

When an Infant Dies: Cross-Cultural Expressions of Grief and Loss

INTRODUCTION

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This bulletin summarizes a panel presentation at the National Fetal and Infant Mortality Review Program, Third National Conference, held July 16–18, 1998, in Washington, D.C. The bulletin reviews cultural traditions of Latino, African American, North American tribal and Muslim families grieving the loss of an infant. It identifies simple strategies health care providers can use to begin the process of providing culturally competent support to them. It also aims to encourage networking and sharing among providers who assist the bereaved.

However, the bulletin only provides a brief overview of the traditions of these four cultural groups. It also reflects the panelists' own unique cultural heritages, as well as their professional experience and expertise. Using this overview alone to predict how any one will respond to loss will probably do more harm than good. No bulletin, book or article can prescribe an appropriate family intervention. In practice, each family has its own unique customs and traditions. The tragedy of the loss of an infant also affects each family member differently. It is essential not to generalize or stereotype using these brief summaries. Providers must take the time to identify and respond to the needs of each family rather than making blanket assumptions based solely on a general outline of cultural traditions.

OVERVIEW

The United States has long been the destination of many culturally diverse groups. Most new immigrants are coming from Central America, Mexico, the Philippines, Vietnam, China, India, Iran, Germany, Turkey and Egypt. In fact, one out of every thirteen people living in the United States today was not born here. By the year 2000, one out of three Americans will be African American, Latino, Middle Eastern or Asian/Pacific Islander. As the cultural composition of the country evolves, providers must grow and change to meet the needs of these new health care consumers.

Cultural heritage strongly shapes expressions of grief and loss. A cultural group can be defined as people who share a common ori-

gin, language, customs, styles of living and a sense of identity. Within each cultural group, other variations of values and beliefs influence an individual's grief response. Some key factors include age of the mourner, family traditions, gender, one's faith foundation, geographic region, educational background, economic status, prior experiences with death and loss and the historical background of the cultural group. Moreover, the degree of assimilation and acculturation will affect an individual's grief response. *Assimilation* is the cultural absorption of a minority group into the main cultural body. *Acculturation* is the process of adapting to a new culture, which may result in the loss of traditional customs and ceremonies. The *generation* (whether an indi-



vidual has relocated to this country or is a descendent of a settler from abroad) may also make a difference.

Adolescence is an example of how age can be a unique factor influencing grief. A teen peer group may more strongly shape a response to loss than the traditions of the family. Adolescents may have other

Key Factors Affecting Grief Response

- ◆ Age
- ◆ Family customs and traditions
- ◆ Gender
- ◆ Faith foundation
- ◆ Geographical region
- ◆ Education
- ◆ Economic status
- ◆ Prior experiences with death and loss
- ◆ Historical background of the cultural group

attitudes and beliefs that significantly differ from those of their parents or grandparents. An adolescent may feel more comfortable expressing emotions with friends than family.

Providers need to offer *culturally competent* support for bereaved families, which includes (Purnell, 1998):

- ▶ Being aware of their own cultural traditions and beliefs, giving special thought to those related to death and dying
- ▶ Learning about the cultural beliefs and customs of the community they serve
- ▶ Genuinely appreciating and respecting the cultural diversity of that community
- ▶ Being empathic, flexible and prepared to tailor their care and/or institutional practices to meet the individual needs of bereaved family members

Health care providers tend to view the actions of others through the filters of their own culture. The challenge in these cross-cultural interactions is to be sensitive to the belief system of the grieving family while not imposing one's own beliefs and biases on them. Providers must be able to identify their own cultural expectations and separate them from the needs of the bereaved family. This process takes careful thought and introspection.

One tool providers can use to think about their skill in dealing with culturally diverse families is the *continuum of cultural competence*, which is adapted from Borkin and others and includes the following phases or steps (Borkin, 1991):

- ▶ Overcoming **Denial** that culture and class differences do exist
- ▶ Resolving **Fear** of unfamiliar cultural beliefs and values
- ▶ Conquering the belief that the provider's own ethnic group is **Superior** to others
- ▶ Avoiding **Minimization** of cultural differences by rationalizing that deep down people are "all the same"
- ▶ Demonstrating **Relativism**, in which the provider knows and respects cultural differences but has not applied this knowledge to the health care setting
- ▶ Progressing to **Empathy**, in which the provider understands the client's cultural knowledge, attitudes and beliefs and their relationship to health and has some experience applying this knowledge in the health care setting.
- ▶ Advancing to **Cultural Integration**, in which the provider understands the client's cultural knowledge, attitudes and beliefs and their relationship to health and has skill and extensive experience applying this knowledge in the health care setting.

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Even if providers do not have in-depth knowledge about every culture, they can still be extremely helpful if they approach family members with a supportive, nonjudgmental attitude, ask families what will be important to them in their grief process and then modify care based on the family's input. Families frequently are willing to discuss cultural traditions that may help them cope with the loss. Families will answer gentle, non-invasive questions about their needs. The health care provider can use active listening skills to learn about the culture and provide appropriate support. The most important question is, of course, to ask members of the family about their needs associated with the death.

Providers must also acknowledge that some families have had to deal with racism and other forms of discrimination in the health care system. These experiences can destroy the family's trust in the system and any expectation that providers will act on the family's

ABOUT LOSS DURING PREGNANCY AND INFANCY

many circumstances: failed infertility treatment, early miscarriage, therapeutic termination, ectopic pregnancy, fetal death, stillbirth, loss after relinquishing a newborn for adoption, neonatal loss, Sudden Infant Death Syndrome (SIDS), birth defects, chronic disease, unintentional injury and homicide. Regardless of cultural background, the death of an infant can create an overwhelming crisis for parents. Grandparents, siblings, other family members and friends may also mourn the loss. Although family members might not remember exactly what providers said at the time of the death, they would certainly recall whether or not the provider displayed a caring attitude and offered comfort. Care and comfort can be shown by taking the time to sit with the family, expressing condolences, explaining what is known about the cause of death and responding to parental needs associated with the death. Parents will take solace in this kindness and remember that support for a lifetime.

