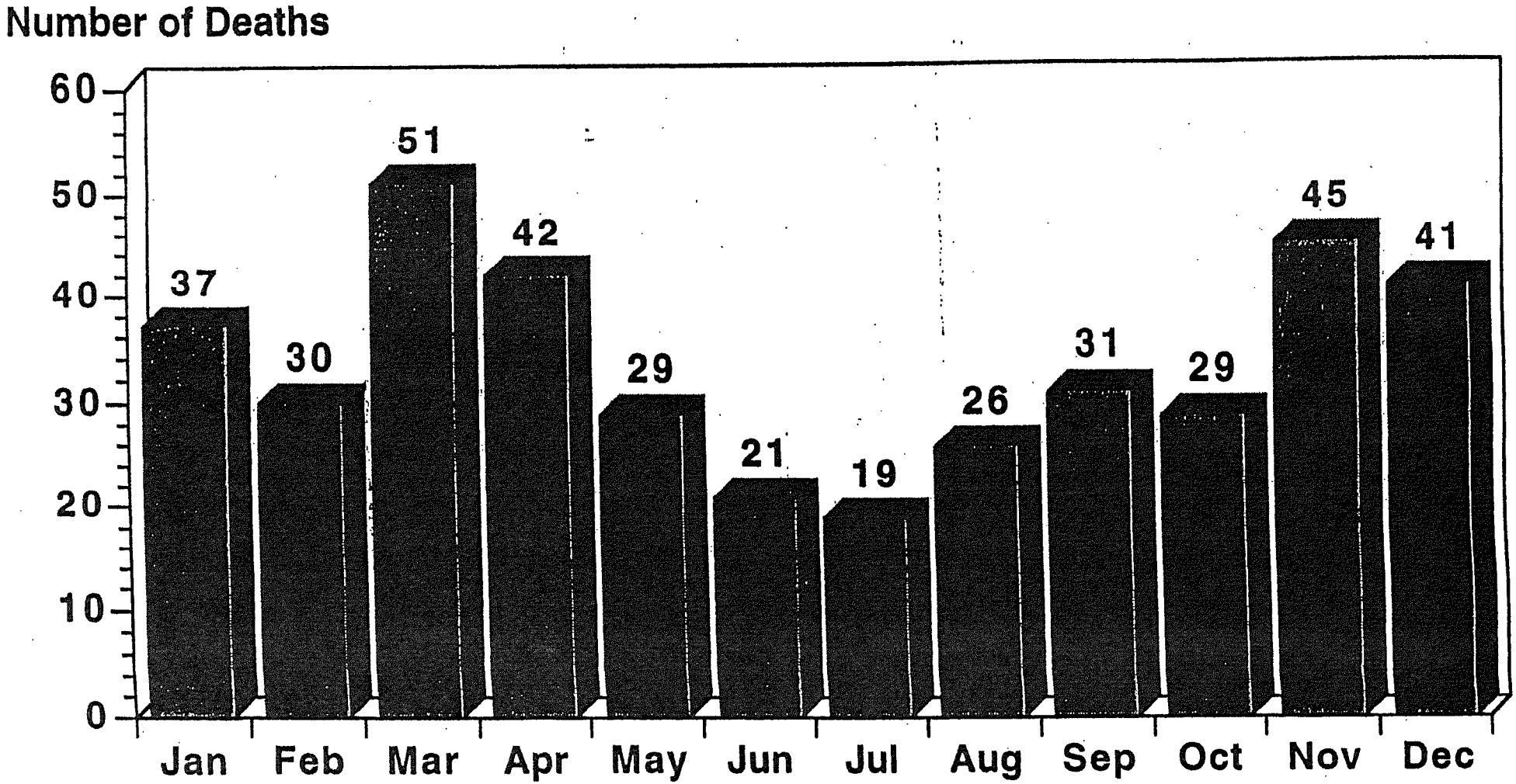
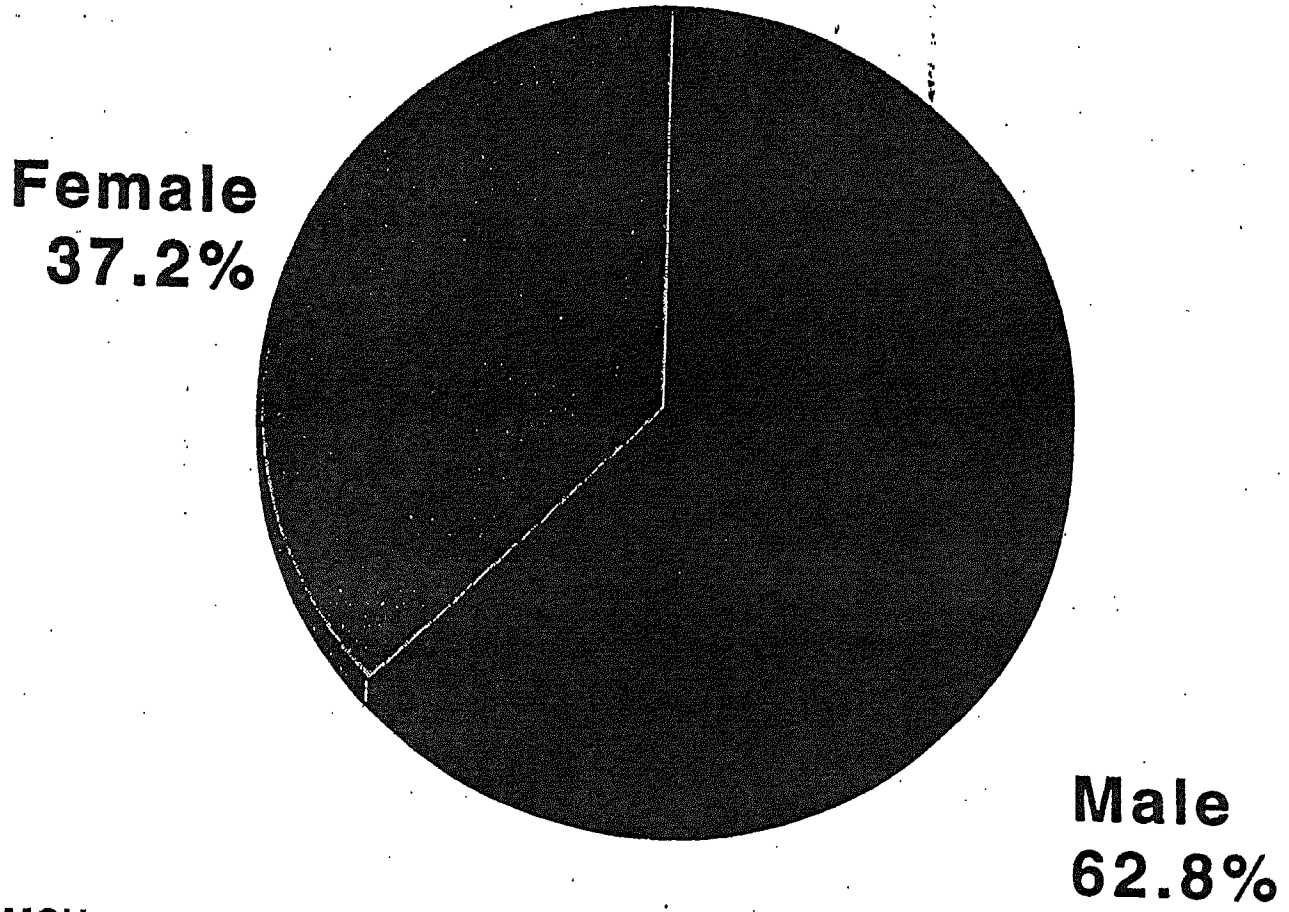
Indiana SIDS Deaths Time of Year 1991-1993



