Bereavement Counseling For Sudden Infant Death Syndrome (SIDS) And Infant Mortality:
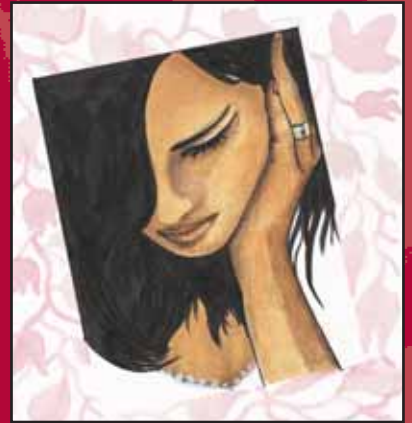
Core Competencies For The Health Care Professional

Association of SIDS and Infant Mortality Programs

Confronting the tragedy of infant and child death through counseling, education, advocacy and research

BEREAVEMENT COUNSELING FOR SUDDEN INFANT DEATH SYNDROME (SIDS) AND INFANT MORTALITY:

CORE COMPETENCIES FOR THE HEALTH CARE PROFESSIONAL

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ASIP

Confronting the tragedy of infant and child death through counseling, education, advocacy and research

The Association of Sudden Infant Death Syndrome (ASIP) and Infant Mortality Programs is made up of health and human service professionals committed to providing culturally competent support, education, and risk reduction to families and communities affected by sudden infant death syndrome (SIDS) and other forms of infant mortality.

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INTRODUCTION

The Association of Sudden Infant Death Syndrome (ASIP) and Infant Mortality Programs is made up of health and human service professionals committed to providing support, education, and risk reduction to families and communities affected by Sudden Infant Death Syndrome (SIDS) and other forms of infant mortality. In the past, ASIP has published guidance papers and training materials to enhance professional knowledge and skills in the area of bereavement support and risk reduction education. (For ASIP publications, see listing under "Suggested Reading" section at end).

In this paper, ASIP presents core competencies essential for the professional to provide appropriate and effective bereavement support for the family. What is "bereavement support," and why is it necessary? Bereavement support consists of immediate grief counseling followed by outreach and multidisciplinary services to provide a continuum of care to families beyond a child's death. The philosophy is nonsectarian and respectful of cultural differences. The approach is firmly rooted in public health.

ASIP supports the belief that grief is an enfolding process through which losses are integrated and from which growth is possible. When a child dies, the grief that follows enables healing and continuation of the family unit, redefined by death.

For the health care professional, an infant or child death, by its tragic nature, permits entry into the very center of a family's being. There, it is possible to assess its structure and function, and develop interventions for the future as well as to lend comfort during the current crisis.

Unfortunately, all too few health care professionals are trained to enter the experience of a grieving family unit to offer comfort, education, and continuing support. Yet it is through these caring strategies that families learn to live with their loss and become transformed in positive ways. By valuing the loss of a child, ASIP is committed to promoting family as well as societal health.

Rationale

In the United States currently, approximately seven infant deaths are associated with every 1,000 live births. SIDS, while declining, is still the third major cause (Mathews, Menacker, and MacDorman, 2003). Despite drops in the overall rate of SIDS, the disparities in death rates among racial and ethnic groups continues to rise (Unger et al., 2003). Infants of black and American Indian mothers are most affected, with SIDS rates between double and triple that for non-Hispanic white mothers (Mathews, Menacker, and MacDorman, 2003). Clearly, additional intervention is needed.

An infant or child death, by its tragic and often unexpected nature, places families at risk. The trained presence of the grief counselor can facilitate healing, education, and risk reduction through awareness and behavioral change.

The Institute of Medicine (IOM) of the National Academy of Sciences (2003) states that: "the goal of health professional education is an outcome-based education system that better prepares clinicians to meet both the needs of patients and the requirements of a changing health system." IOM further advocates that all professionals should be educated to deliver patient-centered care as members of an interdisciplinary team, emphasizing evidence-based practice, quality improvement approaches and informatics.

ASIP members require knowledge and skill to deliver patient-centered care to bereaved families. Here the essential core competencies required of the health care professional to deliver bereavement counseling and support are presented (Table 1).

Table 1

Core Competencies of Bereavement Counseling for SIDS and Infant Mortality

Core Competency	Essential Knowledge and Skills
Understand and use infant mortality statistics.	Data sources
	Leading causes of infant mortality
	Current trends in diagnosis/death classification
Educate about risk reduction.	Explain safe infant care practices
	Integrate with grief counseling and other health care encounters
	Know health beliefs and values of families being educated
	Assess for priority interventions
	Identify health care system deficiencies that are contributing factors
	Community education and advocacy to reduce risks
Provide bereavement counseling.	Basic counseling techniques and for whom they are appropriate
	The nature of grief and healing within the cultural context of the family
	Factors affecting the grief experience
	Grief in special populations (e.g., parents, children, grandparents, care-givers, and foster parents)
Realize impact on self as a health care professional.	Knowledge of self and personal experience with loss within one's own culture
	Entering space of another's grief
	Therapeutic use of self
	Effective communication
	Negative reactions
	Establishing boundaries, coping techniques
	Debriefing, support, and consultation

PART I: UNDERSTANDING AND USING INFANT MORTALITY STATISTICS

Infant mortality is a key indicator of the community's health and well being, from a social, economic, civic, and environmental perspective. Statistics are one way to begin telling that story.

Statistics, when used caringly, lead to a more thorough understanding of the problem. They also can be used to support parents and others in their grief by answering key questions. Finally, statistics figure critically into the design of effective risk reduction programs.

Factors uniquely related to sudden and unexpected death have been described (Worden, 2002). One of these is the need to understand the cause of death. Children are not expected to die before their parents and most often, when an infant or child dies, the death is sudden and unexpected. Parents are left with many questions about how and why it happened. Questioning why the death happened is an important first step for parents and family members to take in coping with their loss.

Another question often asked is: How frequently does this type of death occur in the general population? Leading causes of death vary by racial group and geographical area. Both types of information are essential parts of designing risk reduction programs that are relevant to the local community. Available statistics should be carefully interpreted due to variations in race and ethnicity definitions. Thus, it is essential that health care professionals be knowledgeable about causes of death that are specific to their communities and the populations served by their programs.

Achieving core competency requires examining three aspects of infant mortality statistics: data sources, trends in diagnosis, and leading causes of death.

When Cause of Death is "Pending Further Study" or "Undetermined"

Sudden and unexpected infant death usually occurs outside of the hospital, often at home or in a child care setting. Not infrequently, the cause of death cannot be determined following review of the medical history of the infant, a scene investigation, and a postmortem examination. In many jurisdictions, the medical examiner or coroner will assign the immediate cause of death as "Pending Further Study"; this designation remains at least until the microscopic and toxicological studies are competed. If those results are also negative, the cause of death may remain "Undetermined" on the death certificate. In these difficult cases, families are left without definitive information about why their baby died. Often they continue to wonder and speculate about the cause, and may blame themselves or find someone or something to blame for the baby's death.

Data Sources for Infant Mortality Statistics

Information about infant mortality is available from a variety of sources, including the Internet, libraries, government officials, and organizations. Your local health department may be able to offer preliminary statistics for your area. Check also with your state vital statistics office. In addition, the medical examiner or coroner's office may have statistics regarding sudden unexpected deaths that occur locally. National statistics are generated by the National Center for Health Statistics (NCHS) within the U.S. Centers for Disease Control and Prevention (CDC), and special interest groups.

How Are Statistics Recorded?

"Infant death" refers to a death occurring between birth and one year of age, and may be further classified according to age. A "neonatal" death is one occurring before 28 days of life, and "post neonatal" refers to the period from 28 days up to one year. The infant mortality rate is calculated by dividing the total number of infant deaths by the total number of live births. In common usage, that number is then multiplied by 1,000 to determine the mortality rate per 1,000 live births.

Source: U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, 2003.

Be sure to check the data source for any statistic obtained from the web. Several reliable Internet sites are described below.

Title V Information System (TVIS)

This web site features data from the annual Title V Block Grant applications and reports submitted by all 59 U.S. states, territories, and jurisdictions (on the web at **https://performance. hrsa.gov/mchb/mchreports/search/search.asp)**. Title V is a federal program providing money to reduce infant mortality, administered by the federal Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (DHHS).

TVIS provides information on key maternal and child health (MCH) measures and is a searchable database. Types of state-specific data that can be found at this site include neonatal, prenatal, and infant mortality rates. Each state also reports its MCH health priorities.

PeriStats

This online resource features data for perinatal statistics developed by the March of Dimes. "Perinatal" refers to a period from pregnancy (usually from the point of a viable fetus onward) throughout the early months of life, and is a way of measuring overall health indicators for this vulnerable population. The PeriStats web site **(http://www.modimes.org/peristats)** is an interactive resource providing maternal, infant and child health-related data, including statistics tabulated by states and counties.

