The Psychological Effects of Sudden Infant Death Syndrome on Surviving Family Members

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It has been estimated that 7,000 to 10,000 deaths each year may be attributed to Sudden Infant Death Syndrome (SIDS). Although some clinicians have published their personal observations regarding the psychological effects of SIDS on surviving family members, a literature search failed to reveal more thorough studies of the aftermath of SIDS. This study reports the responses to a 13-page questionnaire of 32 parents who had experienced SIDS. Several major findings were observed: (1) SIDS is the most severe crisis these parents had ever experienced, taking their families an average of 8.3 months to regain the level of family organization they had held prior to the death, and taking individual parents an average of 15.9 months to regain the level of personal happiness they had held prior to the death; (2) a majority of parents suffered personal guilt, and numerous other psychological and/or physiological difficulties; (3) relationships with other family members were affected in various ways in the vast majority of cases; and (4) 60 percent of parents who had experienced SIDS in this particular population could not be found for participation in the study; all of these parents had, within 2 1/2 years of the death, moved from their home towns. Implications for crisis prevention and intervention are outlined.

Historical Review

Sudden Infant Death Syndrome (SIDS) has probably been a major cause of death since Biblical times. Throughout history mothers have often slept with their infants, and if they awoke and found the child dead they assumed they had laid on the child, smothering or crushing it: "And this woman's child died in the night, because she overlaid it" (I Kings 3:19).[1]

This early theory has been superseded by many modern theories.[2] In fact, Beckwith has cataloged 73 theories of the etiology of SIDS, and notes that new ideas are being published almost on a weekly basis.

Bergman, Ray, Pomeroy, Wahl, and Beckwith[3] studied all cases of infant death in King County, Washington, between January 1965 and September 1968. This included autopsies of infants, viral cultures, and home studies. They found that 170 infants under the age of two years out of 73,315

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born in King County during the study succumbed to SIDS. This averaged out to 2.3 deaths attributable to SIDS per 1,000 live births. On the basis of the King County study it was estimated that there are approximately 10,000 deaths in the United States each year from SIDS, making it the major cause of death for infants between one week and one year of age. Later estimates have set the US figure at 7,000 to 8,000 deaths per year.

While many medical researchers focus their work toward the prevention of SIDS, a small number of investigators have made observations on the effect of SIDS on surviving family members.

Pomeroy,[4] a registered nurse working with the King County project, has written of some of her experiences while visiting and interviewing parents who lost a child from SIDS. Grief reactions she witnessed included: (1) difficulty in concentrating, (2) fear of being alone in the house, (3) anorexia and insomnia, (4) time confusion, (5) despondency, (6) fear of the responsibility of caring for children, (7) failure to accept reality, and (8) anger and guilt.

Mandell and Wolfe[5] studied 32 women whose children died of SIDS and their ability to have subsequent children. None of the women had any fertility problems, complications with pregnancy, or spontaneous abortions before the sudden infant death occurred, and all of the mothers wanted additional children. According to Booher and Little,[6] ten percent of previously fertile women will have fertility problems, and spontaneous abortions may occur in 12 to 15 percent of all subsequent pregnancies. In the Mandell and Wolfe study, it was found that 31 percent had spontaneous abortions and 34 percent could not conceive for one year or longer after the sudden infant death. These mothers all experienced a harsh grief reaction and feelings of failure in their ability as mothers.

A conference was held in Kansas City in July 1975, on the mental health aspects of Sudden Infant Death Syndrome. National authorities on SIDS convened to discuss their experiences with SIDS families and to consider guidelines for counseling families. Again, Bergman noted the still existing documentation void regarding the mental health aspects of SIDS. It was reemphasized that the death affects every aspect of family life; some participants felt, however, that the loss could result in some positive changes for the family as well as individuals if there is adequate support from within the family as well as from agencies and professionals outside the family.

Methods

This study was completed in cooperation with the Nebraska State Department of Health, Division of Maternal and Child Health, under the direction of Robert Grant, MD. The Department of Health has investigated every child's death from one week to one year of age in the state of Nebraska since January 1, 1973. Death certificates were checked and physicians contacted if any questions arose. An attempt was made to contact by telephone each parent of a child whose death was attributed to SIDS between January 1973 and June 1975. Names and addresses were obtained from the death certificates. The study's purpose was explained and the parents' participation requested. A 13-page questionnaire covering general information as well as information dealing specifically with the death and the ability to recover from the crisis was sent to individual parents who agreed to participate. Each parent who did not return the questionnaire in three weeks was contacted by telephone to ascertain his/her reasons for not responding.

Deciding whether to use a questionnaire or an interview was one of the most difficult methodological problems faced. With varying degrees of motivation and education, a biased sample could result if there was a poor return of the questionnaire. But, since the Division of Maternal and Child Health offers education and counseling services to SIDS families, it was thought that to intervene in that process and bias any evaluation useful to its work would be harmful. Fortunately, the questionnaire was satisfactory: almost two thirds of the parents who agreed to fill it out did return the instrument. And, in contacting those who failed to do so, none replied that they were overwhelmed by its size, offended by its context, or did not understand it. Rather, they reported to the effect that "they just hadn't gotten around to it"—a phrase indicating low priority that family

science researchers are quite accustomed to. In all continuing research efforts on SIDS, the questionnaire method with all its inherent disadvantages, rather than personal interview, will be used because the parents themselves quite often included in their written replies that they did not think they could handle an interview. As one mother noted:

> I would write a page and cry. Put it aside a few days, and then write a page and cry. If an interviewer would have come to my door, I'd have broken down completely.

Questions for the instrument were adapted from the literature of family crisis studies, death, and bereavement; from clinical impressions in the medical literature of the effects of SIDS on surviving family members; and from exploratory interviews with SIDS parents. More than a dozen professionals in pediatrics, social work, child development, and family studies critiqued the questionnaire. Its validity and reliability were further enhanced by piloting with a statewide SIDS parents' group and making subsequent revisions.

In January 1976, a questionnaire was sent to every parent who could be contacted who had experienced SIDS between January 1, 1973, and June 30, 1975. Ninety-one cases of SIDS had been identified during that time period by contacting the physician or coroner involved in the incident. However, the death certificates in some of these cases showed the death to be attributable to some other cause, and the parents had not been notified that their child actually died because of SIDS. Those parents who had not been notified that their child died of SIDS were not asked to participate in the study. Parents of 63 out of 91 cases were sought for the study.

Two professional staff members of the Department of Health tried to contact the parents by telephone in each of the 63 cases. If the parents could not be located, another telephone number with the same last name in the same community was tried with hopes of locating a relative. A grandparent was located in four cases, but in all four instances would not allow the Department of Health to talk directly to the parents because they felt it would unnecessarily upset the parents. One grandparent stated that the couple had separated as a result of the death. Another stated that an arrest had been made after the death and the couple was still involved with legal problems as a result of the death. A third grandparent stated that the husband had left his wife because he blamed her for the death. This grandparent made it clear that she also blamed the mother. The fourth grandparent indicated that her daughter, a single mother, was in the hospital at the time of the study.

Results

All 50 parents contacted agreed to participate in the study; 32 completed the questionnaire. This group of SIDS parents unanimously rated SIDS, when compared to all other family crises they had experienced, as the most severe crisis they had ever experienced in their lifetimes. Other crises experienced by these parents included: death, separation, illness, alcoholism, and many other kinds of crises.

It took the parents, on the average, 15.9 months to regain the level of personal happiness they felt they had held before the death (Figure 1).

Parents replied that it took somewhat less time to regain the level of family organization (smooth family functioning) that they felt they had held before the death.

Figure 1 may at first strike medical professionals schooled strongly in experimental procedures as rather peculiar. It is, however, adapted from a standard procedure for crisis severity measurement in the 40-year tradition of family sociology.[8-12] The validity and reliability of this genre of crises measures are widely accepted by many social and behavioral scientists. It must be emphasized that these instruments do not purport to tap such qualities as "severity of crisis," "personal happiness," or "family organization." Rather, they tap the subjects' perceptions of "severity of crisis," "personal happiness," or "family organization."

There were no significant relationships or differences ($P<.05$) between recovery time and the following variables: residency on a rural/urban continuum, church activity, membership in social organizations, number of personal friendships, prior knowledge of SIDS, or whether or not an autopsy was performed. The present study does, however,

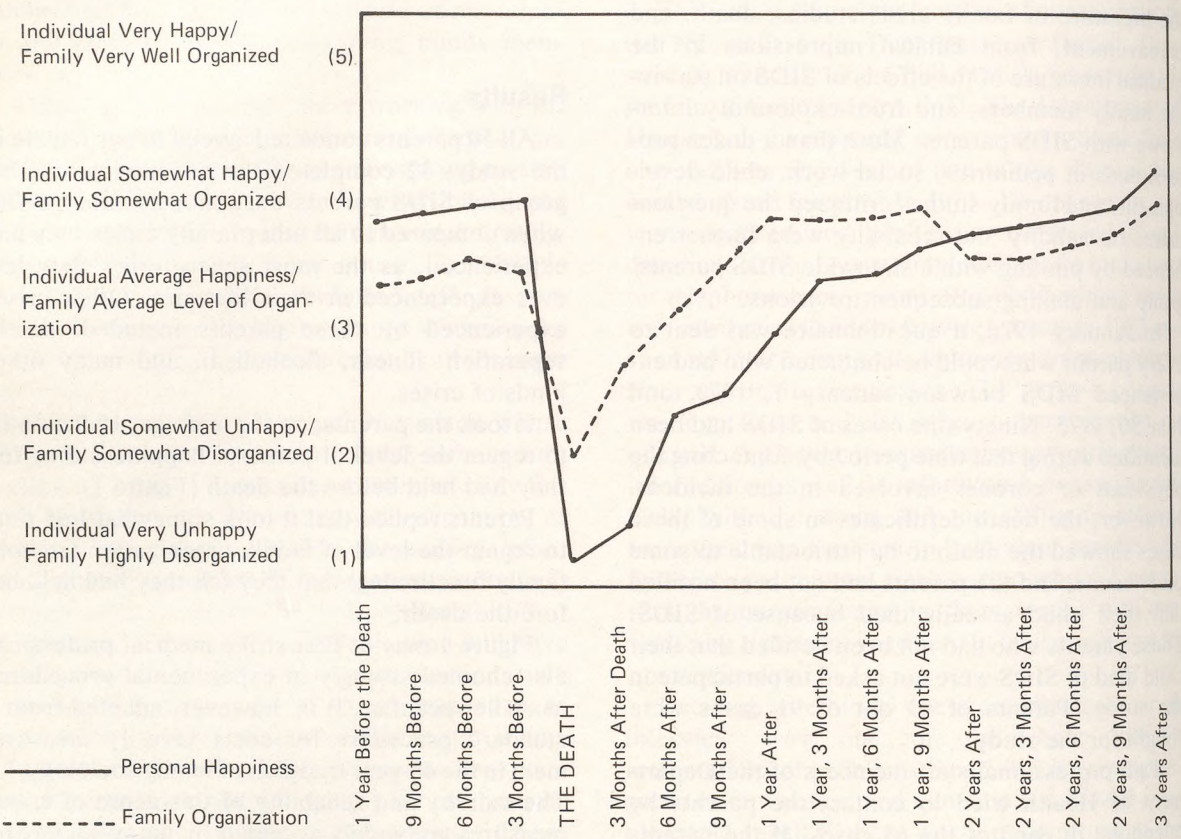

Figure 1. Mean Levels of Personal Happiness and Family Organization in Relation to the Death

support the hypothesis that as income increases personal recovery time decreases: higher income is associated with relatively quicker recovery time ($P<.01$).

Sixty-nine percent of the parents suffered personal guilt; many considered these guilt feelings severe, even though no one can reasonably be held culpable for such a death. At least half of the parents often or nearly always suffered the following physical and/or psychological difficulties during the crisis: trouble sleeping; nervousness and feeling fidgety and tense; loss of appetite; and difficulty getting up in the morning.

For most of the parents, relationships with spouses, children, and grandparents were generally strengthened in the long run after the crisis. The parents turned to their families first for support and quite often received that support. Only 22 percent of the parents stated there was no difference in the behavior of their remaining children. Other parents, however, indicated the following changes in behavior: nightmares, bed wetting, school problems, discipline problems, crying a lot, blackout spells, very quiet, and overprotection by the parents.

Sixty-nine percent of the parents felt that had the general public been better informed about SIDS, it would have helped them during the crisis. One parent stated that the police who were called to the house at the time of the death "treated us as criminals." One said, "I was a Catholic until the priest refused to bury my child." Other parents referred to the cool reaction on the part of friends and relatives; one parent stated that the family did not receive even one sympathy card from relatives.

Discussion

This article reports an initial effort to consider the crisis resulting in families after a SIDS death has occurred. While the sample is small and necessarily not representative of even all SIDS parents in the state of Nebraska, it is quite possible that sampling difficulties may reflect the crisis itself, as a surprisingly large percentage of the parents could not be contacted by telephone after only six months to $2^1/_2$ years from the death. It is reasonable to argue that SIDS had an influence on this factor, since the normal mobility rate in the state is much lower. Possibly, many of these parents felt that only by leaving their homes could they forget or recover from the shock of the death. If this hypothesis is correct, health-care professionals are in a critical position. Their efforts to cushion the shock immediately after the death may be the first and last chance any professionals will have to exert a positive influence in the crisis. Under this assumption, then, professionals would be well advised to move swiftly yet cautiously to offer educational and counseling services to the immediate and extended family members. And following the prescriptions of the parents themselves, the professional community should continue to educate the general public about the nature of SIDS. In some of the parents' perceptions, it is the disapproving eye cast by society that is the greatest problem of all.

Acknowledgement

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