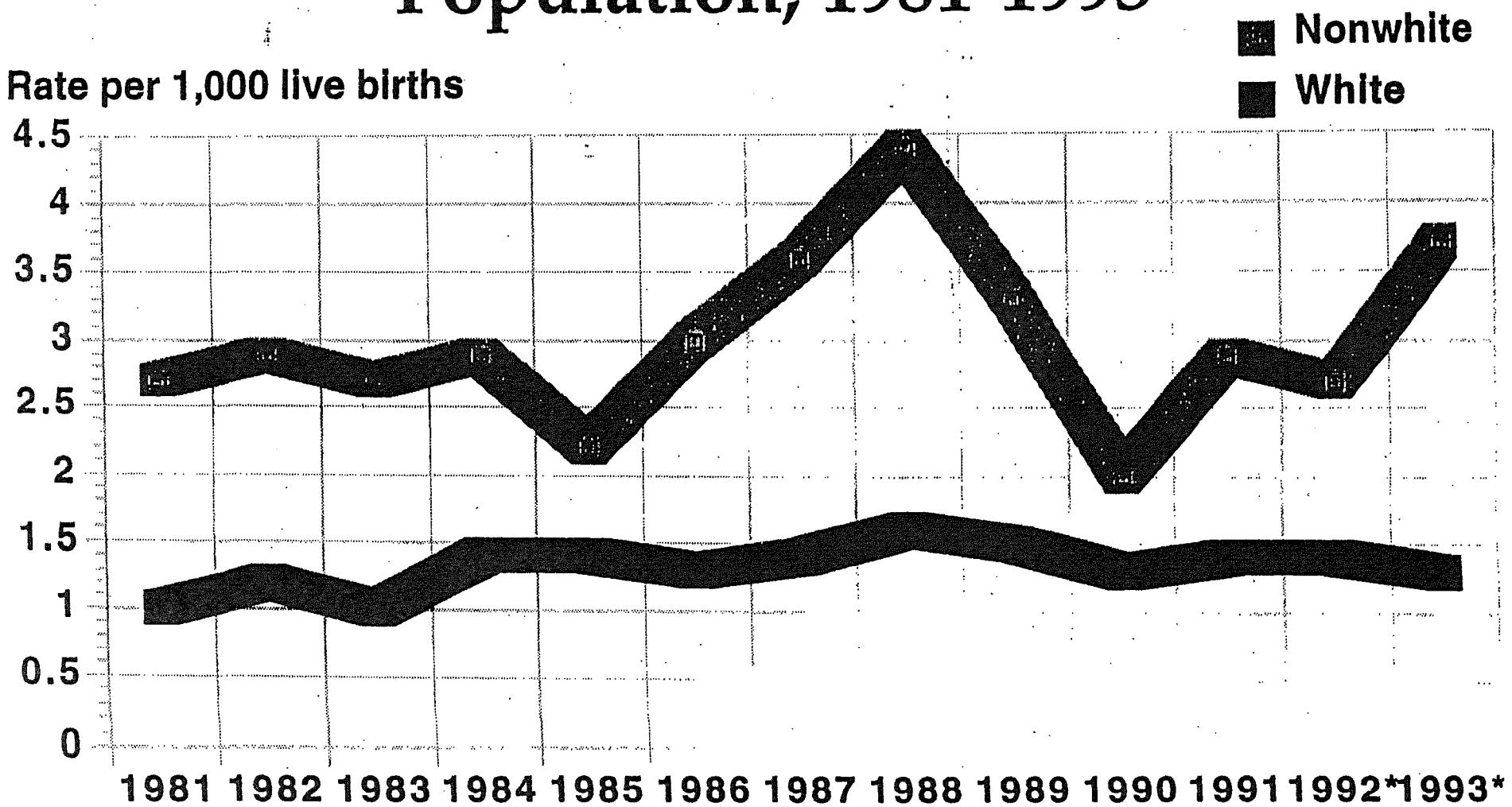
Source: ISDH, MCH

Indiana SIDS Deaths by Sex of Infant
1991-1993



Source: ISDH, MCH

Indiana SIDS Rate White vs. Nonwhite Population, 1981-1993

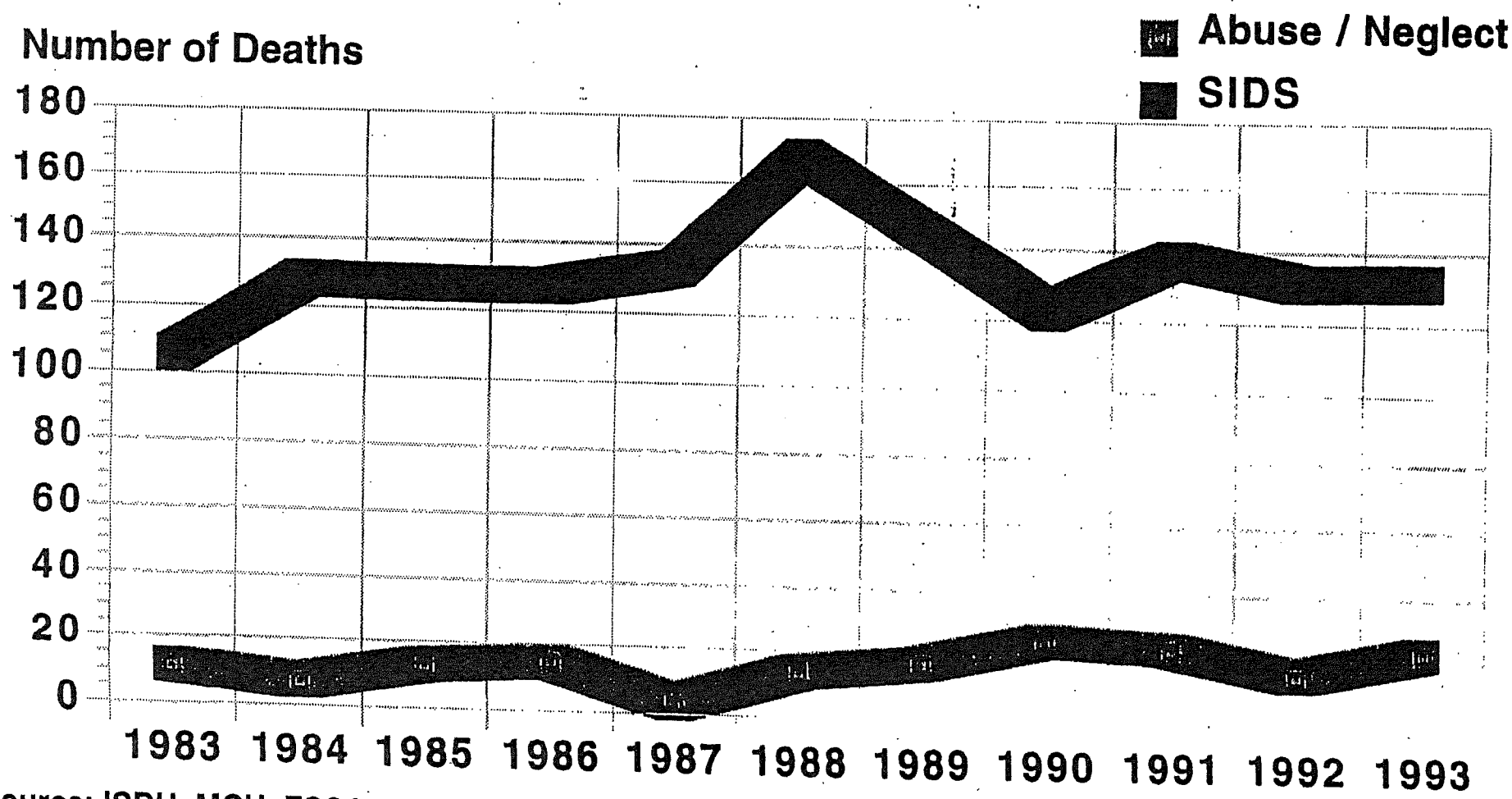


Source: ISDH, Public Health Research, MCH

*Provisional

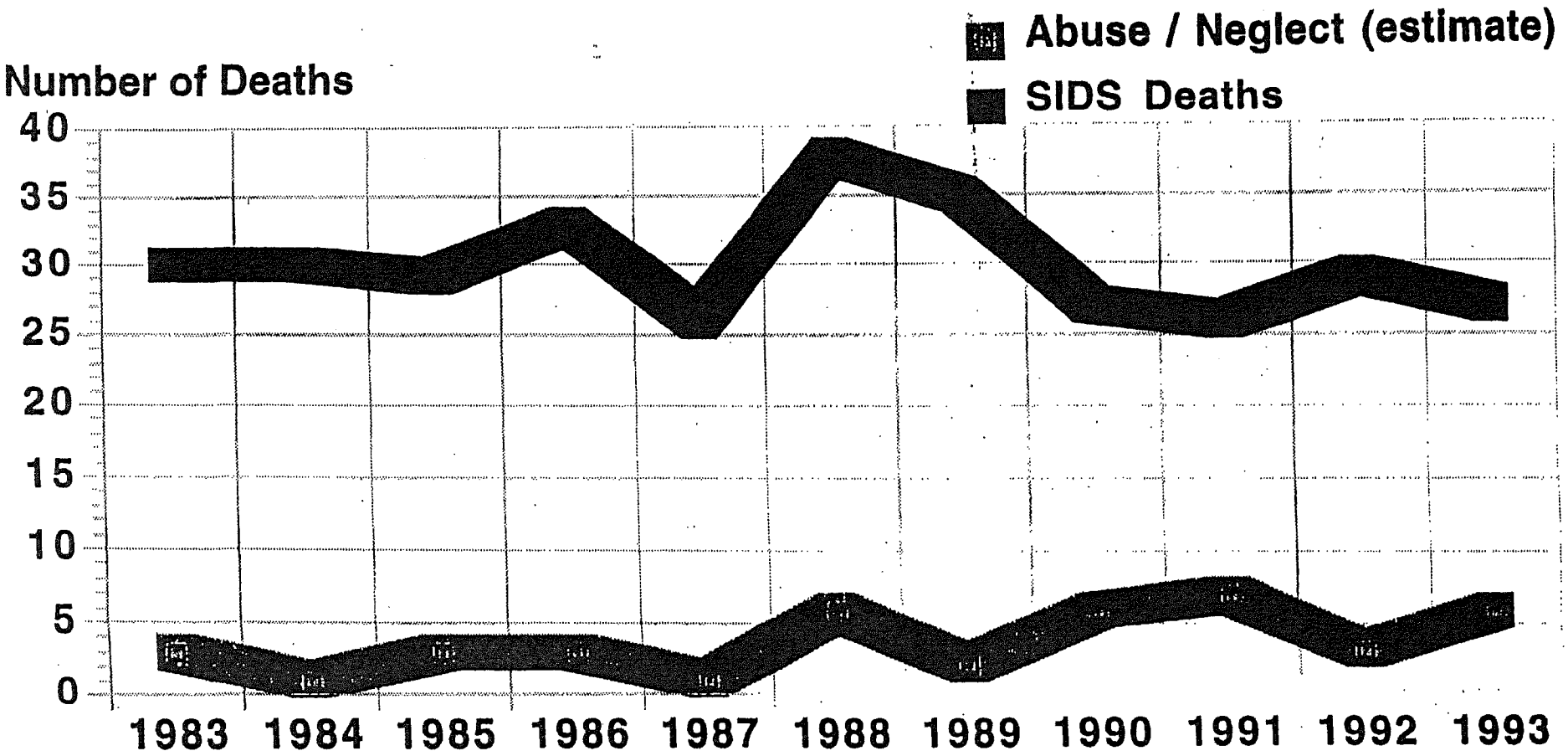
SLIDE 10

Infant Deaths 1 Year and Under, SIDS vs. Abuse/Neglect, Indiana , 1983-1993



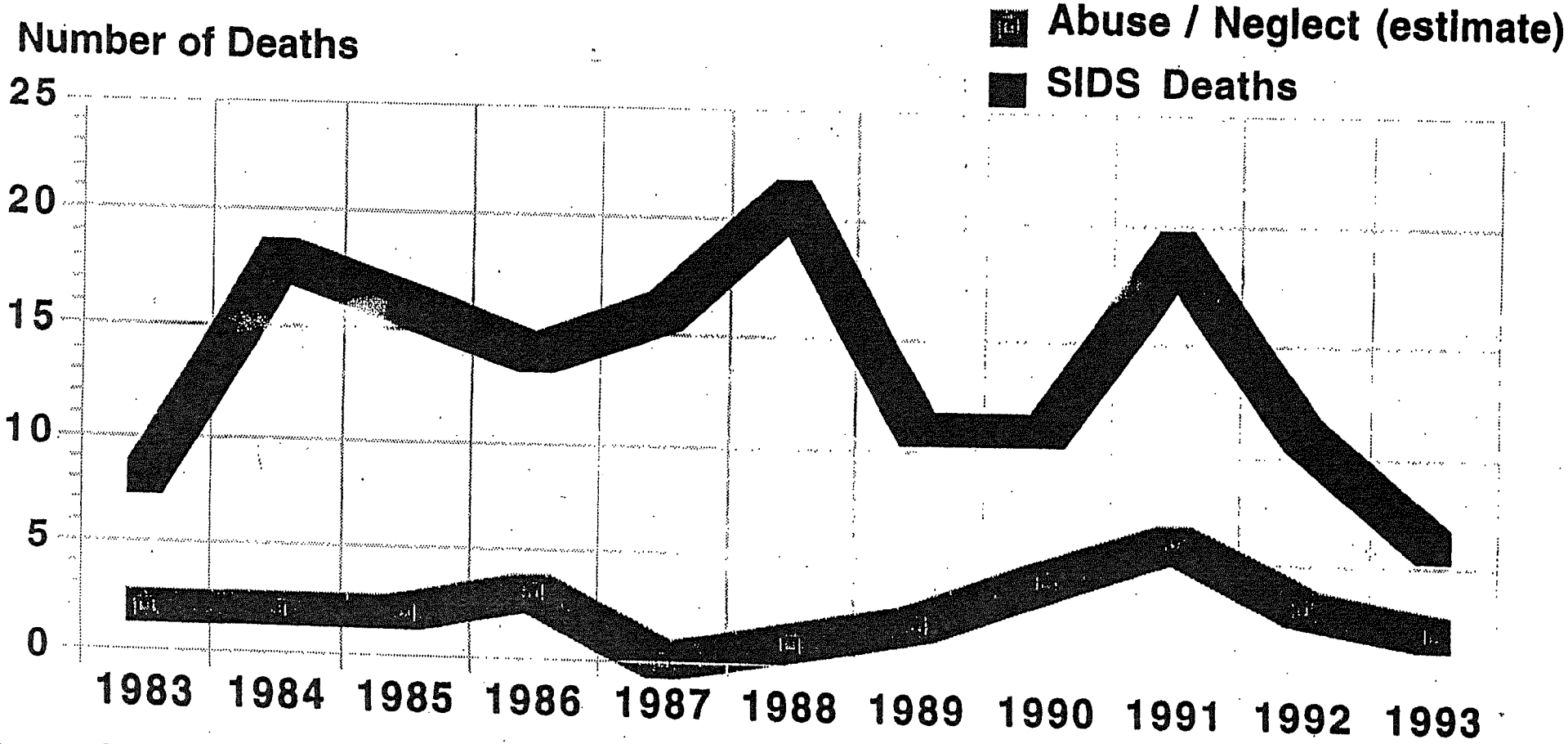
Source: ISDH, MCH, FSSA

Infant Deaths 1 Year and Under, SIDS vs. Abuse/Neglect, Marion County, Indiana 1983-1993



Source: ISDH, MCH, FSSA

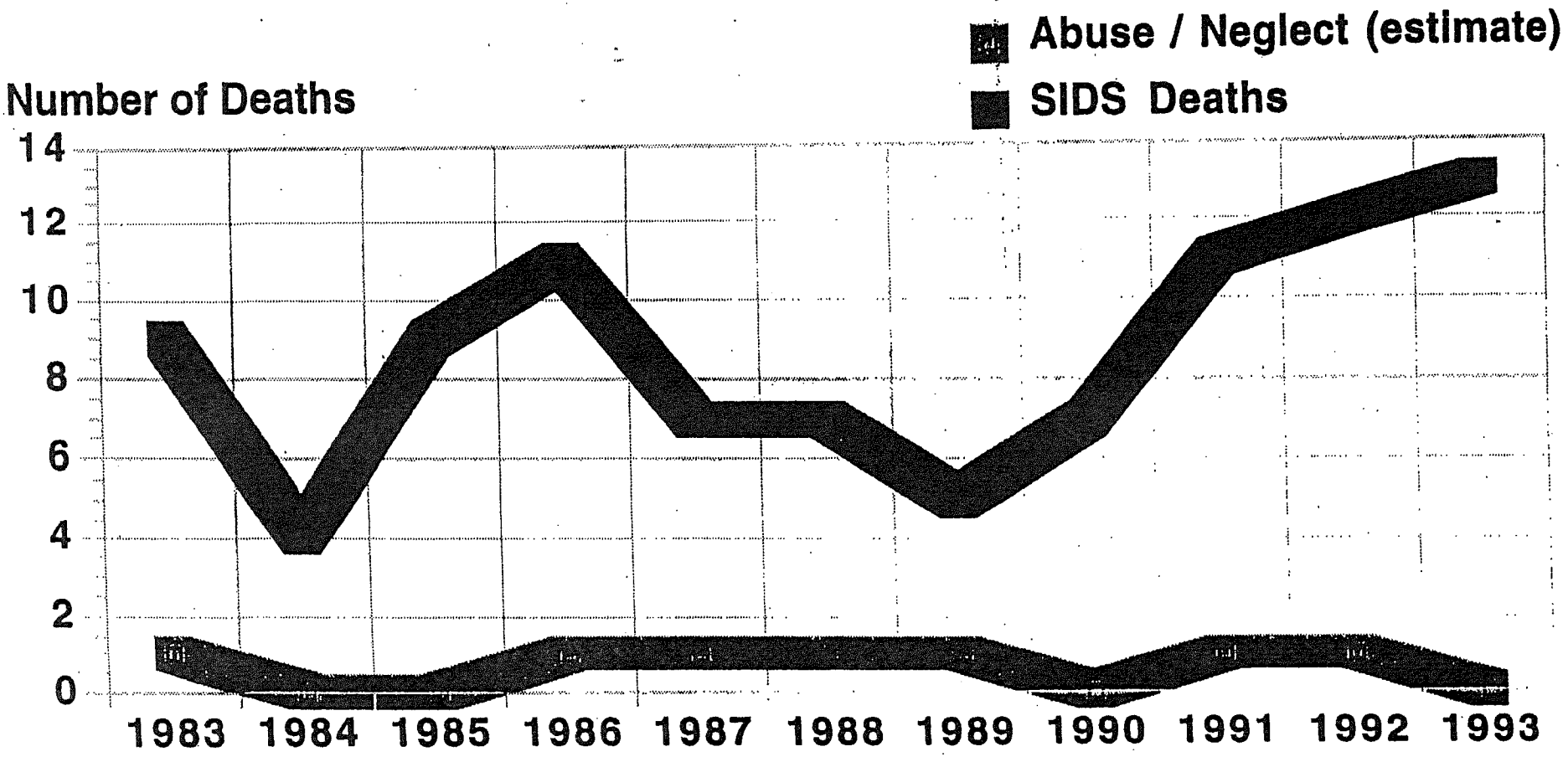
Infant Deaths 1 Year and Under, SIDS vs. Abuse/Neglect, Lake County, Indiana 1983-1993



Source: ISDH, MCH, FSSA

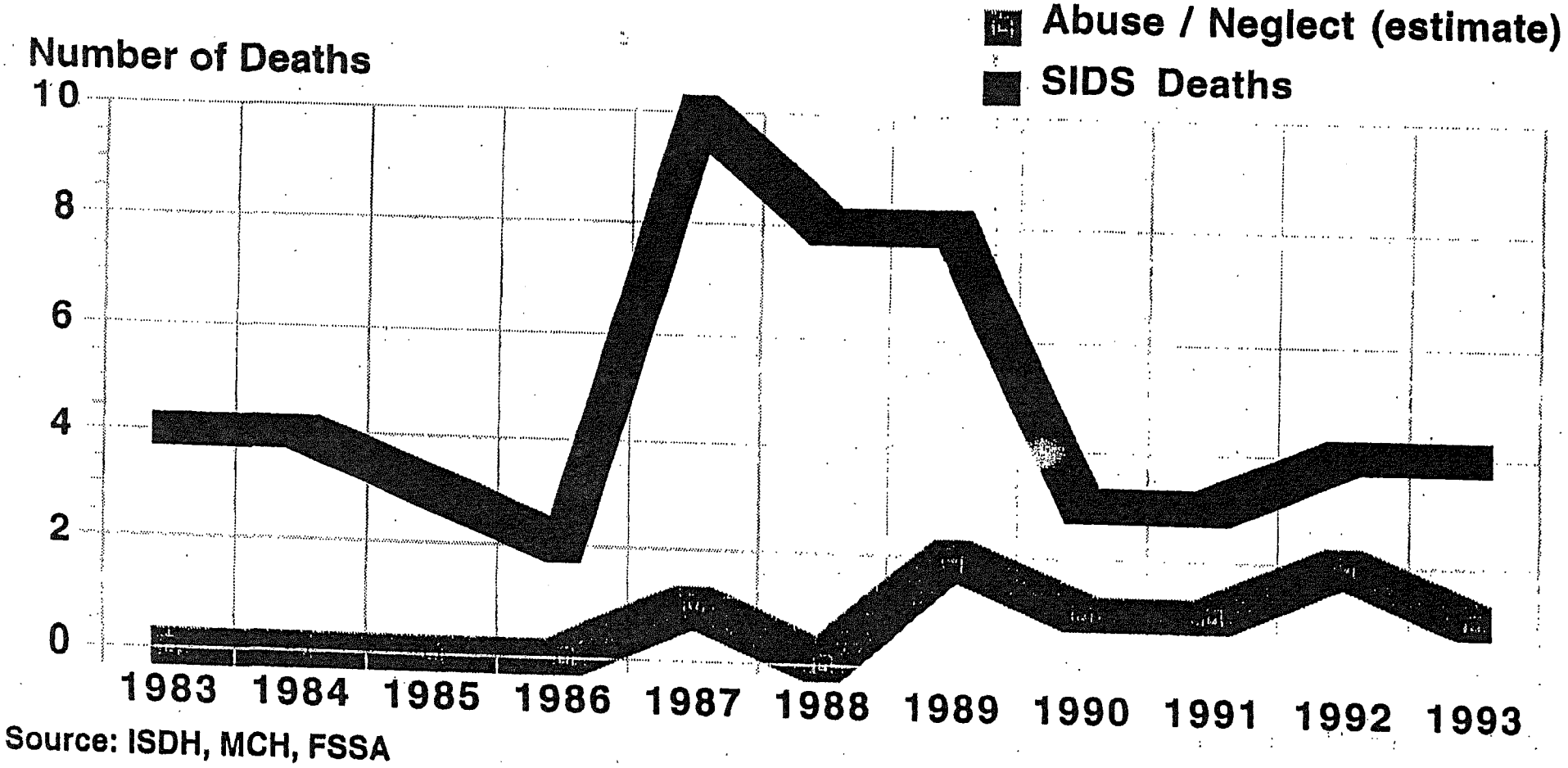
SLIDE 13

Infant Deaths 1 Year and Under, SIDS vs. Abuse/Neglect, Allen County Indiana, 1983-1993



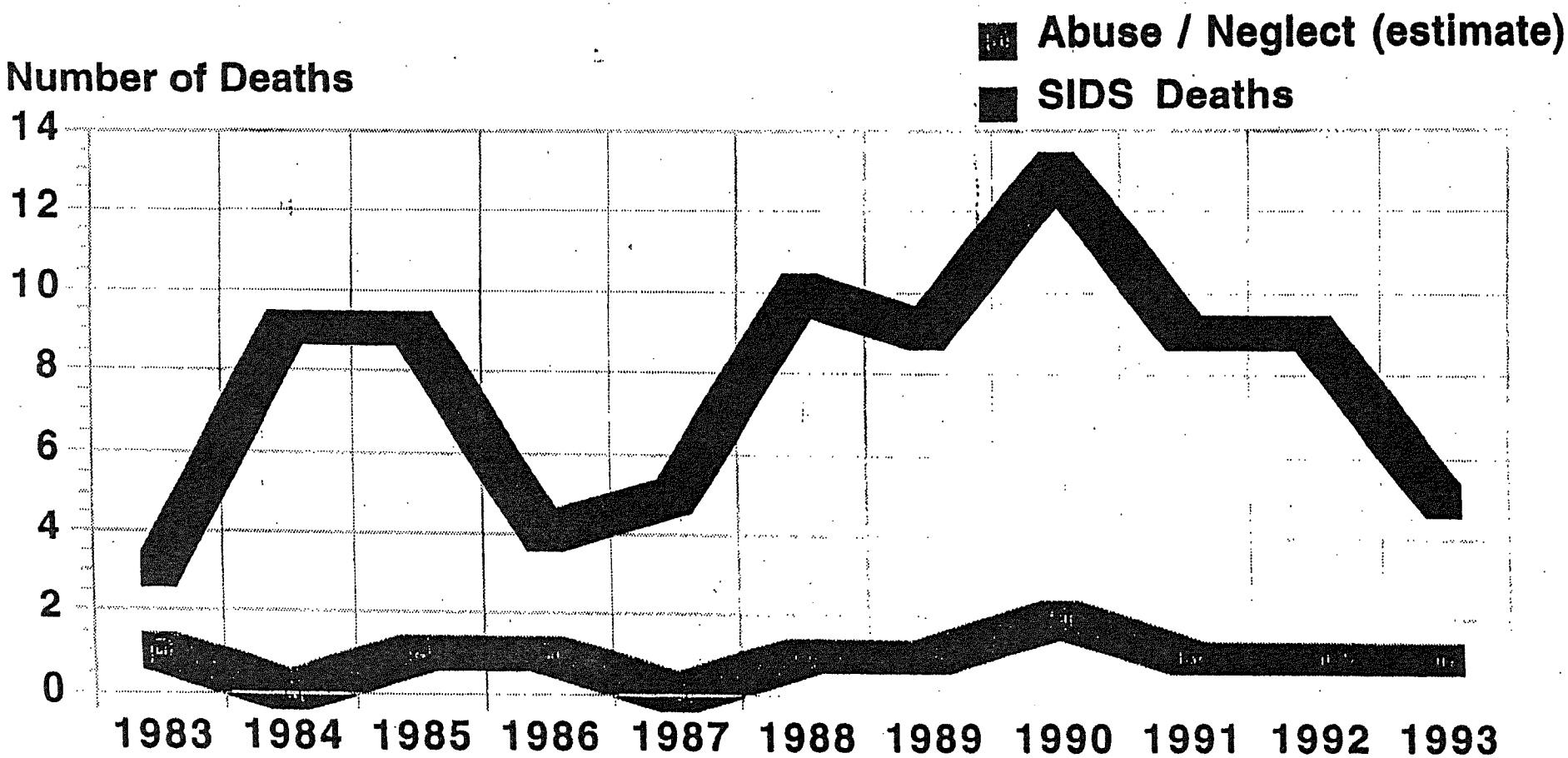
Source: ISDH, MCH, FSSA

Infant Deaths 1 Year and Under, SIDS vs. Abuse/Neglect, Elkhart County, Indiana 1983-1993



Source: ISDH, MCH, FSSA

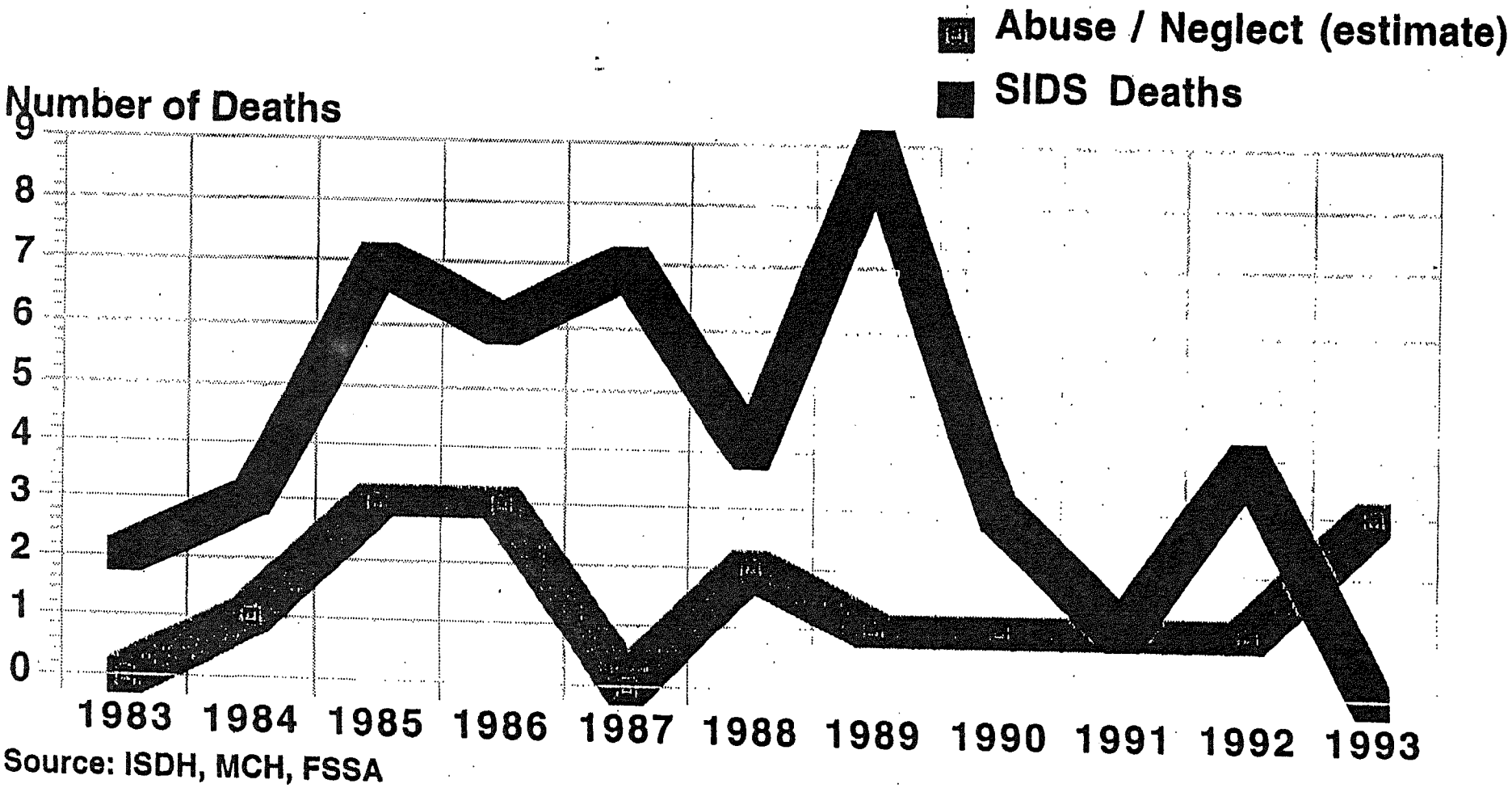
Infant Deaths 1 year and Under, SIDS vs. Abuse/Neglect, St. Joseph County, Indiana, 1983-1993



Source: ISDH, MCH, FSSA

SLIDE 16

Infant Deaths 1 year and Under, SIDS vs. Abuse/Neglect, Vanderburg County, Indiana, 1983-1993



Source: ISDH, MCH, FSSA

SLIDE 17

SIDS CASE MANAGEMENT SYSTEM

- Completely investigate the cause of death, including a complete autopsy and death scene investigation conducted in a sensitive manner.