State Health Facts Online

An information system developed by the Henry J. Kaiser Family Foundation, State Health Facts Online offers state health data and policy information for policymakers, researchers, program administrators and others. Recently updated in May 2003, the site now includes new and redesigned maps, tables, and bar graphs. Numerous types of relevant data are available, including the percentage of mothers beginning prenatal care in the first trimester, preterm births as a percentage of live births, Medicaid birth data, and childhood immunization statistics. Its online address is **http://www.statehealthfacts.kff.org.**

National Center for Education in Maternal and Child Health

Another comprehensive information resource is the new infant mortality knowledge path developed by Georgetown University's National Center for Education in Maternal and Child Health. **(http://www.mchlibrary.info/KnowledgePaths/ kp_infmort.html).** Aimed at health professionals, policymakers, and researchers, it guides

viewers to a selection of current, high-quality data analyses, descriptions of public health campaigns and prevention programs, and research reports, all aimed at identifying both the causes and promising intervention strategies for infant mortality.

Leading Causes of Infant Mortality

Causes of infant death vary by age of the infant. The majority of infant deaths occur in the neonatal period (i.e., from birth through 28 days),

when the causes, in order of frequency, are: congenital anomalies, disorders related to decreased gestation and low birth weight, respiratory distress syndrome, and maternal complications of pregnancy.

Post-neonatal deaths are those occurring between 29 and 364 days of life. SIDS is the leading cause of death in the post neonatal period, followed by congenital anomalies, injuries, pneumonia and influenza and homicide.

Birth defects are the leading cause of infant death overall (i.e., from birth to 364 days). Additional data appear on Table 2 (below).

TABLE 2

INFANT DEATHS AND MORTALITY RATES, UNITED STATES, 2001 (LINKED BIRTH-DEATH FILE)	
CAUSE OF INFANT DEATH*	RATE[†]
Birth defects	137.6
Prematurity/low birth weight	109.5
Sudden infant death syndrome	55.5
Newborn affected by maternal complications of pregnancy	37.3
Respiratory distress syndrome	25.3

*Based on the Tenth Revision, International Classification of Diseases, 1992
†Rate per 100,000 live births
Note. From Mathews et al., 2003.

Current Trends in Infant Mortality

When an infant dies suddenly and unexpectedly, it can be a difficult and lengthy process to determine the cause. Most states require an autopsy, a thorough death scene investigation, and review of the medical history. During this process all possible causes of death are examined.

The problem does not stop there, however, as criteria used to determine cause of death vary throughout each of the United States. While national guidelines have been developed (U.S.

Centers for Disease Control and Prevention, 1996), the standards governing classification of causes typically are determined at the state or local level. Thus, the philosophy and practice of the medical examiner or coroner system will be influential over how the causes and manner of deaths are classified locally, and data should be interpreted accordingly.

Other factors affect infant mortality statistics, including changing trends in diagnoses. SIDS deaths provide an example. SIDS is the sudden

death of an infant under one year of age that 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, James, and Catz, 1991). In recent history, the majority of sudden unexpected infant deaths are due to SIDS. SIDS rates are lowest among Asians and Hispanics, and highest among African Americans and American Indians (U.S. Department of Health and Human Services, 2001).

It is now known that sleep position, bedding and other factors contribute to a SIDS death (American Academy of Pediatrics [AAP], 2000). Risk reduction interventions have been designed and implemented with the Back to Sleep campaign. The resulting impact has been that the number of infants dying of SIDS has decreased significantly, with a resulting overall decline in infant mortality rates. However, while the overall SIDS rates have declined in all populations throughout the United States, disparities in SIDS rates and prevalence of risk factors remain concentrated in certain racial or ethnic groups.

Given the success of the Back to Sleep Campaign and the correspondent decline in SIDS and infant mortality, however, the National

Association of Medical Examiners (NAME) has recommended a modification in classification of SIDS deaths (Hanzlick, Hunsaker, and Davis, 2002). Its report describes the special problems and emerging issues behind classifying manner and cause of infant death, for example, the increasing recognition of fetal, infant, and child abuse as causative factors. Classifications are also complicated by evolving concepts about pathogenesis of injury mechanisms (AAP, 2001).

In summary, determinations of cause and manner of death by the medical examiner or coroner provide the first clue as to why infants are dying in a specific region. However, additional insights must be brought to bear on the problem. Classification of death varies among local jurisdictions, and cause of death criteria evolve and change as new data are available. Given these changing trends, infant mortality statistics must be interpreted in the light of all available data.

Even though statistics may reflect a lessening impact of SIDS upon infant mortality, that does not mean that interventions and risk reduction programs should be discontinued. Instead, they may need to be intensified among certain highly vulnerable groups.

Part II: Risk Reduction Education for SIDS and Infant Mortality

The sentinel event of a child's death provides an opportunity over time to provide not only grief counseling, but also information and education about how to reduce the risk of such a death in the future. Health care professionals in the field of infant mortality have recognized the importance of this task. An integral part of interactions with parents and other caregivers, therefore, is to provide education and guidance to ensure an optimum pregnancy outcome and quality of life for an infant.

The health care professional requires knowledge and skill in the area of infant mortality risk reduction education and should become well versed in a variety of safe infant care practices. This knowledge should be imparted to families as they consider a future pregnancy or care for any infant in their contact. Primary prevention interventions such as these are key to reducing the infant mortality rate.

This undertaking represents a powerful health promotion effort. Any strategy to reduce SIDS and other causes of infant mortality is significant for not only improving the health potential of infants, but also improving the quality of life of communities. When infant mortality is high, the quality of life is inversely related and often associated with poverty, deprivation, a paucity of health and social resources, and a depleted health care infrastructure. Thus, the infant mortality rate is used to measure the health and well being of a community or country, and is an important marker of community life. Improving the quality of life for infants generally improves the quality of life for all.

Risk reduction education encourages behavioral change, which then reduces the risk of infant death. Behaviors can be modified to reflect greater awareness of risks and adherence to safe infant care practices. The health care professional can introduce or review these concepts as part of any encounter. First, factors that place infants at risk for death are identified, followed by recommendations for reducing those risks.

Interventions may include changes in individual behavior, for which parents and/or caregivers can assume responsibility. Additional interventions may involve changing systems, for example, improving access to health care and making health care services culturally competent, thereby improving utilization patterns.

Critical elements in risk reduction are listed in Table 3. Parents and other caregivers must be assessed for adherence to these steps, and educated about the need for them. Many of these concepts are discussed in greater detail below. Every health care encounter is an opportunity to impart anticipatory guidance.

Health care professionals who want to take a comprehensive approach to SIDS and infant mortality risk reduction will not only assess and educate individual families, but will also advocate on behalf of these goals within their institution, communities, and the world at large. All efforts, small and large, and whether directed at the level of the individual family, or of the entire health care system or community, will make a difference.

TABLE 3

INFANT MORTALITY RISK REDUCTION: CRITICAL ELEMENTS

Prepregnancy	Maintain adequate nutrition and healthy lifestyle Schedule routine health checkups Choose appropriate family planning method Use folic acid in preparation for pregnancy
Prenatal Period	Seek early and adequate care Maintain adequate nutrition, avoid "junk foods," exercise, monitor weight Avoid exposure to smoke, alcohol and other drugs Report abuse and ask for help if in an abusive situation
Postnatal Period	Obtain health insurance for child Schedule routine health supervision and immunizations Breast-feed when possible Use supine sleep position in a safe sleep environment Use tummy time while baby is awake and someone is watching Ask about parent support programs Seek referral to public health and mental health program services, if appropriate Learn about family planning Learn to deliver cardiopulmonary resuscitation (CPR) to infants and children
Injury Prevention	Review and follow home safety checklist Learn infant car seat safety Never shake a baby Never leave baby alone in or near water (bathtubs, wading pools, swimming pools, rivers and lakes) Choose a recommended day care provider/babysitter who is trustworthy and responsible Keep emergency numbers where they can be quickly found
Selected Resources to Support Families	Medicaid or other health insurance Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) Healthy Start Early Intervention Programs Public Health Nursing

Source: Adapted from Massachusetts Center for SIDS, 1998; Arnold et al, 2001

EXPLAIN THE RELATIONSHIP BETWEEN RISK REDUCTION, SIDS AND INFANT MORTALITY

Risk reduction strategies for SIDS are part of the larger set of risk reduction recommendations for infant mortality. Since 1994, the Back to Sleep Campaign has recommended that infants be placed on their backs to sleep in order to reduce the risk of SIDS. Supine sleep positioning, combined with other safe sleep environment recommendations, has had a profound effect on reducing the SIDS mortality rate. Included in these recommendations are use of a firm mattress or sleep surface; avoidance of pillows, blankets, comforters, and stuffed toys in the baby's bed during sleep; and not permitting the baby to sleep on sofas or waterbeds. Prevention of overheating is also recommended, by not overdressing the baby.

Parents and caregivers should also be advised to take precautions against second-hand smoke inhalation that can occur when someone (themselves or others) smokes near the baby. Additionally, for proper growth and development, it is important to place the baby on his or her stomach for "tummy time" while the baby is awake and someone is watching. This helps the baby's neck and shoulder muscles get stronger (AAP, 2000).

OPTIMIZE USE OF THE HEALTH CARE ENCOUNTER

The health care professional internalizes risk reduction as part of the process of assessment and intervention. Each contact with an infant's parent or caregiver becomes an opportunity for risk reduction education. Use the opportunity to learn about the family's values and beliefs within the context of their culture. If an infant is brought to an emergency department with symptoms of an upper respiratory infection, for example, this is a perfect opportunity to check on immunization status, make sure a well baby appointment is scheduled, discuss feeding and infant sleep practices, and suggest other safety precautions, such as avoidance of second-hand smoke. If the health care professional is familiar with an inventory of risk reduction strategies, these can be reviewed quickly. If follow-up is required, a home visit or follow-up appointment can be scheduled.

