(1, 72) = 8.22, p \leq .01, \) and \( F(1, 72) = 13.49, p \leq .001, \) respectively).

The satisfaction with emotional support was not related significantly to the decrease in grief over time in either group of respondents. However, satisfaction with emotional support was related to the concomitant effects upon marital relationships, mothers' relationships with surviving children, and surviving sibling adjustment (see Table 1). More specifically, mothers reporting adequate emotional support experienced significantly greater marital closeness than did mothers who indicated inadequate support \( x^2, df(2) = 11.58, p \leq .01. \) Mothers with perceived adequate support described their relationship with surviving children as closer than mothers with inadequate support. Similarly, these mothers reporting inadequate support also indicated having significantly poorer relationships with their surviving children than did mothers with adequate support \( x^2, df(2) = 13.21, p \leq .01. \) Maternal assessment of siblings' grief adjustment at follow-up also was related to perceived emotional support. Although not significantly different initially \( x^2, df(2) = .20, \) significantly more mothers with perceived support reported their children coping well at follow-up (87%) as opposed to 45% of children whose mothers reported inadequate emotional support \( x^2, df(2) = 8.09, p \leq .02. \) The mothers' ratings of the degree of supportiveness provided by various social network resources both immediately after their Infant's death and during the more extended adjustment period are presented in Tables 2 and 3, respectively. It should be noted that not all families received contact from every resource.

Among the respondents, the majority found all sources of support more helpful than not, with one exception. Mental health professionals, with whom the sample also had the least frequent contact, were generally perceived as not helpful. Contrary to a previous study (Rowe et al., 1978), parents in the present investigation had a more favorable perception of the supportiveness of medical personnel (e.g., medical examiner, public health nurse, physician, emergency personnel). However, longitudinally, physicians had less contact with these families than did informal support systems (i.e., family, friends).
Maternal Adjustment

On a symptom checklist of 17 specific items, the majority of the mothers in the present study reported experiencing 16 of the symptoms to a significant degree during the period immediately after the death of their infant (see Figure 1).

The most frequently reported symptom was the experience of sadness and depression (79%), followed by restlessness (63%), fearfulness (58%), sleep disturbance (56%), concentration difficulties (54%), feelings of discomfort around other pregnant mothers (46%), loss of energy (39%), loss of interest in social activities (42%), loss of appetite (41%), guilt feelings (41%), and job difficulties (32%). Thirty percent of the mothers reported having difficulty with "thoughts that the baby is still alive" whereas the majority of mothers reported little or no difficulty with perceptions of the deceased infant crying. Over 50% of the respondents reported experiencing 12 or more of these symptoms during the first few days after the death. However, this figure decreased to 15% by 6 months after the death of the child. The age of the child at the time of death was correlated significantly with maternal adjustment. More specifically, the younger the infant at the time of death, the more likely the mother reported delayed and more difficult adjustment difficulties.

Marital Adjustment

Although it has been observed that the effects of losing a child may result in marital distancing, a significant number of the mothers (60%) in the present study reported increased marital closeness during the period after the death of their child regardless of the judged adequacy of support (see Table 2). However, a small percentage (30%) did report experiencing feelings of increased emotional distance during this period. These findings appear consistent with the literature on crisis theory. That is, the death of a child may be viewed as a crisis or pivotal point that either results in increased supportiveness within the marital relationship or in increased estrangement from one's spouse related to the effects of emotional stress. Indeed, only 10% of the mothers reported that their infant's death had no effect on the marital relationship.

Maternal Perception of Sibling Adjustment

Forty-nine of the families (68%) studied had one or more other children living in the home at the time of the baby's death. The majority had only one other child (58%), with 35% having two other children at the time of the infant's death. With the emotional demands that the death of an infant places upon the parents, the surviving siblings must often endure more than one loss. That is, the child experiences both the death of a sibling and the feelings of loss associated with the decreased emotional availability of the parents in their attempt to cope with their own grief. The majority of the mothers (53%) reported observing that the surviving children were
noticeably disturbed by the death of the sibling at initial evaluation, with a smaller percentage of the children (30%) reportedly coping reasonably well with the sibling's death initially.

Six months after the death of the infant, 76% of the mothers perceived their children as coping adequately, with only 10% of the mothers observing continued signs of significant disturbance \( [x^2, df(2) = 22.31, p \leq .001] \). Consistent with the findings of increased marital closeness and supportiveness, a significant number (70%) of the mothers reported that they became closer to their children after the infant's death, with only 21% reporting feeling more distant from their surviving children during this period. A nonsignificant percentage (9%) of the mothers believed that their baby's death had no effect on their relationship with their other children.