- Consistenly use the term "Sudden Infant Death Syndrome" on death certificates

- Promptly notify the parents as to the preliminary results of the autopsy. The standard notification is within 24-48 hours after its completion

- Provide accurate information on SIDS and initial grief counseling for families. This is usually accomplished through the county health departments.

PARENTS PERSPECTIVE

The parents perspective has always been consistently evaluated as the most helpful and beneficial portion of the Sudden Infant Death Syndrome (SIDS) Training. It is an opportunity for first responders to hear a parent share the intimate details surrounding the death of their child. It is also a chance to gather suggestions from parents on what was and was not helpful at the time of their tragic loss. We strongly encourage you to include this segment in your program.

To aid you in your efforts, we are currently developing a Parent Speakers Bureau. As you begin to plan upcoming training sessions please call Barb Himes, Support Services of Indiana, Inc. at 317/882-2366 or 1(800)433-0746 to schedule a parent to speak at the training session.

If a parent is not available in your community, the following points should be covered for training and discussion along with the video which includes parent testimonials.

- Learn and use baby's name, if possible.

- Talk to parents/child care provider in simple, easily understood terms. They may be unable to think clearly and the simplest task becomes difficult. Do not use professional slang terms around the parents i.e., "The baby's pupils are blown."

- Give parents quiet time with baby. Explain to family that certain things have to be done, routine questions, picture taken, etc. It may be necessary to gently remind them, "You may have a little while longer with the baby, but remember we still have some things we need to do." Keep in mind, this is the first step in the families healing process. Although this may delay your job, please be patient as these memories will remain with the family forever.

- Treat baby with dignity and respect. Families can be given a lifetime of comfort by knowing their babies were cared for tenderly. Transport baby in an appropriate manner. Some parents have anguished over seeing their baby placed on the floor board of a truck or trunk of a car.

- Treat family/child care provider with compassion. There's no need to try to say anthing profound, a simple "I'm sorry" or a gentle pat on the hand or rub on the back would be comforting. Avoid cliches such as "It's God's Will", "I know how you feel" or "You can have another baby."

REMEMBER.....Parents generally don't mind what has to be done, just the manner in which its done

- Dismiss extra responders. Too many cause confusion.

- Help parents/child care provider identify support systems.

family	friends
neighbors	clergy

- Inform family what will happen next
    - Being transported to hospital
    - Where autopsy is being performed
    - When baby will arrive at funeral home
    - Any known information
    - visit from Public Health Nurse
- Act as a buffer if parents are hysterical and/or emotions are running high. You may need to remind colleagues at this time, this is a death scene, not a crime scene. Keep an open mind.
- Follow-up with parents
    - Have they received autopsy results?
    - Have they received death certificate?
    - Letting them know you are thinking of them - sympathy card
    - Have you received grief literature?

IT'S NEVER TOO LATE FOR FOLLOW-UP

- Give phone number of local parent support group, bereavement group, public health nurse or the Family Helpline at the Indiana State Department of Health at 1-800-433-0746.

MOST IMPORTANTLY...PLEASE, PLEASE, PLEASE, TAKE CARE OF YOURSELF - INFANT RUNS ARE PHYSICALLY AND MENTALLY DRAINING. IF YOU DON'T TAKE CARE OF YOURSELF, YOU CAN'T TAKE CARE OF ANYONE ELSE.

IT IS IMPORTANT TO UTILIZE ANY CRITICAL INCIDENT STRESS DEBRIEFING PROGRAM AVAILABLE. IF ONE IS NOT AVAILABLE IN YOUR AREA, YOU MAY WISH TO CONSIDER ORGANIZING ONE.

INSTRUCTORS DISCUSSION GUIDE

TITLE:	"Finding Answers With Compassion" [Infant Death Investigation Guide
PURPOSE:	Training video primarily for police and coroners on how to respond to sudden deaths in children from birth to 2 years of age.
LENGTH:	Approximately 45 minutes.
PRODUCED BY:	Indiana State Department of Health SIDS Project in cooperation with the Indiana Commission on Forensic Sciences and the Central and Northern Indiana Affiliates of the National SIDS Alliance.

Description

The video includes a reenactment of a sudden infant death and provides suggestions to police officers and coroners on how to respond to families in a supportive fashion at the time of death and during follow-up investigations. It also includes unscripted testimonials from parents who have experienced a sudden infant death describing their reactions to the police and coroner and the need for an autopsy.

The video is narrated by Dr. John Pless, Chairman, Department of Pathology, Indiana School of Medicine. Dr. Pless, a Forensic Pathologist, performs numerous autopsies on both adults and infants for various Coroners Offices throughout the state. He is the State's leading expert in cause of death determination and has provided expert testimony in numerous criminal and civil court cases.

Also appearing in the video is David Wade, Chief of Police, City of Gary, Indiana. As a Homicide Detective, Chief Wade responded to numerous infant deaths and has been active in the SIDS Community since his first experience with a SIDS death which he candidly describes in the video.

For Additional Information Regarding the Video Contact:

Larry Humbert, A.C.S.W.
SIDS Project Coordinator
or
Barb Himes, SIDS Parent Consultant
Indiana State Department of Health
1330 W. Michigan Street, Room 236N
Indianapolis, Indiana 46206-1964
317/633-0722 or 317/633-8466
1-(800)-433-0746 [Indiana]

WHY WAS THE VIDEO PRODUCED?

Since August 1991, the Indiana State Department of Health SIDS Project has conducted nearly 50 SIDS in-service trainings to police departments, fire fighters, E.M.S. personnel and coroners offices throughout the State. Common themes from the evaluations indicate the vast majority of participants have not received this type of training and were unaware of the parents feelings and how they could help. Most law enforcement personnel indicated they were trained to consider all infant deaths as homicides until proven otherwise and some felt the response we advocated was in conflict with their crime scene training. Many participants also stated that the personal story by a SIDS parent was the most beneficial aspect of the training so you are encouraged to include a parent in your training if possible. Also, our experience is that police officers respond better to trainings specifically for them, as opposed to attending trainings for other first responders.

KEY POINTS FOR FIRST RESPONDERS:

- Approach each situation with an open mind regarding the cause of death.
- Not all death scenes are crime scenes. In fact, the majority of infant deaths are due to natural causes.
- You can respond to families in a supportive fashion and still conduct a good investigation.
- Parents should be viewed as survivors, not suspects.
- Police, coroners and all others at the scene must work together and communicate with each other.

COMMON THEMES FROM PARENT TESTIMONIALS:

Many of the parents statements could be perceived as being rather strong. This is likely due to the type of treatment they received at the time of their child's death. The parents with the most positive statements and calmer affect [black mother and mother with short red hair] were treated in a supportive fashion. Many parents spoke of the importance of keeping them informed about the progress of the autopsy results and when the final report will be available. Several parents expressed tremendous frustration with the lack of communication from the coroner.

BACKGROUND INFORMATION ON THE INFANT'S DEATH DESCRIBED IN THE OPENING TESTIMONIAL [AMBER]:

Amber died at 14 months of age approximately 5 months before the filming of the video. Despite the performance of a complete autopsy, including microscopic and toxicology studies, the cause of death was listed as "Undetermined". The broken back the mother describes which was discovered during the autopsy can be a common finding in child abuse cases. However, in this case there was no external wounding accompanying these severe deep injuries which were inflicted by the young inexperienced E.M.T. who attempted a Heimlick Maneuver on this small child. The unnecessary accusations against the mother and exaggeration of the injuries were made by the coroner and sheriff responding to a simple request from the forensic pathologist for more information concerning how the child was found and what was done during resuscitation. It appears the mother still has some unresolved feelings regarding this finding.

POSSIBLE QUESTIONS FOR DISCUSSION REGARDING THIS CASE:

- This unusual case was included in the video to reinforce the importance of the autopsy in explaining suspicious findings and the need to approach these deaths with an open mind

- This case also reinforces the importance of communication between E.M.T.'s, police officers, coroners and pathologists regarding resuscitation efforts and other important observations at the scene of death. Had this communcation occurred prior to the autopsy, the unnecessary accusations against the mother may not have occurred.

- This senario also illustrates the need for proper death scene investigations. Questioning the mother at her residence would have been less traumatic for her and would have afforded the opportunity for a more thorough investigation of the scene of death.

SUGGESTED HANDOUTS FOR ALL TRAINING PARTICIPANTS

- What is SIDS
- SIDS and Emergency Medical Personnel
- Parents and The Grieving Process
- How To Distinguish Between SIDS and Child Abuse/Neglect

Not Included in Instructors Resource Packet

- SIDS Blue Card
- Finding Answers With Compassion
- If You Would Be An Effective Comforter to Bereaved Parents
- Discussing The Autopsy
- Facts About SIDS for Police Officers

What Is SIDS?

Sudden Infant Death Syndrome (SIDS) is the "sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history" (Willinger et al., 1991).

What Are the Most Common Characteristics of SIDS?

Most researchers now believe that babies who die of SIDS are born with one or more conditions that make them especially vulnerable to stresses that occur in the normal life of an infant, including both internal and external influences. SIDS occurs in all types of families and is largely indifferent to race or socioeconomic level. SIDS is unexpected, usually occurring in otherwise apparently healthy infants from 1 month to 1 year of age. Most deaths from SIDS occur by the end of the sixth month, with the greatest number taking place between 2 and 4 months of age. A SIDS death occurs quickly and is often associated with sleep, with no signs of suffering. More deaths are reported in the fall and winter (in both the Northern and Southern Hemispheres), and there is a 60-to-40-percent male-to-female ratio. A death is diagnosed as SIDS **only** after all other alternatives have been eliminated: SIDS is a diagnosis of exclusion.

What Are Risk Factors for SIDS?

Risk factors are those environmental and behavioral influences that can provoke ill health. Any risk factor may be a clue to finding the cause of a disease, but risk factors in and of themselves are not causes.

Researchers now know that the mother's health and behavior during her pregnancy and the baby's health before birth seem to influence the occurrence of SIDS, but these variables are not reliable in predicting how, when, why, or if SIDS will occur. Maternal risk factors include cigarette smoking during pregnancy; maternal age less than 20 years; poor prenatal care; low weight gain; anemia; use of illegal drugs; and history of sexually transmitted disease or urinary tract infection. These factors, which often may be subtle and undetected, suggest that SIDS is somehow associated with a harmful prenatal environment.

How Many Babies Die From SIDS?

From year to year, the number of SIDS deaths tends to remain constant despite fluctuations in the overall number of infant deaths. The National Center for Health Statistics (NCHS) reported that, in 1988 in the United States, 5,476 infants under 1 year of age died from SIDS; in 1989, the number of SIDS deaths was 5,634 (NCHS, 1990, 1992).

However, other sources estimate that the number of SIDS deaths in this country each year may actually be closer to 7,000 (Goyco and Beckerman, 1990). The larger estimate represents additional cases that are unreported or underreported (should have been reported as SIDS cases but were not).

When considering the overall number of live births each year, SIDS remains the leading cause of death in the United States among infants between 1 month and 1 year of age and second only to congenital anomalies as the leading overall cause of death for all infants less than 1 year of age.

How Do Professionals Diagnose SIDS?

Often the cause of an infant death can be determined only through a process of collecting information, conducting sometimes complex forensic tests and procedures, and talking with parents and physicians. When a death is sudden and unexplained, investigators, including medical examiners and coroners, use the special expertise of forensic medicine (application of medical knowledge to legal issues). SIDS is no exception.

Health professionals make use of three avenues of investigation in determining a SIDS death:

(1) the autopsy,

(2) death scene investigation, and,

(3) review of victim and family case history.

The Autopsy

The autopsy provides anatomical evidence through microscopic examination of tissue samples and vital organs. An autopsy is important because SIDS is a diagnosis of exclusion. A definitive diagnosis cannot be made without a thorough postmortem examination that fails to point to any other possible cause of death. Also, if a cause of SIDS is ever to be uncovered, scientists will most likely detect that cause through evidence gathered from a thorough pathological examination.

A Thorough Death Scene Investigation

A thorough death scene investigation involves interviewing the parents, other caregivers, and family members; collecting items from the death scene; and evaluating that information. Although painful for the family, a detailed scene investigation may shed light on the cause, sometimes revealing a recognizable and possibly preventable cause of death.

Review of the Victim and Family Case History

A comprehensive history of the infant and family is especially critical to determine a SIDS death. Often, a careful review of documented and anecdotal information about the victim's or family's history of previous illnesses, accidents, or behaviors may further corroborate what is detected in the autopsy or death scene investigation.

Investigators should be sensitive and understand that the family may view this process as an intrusion, even a violation of their grief. It should be noted that, although stressful, a careful investigation that reveals no preventable cause of death may actually be a means of giving solace to a grieving family.

What SIDS Is and What SIDS Is Not

SIDS Is:

- the major cause of death in infants from 1 month to 1 year of age, with most deaths occurring between 2 and 4 months
- sudden and silent—the infant was seemingly healthy
- currently, unpredictable and unpreventable
- a death that occurs quickly, often associated with sleep and with no signs of suffering
- determined only after an autopsy, an examination of the death scene, and a review of the clinical history
- designated as a diagnosis of exclusion
- a recognized medical disorder listed in the International Classification of Diseases, 9th Revision (ICD-9)
- an infant death that leaves unanswered questions, causing intense grief for parents and families

SIDS Is Not:

- caused by vomiting and choking, or by minor illnesses such as colds or infections
- caused by the diphtheria, pertussis, tetanus (DPT) vaccines, or other immunizations
- contagious
- child abuse
- the cause of every unexpected infant death

Any sudden, unexpected death threatens one's sense of safety and security (Corr, 1991). We are forced to confront our own mortality. This is particularly true in a sudden infant death. Quite simply, babies are not supposed to die. Because the death of an infant is a disruption of the natural order, it is traumatic for parents, family, and friends. The lack of a discernible cause, the suddenness of the tragedy, and the involvement of the legal system make a SIDS death especially difficult, leaving a great sense of loss and a need for understanding.

For Additional Information on SIDS, Contact:

American SIDS Institute, 6065 Roswell Road, Suite 876, Atlanta, GA 30328, (800) 232-7437, (800) 847-7437 (within GA), (404) 843-1030, (404) 843-0577 (fax)

Association of SIDS Program Professionals (ASPP), c/o Massachusetts Center for SIDS, Boston City Hospital, 818 Harrison Avenue, Boston, MA 02118, (617) 534-7437, (617) 534-5555 (fax)

National Sudden Infant Death Syndrome Resource Center (NSRC), 8201 Greensboro Drive, Suite 600, McLean, VA 22102-3810, (703) 821-8955, (703) 821-2098 (fax)

Southwest SIDS Research Institute, Inc., Brazosport Memorial Hospital, 100 Medical Drive, Lake Jackson, TX 77566, (409) 299-2814, (800) 245-7437, (409) 297-6905 (fax)

Sudden Infant Death Syndrome Alliance, 10500 Little Patuxent Parkway, Suite 420, Columbia, MD 21044, (800) 221-7437, (410) 964-8000, (410) 964-8009 (fax)

References:

Corr, C.A., Fuller, H., Barnickol, C.A., and Corr, D.M. (Eds). *Sudden Infant Death Syndrome: Who Can Help and How*. New York: Springer Publishing Co., 1991.

Goyco, P.G., and Beckerman, R.C. "Sudden Infant Death Syndrome." *Current Problems in Pediatrics* 20(6):299-346, June 1990.

National Center for Health Statistics. "Advanced Mortality Statistics for 1989." *Monthly Vital Statistics Report*, Vol. 40, No. 8, Supp. 2, January 7, 1992, p. 44.

National Center for Health Statistics. "Advance Report of Final Mortality Statistics, 1988." *Monthly Vital Statistics Report*, Vol. 39, No. 7, Supp. 1990, p. 33.

Willinger, M., James, L.S., and Catz, C. "Defining the Sudden Infant Death Syndrome (SIDS): Deliberations of an Expert Panel Convened by the National Institute of Child Health and Human Development." *Pediatric Pathology* 11:677-684, 1991.

This publication was produced by the National Sudden Infant Death Syndrome Resource Center, 8201 Greensboro Drive, Suite 600, McLean, VA 22102, (703) 821-8955, (operated by The Circle, Inc.). The Resource Center is an affiliate of the National Center for Education in Maternal and Child Health and is a service of the U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, Maternal and Child Health Bureau.

This publication is not copyrighted; it may be reproduced in whole or in part without permission. However, in accordance with accepted publishing standards, it is requested that proper credit be given to the source(s). The views expressed in this publication do not necessarily reflect the views of the sponsoring agency.

Indiana State Department of Health
SUDDEN INFANT DEATH SYNDROME AND EMERGENCY MEDICAL PERSONNEL

Many people have never heard of the Sudden Infant Death Syndrome (SIDS). When it occurs, there is often much confusion and misinformation relating to the cause of death. Since SIDS victims seem to have been healthy prior to death-which occurs suddenly, swiftly, and silently-the grieving parents are jolted by the shock and pain of an unexpected tragedy. Their aching emptiness is rapidly filled with unrelenting feelings of guilt. There is an endless stream of questions and wondering-"I should have noticed something." "I should have taken him to the doctor." "If only I'd been with the baby; I shouldn't have left her with a sitter." "I wish I had checked the baby earlier." These and similar thoughts all imply feelings of guilt and responsibility for the death. However, it seems to be nearly impossible to avoid them. There are several reasons for this:

⇒ Researchers have recently made significant progress in understanding SIDS, however, the exact cause of death remains unexplained!
⇒ There is no known method of predicting or preventing SIDS.
⇒ The death is unexpected. It occurs without warning-without a cry or struggle.
⇒ Most people are not well informed about SIDS. Parents are usually the targets of well-meaning but accusatory advice such as "You shouldn't have done this." or "Next time you better do this."

A baby depends upon his or her parents for every need. When these needs are not met, the parents feel an overwhelming guilt and responsibility for having "failed".

All of these things contribute to the confusion of SIDS parents. One minute, they have a seemingly healthy, happy baby; the next minute, their baby is dead. "What went wrong?" "Why?"

