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News

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*****Parents of Sudden Infant Death Syndrome victims face a grief complicated by doubt and misinformation.

DALLAS--Sudden Infant Death Syndrome has another name--the "if only" syndrome. Parents who lose their apparently healthy infants to SIDS, or "crib death," often face a grief complicated by thoughts of what they should have done to save their child.

"If only I had breastfed my baby."

"If only I hadn't left the baby with a babysitter."

"If only I hadn't covered my baby with a blanket when I put her to sleep."

In truth, medical experts know frustratingly little about SIDS, which has been the leading cause of infant death in babies between one month and one year old. SIDS kills an estimated 10,000 infants each year in the U.S.--that is one out of every 350 live births. And SIDS is second only to accidents as the cause of death for all children under the age of 15.

But why it happens remains one of the bigger medical unknowns.

"We can't tell parents why their baby died," said Leslie Malone, SIDS coordinator for Southwestern Medical School's SIDS Information and Counseling Project for the North Texas area. Under a department of Health Education and Welfare grant, she and the project director, Dr. Ruben Meyer of the medical school's Family Practice faculty, work to identify cause of death of all infants who die suddenly and without apparent cause. Their project also provides funding and referrals for grief counseling of parents who lose a child suddenly (except for cases of stillbirth). And they provide an educational service for public officials working with SIDS infants so that the disease may be accurately recognized.

"It is highly probable that we are dealing with a heterogeneous (or mixed) group of diseases," says Meyer, adding that the word "syndrome" is to indicate a group of clinical symptoms, whether from single or multiple causes.

"Divorce and suicide rates are very high in SIDS families," says Ms. Malone, whose project is in its second year. "Parents blame themselves and each other. We have to tell them, 'No, it was not predictable. No, we don't know why it happened. No, you're not responsible.'"

"We only know it's SIDS because an autopsy didn't reveal a cause of death."

Problems for parents of SIDS victims can be monumental:

--SIDS babies are often found in their cribs lying face down. Since blood pools by gravity the infants may develop red blotches over the underside of their bodies. Police officials unfamiliar with SIDS have been known to arrest the parents for child abuse.

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--Then there is the "suffocation syndrome." In terms of what the autopsy finds, a SIDS victim may look like a child deliberately suffocated by the parents. Parents of SIDS infants may develop paranoia, thinking that others suspect them of infanticide.

--When officials learn that a SIDS baby slept in the parents' bed the parents may be accused of accidental suffocation, called "accidental overlaying" by medical examiners. While studies have shown that babies can breathe under blankets, according to Ms. Malone, parents in these circumstances are cursed with the possibility that perhaps they did suffocate their child accidentally by covering it with the bed clothes or perhaps they did roll over their infant during the night without knowing it.

--Parents sometimes blame each other for their child's death. The child may be discovered in the morning by the mother. She calls the father at work and blames him for not being at home. The father, hearing that the baby has died at home, blames the mother for neglecting it.

--Parents must face blame by relatives and friends. These "outsiders" offer theories on why the child died--the windows were open, the bottles weren't sterilized, the child must have been allergic to the dog or the cat. Coping with the death becomes harder on the parents.

--Parents aren't emotionally prepared for the sudden death, nor are other children in the family. The infant was often without a history of illness, except perhaps for a slight cold.

--The family suddenly finds themselves bewildered by an abundance of case management people--police, paramedics, public health nurses. The baby must be taken away to be autopsied, which can cause additional trauma.

Data on the average SIDS victim are abundant. And most of it can be associated with low birth weight infants. "But low birth weight infants are more susceptible to many conditions," says Ms. Malone.

SIDS babies are usually born to low socioeconomic families; a high percentage are born to mothers under to age of 20. Over 50 percent had mothers who smoked during pregnancy. The children were often premature and many were of multiple births (triplets, twins).

A study done in Dallas county shows that the SIDS percentage is high among illegitimate children, which may support the argument that some of these children were unwanted.

Most SIDS infants had suffered from a slight cold previous to death, according to SIDS statistics. They died during sleep, without noise or crying out.

Apnea, where breathing stops temporarily, has been given a lot of attention as the cause of SIDS. "Yet apnea is not necessarily SIDS;" says Ms. Malone, "apnea has been associated with SIDS." Babies with bouts of apnea can be stimulated to regain normal breathing, she says, by tickling their feet or patting them on the back.

The city of Dallas works under a medical examiner system where all who die without an attending physician must be autopsied. Also, the Dallas Institute of Forensic Sciences, which houses the medical school's SIDS project, investigates all sudden and unexpected infant deaths.

Yet Texas is the only state in the U.S. in which rural counties, without medical examiners, operate under a justice of the peace system. Here a JP, without medical training, determines the cause of death and signs the death certificate when anyone dies in the home or without an attending physician.

All of the 39 counties serviced by the SIDS project are under the JP system, with the exception of Dallas county.

Autopsies, the only way of determining a SIDS death, are usually ordered by the JP when foul play is suspected. But as an elected official the JP often will forego the SIDS autopsy since it puts additional stress on the parents. Learning that the child had a cold a couple of weeks prior to death, the diagnosis often becomes pneumonia and the SIDS death goes unreported.

This gap in SIDS identification is where much of the SIDS educational service directs its energies, according to both Meyer and Malone.

"We try to educate the JP on what SIDS is and show them the necessity of calling our office and ordering an autopsy," says Ms. Malone, who adds that her project will provide funding for transportation of the infant to Dallas and for the autopsy.

"Except for a few pathological changes the autopsy will not show why the infant died. But an autopsy can tell that it wasn't anything besides SIDS."

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