While the expression of grief will vary among cultures, the deep sense of loss and sorrow is almost universal. Moreover, the perception of loss may not depend on the length of the pregnancy or the age of the infant. The couple who miscarries or has an

Questions Providers Can Ask to Assist the Bereaved

- ◆ I am so sorry for your loss. How can I help you?
- ◆ What are your traditions when an infant dies?
- ◆ Is there someone I can call for you?
- ◆ Has your family ever had this experience before?
- ◆ How did they handle it?
- ◆ Did you have a funeral service? Was it helpful?

behalf. Providers may have to increase their efforts to identify and overcome these barriers.

Finally, while cultural traditions play a role in the way a person responds to loss, these beliefs are not static. Especially in today's world, communication technologies, global news broadcasts and extensive migration are creating an environment in which traditional customs are ever changing.

Loss during pregnancy and infancy encompasses

ectopic pregnancy might be just as devastated as parents whose older infant died of SIDS. Some initial grief reactions can include shock, disbelief, guilt, blame, anger and hostility, tears and somatic complaints. Some parents report hearing the baby cry or seeing the baby. After stillbirth delivery, mothers may describe feeling fetal movement. The provider can reinforce that such experiences are common

"When a parent dies, you have lost your past. When a child dies, you have lost your future."

Schill L. *The bereaved parent*. New York: Penguin Books, 1977:23

among many grieving parents. Other parents report that they feel they are 'going crazy'. Providers can again reassure the bereaved that other parents spoke and felt the same way. Parent to parent peer support can be very helpful. Many families benefit from culturally relevant infant loss literature in the appropriate language. Providers should also know about and be prepared to link parents to culturally appro-

appropriate pastoral care or offer other information, such as available funeral and burial options, as appropriate.

The death of an infant can create stress in the relationship between the parents. Some parents might blame themselves and /or blame each other for the loss. They may feel that they have failed as

"I often wonder how the death would affect my own personal life if I were the parent."

"I do burn out at intervals. I get tired, frustrated, withdrawn and have an intense personal sense of loss."

Chez R. Acute grief and mourning: one obstetrician's experience. *Obstetrics and Gynecology*. 1995; 85 (6): 1059 – 1061

parents. Parental grief reactions also might vary, leading to a situation where one partner judges the other as not grieving as much. The provider can help by assisting the parents to be aware of the differences in ways individuals grieve and the importance of maintaining communication.

The surviving children, too, may experience sadness, confusion and anger, and may blame themselves for the death. Generally, providers give the

information to parents who then explain the death to the children. Parents need to consider the child's age, developmental level and prior experiences with death in explaining the loss. Children often grieve deeply. Parents and extended family members need to support them during this crisis.

Sometimes health care providers say that they feel powerless to 'fix' the grief of family members. In fact, providers are in a very powerful position to model and encourage a salutary response to loss. Providers can teach healthy grieving practices by their own actions — expressing sadness about the death, offering condolences, encouraging parents to talk to each other and advocating to see that parental needs are met. These elementary practices generally cut across many cultural variations in grieving customs.

Finally, while trying to provide therapeutic grief support to parents, some health care providers might also be dealing with their own sadness about the death. Those who are pregnant or parenting infants can sometimes have an intense personal response to the loss, as well. Provider feelings and responses, also in part determined by their own cultural background, may be different from that of the family. Staff discussions can be useful. They provide an opportunity for staff to acknowledge their sorrow and help each other in their efforts to assist bereaved families.

CUSTOMS AND VALUES THAT MAY AFFECT LATINO GRIEF

Adapted from the presentation of Yolanda Thompson

Latinos are one of the largest minority groups in the United States. They number 29 million and constitute 11% of the total population. Latinos may originate from many culturally diverse countries including, but not limited to, Mexico, Cuba, Santo Domingo, Nicaragua, Columbia, El Salvador, Guatemala, Chile, Brazil, Argentina, and Peru, as well as the United States Commonwealth of Puerto Rico. Three quarters of this Latino population live in four states: California, Texas, New York and Florida.

Latinos in the United States represent a wide variety of cultures. Their cultural differences are distinct and the people are proud of their unique

heritages. Cultural customs and traditions related to grief and loss also vary. **There is no single way that Latinos grieve the loss of a loved one or respond to any of life's circumstances.** This brief section simply provides an introduction to some of the more common customs.

Some clarification of terms is important for this discussion. The word *Hispanic* does not reflect a race of people. It is a general term used by the United States Bureau of the Census to group all the Spanish-speaking people into one category. The term *Latino* identifies all different cultures of the Americas (North America, Central America and South America) who speak Spanish. It is used and

preferred by some people to validate and reflect their different cultures.

All Latinos do not speak the Spanish language exactly the same way. There are many Spanish dialects that include unique expressions and idioms. Language differences may be a significant barrier, but can be overcome with fluent, sensitive and insightful interpreters. Health care providers must not assume that a Latino who speaks English with an accent is a recent immigrant. Many Latinos who speak with an accent were born in this country and can trace their North American history and heritage back centuries. Finally, providers should be mindful that some third or fourth generation Latinos might not speak the Spanish language at all.

When working with bereaved families, providers must understand the Latino concept of *respeto* (rules guiding social relationships). Traditionally, there is a strict hierarchy in many Latino families that should be honored. Status usually is ordered from older to younger, and male to female. Providers should shake hands when greeting family members and address individuals formally, using Mr. and Mrs. with the last name.

Many Latinos also value the concept of *personalismo* (warm, friendly, personal relationships). They would generally expect a provider to interact with them in a caring and cordial manner and take the time to ask about their well-being. Personalismo also means that Latinos have a strong allegiance to their individual provider, rather than the hospital or other health care setting. In the emotional crises of the loss of a loved one, Latinos may count on their primary provider to be present, provide information, offer condolences and find out what will be helpful to them.