At the present time, the answer to these questions are not fully understood. But there are many things we do know and understand about SIDS—commonly called "crib death".

By definition, SIDS is the sudden, unexpected death of an infant under 1 year of age, that remains unexplained after a complete post mortem exam.. It is the number one cause of death in infants between the ages of three weeks and one year, although it occasionally happens to younger or older infants. Each year, approximately 6,000 infants in the United States succumb to crib death. In Indiana SIDS takes the lives of approximately 135 babies every year.

Typically, the infant seems to have been well cared for. Death usually occurs while in a sleeping state, either during a nap or during the night. As described in witnessed cases, the baby simply stops breathing—not uncommon for short periods of time in normal infants—then turns blue, and becomes limp. The baby does not gasp for breath or struggle and, therefore, it is felt that the death is not accompanied by suffering.

It may be several minutes or even hours before the baby is discovered, especially if the death occurs during the night. During this time, the appearance of the baby may change drastically. Areas of the body may take on the appearance of bruising due to postmortem lividity. There may be vomitus, fluid, or froth—often blood-tinged—in and around the mouth and nose. In some cases, there may be indentations on the body or the face of the infant may appear to be "squashed".

In these cases, the body is usually found wedged into a corner of the crib or pressed into the mattress due to a spasm which sometimes occurs at the time of death. In other instances, the baby will appear to be sleeping peacefully. Not to be overlooked is the fact that "crib death" does not always happen in a crib. It has been known to take place in infant carriers, car seats, and even while in the arms of parents.

In cases of sudden and unexpected infant death, five possible causes of death must be considered:

1. SIDS,
2. a diagnosed disease or condition,
3. an unsuspected disease or condition,
4. accidental injury
5. child abuse.

When the infant's history is compatible with SIDS—that is, an apparently healthy infant, under one year of age, and who died during a sleeping period—it is possible that the baby is a SIDS victim. However, a complete autopsy and death scene investigation are essential to accurately diagnosis SIDS.

Resuscitation is attempted if there is any possibility that the infant is still alive. There have been reports of infants within the susceptible age for SIDS who cease breathing spontaneously, but whose lives are saved by timely intervention. Various resuscitative measures have been successful, including tactile stimulation as well as cardiopulmonary resuscitation. However, it is not known if these cases are linked with SIDS, in which immediate resuscitative measures have been attempted to no avail.

SOME BASIC FACTS ABOUT SIDS

- A minor illness such as a common cold or the "sniffles" may have been present, but is not the cause of death.
- SIDS is not caused by smothering, choking, or abuse.
- SIDS is neither contagious nor hereditary.
- SIDS is neither predictable nor preventable.

THE ROLE OF EMERGENCY MEDICAL PERSONNEL

The role of emergency medical personnel is particularly difficult in a case of SIDS, in that they must respond not only to the infant's medical needs, but to the emotional needs of the parents as well. In most cases of SIDS, the infant has been dead for quite awhile by the time emergency medical technicians and/or paramedics and hospital emergency department staff encounter the crisis. Very often, it is up to the emergency medical personnel to respond to the "other victims"--the family of the baby.

This type of death may trigger emotional reactions resulting in family disintegration, divorce, alcoholism, or other serious psychological problems for the parents of the infant and their surviving children. Emergency health care personnel can minimize the potential psychiatric damage among family members.
A controversial issue concerns the question of whether resuscitation should be initiated when the infant has obviously been dead for some time. Some believe that attempts to do so will help the parents by letting them feel that something is being done. Others feel that such attempts are harmful in that false hopes are aroused, thereby hindering the parent's acceptance of reality. Response to this issue may vary from one situation or locality to another.

A related issue concerns problems regarding transport of the body. Local death investigation laws may prohibit removal of the body until the coroner is notified and in some cases until he visits the scene. As reported in cases of SIDS, this may result in confusion and misunderstanding over the reason for the delay, as the parents may interpret this as an accusation of foul play.

If the baby is taken to the hospital emergency department, a member of the emergency team should try to find a private waiting area and should stay with the family as much as possible. It may be helpful to take an account of recent events as well as an essential health history. The family physician or pediatrician who provided the baby's usual health care should be informed. This information may have immediate lifesaving implications or may later help determine the cause of death.

The family should be kept informed about what is being done for the baby, who the doctor is, and about any other questions they have. It may be helpful to call a minister, rabbi, or priest--or other close family members.

When the family is informed of the baby's death by the emergency physician or family physician (if present), the staff should be prepared for a variety of reactions, as individuals express grief differently. In the event of severe reactions, a counselor or social worker may be contacted for immediate crisis intervention.

If the parents have been told that SIDS is the probable cause of death and that a medical examination will be done to confirm the diagnosis, a member of the emergency team should try to answer their questions. It may be helpful to offer SIDS literature to the family. Let them know that a public health nurse will visit them to help them through this crisis.
Before the parents leave the emergency department they should be offered the opportunity to say "good-bye" to their baby. If they are not asked, they may be reluctant to ask and regret it later. For some parents, this will enable them to focus upon the reality of the death. They may wish to take a piece of the baby's clothing to hold onto. However, some parents will not feel comfortable being with the baby. On this matter, individual feelings should be respected.

There is no clear-cut method for assisting SIDS family. The most effective approach to these families is a sensitive and caring attitude. By being knowledgeable and sensitive to the needs of these families, emergency medical personnel can be of great assistance at a time when it is most needed.

FOR MORE INFORMATION, CONTACT:

THE STATEWIDE SIDS CASE MENAGEMENT SYSTEM
INDIANA STATE DEPARTMENT OF HEALTH
1330 WEST MICHIGAN STREET
INDIANAPOLIS, INDIANA 46206
TELEPHONE: 317/633-8459
TOLL-FREE 1-800-433-0746

Fact Sheet: Parents and the Grieving Process

Grief is an intense, lonely, and personal experience. Everyone learns about grief and grieving in the course of natural separations that occur during infancy and childhood and through their encounters with the deaths of loved ones. The death of an elderly loved one is mourned, but is usually expected. The death of a child, however, especially the death of an apparently healthy child, is an unexpected event. When a child dies not only does the death destroy the dreams and the hopes of the parents, but it also forces all family members to face an event for which they are unprepared. Most parents who experience the death of a child describe the pain that follows as the most intense they have ever experienced. Many parents wonder if they will be able to tolerate the pain, to survive it, and to be able to feel that life has meaning again.

The intense pain that parents experience when their child dies may be eased somewhat if they have insight into what has helped other parents overcome a similar grief. For example, one of the most important things for parents to realize is that recovery from the loss of a child takes time. Each person will have to establish his or her own method for recovery. There is no right or wrong way to grieve, but there is a pattern to the resolution of grief, and there is help available to family members. It is crucial that parents realize that they are not alone and that others have experienced such grief and have survived.

Often the first reaction of a parent after the death of a child is one of shock, disbelief, denial, or numbness. These reactions are instinctive and soften the impact of the death until the parent is better prepared to face the reality and the finality of the child's death. These reactions, as normal as they are, can be deceptive to others who are unacquainted with the grieving process. They may incorrectly assume that the parent either is strong and holding up well, or is insensitive and incapable of expressing his or her feelings about the loss. What they fail to realize is that shock, disbelief, denial, and numbness allow the parent to begin to face the tragic occurrence without losing control. Many parents have said that they seem to be "functioning in a fog" during the first few weeks after their child's death. "Some parents describe their experience at the wake or funeral as 'being an observer' or 'not really (being) emotionally involved.'"[1] All of these reactions are nature's way of helping the parents confront the death of their child. These reactions may last minutes, hours, days, or weeks. The parent will determine subconsciously when he or she is better able to face the death. Crying, or some similar emotional release, usually marks the end of this initial period of grief.

When the child's death becomes a reality to the family, intense suffering and pain usually begin. During the weeks and months that follow, many parents say that they are frightened by the intensity and the variety of the feelings that they experience. Crying, weeping, and incessant talking are all normal reactions. The parent may find that he or she feels very much alone. Parents may express their grief differently and may have difficulty sharing their feelings. Relatives and friends may be uncomfortable with the actuality of death, may be busy with their own lives, or may be unable to meet the parents' needs for comfort and support. For some parents, help may be obtained from the clergy, physicians, counselors, other bereaved parents, or willing friends and relatives. It is important to remember, however, that no one can resolve the parents' grief but the parents themselves. Resolution can be achieved only by experiencing and working through these emotions.

It is important for the parents to allow themselves full expression of the emotions they feel. Margaret S. Miles and others have concluded that it is essential for these emotional feelings to be expressed at the time when an emotion is first experienced. It is vital that emotions not be held in for a "correct time." It is necessary for parents to express their emotions, though not necessarily in words, to gain a resolution to their child's death. Emotions that parents may experience include:

- *Guilt*–As the parents try to understand the reason their child died, they may develop feelings of guilt. Parents may blame themselves for something they did in the present or the past, or for something they neglected to do. Also, each parent might blame the other. "If only" becomes a familiar phrase. Many times parents feel guilty when thinking of all the things that they wish they had done with their child. For instance, a father may feel guilty for not having spent more time with his child. Guilty feelings may also arise in the mother who thinks, "If only I hadn't returned to work." And either parent could feel regret for not having given the child something that he or she wanted. In most instances there is no rational basis for these feelings. It can be extremely beneficial for parents to talk with people who will encourage the expression of these feelings, and who can help them to understand these feelings more clearly.

- *Anger*–Depending on his or her personality, a parent may express feelings ranging from mild anger to rage. Parents can feel angry at themselves, their spouse, the physician, or the child for having died. Religious beliefs may be questioned and parents may find themselves angry at a God who allows children to die. These thoughts, though normal and experienced by many grieving parents, may cause an extreme amount of anxiety. Anger that is left unreleased may be suppressed and may manifest itself at an inappropriate time or place or in an inappropriate manner. Anger can be expressed healthily and worked through in a number of ways: screaming in private, hitting something, or strenuous exercise.

- *Fear*–After the death of their child many parents experience an overall sense of fear that something else horrible is going to happen. Often, parents with older children become extremely overprotective of them. At the same time they may find themselves fearful of their responsibilities. After the death of their child, many parents find it is difficult to concentrate for any length of time. Their minds wander, making it difficult to read, write, or make decisions. Sleep may be disrupted, leaving parents overtired and edgy. Even in getting enough sleep, parents may still feel exhausted. Those in grief may experience physical symptoms centering around the heart, in the stomach, or throughout muscles. Many times parents feel an irresistible urge to escape. As normal as all these reactions are, grieving parents often fear that they are "going crazy." Talking about these feelings with other parents who have experienced a similar loss can be extremely helpful for some grieving parents.

- *Depression*–As the parents continue to work through their grief, depression often occurs. Depression can take different forms for different parents. Some parents may feel constantly "down," unhappy, or sad; others may feel worthless or as though somehow they have failed. Many are continually lethargic, tired, or listless. This may be an ideal time for parents, with the help of family or friends, to become involved in some type of activity. Caution should be taken to avoid frantic activity which, like running away, avoids facing the reality of the child's death. Grieved parents, in the midst of deep depression, may feel that life has little meaning for them. Occasionally thoughts of suicide may arise. Many parents say that thoughts of their child are constantly in the forefront of their minds. Aching arms, hearing the child cry, or continuing with routine tasks of caring for the child are all normal experiences for grieving parents. As the parents begin to recover, depression will lift slowly. "Down" times will come and go, but the time between the "downs" will become longer. It's a long, slow process that may take years. But resolution and recovery will come.

"No matter how deep your sorrow, you are not alone. Others have been there and will help share your load if you will let them. Do not deny them the opportunity."[2]

Resolution and Recovery

As the finality of the child's death becomes a reality for the parents, recovery occurs. Parents begin to take an active part in life and their lives begin to have meaning once again. The pain of their child's death becomes less intense but not forgotten. Birthdays, holidays, and the anniversary of the child's death can trigger periods of intense pain and suffering. As time passes, the painful days become less frequent. There is no set time in which recovery takes place after a child dies. The only comforting thought that one can give a parent is that it does occur; the process is slow, but it will happen. Parents need to be patient and loving with themselves, their spouses, and their families.

[1] Miles, M.S. *The Grief of Parents When a Child Dies*, Compassionate Friends, Oak Brook, IL 1978.

[2] Jensen, A.H. *Healing Grief*, Medic Publishing Co., P.O. Box O, Issaquah, WA, 1980.

FOR LOCAL REFERRALS AND ASSISTANCE, BEREAVED PARENTS MAY WISH TO CONTACT THE MUTUAL HELP GROUPS FOR PARENTS LISTED BELOW:

- The National SIDS Foundation
  10500 Little Patuxent Parkway, Suite 420
  Columbia, MD 21044
  (800) 221-7437

- SHARE
  National Headquarters
  St. Elizabeth's Hospital
  211 South Third Street
  Belleville, IL 62222
  (618) 234-2415

- The Compassionate Friends
  National Headquarters
  P.O. Box 3696
  Oak Brook, IL 60522-3696
  (312) 990-0010

- Pregnancy and Infant Loss Center
  1415 East Wayzata Boulevard
  Suite 22
  Wayzata, MN 55391
  (612) 473-9372

This Fact Sheet was produced by:
NATIONAL SIDS CLEARINGHOUSE
8201 Greensboro Drive, Suite 600
McLean, VA 22102
(703) 821-8955
Operated by The Circle, Inc.

The Clearinghouse is a service of:
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Health Resources and Services Administration
Bureau of Maternal and Child Health and Resource Development
SUDDEN INFANT DEATH SYNDROME PROGRAM

This publication is not copyrighted; it may be reproduced in whole or in part without permission. However, in accordance with accepted publication standards, the National SIDS Clearinghouse requests that proper credit be given to the source(s). The views expressed in this publication do not necessarily reflect the views of the sponsoring agency.

8/89

How To Distinguish Between SIDS and Child Abuse and Neglect

Sudden Infant Death Syndrome	*Child Abuse and Neglect*
Deaths: Indiana 130/yr--U.S. 6,000/yr Age Range: 3 weeks to 6 months When: More frequent in winter months	Deaths: Indiana 45/yr--U.S. 1,250 Death in infants: Indiana 18/yr--U.S. (estimate) 650/yr When: No seasonal difference
Physical Appearance: Exhibits no external signs of injury. Exhibits "natural" appearance of deceased baby: Lividity - settling of blood; frothy drainage from nose/mouth. Small marks (e.g., diaper rash) look more severe. Cooling/rigor mortis - takes place quickly in infants. (about 3 hours) Purple mottled markings on head and facial area. Appears to be well-developed, though may be small for age. Other siblings appear to be normal and healthy.	***Physical Appearance:*** Distinguishable and visible signs of injury Broken bone(s) Bruises Burns Cuts Head trauma (e.g., black eye) Scars Welts Wounds May be obviously malnourished. Other siblings may show patterns of injuries commonly seen in child abuse and neglect.
May Initially Suspect SIDS When: All of the above characteristics appear to be consistent with autopsy findings. **PLUS** Parents say the infant was well and healthy when put to sleep (last time seen alive).	***May Initially Suspect Child Abuse/Neglect When:*** All of the above characteristics appear to be consistent with autopsy findings Parents' story does not "sound right" or cannot account for all injuries on infant.

ARTICLES

- Guidelines for Emergency Responders

- The Family and Sudden Infant Death Syndrome

Sudden Infant Death Syndrome: Who Can Help and How
Corr et. al. Springer Publishing Company 1991

CHAPTER 8

Guidelines for Emergency Responders

Connie Guist and Judy E. Larsen

EMERGENCY RESPONDERS AND THEIR RESPONSIBILITIES

The support and care offered to surviving family members immediately following the sudden, unexpected death of an infant or young child greatly impact on how they cope with this tragedy long after the immediate crisis is over. No one can prevent the pain a family will feel or protect them from experiencing grief following a sudden infant death. However, if the professionals who help with the infant and interact with the infant's family immediately following the death are compassionate and knowledgeable, they can facilitate a more healthful recovery of the surviving family members from this devastating life event.

Providing sensitive care to families immediately following a sudden, unexpected infant death requires the involvement and cooperation of professionals from various specialty areas. Examples of people who have immediate contact with the family are: (1) the emergency medical dispatcher, usually the first person to hear a parent's plea for help; (2) the first professional arriving at the scene of a death; (3) the health care provider who confirms what family members fear but do not want to believe; and (4) the funeral director and the clergy who help the family with possibly their first experience with death. What is said and done (and *not* said and done) by these people will play an important role in determining how the death of the infant is viewed and interpreted by those most deeply touched by this tragic event.

It is important to provide intervention guidelines to the professionals who are often involved immediately following a sudden, unexpected infant death. This assures that families experiencing this crisis will be cared for in an effec-

tive manner. Those who respond to a sudden death of any nature represent a multilevel network of support personnel and are referred to by various titles from first responders to paramedics. Each represents a different level of knowledge and responsibility. To facilitate discussion in this chapter, the phrase "emergency medical (EM) personnel" refers to any medical personnel responding to a medical emergency in the community. Therefore, no distinction is made here between first responders, emergency medical technicians (EMTs), and paramedics. Further, there is no distinction here between volunteers and paid professional emergency service providers.

Because of the unanticipated nature of the death, other persons commonly involved immediately after a sudden infant death include representatives of the medical and legal system, such as the police, the medical examiner or coroner, emergency department staff, and pathologists. In this chapter, the phrase "emergency responders" refers to anyone responding to a citizen's call for help at the time of a sudden, unexpected death.

Many of the contacts families have with EM personnel may be brief. During the initial crisis, events often are blurred and specific details may be forgotten by the infant's family. However, grieving parents tend to remember those who were particularly helpful, as well as those who were perceived as not supportive or who made the situation more painful. It is important for emergency responders to provide a smooth transition from their care to other caregivers who will have more long-term contact with the infant's family. If the infant is transported to an emergency facility, the hospital emergency department staff and, frequently, clergy may be the next support people available to the family. After death has been confirmed, no matter where the infant's body is, contact with funeral service personnel generally occurs within a few hours of the death.

Three areas of responsibility are associated with the care initially provided following an infant's sudden death: clinical tasks; legal tasks; and human tasks. The clinical tasks relate to the practical, intervention, action-oriented activities of the emergency response. These include (but are not limited to) physical assessment of the infant, initiating basic life support measures, obtaining a history of events leading to the call for help, and determining what may be the best plan of intervention.

The legal tasks relate to protecting the rights of all persons involved, including the rights of the infant, the parent(s) and other family members, and the caretaker at the time of the death. Emergency responders are responsible for following the policies and procedures of their organization, collecting data about the events surrounding the crisis, and contacting the appropriate authorities. All EM personnel must be aware of legal mandates of their community and state related to sudden, unexpected infant death.

The third aspect, the human tasks are perhaps the most intangible and yet

the most challenging care responsibilities to address. Knowing what clinical care to provide while considering the legal constraints is only part of knowledgeable, compassionate care. The important aspect is *how* that care is provided. The people providing support must be caring individuals who have come to terms with their own feelings about death, are aware of normal grieving responses, and are able to avoid projecting onto a family what they *think* the family should be feeling (Smialek, 1978). All those who come in contact with sudden infant death, in essence, become victims. Acknowledging how the sudden death of an infant affects the professionals involved at the time of the death, as well as the family members, is essential to assure effective intervention. In order for caregivers to be effective, they must be aware of their own feelings before attempting to help others deal with their feelings.

