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Abstract

This report focuses on the responses of 35 brothers and sisters of babies who died of sudden infant death syndrome (SIDS). Most of the children were obviously affected - the family unit and their role in it has changed, and their security was threatened. The report suggests that physicians need to be sensitive to and aware of guidance parents may need during the complex process of grieving which involves all family members. **Keyword: Families**

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Unexpected Death of an Infant Sibling

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Abstract. When infants die suddenly and unexpectedly, family structures are abruptly altered. This loss and its subsequent changes affect remaining older siblings. New "big brother" and "big sister" roles are suddenly terminated, often in a catastrophic manner. Young surviving children are sometimes unable to understand the meaning of this event, its impact on the family, and their own role in what has occured. In this study, 26 families that had sustained the sudden and unexpected death of an infant and that had surviving children were interviewed to obtain data about surviving siblings at least 10 months following the loss. Among the 26 families, there were 35 surviving siblings (ages 16 months to 6 years). The interview schedule sought information relevant to changes in patterns of sleep, toilet training, feeding habits, peer relationships, and parent-child interaction. Among these 35 surviving siblings, parents of 28 siblings (80%) perceived changes in their child's interaction with them, 24 siblings (69%) demonstrated changes in sleep patterns following the baby's death, and 13 siblings (37%) showed changes in social interaction. Regression in toilet training and changes in feeding patterns were infrequent and not areas of major concern for parents. These behavioural changes reflected both a continuum of adjustment by the child and persistence of parental worries. *Pediatrics 1983; 72:652-657; sudden infant death syndrome, sibling death.*

As Hermann Hesse wrote:

> *Grownup people die:*
> *Uncle, Grandpa.*
> *But I, I shall remain*
> *Ever, ever here.*

The sudden and unexpected death of an infant in a family provokes significant emotional responses in all family members. this is particularly true for siblings because they are frightened by the catastrophic nature of the death and are unable to understand its full meaning and its impact on the family.

The grief reaction which follows the unanticipated loss of an infant is especially harsh for parents. Most parents are overpowered by feelings of loss and self-blame. the abruptness of the loss of an active, healthy-appearing infant in the void of a known and explainable pathological course, seems to intensify these feelings. In this psychological atmosphere, surviving siblings also experience loss, disruption and fear.

This report focuses on the responses of 35 siblings of sudden infant death syndrome (SIDS) victims. When the infant dies, the pediatrician has the potential to provide major assistance to families. Awareness of

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and attentiveness to issues such as sleep disturbances and altered parent-child relationships among surviving children is critical to care that continues for surviving siblings. However, the work of grief is not circumscribed to the several weeks following the death. The confusion and inadequacy experienced by bereft parents precludes the spontaneous expression of concerns around surviving children. Behavioural responses in young children may be misunderstood by parents and health professionals, and consequently obstructed, jeopardizing the eventual stability of emotional health.

METHODOLOGY

Twenty-six families that had sustained the sudden and unexpected death of an infant for at least 12 months, and that had surviving children, ranging in age from 16 months to 6 years of age at the time of the infants death, were contacted 12 months to 2.5 years following the death.

Our sample was limited to those families that were in our geographic area and could be located by phone. There was no attempt to exclude any family within the 18 month study period. The sample was limited however, by families that had no siblings at the time of the infants death and also by the numbers of families who had moved and could not be located. Whereas the families interviewed represented all socioeconomic groups, there was a preponderance of lower-middle-class and upper-lower-class families as described by parental education and income. This survey makes no attempt to match our bereaved population with a population of children whose younger siblings did not die.

All of the parents contacted agreed to participate in the study and were eager to share their feelings. In all of the cases, the mother was interviewed by one of the authors using an interview schedule that sought information about surviving siblings relevant to changes in patterns of sleep, toilet training, feeding habits, peer relationships and parent-child interaction. In addition, information about circumstances at the time of death, inclusion of this sibling in practices of mourning, and the availability of guidance as perceived by parents was also explored. The interview lasted for 30 to 60 minutes. In several instances, the need for further counselling was evident and referrals for further assessment were made to primary providers or to the locally trained nurse counsellor for SIDS.