WHEN INTERACTING WITH FAMILIES, DETERMINE WHICH ASSESSMENT FACTORS AND INTERVENTIONS ARE NEEDED OR SHOULD BE CONSIDERED

Appropriate education about risk reduction interventions, including safe infant care prac-

TABLE 4

PRIORITY INTERVENTIONS FOR INFANT HEALTH AND SAFETY

- Refer for prenatal care
- Counsel about smoking cessation and a smoke-free environment
- Recommend regular folic acid intake for prevention of birth defects
- Conduct a risk inventory for substances, violence, and medical, psychological, or social problems
- Identify all infant caregivers for education and guidance
- Evaluate home and sleep environments for safety
- Provide Back to Sleep guidance; discuss safe sleep recommendations
- Inform all infant caregivers about shaken baby syndrome
- Review infant feeding practices
- Appraise immunization records and well baby history
- Determine growth and development milestones
- Suggest different ways to calm and comfort an irritable infant
- Offer strategies for coping with the stress of infant care giving
- Plan home visits for further evaluation and guidance
- Make appropriate referrals for all needed services

Note. From Arnold et al., 2001.

tices, should be based on a thorough assessment by the health care professional. Assessment involves several parameters: infant health status, infant care practices, parent-infant interactions, family dynamics, cultural beliefs and values, household environment, neighborhood, and relationships with agencies and community services. Priority interventions have been identified in Table 4.

IDENTIFY AND COMMUNICATE TO FAMILIES SAFE INFANT CARE PRACTICES THAT SERVE TO REDUCE THE RISK OF INFANT MORTALITY

Safe infant care practices involve every aspect of an infant's life and changes as the infant grows and develops. A preliminary list to recommend to parents and prospective parents includes the following (Arnold et al, 2001):

- Obtain prenatal care
- Keep a smoke-free home
- Never shake a baby
- Put the baby on his or her back to sleep
- Create a safe sleeping environment
- Use comfort measures when a baby is irritable
- Choose responsible caregivers
- Teach other caregivers safe infant care practices
- Enjoy the baby

IDENTIFY DEFICIENCIES IN THE HEALTH CARE SYSTEM THAT CONTRIBUTE TO INFANT MORTALITY

Infant mortality risk reduction ought be a priority of every professional and organization providing health care services. Reduction of infant mortality through risk reduction strategies improves the health potential of infants and the well being of all members of the community. Families will seek and sustain health care when a trusting relationship is possible with health care providers and the system of care is responsive (i.e., consumers believe they are central in the caregiving process, and that the system of care is negotiable and receptive). Consumers tend to prefer health care systems offering the following characteristics (National Institute of Nursing Research, 1995):

Availability—refers to the number, types, range, and frequency of health and social services offered

Accessibility—refers to the ability of persons to make use of services, encompassing distance, effort, cost, awareness of services, and attention to other qualities such as the comfort level of persons entering the health care system

Affordability—refers to the ability of consumers to pay for services and the mechanisms to secure payment for programs

Appropriateness—refers to the ability of the health care system to provide services that are needed, desired, and performed

Adequacy—refers to the ability of a program to allow persons to enter at the levels they need

Acceptability—refers to the congruence between the service and the expectations, attitudes, values, culture, and beliefs of the target population. Acceptability is paramount, for if health care is not acceptable to the target population, the services provided will not be effective.

COLLABORATE WITH OTHER HEALTH CARE PROFESSIONALS, FORM COALITIONS, AND MONITOR COMMUNITY PROGRESS

The health, social and systems factors that contribute to infant mortality make it an exceptionally complex problem to ameliorate. No one service or intervention alone will succeed, but combined efforts can be powerful. Reducing infant mortality is a public health goal rooted in collaboration and partnerships. It involves the efforts of a vast array of agencies and health care professionals, all joining together, yet each contributing their own unique approach and delivery of services.

Among the best indicators of progress in infant mortality reduction is the formation of coalitions and perinatal forums dedicated to this issue. When agencies and health care professionals who are knowledgeable about each other's services come together to jointly plan efforts for referral and consultation, the

community of support operates in a coordinated fashion and fewer families fall between the cracks of the health care system.

The impact of these various programs and outreach efforts is measured as progress is made. Once infant mortality reduction becomes a shared goal of agencies and professionals, progress is palpable. Improved statistics can be tracked at different levels of coordination, from the infant mortality rate at the health district level to the city level, to the country level and finally as a global health indicator.

ADVOCATE FOR INFANT MORTALITY REDUCTION

All health care professionals, through their knowledge and actions, can advocate for efforts to reduce infant mortality and help others to recognize this as a major public health issue. They can start by insisting that infant mortality risk reduction be made a priority of service delivery at their institutions and agencies.

To stay informed, they should attend professional conferences focusing on infant mortality issues and concerns, such as the ASIP Annual Conference. Political advocacy is another route to change: writing to members of Congress, lobbying, and signing petitions to seek improvements in health and social services for families.

PART III: BEREAVEMENT COUNSELING FOR SIDS AND INFANT MORTALITY

The death of an infant is a loss like none other. It marks an extraordinary crisis.

Parents, in particular, are left shattered and bewildered. They grieve for their dead child, who will never be able to grow up or grow old. They also grieve for themselves, fearing they will never feel whole again.

The intensity of the loss extends to the entire family, to caregivers and others who are involved in the family's life. A vital member of the family is gone, and the family is changed inexorably.

It can be very difficult for someone from the outside to approach the family at this point in time. In order to be of service to the family, the health care professional must be properly trained and equipped with basic skills and knowledge (Table 5). The skilled counselor will also direct appropriate interventions to the grieving participant, be it a parent or grandparent, sibling, or another caregiver. The differing nature of grief experienced by these individuals is discussed throughout Part III.

TABLE 5

BASIC SKILLS OF BEREAVEMENT COUNSELING

❖ Listen and attend to story of baby's life and death, and to parents' expressions of grief within their cultural context

❖ Convey sense of empathy

❖ Gain knowledge about cause of death, family development, and family dynamics

❖ Assess: a) grief response of family members, including suicide ideation and risk; b) availability and appropriateness of social support networks; c) parental knowledge and understanding of cause of death

❖ Provide anticipatory guidance for grief process, explaining how grief is expressed and what to expect over days and weeks ahead

❖ Make appropriate referrals for grief therapy and/or to other community health and social service programs, including natural supports and healers appropriate for the family's culture

Note. Adapted from Shaefer, Noell, and McClain, 2002.

Counseling The Bereaved Parents

When a child dies, the grief that enfolds parents is characterized by feelings of intense loss, sadness, emptiness, and failure. Parents often perceive themselves as having failed in some way to protect their child from death.

The loss may be the parents' first death experience. It may elicit parental guilt, magnification of minor omissions, and anger, and may have a profound affect on family functioning for an indeterminate period of time. The hopes, plans and dreams for this baby are shattered (McClain and Mandell, 1994). Death becomes the ultimate separation, as parents are not able to fill their emptiness, even with another child or children born before or after the deceased.

Grief is enduring. For bereaved parents, its beginning marks a lifelong process of learning to live without their child. Ultimately, they will begin to integrate their loss and continue to find meaning in their lives. Nonetheless, the experience shapes their personal identity, as well as that of others, in ways both good and bad.

Skilled counseling can have an enormous impact on parents' ability to cope with grief successfully. This intervention offers multiple benefits for parents themselves and for their families and communities, now and in the future.

Like grief itself, counseling has numerous dimensions and should take place over time. The health care professional should prepare in advance. The essential tasks involved in counseling bereaved parents are shown in Table 6. The importance of each of these tasks is later discussed.

TABLE 6

ESSENTIAL STEPS TO COUNSELING BEREAVED PARENTS

1. Gain knowledge of factors affecting this parent's grief experience.
2. Anticipate parental behavior and expressions of grief.
3. Portray grief as a lifelong process that is unique to each individual.
4. Distinguish normal from complicated grief reactions.
5. Assess parent's emotional state and ability to care for self and others (i.e., ability to provide both functional capacity and emotional support).
6. Determine family's multiple needs and sources of support.

Note. Adapted from Shaefer et al., 2002.

Factors Affecting the Grief Experience

Factors that might have an impact on how different parents experience and cope with their loss are shown in Table 7. The competent health care professional will assess for these factors and structure the interaction with parents accordingly.

CULTURAL INFLUENCES

Every culture has its own distinct way of easing the suffering of grief. These cultural beliefs and practices, including religious affiliations and spiritual beliefs and practices, offer the bereaved an explanation for the meaning of death and a prescription for how to proceed with life. Some families may be more affected than others by these cultural influences. It depends in part on immigration status, socioeconomic status, and extent of acculturation (Shapiro, 1994; Shaefer, 1999, Shaefer 2003).