These three areas of responsibility are interwoven. In the first moments of an emergency, clinical tasks tend to take priority without totally displacing legal and human concerns. After the initial crisis, the situation changes and other responsibilities may assume greater prominence. Thus, the order in which these tasks are addressed will vary in the discussion that follows.

THE CRISIS

No matter how much one attempts to prepare for responding to the sudden, unexpected death of an infant, it is impossible to anticipate fully each situation. For the most part, many aspects of any suspected instance of Sudden Infant Death Syndrome (SIDS) will seem familiar to the seasoned emergency responder, yet very few of the deaths can be considered ordinary or *typical*. Parents often have commented that their experience with a SIDS death was not typical. There was something out of the ordinary, something that made their situation unique. A parent may have been in the same room as the infant for some time before discovering its lifeless body. The person who found the child may have been an older sibling, another relative, or a day care provider. The mother may be a single parent who feels very much alone. The infant may have been riding in a car seat or sleeping in a camper. The body may have been found in an unusual or peculiar position, or in bed with the parents. The death of the infant may have been obvious to the parent(s), but they called the emergency number because they did not know what else to do. There are many circumstances which make each suspected SIDS death different from the typically described SIDS death. Therefore, the best approach to the sudden, unexpected death of an infant is to expect the unexpected.

It is difficult to outline a standard response to a sudden infant death. Who is

called upon for intervention and who responds depends on the local emergency response network. The protocol may require that the body be transported to a local hospital emergency room or that the medical examiner or coroner be called to the scene. Law enforcement personnel could be the county sheriff or the neighborhood police officer in a metropolitan community. Clergy from the family's church or synagogue may be the source of spiritual comforting or the pastoral care department at the hospital might be the family's first source of consolation. The body could be taken to the local hospital or morgue or it might be sent to a university-based or statewide laboratory for autopsy. There is no universal scenario for all circumstances.

At the moment a call for help is initiated, it is known only that there is a crisis which may involve the death of an infant and the cause of death is unknown. Only an autopsy can determine the actual cause of death. Therefore, it is best to make no assumptions about why the infant died. The general appearance of the infant may be misleading and it is imperative that emergency responders are knowledgeable about distinguishing between SIDS and child abuse or neglect. Since approximately 85% of such sudden, unexpected deaths are later confirmed to be SIDS, emergency responders are encouraged to give the parents the benefit of the doubt until an autopsy proves otherwise (Bureau of Community Health Services [BCHS], 1979).

Knowledge of the major causes of infant death also will guide the emergency responder's assessment of the crisis and facilitate accurate determination of the cause of death by the medical examiner or coroner. Although it is not the responsibility of emergency responders (apart from medical examiners or coroners) to determine the diagnosis or cause of death, Table 8.1 may be useful as a guide to differences between SIDS and child abuse or neglect. Other causes of sudden death in infants and young children include congenital birth defects, injury, and overwhelming infection (Jones & Weston, 1976).

GUIDELINES FOR RESPONSE

Before the Crisis Occurs

EM personnel have a responsibility to be prepared for the possibility of responding to a sudden, unexpected infant death at any time. Although this type of crisis may not occur frequently in any given area, it is essential that all components of the emergency medical system be ready to provide comprehensive, compassionate care. By following some basic guidelines, EM personnel can insure that everything possible has been done for the infant and family.

TABLE 8.1 How to Distinguish Between SIDS and Child Abuse and Neglect

Sudden Infant Death Syndrome	versus	Child Abuse and Neglect
Incidence: Deaths: 7,000/year Highest: 2 to 4 months of age When: More frequent in winter months		**Incidence:** Deaths: 1,000 to 4,000/year Deaths in infants: 300/year When: No seasonal difference
Physical Appearance: • Exhibits no external signs of injury. • Exhibits "natural" appearance of deceased baby: —Lividity—settling of blood; frothy drainage from nose/mouth —Small marks (e.g., diaper rash) look more severe —Cooling/rigor mortis—takes place quickly in infants (about 3 hours) • Purple mottled markings on head and facial area. • Appears to be well-developed baby, though may be small for age. • Other siblings appear to be normal and healthy.		**Physical Appearance:** • Distinguishable and visible signs of injury: —Broken bone(s) —Bruises —Burns —Cuts —Head trauma (e.g., black eye) —Scars —Welts —Wounds • May be obviously malnourished. • Other siblings may show patterns of injuries commonly seen in child abuse and neglect.
May Initially Suspect SIDS When: • All of the above characteristics appear to be accurate PLUS • Parents say that infant was well and healthy when put to sleep (last time seen alive).		**May Initially Suspect Child Abuse/Neglect When:** • All of the above characteristics appear to be accurate PLUS • Parents' story does not "sound right" or cannot account for all injuries on infant.

Note: The determination of whether the child is or is not a SIDS victim is the responsibility of the medical examiner or medical coroner. It is NOT the responsibility of the Emergency Medical Technician.
Source: Produced by the Department of Health, Education and Welfare (now the DHHS), office of Maternal and Child Health (Title V, Social Security Act), Contract HSH 240-7701.

These guidelines include anticipating the event and being prepared for the situation; assessing the situation; identifying what is needed in a particular situation; and being sensitive to the needs of the family.

Clinical Tasks

For emergency responders, continuing education is a vital part of obtaining current information about low-occurrence, high-impact situations like sudden infant death. Demonstrating competency in basic life support and advanced life support techniques for children also is essential. Refresher courses on the use of equipment and technical skills that may be used infrequently are required to have competent practitioners in the field. The immediate need of the family at the time of a medical emergency is for efficient action when EM personnel arrive.

Legal Tasks

Many EM systems have established policies regarding the care and transportation of victims of sudden infant death and their family members. Written policies and procedures should include guidelines about: (1) who responds to a pediatric medical emergency in the community; (2) what is the extent of on-the-scene treatment; (3) who will transport the infant; (4) how and where will the infant be transported; (5) who may or should accompany the infant during transport; (6) who is contacted to investigate the death; and (7) who is responsible for the pronouncement of death. Coordination among the various levels of the EM system is necessary in order to assure appropriate intervention at the time of a crisis. In other words, law enforcement agencies, fire departments, ambulance services, area hospitals, and the medical examiner or coroner's office must all determine the policies and procedures related to sudden infant death to assure that legal mandates are carried out.

Human Tasks

Knowing the community resources before the time a crisis occurs is also necessary to provide comprehensive support to families experiencing sudden infant death. It is essential that periodic review includes information on the emotional and psychological impact of sudden infant death, as well as technical skills. Are there local support groups for bereaved parents? Is there a professional SIDS network available not only for the family, but to help emergency responders deal with their feelings following an infant death?

How individuals respond to death may depend on their religious or cultural background. It is important to be aware of various religious practices and ethnically diverse groups in the community, and to know how different religions and cultures treat an infant's death. Failure to appreciate these influences on a

person's grief response may lead to misunderstanding the response and inaccurately assessing the grief response itself (Rando, 1984).

Continuing education of emergency responders must include information about how to cope with their own feelings about childhood death. Contact with death may heighten awareness of past personal losses or fear of future personal loss (Worden, 1982). It is important to acknowledge that "helping" professionals often have difficulty seeking support for themselves. The culture of many EM organizations historically discourages admission of a need to express feelings or to acknowledge that individuals are somehow affected by what they experience in their job. More and more organizations are setting up ongoing encounter or support groups for emergency responders to provide a forum for open discussion (Hansen & Frantz, 1984).

Responding to the Call for Help

Perhaps no call provokes a greater emotional reaction for an emergency responder than "baby pulseless and not breathing." Travelling to the scene, one begins to prepare physically and mentally for what may lie ahead. Assignments are made so that personnel are clear on their roles. Once at the scene, each emergency responder must proceed in a calm and deliberate manner. Remember that no assumptions should be made about what is wrong with the infant or why the infant may have died. The only fact that is known is that the infant is dead or has experienced an unexplained life-threatening event. Support of the family begins when the care providers project an attitude of confidence in a calm, efficient manner and exhibit concern.

Clinical Tasks

The first person responding to a call involving a life-threatening event or suspected death of an infant assesses the situation and makes decisions about the best way to proceed. The assessment includes the status of the infant, the physical environment, who else is present, and if cardiopulmonary resuscitation (CPR) has been started. Once started, CPR should be continued until the proper authority pronounces the infant dead.

There are several factors that will determine what occurs next. These include the policies and procedures of the EM system organization, what is observed at the scene of the death, and the wishes of the parent(s). In many instances, it is customary for the emergency responders to transport the infant immediately to a hospital emergency department. If this is the case, parents must be informed of the destination and, if permitted, at least one parent is encouraged to accompany the infant in the ambulance. A neighbor, relative, or other emergency responder may assist with the transport of the parent(s) to the hospital. Allowing a distraught parent to drive from the scene to the hospital alone is not considered a safe practice. If other children are in the home, arrangements must be made so they are not left unattended. A brief explanation of the situation should be provided to the children in an age-appropriate manner.

In other situations, the infant remains at the scene and an attempt at resuscitation occurs there. If this is the case, it is essential to keep the parent(s) informed and to continue resuscitation efforts until the appropriate authority pronounces death. Convey to the family that everything that can be done is being done.

Often there is little that can be done for the infant. The infant obviously is dead, resuscitation is not needed, and it is the family members who require attention. Extreme care must be taken by the emergency responders not to suggest by word, facial expression, tone of voice, or nonverbal actions that any blame or suspicion is being attached to any individual. The family may misinterpret the slightest gesture or casual comment. Again, sensitive support at this time helps to alleviate future emotional burdens for family members (BCHS, 1979).

Human Tasks

To repeat, it is often the family members who will need support. Emergency responders must be prepared to deal with a wide range of responses from hysteria and anger to withdrawal and denial. Each person is unique and will respond differently to the crisis of sudden infant death. Some factors which may affect the grief reaction are:

1. The personality and level of maturity of the person;
2. The situation surrounding the death;
3. Interpersonal family relationships;
4. The meaning of the child to the person;
5. Sociocultural and ethnic background;
6. The parent's religious convictions;
7. Other concurrent family stresses; and
8. Previous experiences with death and how the individual dealt with those experiences.

Asking questions about the infant and what happened is never easy. It is even more difficult with young parents, a single parent, a babysitter, a day care provider, or another relative, especially at the time immediately after finding the infant. It is important to obtain essential information with minimal trauma to the parent or guardian.

Keep in mind that the purpose of an investigation is to determine what happened to the infant, *not* what the parents or caretaker did or failed to do. The

family has the right to a presumption of parental innocence unless the postmortem examination reveals evidence to the contrary. When obtaining information from the parent(s), avoid using the phrase "did you" when asking questions. In this way, the parents will feel less threatened and their almost inevitable feelings of guilt will not be reinforced by the way in which the question is phrased. Examples of how questions can be asked to avoid the use of "did you" are as follows (Guist, 1988).

Ask: What time was the baby (use name when possible) put to bed?
NOT: When did you put the baby to bed?

Ask: When did the physician last see the baby?
NOT: When was the last time you took the baby to the doctor?

Ask: What time was the baby last fed? Seen alive?
NOT: What time did you feed the baby? Check the baby?

Ask: How was the baby found? And by whom?
NOT: Did you find the baby? How did you find the baby?

In addition, open-ended questions will provide more accurate information than will leading questions. A leading question is one in which the answer is contained in the question. Even if not intended, leading questions are often perceived as a form of implied accusation. For example, "You did cover the baby when you put him down, didn't you?" Open-ended questions cannot be answered with a "yes" or "no." *What, when, tell me, how,* and *which,* are good ways to begin questions that will elicit the most information.

Allowing the parent(s) to talk and actively listening to them will provide much of the information needed. Statements such as, "It's my fault, I should have checked her earlier," are responses to the situation and not an admission of responsibility. Avoiding comments like, "I know how you feel," is important to maintaining open communication. No one can actually know how another person is feeling in this type of situation. A statement such as, "I can't imagine what you are going through," is a far better way of encouraging the family to talk. Simply saying nothing may have the same effect. Again, the importance of understanding common reactions to sudden infant death cannot be overemphasized.

Legal Tasks

In a majority of communities in the United States, all instances of sudden, unexpected death are, by law, reported to the legal authorities, usually the medical examiner or coroner, who have the responsibility of determining the cause of death. An investigation is conducted which includes information obtained from the parents about the infant's medical history and events occurring prior to the death. Observation of the scene is another essential part of this investigation and is conducted according to routine investigation protocol (BCHS, 1979). In addition, there are several things to look for and note.

- Physical appearance of the infant
- Position of the infant at the time of death (this may account for marks found on the infant)
- Physical appearance of the place in which the infant was found and the presence of objects in the area
- General appearance of the room or house
- Unusual items or medications in the area where death occurred.

There may be little time to assess the scene and gather data. Remember that in many instances, the infant has been turned over or moved from the original position when discovered. Parents may have difficulty recalling the specific order of events, and the investigator will have to rely on observation skills to aid in data collection. All types of information (verbal, nonverbal, observed) will be helpful in determining the cause of death. Any investigation must be thorough and yet done as discreetly as possible. In the long run, a well-managed investigation not only allows for an accurate determination of the cause of death, but also reassures parents that all possible theories were researched and that they are not responsible for the death of their infant. If appropriately conducted, the investigation is another way of providing support to the surviving victims.

Follow-Up

Whether the infant is transported to a hospital emergency unit and pronounced dead or the body remains in the home until released to the funeral home or the place where the autopsy will be performed, the support offered to the surviving victims at this time is critical. Transferring responsibility for the infant's care is vital. Letting the family know when the emergency responders are leaving and who will be available to provide continued support to them insures continuity of care and shows compassionate concern for the family. Assuring that the family remains informed and knows how to get information about their infant is also important. The most critical role for the emergency responders at this time is to be available to the family, to answer questions tactfully, and to LISTEN. If one or both parents are not present, vigorous attempts to contact them should be made.

Usually, at this point in the crisis, clergy, funeral directors, and other counseling personnel have initiated contact with the family and have created at least the foundation for a bridge between crisis intervention and long-term

support. Their contacts with the family continue long after the infant is pronounced dead and the EM providers have completed their tasks. The guidelines in this section relate not only to emergency responders who initially may be on the scene of a sudden, unexpected infant death, but also to those persons involved in this transitional period of support.

Human Tasks

Although an emergency responder may have some previous experience with infant death, probably the family does not. Most parents do not know what they can do or cannot do. For example, the mother may wish to wash the body of her infant and prepare it for transport. However, fearing that someone might consider her odd or her wish unusual, she may suppress her desire. Similarly, the family may wish to spend time just being with and holding their infant. Unless the parents are given permission to do what *they* need to do, many opportunities to aid in the grief and mourning process will be missed. Some general guidelines to follow include:

- Provide a quiet, private place for the parents to express their grief, be with other loved ones, and be with their infant. If possible, a caregiver should stay with the family. It can be uncomfortable and awkward standing by and observing a family in grief and it is difficult to know what to say. Often, it is not the words that parents will remember, but the gentle touch, a hug, or just the presence of a caring person.
- Allow and encourage an opportunity for the parent(s), siblings, and other family members to see and hold the infant after the infant is declared dead. Parents may wish to see and hold their infant several times between the time of death and the funeral, including after the autopsy has been completed (Schofield, 1987). This provides an opportunity to acknowledge the reality of the death and to say goodbye. Have the infant clothed and made as presentable as possible. The parent's wishes are the most important consideration in determining what occurs shortly after the infant's death. Basically, anything parents wish to do that will help with the grieving process should be encouraged. In other words, anything goes unless it inflicts emotional or physical harm on themselves or others. The effective caregiver will be able to respect the family's desires even if they are radically different from those of the caregiver.
- It is important to handle the infant as an infant. Parents have commented about the devastation they felt seeing their infant's body placed in the back seat of the coroner's car, on a high, narrow ledge in the emergency room, or on a table without any attendant or supervision. Even though the infant is dead, the need to care for and protect the infant still exists for the parent. Many emergency department staff have found that wrapping the infant in a blanket and carrying the infant to the parents rather than taking the parents to the infant is an effective way of handling the body. Some hospitals even use an infant crib from the nursery to move the body. The family will long remember the respect shown for the infant's body.

- Legitimize the family's feelings. Say, for example, "It's okay to be mad, sad, afraid—even to feel guilty." Some professionals suggest that parents should not *feel* guilt, saying "Don't feel guilty, it's not your fault." It is more supportive to acknowledge the feeling of the parent with a comment like, "It is common to feel a sense of guilt, even though the death is not your fault." Avoid using "Don't" when attempting to support the bereaved. In spite of such requests on the part of caregivers, parents will continue to feel the way they do. Even though it is known that the death was not their fault, they also need to know that their feelings, including guilt, are common responses often experienced by other parents in similar situations. If they repeatedly hear "don't cry" or "don't feel guilty," they likely will begin to feel guilty about the feelings they are having, which, in turn, can interfere with healthy grieving.

Another feeling that may be felt by a parent, but very rarely expressed, is one of relief, or calm. The feeling may be fleeting in nature and may be an attempt to make some sense of the death. This can cause parents to feel confused or add to their sense of guilt. They wonder how they can be experiencing such a feeling while struggling with all the other emotions caused by their infant's death. Casual comments by parents about not having to worry about nighttime feedings anymore, or not needing a babysitter next weekend, may be perceived as flippant, callous, or unfeeling by an observer. Such comments usually are no more than attempts to put some order into a chaotic situation. Parents need to be reassured that experiencing such a feeling does not mean that they did not love their infant or that they are uncaring parents. It is only another emotional response that they may experience in response to this tragedy.

The simplest of words can have heightened significance to a newly bereaved person. For example, it may be more helpful for parents to know that what they are experiencing is "okay" or "common," but not as helpful for their feelings to be considered "normal." Normal refers to conforming to an accepted norm or standard, anything normal, natural, or usual. There is probably very little, if anything, about a sudden infant death that feels normal, natural, or usual. By contrast, "common" is defined as belonging or shared by each or all, general, or widespread (Arnold & Gemma, 1983; Guralnik, 1984). It is helpful for family members to feel that they are not alone, that others have had similar reactions, and that they are not "going mad" or losing their minds.

- Keep the family informed. Most imperative is the prompt notification of the cause of death. Historically, a large number of parents had not been given an adequate explanation of the cause of death or were told that death was

caused by something other than the cause listed on the death certificate (Bergman, 1973). Know who is responsible for informing the family of the autopsy findings and let the family know who they can call with questions about the cause of death. Providing informational brochures about Sudden Infant Death Syndrome may answer the family's basic questions. Such brochures can be given to others or can be taken home and read later. However, this does not replace the need for parents and family members to know the specific cause of death for their infant.