**Subsequent Pregnancies**

Regarding the effect of SIDS on decisions to have children in the future, mothers responded in the following manner: 36% reported that it had a significant effect on their decision, 44% reported that it had no effect, and 20% reported that they were unsure of the effect. The majority (63%) reported that they planned to have another baby. Whereas 47% of the mothers reported that they desired a polygraphic sleep study completed on any subsequent children in order to assess the presence of apnea, 33% expressed a desire for more information in order to make the decision regarding the need for a sleep study.

**Environmental Change**

Consistent with observations of other investigators who have studied SIDS families (Detrain & Ernst, 1978, Rowe et al., 1978), the present investigation indicated that 51% of the 73 families responding to the present study had moved shortly after the death of their child. Of the 37 families who moved, 83% of these families
moved within the first 6 months after the child's death, with 51% of the total having moved within the first month. In addition to these families were the 75 families whose questionnaires were returned by the post office as undeliverable, indicating that an even greater percentage of the families relocated soon after the Infant's death.

**DISCUSSION**

The purpose of the present study was to examine both the psychosocial sequelae of the loss of an infant to SIDS and the perceived effectiveness of informal and organized sources of support in ameliorating the distress experienced by the survivors. Based on descriptive data obtained from 73 mothers, the results are generally consistent with the previous literature on crisis theory. That is, the death of the infant was viewed as a life crisis that forced that family to reorganize into a more or less effective mode of functioning. In fact, only a small percentage of the mothers viewed the death as having a neutral impact on their personal or marital adjustment or the surviving siblings' adjustment. The majority of the mothers surveyed reported generally satisfactory adjustment anywhere from 6 months to 25 years after their infant's death. However, approximately one quarter of the sample reported an unsatisfactory adjustment. Unfortunately, it is not clear from the present data whether any variables distinguished these mothers from the majority of the sample. Future research and supportive efforts should be directed toward identifying prognostic indicators that would result in the earlier identification of families predisposed toward a more difficult adjustment.

Although the majority of symptoms experienced by the mothers subsided during the first few months, the primary symptoms (i.e., significant feelings of fear, sadness, and depression) were still present several months to 25 years later in almost half of the mothers responding to the survey (cf. Kobasa, Maddi, & Puccetti, 1982). Indeed, maternal grief reactions may be more extended than previous findings from other populations experiencing grief indicate (e.g., Rando, 1983). Should this finding be replicated the data suggest that a prolonged grief reaction may not be abnormal in this population.

The present findings suggest that one factor contributing to the overall favorable adjustment of the present sample was the number of professional and lay contacts received as well as the perceived helpfulness of these contacts. A significant majority of the mothers reported that they received sufficient information and emotional support. This support came from a variety of informal and formal sources ranging from friends and family to legal and medical personnel as well as clergy. The present study revealed that perceived emotional support influenced not only maternal grief symptoms initially and those present at least 6 months after the death, but also the quality of the marital relationship, the parent-surviving child relationship, and sibling grief adjustment as perceived by the mothers. These findings support previous research regarding the important role of social support variables in mediating the response to stressful life events (Schaefer, Coyne, & Lazarus, 1981).

An important point to consider when providing support for families experiencing a death from SIDS is the finding in the present study that, the younger the infant at the time of death, the more likely the mother was to report delayed and more difficult adjustment. As noted in one study (Sahler, McAnarney, & Friedman, 1981), some professionals believe that parents would have less intense reactions the younger the age of the infant at death because of limited parent-child contact and thus decreased opportunity for attachment. In fact, Benfield et al. (1978) report that parental grief after a neonatal death was not significantly related to the infant's life span. However, several studies examining parental reactions to a neonatal death (Friedman, 1974, Naylor, 1982) or a congenitally malformed child (Solnit & Stark, 1961) as well as some of the classic psychoanalytic literature on mourning and object loss (Lindemann, 1944) indicate that the age of the child at the time of death does affect subsequent grief reactions. More specifically, as noted by Solnit and Stark (1961), one of the early tasks of parenting is to resolve the discrepancy between the idealized image of the "hoped-for" child and the actual infant. Considering that most deaths from SIDS occur between 2 and 4 months of age, the process is often incomplete before the parent must undergo the additional task of mourning. Thus, the grief process may be delayed. Similarly, Naylor (1982) notes that with the death of an older child, the "positive aspects of the [established] relationship would tend to mitigate the effects of the parents' negative emotional reactions" (p 685)

Regarding the seemingly contradictory evidence in the study by Benfield et al. (1978), all infants in the study
died before 42 days of age, suggesting that none of the parents had completed this deindividuation process and thus contributing to a lack of variability in the grief process based on the infant's age at the time of death.