FAMILY SYSTEM

The child's death becomes a crisis of family development. Grief increases the family's emotional burden and shatters the family's ordinary life routine and ways of coping with

emotions. Thus, the first priority for a grieving family is to reestablish equilibrium in order to support ongoing family development (Shapiro, 1994). For the grief counselor to support this task, it is helpful to know the family members, roles of each member, and communication patterns. There are numerous variations in family composition; for example, there are two-parent, single-parent, teen-parent and multigenerational families. In addition to coping with loss and grief, many families are faced with complex issues of poverty, homelessness, domestic violence, social isolation, and multiple types of loss.

In counseling, it can be helpful to address the parent's ability to deal with the needs and grief reactions of surviving children, as well as any other children in the future. Often they are too emotionally drained and consumed in their personal grief to give their energies to their surviving children. Assisting parents, helping them to deal with the needs of their other children, can be crucial to their recovery, and may signal the return of their ability to feel capable as a parent. Grieving parents may also feel incapable of decision making and wonder if they are safe or competent enough to be parents since their child had died. Assisting their surviving children to grieve and join with them in grieving is important for building parenting capacity and family functioning. Anticipatory guidance about subsequent children is also pertinent to family health.

MANNER AND CAUSE OF DEATH

Infants and young children die for many reasons: miscarriage, stillbirth, complications of prematurity, sudden or unexplained illness, infection, congenital or inherited problems, injury, and SIDS. The manner of death may be natural, accidental, homicide, or undetermined. All of these factors and others may affect the grief response (i.e., the type and timing of the loss, parental expectations and attachment to the infant, repeated loss, sudden versus anticipated death).

TABLE 7

FACTORS AFFECTING THE GRIEF EXPERIENCE	
Cultural influences	Culturally-rooted beliefs and practices that attempt to explain the meaning of life and death as well as rituals and ceremonies for processing loss
Family system	Family composition and role of various members; social circumstances and preexisting difficulties facing family
Manner and cause of death	Natural, accidental, homicidal, or undetermined; first experience versus repeated loss; sudden versus anticipated
Hopes for the future	Extent of parents' emotional investment in child
Child's age, siblings	Impact of death on family developmental issues
History of loss	Multiple losses that overwhelm and place the parent at risk for a prolonged and complicated grief reaction
Medical and legal issues	Impact of continuing investigation, legal repercussions
Professional and social network	Influences of friends, caregivers and health care professionals

Note. Adapted from Shaefer et al., 2002.

HOPES FOR THE FUTURE

Parents invest in their children important aspects of themselves, including their hopes, plans, and dreams for the future.

Consequently, the grief experience is centrally connected to the experience of self. After losing so much and giving up many expectations, parents sometimes feel as though they have lost their reason for living. Among the things that have been taken from them is pride in their infant as a manifestation of their own fertility and vitality; their maternal/paternal role; excitement and anticipation about their child's special firsts; the chance to see the baby grow, prosper, and become a vital part of the family; and their connection with the child as a bridge to the future. For some families, the concept of self is intertwined with familial, communal and religious beliefs, making grief a collective response.

AGE OF THE CHILD AND PRESENCE OF OTHER SIBLINGS

The age of the infant or child at death may not alter the severity of parental grief, but it can influence the impact of the death upon family developmental issues.

Sibling grief may also have an impact on parental grief. If there are other children in the family, their thoughts, feelings and behavior may be influenced by the age of the deceased child, as well as factors such as how the death was explained to them, and how parents and caretakers respond. (For more about sibling grief, see section entitled "Counseling Children about Death and Grief.) All this may have an impact on parental stress and the intensity of their emotions. How they cope, and how they respond to their other children, may have lasting impact on their own emotional health and that of all within the family system.

Helping Parents Help Their Children

Siblings of the deceased fare best when their parents understand and attend to their grief process. Parents may need advice and help about how to handle this responsibility. It is a necessary part of the counseling and support that the health care professional provides.

Bereavement home visits as well as pediatric office visits provide an opportunity to observe the dynamics of the grieving family. As part of their job, health care professionals should listen to and observe the talk and behavior of any bereaved siblings, and also should ask the parents about their children's behavior. Parents should be encouraged to discuss any changes in their child's interaction with them that have occurred after the baby's death.

For example, some parents report that following their sibling's death, the other children demonstrate higher levels of anxiety when separated from the parents. Some children express fear that the parents also might disappear, as did the baby. One child, aged two and one-half years, had temper tantrums when she was separated from her mother for several months after the event of the baby's death. In another instance, a mother had to remove her child from a day care center for a year because of the child's intense negative response to being away from home during the day. (Mandell, McAnulty, and Carlson, 1983).

Parents' responses, including how they act and explain the death, may influence their children's grief and adjustment. Some parents report that they derive comfort from being physically closer to their surviving children, while other parents feel overwhelmed by their children's needs (i.e., for comfort and to ask questions about what happened to the baby). Children's grief responses are influenced by their age and circumstances. Parents need to be educated about normal and complicated grief responses. (For more information, see next section, **"Counseling Children about Death and Grief "**).

HISTORY OF LOSS

This is an important marker for the parent's emotional health and well being. Multiple losses can result in overwhelming emotions, a sense of being victimized, and feelings of futility, all of which place the parent at greater risk for a prolonged and complicated grief reaction. Some families may have more losses due to racial disparities in the rate of SIDS and other infant deaths related to violent neighborhoods and other risk factors. Refugees may have had losses and experiences of abuse before arriving in the United States.

Parents without social supports, experiencing deprivation and dehumanizing poverty, and a sense of being alienated, are at greatest risk. Taking an inventory of support both within their network of family and friends, as well as through agencies, is essential in determining the extent to which parents are able to feel supported and are linked to available community services. They will need concrete services and assistance with entitlement and other forms of support. Without such a safety net, the loss of their child can precipitate other crises.

MEDICAL AND LEGAL SYSTEM INVOLVEMENT

Depending on the circumstances of the death, parents may be in contact with medical professionals, police investigators, medical examiners, and coroners. Their grief reaction will be influenced by the circumstances of the death as well as the sensitivity and intrusiveness of the professionals involved (Longchamp, Hall, and Arnold, 2003).

SOCIAL NETWORK

Individuals close to the bereaved parents, including friends and others who care for the infant, carry with them their individual and family grief history, as well as their cultural beliefs about death, dying and bereavement. All this may have an impact on the parental

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When Parents Are Forced to Put 'Grief on Hold'

As was their usual pattern, the wife worked nights and the husband was at home caring for their two children, a daughter aged three months and a three-year-old son. This particular night, their world shattered in an instant.

At around 10 p.m., the father went to check on the baby, asleep in her crib. He discovered that the infant was not breathing and immediately called the police. The police arrived at the home and viewed the father (an African American male left at home with two small children) with suspicion. Yellow tape was being used to mark the inside of their home as a potential crime scene.

When the mother arrived at home following an emergency call to her job, the police separated her from her husband and questioned them separately. She was terrified. She was asked if she wanted to be taken to the hospital, where their baby had been transported, but she felt she must remain at home to protect her husband. She wanted to call the family attorney to gain some assurance that her husband was safe in this very hostile situation.

Under these disturbing circumstances, parents may be forced to put their "grief on hold" while dealing with the authorities. For this couple, their baby was in the emergency room without them; grief was suspended, and the situation was extraordinarily painful and traumatizing. Ultimately, the infant's death was determined to be a case of SIDS, and the family received services from the SIDS Office. Three years later, the same couple became volunteer peer supporters and risk reduction educators for the SIDS office. They continue to talk about their story and about having to put their "grief on hold."

grief experience. Healthcare professionals may be uncomfortable in the presence of parents' raw grief, and may respond with an urge to avoid the pain by leaving the parents alone, or by medicating them or encouraging them to self-medicate. To some extent, the parents' preexisting life circumstances (i.e., stress, emotional health, and support network) will determine how parents are apt to respond.

Parental Behavior and Expressions of Grief

When an infant dies, regardless of cause, parents may feel confused, lost, sad, out of touch, numb, guilty, angry, empty, alone, discouraged, depressed, helpless and fearful. The spectrum of emotions is not only intense, but one over which they have little control (Woods and Woods, 1998).

Initially, they may experience numbness and shock characterized by a feeling of unreality, i.e., sometimes feeling as if the baby is not dead. There may be a strong desire to be reunited with the baby, and sometimes auditory and visual sensations of hearing and seeing the baby. Physical symptoms at this time may include loss of appetite, sleep disturbances, aching arms, and signs of stress, such as headaches and high blood pressure. Psychological changes may include indecisiveness, inability to concentrate, and disorientation.

Parents often feel helpless, and experience a sense of loss of control, which can lead to anger and depression. Sometimes they express feelings of guilt that they are somehow responsible for the baby's death. For example, they may believe that the death was due to their inability to carry a baby to term, to being carriers of a genetic defect, or because their actions may have in some way contributed.

Parents need to be assessed for feelings of guilt and told to expect these flights of emotion. They may be visited by feelings of doubt, guilt, self-blame, helplessness, and anger over the coming weeks and months. Eventually, with healing, they will begin to perceive their circumstances in a new and more forgiving light. Gradually their

sense of well being will return, and the bereaved parents will be able to attend to the tasks of living, moving forward in time (Shapiro, 1994).