- Offer spiritual support. Offer to call other family members, the hospital chaplain, or their own spiritual advisor. The parent(s) may also request that the child be baptized. Again, the more responsive caregivers can be to the family's needs, the more support the family will receive. Avoid saying things like, "It was God's will," or "You have an angel in heaven," unless these are first said by the parent(s). These ideas may be comforting to some people, but they are very upsetting to others. Listen for terms or words that the parent(s) use and repeat those terms to express concern. This will aid in assessing the family's religious convictions.
- Offer basic assistance. Offering a cup of coffee, calling the funeral home, arranging transportation back home for the family, or calling other family members to come to the hospital or to the home are thoughtful responses that provide comfort. The simplest tasks may become burdensome to the parents and they may not even think of practical tasks at this time. Suggesting that a call be made to the parents' places of employment if they will not be going to work, or to the siblings' schools may be very helpful.
- Make appropriate referrals for follow-up. Contact the local SIDS support network. Even if someone else has contacted them, it is better to err on the side of too many referrals than to have no referrals made on behalf of the family. Provide written information to the family about the emergency personnel who cared for their infant and how to contact them if there are questions in the future. It is often helpful to identify one person at the hospital who knows the family and who the family may feel comfortable contacting in the future.

Remember the individuality of responses that may be encountered. One parent may be reassured by seeing resuscitation equipment or physical evidence that the emergency department staff did everything possible to revive the infant. Another parent may want to cut a lock of the infant's hair or have the infant's blanket. The key is to give the family permission to do what they need to do and to facilitate the realization of their wishes. It is important that families are told that there are no rules, no right or wrong way to grieve or to deal with their infant's death.

Most parents benefit greatly from seeing and holding their infant after death and may later regret the decision not to see the infant. Therefore, it may be

difficult to support the decision of parents who choose not to do this. All one can do is to identify the options available and respect the individual parent's choice. Some hospital staff routinely take a picture of the infant and place it in the infant's medical record so that it may be available to the family at a future time. This is especially helpful if the parents choose not to see the infant at the time of death. After all is said and done, one must accept that the parents made the right decision for themselves at the time.

Acknowledging one's own responses to a sudden infant death is an important aspect of the human tasks at this time. Emergency responders have a responsibility to themselves to assess how they feel about the death, to identify their reactions to the death, and to determine if they need support in coping with their feelings. No one benefits from hiding behind a mask or projecting an unaffected facade. Society as a whole does not wish to observe public displays of grieving, but caregivers must allow themselves to feel, express, cry, and talk about the effect this experience has had on them (Schneider, 1984). Seeking help or talking about one's feelings in a group that has had similar experiences can reinforce that the response is not uncommon and the responder is not alone.

Clinical Tasks

It is very difficult to separate the human tasks from the clinical tasks at this point. It has been determined that the infant is dead and attention turns to providing support to the surviving family members. Except for one major clinically related concern, intervention revolves around assessing the needs of the family and responding accordingly. The one exception is securing permission (if needed) for an autopsy, completing the autopsy, and informing the parents of the preliminary cause of death. Accurate diagnosis is more than a medical necessity. It is an essential component in helping the parents cope with their infant's death. An accurate diagnosis relies on a thorough postmortem examination. Without an autopsy, other identifiable causes of death may be overlooked, and the diagnosis of SIDS is not used appropriately (Krous, 1984). Even though it may take several weeks or months to obtain all laboratory results, it is imperative that the family is informed of the preliminary cause of death in a timely manner, if possible within 24 hours of the death. The final postmortem report can then be forwarded to them when it is available.

Legal Tasks

In this situation, it is not a matter of whether or not the infant's death is reported, but rather, to whom is the death reported. Accurate documentation of the EM personnel response efforts, as well as the cause of death, is imperative. Appropriate use of the medical diagnosis of "Sudden Infant Death Syndrome" on the death certificate, rather than non-committal phrases like "car-

diorespiratory arrest" or "undetermined cause" is encouraged. Emergency responders also are encouraged to review the response routinely in order to learn from the experience and improve future responses to this type of emergency. Case study conferences and record reviews can insure the deliverance of sensitive, quality care to the victim and to the victim's family and loved ones.

NEXT STEPS: THE FUNERAL AND BEYOND

Rando (1984) stated that "A rite of passage is necessary after the death of a loved one, for the passing of that person must be recognized, his survivors must be supported as they start a new life without him, and they must be reintegrated into the community . . ." (p. 190). Hence, a funeral is a vital part of the mourning process and acts as a vehicle for expressing and acknowledging grief. Often, the funeral director has more contact with the whole family shortly after the death than any other caregiver. How the family perceives the support received at this time will impact greatly on their ability to cope with this crisis and future losses. Research has shown that many families have been grateful for the assistance which they received from thoughtful funeral directors (Center for Death Education and Research, 1971; Cook, 1983).

A funeral is ". . . an organized, purposeful, time-limited, flexible, group-centered response to death, involving rites and ceremonies during some or all of which the body of the deceased is present" (Raether & Slater, 1983, p. II-72). Critical psychological, spiritual, and social needs are fulfilled through the rituals of a funeral. Since the family experiencing a sudden infant death is usually young, it is likely that they have not had previous experience planning a funeral and may never have attended a funeral before.

The role of the funeral director is to be a skilled and compassionate guide and facilitator. As previously mentioned, caregivers, especially the funeral director, must understand the customs, religious and cultural values, and norms of the society in which they provide service. By following the guidelines related to *human tasks* that are set forth in this chapter and by responding to the individual needs of each family, funeral directors can insure that their services are delivered in an effective manner. Often, it is difficult to address differing needs of the various individuals within a family. By facilitating open communication among the family members, it is more likely that all of the needs of each person will be met (Rando, 1984).

The funeral director who is sensitive to the family's unspoken and spoken needs and who explains that there is no right or wrong way to arrange for a funeral (or to grieve) will assure a meaningful experience for the bereaved

(Horan & Jensen, 1985). Above all, families have indicated that what they needed the most was someone willing to sit down with them and listen, to reassure them that there was nothing they could have done to prevent their infant's death, and to confirm that what they are feeling is both common and healthy (Schofield, 1987).

How involved the family is with the actual planning of the funeral service often depends on the funeral director giving the family permission to make the service as personal as possible. Again, families usually do not know what options are available to them. Opportunities to hold the infant again, to cut a lock of hair, to take pictures, or to put mementos in the casket can be very comforting to the family members. Also, the use of colored helium-filled balloons, stuffed animals or toys, and/or children's songs instead of funeral hymns during the service, may be appreciated by the parents. But the opportunity to do any of these things must be presented to the parents in order for them to know that such options exist.

Anticipatory guidance about what the parents may experience in the near future is also helpful. Thinking that they hear the infant crying or finding themselves fixing the infant's formula or both, even after the funeral, can be very frightening for parents unless they are told this may occur. Anger at God, the medical personnel, the funeral director, or even at their infant who died is often immobilizing to parents and needs to be validated as a common reaction to the death of a loved one. Referrals to the local SIDS support network, including bereaved parent support groups, will provide the family with resources long after the initial contact with the funeral director ends.

CONCLUSION

No one can prevent the pain a family will feel or protect them from experiencing grief following the sudden, unexpected death of an infant. If professionals who assist with the infant and interact with the infant's family are compassionate and knowledgeable, there is potential for the surviving family to achieve a more healthful outcome from this difficult experience.

Those persons most likely to be involved at the time of an infant's death and immediately following the crisis include: (1) emergency medical personnel, such as paramedics, emergency medical technicians, and first responders; (2) law enforcement personnel; (3) the medical examiner or coroner; (4) hospital emergency room staff; (5) clergy; and (6) funeral service personnel. All personnel responding to this medical emergency and human tragedy must be prepared to respond in an effective and caring manner.

The tasks related to the care initially provided following an infant's sudden

death can be viewed from three perspectives: clinical, legal, and human. Clinical tasks relate to the practical, intervention, action-oriented aspect of the emergency response. Legal tasks relate to protecting the rights of all persons involved. Human tasks, perhaps the most important aspect, relate to *how* the clinical and legal tasks of the care are provided. Each situation is unique and by learning to expect the unexpected, emergency responders can respond to each situation in a compassionate and caring way.

In reality, all those who come in contact with sudden infant death are victims. Acknowledging how sudden infant death affects the professionals involved at the time of the death, as well as the family members, is essential to assure effective intervention and a healthful outcome. Guidelines for meeting the needs of the infant, the family, and themselves have been suggested for emergency responders involved immediately following the discovery of a "baby pulseless and not breathing."

REFERENCES

Arnold, J. H., & Gemma, P. B. (1983). *A child dies: A portrait of family grief.* Rockville, MD: Aspen Systems.

Bergman, A. B. (1973). *A study in the management of sudden infant death syndrome in the United States.* Baltimore: Central Maryland SIDS Center.

Bureau of Community Health Services (HSA/PHS). (1979). *Training emergency responders: Sudden infant death syndrome. An instructor's manual.* DHEW Publication, No. (HSA) 79-5253. Rockville, MD: Author.

Center for Death Education and Research. (1971). *A compilation of studies of attitudes toward death, funerals and funeral directors.* Minneapolis: University of Minnesota.

Cook, J. A. (1983). A death in the family: Parental bereavement in the first year. *Suicide and Life-Threatening Behavior, 13*, 42–61.

Guist, C. (1988). Responding to an unexpected infant death. *Information Exchange*, June, pp. 1–3. McLean, VA: National Sudden Infant Death Syndrome Clearinghouse.

Guralnik, D. B. (Ed.). (1984). *Webster's new world dictionary of the American language.* New York: Warner Books.

Hansen, J. C., & Frantz, T. T. (Eds.). (1984). *Death and grief in the family.* Rockville, MD: Aspen Systems.

Horan, J. J., & Jensen, J. P. (1985). Sudden infant death syndrome: The funeral home experience. *Forum Newsletter, 8*(7), p. 7. Lakewood, OH: Forum for Death Education and Counseling.

Jones, A. M., & Weston, J. T. (1976). The examination of the sudden infant death syndrome infant: Investigative and autopsy protocols. *Journal of Forensic Sciences, 21*, 833–841.

Krous, H. (1984). Diseases masquerading as SIDS—The need for autopsy in sudden unexpected infant deaths. *Oklahoma SIDS Newsletter.*

Raether, H. C., & Slater, R. C. (Eds.). (1983). *Advocating understanding: A manual for funeral directors to care-giving organizations.* Milwaukee, WI: National Funeral Directors Association.

Rando, T. A. (1984). *Grief, dying, and death: Clinical interventions for caregivers.* Champaign, IL: Research Press.

Schneider, J. (1984). *Stress, loss and grief.* Baltimore, MD: University Park Press.

Schofield, P. M. (1987). Sudden infant death: Parents' views of professional help. *Health Visitor, 60*, 109.

Smialek, Z. (1978). Observations on immediate reactions of families to sudden infant death. *Pediatrics 62*, 160–165.

Worden, J. W. (1982). *Grief counseling and grief therapy: A handbook for the mental health practitioner.* New York: Springer Publishing Co.

Sudden Infant Death Syndrome: Medical Aspects and Psychological Management Culbertson et. al., John Hopkins University Press 1988

9

The Family and Sudden Infant Death Syndrome

FREDERICK MANDELL, M.D.

My first contact with a child who had died of sudden infant death syndrome (SIDS) was as an intern in a large city hospital. I responded to a call to the Emergency Room. A four-month-old infant was dead. I remember thinking that there was nothing more to be done. The emergency room was busy and I continued to see other patients, but frequently found myself staring into a small examining room where a young mother sat crying; she seemed to have been there an inordinately long time. I noticed the woman who had been cleaning the floor put down her mop; she walked into the room, put her arms around a sobbing, lonely human being and just sat with her. She did what I should have done.

Historical Overview

For hundreds of years, infants who died suddenly and unexpectedly were thought to have died of overlaying by the mother or wet nurse. Many of these tragic deaths were attributed to infants smothering in their bedding. At the end of the thirteenth century, a public notice cited the danger of suffocating infants by overlaying and forbade mothers from taking to bed with them infants who were under three years of age [1]. Although unexpected deaths did not arouse medical interest at the time, there is evidence of major concern about sudden and unexpected deaths caused by overlaying. The arcutio may be the first device used to protect infants from SIDS (Figure 9.1) [2]. The infant slept in it and the mother could breast feed by placing her breast in the notch (c). The arcutio would not allow her to roll over on the infant. The astounding infant mortality from infectious diseases and malnutrition probably conditioned parents to be more accepting of early death even if it was unexpected. Nevertheless, even in this setting, there were those whose questions implied that SIDS was a fairly frequent phenomenon prior to the nineteenth century. One such provocation appeared in the January 1855 issue of *Lancet:*

Medical Jurisprudence: Infants Found Dead in Bed

Who has not heard of cases of "overlaid" children found dead in bed? A few years since the metropolitan newspaper teemed with reports of such cases: the country journals still exhibit similar records. Yet we believe it may be stated as a fact, that not one child out of two hundred who has been found dead in bed has lost its life in consequence of having been overlaid. In Middlesex, fourteen years since, the constables, in cold weather, made incessant applications for inquests in such reputed cases. Several facts, however, soon occurred, which led to a conviction that other causes than pressure produced the death in instances where children were found dead in bed.

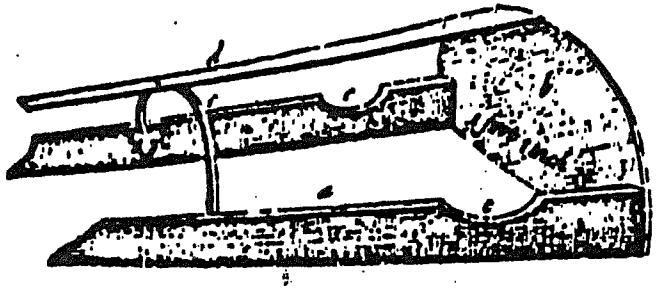
Had the office of coroner been generally occupied by members of the medical profession, it is impossible that the real degree of death, in these instances, would have been so long overlooked and misunderstood. But the ascertained facts lead to inferences which we believe to be irresistibly conclusive. It was due to science, to the interests of humanity, having due regard to the preservation of human life, and not less so to the feeling, and bestowed upon infantile life every possible care and attention, that the real cause of mortality, in the numerous examples of infants found dead in bed, should be thoroughly investigated. After fond and attentive parents, during weeks and months, have devoted the utmost possible attention to their helpless infant, what can be more distressing to their feelings than the imputation that the sacrifice of their offspring has arisen from their own mismanagement, carelessness, or criminal neglect? Assuredly it is the duty of coroners and medical practitioners to set the public mind right on this deeply interesting subject. Even jurors, from previously conceived erroneous notions, are often disposed to rush inconsiderately to wrong conclusions.

It must be admitted that in instances where the causes of death are precisely similar, neither externally nor internally is there a corresponding exactitude with reference to the postmortem appearances of the body. Some extraordinary examples we shall place upon record at a future period. If all postmortem examinations were to be conducted on one uniform plan, enough would doubtless soon be discovered of exact resemblance in a series of cases to enable practitioners to ascribe the causes of death to precise and adequate influences. We hope soon to be enabled to issue a tabular form for the reception of a record of all useful facts found on a scientific examination of every human body. The general use throughout the kingdom of such a form would afford an opportunity for collecting and classifying facts which would be of the utmost possible use, and within a comparatively brief period medical practitioners would be enabled to point to a portion, at least, of a code which would sustain them in their evidence against the impertinent audacity of hired bullies, who but too frequently are absurdly styled learned gentlemen.

Some of the most interesting facts connected with the discovery of infants found dead in bed are the following:

These lifeless bodies are discovered in at least ninety-five instances out of every hundred, after three o'clock in the morning. Not one out of a hundred of such bodies is discovered dead between nine and twelve at night.

The greatest number of such bodies found dead are discovered in the months of December, January, and February; the next greatest number in September, October, and November. The spring months—namely, March, April, and May, exhibit



WHEN it is conſidered how many are charged Over-laid in the Bills of Mortality, it is to be wonder'd that the ARCUTIO's, univerſally uſed at *Florence*, are not uſed here in *England*. The Deſign above, is drawn in Perſpective, with the Dimenſions, which are larger than uſual; and is thus deſcribed:

a, *The Place where the Child lies.*
b, *The Head-Board.*
c, *The Hollows for the Nurſe's Breaſts.*
d, *A Bar of Wood to lean on, when ſhe ſuckles the Child.*
e, *A ſmall Iron Arch to ſupport the ſaid Bar*
The Length three Feet, two Inches and a half.

Every Nurſe in *Florence* is obliged to lay the Child in it, under Pain of Excommunication. The ARCUTIO, with the Child in it, may be ſafely laid entirely under the Bed-Cloaths in the Winter, without Danger of ſmothering.

FIGURE 9.1. Arcutio Used to Prevent Overlaying.
When it is considered how many are charged Over-laid in the Bills of Mortality, it is to be wonder'd that the Arcutio's, universally used at Florence, are not used here in England. The Design above is drawn in Perspective with the Dimensions, which are larger than usual and is thus described:
a. The Place where the Child lies.
b. The Head-Board.
c. The Hollows for the Nurse's Breasts.
d. A Bar of Wood to lean on, when she suckles the Child.
e. A small Iron Arch to support the said Bar.
The Length three Feet, two Inches and a half.
Every Nurse in Florence is obliged to lay the Child in it, under Pain of Excommunication. The Arcutio, with the Child in it, may be safely laid entirely under the Bed-Cloaths in the Winter, without Danger of smothering.

them in the third degree; and beyond all questions, the least number are found i the summer months—June, July, and August.

Of the days of the week when such bodies are found dead, the greatest numbe are seen on Sunday mornings, next on Monday mornings, and the fewest on Saturday mornings.

An experience of fourteen years, in a Coroner's jurisdiction embracing between eight and nine hundred thousand souls, many portions of which are densely populated, has established the accuracy of these statements by proofs which admit of no dispute. Equally true is it that out of hundreds of examples of infants found dead in bed, only two instances have been seen in which the proof was conclusive that the little creatures had been destroyed by the pressure of persons who had been lying with them in bed. Even in one of those cases, the question might have been fairly raised, whether the signs of pressure visible on the body had not resulted from contact after death with the person who had slept with the deceased infants [3].

The first writing of sudden and unexpected death in American literature appeared in the Diary of Samuel Sewall in 1674 as, "Mr. Eyre's little son dyed, went well to bed; dyed by them in the Bed. It seems there is no symptom of Over-laying" [4].

The humanitarian approach to the problem of sudden and unexpected death was bolstered by emergence of the thymus theory; that is, that death was caused by a large thymus compressing the heart and great vessels. The acceptance of this physiologic explanation diminished the intensity of feeling that these deaths were due to neglect, accidental suffocation, or even deliberate homicide [1]. Sorrowful and guilt-ridden parents could be declared blameless when the thymus theory was demonstrated. However, in the 1850s, the thymus theory fell into disrepute when the glands of SIDS victims were compared to those of controls who had died of other causes, and it became the general attitude that suffocation was the mechanism of death.

Parents whose infants died suddenly and unexpectedly continued to live with the belief that their babies had suffocated until the 1940s and 1950s when several authors presented evidence for a natural mechanism of death and discounted suffocation. Since the 1970s, sudden infant death syndrome has been recognized as a naturally occurring entity for which parents are not responsible. Despite the academic disagreements as to cause, in the past ten years there has been a major research thrust in the area of SIDS. Federally and privately funded educational programs have reduced the amount of erroneous information that previously had subjected families to cruel and undeserved treatment and even prosecution.