CHARACTERISTICS OF SURVIVING SIBLINGS

Among 26 families of SIDS victims, the adjustment responses of 35 surviving children were discussed. At the time of the infant's death, five of these children were between the ages of 15 and 24 months; six were between 24 and 30 months; six were between 30 months and 3 years; ten were between 3 and 4 years; and eight were between 4 and 6 years. Twenty five of the children were first in birth order, five were second in birth order, four were third and one child was fourth. Of the siblings studies, 18 were female

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and 17 were male. All of the infants who died were between the ages of 1 and 5 months with the exception of one infant who was 18 months old at the time of death,. All but one infant died at home, and as is typical among victims of SIDS, the infants were found to have died during periods of sleep. Of the DIDS victims, 21 were male and five were female; 23 were white, 2 were black, and one was Oriental. Two of the SIDS victims were one of a set of twins and, in each case, the surviving twin was on a respiratory monitor with an apnea alarm for several months following the death.

REACTIONS

All but one of the 35 surviving children had responses to the death that were perceived by the parents as notable in the areas explored by the interviewers.....and a persistence of parental worries are described below and include: parent-child relationships, changes in sleeping patterns, changes in social interaction, regression in established toilet training, and changes in eating patterns.

Parent-Child Relationships

Mothers of 28 (80%) of the children perceived changes in the child's interaction with them. In six cases (17%), this was the only area in which change in behaviour was noted. Although all age groups demonstrated changes in interaction with parents, all the children who were between 16 months to 2 years evidenced dynamics of a relationship change. In nearly all of the cases, and particularly in this age group, the parents spontaneously described their own needs to be physically closer to their surviving children for comfort. Representative of the group are comments of two mothers:

"We wanted and needed to hold her more...."
"I don't know who needed the hugging more her or us."

Several of the parents expressed fears that perhaps they had 'babied' a surviving child too much. Implied, if not openly stated, was the mother's need to recapture the intimacy afforded in a mother-infant bond, as well as the fears for the safety of surviving children. One mother, after 2 years and the birth of a subsequent child stated:

"I knew I couldn't bring J. back, but holding M. brought comfort that no-one else could. I had to know he was safe and I could only know that by holding onto him. I wonder now, if his jealousy of my time with the (new) baby isn't the result of my again making him the baby for one year."

Conversely, a few mothers expressed anxiety about their surviving children and several were able to express a painful need for distance from them. One mother articulated this with a particular poignancy:

"I couldn't stand to be near S. I was so scared of what would happen she had a (febrile) seizure 3 months after B. died and I wanted to run in the other direction....I insisted that my husband handle the trip to the hospital."

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Although the parents' responses to their surviving children were not specifically solicited, several parents volunteered that they were overwhelmed by the needs of their children for comfort and rationalization of the baby's absence. The confusion experienced by parents in responding to other children is represented by one mother's comments:

"I didn't know which way to turn, I was so mixed up inside. I spoiled K. after the baby died. I didn't want to hit her when she was bad....I would just yell. I would let her sleep with me, and I wouldn't before D. died."

For the many of the surviving children, the experience of seeing their parents crying and frequently incoherent was bewildering and frightening. One 3.5-year-old child who, following the baby's death, tended for the first time to favour her father's company rather than her mother, tried to return the reassurance her parents had attempted to give her:

"It's okay....J. is in heaven with the angels."

Another reminded his parents:
"Don't be too sad, you still have me."

In describing changes in parent-child interaction, the majority of parents described anxiety manifested by their children in separation form them. Some children were able to articulate a fear that their parents would also disappear. One mother had to eventually remove her child from a day care center for a year because of the child's intense negative response to being away from home during the day. Another 2.5 year old child had temper tantrums when she was separated from her mother for several months after the event of the baby's death.