Typically, Latinos express their loss by crying openly. Crying is viewed as a healthy and appropriate emotional response. Family and friends will often encourage parents to outwardly express their grief. Another less common expression of grief and loss among some Latino cultures is *ataque de nervios* (general shaking that is believed to help release the pain of loss). These traditions are very different from the more stoic Anglo-American customs and some insensitive providers have even interpreted these mourning behaviors as hysterics.

Religion and spirituality are very important to nearly all Latinos. Although a growing number embrace Protestant religious affiliations and a small number are Jewish, most are Catholic. Very few have no faith foundation. Regardless of religion, many Latino families believe in spiritual and psychological continuity between the living and the dead. As a part of that spirituality, the family continues a relationship with the deceased after death through prayer and visits to the gravesite.

In many Latino cultures, the entire family — not an individual or even a child's parents — make important decisions about life, including medical care. A mother must have time to talk with her husband and extended family before decisions about medical care for herself or her child can be made. Likewise, the major support for the bereaved parents comes from both the nuclear and extended family. Extended family members (cousins, aunts, uncles, grandparents and godparents) may travel great distances to be with a terminally ill infant and to comfort the bereaved family. Therefore, health professionals should communicate with the whole family to help them advise and support the parents. However, families new to this country may not have such support. They will need help in locating pastoral care and funeral/burial information.

When an infant dies, some family members may face not only sorrow, but also anger and confusion evoked by conflicts between their traditional values and beliefs and the health care system. For example, when an ultrasound scan or other prenatal test detects severe congenital problems, a provider may suggest to the family that the pregnancy be terminated. Latino parents with strong cultural values and beliefs about the sanctity of life may not accept abortion as an option. When a fetal death occurs, many providers will recommend waiting several days for spontaneous labor and delivery to ensue, rather than inducing labor. Some Latinos may believe that the mother will develop cancer if she waits. To determine if these beliefs are relevant to a particular Latino family, providers simply need to ask. When providers transfer a seriously ill newborn to a special care unit, parents may not understand what is happening, especially if a language barrier exists. They

may feel powerless and ignored. Providers should use trained interpreters to ensure that these families can participate fully in making decisions about the care of their infant.

Earth burial is the common practice in Latino families. Cremation is rarely chosen. The main reasons for choosing it are financial hardship, difficulty

Common Grief Terms/Phrases in Spanish

¿En que le puedo ayudar?

How can I help you?

Su pena es muy profunda.

Your pain is very deep.

Se hizo todo lo posible.

Everything possible was done.

Lo siento mucho.

I am very sorry.

Dolor

Literally means pain, grief.

Pena

A very personal/unique pain.

Afflicion

Affliction, used to describe all of the emotions of grief and loss.

in transporting the body home to their country of origin or both. When making decisions about funeral and burial, the parents must understand the meaning of cremation. Most often the church, family and friends contribute towards the burial and funeral expenses. In many Latino communities, parents will hold the wake in their home for at least one day before the funeral. However, having the wake in a funeral home also is acceptable.

The countries of origin, beliefs and religious preferences determine rituals that express the mourning process. These rituals help establish a sense of stability, social support and continuity within the family. Although rituals vary within each Latino culture, wearing black or dark colors is a common way to mark *luto* (mourning). *Luto* is not only a sign of respect for the dead, but also an indication to others that a person is grieving for their loved one. During that time, the parents and immediate family usually do not play the radio, watch television, or attend movies, dances or other social events. Middle-aged or elderly family members may observe a longer period of remembrance that lasts from months to years.

Family and friends may offer prayers for the deceased at various times. A novena (prayers for nine consecutive days) may be done, or prayers may be said once a month and then once a year. Special prayers and religious services are held on All Saints Day (November 1) and All Souls Day (November 2). Traditionally, these are days for visiting cemeteries. Relatives and friends bring wreaths of flowers, crosses, and other floral arrangements to decorate the graves of the dead in remembrance. Lighting candles and blessing the dead and their resting places also are important to many Latinos.

Latino family and community members usually will provide most of the support needed during the grieving process. Providers who are willing to listen to what the bereaved know about living with death and grief will be in a much better position to support them. Finally, for Latinos, human touch shows respect for the bereaved and is, therefore, an important gesture for providers to include in their support of the family.

UNIQUE CUSTOMS AND BELIEFS THAT MAY INFLUENCE GRIEF IN FOUR INDIGENOUS TRIBES OF NORTH AMERICA

Adapted from the presentation of Darlene Johnson

The term *Native American* has typically been used to describe the tribes of indigenous people living on this continent before the arrival of white Europeans. However, some people whose ancestors immigrated to the United States centuries ago also consider themselves Native Americans. To avoid confusion, the term *indigenous people* is used in this discussion of the culture and expressions of grief and loss among selected tribes.

Today, about 500 federally recognized tribes comprise 2.5 million people or 0.9% of the United States population. Beliefs, traditions and ceremonies among them differ widely. Consequently, **indigenous people are not one people or one culture.** The current culture of each tribe also reflects many influences, including levels of assimilation and acculturation, experiences resulting from relocation and education at boarding schools. Many indigenous children missed growing up with the traditions of their ancestors because the Bureau of Indian Affairs relocated them to distant boarding schools away from their clan. The Bureau sent Sioux children to Kansas and Navajo children to Sioux country. To promote their acculturation, teachers forced these children to cut their hair and forbade them to speak their native language. Competing missionary efforts also have left their mark. Indigenous people now practice several Christian religions (eg, Catholic, Presbyterian or Jehovah Witness). It was easy for missionaries to convert indigenous people to Christian religions because they also believed in one Creator.

Today, the unique culture of each of the 500 tribes is rooted not only in the separate beliefs, customs and traditions that have been passed down through the generations, but also reflects exposure to the majority culture. Even families that share a common tribal heritage may have different customs as the result of their own experiences and levels of assimilation. In addition, personal beliefs, the extent and nature of family support and the status of the deceased in the tribal community also affect mourning practices.

Traditionally, some tribes or clans have been matriarchal societies. Mothers, daughters, aunts and grandmothers make the important decisions. Other tribal societies may be bilinear or patriarchal. In all tribes, the wisdom and experience of elders are honored and respected. In each family or clan, one elder may be designated as the final decision maker. Sometimes, the family must have permission from this elder before any medical treatment or hospitalization can occur.

One custom that some indigenous people retain is not talking about an impending death of family or friends. To do so would mean that the speaker wishes the person who is ill to die. Discussions about death can occur but should be indirect and use the third person. In addition, because some tribes also fear the spirits of the dead, talking about the dead may be considered impolite and the deceased's name is never spoken aloud. Any discussions about the deceased that must occur are indirect and use the third person.

Giveaways are another tradition in which some or all the belongings of the deceased are bequeathed to friends. Personal effects are given away because they have been important in the person's life. Families usually give belongings to those tribal members who have influenced the life of the deceased or provided support to them over time. In times past, when a male in the Sioux tribe died, it was the custom to give away his home and all of his belongings. Someone in the tribe then became responsible to provide for the surviving family.

Some tribes may also believe that an infant becomes a formal member of the clan or tribe only when the baby has received a clan name. If the infant was given a tribal name, a traditional funeral is held. If the naming has not taken place, a small family funeral is planned.

The Sioux

The Sioux refer to themselves either by that name or by the ancestral tribal name *Lakhota* (An Alliance

of Friends). In the traditional ways of the Sioux, life is viewed as a circle. Seen in this way, all life has spirit and time is not linear. In accordance with this view, some Sioux might not wear a watch or worry about missing an appointment. They believe that if one opportunity is missed, another will come along. Within the life circle, a person is born and lives by feeding on plants and animals. In times past, at death, a family dresses the deceased in the finest

You have noticed that everything an Indian does is in a circle and that is because the Power of the World always works in circles and everything tries to be round...The Sky is round and I have heard that the Earth is round ... and all the Stars. The Wind in its greatest power whirls. Birds make their nest in circles, for theirs is the same religion as ours...

Even the seasons form a circle in their changing and always come back again to the way they were. The life of a man is a circle from childhood to childhood and so it is in everything where Power moves.

Black Elk, Sioux Holy Man (1863–1950)

clothes, as a sign of honor. They place moccasins with beaded soles on the feet so the deceased can walk to the spirit world. The family then wraps the body in a buffalo robe and puts it in a tree where birds and small animals feed on it. Eventually, the body drops to the ground and feeds larger animals. The remains regenerate the earth, so grass will grow and provide food for the buffalo. The Sioux people kill the buffalo that, in turn, provides food, warmth, shelter and weapons. This circle is complete and creates harmony for all living things.

The number seven is another important concept for the Sioux. The Sioux Indians have seven directions, and so everything is in sevens. The directions are North, East, West, and South, the sky, mother

earth and the spirit within. The Sioux have seven councils, and each council has seven fires.

Traditionally, the Sioux hold strong beliefs in the influence and guidance of spirits and in the philosophy of *Mitakuye Oyasin* (we are all related). The Sioux also believe in an afterlife and prayers are sent to the grandfathers. Over time, Sioux beliefs have become a mixture of traditional values and modern Christian beliefs. However, the two often conflict. Outside influences have altered customs so much that in some areas even sweat lodge ceremonies have changed.

Today, Sioux burial customs are based on the family's religion. Usually, the funeral home prepares the body and transports it to the town hall or church. The wake lasts from one to three nights, with evening prayers or religious services. Someone is with the body at all times. During the wake, women tend to cry quietly, while men appear more stoic. Family members and friends bring gifts of food and help with preparation of three or four meals each day. The family digs the grave and places the body into it. Family and friends then fill the grave. A feast follows the burial and the family gives away all the leftover food. The Sioux bring their own bowls to take any leftover food home. The family is honored when what they have is taken. Some or all of the deceased's belongings are given away to friends. The Sioux do not fear dead people's spirits or consider them unlucky. They may call on them for help and guidance.

The Omaha

The Omaha Tribe of Nebraska follows the practices of the Native American Church (NAC). These include the ancient custom of smoking *peyote* (the dried fruit of a small cactus) at church meetings. Peyote contains the substance mescaline, which has hallucinogenic properties. NAC members believe that when they smoke peyote they will have useful dreams or visions. These visions offer solutions to life's problems and help guide the dreamer to live well. Since 1978, the use of peyote by indigenous people during religious ceremonies has been protected by the federal American Indian Religious Freedom Act. The NAC has numerous chapters

throughout the country and membership is growing. Individuals from many different tribes belong. NAC teaches devotion to the family, right living and abstention from alcohol. A NAC religious leader is called the Road Man or Road Chief. He is responsible for directing the chapter ceremonies and guiding individual members along the *Peyote Road* (the path to well-being and right living). The ceremonies are usually held in a special teepee and last all night. The leader's wife is called Peyote Woman or Earth Mother. Depending on the chapter's views, she may be the only woman allowed to attend the meetings.

When a member of the Omaha Tribe dies, a funeral home usually prepares the body for burial and takes it to the home of a relative. Friends and relatives gather together for four days and stay up with the body each night. They offer special prayers each night at 2:30 AM. The Road Man conducts the nightly ceremony. He receives a ritual gift of tobacco from the family for his services. The Peyote Woman or Earth Mother takes charge of preparing the food for all three meals each day. The family of the deceased buys most of the food. Friends also bring food. On the fourth morning, there is a special ceremony at 2:30 AM. At that time, the coffin is brought to the doorway of the teepee and participants inside pray, smoke peyote and sing. The family then prepares the grave and buries the body by 2:30 PM that day. Only those who help serve and assist the family receive giveaways of the deceased's possessions.

The Sauk and Fox

The Sauk and Fox originally were two distinct Algonquin-speaking tribes living near the Great Lakes in Michigan. In colonial times, they united to fight bitter battles against the French. The French finally killed many of the Fox tribe. The Sauk hid the Fox adult survivors and adopted the children. In the 1860s, the Bureau of Indian Affairs relocated the Sauk and Fox tribes first to Kansas, later to Iowa and finally to Oklahoma. The customs of the tribes were threatened by this migration. However, they have been able to preserve not only their beliefs but also the Algonquin language.

When a Sauk and Fox tribal member dies, family and friends bring the body home. Someone always stays with it. After several days of mourning, they bury the body and build a little house over the grave. The house is about three feet high and six foot long. The spirit lives in this house until it is ready to go on to the next world. The Sauk and Fox then build a big fire near the grave and cook all the food that the deceased person liked. Before the family serves this food, however, they also prepare a special tray of food and a bottle of whiskey to feed the spirit. Next they throw these offerings into the fire. After the ceremonial meal is over, it is important that Sauk and Fox people do not look back at the grave because they believe that they may become tied to the spirit. Being tied to the spirit is considered very bad luck. The spirit may take the living person who is tied to it into the next world.

The Navajo

The Navajo have always referred to themselves as *Dine* (The People). They make up the largest tribe in the United States today, numbering about 200,000. The Navajo have maintained very strong

This covers it all
 The Earth and the Most High Power
 whose ways are beautiful
 All is beautiful before me
 All is beautiful behind me
 All is beautiful above me
 All is beautiful around me

—Navajo Song

tribal beliefs and customs. Historically, Navajo were skilled shepherds and farmers. Some Navajos may still live in traditional *hogans* (one room mud and log cabins), farm their own land and tend flocks of sheep. If a person dies in his hogan or any other dwelling, that dwelling must be abandoned because it is believed that the spirit is trapped inside. When someone has died in the hogan, people hurry to get

the body outside the hogan to prevent the spirit from becoming trapped. Because of this belief, some Navajo might not choose for a loved one to die at home.

The number four is sacred to the Navajo. They assume all earth's cycles are harmonious and come in fours: four winds, four seasons and four directions. The center of *Dinetah* (Navajoland) is Canyon de Chelley in Arizona. Four sacred mountains protect Navajoland. The four sacred mountains represent the four directions and are: Mount Hesperus (North) La Plata Mountains, Colorado; Mount Taylor (South) Laguna, New Mexico; Mount Blanca (East) San Luis Valley, Colorado and San Francisco Peaks (West) Flagstaff, Arizona. There are also four basic colors: black, blue, yellow and white. The Navajo also believe that they have journeyed from a dark world full of perils to the fourth world of light, the turquoise world. The Dine call Navajo Mountain in southeast Utah 'Turquoise' Mountain and consider it a sacred place. Achieving the four ideals of beauty, peace, happiness and righteousness leads to *Hozho* (spiritual balance and harmony with the Creator and nature). The Navajo have developed an extensive set of customs, prohibitions, songs and ceremonies to help them maintain hozho. Sickness is believed to derive from lack of spiritual balance or failure to follow the customs or prohibitions that maintain hozho.

Overall, the Navajo have a real fear of the spirits or ghosts of their dead. The spirits of the dead are thought to be able to take the shape of natural objects. For example, spirits may take the shape of whirlwinds and lightning. Contact with these spirits or dreaming about someone who has died may result in lack of hozho (spiritual balance) and sickness. To re-establish hozho, a *hand trembler* (a spiritual diagnostician) will determine the cause of sick-

ness. Then a *singer* (medicine man) will perform an appropriate ceremony to bring about the cure, restoring spiritual harmony and balance. Some specific ceremonies that are thought to remedy contact with spirits of the dead include:

- ▶ Enemy Way: checks the influences of ghosts or living enemies
- ▶ Shooting Way: counteracts influences of lightning
- ▶ Wind Way: removes sickness resulting from whirlwinds
- ▶ Upward Reaching Way: fights ghost movement up from the underworld

In the past, when a Navajo died, only certain tribal members were allowed to prepare the body for burial. They had to be purified in a special ceremony beforehand to protect them from being ensnared by the spirit of the dead. Today, it is likely that a non-tribal mortician will prepare the body. A piece of turquoise is usually placed in the casket. The burial takes place on or after the fourth day. During that time, a special ceremony may be performed to keep the spirit of the dead from trapping the souls of the living. The body can either be buried in the desert without markers or in a graveyard. Customarily, family and friends help to dig the grave and cover it with earth. Because the Navajo have so strongly maintained their tribal beliefs and customs, it may be less likely that the majority culture or Christian religions will influence funeral and burial rites.

In summary, it is difficult to anticipate what kind of help is appropriate or useful for bereaved indigenous people. Exposure to the dominant culture continues to influence native traditions and has resulted in a wide combination of traditional and modern beliefs and practices. A provider must become more skilled at learning what is helpful to an individual family, rather than continuing to rely on vague ideas about tribal customs. Finally, remem-

DIVERSE GRIEVING PATTERNS OF AFRICAN AMERICANS

Adapted from the presentation of Barbara Julion

ber Mitakuye Oyasin - we are all related.

The grieving patterns of African Americans have evolved from their unique historical background. For African Americans, traditional practices from their African cultures changed when they were brought to America as slaves. Slaves viewed death as a celebration of life and not a morbid event. They believed that when a person died, he was a soldier who had fought the battle, borne the burden and finished the course. Their funeral practices reflected this celebration of life with such hymns as *Swing Low Sweet Chariot*. They believed that life after death was better than the oppressive life on earth under slavery. Another traditional song, *Precious Lord Take My Hand*, speaks to their hope of this other life and the celebration of the promised after-life.

Today, there are about 30 million African Americans in the United States, 12.7 % of the population. Cultural patterns of grieving may depend on ancestral backgrounds. However, most traditions are shaped more by customs than by race. Educational background, gender and economic status are other influential factors. **There is no single way that African Americans grieve.**

Religious denomination also plays an important role. Historically, African Americans have had a strong faith foundation, but the exact nature of that foundation varies among families and individuals. Funeral services at a Pentecostal church are different from those at a Lutheran, Episcopal or Roman Catholic church. Even within a particular faith, variations occur. For example, the missionary Baptist grieves differently than the Southern Baptist. Not all African Americans are Christian. Some embrace the Muslim faith, a few are Jewish. It is inappropriate to generalize that an African American will grieve or conduct a funeral service in a certain way. Because African Americans are from many different faith foundations, service providers should ask the family about their beliefs and what is important to them.

Social status and role expectations also are impor-

tant factors that influence the grief response. For example, when Dr. Martin Luther King, Jr. was assassinated, Coretta Scott King conducted herself as the wife of a national civil rights leader, despite her personal pain. Many people held expectations of how she should carry herself. Furthermore, she was the wife of a Baptist minister who had taught his congregation how to deal with grief and loss. These

"For no other group in American life is the matter of family life more important than to the Negro. Our very survival is bound up in it..."

Dr. Martin Luther King
Address delivered at Abbott House, Westchester County, NY 1965.

role expectations shaped the way she presented herself. Dr. King's mother also was assassinated, while playing a piano in front of the whole church. The senior Dr. King, as the congregation's pastor and leader, had to conduct himself in accordance with his Southern Baptist faith.

Grief responses and rituals also vary by geographic region. For example, in some areas of the southern United States, drivers sometimes stop their cars along the roadside, get out and tilt their hats to the funeral car to show respect. This gesture acknowledges that another soldier has gone on to his reward.

Customarily, all the extended family and church members provide support to the family during an infant's illness. Extended family members include cousins, aunts, uncles, godparents and parents and grandparents as well as their close friends. Family members may also count on their minister, deacons, choir members and others to visit the sick infant in the hospital and attend the funeral. Parishioners will feel they have a duty to do so, as well.

One traditional African American value is respect for elders. When an infant dies, the oldest family member is likely to be the responsible individual

and the person with whom service providers will interact. Care providers must determine whom the family has designated as being in charge. This person will probably take care of planning with the funeral home, contacting the minister or priest and receiving visitors.

In addition, the grandmother's role will be central to many African American families. A classic definition of this role still rings true, "Black grandmothers are the guardians of the generations". (Staples, 1973) Family members may seek out and follow her advice about pregnancy, child care, health and treatment for illness. She might have an active part in rearing her grandchildren. When an infant is ill at home, the grandmother may be the one who sits up with the child. When an infant is hospitalized, she could be a decision maker concerning treatment. When an infant dies, the grandmother may be the main source of solace and support for the parents and other family members.

Another custom that has survived from generation to generation is having friends in the community take care of the bereaved family. These friends immediately prepare food to bring to the family. They recognize that the bereaved may forget to eat when they are completing tasks such as notifying family members and making funeral preparations. The community helps out with house cleaning and food preparation as a way of paying respect. Families who have disagreed in the past also forget their misunderstandings and send a family member to participate in the events out of respect for the life of the relative who has died.

Traditionally, it is appropriate for providers to address African American family members formally, using Mr. and Mrs. with the last name. Not using the last name may be seen by some as a sign of disrespect. Providers need not be African American to reach out to African American families. One strategy for reaching out to a family is to ask about their faith foundation, beliefs and practices. A provider who is not familiar with those customs can say, "I am not familiar with your faith, but how can I help you?" Sincerity is what is essential, and a willingness to want to learn about the family's traditions. Providers should be there for the family, respect their customs

and reassure them that no one is there to impose certain beliefs.

Some African Americans may not express grief openly to non-family members. They may appear stoic. Grief and loss are more likely to be expressed at the funeral in the presence of family and close friends. For some, a custom of singing and praying over the open casket of the deceased during the funeral may encourage family members to grieve and show strong emotion. One less common emotional custom is *falling out* which is manifested by collapse and an inability to see or speak. This response is a traditional way to grieve openly.

Care providers must not make assumptions about a person's grief based on failure to show emotion. The example that follows shows how a person's stoic grief reaction was misunderstood. A bereavement counselor learned that a young mother had suffered a stillbirth while the counselor was away. The mother had taken a picture of her baby and mementos. Then, she signed out of the hospital without even spending the night. The mother stated that she did not want a funeral for the baby. Staff commented that the mother did not seem upset and must not really care about losing the baby. A few months later, the young woman came to talk to the counselor and started sobbing. The mother said she wanted a funeral for her baby, but could not have one. Her grandmother died of cancer the same day her baby died. Her own mother had been taking care of the grandmother during her long illness. The young woman felt it was not right to ask her mother for help with the baby's funeral while her mother also was planning her own mother's funeral. She left the hospital to go home to help with the grandmother's funeral. She believed that God would have to take care of her baby.

In summary, African Americans comprise a diverse group of people. Their grief reactions are influenced by a broad array of historical, religious, traditional and cultural factors. Individuals vary according to their faith foundation, geographic location, educational preparation, economic level, gender, role expectations, and family customs. A service provider can reach out to bereaved African Americans by asking about their beliefs and traditions, prefer-

A MULTI-NATIONAL MUSLIM PERSPECTIVE

Adapted from the presentation of Nancy Ali

ences and desires and by being open and responsive to what the family members say.

Bismillah-ar-rahman-nir-raheem!

In the Name of God, Most Compassionate, Most Merciful, peace be upon you.

Muslims share one religion, Islam, but they come from many different countries of the world. More than one billion people worldwide practice the Muslim faith. Most live in Central and East Asia, North Africa and the Middle East. About eight million Muslims live in the United States. While the burial rites are basically the same in most Muslim countries, grief reactions will vary. Within each cultural group, gender, economic status, educational background and level of family support will also influence grief reactions. Because Muslims come from so many countries with such a wide array of different customs, **providers must be especially sensitive to the needs of individual family members rather than relying on preconceived ideas about Muslim traditions.**

Muslims believe in one God and honor Mohammed as his prophet. They believe that Abraham, Moses and Jesus were also prophets. The prophet Mohammed wrote the Muslim bible, the Holy Qur'an. Devout Muslims pray five times every day: at sunrise, noon, late afternoon, sunset and late evening. They kneel to pray and face toward the Holy City of Mecca, where the Prophet Mohammed was born in 570 A.D.

Muslim society is built around the nuclear and extended family. Most Muslim families tend to have a similar social structure — strongly patriarchal and hierarchical. The father of the family has authority and makes decisions. Women are subordinate to men and younger people to older people.

The Islamic faith teaches that nothing that happens is an accident or coincidence. Rather, every event has a meaning and a purpose, which is known to God alone. *Inshallah* (if God wills) is a phrase Muslims use to acknowledge God's power over all life's circumstances. While this is a general Muslim belief, providers must not assume that family mem-

bers will relate to the health care system — or for that matter, any of life's experiences — with a passive nature. When faced with difficulties, the Muslim does everything possible to either remove or deal with them. If removing the problem is impossible, a Muslim tries to be patient and steadfast with what the Qur'an calls a beautiful patience. However, a sense of hope in the face of difficulties, even impending death, always remains.

Islam does not discourage grieving which it considers a mercy from God. Even the Prophet Muhammad wept when his infant son Ibrahim, the only son born to his wife Miriam, died. He said, "The eyes shed tears and the heart feels pain, but we

The Holy Qur'an Guides a Sincere Muslim to Bear Trouble and Affliction:

And we shall undoubtedly test you with something of fear and hunger, some loss of wealth and lives and fruit. But give glad tidings to the patient, who say when afflicted with calamity: "To God we belong and to Him is our return." They are those upon whom is God's blessing and mercy, and they are the ones who are guided.

utter only what pleases our God. O Ibrahim! We are aggrieved at your demise." The Prophet also wept when his granddaughter died. Then the Prophet said to his followers, "This weeping is the mercy that God has placed in the hearts of his servants."

Prophet Muhammad provided solace for bereaved families in his teachings. Mohammed teaches that the innocent children lost in this life will refuse to enter Paradise without their parents and God will admit the parents to Paradise.

In situations such as the loss of a child or infant, western parents may ask, why? or could I have done something to prevent this? Islam teaches that when God wills something to happen, nothing can prevent it. The believer must trust in God's wisdom. According to Islamic religious tradition, family members and close friends would offer the following condolences, "I am sorry for your loss, may God give you patience." Though Muslims have a belief in *Inshallah*, family members will not easily accept the death of a child, one of the most painful experiences in life.

Grief responses to infant death may vary widely from one Muslim culture to another. In the Arab culture, parents try to show patience in the face of adversity by appearing stoic. They do not cry in public. In the Indo-Pakistani culture, parents who have lost their child are expected to weep a great deal. If they do not weep, they may be perceived as uncaring. In Bali, conventional mourning practices require that the bereaved not only appear outwardly composed but also cheerful.

A Muslim also does not look at death as final. In fact, the term used for death is *Intekal* (crossing over to the next and eternal life). To the Muslim, death is simply the return of the soul to Him who gave it, the last stage of the journey from God to God. Parents may request that a dying infant or one who has died be turned to face the holy city of Mecca. That way, the infant may begin the journey home to God.

As soon as an infant dies, Muslim custom requires that the family immediately prepare the body for burial. At that point, Muslims usually believe only family should touch it. If providers have to touch the body, they should wear gloves. The family will close the infant's eyes, straighten the limbs and wash the body. As they are preparing the remains, they will offer prayers for the deceased. Then they wrap the body in a white shroud. After the head has been covered with the shroud, it should remain veiled. If the infant dies in a health care setting, providers need to allow sufficient time and privacy for these preparations and prayers to take place.

In the Islamic faith, the fetus is first considered a whole human being with body and soul at four months gestation, the time fetal movement first occurs. When a Muslim woman loses her baby by spontaneous abortion before this stage, Islamic tradition requires that the fetus be washed and buried but not prayed over. Care providers should ask the mother if she wants to take the fetus with her for burial. A severely premature baby, at four to six months' gestation, is treated as an adult if it gave a cry, sneezed or coughed when delivered. The baby is washed, shrouded, buried and prayed over since its life and death would have been verified. Any still-born baby is treated as an adult if the mother felt the

baby move. In this case, the baby would be bathed, shrouded, buried and prayed over.

In the Islamic religion, when a baby passes away, the funeral prayers do not contain passages asking God's forgiveness for the deceased, as is done when adults pass away. According to the Holy Qur'an, every baby born to this earth is free from sin. If God calls the infant back to Him, the soul returns to Paradise.

Islamic burials are done as swiftly as possible. Burial within the first twenty-four hours after death is a strict religious mandate in all Muslim cultures. In fact, if the baby dies after sunrise, a few Muslims may even prefer the burial by sunset. If the baby dies after sunset, burial before sunrise may be preferred. Traditionally, the family and friends would dig the grave and cover it. The body is usually laid on its side facing Mecca. The family may place a headstone to mark the gravesite, but customarily it may not contain any writing. In some countries, the mother of the deceased infant and the other female relatives do not attend the burial. Instead, they gather together at the mother's home to comfort her, read from the holy Qur'an and pray.

The best help that health care providers and the hospital can give to the bereaved is releasing the body from the hospital as quickly as possible so the Islamic funeral may take place without delay. Islam does not encourage autopsies unless the cause of death was murder, poisoning or an unusual circumstance. Cremation is not allowed. The injection of artificial fluids such as embalming agents or preservatives into the body is totally forbidden.

