Health care providers in the U.S. are increasingly challenged to meet the needs of clients from many diverse backgrounds and cultures. This fact was recently emphasized in a report from the Institute of Medicine (IOM) titled Unequal Treatment Confronting Racial and Ethnic Disparities in Health Care that indicates other racial and ethnic groups, when compared with whites, experience a lower quality of health services and are less likely to receive even routine medical procedures than are white Americans. (1). Even when insured at the same level as whites, minority populations may face such barriers as language differences, geographic isolation, and lack of cultural awareness on the part of health care providers. The IOM report recommends a variety of actions including increasing health care providers' awareness of racial and ethnic disparities, integrating cross-cultural education into provider training programs, and educating patients about how to access care and participate in treatment decisions.

This bulletin is offered to assist perinatal and pediatric staff who help families cope with fetal and infant loss and to present the cultural examples of different traditions. Cultural traditions play a particularly strong role in a family's expression of grief and loss. This bulletin provides an overview of the history and customs of four diverse cultural traditions of families grieving the loss of an infant and the strategies providers can use to provide culturally competent support to individuals and families.

It is based upon a presentation at the National Fetal and Infant Mortality Review Program's Fourth National Conference, held August 2–4, 2001, in Washington, D.C. This bulletin expands information published in the 1999 National Fetal and Infant Mortality Review (NFIMR) Bulletin When an Infant Dies: Cross Cultural Expressions of Grief and Loss. (2) Readers are encouraged to review the 1999 bulletin as it provides additional information about grief and loss in the perinatal period as well as with reflects the panelists' different cultural backgrounds as well as their clinical experiences. However, one common theme expressed by each panelist is the diversity within any cultural group. For example, the Chinese are the largest group of Asian Americans. They come from a vast country whose regions differ widely in history, politics, traditions, and dialects. Therefore, the Chinese American population actually consists of many groups with different backgrounds, cultures, beliefs, and languages. The panelists also emphasize the uniqueness of individuals within a cultural group and the importance of treating each family according to their needs. They encourage providers to ask families what would be helpful to them when coping with an infant's death.
Working with the members of a family in which an infant has died can be one of the most difficult challenges health care providers face. It is often hard to listen to a family member describe their pain as they relate the birth and death of their child. Encounters generate a variety of feelings in the provider. Providers need to be aware of their own feelings before reaching out to bereaved families. They must be knowledgeable and capable of working with families from diverse cultures. Most importantly, providers must be comfortable asking the bereaved family member how they can help. 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.

While this bulletin provides an overview of the traditions of the four cultural groups, exploring general variations in grieving, it should not be used to predict how any individual would respond to loss.

No bulletin, book, or article can prescribe an appropriate family intervention that is suitable for everyone. In practice, each family has its own unique customs and traditions. Also, an infant's death affects each family member differently. It is essential to not 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. Moreover, providers are encouraged to learn about the various cultural groups in their communities and locate the local resources available to help them.

**CHANGING DEMOGRAPHICS**

The demographics of the United States have changed significantly over the last decade. In 2000, 12.3% of the population identified themselves as Black compared with 12.6% in 1990, indicating a relatively stable African American population. The percentage of Asian Americans tripled, from 1.2% to 3.6%, over the same decade, with Chinese representing the largest portion of this group. The Hispanic population increased from 6.3% in 1990 to 12.5% in 2000. The proportion of Native Americans/Alaskan Natives remained steady at 0.9%. (3) Further, in the 2000 census, for the first time, respondents could designate more than one race and 6.8 million individuals, or 2.4% of the population, identified themselves as multiracial. (4)

Another demographic shift that is important for health and social service provision is the increased percentage of immigrants. In 2000, the Census Bureau estimates 28.4 million residents were foreign-born. The immigrant population is estimated...
at 10.4%, up from 7.9% in 1990. Fifty percent are from Latin America, with Mexicans accounting for the majority. Six states account for 70.4% of the total immigrant population. These are California, New York, Florida, Texas, New Jersey, and Illinois.

The degree of assimilation and acculturation is one of the factors affecting 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. Foreign-born and first-generation immigrants are faced with daily challenges as they learn to adapt to life in the United States and honor their cultural heritage. These families are in transition from their homeland to this country and may not be immersed in American culture or speak the language, which further isolates them from assimilation and acculturation.

LOSS DURING PREGNANCY AND INFANCY

While expressions of grief will vary among cultures, a deep sense of loss and sorrow is nearly universal. The depth of the sorrow is not necessarily related to the length of the pregnancy or the age of the infant. Parents who lose a fetus to miscarriage or ectopic pregnancy might be just as devastated as parents whose older infant died of SIDS. The initial grief reaction can vary widely and may 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, some mothers continue to feel fetal movement. Although the specific experiences vary, all parents endure the difficult process of mourning their infant's death.

Worden describes four tasks of mourning. (6) The first task is accepting the reality of the loss. This includes both an intellectual and emotional acceptance of the baby's death. Most parents intellectually understand the death before they accept it emotionally. Traditional rituals such as holding the baby, seeing the infant after the death, helping to prepare the body, and having a funeral can help parents accomplish this task.

One mother whose baby was stillborn at 35 weeks gestation repeatedly needed to hold the baby in the hospital. After discharge she called the funeral home to arrange to hold her daughter again. Afterwards, she said she felt as if a rubber band that had been tightly around her chest was released. She had begun to emotionally accept her daughter's death and was ready for her burial.

The second task described by Worden is working through the pain of grief. After accepting the reality of a death, parents become immersed in the task of dealing with their pain. They must experience this pain to get through it. A family that moves immediately after the death may be trying to avoid this task by leaving the pain behind. However excruciating, the family will have to deal with the loss in order to heal. The third task is to adjust to a life without the baby. This may require a significant change in daily activities. For example, if the mother stayed at home to care for the baby, she will now face empty days that need to be filled in other ways.

The final task is to remember the child but go on with life. Parents remember the baby but reinvest their emotional energy in new and ongoing relationships with family and friends. Their relationship with the baby changes from one of presence to one of memory. Many parents whose child dies want to continue their role as parents and some try to become pregnant again. A new pregnancy offers the opportunity to be successful parents with a live child.

While grief is described in terms of discrete tasks, the grief process is fluid. Generally, there is not an orderly progression from task I to task IV. A grieving person can concurrently work on more than one task. Tasks can be revisited and reworked over time.

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<td><strong>Task I:</strong> To accept reality of the loss.</td>
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<tr>
<td><strong>Task II:</strong> To work through the pain of grief.</td>
</tr>
<tr>
<td><strong>Task III:</strong> To adjust to an environment in which the deceased is missing.</td>
</tr>
<tr>
<td><strong>Task IV:</strong> To emotionally relocate the deceased and move on with life.</td>
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Perinatal loss is sudden and unexpected

All perinatal losses or infant deaths can be considered sudden and unexpected. Pregnancies are supposed to be carried to term, and children are not supposed to die before their parents. Worden described several factors uniquely related to sudden and unexpected death. (7) These include a sense of unreality about the loss, feelings of guilt, a need to blame, the involvement of medical and legal authorities, a feeling of helplessness, agitation, the implication of unfinished business, and a need to understand the death.

These features of sudden death described by Worden help to explain the behaviors observed in families following a perinatal loss or infant death. Initially, the death does not seem real to parents. They are shocked and often have difficulty accepting that the death has occurred. Later, feelings of guilt emerge, aggravated by expressions of ‘if only’ regarding the circumstances of the death. These feelings may evolve into blame directed at a spouse, health care provider, or a supreme being. The involvement of legal and medical authorities can increase a parent’s sense of guilt or blame. The presence of police investigating an infant’s death may reinforce feelings of responsibility or accusations regarding the baby’s death. Eventually, parents feel helpless—they could not protect their child and have no control over the situation. Agitation is another common response. Sometimes, health care providers may be challenged to support agitated family members.

A minister was with a family in the emergency room when they were notified of their infant’s death. The father became extremely agitated and started pacing. He left the emergency room. The hospital was in a high crime neighborhood, and the father did not know the area. The minister quickly caught up with him. They walked through the surrounding neighborhoods and talked. Eventually, the minister was able to bring the father back to the hospital.

A sudden death often manifests as unfinished business. A pregnancy loss or infant death is the loss of the future. It leaves a yearning for developmental milestones never achieved.

Finally, parents need to understand why the death occurred. On the other hand, as is the case in some fetal deaths, if the exact cause of death cannot be determined, the parents should be told that too. This is critical for families facing a pregnancy loss or infant death. These parents have many questions about how and why their baby died. It is often helpful to review the autopsy results with them a few weeks after the death. This gives the family time to think about what they want to ask and to prepare themselves for the answers. If parents are not given information about the cause of death, they may think the health care provider is hiding something. It is critical for providers to be open with families and share what is known about the cause of death.