Several of the parents described anger manifested by a surviving child and directed towards them. One 5.5 year old child expressed blame towards his mother for causing the baby's death, while at the same time, he was perceived to need closer physical contact and reassurance. Another preschooler expressed bewilderment that his mother had 'lost' the baby and asked if she would also 'lose' a subsequently born baby. In only one case, did a parent describe a child's tendency to pull away from the parent following the loss of the baby and, in this instance, the 3.5 year old girl demonstrated a previously unmanifested need for affection from her father.

Some parents talked of a disquieting tendency of surviving children to test limits of discipline for several months after their sibling died. In a few cases the parents conjectured that following the crisis, they had allowed their children 'to get away with too much'. One mother commented on her 3.5 year old's daughter's defiant behaviour:

"I was just so exhausted and it just seemed that at home (unlike nursery school) J. would do anything to stir up my anger."

One 2 year old boy, the youngest of four siblings, persisted in a renewed attachment to his mother which she perceived as problematic one year following the death when the

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interview took place. This mother acknowledged that she drew toward this child more than her other children. One year later, when she was near the conclusion of a subsequent pregnancy, this child's behaviour had regressed to the extent that a referral for evaluation was necessary.

Changes in Sleeping Patterns

Of the 35 children, 24 (69%) demonstrated changes in sleep patterns following the baby's death. In most of these cases, the new behaviour emerged within a few days, although three children did not have any problems until after 2 months. Among these 24 children, the disruptions persisted for 2 months in two children; 3 to 6 months in five children; 6 to 8 months in four children; one year in four children; and were still problematic after a year in four children.

A majority of children in all age groups had at least one sleep-related difficulty; problems in this area were most prevalent in the 245 through 36 months age group in which nighttime was difficult for 83%. The largest number of sleep-related difficulties was seen in resistance to go to bed and sleep.. Older children were able to describe their fears of sleep approximately half of the time. Many of the 3- to 4-year-olds expressed a fear of dying at night. A child who was 3.5 years old at the time of her 13-month-old sibling's death was especially troubled for almost 2 years. This SIDS victim was one who died in the hospital and the sibling's troubles with bedtime fears, particularly about 'not waking up' did not begin until 4 months after the death. Another example of this fear of not waking up, which is more typical, was related:

"We were just not able to reassure her. When we would tell her that she would be okay, she would say, 'How do you know?'"

One child, who was 3 years old at the time of her sibling's death, had sleep disturbances that persisted for a year, although the severity gradually decreased:

"Before K. died, A. went to bed at 8.30 without much fussing. About a week later, I couldn't get her to settle down until 12.30 or 1a.m. She was reacting too."

Another 10-month-old child, who did not overtly express fears of dying, was resistant to bedtime and refused to sleep in the crib she had been in prior to the baby's death.

The disruptions in sleep experienced by half the children with changes in sleep patterns were usually accompanied by nightmares. Older children were better able to recount the content of the nightmares. A frequent theme of nightmares was pursuit of monsters. One three-year-old resisted sleep because of her fear that a 'monster' would 'take' her because she had killed her infant brother. Another 2-year-old girl would wake up screaming that the monster would take her to heaven with her brother. Eight children had problems with enuresis and nocturesis which persisted from a few weeks to a year or longer. All of the children with toilet training

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problems also had changes in their relationships with their parents and all but one child had sleep disturbances.

Changes in Eating Patterns

Approximately one third of all children had changes in eating habits which were usually a transient lack of appetite. Four (25%) of the 2- to 4-year old-children demanded to be fed from a bottle after previous weaning. In our survey, this was not an area that was of major concern to parents.

RITUALS OF COMMEMORATION

Ten of the 35 children surveyed attended the funeral of their sibling. Most of the parents felt that the children were too young and, in many instances, the surviving children stayed with relatives or neighbours at the time of the funeral. Some of the parents later regretted that their other children had not participated in funeral ceremonies. In all but a few of the families, there are pictures of the baby in the home to reinforce memories. Although many of the mothers make visits to the cemetery, they are often unaccompanied.

DISCUSSION

The practice of preparing children for the older-sibling role provides expectation and participation in a significant family event. With the presence of a new infant, that role is crystallized. In cases of sudden, unexpected loss of smaller siblings, death has entered the security of the family and removed another child close in age. The acquired role of older sibling is harshly disrupted and the sibling must deal with the void of a developmental opportunity that has been abruptly denied. The child, as a survivor, immediately comes to possess some very special qualities that result from the loss.

Often a child is not able to conceptualize that another child can die. The child is immediately faced with one of life's most bizarre occurrences. It is too conspicuous to be neglected by family or professionals and its consequences can be a source of confusion and persistent fear and dread for the surviving child. During the time following the sibling's death, children feel especially vulnerable. The family unit has changed, communication between husband and wife had changed, and parents behaviour towards the surviving sibling has also been altered. Most often, parents assume a kind of over-protectiveness and permissiveness. Occasionally however, parents fear attachment and loss and move away from the surviving child. Previous studies have made us all aware that death has significantly influenced the lives of many of our patients and that many have suffered the loss of a sibling.

In this report we have described some of the behavioural changes that occur in siblings following a sudden and unexpected death. Whereas this group of families had socioeconomic characteristics generally similar to those of other families with a child who was a

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SIDS victim, we cannot suggest that these data can be extrapolated to all families. However, these findings do suggest that behavioural issues constitute a significant concern in some families of victims of SIDS. Although we cannot exclude the possibility of overreporting of behavioural changes, this appears less likely because of the consistency of parental responses.

Most of the children in this study experienced changed in their relationship with their parents, had difficulty getting to sleep, and experiencing fear around bedtime. As in most cases of SIDS, most of the babies in this study died during times of sleep. Because sleep represents losing control, it is not surprising that a few children had extraordinary fears with persistent and disruptive behavioural and somatic responses. Certainly, parental anxiety about their surviving children is heightened by these occurrences.

Whereas these data are not derived from a controlled study, they do suggest that physicians need to be sensitive to and aware of parental perceptions. Physicians often encourage adult patients to talk about crises. Children also need to talk about their perception of what happened; either through talk or play, or stories, or drawings. Following the sudden death of a sibling, children respond with different kinds of behaviour. Some children may have questions and often want to know what happened. In others, feelings of normal sibling rivalry sometimes involve the issue of "did I do something wrong?" Fears may also stimulate thoughts such as "can this happen to me or my parents?" Because of the need to try to understand the events that have transpired, the preschool child may not allow parents to deny the loss. The child asks questions about the loss, just as he asks about other things he does not understand.

These issues were of concern to parents in the study. However, parents will often not discuss these issues because they are so overwhelmed by the mourning process or would prefer to deny an additional "medical problem." Also, parents may be reluctant to initiate expressions of concern about the disturbed behaviour of their children at a time when they are experiencing feelings of inadequacy. During this study, there was a remarkable willingness to talk about their specific concerns among their children. In some cases, arrangements were made for future discussion. When the health professional is familiar with possible changes in surviving children, parents may be more apt to acknowledge these difficulties. With awareness that behavioural changes can occur, pediatricians can provide some guidance during the complex family process of grieving which involves all family members. The pediatrician is also available to validate parental concerns over these issues and provide assurances and intervention if necessary. By validating these issues as childhood fears following a loss, practitioners can be of assistance to parents who are struggling with changes that take place in the family after the sudden loss of an infant.

The pediatrician can help create a climate in which parents and children are assisted in expressing

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painful feelings immediately after the death, and even utilizing the time when the autopsy is reviewed to inquire about the adjustment of the other children, could be supportive. This kind of inquiry allows parents to know that we are concerned about the surviving family and that we can be a source of help as the family begins to develop acceptance of the new reality.

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