The vignette that follows illustrates the needs of one Muslim family. A family from Pakistan came to the United States so their eleven month old daughter could have open-heart surgery. The surgery was unsuccessful and the baby expired in the operating room. The family needed assistance in making funeral arrangements. The hospital contacted a local Muslim family that offered to help. Two days had already passed since the child had died. According to Islamic tradition, the burial was already one day too late. The parents could not understand why they had not gotten their child back. Finally, with intercession from the local Muslim family, the hospital released the body to the funeral home at the end of

the second day. All the way to the funeral home, the mother uttered words of desperation and helplessness. At the funeral home, the child's father bathed and wrapped the child in a white shroud. Meanwhile, the mother waited to see the child. When the time finally came, the mother kissed the tiny girl's face and cried aloud, "my daughter, my daughter," and fell to the floor. The local family went with the mother and father to the mosque to offer the prayers for the dead. In the mosque, the mother continued to cry until a Muslim woman embraced and comforted the mother. She said, "Don't cry. This is a blessing from God. This child will pray for you until

Meeting the diverse needs of bereaved families is a challenge to health care providers. At the same time, the experience affords a unique opportunity for providers to assist and support families through one of life's most difficult times, the death of a loved one. To do this effectively, care providers must appreciate culture beliefs and behaviors that differ from their own. Such awareness can avoid misunderstanding and unneeded distress that the bereaved family might remember and grieve for a lifetime. Simple

the end of your life. She will not go to Paradise without you and God will give you Paradise. Read the Qur'an and you will feel comfort." She proceeded to get a Qur'an from a shelf in the Mosque. The mother began reciting from it and within a minute or two, had begun to accept the will of God.

The death of a young child is probably the most difficult event that can occur in a parent's life. All religions and cultures have found their own solutions for coming to terms with it. Muslims believe with every hardship God sends, He will also send the means to ease the burden.

CONCLUSION

questions can provide an opportunity for the bereaved to share their feelings and unique customs. One key question can begin to build a therapeutic, culturally competent relationship,

"I am so sorry for your loss. How can I help you?"

ABOUT THE PANEL

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Dr. Shaefer has worked with bereaved families and service delivery systems for bereaved families during most of her nursing career. As ASIP president, she headed a national network of individuals who work with families around bereavement issues and advocates for services so that every family receives appropriate care when faced with this tragedy. She is Director of the Center for Infant and Child Loss at the University of Maryland School of Medicine. The Center provides direct services, education, training and advocacy throughout the State of Maryland.

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Mrs. Ali is an Islamic high school teacher in Villa Park, IL. She has her BS in microbiology from the University of Pittsburgh and speaks on women's issues, the Islamic faith and other Muslim topics. She is a member of the Dupage Interfaith Network and the Humdarth Organization for Battered Women and Child Abuse in Middle Eastern and Asian families.

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Ms. Johnson is a registered nurse and an enrolled member of the Rosebud Sioux Tribe in South Dakota. Her experience includes serving in the Army in Korea, the Veterans Administration and the U.S. Public Health Service as Director of

Nursing at the Pine Ridge and Rosebud Indian Hospitals. She is a maternal child health consultant for the Infant Mortality Committee, South Dakota.

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Ms. Julian is a nurse and the Perinatal Loss Coordinator for the Touch Program at Bethany Hospital, Chicago, Illinois. She has 25 years experience as a Maternal Child Health Nurse, and has been providing direct services to families both in the hospital at the time of the death and after discharge.

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Mrs. Thompson was born in Columbia, South America. She is both a FIMR interviewer and a case manager. For many years she has worked with Spanish bereaved families in the San Gabriel Valley in Southern California. In addition to working with bereaved families, Mrs. Thompson had first-hand experience with bereavement after miscarriages, the death of her infant son and the recent death of her granddaughter to SIDS.

These panelists are available for consultation.

RESOURCES

The following resources may provide additional help for providers who work with bereaved families

from diverse cultures.

Association of SIDS and Infant Mortality Programs (ASIP) provides training and technical assistance related to cross-cultural grieving. Contact Jodi Shaefer (410)706-5062 or www.ASIP1.org.

Cross Cultural Health Care Program provides bilingual medical glossaries and a training guide for medical interpreters. Contact CCHP at (206)326-4161 or www.xculture.org.

Diversity Rx is a WEB-based clearinghouse of information about meeting the language and cultural needs of diverse populations seeking health care. Contact www.diversityrx.org.

National Center for Education in Maternal and Child Health The NCEMCH prepared a list of **32 web sites**. The web address and a brief description of the organization are included. Both public and private organizations are included. Some web sites included are Indian Health Services, Asian Health Services Online, HRSA Office of Minority Health, National Coalition of Hispanic Health and Human Service Organizations, Diversity Rx and Coalition of Hispanic and Human Service Organizations. Contact www.ncemch.org/pic/racdispwebsites.html

The Health Advocate is published by the National Health Law Program (NHLP). Contact www.healthlaw.org or (310)204-6010.

The National Center for Cultural Competence, Georgetown University, is funded by the federal Maternal and Child Health Bureau (MCHB) to increase the capacity of health care programs to

design, implement and evaluate culturally competent service delivery systems. Contact Tawara Goode (800)788-2066.

National Healthy Mothers/Healthy Babies Coalition is developing a best practices report on producing and translating health education materials for people with limited English speaking ability. Contact: www.hmhb.org or (703)836-6110.

The **March of Dimes Birth Defects Foundation** has recently developed a new *Bereavement kit*. The set of useful resources includes information for both bereaved parents and friends and family; a remembrance package, an insert titled “When You Are Ready to Try Again;” a resource directory and a set of five fact sheets about miscarriage, ectopic and molar pregnancy, stillbirth, neonatal death and birth defects. Contact 1-800-888MODIMES or www.modimes.org and ask for item #09-1107-98.

The **University of California at San Francisco Nursing Press** has published an excellent resource titled *Culture and nursing care* (See references). The book briefly reviews customs and beliefs of 24 different cultural groups. It is particularly useful for Fetal and Infant Mortality Review (FIMR) programs because the book gives a general outline of customs related to birth and death for each of the 24 groups. This book received the American Journal of Nursing Book of the Year Award in 1996. Contact (415)476.4992 or <http://nurseweb.ucsf.edu/www/book4o.htm>

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