A four-month-old infant died of Sudden Infant Death Syndrome. The baby had been to the pediatrician for a minor upper respiratory congestion two days before his death. The mother was very angry and blamed the pediatrician for the death. The pediatrician also was upset and avoided the mother’s repeated calls. The mother brought a lawsuit against the pediatrician because she believed he was hiding information her. Ultimately, the suit was dropped when a counselor arranged a joint session with the mother and pediatrician.

Providers should consider the parent’s stage of progression through the tasks of grieving when formulating interventions. A number of options are available. They can refer parents to professional bereavement counseling or parent-to-parent peer support. Many families benefit from culturally relevant infant loss literature in the appropriate language. In addition, providers can link parents to culturally appropriate faith-based care and other community services, as well.

In addition to supporting parents in their grief, providers may have to help them cope with other effects of the child’s death. The death of a child can create
stress in the relationship between the parents. Some parents blame themselves or each other for the loss. They may feel they have failed as parents. In some cases, one parent feels the other is not grieving enough. The provider can intervene by helping these parents understand the differences in the ways individuals grieve and the importance of maintaining communication.

Surviving children, too, may experience sadness, confusion, and anger. They may even blame themselves for the death. Generally, providers give information to the parents, who then explain the death to the children. Information is based on the child’s age, developmental level, and prior experiences with death. Children often grieve deeply, but their needs may be overlooked. Parents and extended family members need to support them during this crisis.

Sometimes providers say they feel powerless to ‘fix’ the grief of family members. In fact, providers are in a very powerful position to model and encourage grief expressions. 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 ensure that family needs are met. These compassionate practices generally cut across cultural variations in expressions of grief.

Finally, while working hard to provide therapeutic grief support to parents, providers also have to deal with their own feelings about the death. Those who are pregnant or parenting infants can sometimes have an intense personal response to the loss. The provider’s reaction, determined in part by her own cultural background, may differ from that of the family. In these cases, she must be careful to keep these differences from affecting her work with the family. Staff discussions can be useful to help cope with these issues. They provide an opportunity for staff to acknowledge their sorrow and encourage each other in their efforts to assist bereaved families.

**AN AFRICAN AMERICAN PERSPECTIVE**

*Adapted from the presentation of Evelyne Longchamp*

African Americans represent close to 13% of the U.S. population, or a total of 35 million people. (8) Providing culturally competent services is especially important in light of the significant racial disparity in infant deaths.

Unfortunately, research about effective strategies for providing bereavement support for African American families is not available. Consequently, such services tend to be based primarily on anecdotal information. While that information is illustrative, service providers are cautioned to not over generalize. It is critical to remember that each individual’s response is unique.

This section explores some of the issues and circumstances that affect the African American family’s response to grief and loss. It describes some of the rituals of French Caribbean, British Caribbean, and African America origin, and offers recommendations for practice.

The legacy of slavery has had a significant impact on the current culture of African American families and, consequently, their response to loss. Despite a history of forced separation from family members, African American families maintain strong ties with ancestral traditions. Many families have preserved customs and values that were brought here from Africa centuries ago. These include spiritual, family life and child rearing practices. For example, the expression, “It takes a village to raise your child,” is a proverb from the Uba people in Nigeria that has become a popular slogan in the United States.

The diversity within the African American community stems from its history. African Americans originally came from many regions in Africa, most commonly those on the west coast. Most African Americans are descendents of these Africans who were shipped to the United States and the Caribbean as slaves. These Africans lived in countries colonized by the French, British, Spanish, Portuguese, Dutch, and others. They developed a unique culture with roots in the traditions of Africa as well as southern U.S. traditions and those of Caribbean countries.

Historically, African American family members have moved primarily for economic reasons. Since the 1960’s there has been a large influx of African
Americans from the Caribbean islands, Central and South America, and various African countries. So, U.S. African Americans bring very diverse cultural heritages with them. The cultural traditions of these immigrants vary further depending upon whether they are from urban or rural settings in their countries of origin. Additionally, from the 1940’s to 1970’s there was a significant migration of African Americans from the southern United States to the north. These individuals were seeking to improve their economic situation by relocating in northern states with better job opportunities. Unfortunately, in many cases the northern migration resulted in further separation and isolation of black families.

"Of all the forms of inequality, injustice in health care is the most shocking and inhuman."

Martin Luther King, Jr.

Despite their common past, African American families have diverse careers and economic levels. While most African American families started out living in the south in an agricultural environment, those who moved north got jobs in various industries and service organizations. This development led to a change in the structure of the African American family. As families split up and moved to new locations, they did so as smaller, nuclear families who no longer had access to the large network of kin. Although the nuclear family has become more prevalent, historically, a ‘flexible’ patriarchal family predominated with ties to distant relatives. The head of the household varied according to family circumstances. For example, if the father died or wasn’t available, an uncle or grandfather might become head of the family. Grandmothers have also assumed this role. The extended family included aunts, cousins, godparents, adoptive parents, and others. There is no one family structure that characterizes African American families.

Practitioners who work with families from diverse backgrounds have learned that there are many ways people grieve the death of a child. The next section will describe the grieving traditions of French Caribbean, British Caribbean and African American families. Although there some similarities and differences across these groups, there are individual variations as well, determined in part by social status, level of education, economic status, and expectations of family and friends.

French Caribbean

Caribbean families typically have many extended family members who are not blood related. For example, in Haiti there are ‘yard siblings’ who are the children that grew up in the same compound. There also are ‘baptism siblings,’ the children of one’s godmother and ‘arm siblings’ who walk together for first communion. These non-blood relatives provide a large network of kinfolk who can be contacted if one needs a job as well as family support.

A Haitian pediatrician who became a forensic specialist and is now a New York Medical Examiner provided some valuable insights into bereavement among Haitian families. (9) She reported being greatly saddened when telling a Haitian family that their baby died. Not only did the baby die, but also the family’s hopes and dreams for the family’s future. The family planned to give as much as possible to the baby. They hoped the child would get a good education and improve their financial/social situation. The child’s death was the loss of the future. This is especially significant in Haiti because Haiti does not have a Social Security system, and so children have an added responsibility of helping parents in their old age.

This physician described various reactions to an infant’s death. In some cases, she said, the poor mothers would ‘go out of their minds,’ jumping, screaming, running, and holding on to their stomachs. The loss of an infant in the Haitian culture is sometimes translated into pain in the uterus which is called ‘Matrice’ in French. Mothers often say the uterus starts contracting like they are in labor again, and this produces a very searing pain. In contrast, Haitian fathers want to be in control. They do not cry openly and usually help make the arrangements for burial. However, responses vary by social class, economic level, and education. For example, the response of wealthy French-influenced families is typically more controlled.

In the Haitian culture, the family takes over when a baby dies. They understand the mother’s pain.
she is lactating, they concoct herb and root tea to suspend her lactation. A head tie is also applied. A copper penny with butter or margarine rubbed on it is placed on her head to keep her from ‘losing her mind.’ Haitians also believe that the circulation is compromised by great emotion. Therefore, the mother is given strong unsweetened black coffee with oil to help circulate the blood. To calm the uterus, her waist is tied with something that has touched the dead baby, such as two diapers tied together. Family and friends gather night and day to be in the house where the death occurred. They pray and provide support to the grieving family. Friends and neighbors bring food and drink. The family and friends gather to reassure the family that they have seen death before, understand what she is going through, and will help her.

Generally, a male member of the family makes the burial arrangements. The body is bathed and dressed by a specialist who comes to the home. Because Haiti is tropical, the burial occurs within 24 hours. The mother is not allowed to go to the funeral service. The following day she can visit the grave. For nine days after burial, family and friends gather every night at home of the deceased to provide support for the family and pray. The prayers are to ensure a safe journey for the deceased into heaven.

Black or somber attire signifies mourning. However, the mother wears white for a year and also refrains from entertainment. The father wears toned down colors. Black armbands are no longer worn. Siblings also do not wear bright colors for a period of time.

In middle and upper class families, the process is less dramatic and crying is muffled. Parents will observe the nine days post burial by attending mass every day, visiting the cemetery, and bringing flowers to the gravesite. In the United States, families may opt for cremation.

Recent immigrants to the United States often do not have the social support they had in their country. In many cases, there are few family members to surround and support them. Families may feel isolated. The family and neighbor support is shortened due to distance and work obligations. The length of official mourning varies for each family. Those with religious affiliations may receive support and prayers from the congregation. Many recent immigrants want to return to their homeland as soon as possible after the death. They go ‘home’ to be with family and get renewed, so they can better cope with the loss. They usually welcome a bereavement home visit and will talk, but may not feel comfortable attending a bereavement support group meeting.

Many Haitians do not believe in the SIDS diagnosis. They think that death occurred because the baby was so beautiful that someone put an evil eye on him/her. The evil eye is their explanation for the sudden and unexpected death. It is important not to challenge their beliefs about the death; instead, explore their understanding while offering alternative reasons.

Johnny was only 5 weeks old when he died. His 19-year-old immigrant mother was very upset about his death. She was searching for the reason the baby died, so her mother took her to a seer, a psychic in the neighborhood. The seer told her that Johnny was really an angel who was having a dream and he took her as his mother. When he woke up he went back to heaven. For this young mother, having this baby so powerful and an angel who chose her was extremely helpful to her. Johnny also had several godmothers. Each of the godmothers took a turn to bring the young mother to a SIDS support group. She also returned briefly to the Caribbean for her grandmother to care for her. She is back in New York and very happy to be expecting another baby.

**English Caribbean**

There are similarities and differences among blacks from the English Caribbean. A nurse midwife from Barbados reports that the British influence is alive and well among her people. They have been taught to be strong during adversity. They prefer to ‘keep a stiff upper lip’ and stay in control. However, this midwife found that the longer mothers tried to ‘be strong,’ the longer it took them to come to terms with their grief.

As in Haiti, African influence is seen in the practices of family and kin coming to the home to provide support and herbal remedies. These remedies are called ‘bush teas’ and are given to the mother to help her cope with her grief. Like Haitian mothers, Barbadian mothers do not go to the burial. They believe that children should accompany their parents to the grave, not the
November 2003

reverse. The mother goes to the cemetery after the burial. She brings flowers and observes mourning by wearing somber colors for one year.

Barbadians who immigrate to the United States often lose the support of their extended family members. Relatives no longer live nearby or are not available due to work obligations. In these cases, a strong religious community can provide a level of support similar to that provided by kin in the homeland. Again at the earliest opportunity, these mothers will travel to their homeland for special family ministering and support. These families will respond to the offer of bereavement home visits and will attend a support group. Grief and loss is viewed as part of life experience.

African American

Among African American families, the elders are very important and revered. The elders pass along practices surrounding birth, death, and child rearing.

Some families experience racism, however, and may have had a bad experience with the traditional support system. One middle class African American mother was not able to go to the hospital when her baby died. The police had detained her husband who was caring for the infant when she died. The mother had to seek legal support for his release. This mother said 'she had her grief for the infant on hold' to help her husband. When the situation was over, arrangements were made for the baby's burial. Both parents believed that their baby was safe because she was buried next to their great-grandparents. This was a comfort to them. This family accepted the full range of bereavement program services. They attended the support group and presented their story at conferences. They also provide peer support to other families. This is all done in memory of their daughter, Ayesha.

Drs. Palmer and Patterson report that African American mothers experience a variety of responses following the death of their baby. (11) One underlying sentiment is resignation that 'it happened for a reason.' Mothers frequently rationalize that many 'black teens are dying and maybe it is better that their babies died young.' 'He is too good for this world' is commonly heard. Palmer and Paterson found that mothers with a significant other and those who had deeper spirituality were able to come to terms with the death more quickly than mothers who were isolated and without spiritual/church connection. Many of these mothers had reassuring dreams that their infant was in a better place. The baby was viewed as the mother's protector and intercessor in heaven. It is important to always offer a full range of bereavement services because of these variations in responses. However, the mothers who had a wide network of extended families usually relied on family support and only accepted bereavement literature and phone calls from the SIDS program.

Recommendations for Practice

Grief is a crisis in family development. (12) It is overwhelming because it increases the family's emotional burden while shattering the life routines and ways of coping. One task of the grieving family is to re-establish the stable equilibrium necessary to support family development. Therefore, the family will need to re-establish their daily routines and find a stable way to cope with emotions without disturbing routines. This strategy will increase their sense of competence at meeting family needs and enables them to search for understanding and meaning for the death.

Communication is key in helping families cope with this crisis in development. The grief process is highly individualized and will be affected by variables such as stressors from the death and available resources and support. Assessment of support is key to assist families tap available resources.

One commonality and support among African American families is their spirituality. Throughout their history in America, religion has been a source of strength that has helped them cope and survive. Consequently, spirituality should be a component of support services for grieving African American families.

In summary, there is wide diversity in the African American population due to the influx of newly migrated groups with different cultural influences. Families are also from diverse educational, economic, and social backgrounds that affect their grief response and coping strategies. Providers must be open to new ideas and willing to learn by asking clients what would help them. Flexibility in this interaction is the key to supporting and assisting families as they deal with the tragedy of their infant's death.
HISPANIC/LATINO MULTICULTURALISM & UNIQUENESS

Adapted from the presentation of Yolanda Thompson

Immigrant values and aspirations

Immigrant families come to the United States to improve their quality of life. They come to fulfill that universal vision which lies within the soul and consciousness of every human being for freedom, respect, hope, and a chance to make an important contribution to family, community, and the world.

For many, the immigration process is a story of separation and loss, hardship and hope, faith and trauma, and learning to live with uncertainty. Immigrants usually arrive in the United States disoriented and distrustful of strangers, yet dependent on whatever help they can find. And, if their legal status is open to question, they face hardships gaining access to essential services as well as the ever-present threat of deportation.

A high rate of immigration combined with a high birth rate make Hispanic Americans the fastest growing ethnic group in the United States. From 1900 to 2000, the Hispanic population increased 60%, four times faster than the total population. According to Census 2000, Hispanics currently represent the largest minority group in the United States, with approximately 35 million including nearly 21 million of Mexican origin. (13)

The Hispanic presence in the United States predates the Declaration of Independence by more than 250 years. Spanish explorers established colonies in what would become the Southeast as early as 1513 and were present in the Southwest and present-day California by 1769. The richness of the Hispanic culture flows in large part from the blend of the Spanish and indigenous Native Americans, resulting in an Amerindian population in Latin America of 49 million. Roughly 24 million people in Mexico are Amerindian.

The term ‘Hispanic’ was created by the U.S. Census Bureau in 1970 as an ethnic category for persons who identify themselves as being of Spanish origin. Unlike other Census Bureau designations, ‘Hispanic’ denotes neither race nor color, and a Hispanic person may be White, Black, or American Indian. This classification includes people of many different origins and cultures due to the different patterns of interactions among Spanish settlers, indigenous Indian populations, and imported African slaves across the many Latin American countries. Although the term is widely used by Hispanics and non-Hispanics alike, many members of the Hispanic population prefer the term ‘Latino.’

One effect of assimilation in the United States is that much of the cultural richness and diversity has been sacrificed on the altar of the “melting pot,” that is, the belief that each family’s heritage is supposed to be melted into one American culture.

In contrast, Hispanics/Latinos prefer to be identified as a “culture of many nations,” with each bringing and retaining the richness of their country of birth. They represent twenty countries: Argentina, Bolivia, Colombia, Costa Rica, Chile, Cuba, Dominican Republic, El Salvador, Ecuador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, Puerto Rico, Spain, Uruguay, and Venezuela.

Importance of culture in supporting the family’s grieving process

After the death of a baby, the type and degree of support needed by each family is related to their spiritual beliefs and cultural practices. To ignore a family’s spiritual beliefs and cultural practices is to deny a family’s identity and the significance of the death event in their lives. Ignoring these practices may also interfere with the necessary grieving process.

In many cultures, including the Hispanic/Latino culture, religion dominates life in an all-encompassing way that is unusual in Western culture. More than any other support, faith in God is heavily depended upon as a day-to-day living experience and the source of all comfort and strength through the journey of grief.

In the Hispanic/Latino world, family care is a source of emotional and physical support. Since family ties are so strong, a fetal/infant death impacts not only the primary family of parents and siblings but extended family as well: grandparents, uncles, aunts, and cousins. The whole family is expected to participate in all decisions making after the death of a baby. Louisa’s baby had trisomy 18. The baby died shortly after birth. She was an assertive Latina, fluent in English. She was able to make special arrangements for the care of her baby after birth,
including having their pastor bless the baby. Her family was with her and they held the baby as much as possible. She knew that she had to advocate for herself because hospital staff were not knowledgeable of the needs of Latino parents.

The art of listening, is of critical importance in supporting the bereaved:

"With the gift of listening comes
The gift of healing, because
Listening to the bereaved until they have
said the last
Words in their hearts is healing and consoling
Someone said that it is possible to
Listen a person's soul into existence."