The Nature of Grief: A Lifelong Process, Unique to Each Individual

Parents grieve in different intensities throughout their lives. This lifelong process is necessary for healing. Through it, parents learn to live without the physical presence of the child while still incorporating his or her memory into other aspects of their lives.

UNIQUENESS OF GRIEF
Everyone will grieve differently: mothers, fathers, grandparents, children, and other family members and caregivers. Some participants may think that others do not understand how they feel, or believe no one cares as much as they do. One parent may measure the partner's expressions of grief against his or her own. It may help to point out that each parent has a unique relationship with a child, and that those special dynamics enter the grief relationship with the dead infant. Gender, role relationships and cultural background may contribute to unique as well as common characteristics of parental grief.

MISCONCEPTIONS
Parental grief is often misunderstood. Misconceptions hinder understanding and acceptance. Among these misconceptions is the view of grief as an episode, rather than a lifelong continuous experience. Grief cannot be plotted on a timeline, with a beginning and end date, but rather is a timeless and boundless phenomenon. Grief is also sometimes seen as a way of letting go, or detaching, rather than as a way to keep connected with the dead child. The goal may be to reach some final resolution or acceptance; instead, grief tends to be a lifelong process. In addition, grief is sometimes avoided, whereas it is necessary for healing.

HEALTHY VERSUS COMPLICATED GRIEF

Just as death is a part of life, grief and its accompanying pain are a part of healing. However, in some cases the recovery may go wrong.

It may be helpful to analyze the parents' functional capacity, i.e., their ability to carry out regular activities of daily living. Patterns of daily living can be dramatically altered by grief, which has the capacity to erode interest in self-care. Sleeping patterns, nutritional intake, ability to work, relationships with others and the ability to conduct self-care activities, all should be assessed.

If, after several weeks, there is an inability to return to daily routine; total lack of affect; sensations of hearing and seeing the baby persisting several months after the death; parental neglect or overprotection of siblings; significant alcohol/drug abuse; hostile aggressive behavior; or prolonged social withdrawal, then it may be necessary to refer the parent for more intensive mental health interventions, including grief therapy (Worden, 2002; Arnold, McClain, and Shaefer, 1998).

Parents with multiple needs are most susceptible to grief complications. The death of a child is often an entry into a family situation that reveals multiple needs. For example, grieving parents may have significant untreated personal health problems requiring referral and treatment, or social and economic problems, which limit their capacity to grieve for the dead child. Situations like eviction, homelessness, and inability to pay for the child's funeral all take a toll on the parent and require that energies be directed to these situational crises, making it impossible for them to grieve properly (Arnold, 1994). Parents may be concerned about immigration status and fear the death will expose them. They may not be able to take the baby to their homeland to bury and fear accepting support from government agencies here in the United States.

Counseling Children about Death and Grief

The death of a brother or sister affects the surviving child in profound ways. Besides losing a sibling, the child experiences a change in the relationship with parents. He or she may struggle to understand the concept of death, often for the first time.

A child often grieves deeply, although their grief differs from that of adults in expression, intensity and duration. Their ability to grieve is affected by the context of the death, their relationship with the baby who died, and their preexisting emotional and cognitive development.

Children's emotional and behavioral responses to death are described in Table 8. They may include regression to earlier developmental levels, physical symptoms, and a tendency to internalize the death as punishment for their own bad deeds. For example, children still in the magical thinking phase may believe they caused the death by wishing the sibling would 'go away.' Children often act out their feelings of loss through play, which becomes therapeutic, helping them to cope with the death.

TABLE 8

CHILDREN'S REACTIONS TO DEATH	
Anxiety and fear	Children may cling to parents or other adults, seeking reassurance that they are loved.
Anger and resentment	Children may be angry with their sibling for dying, and at God and their parents for not keeping the baby alive. They may be angry about not getting the attention they need during the crisis.
Guilt	Children often feel guilty because of what they may have said or done before the baby died, and for being alive when baby is dead.
Shock	Children may not fully understand that the baby is not coming back; they may not show any emotion.
Sadness	Children's activity may decrease; they may become quiet, cry, or daydream without knowing why.
Role adjustment and regression	Children may return to earlier behavior for a short period of time, such as thumb sucking, using a bottle and bed-wetting

Note. Adapted from McClain and Shaefer, 1995.

At a minimum, it is important to clear up any misconceptions about causality or blame, and to ease the child's anxiety and fears. There are certain basic questions that most children will need to have answered (Adapted from AAP, 1992):

1. What is death?
2. What made the baby die?
3. Where is the baby who died?
4. Can it happen to me?
5. Who will take care of me?

Children tend to be greatly affected by the reactions of adults in the environment, including the way the death is explained to them. The role of the bereavement counselor in educating parents about this task can be tremendously important. Often parents, in an effort to protect their children from unnecessary pain or sadness, will discuss the death in a hushed voice, or in private. There is a better way, and parents should be encouraged to discuss the events with their children in age-appropriate ways. The health care professional can make suggestions and assist the parent in developing the necessary communication skills (see Table 9).

The age of the child and the child's feelings and expression of grief all will dictate the support needed from the parents and other caregivers. For example, young children will benefit from reassurance, being told they are loved and that the parent will not leave. Teens appreciate an honest discussion about feelings and circumstances surrounding the death.

By helping children to confront the loss, and to process it, parents and caregivers equip children with greater strength and capacity for enduring significant losses in their own lives up ahead. They also extend their own humanity to children, instilling within children a greater capacity for empathy and a sense of caring.

Children's Developing Concepts of Death

Death can be explained to children in much the same way life is explained. Both life and death are part of the same continuum, called a "lifetime." Mellonie and Ingpen (1983) say simply, "There is a beginning and an ending for everything that is alive. In between is living."

There are four concepts related to death that have particular relevance to children. These concepts are developmentally linked, that is, they will have varying impact depending on the child's age and developmental maturity (Smilansky, 1987; Siegel, 1985).

SEPARATION

Separation is poorly understood by young children, and can be a painful experience when imposed through death. The child experiences a void and may feel cut off from what was secure. That causes the child to feel unsafe, exposed, anxious, and fearful of the unknown.

Anxiety over separation, including that imposed by death, tends to be intensified in infants and children younger than two years, in whom this aspect of emotional development is still unformed. Because the stability of their world is threatened, young children may exhibit fear and/or anger, have nightmares, or act out in rowdy play. They may regress, demand more attention, talk baby talk, or need a security item to cope.

FINALITY

Understanding that death is "final" is a developmental task that evolves over time and is understood differently during each developmental period.

Between two and four years of age, children tend to view death as reversible. Accepting death's finality requires an appreciation of separateness, which is still being formed. Consequently, young children tend to believe in the interchangeability of life and death. For example, they may believe that the dead baby is coming back, or "living" in the cemetery. This gives them the capacity to grieve for a while, and then return to their play or usual activity. The young child will need clarity, in the form of a concrete explanation that the dead baby is not coming back, and that being dead means not breathing, not moving, and not living.

As the child progresses in development, the idea that death is a reversible phenomenon is replaced with the concept of death as irreversible and final. By seven to nine years of age, children are expected to grasp this concept. Still, death's finality tends to be struggled with throughout the life process. Even grieving adults think they may awaken from a bad dream and become reunited with their child, as if death's permanence could be reversed.

Family, culture and religious beliefs also shape the concept of finality. Some religions portray death as being in a "better place with God." Many parents find comfort in the belief that they will be reunited with their infant after their own deaths. In such cases, the infant's death may be appreciated as a final condition, yet the spiritual life continues. Some cultures believe in reincarnation. Death and its finality are interpreted through the lens of religious understanding and expectations.

INEVITABILITY

Believing in the inevitability of death is to recognize that all living things must eventually die. In other words, death is an inescapable part of life.

Children can be assisted in this notion if they are encouraged to recognize death in other living entities, especially those that have a much shorter life cycle than human beings. A common childhood pet, the goldfish, provides an example and a valuable life experience. Its short lifespan virtually guarantees that the child will be exposed to death's inevitability as witnessed through nature.

Eventually, an older child will come to witness the death of a significant person,

most probably an elder member of the family, and learn that aging is associated with death as the end of life. However, death of a sibling brings with it the realization that death can also be unexpected and "unnatural," i.e., can occur out of the natural order of the lifespan. This can be a difficult lesson.

CAUSALITY

Children's understanding of the cause of death should be explored to clarify misinformation and misconceptions and address questions about who or what was responsible. It is not until between five and nine years of age that children come to realize that death has a logical cause. At this age, by virtue of their life experiences, children are better able to accept physical causes of death. They recognize that living things must die, i.e., that death is real, but not necessarily a threat to them.

Younger children are more susceptible to misconceptions. For example, young children may view death as a "taker"—something, often violent, that comes to "get" you or "take" you away. They may personify death as a scary figure, or may view death as contagious, something that can be caught. At times, children may even think they are personally to blame for the death, i.e., that it happened because of something they said or thought.

Children of all ages are best able to cope with death when they are offered simple, honest, and accurate information explaining the cause. Explanations should be consistent with family and cultural values and beliefs, for it is through these explanations that the child forms a philosophy about death. For example, one philosophy may portray the cause of death as a disease process that inexorably progresses until death occurs. Another may offer a spiritual outlook in which death represents a transition to another life beyond death, or may offer assurances that death is transformative and another life is possible.

TABLE 9

HELP FOR THE GRIEVING CHILD

Open communication	Take time to listen and answer questions
	Use simple, truthful words to explain the death (e.g., "the baby died").
	Do not equate death with "sleeping" or "going away"
	Be consistent and open, but not overwhelming with details
	Allow children to talk to you about the death as often as they want
	Encourage children to talk with each other about the death
	Listen to what the child is saying; observe what the child is not saying
	Take the word "dead" off taboo list
Active expression of grief	Let children cry or be sad; allow them to express emotions
	Do not force child to talk about his or her feelings
	Encourage children to remember the baby (i.e., keep a diary, box of mementos; create stories or drawings; play activities; books, memorial or funeral services to explain death
	Do not be afraid to express your own emotions; instead, convey that grief and sadness are appropriate for people of all ages, (i.e., that you too are sad and it is okay for you to cry or be angry)
	Obtain professional help if child's fears are unusually severe or last unusually long
Support for adjustment	Show children love, support and care, physically and emotionally
	Maintain a normal routine
	Do not tell your child he or she is now the "grown up" of the house or to "be brave"
	Seek help if you feel unable to deal with your child during a crisis
	Contact child's school and inform teacher and nurse of a death in the family

Note. Adapted from Massachusetts Center for SIDS, 1998.

Counseling Grandparents

Grandparent grief is often described as double by nature. They suffer the death of their precious grandchild and they also witness the devastating effects the death has on their own child, the baby's parent. Layers of loss compound their grief.

They may have formed a special relationship with the child, and be stricken by the sudden loss. Or, in many cases, grandparents have assumed responsibility for day-to-day infant care, and their grief is compounded by their heightened sense of responsibility for the infant's health and well being.

In addition to their relationship with the dead infant, grandparents often serve many roles within the family system, some of them vital to the family's functioning. Often they are the key to family organization, and may have the capacity to not only influence the expression of family grief, but also keep their families together in the face of disrupting and disorganizing loss. In many situations, grandparents serve as the infant's primary caregivers. Because of their special role, their grief is deserving of special attention.

Relationships Between Grandparents, Parents, and Grandchildren

Grandparents have a special relationship with their grandchild or grand children. Often they are free to offer unconditional love to the grandchild in a relationship unencumbered by the responsibilities of direct care. Even when grandparents visit or baby-sit, they are free to enjoy this special relationship and dote on their grandchild, as the parent is ultimately responsible for the infant. This can be a "win-win" situation, as the grandparent offers needed support and also has opportunities to form a positive bond with the grandchild.

The grandparent can be the repository of wisdom not only about family life but also about infant care practices. It is natural for young parents to turn to their own parents for assistance and support, as well as answers to their specific child-rearing questions. Grandparents have the benefit of experience. Their methods of childrearing have been tried and found true. Their

longevity and success as parents has been established, and they are respected for their special knowledge and experience with raising children. When grandparents pitch in to help out with infant care, they form a bond with their own children and gain thanks and recognition for the invaluable assistance (Hunter, 1997).

Grandparents' Role in Family Structure and Organization

Grandparents often are at the core of family life, exerting an influence on how families are organized and helping to define the roles assumed by each family member. Their degree of personal power usually relates to cultural expectations. The bereavement counselor should take into account the family organizational structure and family dynamics. This can be researched through the use of a family tree as well as inquiring into the nature of relationship among family members (Harrison, 1993).

The power attributed to grandparents is often rooted in cultural norms and mores, particularly in situations where elders are held in high esteem. In many cultures, the grandparent is revered and considered the key to family wisdom. He or she fulfills this role by providing information about family history and mores. The grandparent willingly assumes power within the family network and is instrumental in maintaining family connections through relationship building. As a result, grandparents may be given social status and considerable stature in the family hierarchy. In these situations, family members will defer to the grandparent for decision making (Wilson, Tolson, Hinton, and Kiernan, 1990).

Even without a cultural precedent, the extended family network often places the grandparent in charge of generations of children, their own as well as their grandchildren. Grandparents often serve as the primary caretakers of the grandchildren. This is frequently the case when the parent happens to be an adolescent or young adult who may be attending school or working. It may also be true in situations when the parent is absent due to incarceration, the requirements of protective shelter, or immigration status. In these latter cases, the grandparent may be the only accessible contact and have full responsibility for infant care.

It is not uncommon, therefore, to find that the grandparent is the "gatekeeper" of the family, i.e., the one who regulates the flow of information and support. Sometimes day care providers and other caregivers must gain the trust of the grandparent before being given permission to contact the parent directly. When an infant death occurs, grandparents may find themselves confronted with decisions about funerals or services for the baby. They may also serve as the family spokesperson in charge of responding to medical and death investigative personnel.

Providing Grandparents With Support

The infant death can be devastating for grandparents. It is agonizing to witness the grief of their child and to feel their own grief for this infant. Grandparents can benefit from the support of other grandparents to share their grief and experiences of loss. It is helpful to refer grandparents to organizations specifically offering support to grandparents and to develop literature specific to the grief of grandparents.

Outreach to Grandparents as Advocates of Risk Reduction

Grandparents are an important population to address about safe infant cares practices. As partners in infant health and protection, they are already stakeholders in the issue. Once they become more fully informed about the extent of the problem, they can become effective advocates of risk reduction and safe infant care practices.

They have a powerful voice, not only in their own families, but also in their communities. They should be encouraged to share their wisdom, to inform other grandparents and community members about risk reduction strategies (Longchamp, Hall, and Arnold, 2003).

Reaching out to grandparents involves identifying places or venues where they gather. Faith-based outreach has had recognized success. Places of worship are often a cornerstone of community life and attract elders steeped in the traditions and practices of religious belief. Thus,

forming alliances with clergy and offering educational services at churches, synagogues, and mosques are highly effective ways to engage grandparents who are active members of the congregation. Storefront houses of worship should not be overlooked. They may be less formal, but are equally effective in providing access to their congregations.

Other good places to reach grandparents are at senior citizen and community centers. These centers are often interested in speakers and programs for their participants. It may be possible to enlist the help of directors or program coordinators in organizing a special program on the role of grandparents in risk reduction and safe infant care practices. This effort may be viewed very positively as offering a programming benefit to the senior citizen program or community center (Flick, Vemulapalli, Stulac, and Kemp, 2001).

Counseling Day Care Providers and Foster Parents

The loss of an infant has an impact on all persons directly involved in the infant's life and care. Day care providers and foster parents have unique experiences. They are profoundly affected, grieve the loss of the infant, and have questions and concerns signalling their need for supportive services.

These care providers may feel guilt and self-blame about the circumstances of the death, particularly if they were involved in the direct care of the infant at the time. The parents may blame these individuals, and try to hold them accountable as caregivers entrusted with the infant's safety and protection.

Provider's Relationship With The Bereaved Family

The starting point is to review the dynamics of the care provider's relationship with the family (Moon, Patel, and Shaefer, 2000). Typically, the infant care provider will have formed a unique bond with the parent and family, one that is based on trust. It can be helpful to discuss "normal" parental responses in situations such as this, including parental grief.

The relationship between the day care provider and parents may become strained. The care provider may avoid or limit contact with the parents out of fear of being blamed. Conversely, parents are sometimes relieved that the provider was the one who discovered the baby's death. However, if they were away from the child at the time of death, bereaved parents may look to the provider for details of the baby's last hours. They may ask about every minute prior to the death's occurrence. This request for information does not necessarily mean the parents are blaming the provider, just that they want details of the day.

Day care providers are encouraged to document everything they can remember about the time surrounding the child's death. This information generally is required by the licensing agency, and can be shared with parents, if requested. The parents may or may not seek this information immediately. For example, one parent arranged to meet with the provider after the funeral to discuss these events. Another parent did not want to see the provider and sent a friend to pick up her child's toys.

FOSTER CARE

The death of an infant in foster care presents its own special dynamics. Parents may feel angry and guilty that their child was placed in foster care and project these uncomfortable feelings onto the foster parent(s) and the agency that mandated the decision to remove the child from the parental home. Parents may not accept the reason for the placement, or deny their own behavior that led up to it.

When an infant dies in these circumstances, the parent will express dismay and blame the system that took their child away. They may feel that the child's placement in the foster system was directly responsible for the death, and that if the child had remained with them, the death would have been averted. The combination of anger and guilt expressed by the parent are difficult emotions to confront. Nonetheless, they need to be expressed, and parents should be supported in this grief expression. Parents who do not have opportunity to vent their frustration and grief may remain locked indefinitely into expressing these destructive emotions.

Experience of Loss From the Care Provider's Perspective

Even though the emotional bond between care provider and infant may be strong, care providers tend not to be recognized for their loss in the same way as parents. Yet care providers may experience feelings of sadness, depression, guilt, anger and fear. They may have pronounced physical and psychological reactions to the death.

Care providers need support and understanding from parents of the baby, parents of the other children in the day care and from their own families, friends and their licensing agency. They require information about the nature of the investigation into the death and the status of their day care license. Eventually, they will need to know the cause of death. In the meantime, they need not be blamed: there should be no presumption of blame or innocence prior to the investigation's conclusion.

LEGAL IMPLICATIONS

When an infant death occurs in the day care or foster care setting, there are certain reporting requirements and legal obligations placed on the care provider. A death investigation will likely ensue. Care providers will be asked to provide information to assist the death scene investigation, as well as to clarify their own actions.

Both law enforcement and the childcare licensing agency may conduct investigations. These may consist of a provider interview, and observation or photographs of the scene. Providers will be asked when was the baby last seen alive and by whom, who found the baby, and what emergency procedures were initiated (Table 10). Investigators may take bedding, formula, medications, or other items to assist the coroner or medical examiner in ascertaining cause of death.

TABLE 10

Initiate one sequence of cardiopulmonary resuscitation (CPR)
Call 911 or emergency response system
Return to CPR
Call emergency child care back-up providers
Notify supervisor
Notify parents
Notify parents of other children
Send/bring infant's information to hospital
Accompany infant to hospital, if possible
Document sequence of events.

Note. Adapted from U.S. Department of Health and Human Services, 1993.

COMMUNICATING WITH THE BEREAVED FAMILY

The care provider can practice effective communication skills when confronted with blame and anger from bereaved family members. Often care providers will blame themselves as well as be blamed by the parents and family members when an infant dies in their care. Self-awareness—uncovering and interpreting feelings of guilt and blame—will assist providers in clarifying the situation and communicating with the bereaved family. It is important to assist the care provider in self-advocacy and to defuse the potential for ineffective or defensive communication.

COMMUNICATING WITH OTHER CLIENT FAMILIES

The provider also needs to communicate effectively with other families in their care (Table 11). Parents, providers, and professionals need to work together to ease everyone's adjustment.

As soon as possible, other parents should be informed and given reassurance and information about the cause of death (if known). Informational materials may be helpful. The provider should consider holding an informational session.

The other children themselves need to be told about what occurred and have the death explained to them. Children who were pres-

ent at the scene may be especially affected. The explanation should be honest, accepting, truthful and consistent. The care provider must maintain a balance between being open, but not overwhelming children with details. Children's responses will be influenced by their developmental age. (See earlier section entitled, "Counseling Children about Death and Grief," particularly Tables 8 and 9.)

This can be a painful and bewildering time for the care provider. Once the trusted extender of care for the infant, he or she may now be suspected or held responsible for causing the infant's death. There may be confrontations with angry and frustrated parents who project their sense of helplessness onto the care provider. Care providers must be prepared to offer support and consolation, in the face of their own personal loss, and be accepting of parental anger and accusations. The potential aftermath of the experience, and its impact on the care provider, has to be considered.

TABLE 11

INFORMING OTHER FAMILIES ABOUT THE DEATH	
Parents	Notify as soon as possible
	Reassure and inform about cause of death
	Provide informational materials
	Arrange informational session
	Work together (parents, providers and professionals)
Children	Be honest, accepting, truthful and consistent
	Be open, but do not overwhelm with details
	Children present at the scene will be especially affected
	Response to death based on developmental age

AFTERMATH

Death in the care provider setting is stigmatic. Care providers may find that other parents no longer wish to use their services and remove their child from the care situation due to fear and misinformation. Providers must consider how to maintain the integrity and standing of their day care services in the community. Some care providers are so devastated they decide to no longer care for infants after a death.

When a death occurs in a foster care setting, a similar situation unfolds. The referring agency may not make referrals to the foster parent until a negative autopsy proves the foster parent was not responsible in any way for the death. The final cause of death may take weeks to months or longer to be determined. In the meantime, other foster children could be removed from the home. The foster parent's personal grief may be compounded by the experience of being blamed by the parent and held in suspicion until the autopsy is finalized. There may be a loss of livelihood.

Health care professionals should identify community-based resources that are available to help either type of individual (e.g., day care providers and foster parents). They need information and support about loss and grief, infant mortality, and counseling services. A wide range of services may be available, either locally or through state and national organizations. Connecting the care provider to such resources will be of benefit to this situation as well as in the future, when other clients use the same services.

With that in mind, health care professionals should also take the time to review risk reduction strategies for infant mortality. By carefully reviewing and identifying interventions that are applicable to this specific day care/foster care environment, health care professionals extend their reach and role in providing risk reduction education. The care provider is armed with knowledge of preventive interventions that can be implemented immediately. The care provider also becomes an advocate for safety within the day care/foster care setting, and a teacher and information resource within the community at large for infant safety and health promotion (AAP, American Public Health Association, and National Resource Center for Health and Safety in Childcare, 2002).

IMPACT OF GRIEF COUNSELING ON THE HEALTH CARE PROFESSIONAL

The health care professional who works directly with bereaved families is greatly affected by their grief. That individual enters this space of intense loss and grief as a knowing participant, offering human support, compassion, and undaunted acceptance.

To offer supportive counseling as a therapeutic intervention means extending oneself as the therapeutic agent of caring. It means being open to another's pain with focused attention skills, skillful listening, awareness of own cultural perspectives on death, mourning, and grief, and a willingness to be reflective about one's own losses and grief experiences.

Qualities such as these enable the health care professional to be truly open to another without imposing his or her own personal issues onto the grief of another. At the same time, this openness means that he or she is exposed to the pain of loss and grief and becomes personally affected by the intensity and depth of these emotions.

Health care professionals require training, supervision, and support as they reach out to families during this time (Bronheim 2003). Some boundaries must be established, as it is only by maintaining some objectivity in the therapeutic process that the listener can interpret expressions of loss and grief and offer anticipatory guidance. As the health care professional is repeatedly exposed to experiences of loss and grief, vulnerability increases. This necessitates self-care: the health care provider must seek out opportunities for reflection and concrete support to process the significance of these exposures.

The Health Care Professional's Role in Grief Counseling

The health care professional provides both immediate initial and long-term grief counseling and support to families and caregivers. The over-all goal of such counseling is to mobilize the strengths of the family in dealing with the death of the child. They are encouraged to grieve, told what to expect, and supported in their expression of grief in ways that allow them to incorporate the death of the baby, yet still function. Counseling also should help them to complete the tasks of grieving within a reasonable time frame. Eventually, parents and family members will recognize life is worth living and happiness possible.

Health care professionals bring their knowledge and skills to the counseling experience: knowledge of families and communities, of causes of infant mortality, and of grief and bereavement processes. They bring skills of listening, responding, and providing anticipatory guidance. Emotionally, they bring a desire to care for others and an ability to reach out to those in need. As human beings, they also bring their own cultural beliefs and values, their attitudes about death and dying, their previous experiences with death and loss, and their preconceptions, including views about quality of parenting and families who come from cultural backgrounds other than their own (McClain and Mandell, 1994).

Requisite Knowledge and Skills

Skills for bereavement counseling include listening and attending and assessment skills, empathy, and the ability to evaluate grief responses, coping mechanisms and social support. To be effective, health care professionals require knowledge of the cause of death, the process used to investigate and determine cause of death, and local infant mortality statistics. They need to know dynamics of the grief process for adults and children, cultural factors that influence the grief response, the impact of the death on the families, care providers and the community, and community resources, including mental health referral sources. Finally, they must be able to discern the impact of grief work on themselves as professional caregivers.

SELF-KNOWLEDGE AND PERSONAL EXPERIENCE WITH DEATH AND LOSS

Key to the development of effective skill as a bereavement counselor is the willingness to seek personal insight and gain objectivity about one's motivation to do this work. Every person has a history of loss, and has processed loss in unique ways influenced by the nature of his or her relationships, family dynamics and cultural context.

The history and processing of loss provide a foundation of experience, and issues emanating from personal experiences of loss tend to be played out in the helping context. It is imperative, therefore, that the bereavement counselor seeks insight and gains objectivity about personal experiences of loss in order to achieve objectivity in the therapeutic relationship with bereaved parents and others.

To become more effective, the bereavement counselor should take time to explore personal loss experiences (Harper, 1977). This exploration can be accomplished individually or with others using a standardized questionnaire during bereavement training. The participant reviews his/her experience with death, loss and grief; the duration of mourning, and coping strategies that seemed to help. This exercise helps the participant identify resources available to the bereaved, as well as any personal conflict or lack of resolution regarding prior losses. The health care professional may identify motives for working with the bereaved and become aware of limitations with respect to clients and grief situations, conflicts that are then dealt with more effectively.

ENTERING THE SPACE OF ANOTHER'S GRIEF

Doing bereavement counseling requires a willingness and courage to enter the territory of another person's pain. The ability to willingly offer oneself, emotionally, to another person in great need is a rare capacity. Few people, when asked to expose themselves to pain, willingly volunteer! Yet there is no way to enter this space of pain and loss while remaining defended and protected against the emotional impact.

In situations of infant death, the pain experienced by parents is extraordinary. The health care professional's own exposure to it is also intense. This consuming pain may cause the health care professional to feel helpless, overwhelmed, and defeated. It may be difficult to gain composure and find meaningful ways to build rapport and be of assistance to the affected family.

The health care professional needs to cultivate a well of energy and emotion to support therapeutic interaction and interventions. What he or she offers, in a phrase, is compassionate objectivity. Objective compassion is the merging of two ideas that are woven together to create and guide the therapeutic process. Objectivity requires the definition of boundaries that enable separateness and compassion and enables unconditional acceptance.

As these ideas are woven together, they create a balanced perspective on maintaining a clinical relationship while shaping it with genuine emotion and caring. This merging of objectivity with compassion helps prevent disengagement, the process by which the health care professional separates herself from her client in order to be self-sustaining. It makes it possible for health care professionals to care for themselves and replenish their energies at the same time that they willingly offer others compassion and genuine caring.

Objective compassion requires vigilance to maintain; it is difficult to avoid becoming personally absorbed into the family's grieving. It helps to keep in mind that the health care professional's role is to offer unconditional acceptance and employ skill to encourage expressions of grief on the part of the family and other involved individuals. The role of the bereavement counselor requires not only a genuine willingness to expose oneself to another's pain, but also the belief that these expressions of grief are healing, and therefore should be facilitated and encouraged.

THERAPEUTIC USE OF SELF

Caring for bereaved individuals involves

using oneself in a therapeutic way. Offering of one's self as a concerned, compassionate and competent professional is essential in establishing a relationship. Building rapport depends on the health care professional's ability to engender trust, for without a trusting and supportive foundation, the therapeutic relationship cannot thrive. Human connection is the key, and the counselor is guided by the family member's willingness to engage and offer information.

Once trust is established, the therapeutic use of self is best described as the capacity to express compassionate acceptance, that is, to have no expectations and place no demands. Instead, the sole purpose of the therapeutic relationship is to offer support and assistance. Sometimes, sitting together in silence is the best form of support. This validates the enormity of grief: nothing can be said or done to take away the pain of loss.

Effective communication
To communicate effectively with bereaved individuals, the health care professional must be skilled at both verbal and nonverbal communication. Listening is the most important communication skill and a form of validation. Skilled listening involves the capacity to be present for another and to hear themes of concern. The listener offers undivided attention and focus, and affirms what the bereaved individual is saying through nonverbal signs of support (i.e., direct eye contact, a compassionate expression, face-to-face position, and body language that signifies a dedicated presence). In addition to these types of nonverbal communication, the health care professional clarifies the messages of the bereaved individual by summarizing or repeating them and waiting for assurance that the message was heard accurately.

The health care professional should ask the bereaved individual how she could be helpful. This approach enables the participant to think about what may be helpful and to ask for help—an empowering experience in itself. If the question cannot be answered, then the health care professional can offer suggestions for intervention based on a careful assess-

ment. Lines of communication are not broken; the door remains open and services are available and accessible. Plans for a follow-up meeting or call should also be made.

Communication skills cannot be learned overnight, but can be studied and perfected. Health care professionals who are committed to providing bereavement counseling should seek professional development in this area, attending workshops and conferences to learn about communication strategies and receive feedback about their communication patterns and skills.

Negative Reactions and Coping Skills

Bereavement work makes the health care professional aware of his/her own losses. It may also create anxiety. Some health care professionals may come to fear the loss of their own child or grandchild. Such fears may interfere with their ability to help the bereaved. Health care professionals may also become more aware of and anxious about their own death (Harper, 1977).

In addition, through repeated exposure to hurt, powerlessness, rage, and emptiness, health care professionals can be traumatized secondarily in working with those who are suffering. This vicarious trauma can lead to intense physical and emotional reactions: grief, anger, frustration, emotional numbing, depression, cynicism, inability to cope, social withdrawal, and cognitive and perceptual impairment. Trauma such as this may lead to loss of boundaries with families, diminished ability to care about others, and the inability to sustain job performance or to maintain family relationships (McClain and Mandell, 1994; Worden, 2002; Rando, 1986).

Keeping the focus on the client
This is one strategy for avoiding the potential negative impact of offering bereavement counseling. Try to imagine a spotlight that shines on the bereaved individual. The spotlight signifies the client is the focus of the interaction. The light is always shining on the client. In this way, the health care profession-

al creates and maintains a therapeutic focus and milieu. As health care professionals experience need, or feel depleted, the onus is on them to find ways to revitalize and replenish their energy and the constructive emotion needed to continue their work.

ESTABLISHING BOUNDARIES AND USE OF COPING TECHNIQUES

The health care professional also needs to know his or her personal needs and limitations. This self-awareness may require limiting the number of families being counseled, and having a heightened awareness of boundaries, i.e., of being involved and concerned about client families, but remaining separate from their grief.

Another coping technique is to acknowledge and experience feelings of sadness, and to use such resources as meditation, creative imagery, relaxation techniques, yoga, massage, writing, drawing, and exercise to cope.

For bereavement work, ongoing training and adequate supervision are essential. It is also appropriate to take time away from bereavement work to deal with feelings and to rekindle energies.

DEBRIEFING AND RECEIVING SUPPORT AND CONSULTATION

Confronted by such a breadth and depth of emotions, the health care professional needs to find support in order to continue providing support. It is important to build collaborative networks with peers and supervisors, and to seek out opportunities to discuss feelings, needs, and reactions, and build an understanding of personal strengths and limitations. The support network helps to replenish personal energy and interest in the work of grief.

Opportunities for debriefing are essential, and an excellent way for the health care professional to analyze and gain insight into the therapeutic process. The debriefing experience allows one to review personal feelings, reactions and the nature of dialogue in the counseling experience. It is a respite and a way of seeking relief from the intensity of the bereavement encounters.

When continuous in nature, debriefings permit a deeper understanding of personal reactions, issues and themes of concern. The result is a health care professional who has greater insight and clinical expertise.

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The Dead Bird by Margaret Wise Brown (Addison-Wesley).

Lifetimes: The Beautiful Way to Explain Death to Children by Bryan Mellonie & Robert Ingpen (Bantam Books).

Talking About Death: A Dialogue Between Parent and Child by Earl A. Grollman (Beacon Press).

The Tenth Good Thing About Barney by Judith Viorst (Atheneum).

Thumpy's Story: A Story of Love and Grief Shared by Thumpy, the Bunny by Nancy C. Dodge (Prairie Lark Press).

Where's Jess by Marv and Joy Johnson. Compassion Books

ASIP Publications*

ASIP Information Papers

Bedsharing and the Risk of Sudden, Unexpected Death in Infancy (SUDI): Counseling Implications. (2001).

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Additional Resources

American Academy of Pediatrics (AAP)
The AAP provides professional and community health-related information **(http://www.aap.org/)**. Books and pamphlets are available for purchase.

Association of Death Education and Counseling (ADEC)
ADEC **(http://www.adec.org/)** is a multi-disciplinary professional organization dedicated to promoting excellence in death education, bereavement counseling, and care of the dying.

Association of SIDS and Infant Mortality Programs (ASIP)
ASIP is for health and human service providers committed to bereavement support and risk reduction activities **(http://www.ASIP1.org)**. Materials are available for purchase.

Back to Sleep (BTS)
 The BTS campaign **(http://www.nichd.nih.gov/sids/)** is named for its recommendation to place healthy babies on their backs to sleep to reduce the risk of SIDS. The BTS campaign web site provides up-to-date information on SIDS research and campaign materials at no charge.

Centering Corporation
Centering **(http://www.centering.org/)** provides a nonprofit network for distributing supportive grief literature from other sources. They have a wide variety of grief literature available for children and adults.

Centers for Disease Control and Prevention (CDC)
The CDC **(http://www.cdc.gov/)** is the lead federal agency for protecting the health and safety of people at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships.

Compassion Books
This publisher **(http://www.compassionbooks.com/)** offers resources to help children and adults through serious illness, death, loss, and grief and bereavement.

Consumer Product Safety Commission
An independent federal regulatory agency, CPSC works to save lives and keep families safe by reducing the risk of injuries and deaths associated with consumer products (CPSC)**(http://www.cpsc.gov/)**.

Hospice Foundation of America (HFA)
HFA **(http://www.hospicefoundation.org/)** works to educate professionals and the families they serve in issues relating to care giving, terminal illness, and loss and bereavement.

March of Dimes (MOD)
MOD's goal is for all babies to be born healthy. They have publications available to promote this mission, as well as bereavement publications **(http://www.modimes.org/).**

The National Center for Cultural Competence (NCCC)
The mission of the NCCC **(http://www.georgetown.edu/research/gucdc/nccc/)** is to increase the capacity of health care and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems.

National Center for Education in Maternal and Child Health (NCEMCH)
NCEMCH **(http://www.ncemch.org/)** provides national leadership to the maternal–child health community in program development, policy analysis, and education.

National Fetal and Infant Mortality Review Program (NFIMR)
NFIMR **(www.acog.org/goto/nfimr)** has publications and resource materials designed to support and enhance fetal and infant mortality review programs. It is funded by the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration of the U.S. Department of Health and Human Services.

National Healthy Mothers, Healthy Babies Coalition (HMHB)
The mission of HMHB is to improve the health and safety of mothers, babies, and families through education and collaborative partnerships of public and private organizations **(http://www.hmhb.org/)**.

National Institutes of Health (NIH)
NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States **(http://www.nih.gov/)**. Its mission includes supporting research and fostering the communication of medical information.

National Sudden Infant Death Syndrome Resource Center
Information services and technical assistance on SIDS and related topics are provided. This MCHB site also has a variety of publications including annotated bibliographies and referrals to resources **(http://www.sidscenter.org/).**

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