Psychological Effects of SIDS on Survivors

Parents and Other Caretakers

In spite of existing programs and continued research efforts to find a cause and cure for crib death, there remains a mystique about a baby who dies suddenly from sudden infant death syndrome. The unexpected loss of a well-cared-for child evokes the harshest kind of grief reaction. Most parents talk about initial shock. One woman stated, "In the beginning, I lost all sense of being" [5]. Very few parents who have lost their infants suddenly and unexpectedly have not thought about blaming themselves. In most instances feelings of guilt are overwhelming. Parents typically recreate the events around the time of death and magnify minor omissions. Many parents talk about "if onlys;" if only I had checked the baby or hadn't changed the formula, or had taken the blanket away, or hadn't gone out that night. These parents need immediate assurance that such magnified minor omissions did not cause the baby's death. Parents feel guilty that in some way they neglected the needs of the baby. An extreme example of this was a mother who kept repeating to the Emergency Room staff that she had killed her infant. What she meant, of course, was that she must have been responsible for the baby's death.

The immediate effect on parents is overwhelming. The initial shock gives way to guilt, which often persists in spite of rational explanation. An early stage in the usual grief process is internal bargaining. When a death is sudden and due to a known cause, the concrete character of the event can be incorporated into the normal rationalization of mourning. When, however, as in SIDS, death is due to an unknown mechanism, feelings of self-condemnation and inadequacy of parenting are reinforced. This type of death is almost unique in the spectrum of pediatric disease and denies parents a prior mourning process, which in other childhood deaths may begin at the time of terminal diagnosis.

For young parents, this loss may be their first experience with family death. Uninformed relatives and friends add further remorse with innuendos of parental blame. When death involves an older person, reminiscing is a therapeutic tool in helping survivors work through their grief. In cases of SIDS, however, there is an almost universal absence of discussing any of the happy events surrounding the infant. This pattern extends beyond the limited time the infant has spent in the family and seems to relate to self-imposed restrictions on the part of family, friends, and neighbors. When visitors do come, they enforce these restrictions by avoiding talk about the infant and not allowing the parents the opportunity to reminisce or use reminiscing to help work through the grief process. Parents have stated that they would like to be able to talk about the infant, but recognize the taboo and discomfort that others have about discussing children who die. In some instances, the inability to talk about the infant delays grieving. The delayed process of grieving is more difficult, because after several days most active supports are gone.

Infants who die suddenly often are taken to an Emergency Room. Here, parents require understanding and compassion. They should be informed that their infant probably died of sudden infant death syndrome, even though this cannot be confirmed until a postmortem examination has been performed. In the emergency room, I am not afraid to tell parents that I think their child died of sudden infant death syndrome. Parents need to know why their baby died and this consideration should be given to them as soon as possible. When an adult dies, relatives are told of the possible cause of death; one may say, "I think your husband died of a cerebral vascular accident or a massive heart attack." In the case of a child, similar consideration and information should be available.

Parents advised to have an autopsy performed on their infant usually feel that this is good advice. I have never met parents who have regretted agreeing to an autopsy, but I have met many parents who have been sorry that a postmortem examination was not done. By providing information about SIDS in a sensitive manner, the physician helps parents understand that this sudden, unexplained death is a natural phenomenon even though the cause is unknown.

Not very long ago, a man woke up early in the morning to go to work. As he was leaving, he stopped to check his young infant sleeping in the crib. The baby was not breathing. He called the police to help with emergency care. After seeing that the infant was dead, the police informed the father of his rights to remain silent. In another instance a mother vividly described to me the events surrounding her baby's death, as if the death had just occurred. When her child was taken to the Emergency Room, a nurse looked at the mother in a way that insinuated somehow she was responsible for the death of the child. The mother described the nurse's innuendo vividly: "She whispered to others, she was cold and distant, and she looked at me with gleaming eyes." Then the mother told me that her baby had died fifteen years ago. In these two instances, judgment was passed on the parents by others. The lasting effect of this kind of behavior is significant. Sometimes it occurs between husband and wife. One spouse in some way blaming the other or a grandparent blaming a parent has not been an infrequent situation in cases of SIDS.

Caretakers, such as babysitters, also require information when a baby dies in their care. Caretakers may involve extended family, young adolescent sitters, or daycare centers. In cases of extended family, their closeness to the death serves as constant reminders of the tragedy. Young adolescent sitters also have feelings of guilt and responsibility for the death. They may not fully comprehend the events surrounding the death or their

role as the protector of the infant. Among involved young sitters, issues of lingering or even long-term guilt and fear of caring for children in the future can become significant.

As demands for daycare increase, more and more daycare centers are facing the issue of an infant dying suddenly and unexpectedly while in their care. In some instances direct accusations of deliberate harm and neglect have been made. In other instances, the community response has been so negative that centers have been unable to continue to function. Sometimes news reports of an unexpected death in a daycare setting have created suspicion that the daycare workers have not been acting responsibly. One daycare center provider closed her facility after a second death occurred when the infant was in her care. A second daycare provider closed her home because of her perception of negative community response. In general, all caretakers need assurance that they are not responsible for these deaths. Daycare providers need counselling and information about sudden infant death syndrome. Young babysitters and extended family also require help over a longer period.

Fathers

Mothers have known the backaches of pregnancy and traditionally have been the caregivers for most infants. In fact, most research has been done on mother/infant reactions. Professional support provided to families experiencing the loss of an infant has concentrated on understanding the effects of the disruption of mother–infant bonding and its consequences on the mother's sense of self. However, expectant fathers also have hopes and fantasies for their babies. Their thoughts are filled with happy expectations and aspirations. Fathers also form significant relationships with their infants and feel the frustrating loss of hopes and dreams.

In Western society, we are only just beginning to observe the emotional importance of father–infant tenderness and loyalty. It is apparent that the behavior of the father in response to the loss of his child also requires special consideration. In a study of twenty-eight fathers who lost children to SIDS, patterns of behavior peculiar to men were identifiable [6]. For example, all but one of the fathers in the study assumed a manager-like role; they controlled their emotional expression and were preoccupied with the emotional support of the wife. These fathers became directly involved with the funeral arrangements and sought to find an explanation for the cause of death. One father stated, "Things like this happen. I don't want S. to blame herself. She was the perfect mother . . . I have to stay strong for everyone else."

This group of fathers appeared to direct their energies and attention outward whereas the mothers appeared to withdraw. The behavior of the fathers sometimes directly contrasted with that of their wives who were tearful, frequently incoherent, very much absorbed in grief, and seemed

to notice very little around them. On the other hand, fathers frequently seemed almost awed by the responses from relatives, friends, and the community. "I'm telling you, this is beautiful. The whole office came to the funeral. People are just coming out of nowhere . . . I never thought they would care."

In this report, six mothers talked about the necessity to verbalize their feelings. This was generally not the pattern for fathers; their predominant coping mechanism was to keep busy. This meant taking extra courses or an additional job, accepting added work load responsibilities, or seeking energy-absorbing hobbies. Fathers also appeared to have different attitudes than their spouses in their feelings about subsequent children. Whereas many of the mothers described a sense of fear of another pregnancy, the fathers seemed to have an urgent desire to have another child as soon as possible. In the period following the SIDS death, this issue was mentioned as a frequent source of conflict.

Another difference between mothers and fathers was the fathers' lack of desire to talk about the death and their feelings about the loss. In eighteen of forty-six families, fathers seemed purposely to avoid being at home at the time of a nurse visit [6]. Mothers frequently commented that their spouses felt that talking about the baby's death would not help. In some instances mothers were secretive about their contacts with the community health nurse. One mother stated, "He doesn't want me to talk about our private problems. If I tell him that you were here, he will say, 'I don't want to know about it.' When I call you I need to wait until he is out of the house." Another father stated that he would not tell anyone about his problems because it wouldn't bring his baby back. However, when mothers did request crisis intervention, the difficulties often centered around communication with the husband or specific concerns about his behavior.

When fathers were able to discuss their involvement with the baby who had died, they frequently expressed remorse over their lack of inclusion in infant care. One father said that he kept thinking when the baby got older he would have more time. Fathers who were able to express themselves also talked about feelings of diminished self-esteem. They spoke about feeling inadequate, feeling that a part of them had died with the baby, and feeling less of a man. Special feelings of frustration and powerlessness were expressed by fathers who attempted to resuscitate their infants.

Behavioral scientists have had disproportionately little to report on the impact of the father on early childhood development. It is not surprising to note a reduction of the father's role at the time of the death of the infant. One father pointed out that when he finally broke down and cried, no one was able to hold him although they had been doing this for his wife for days [6].

In general, men seemed to be angrier and more aggressive than women, who appeared more depressed and withdrawn [6]. Sometimes fa-

thers talked about wanting to strike out at someone. Sometimes they blamed physicians for the death or angrily magnified minor omissions. In some cases, there were thinly disguised statements of blame toward the mother who was the primary caretaker. If they were not present when the infant was found, some fathers found it difficult to accept that nothing could be done. Fathers generally have less insight into the day-to-day child rearing and child health risks, and therefore may be less equipped to accept the fragility of life and their inability to control their child's destiny.

Studies of infant attachment demonstrate that fathers interact deeply with their infant sons and daughters, and this interaction can be as sensitive to infant needs as that between mothers and infants [7–9]. A new father accommodates to the experiences of fatherhood and reshapes his world, his expectations, his images of himself, his wife, and his family. The crisis aroused by childhood death is profound.

Societal expectations for fathers are of significance. In the study by Mandell et al., the concreteness of assuming a managerial role seemed to reinforce the reality of death and provided an outlet for expression of finality [6]. Fathers indicated a need to grieve but required different outlets. Even those who sensed their own need for help either limited their requests for assistance or found that their requests were not recognized. Exposing feelings of helplessness sometimes exacerbated an already diminished feeling of self-esteem. However, if fathers are given an opportunity to express their feelings and these feelings are understood and validated in the context of their own family, their virility, and the pressures of masculine roles, fathers can utilize support constructively. Health professionals, friends, and families need to be aware of the special bondings between infants and fathers and to be sensitive to the particular effects when that bond is broken.

Surviving Siblings

New infants are quickly incorporated into family life. When infants in the home die unexpectedly, family life is suddenly changed [10–12]. Infant mortality in this country has so decreased that most children are not familiar with death by natural causes. Some children are knowledgeable of death by accidents or remote experiences such as war or natural catastrophes. In our world of television, children often think that death can be prevented if outside influences are controlled; in a sense, this gives the child a feeling of control and power over death. When death is in a remote place it has little meaning because it happens to others. Young families have not had to cope with death. Our own adult fear of death and a kind of taboo that surrounds discussions regarding the death of children does not provide an open environment in which to discuss the death of an infant with an older surviving child.

The loss of an infant in a family is particularly frightening for siblings

in the home due to the catastrophic nature of the death and their inability to understand its meaning and influence on the family. The abrupt loss of an apparently healthy infant without an explainable pathologic cause intensifies family grief. In this psychological environment, surviving siblings experience loss, uncertainty, family disruption, and fear.

Readying children for the role of older sibling provides direct participation in an important family event. That place in the family is crystalized with the birth of a new infant. These new big brother and big sister roles, however, are suddenly terminated with the death of their new infant sibling. Death has entered the confines of the family and has taken another child close in age. Often children do not understand that other children can die. The role of older sibling is lost. There is a void of developmental opportunity and the child, as a survivor, immediately develops some very special qualities as a result of the loss [13].

Following the death of a sibling children feel especially vulnerable. The family entity has changed, communication and interchange between husband and wife has changed, and parental behavior and responses toward the surviving child also have changed. Parents often are able to acknowledge their overprotectiveness and permissiveness. However, the confusion and difficulties experienced by parents who are mourning often forestall the spontaneous expression of concern around surviving children. Behavioral responses in young surviving siblings may be misinterpreted by parents and health professionals. The consequences of the sibling death could become a source of distraction, dismay, and fear for the surviving child.

In a recent study of thirty-five surviving children, 80 percent of the mothers perceived changes in the child's interaction with them after the sudden and unexpected loss of a sibling [14]. Most parents described their own need to be physically closer to the surviving children. One mother stated, "We wanted and needed to hold him more . . . I don't know who needed the hugging more, him or us." Some parents remarked that they had babied a surviving child too much. This normative behavior seemed to imply the parents' need to feel once again the closeness of a parent–infant bond as well as fears for the safety of surviving children. Only a few mothers were able to express a painful need for some distance from their surviving children. There were many instances of children attempting to comfort their parents in the time of distress, but for most of the surviving children, the sight of parents crying and confused was perplexing and frightening. In some instances, this led to children's comforting parents themselves or to the older child's learning not to talk about the baby.

The changes in parent-child interaction included newly acquired separation anxiety [14]. Some of the children were able to present, with particular clarity, the fear that their parents also would disappear. Some parents also talked about the provoking tendency of surviving children to test

the limits of discipline for several months after the death of a sibling.

Almost 70 percent of the children in the study demonstrated changes in sleep patterns following the baby's death [14]. In most instances this new deportment emerged within a few days after the death, although several children did not have sleep problems until several months later. Most sleep-related difficulties were seen as resistance to going to bed and to sleep. Children often expressed fears about not waking up; "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? [14]' " Many of the sleep disturbances were accompanied by nightmares. Older children who were able to describe the nightmare often talked about the frequent theme of pursuit by monsters. One three-year-old rebuffed sleep because of her fear that a monster would take her because she killed her brother. Typically, parents relate these nighttime ordeals to the event of the baby's death. "She was right there when it happened; I was screaming; she wakes up screaming." Most children who experienced nightmares responded to comforting and parental assurance and were able to settle back to sleep. In some families, nightmares occurred more than once in the night. Some families responded by allowing their children to sleep with them. In some instances this seemed to reassure the expressed fear that their parents would leave them and not return [14].

Changes also were noticed in some of the children's social interactions with peers. These changes ranged from a noticeable quietude and withdrawn behavior to increases in aggression, which included hitting other children. Many of the children evidenced a new reluctance to go to school and others became so aggressive toward siblings and children that parents qualified their behavior as mean [14].

Health professionals encourage adult patients to talk about crises. Children also need to express their perception of what happened through talk or play or drawings. Children respond to death with different kinds of behavior. Some children have many questions, and they question the death just as they question other things they do not understand. Other children have fears that they or their parents will die. Children think magically, and they may have wished that their new brother or sister would go away. These children need to be reassured that they are not responsible for the events that have transpired and that the same thing will not happen to them. Children readily participate in silence surrounding infant death, especially when talking about the baby causes the parents to become upset. They quickly understand that the silence is a cover for something awful. Children's fantasies of death can be more frightening than the tragedy itself. Parents need to be encouraged to use the words "death" and "died." They also need to be reminded that some euphemisms may be more confusing and frightening than comforting. Parents also need to know that although the death may be explained, it is not a closed issue among surviving children and probably will come up at the most inopportune times. Children need to know that it is all right to cry, to question, and to express feelings, and parents need to assure children that their emotions are normal. Children may avoid thinking about death. It is one of their best defense mechanisms and should not be considered disinterest [15].

Professionals need to know that children's ideas about death are quite different at different age levels [16]. To the preschooler, death represents going away, is temporary, and probably reversible; he or she is unable to accept it as final. To the five-to-nine-year-olds, death happens, but it happens to other people. After this age, children understand death and its finality and that it happens to everyone. For these issues alone, the professional needs to know the age of the child, the circumstances of the death, and what the child has been told.

The behavioral issues of surviving children are of significant concern to the parents of SIDS victims. However, many parents prefer to deny additional problems or are so overwhelmed by the loss that they do not bring up these problems with health professionals. Other parents may be unwilling to open discussions about disturbed behavior at home while they are experiencing feelings of inadequacy. With an awareness that behavioral changes can occur in surviving children, those who are involved in helping these families can alleviate parental concern over these issues by providing the necessary assurances that these kinds of family interactions are not abnormal. These kinds of assurances allow parents to know that the family process of grieving involves all family members and that there is concern about the survivors as they begin to build a new family structure.

Health Professionals

Many health professionals, even those who work with children, are uncomfortable during encounters with newly bereaved parents and find these times particularly anxiety filled. Providing adequate support at a time of bereavement can be extremely difficult even for the trained and experienced counselors who provide effective support by sharing the family grief. It is an emotionally draining experience. Grieving families need someone who is genuinely interested. Nurses who visit these families often are responsible for assessing their unique needs [17]. Zoe Smialek, Nurse Coordinator for a SIDS information and counseling project, has had experience with more than 350 families who have lost infants suddenly and unexpectedly. She wrote, "Families are entitled to assistance during this distressing time from a warm, caring professional who is able to allow free expression of grief however it is manifested, and accurately answer their disturbing questions about the death of the infant [18]."

Parents' reactions to home visits by nurses have been generally positive. In Massachusetts, the acceptance rate of a home visit is 95 percent,

which indicates support for professional input. Most of these families also accept a second or third professional visit. Nurses who do this well encourage parents to express themselves freely in an accepting manner. Often these feelings are not expressed to friends or relatives because they might not understand what they are hearing or they might be frightened by the overwhelming grief. In this situation, well-meaning friends tend to cut off discussion by telling parents that everything will be all right or by telling them to talk about the future when the parents want to express how they feel. Nurses in general have felt positive about their intervention with grieving parents if they are prepared with factual knowledge about sudden infant death syndrome, knowledge of the normal and abnormal grieving response, some counseling skills, and an awareness of their own reactions to death.

There are no formal educational processes to prepare physicians for the death of a child. The suddenness of SIDS adds to the state of unpreparedness. SIDS babies are also very young and if this is a first child, the physician may not know the family well. Many physicians are devastated by the unexpected death and search for reasons why. One pediatrician stated, "You always wonder if you missed something in the exam." Another remarked, "I kept reexamining the case. I had to feel there were not circumstances I could have changed" [19]. Some pediatricians react by withdrawing and not following through; in a sense, allowing families to fend for themselves. A physician wrote, "I was sad; maybe the baby had something wrong that I missed. I was disappointed that I wasn't more involved and my own guilt was magnified." In a survey of some forty-five pediatricians who lost patients to SIDS, most felt that they were educationally unprepared for this kind of loss and most felt that they wanted to talk to someone about it [19]. In general, professionals also need support in order to cope with their own feelings in response to parents in pain. One physician said, "Most deaths I can sort out, but SIDS is different. I needed a support person to help me deal with this."

Parents need encouragement and support to cope with their baby's death. This support can be provided in a variety of ways from a professional grief counselor, individual/family counseling sessions, parent-to-parent support on an individual basis, or support from a bereavement group for SIDS families. The support group aids in the resolution of early trauma of grief experienced by parents after the sudden and unexpected death of their baby. The group provides the opportunity to meet other parents who have experienced the death of an infant and who extend their friendship and understanding to newly bereaved parents. In the group setting, parents are encouraged to talk about the baby who died and express their feelings about death in a safe environment. Gradually, parents begin to cope with their loss and are supported in the process.