Author Unknown

Cultural competence and the health care provider

The role of the health care provider is to assist parents in making their own choices, provide resources and accessibility to needed services, and offer support and encouragement. These simple actions on the part of the caregiver can make a difference in how immigrant families experience the death of their baby and how well they accept help. If the health care providers as well as other caregivers want to provide meaningful support to the Hispanic/Latino bereaved, several cultural considerations must be understood and embraced:

Cultural Identity - This is key to understanding the needs of the grieving. It is important for caregivers to distinguish how the bereaved describes "self". The bereaved mother's self-identification reveals several things including her economic status, race, residential geographic location, education, faith foundation, and sense of helplessness.

Cultural Humility - Cultural humility is essential for caregivers. It means that no matter how many courses the caregiver has taken on cultural diversity or how many bereaved families have been encountered, there is still a need for openness to hear and be sensitive to the needs of the bereaved.

Cultural competence is essential to help the bereaved from another culture. It is about cultivating an open and sensitive attitude. It involves exploring and honoring your own culture, while at the same time learning about and honoring other people's cultures, thereby enabling a conduit for respectful and meaningful interaction.

Providers can exhibit cultural competence in the following ways:

- Offer words of comfort and compassion in the family's own language.
- Immediately connect parents to the appropriate support systems, such as family, faith community of their choice, and their own cultural community.
- Maintain clear communication with all family members while respecting the communication pattern of the family's culture.
- Reassure parents that their expressions of grief and the intense feelings associated with it are accepted.
- Provide culturally appropriate referrals to facilitate bereavement interventions in their community.

Cultural Hispanic issues for health care providers

Providers or practitioners must recognize that ethnicity is an important variable in relating to families. Cross-cultural issues can affect the grieving process as well as the overall decision-making process. Make an effort to learn something about the client's country of origin, its culture, and its people. At the very minimum, be aware of the following issues: the education/literacy level of the patient and the notions of simpatia and respeto.

Simpatia: This is described as politeness and pleasantness in the face of stress in order to hide pain or discomfort. Have you worked with clients who didn't understand a word you said, yet at the same time were gracious, smiling and nodding their head?

Respeto: People from many Hispanic cultures offer (and expect to receive) deference on the basis of age, sex, and status. Patients will naturally offer respeto to the health provider, an authority figure with high social, educational, and economic status. This sense of respect for authority may cause them to avoid conflict or confrontation.

Educational/Literacy Level: Having Spanish language brochures is a great step toward being culturally sensitive, but it may not be enough if the client is illiterate in Spanish, or can read but is not familiar with the technical terminology associated with certain services.
Juanita’s baby died at 22 weeks gestation due to placental abruption. She needed a translator to explain why her baby died. The only translator available was the janitorial staff and consequently she did not receive a proper interpretation. She also did not understand the difference between cremation and hospital disposal of the body.

"You win a person’s mind when you speak a language they can understand. You win a patient’s heart when you speak to them in their language."

Nelson Mandela

Many grieving Hispanic parents complain that health practitioners, by discounting the importance of spirituality and cultural beliefs, offer a fragmentary approach to care after the loss of a pregnancy or infant death.

Maria’s baby died due to multiple congenital anomalies. At 20 weeks gestation, she was aware of her baby’s condition. Medical staff did not understand her religious beliefs and choice to not terminate the pregnancy. Staff support was limited to weekdays, not weekends or holidays. After delivery, Maria needed a caring, knowledgeable person to help her hold and spend time with her baby.

In summary, in order for public and private systems of care to work in the interest of the Hispanic/Latino community, the following services are needed:

- Dissemination of culturally and linguistically appropriate information about health resources and eligibility requirements written in plain language.
- Spanish speaking staff who can discuss health, medical, and social service issues directly with parents, not their dependent children or other inappropriate interpreters.
- Health care providers who protect and respect the rights of the parents in decision making.
- Practitioners who acknowledge and respect the importance of the patient’s spirituality and culture.

A special note on death, grief and mourning in the Hispanic culture and the ‘Day of the Dead’

Since infant and maternal mortality and life-threatening illness in general are more common in Latino America and the rest of the world than they are in the United States, death, grief, and mourning are normal life events. Though all cultures have developed ways to cope with death through unique mourning ceremonies, traditions, and behaviors to express grief, death is a topic largely avoided in the United States. Death is viewed as the final end of the relationship. There seems little recognition that, in reality, one grieves the loss of a loved one for a lifetime, and one really never gets over it. One learns to live with it.

In contrast, the remembrance of deceased ancestors and loved ones is traditional among diverse cultures around the globe. Hispanic families remember the departed by telling stories about them. This is a way of helping children learn about their ancestors and how to cope with death.

Mexicans treat death with a healthy mixture of respect and irreverence. So it’s not so strange that today the Day of the Dead is considered one of Mexico’s most wondrous celebrations, merging the Spanish Catholic religion and traditions with ancient beliefs and pre-Colombian Indian culture dating as far back as 1800 B.C. However, many in the US today do not understand the tradition of the “Day of the Dead”.

**Misconceptions about the Mexican “Day of the Dead”:**

- It is not the Mexican version of Halloween. Mexicans have celebrated the Day of the Dead since 1800 B.C.
- It is not scary or morbid. There are no images of dead people, ghosts, witches, or the devil.
- It doesn’t honor death. The opportunity to reflect upon the lives of our ancestors, our heritage, and the meaning and purpose of our own existence.

This is an ancient festival, though it has been transformed through the years. More than 500 years ago, when the Spanish conquistadors landed in what is now Mexico, they encountered natives practicing a ritual
that seemed to mock death. It was a ritual the indigenous people had been practicing at least 3000 years, a ritual the Spaniards would try unsuccessfully to eradicate, a ritual known as the “Day of the Dead.”

Unlike the Spaniards, who viewed death as the end of life, the Mexicans viewed it as the continuation of life. Instead of fearing death, they embraced it. To them, life was a dream and only in death did they become truly awake. Death held a significant place in the rituals of Mexico’s ancient civilization. Among the Aztecs, it was considered a blessing to die in childbirth, for this assured the victim a desirable destination in the afterlife. The pre-Hispanic people didn’t separate death from pain or wealth from poverty, like they did in Western cultures.

The Day of the Dead is a uniquely Indo-Hispanic custom; it was originally intended to celebrate both children and the dead. It demonstrates a strong sense of love and respect for one’s ancestors; celebrates the continuance of life, family relationships, and community solidarity; and even finds humor after death. It is a holiday that preserves folk art and folklore as no other holiday does. It is created annually in the community, by the community, and for the community.

In the urban setting of Mexico City and in other large towns everywhere in Mexico, the celebration can be observed at its most exuberant. Figures of skulls and skeletons are everywhere. These mimic the living as they contort themselves into a modern dance of death. The celebration is a tourist event.

However, in rural villages and small towns, each household prepares its offerings of food and drink for the dead. In most localities in Mexico, November 1st is set aside for remembrance of deceased infants and children, often referred to as Angelitos (little angels). The children’s spirits are expected to arrive just before dawn on November 1st for only a few hours. Prayers are said at the altar in the home or church, which has been previously decorated with an abundance of flowers, toys, and other decorations. Incense is burned and food is offered until dawn. The grandmothers decorate the grave with toys and colorful balloons.

Adults who have died are honored on November 2nd. During the course of the celebration, families visit gravesites of their close kin. Gravesites are decorated with flowers, and picnics are held. Meals prepared for these picnics are sumptuous. There is a great deal of social interaction with other families and community members who have gathered at the cemetery. Like a Fourth of July celebration, exploding rockets, set off to mark the fulfillment of an obligation deeply felt, shatter the outside peace. The whole company of the living and the dead share in flowerage and fruitage of a land which both have cultivated. Such interaction between the living and the dead recognizes the cycle of life and, in a practical way; one gains an understanding and acceptance of death as a part of life.

Today, the “Day of the Dead” is celebrated in Mexico and certain parts of the U.S., Central America and South America and is celebrated differently in various geographical locations.

GRIEVING TRADITIONS IN THE CHINESE CULTURE

Adapted from the presentation of Virginia Tong

Chinese Diversity

According to the 2000 US Census, the Chinese make up 20% of the US Asian population and are the largest Asian group in the United States. Discussing Chinese culture is a complex task because of the diversity among Chinese people. Chinese people immigrating to the United States also come from very different urban and rural cultures. Dialects and traditions vary from one village to another in this vast country. The various regions of China differ in history and politics as well. Some are from Mainland China, while others are from Taiwan or Hong Kong. Mainland China is under Communist rule, and its people speak more than 60 major dialects. Taiwan, an independent island with its own government, has been free of Communist control. Hong Kong was a British colony until 1997, when it returned to Chinese rule. Because of the British influence, this city is very cosmopolitan—they get fashions from Europe even before the Americans get them.

Some Chinese immigrants to the United States have come from other countries. For example, the
initial ‘boat people’ from Vietnam were mostly ethnic Chinese who had been thrown out by the Vietcong at the end of the war. They were typically business people and upper class citizens. Those who came later were usually Vietnamese. Chinese people from other parts of Asia, Europe, Central America, and South America also have made their way to the United States. Some Chinese immigrants have entire families who were brought up in Panama, Peru, or Chile. Some of these families are bilingual in Spanish and Chinese. Service providers working with these families can use a Spanish translator if a Chinese translator cannot be found.

The differences among Chinese people also affect service planning and delivery. For example, if a family needs a translator the service provider will need to know which dialect is spoken. When talking about the Chinese American community, remember that this is a very large, diverse population made up of many groups with different backgrounds, cultures, beliefs, and languages.

Belief Systems

Despite the diversity, some generalizations can be made about the values and belief systems that are taught in traditional Chinese families. Most Chinese families do not have the typical church-based belief systems. Taoism is a Chinese philosophy based on the doctrines of Lao-tse that advocate simplicity and selflessness. Confucianism is founded in the ethical teachings of Confucius and emphasizes devotion to parents, family, and friends and the maintenance of peace and justice. Neither “religion” involves attendance at church. Buddhism is a religion and philosophical system that originated in India in the 6th century B.C. Buddhists go to a temple, but not necessarily every day. Many Buddhists go a few times a year, similar to Christians who go to church only at Christmas and Easter. Most Chinese people practice ancestor worship. Pictures of ancestors are kept on tables in the home, and families make offerings to the spirits of the dead. Families also go to cemeteries once a year to give offerings to the ancestors.

Family Values

Family is central to the Chinese way of life. It is the structure that holds everything together and forms the basis of all judgments and decisions. The Chinese family includes not just the nuclear family but the extended family as well. To the Chinese, extended family means not only the uncles, aunts, and cousins but also second and third degree cousins and even more distant relatives. In many cases, people who have the same last name are considered kin. For example, the Tong family believes that all Tongs in the world go back to one ancestor, so that all Tongs today are related in some way. Also, especially among immigrants, there is a sense of family among people who came from the same village. Because China is so large, people who come from the same locality are bound by a geographical kinship.

One key family value is the precedence of family needs over individual needs. Because individuals are relatively unimportant, their needs are considered only in the context of what they mean for the family, the family’s status in society and government, and the country. Individuals’ behaviors are judged in terms of their impact on the family. There is another unique concept in the Chinese culture—the idea of family extending forward and backward in time. Family includes ancestors from a generation ago, two generations ago, and even longer, as well as generations of family to come. Family members are considered to be responsible for past and future generations. Both success and failure reflect on the family. If an individual does something good, it is good for the family; if he does something bad, it is a shame for the entire family. Family members also have a duty to produce a new generation to carry on the family name.

In China, male offspring are more valued than female offspring. They are responsible for carrying on the family name. In particular, the eldest son is expected to provide for his father and mother in their old age. For this reason, having a male child is vital for Chinese families. Even families who already have six daughters will continue to have children, trying to get a male heir. Since the inception of the ‘one child rule,’ however, many girl babies have been abandoned or even killed to make room for a male child. These practices have affected the demographics of China, resulting in many more males than females as well as an overwhelming abundance of female children in the country’s orphanages.
The value placed on boys and girls also affects a family's grief when a baby dies. Because the male is expected to carry on the family name and ensure financial well being for the family, the death of a male child may be considered a greater loss. Thus, the death of an only son may be viewed as more tragic because no one is left to carry on the family name or care for the family elders.

Family Roles and Responsibilities

Chinese parents have complete authority over their children. This principle applies to children of all ages, not just young people. For example, even adult Chinese have to listen to their mothers, who in turn have to listen to their mothers. Outsiders do not have the same authority. In fact, most Chinese people are distrustful of anyone who is not a family member.

The members of a Chinese family have different roles and responsibilities. The father is somewhat distant. He carries the main authority and is in charge of financial matters. He is the primary disciplinarian and is often stern. The mother is the nurturer—she bears the children, raises them, listens to problems, and cares for the sick. Bearing sons is a key role for her. In old times, if a wife did not have sons, her husband could marry a second, third, or fourth wife so he would be assured of having a son. This was considered a good reason to have multiple wives. Chinese sons are responsible for bringing women and children into the family and passing along the family lineage. The oldest son is a role model for younger children. The terms ‘number one son’ and ‘number two son,’ sometimes heard in old movies, indicate the son’s status in the family as well as the birth order. The oldest, ‘number one’ son has more authority and responsibility throughout his life. He becomes the head of the family when the father dies. Daughters are less valued members of the family. They are raised for other families. Historically, daughters were sold to a male’s family and never seen again. Their worth in the family was based on the price they could bring as a bride. This is very traditional thinking, and most Chinese-American families no longer follow these practices.

The Natural Way

Another unique aspect of Chinese culture is belief in the natural way, or acceptance of one’s circumstances. The Chinese believe that people cannot control what happens to them—it is fate and beyond their power to change. Therefore, people must mobilize their thoughts and actions to adapt to the reality of their situation. There is a sense of fatalism, which can interfere with parents’ ability to work through their grief and mobilize actions to resolve problems. If they believe that what happened is their destiny, and it was meant to be, they are not likely to try to change things or believe that any action on their part can produce change. The Taoist philosophy emphasizes the natural way, acceptance of the circumstances and the belief that a certain amount of suffering is to be expected. Chinese people have a very different way of thinking about adversity.

Suppose a Westerner and a Chinese are walking down a road and find their path blocked by a big boulder. The Westerner will try to figure out a way to move the boulder or get rid of it. He may say, “Let’s blow it up.” The Chinese will figure out how to get around the boulder. He accepts that the boulder is in its place and should be left there. The boulder does not have to be changed. Instead, he has to find a way to deal with it.

In this way, the Chinese differ from Westerners in how they respond to life’s challenges. Some things are meant to be, and the individual has to adjust.

Communication

Communication is an important issue in the Chinese culture. There is a stereotype that Chinese people are always smiling, nodding, and bowing. A lot of that perception is based on the fact that Chinese people want to present harmony and avoid confrontations. They don’t want to show emotions, particularly to strangers. Even if two people totally disagree with one another, they might smile and nod their heads. Chinese people tend to hide their feelings to prevent conflict and stress. They don’t want to do something that is embarrassing and cause them to lose face. The idea of ‘face’ and being proud is a strong Chinese tradition. If a Chinese person is asked something he cannot answer, rather than saying, “I don’t know,” he may tell a long story as a distraction or to change the subject. These differences in Chinese communication are important to remember when dealing with grieving parents who do not appear to be communicating their feelings.
Funeral Rites

Funeral rites and burial customs are determined by the age of the deceased, the manner of his/her death, his/her position in society, and his/her marital status. Someone who had 14 grandchildren and 16 great grandchildren, a lot of money, and status in the community must be honored with an appropriate funeral. Chinese funeral processions are characterized by pomp and ceremony. The family puts a picture of the deceased on the car, and the coffin is left wide open. One or more cars are filled with flowers—this is very important. Someone who is prominent in the community should have two or three limousines full of flowers. The procession goes all around Chinatown, for example and then to the home of the deceased to let the spirit back in. It is critical to have an impressive display for someone important. If the funeral is not good enough, ill fortune and disaster will befall the family of the deceased.

The Chinese show particular respect to older people. Funeral rites for an elderly person must convey the reverence befitting that person’s status and age. However, older people do not show respect to younger people. Chinese people believe that children don’t deserve respect because of their youth. They have not contributed or done anything meaningful for the family. Because respect cannot be shown to a younger person, there are no major funeral rites for a baby or child and many people (including family members) will not attend should one be arranged.

Grief and Loss of a Child

A mother’s reaction to the loss of child will vary depending upon the sex of the child, cause of death, and other family circumstances. The loss of a male child is usually considered worse than the loss of female child because the male was to continue the family’s lineage.

The mother must accept that her child’s loss will not be mourned with the same funeral rites and respect given to older people. To make matters worse, she may be blamed for the loss. This will depend upon the circumstances of the death, so it is important to know how the child died. If there was a medical problem, the mother will probably not be held responsible. If the child died in a car accident, however, the mother may be blamed for not protecting him. If there is no explanation about how or why the child died, the death is considered the result of bad luck, bad ancestry, or barrenness. Much of this reaction will depend on how traditional the family is, whether elders are around and the information provided by health care providers.

The Chinese typically look to the family for a support system. However, immigrants may not have family members nearby. Sometimes the father’s family is around but the mother’s is not. In these cases, a mother who is being blamed for the child’s death may not have any support at all.

The grieving process also is affected by traditions concerning the display of feelings. Grief-stricken parents are supposed to suppress their emotions. This can present problems when parents learn of their child’s death in the hospital.

A mother whose baby had just died was distraught and crying loudly. Her husband became embarrassed and told her in Chinese, “Stop! Stop that, don’t do that!” Hospital staff wanted to intervene, but they could not understand what was being said. The parents were obviously upset and seemed to be fighting.

In this example, the staff correctly did not involve security personnel but later were able to find an interpreter to help explain what had happened and offer support.

Service Delivery Issues

One common problem concerns the use of mental health services or bereavement groups by grieving Chinese parents. In China, there are no support groups or mental health services for grieving parents. Individuals requiring mental health services are thought to be ‘crazy’ and institutionalized. The Chinese believe that ‘talk therapy’ does no good and is a waste of time. For this reason, they may not participate in conventional support groups or therapy sessions.

So how can service providers help bereaved Chinese mothers? Most importantly, they need to be very practical and task or goal oriented. The provider might ask the mother to come in and fill out papers for a death certificate or sign a document. When she comes in, the provider can integrate supportive coun-
counseling with the task. While helping her fill out the papers, the provider can casually ask, “How are you doing? How are things at home? Is your mother-in-law supportive? Do you have any friends you can talk to?” The provider can extend the contact by completing only part of the task at each visit. For example, she can ask the mother to make a copy of a certain paper and bring it back another day. This gives the mother a valid reason to return and talk further. Thus, providers have to take an indirect approach to counseling bereaved Chinese mothers.

Summary

The Chinese community is a large and diverse group of people with different backgrounds, traditions, and languages. However, several common threads can be found throughout traditional Chinese families. To the Chinese, family includes past and future generations as well as living relatives. Families revere their elders and ancestors. Individuals’ needs are relatively insignificant, and their behaviors reflect upon the entire family. All family members have certain roles and responsibilities. It is the man’s duty to produce a new generation and continue the family line. For this reason, males are more valued than females. Consequently, the loss of a male child may be considered worse than the loss of a female child.

Service providers face several challenges in providing support to grieving Chinese parents. Their reaction may seem unusual or even inappropriate to Westerners. Several cultural factors may affect the grief response:
- the Chinese belief in the natural way, or fate
- the tendency to hide emotions and avoid behaviors that may cause a loss of face
- the greater value placed on males compared with females
- the lack of funeral rites or respect for children in the Chinese culture
- the possibility of being blamed for the child’s death
- a lack of support by family members
- language barriers
- negative attitudes about mental health counseling services

Recommendations for service providers:

- Do not routinely rely on conventional support groups, bereavement groups, or counseling, for parent support.
- Give the mother a practical reason to visit, such as filling out paperwork.
- Integrate counseling with the completion of a task such as signing papers.
- Extend the task over several visits to give the mother a reason to return and talk some more.

OJIBWE GRIEVING

Adapted from the presentation of Kathleen Headbird

History

Madeline Island is in Lake Superior and is part of a group of islands now called the Apostle Islands. It is not far from the city of Ashland, Wisconsin. Many years ago, my Ojibwe ancestors migrated to this area from their original homeland on the Eastern shores of North America. Now the Ojibwe’s and their offspring are spread from the Atlantic coast, all along the St. Lawrence River, and throughout the Great Lakes region of this country. Madeline Island was the final stopping place on the great migration. This island later became the capital of the Ojibwe nation.

During this migration, the Creator told the Ojibwe people to keep going until they came to where the food grew in the water. This food is wild rice, which has special spiritual significance to the Ojibwe people.

The Ojibwe spread over a vast territory that reached from the northeastern plains of present-day North Dakota across Minnesota, Wisconsin, and Michigan to the forests just east of Lake Superior and Lake Huron. It extended northward into present-day Canada, from central Saskatchewan across Manitoba and Ontario. Much of this region was shared with other tribes, but the Ojibwe became the dominant people and, eventually, one of the largest Native American tribes.

The Ojibwe language is a group of several closely related languages that belong to the large
Algonquian family of languages. This group consists of more than thirty languages spoken throughout North America from the Atlantic coast to the Rocky Mountains. Many Native American tribes speak Algonquian languages, including the Arapaho, Cheyenne, Blackfoot, Fox, Shawnee, Abenaki, and Delaware.

Culture

The Ojibwe were primarily a people of the forest, although some adopted the ways of the Plains tribes after moving into the prairies of North Dakota and Saskatchewan. They believed the land was given to them by Kitche Manitou, the Great Spirit, and it belonged to everyone in the tribe. Like other Native American tribes, the Ojibwe lived according to the cycle of the seasons, providing for themselves with game, fish, wild rice, corn, berries, and other bounty from the forest and fields.

Historically, the Ojibwe referred to themselves as Anishinabe, which means 'original people' in their language. Later, the Europeans called them Chippewa, a name that is still often used today. Although the Ojibwe spoke closely related languages and shared many customs, they were not united around a central government. Instead they lived in bands made up of several families who moved around according to the seasons. During the fall time, they moved to the rice camps. Our people set up their camps on the shores of the rice beds. Also, during the fishing season they moved to the fish camps. The whole village would move and set up the camp. At Leech Lake, we moved to what is called Cedar Point. Cedar was one of the most well known fish camps. During the summer, they set up camp to gather berries, especially blueberries. Women and children usually gathered the berries. The children were taught not to eat any of the berries until the spirits were feasted. During the winter, the band moved back in to the woodlands to find shelter amongst the trees.

Each band had its own leaders who were selected for their wisdom, leadership abilities, and concern for the people. Each person in an Ojibwe band was born into a clan, a kind of extended family, named for a bird, fish, or mammal. Some of the major clans were the Crane, Fish, Loon, Bear, Martin, Deer, and Bird. Each clan had different responsibilities in the community. For example, the Fish clan was usually responsible for resolving conflicts between other clans.

The Ojibwe were patrilineal, which means that family descent, including clan membership, was traced through the father's side of the family. People were not allowed to marry other members of their own clan. The Ojibwe welcomed babies into their lives and cherished their children. However, couples did not have large families; most had about two children. A birth was celebrated with noisy rejoicing in the belief that babies who entered a rowdy world would grow up to be brave. Babies spent their first year of life strapped to a cradleboard. This helped keep the baby's back straight, which was important to the Ojibwe. A hoop across the cradleboard head held toys to amuse the baby and charms to keep him safe.

When Ojibwe people died, they were carefully prepared for the journey to the land of the spirits. They were washed in cedar water and dressed in their best clothes. A small hole was cut in the soles of the babies' moccasins to provide a way for the baby's spirit to leave. The hair was combed and braided and the cheeks painted red. The Ojibwe believed that the northern lights were the dancing spirits with similarly painted faces. Painting the faces of the dead enabled them to join these spirits. The body was wrapped in a blanket and birch bark before being carried from the wigwam. It was buried with the feet pointing west, toward the land of the spirits. Also the coffin is drilled with a hole for young and old alike so the spirit of the deceased can be released. A family member danced as the Mide priest conducted the burial ceremony. Later, the grave was filled with soil. Relatives placed a clan totem and erected a small bark house over the grave. The same funeral rituals were performed for a dead fetus resulting from a miscarriage. If a baby died, the mother carried his or her clothing in a cradleboard for a year.
Changing Way of Life

Although the Ojibwe had engaged in a profitable fur trade with first the French and later the British, by the 1830s their way of life had started to change dramatically. Due to increasing pressure to remove Indians from the Great Lakes region, the Ojibwe and other tribes were forced to move to special lands reserved for them in the United States and Canada. By 1854, the Ojibwas were living on established reservations within their tribal territories and their traditional way of life was further eroded. The allotment of land was not large enough to allow them to continue hunting, fishing, and gathering food in the old ways. They were expected to become farmers, but the condition of the land, short growing season, and lack of machinery made it nearly impossible to farm.

The Ojibwe were further disenfranchised under a policy called allotment, which caused them to lose much of their reservation land. Individual families were assigned small plots of land, and much of the rest was sold to whites. This policy showed complete disregard for the cooperative nature of Indian life, and did not allow for growth among the Indian people. The Ojibwe were pressured to adopt the white way of life. Their wigwams were replaced by permanent housing, and their deerskin garments with non-native clothing. The children were sent to reservation schools run by the government. These schools used only the English language and presented history from an American point of view. Some children were sent to boarding schools far from their homes. They were not allowed to speak in their native language or practice any of their tribal customs. In this process of acculturation, many Ojibwe became isolated and impoverished.

Today, there are many tribal factions resulting from the government policies of displacement and cultural disassociation for native people. Many Native Americans have struggled to maintain ties with their cultural roots. The Anishinabe have come from an oral tradition that relied on their elders to teach new generations about their heritage and clan systems. However, many Anishinabe today do not know the traditional language of the Ojibwe. This makes it difficult to learn about the old ways, which are handed down in the native language. Consequently, there are many disparities among the Ojibwe in their knowledge and practice of their cultural roots. Some have abandoned the old ways entirely and kept the younger ones from learning the language and the teachings. Others fear that if they do not know the language they will not be able to talk to ancestors when they enter the spirit world.

Midewiwin—Grand Medicine Society

The practices of the Midewiwin, or Grand Medicine Society, were central to the Ojibwe way of life. The Ojibwe believed that good health was dependent upon good relations with the spirits. Therefore, the sick and injured must be healed in body, mind, and spirit. Healing was the highest religious calling, and most healers belonged to the Midewiwin. This secret religious society was devoted to the spirits, especially Mide Manitou (the creator), and to safeguarding the knowledge of medicine. Drawing on their expertise with medicinal herbs and a special relationship with the spirits, members of the Midewiwin oversaw the health and well being of the Ojibwe. Their ceremonies were times of sacred song and dance, accompanied by the beating of drums. The songs are the stories being told to the creator. Their teachings were recorded on birch bark scrolls. Both men and women could become members of the Midewiwin if they were respected and trusted members of the tribe. They entered the society by completing several days of intensive instruction followed by an initiation ceremony. Over time, members rose through eight ranks of the Midewiwin, the highest of which was the Great Medicine Spirit. A healer had to achieve at least the fourth level of experience and knowledge before he or she could treat a patient. A Mide bag, or medicine bag, held the herbs, charms, and sacred white shells used in the healing rituals. If someone was sick or injured, family members brought that person to the Midewiwin lodge. The medicine man or woman smoked tobacco offered by the family, then burned sage or cedar to purify the air. Calling for absolute silence, he or she entered into a dream state and called forth the spirits to approve the chosen treatment. The healer also sang and administered remedies from the Mide bag. These practices continue to this day.

As a traditional healer, I belong to the Midewiwin Society. In our culture, healing is a religious call-
ing. I also have had the privilege of naming children since I was 8 years old. My mother had the same gift. By the time she died at age 94, she had taught me many Ojibwe traditions. Because of our standing in the community, families would sometimes leave their children with us. The family was often gone for many days, frequently because of alcoholism. We remained in contact with many of these children even after they became adults. I met one such child years later at the Leech Lake Reservation. She was in treatment for chemical dependency. Upon this meeting, I informed her that I had a name for her, and she gave me tobacco in return. This is the traditional naming approach to seeking knowledge among the Ojibwe.

Grieving Traditions

The Ojibwe way of thinking is different from that of Europeans. Life is viewed as circular, not linear. Ojibwe people believe they come from the Spirit World. At birth, the Creator gives each person a vision and a certain length of time to perform that work (the vision) on mother earth. At death, one is returned to the Spirit World. During the grieving process to help deal with the loss, thoughts return to the vision.

The Ojibwe believe that the Creator gives us children, but not to keep as our own. The children will eventually return back to the Creator, as depicted in the individual’s vision. This may be a short or long time, depending on the vision. The Creator selects a woman to help Him bring the child to the earth. It is an honor to be selected for this task. Ojibwe mothers try to bring the best to the child, so when it is time for breastfeeding they nourish the child with more than just food—they also strengthen the vision that put the child in place by the Creator. The mother talks to the child continually. She wants to give the Ojibwe words and teachings to her child from the very beginning, when the child is still in utero. When she goes to ceremonies and hears the water drum, and when she goes to pow-wows and hears the drum there, her baby is being introduced to sounds which are important to the Ojibwe way of life.

Some Ojibwe traditions are related to the menstrual cycle. In the old days, Ojibwe women were put into a moon lodge during their cycle. This has been modified and now mothers may put their daughters into a bedroom to keep them from all little ones that are growing. For the year after her first cycle, that woman may not gather berries unless another person feeds her berries by hand. A similar custom exists when a loved one dies. When a loved one dies, someone has to feed wild rice and berries to grieving family members.

I was working at the Leech Lake Health Division when my mother died. I asked the nurses to feed me and they fed me blueberries. One of the more traditional nurses, Bernadette, brought into the wild rice to feed me. I gave her my ‘sema’ to help me so that I would not harm the season’s crop or cause other difficulties for the community.

When young Ojibwe women are in the moon lodge they are taught about the woman’s role in the community and the Anishinabe way of life. One important role is protecting the waters. Women are the keepers of the waters because the baby grows in a bag of water. During birth, the water is the first thing to come out, as a sign that women have been given this responsibility by the Creator.

The Ojibwe do not accept autopsies. They believe people must be sent to the Spirit World with all of their vital organs. Even adults who have had an amputation must be buried with the detached limb.

Certain traditions exist for pregnant women. For example, it is taboo for them to view a deceased person, although the decision is ultimately up to the individual. Instead, pregnant women can help in the kitchen or speak to the bereaved and offer them assistance. In this way, they can participate without viewing the deceased. The belief is that something bad will happen to the fetus if the mother views a dead person.

The loss of a child affects the whole family, which includes extended kin and clan members in the Ojibwe culture. The traditional attitude is that the baby will go back to the Creator. This is a comfort to some families. It is considered to be the circle of life. This circle is represented in the Four Sacred Hills of Life: infancy, adolescence, adulthood, and, finally, old age.

A man whose legs had been amputated asked me to help him get the legs from the hospital. When
the hospital notified me that they had completed all necessary tests, I called him to let him know. He said, “I’m drinking today—I can’t do the ceremony,” so I said, “Alright, I’ll give you some more time.” Then I called the hospital and told them I needed a little more time. A few days later, I got back to the patient, who again said, “I can’t do it, I’m drinking today.” I said, “Well, I have to go and get your legs now.” I put his legs in my freezer that I had outside and let him know what I planned to do. I said, “I’m going to have my husband assist me to make your legs and put them where you instructed, by your grandparents’ grave.” He said, “Well, I want you to do it this way. I want you to wrap them in blue cloth, not red, and I want you to tie them with a yellow, white, and blue ribbon.” And so I did that, but he did not come with me to the cemetery when I put them in the ground.

A few years later, he died. A nurse remembered I helped him and called. The family was planning the funeral and needed to know where he wanted to be buried. I said that I knew the spot. However, we had a hard time finding the old burial ground because it was all covered with trees that had fallen down and graves that were sinking in. The burial ground was not well maintained like modern cemeteries because of Midewiwin traditions. We put little houses over our gravesites so we can leave food offerings for the dead. We bring ‘asema’ and anything else the person enjoyed in life to the little house. The house is never redone when it starts to fall down. We always let it go back to the earth. I was able to find where the legs had been buried, and they put the man’s grave as close as they could to that spot.

When an infant dies of SIDS, an autopsy is done. Even though the Ojibwe do not approve of this procedure, it is usually required by law. Still, families want to know why their baby died, and they can be assured that the autopsy will help answer those questions. But in most cases the families believe that nothing can bring their loved one back to this earth, that it was their time to go to the spirit world. It may be easier for the family if they can spend time with the baby first. They should be encouraged to come to the hospital and sit a while with the baby before the autopsy is done. In one case where the autopsy was done before the family could spend time with the baby, they had a very difficult time with the grieving process.

I learned about our customs and traditions from my mother. I would say, “Mom, if you go before me, would it be all right if I do this or do that,” and so forth. And she’d tell me what was appropriate. Because she always chewed Copenhagen, I said, “Mom, I’m going to put a beaded bag in with you when you die, and I’ll put your snuff in there so you have enough to share with the ancestors.” My mother had a sense of humor and said she would not be sharing her snuff with anyone. I reassured her that she would have more than enough to share with the ancestors. When I buried her I put all of her snuff in the beaded bag.

Anishinabe people do not bring flowers to funerals. If flowers are used, it is by Ojibwe who have become Christian. An elderly man once said that flowers are not taken because they will weigh you down on your journey to the spirit world. The custom is to talk with the individual and determine their wishes about the burial. Ask the person what he or she would like to take with them to the spirit world.

My mother did not want to wear any medals or jewelry. She also did not want new things because she feared the ancestors would not recognize her. At the mortuary I told her, “You are really an Anishinabe—you look very Anishinabe.” I did get her a new Pendleton coat. My friend who was going to make the coat was with me at the mortuary. I said, “Mom, we are going to measure you now so my friend can make you a new coat.” And that’s what we did.

The Ojibwa believe that there is a purpose for everything in this world. Even if one is only briefly on earth, there is a reason. One young Ojibwe mother lost a baby at only 19 weeks of gestation. She wanted to see her baby and attend to him before he was taken away. She talked to his spirit and told him how important it was that he had come into the world. In the Ojibwe culture, even this tiny infant had a role, perhaps as a teacher, for the community.
One time I talked to another Anishinabe woman when I was going through a hard time. I told her that I didn't know what I was to do for my community. She stated that she stopped asking the Creator that question because he took her son. Her son was killed in a car accident due to drunken driving. He was a young person. At the wake, there were many young people sitting by his side. He was teaching them what alcohol and drugs can do to the community. “Now I no longer ask what I can do for my community. I just use my 'asema' and every day I say thank you because now I know what I have to do for my community.”

Ojibwe believe that everything is connected and that we go back to the earth. Ceremonies include coping strategies. The Ojibwe do not cry around a dead baby or person. They believe that if tears fall on the baby, even though he is dead, tears will come out of him, too. The Ojibwe are told to be strong. If you must cry, go cry by a tree or by a rock. Drinking is prohibited for one year after death because bad habits started at that time will last the rest of your life.

The Ojibwe approach to dealing with death varies depending on their way of life. Grief workers in an Ojibwe home will observe many different customs. They should just listen and not talk too much because that talk might be irritating. Encourage the bereaved family to talk about the deceased loved one.

Teamwork is a good approach when working with Ojibwe families. I have often worked with a non-Ojibwe nurse. When we go into a home, I go as the traditional healer but she takes the lead. I tell the family, “The nurse is coming to do the well baby check, and I'm here if you need me.” I work for awhile with my pipe and tobacco, and then I just sit back and watch her interact with the family. So, if you know individuals who are from the Ojibwe community, you should work with them to gain their trust. After you work together for a while as a team, the people will come to know you and eventually you can visit families independently and be accepted by the Ojibwe people.

When my mother died, I got a little memorial card from the hospice people. It talked about a ship that is sailing. This ship, called Out of My Sight, is strong and able to get to its port. On its way, it goes into the clouds and cannot be seen for a while. Then a voice says, “Here she comes.” This is how the Ojibwe look at dying—as a return to the spirit world. That card helped me so much when I was grieving. My mother never had a car and always traveled by boat, so I adapted this message for her memorial card. It showed a boat with a small motor arriving at a dock, representing her journey to the spirit world. And so, with that I say, “Good luck to you in your interaction with the Anishinabe people.”
CONCLUSION

Professionals providing grief support and completing a FIMR interview have the unique opportunity to support and validate the family's grief experience. While emotionally challenging, it is greatly appreciated by families that their baby's life and death is acknowledged.

As our country's diversity expands, it is essential that providers learn the culture of the families they serve. Providing grief support is not an intuitive process. Cultural beliefs may be in direct opposition to the provider's beliefs. Provider knowledge is needed to provide culturally competent care.

There is much to learn about cultures and individual responses to infant death. It can be rewarding and a true service to a family. The challenge is to learn and respect a family's culture. We can ask a family what would be helpful, listen, and provide requested support.
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. She has served on various ASIP committees since 1987 while working as counseling coordinator and then director of the Center for Infant and Child Loss, University of Maryland School of Medicine, Baltimore. She is an Assistant Professor at the University of Maryland School of Medicine Department of Pediatrics. She is founder and principal of Health Care Answers, a company that is committed to assisting individuals navigate the health care system and providing consultative services.

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 Ms. Headbird works as a traditional healer for the Leech Lake Health Department. She has provided chemical dependency counseling and completed her BS in Native American Studies with a minor in the Ojibwe language. She will be working for her Master's Degree in indigenous knowledge/philosophy. Her thesis is on the spiritual resilience of the Anishinaabe people. She believes her people have survived because of their spiritual strength and connectedness to the earth, Mother earth. Living in harmony with all living things is the reason they have survived throughout these years.

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 Ms. Longchamp has also worked extensively on city-wide projects to reduce infant mortality for over two decades where she acquired rich experience in working with families from diverse cultural backgrounds. In 1990, she received the Maternal Child Health Nurse of the Year award from the Greater New York March of Dimes. She is a member of national and local cultural diversity panels.

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

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 Ms. Tong was raised in New York City's Chinatown community. She was the former Assistant Executive Director of the Chinatown Health Clinic and has served on the Governor's Health Care Advisory Board, the Mayor's Child Health Advisory Board and HHC's Blue Ribbon Panel on Women's Health and currently serves on the Executive Advisory Committee for the Center for Immigrant Health. She currently develops programs for immigrant populations for the ambulatory care network and inpatient service.

The panelists are available for consultation.
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 Kathleen Fernbach, ASIP President, Minnesota SIDS Center, Children's Hospitals and Clinic, 2525 Chicago Ave South, Minneapolis, MN 55404, 612-813-6285 or www.asip1.org.

**Cross Cultural Health Care Program (CCHCP)** Through a combination of cultural competency trainings, interpreter trainings, research projects, community coalition building, and other services, the CCHCP serves as a bridge between communities and health care institutions to ensure full access to quality health care that is culturally and linguistically appropriate. Contact: CCHP 2821 Beacon Ave. So, Seattle, WA 98144, (206)860-0329 or www.xculture.org.

**Diversity Rx** promotes language and cultural competence to improve the quality of health care for minority, immigrant, and ethnically diverse communities. Its annual meetings focus on these issues. It is also a WEB based clearinghouse of information about meeting the language and cultural needs of diverse populations seeking health care. Contact: Resources for Cross Cultural Health Care, 27 Aspen Circle, Albany, NY 12208, 518-435-1972 or www.diversityrx.org.

**March of Dimes** researchers, volunteers, educators, outreach workers and advocates work together to give all babies a fighting chance against the threats to their health: prematurity, birth defects, low birthweight. Health promotion and bereavement materials are available in English and Spanish. Contact 1-888-MODIMES (663-4637), March of Dimes Birth Defects Foundation, 1275 Mamaroneck Ave., White Plains, NY 10605 or www.modimes.org.

**The National Center for Cultural Competence**'s mission is to increase the capacity of health care programs to design, implement and evaluate culturally and linguistically competent service delivery systems. Contact: National Center for Cultural Competence, Georgetown University Center for Child and Human Development, 3307 M Street, NW, Suite 401, Washington, DC 20007-3935, 800/788-2066 or http://www.georgetown.edu/research/gucdc/nccc/.

**National Center for Education in Maternal and Child Health (NCEMCH)** has an MCH library database can be searched for minority health organizations. The web address and a brief description of the organization are included with both public and private organizations listed. Some web sites included are Indian Health Services, Asian Health Services Online, National Coalition of Hispanic Health and Human Service Organizations and Coalition of Hispanic and Human Service Organizations. Contact: NCEMCH, 2000 15th St., North, Suite 701, Arlington, VA 22201, 703-524-7802 or www.ncemch.org.

**The National Health Law Program (NHLP)** works for justice in healthcare for low-income people. It has many publications and links to resources. Offices are located in Los Angeles and Oakland California, Washington, DC and Chapel Hill, North Carolina. Contact: www.healthlaw.org or (310) 204-6010.

**National Healthy Mothers/Healthy Babies Coalition** is a recognized leader and resource in maternal and child health. Its mission is to improve the health and safety of mothers, babies and families through education and collaborative partnerships of public and private organizations. Contact: National Healthy Mothers, Healthy Babies Coalition, 121 North Washington St., Suite 300, Alexandria, VA 22314, 703-836-6110 or www.hmhb.org.

**Office of Minority Health's (OMH)** mission is to improve the health of racial and ethnic populations through the development of effective health policies and programs that help to eliminate disparities in health. OMH advises the Secretary and the Office of Public Health and Science (OPHS) on public health issues affecting American Indians and Alaska Natives, Asian Americans, Native Hawaiians and Other Pacific Islanders, Blacks/African Americans, and Hispanics/Latinos. Contact: Office of Minority Health Resource Center, P.O. Box 37337, Washington, D.C. 20013-7337, 800-444-6472 or http://www.omhrc.gov/.
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