Based on this literature as well as research from developmental psychology, one anticipates that maternal perceptions of sibling adjustment as well as the sibling's actual adjustment to the death is affected by the age of the sibling. Unfortunately, the scope of the present questionnaire did not provide sufficient data to examine this issue. Certainly, both these issues require further investigation as they appear to be important variables in the adjustment of families to SIDS.

The evaluation of the perceived adequacy of the SIDS project's support network was generally favorable. However, approximately one quarter of the respondents indicated that the support they received was inadequate or they did not evaluate the quality of the support at all. Analyses of the data indicate that these respondents were also members of the subgroup who experienced a less effective adjustment to their infant's death. The results further emphasize previous research findings that perceived social network support is related to adjustment to a variety of other life experiences and crises (Carter & Elkins, 1982).

One potentially unsettling finding for the mental health field was the fact that relatively few families had contact with mental health professionals. Furthermore, among those that did, their perception was that this contact was of little or no value in achieving an adequate adjustment. Although it may be hypothesized that those families referred for mental health services manifested more severe adjustment problems, the current data do not permit confirmation of this hypothesis. Thus, the role and benefit of mental health professionals in assisting the families of SIDS victims requires further evaluation. This information would be of obvious importance in increasing the effectiveness of these professionals in their intervention with the families of SIDS victims.

Within the context of the present study, the parents' individual coping strategies were not specifically evaluated other than their utilization of available support systems. One observation was that a significant number of the families in the present study may have viewed environmental change as a viable coping mechanism. Indeed, over one third of the questionnaires were returned for lack of a forwarding address, with an even larger percentage of the families responding to the questionnaire moving within the first month after their infant's death. Similar figures have been reported in other studies as well (e.g., Rowe et al., 1978). It may be that families moved in an attempt to escape the painful associations present in the home environment where the infant most likely was found dead. However, the advisability of such an abrupt transition during this stressful crisis is questionable in light of knowledge of the potential stress associated with moving (Carter & Elkins, 1982). In addition, as in the present sample, the moving interfered with the provision of support services. Thus, it might be advisable for professionals to address this issue at the first available contact with the family and to offer alternative strategies for managing the family's response to this tragic life event.

In addition to an evaluation of the impact of SIDS and the perceived effectiveness of available support services, a secondary focus was the identification of any infant and/or parent variables associated with SIDS. In general, the findings confirmed earlier research that these infants were perceived by their parents as generally healthy before their death (Bergman, 1979). Furthermore, there are few demographic variables that distinguish these parents from the general population with the exception of a higher percentage of smoking among this sample as compared to estimates of smoking within the general population.

There has been some speculation and tentative support that some infants experiencing sleep apnea are at greater risk for SIDS as are the subsequent siblings of a SIDS infant (Brooks, 1982). If such speculation is valid, then it appears that subsequent siblings of SIDS may benefit from a polygraphic study of sleep parameters (Guilleminault, Ariagno, Korobkin, Coons, Owne-Boeddiker, & Baldwin, 1981). Unfortunately, many of the mothers responding to the questionnaire in the present study did not feel that they had adequate information to make a decision regarding the need for such a sleep study with subsequent siblings. One aspect of supportive
intervention that might be considered is additional information about sleep apnea and the possible benefits of a sleep study for subsequent siblings.

In conclusion, although the present descriptive study provides additional insight into the impact of SIDS on maternal reactions and the effectiveness of an available support system, it also identified many areas still in need of investigation. One of these issues relates to the low response rate from the fathers. Although both parents were sent questionnaires, fewer fathers than mothers returned and/or completed the questionnaires. The present data do not indicate a reason for the low rate of response. However, previous literature may indicate that cultural expectations of the fathers' role in the family and grief process may have influenced them to not complete a questionnaire designed to elicit retrospective analyses of their emotional reactions to the death of their child. Although recent literature points to the importance of the father-child relationship (Lamb, 1979), Weinraub (1979) notes that "because the father's biological relationship to his child is not immediately obvious the extent and quality of the father-child interaction have been more heavily determined by cultural factors" (p. 119). Regarding cultural expectations of grieving, Klaus and Kennell (1976) comment that the cultural expectations for the male encourage a pattern of "keeping busy to keep his mind on other matters when a death occurs" and thus often "avoid facing their feelings" (p. 225). Although these expectations may be changing, it is important to evaluate not only paternal responses to SIDS but also what type of support mechanisms may be most beneficial to this group given these expectations.

A replication of the present study utilizing similar questionnaires with another population is desirable. However, other variables may be evaluated more appropriately by in-depth analyses utilizing observational, interview, and sociometric instruments. It is obvious that more longitudinal data are necessary in order to document the progression of parental coping with the loss of an infant from SIDS. The data obtained from a series of such studies should be beneficial in developing more effective preventive interventions in order to lessen the pain experienced by these families and to facilitate a more adequate adjustment to this life crisis.

References