Subsequent Children

For parents who have lost a child, the decision to have another is difficult. Relatively few parents have experienced the loss of an apparently healthy baby. This fact most influences a parent's decision to have another child after the loss. The death of a previous sibling also has a great influence on the new child. Parents are deeply plagued by the fear of losing another child. For this reason, it is not unusual for parents to wait a long time, even years, before they decide to have another child. There are others, however, who require a subsequent pregnancy immediately. Some parents have been encouraged by relatives, medical personnel, and friends to have another child quickly in order to take their mind off the loss. Parents who have had this experience are painfully aware of the problems for both parent and child. The parent, never having worked through the original loss, finds his or her lost infant in the replacement child. The child is constantly compared with and lives in the shadow of the dead child [20]. This has been described as a "replacement child syndrome" [21], and some of these children are incapacitated by death phobias and fears of abandonment. Becoming pregnant to resolve a loss appears to be harmful to all parties.

In other instances, under psychological conditions of mourning and guilt, women who have lost children and are attempting to conceive a "replacement" child quickly may have difficulty. Investigators have been aware for a long time of the influence of emotional factors on the menstrual cycle. It is well known that its rhythm can be disrupted by stress and personality disturbances. Transcultural studies have cited a number of non-physical techniques that can cause abortion, and these kinds of spontaneous abortions have been documented in societies older than our own. In a study of women whose children died of SIDS, thirty-two attempted to have another child [22]. The expected rate of infertility in a normal population is 10 percent. Spontaneous abortion has an incidence of 15 percent. Among the thirty-two women who attempted to conceive after the loss of their child, over 30 percent had their first spontaneous abortion and almost 35 percent could not conceive after attempts for at least one year [22].

In our society, the acute grief process is spread out over time. If parents are able to work through the mourning process, the psychological environment for the subsequent newborn will be healthier. There is no replacement for a lost child, and parents who expeditiously decide to have another child may be further frustrated by difficulty in achieving pregnancy or by spontaneous abortion [22]. When pregnancy does occur, anxiety may be high. The pregnancy is often wrought by fear of a repetition of the unexpected death. Expectant mothers require patient answers as they compare pregnancies and feelings during pregnancies.

In a sensitive and informative article for parents entitled, "The Subsequent Child," Szybist wrote, "Waiting for baby is the time to seek counsel

if you need to and to be honest with yourself and others. It is also a time to prepare for a rather remarkable experience—the birth of a 'subsequent child.' " She continued, "You will probably check on your sleeping baby more frequently than you did your other child. Parents of subsequent children are the first to admit that in the past they used to check their babies to see if they were covered, but now they check respirations" [23]. The article also talks about moments of panic with the subsequent child. These moments occur with the first upper respiratory infection and at the anniversary of the death of the previous infant. Also, many decisions that were at one time easy now require much effort. Breast- and bottle-feeding decisions, where to sleep, whether to smoke, room temperature, visitors, tests, and monitors are issues that may become greatly magnified.

During the first months of the subsequent infant's life, parents fear another uncontrollable sudden loss. Family relationships may be strained. Parents continue to compare illnesses, feelings, and personalities throughout the first year of life. Usually this is done inwardly and there is great relief when the subsequent child reaches the year-old mark. Parents need reinforcement of the healthy aspects of their babies. These distinct conditions test the sensitivities and perception of the health professional. Times of crisis, episodes of overprotectiveness, and moments of panic are times when invaluable psychological support can be provided with open compassion, understanding, and familiarity of the issues facing the parents who are attempting desperately to do their best with their new subsequent child. The supportive role of an understanding human being will help mitigate the emotions of family pain and the anguish of losing a child to SIDS.

References

1. Beckwith, J.B. 1975. *The Sudden Infant Death Syndrome*. U.S. Department of Health, Education, and Welfare. DHEW Publication No. 75–5137.
2. Caulfield, E. 1930. The infant welfare movement in the eighteenth century—Part I. *Annals of Medical History* 2:480–494.
3. Medical Jurisprudence: Infants found dead in bed. 1855. *Lancet* 1:103.
4. Thomas, M.H., ed. *Diary of Samuel Sewall*. 1674-1729. New York: Farrar, Straus, Giroux, 2 volumes.
5. DeFrain, J., J. Taylor, and L. Ernst. 1982. *Coping with Sudden Infant Death Syndrome*. Lexington, Mass.: D.C. Heath and Co.
6. Mandell, F, E. McAnulty, and R.M. Reece. 1980. Observations of paternal response to sudden, unanticipated infant death. *Pediatrics* 65:221–225.
7. Greenberg, M., and N. Morris. 1974. Engrossment: The newborn's impact upon the father. *Am J Orthopsychiatry* 44:520–531.
8. Abelin, E.L. 1975. Some further observations and comments on the earliest role of the father. *Int J Psychoanal* 56:293–302.

9. Lamb, M. 1975. Fathers: Forgotten contributors to child development. *Hum Dev* 18:245–266.
10. Mandell, F, and B. Belk. 1977. Sudden infant death syndrome. *Postgrad Med* 62:193–197.
11. Bergman, A.B., M.A. Pomeroy, and J.B. Beckwith. 1969. The psychiatric toll of sudden infant death syndrome. *GP* 40:99–105.
12. Krell, R., and L. Rabkin. 1979. The effects of sibling death on the surviving child: A family perspective. *Family Process* 18:471–477.
13. Weston, D.L., and R.C. Irwin. 1963. Preschool child's response to death of infant sibling. *Am J Dis Child* 106:564–567.
14. Mandell, F, E. McAnulty, and A. Carlson. 1982. Unexpected death of an infant sibling. *Pediatrics* 72:652–657.
15. Hardgrove, C., and L.H. Warrick. 1974. How shall we tell the children? *Am J Nurs* 76:448–450.
16. Koocher, G.P. 1974. Talking with children about death. *Am J Orthopsychiatry* 44:404–411.
17. Nikolaisen, S. 1981. The impact of sudden infant death on the family: Nursing intervention. *Topics in Clin Nurs* 3:45–53.
18. Smialek, Z. 1982. Observations of immediate reactions of families to sudden infant death syndrome. *Pediatrics* 62:160–165.
19. Mandell, F, M. McClain, and R. Reece. Sudden and unexpected death: The pediatrician's response. *Am J Dis Child* 141:748–750.
20. Kirkley-Best, E., and K.R. Kellner. 1982. The forgotten grief. *Am J Orthopsychiatry* 52:420–429.
21. Cain, A., and B. Cain. 1964. On replacing a child. *American Academy of Child Psychiatry* 3:443–455.
22. Mandell, F, and L.C. Wolfe. 1975. Sudden infant death syndrome and subsequent pregnancy. *Pediatrics* 56:774–776.
23. Szybist, C. 1973. *The Subsequent Child*. Chicago: National Sudden Infant Death Syndrome Foundation.

ADDITIONAL

RESOURCES

- SIDS Resource List
- First Responders Literature Order Form
- Indiana Family Helpline Flyer
- SIDS Case Management Flow Chart

S.I.D.S. RESOURCE LIST

SUDDEN INFANT DEATH SYNDROME PROJECT

Indiana State Department of Health
Maternal and Child Health Services
1330 West Michigan Street
Indianapolis, IN 46206-1964

Project Coordinator	Larry Humbert, A.C.S.W.	317/633-0722
Parent Consultant	Barb Himes	317/633-8466
Administrative Assistant	Susan Hopkins	317/633-8459

Parents and Professionals may also contact the S.I.D.S. Project Staff of the Indiana State Department of Health at:
Indiana Family Helpline **1-800-433-0746**

LOCAL SUPPORT NETWORKS

CENTRAL INDIANA SIDS ALLIANCE

Serves Marion, Hamilton, Southern Boone, Hendricks, Johnson, Shelby and Hancock.

Central Indiana SIDS Alliance **317/359-0402**

NORTHERN INDIANA SIDS ALLIANCE

Elkhart County	Gladys Stevens	219/262-0245
St. Joseph County	Cathy Rosenthal	219/259-4836
Marshall, Kosciusko, Noble County	LuAnn Kolbe	219/546-5464
Cass County, Michigan	Lyn LaPierre	616/699-5886

ALLEN, ADAMS, DEKALB, HUNTINGTON, WELLS and WHITLEY COUNTIES

Denise Lock	219/483-6393
Suzanne Washler	219/337-5360

VANDERBURGH COUNTY

Carol Palmer, Alexander Family Services	812/428-0102
	Home 812/863-0348
	Work 502/827-1867
Jo Sayle, Vanderburgh County Health Dept.	812/426-5813

CLAY, PUTNAM, HENDRICKS, MONTGOMERY and PARKE COUNTIES

Gloria Beau	317/657-0003

CLARK and FLOYD COUNTIES

Maria Donohue	812/283-0559

MORGAN COUNTY

Judi Grebel	317/831-5059
Theresa Staggs	317/831-7511

JACKSON COUNTY

Bema Jones	812/497-2405

TIPPECANOE, BENTON, NORTHERN BOONE, CARROLL, CLINTON, FOUNTAIN, WARREN and WHITE

Jackie Bahler, Kathryn Weil Center	317/449-5133
Marcia Muller, Tippecanoe County Health Dept.	317/423-9221

FULTON, WHITE, STARKE, PULASKI, CASS and JASPER COUNTIES

Joan Lauder, Pulaski Memorial Hospital	219/946-6131 Ext. 1180

FIRST RESPONDER'S ORDER FORM

Sudden Infant Death Syndrome Project

1-800-433-0746 or 317/633-8459

PAMPHLETS FOR FAMILIES

Title	Quantity
Crib Death	
Facts About SIDS for Child Care Providers	
For Grandparents...A Double Grief	
Healing a Father's Grief	
SIDS Blue Card (Fact Card)	
Robots and Goodbyes A Grief Storybook *$1.50 each*	

HANDOUTS (1 page each)

Title	Quantity
Apnea and Other Apparent Life-Threatening Events	
Infantile Apnea and SIDS	
Parents and the Grieving Process	
SIDS Information for the EMT	
The Grief of Children	
What is SIDS?	

INFORMATION FOR PROFESSIONALS

Title	Quantity
Infant Death: Guidelines for Support of Parents in the Emergency Department and the Delivery of Death Notification.	
How to Distinguish Between SIDS and Child Abuse and Neglect	
SIDS and Emergency Medical Personnel	

INFANT DEATH SUPPORT SERIES

Title	Quantity
Finding Answers with Compassion	
Facts About SIDS for Police Officers	
Discussing the Autopsy	
If You Would Be An Effective Comforter to Bereaved Parents	

Enclose a check or money order for the pamphlet entitled, "Robots and Goodbyes A Grief Storybook" Make check or money order payable to: **Indiana State Department of Health**

SEND PAMPHLETS AND BROCHURES TO:

NAME: _____

ADDRESS: _____

_____

CITY/STATE/ZIP: _____

PHONE: _____ _____
(AREA CODE)

COMPLETE AND RETURN TO:

INDIANA STATE DEPARTMENT OF HEALTH
MATERNAL AND CHILD HEALTH SERVICES
1330 WEST MICHIGAN STREET
P.O. BOX 1964
INDIANAPOLIS, IN 46206-1964

INDIANA FAMILY HELPLINE

1-800-433-0746

TTY / TDD

The Indiana State Department of Health's TOLL FREE telephone helpline.
Call to locate or receive information on:

PREGNANCY HEALTH CARE
WIC SITES / BREASTFEEDING SUPPORT
HEALTHWATCH PROVIDERS
CHILDREN'S SPECIAL HEALTH CARE SERVICES
CHILD / ADOLESCENT HEALTH CARE
MEDICAID PROVIDERS
WOMEN'S HEALTH / FAMILY PLANNING SERVICES
SUBSTANCE ABUSE PROGRAMS
IMMUNIZATION / LEAD SCREENING SITES
EMERGENCY SHELTERS / FOOD PANTRIES
SUPPORT GROUPS
SUDDEN INFANT DEATHS (SIDS)
GENETIC/NEWBORN SCREENING SERVICES
GED / JOB TRAINING SITES
DAY CARE / RESPITE CARE
STOP SMOKING / DRINKING PROGRAMS
DENTAL CARE SERVICES
MEDICAID TRANSPORTATION PROVIDERS
and MUCH MORE....

MON. - FRI. 7:30 A.M. TO 6:00 P.M.

ANSWERING MACHINE AVAILABLE AT ALL OTHER TIMES

Indiana State Department of Health

Bureau of Family Health Services

SIDS CASE MANAGEMENT SYSTEM
FLOW CHART

SUSPECTED SIDS DEATH

COUNTY CORONER NOTIFIED

Duties

— orders autopsy
— communicates results of preliminary autopsy results to family in writing or by phone within 24-48 hours
— notifies public health nurse *
— communicates final autopsy results to family when report is available

PUBLIC HEALTH NURSE NOTIFIED

Duties

— contacts family to schedule home visit
— conducts home visit and gives literature to family
— contacts local SIDS support group or SIDS parent contact (if available)
— makes follow-up calls and/or visits, if needed
— submits home visit report to Indiana State Department of Health, MCH Services

INDIANA STATE DEPARTMENT OF HEALTH

Duties

— sends SIDS Community Council letter to family that includes toll-free phone number
— receives copy of death certificate, creates case file and computerizes record
— reimburses public health nurse for completed home visits upon receipt of report form and claim voucher

* In Marion County, coroner notifies Maternal and Child Health Services who then notifies Prenatal Care Coordination Teams.

* In Putnam County, home visits are conducted by staff of Health Services Clinic of Putnam County, Ruth Ralph, Director.

* In Pulaski County, home visits are conducted by Nurse from Pulaski Memorial Hospital, Amy Bean.

* In Miami County, home visits are conducted by Jennifer Trobaugh, Social Services Director. (Dukes Memorial Hospital)

Note: Completion of this course does not meet the requirement for competency at the Hazmat Awareness and Operations Levels as set forth by OSHA 1910.120 and NFPA 472.

Course Objectives for Hazardous Materials for EMS Responders

At the completion of this course, the student

1. Shall be able to satisfy the knowledge competencies for First Responder Awareness and Operations Levels as set forth by OSHA 1910.120 and NFPA 472. Skill competencies are not included in this lesson.
2. Shall have the knowledge to complete the following tasks:
    a. Analyze a hazardous materials incident to determine the magnitude of the problem in terms of outcomes by completing the following tasks:
        i. Survey the hazardous materials incident to identify the containers and materials involved, determine whether hazardous materials have been released and evaluate the surrounding conditions
        ii. Collect hazard and response information from MSDS; CHEMTREC/CANUTEC/SETIQ; local, state, and federal authorities; and shipper/manufacturer contacts
        iii. Predict the likely behavior of a material as well as its container
        iv. Estimate the potential harm at a hazardous materials incident
3. Plan an initial response within the capabilities and competencies of available personnel, personal protective equipment, and control equipment by completing the following tasks:
    a. Describe the response objectives for hazardous materials incidents
    b. Describe the defensive options available for a given response objective
    c. Determine whether the personal protective equipment provided is appropriate for implementing each defensive option
    d. Identify the emergency decontamination procedures
4. Implement the planned response to favorably change the outcomes consistent with the local emergency response plan and the organization's standard operating procedures by completing the following tasks:
    a. Establish and enforce scene control procedures including control zones, emergency decontamination, and communications
    b. Initiate an incident management system (IMS) for hazardous materials incidents
    c. Understand the limitations of the average EMS responder regarding limited manpower, equipment, resources, etc.
    d. Perform defensive control functions identified in the local emergency response plan of action
5. Evaluate the progress of the actions taken to ensure that the response objectives are being met safely, effectively, and efficiently by completing the following tasks:
    a. Evaluate the status of the defensive actions taken in accomplishing the response objectives
    b. Communicate the status of the planned response

Surveying the Hazardous Materials Incident.

Given examples of both facility and transportation scenarios involving hazardous materials, the student shall survey the incident to identify the containers and materials involved, determine whether hazardous materials have been released, and evaluate the surrounding conditions and also shall meet the following requirements:

1. Given three examples each of liquid, gas, and solid hazardous materials, including various hazard classes, the student shall identify the general shapes of containers in which the hazardous materials are typically found.
2. Given examples of the following tank cars, the student shall identify each tank car by type as follows:
    a. Cryogenic liquid tank cars
    b. High-pressure tube cars
    c. Nonpressure tank cars
    d. Pneumatically unloaded hopper cars
    e. Pressure tank cars
3. Given examples of the following intermodal tanks, the student shall identify each intermodal tank by type and identify at least one material and its hazard class that is typically found in each tank as follows:
    a. Nonpressure intermodal tanks, such as the following:
    b. IM-101 (IMO Type 1 internationally) portable tank
    c. IM-102 (IMO Type 2 internationally) portable tank
    d. Pressure intermodal tanks
    e. Specialized intermodal tanks, such as the following:
        i. Cryogenic intermodal tanks
        ii. Tube modules

4. Given examples of the following cargo tanks, the student shall identify each cargo tank by type as follows:
    a. Nonpressure liquid tanks
    b. Low pressure chemical tanks
    c. Corrosive liquid tanks
    d. High pressure tanks
    e. Cryogenic liquid tanks
    f. Dry bulk cargo tanks
    g. Compressed gas tube trailers
5. Given examples of the following tanks, the student shall identify at least one material, and its hazard, that is typically found in each tank as follows:
    a. Nonpressure tank
    b. Pressure tank
    c. Cryogenic liquid tank
6. Given examples of the following nonbulk packages, the student shall identify each package by type as follows:
    a. Bags
    b. Carboys
    c. Cylinders
    d. Drums
7. Given examples of the following radioactive material containers, the student shall identify each container/package by type as follows:
    a. Type A
    b. Type B
    c. Industrial
    d. Excepted
    e. Strong, tight containers
8. Given examples of facility and transportation containers, the student shall identify the markings that differentiate one container from another.
9. Given examples of the following marked transport vehicles and their corresponding shipping papers, the student shall identify the vehicle or tank identification marking as follows:
    a. Rail transport vehicles, including tank cars
    b. Intermodal equipment including tank containers
    c. Highway transport vehicles, including cargo tanks
10. Given examples of facility containers, the student shall identify the markings indicating container size, product contained, and/or site identification numbers.
11. Given examples of facility and transportation situations involving hazardous materials, the student shall identify the name(s) of the hazardous material(s) in each situation.
12. The student shall identify the following information on a pipeline marker:
    a. Product
    b. Owner
    c. Emergency telephone number
13. Given a pesticide label, the student shall identify each of the following pieces of information, then match the piece of information to its significance in surveying the hazardous materials incident:
    a. Name of pesticide
    b. Signal word
    c. Pest control product (PCP) number (in Canada)
    d. Precautionary statement
    e. Hazard statement
    f. Active ingredient
14. Given a label for a radioactive material, the student shall identify vertical bars, contents, activity, and transport index.
15. The student shall identify and list the surrounding conditions that should be noted by the first responders when surveying hazardous materials incidents.
16. The student shall give examples of ways to verify information obtained from the survey of a hazardous materials incident.
17. The student shall identify at least three additional hazards that could be associated with an incident involving criminal or terrorist activity.

Collecting Hazard and Response Information.

Given known hazardous materials, the student shall collect hazard and response information using MSDS; CHEMTREC/CANUTEC/SETIQ; local, state, and federal authorities; and contacts with the shipper/manufacturer and also shall meet the following requirements: