

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

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INTRODUCTION

This bulletin summarizes a panel presentation from the **National Fetal and Infant Mortality Review Program's Fifth National Conference**, held August 12–14, 2004 in Washington, D.C. It explores the cultural traditions of Hmong, African American, and Jewish families grieving the loss of an infant. The Bulletin is the third in a series focused on cross-cultural grief and loss. The introduction contains an updated review of the literature on grief and loss.

Readers are encouraged to review the two previous NFIMR bulletins. *Cross Cultural Expressions of Grief and Loss II: When an Infant Dies* (2003) addresses changing U.S. demographics and presents perspectives on loss during pregnancy and infancy from the African American, French and English Caribbean, Hispanic/Latino, Chinese, and Ojibwa cultures. *When an Infant Dies: Cross Cultural Expressions of Grief and Loss* (1999) provides insights on the customs and values affecting expressions of grief in Latino, Native American, African American, and Muslim populations. These documents can be accessed on line at www.nfimr.org. Hard copies are available by writing to NFIMR at 409 12th Street SW, Washington, DC 20024.

It is evident that there are similarities and differences in the grieving process for families from different ethnic and cultural

backgrounds. There are significant variations even within a particular population. Broadly defined groups such as Arab Americans and African Americans encompass people of considerable diversity in nationality, religion, history, culture, and politics. Members of more narrowly defined groups such as the Hmong and Jews still differ in important ways such as level of assimilation into the majority culture, religious conventions, and national heritage. Service providers are challenged to assimilate both the cultural and personal aspects of each family to understand their unique experience. There is no 'magic formula' or 'cookbook' for working successfully with families of different cultures. The best approach is perhaps the simplest—ask family members, "How can I help you?" and then listen carefully to their answers. Each bereaved mother, father, and family member may have different needs. Learning how these needs may be shaped by cultural traditions and values can help providers avoid being judgmental and determine how to provide the most effective, respectful support in each case.

Effective support of families who have suffered a fetal or infant loss begins with a self-assessment of one's own cultural background as well as one's knowledge of and attitudes toward other cultures. It is important to note that every person views different cultures



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This third Bulletin summarizes a panel presentation at the National Fetal and Infant Mortality Review Program National Conference August 12–14, 2004 in Washington, DC. The panel and this Bulletin were produced in partnership with the Association of SIDS and Infant Mortality Programs. NFIMR gratefully acknowledges their contribution to the development of this topic.

through their own cultural lenses, and this view may affect their ability to provide competent care for families whose backgrounds differ. The National Center for Cultural Competence, Georgetown University Center for Child Health and Human Development provides tools for self-assessment at (<http://gucchd.georgetown.edu/nccc/selfassessment.html>). A self-assessment checklist specific for SIDS and infant death is available on the website.

Recent Studies of Grief

Most studies of parental grief following a perinatal loss or infant death are descriptive and include qualitative analysis of the grief experience. Research on the effectiveness of any form of support following an infant death has been neglected (Changers and Chan, 2003). Forte, Hill, Pazder and Feudtner (2004), in their systematic review of all bereavement care interventions, evaluated 74 studies of interventions designed to ameliorate a variety of outcomes associated with bereavement. Other than pharmacological treatment of bereavement related depression, no consistent pattern of treatment benefit was identified. Randomized studies of treatment models are very challenging because of potential ethical problems arising from the assignment of participants to a control or comparison group.

Qualitative research avoids this methodological and ethical dilemma. It is often used to examine the grief process. This approach allows participants to share their very personal and unique perspectives in

their own words. The benefits from this approach are twofold: 1) families may receive possible therapeutic help, and 2) families may impart valuable insights into the coping and recovery process for other bereaved parents. Still, there remains a paucity of literature documenting minority families' experiences following infant death. Because of the limited research in this area, practitioners typically rely on their professional expertise and personal insights to guide their approaches to intervention.

Davies' (2004) literature review traces how theoretical perspectives of parental grief have changed in the last century. The literature is focused on Anglo-American cultural perspective and starts with Freud's analytic tradition that emphasizes breaking bonds with the deceased, or 'letting go.' This approach is the basis of traditional models of the grief process and tasks of grief.

Rando (1992) points out that the traditional criteria for abnormal grief are normal components of parental grief. For parents, attempting to 'let go' of the dead child may not be possible or therapeutic. Furthermore, qualitative studies reveal that an enduring bond is a common phenomenon among parents learning to live with the death of their child. Newer models of parental grief include continuing attachment as an integral part of process of honoring and remembering the dead child.

In Lamb's (2002) review of the literature, she identified four recurring themes related to pregnancy following the death of a child: the effects of grief on the

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subsequent pregnancy, the notion of a replacement child, parenting issues with the subsequent child, and coping mechanisms during the subsequent pregnancy. Similarly, Cote-Arsenault, Bidlack, and Humm (2001) examined the experiences of 73 women participating in two hospital-based pregnancy-after-loss support groups. The women completed a mailed survey with open-ended questions about their emotions and concerns during the post-loss pregnancy. Content analysis of their responses revealed that the most frequently used descriptor was 'anxious,' followed by 'scared' and 'nervous.' During the post-loss pregnancy, the mothers' top five concerns were losing another baby, the overall health of the new baby, their own emotional stability, the impact of another loss on their future, and the lack support by others.

DiMarco, Menke, and McNamara (2001) examined differences in grief reactions among parents who had used or not used a support group following the loss of an infant. A convenience sample was obtained from a mail survey sent to parents who were receiving a perinatal loss newsletter. The survey was completed by 121 parents (32% return rate). The time since loss ranged from 1 month to 13 years. Sixty-seven of the parents had attended at least one support group meeting and 54 had not attended any meetings. There was no significant difference between the two groups on a quantitative measure of grief, the Hogan Grief Reaction Checklist. However, qualitative responses indicated that the support group was helpful to those who had attended. All parents reported that crying with family, being with their own parent, having someone listen to them, having baby pictures, and assigning meaning to the death were the most helpful supports. Least helpful were being told not to cry, not acknowledging the death, making light of the death, and being told that the death was for the best.

The two studies just cited and many others on the grief experience use data from parent support groups. However, it is important to note that these groups may not reflect the perspectives of different racial/ethnic groups. There is some evidence that support group attendance rates are highest for middle class white families. In the study by DiMarco and colleagues comparing grief responses among parents who attended and did not attend support groups, a

substantially larger proportion of white respondents were support groups users (62%) compared with black respondents (29%). Minorities may face cultural, social, or economic barriers to seeking help from health services providers, or they may already be getting the support they need from their own families or ethnic communities. It is difficult to draw conclusions since there has been little research into service utilization by bereaved families from different ethnic and cultural backgrounds. Providers are advised to interpret data from parent support groups with caution as they may not generalize to minorities or other ethnic/cultural groups.

Recent studies provide some information on the grief experience of families from different cultures. Van (2001) reports that the initial grief experience of African American women is similar to what is described in the grief literature. The coping strategies are varied for African American women. Kavanaugh and Hershberger (2005) examined the lived experience of low-income African American parents, focusing on the unique stressors affecting these families. They found that stressors such as the death of a close family member and undesirable employment occur before, during, and/or after the pregnancy loss. The stressors contributed to women's reported difficulty identifying or responding to symptoms of pregnancy complications. Some mothers and fathers described feelings of racism from the medical system. Parents also reported not understanding all the burial options offered.

Van and Meleis (2003) used a grounded theory approach to describe coping strategies of African American women following their perinatal loss. Twenty adult women were interviewed within three years of the loss. Women report using inner resources to develop self-help strategies to cope with the loss. Religion and spirituality were extremely valuable to these women. The authors challenge nurses to harness the influence of family, friends, religion, and cultural traditions to assist women in processing the trauma.

Lundqvist, Nilstun, and Dykes (2002) examined the influence of health care providers in a different population. Their phenomenological study of Swedish mothers following an infant death revealed that health care providers had a major impact on the mothers' feelings of empowerment. Caring providers

facilitated feelings of empowerment whereas providers who did not provide humane care were associated with maternal feelings of powerlessness.

The ethnographic study by Hsu, Tseng, Banks, Kuo et al (2004) explored Taiwanese mothers' interpretations of stillbirth within their unique sociocultural context. Twenty women with a pregnancy loss at 20 weeks or greater were interviewed. The major themes that emerged included a loss of control, broken dreams, shattered self, and the feeling that 'something is wrong with me.' The Taiwanese women also reported a sense of personal failure in maternal identity and the female cultural role. Talking about the death and expressing grief are some of the culturally-bound taboos in this population. The authors recommend that nurses talk with the mothers to help them deal with the death. However, knowledge of their cultural beliefs is necessary to effectively support these mothers.

Hutti (2005) reviewed the literature on perinatal loss and offered innovative recommendations for nursing care following the loss. The first recommendation is that providers make an effort to understand the personal meaning or significance of the loss to the parents. For some parents, an early miscarriage is as traumatic as an infant death. The parent's perception of the loss is important for the health care provider to know. Second, providers should assist parents in evaluating whether their experience was consistent with the existing standard of care. A parent's perception that care was sub-standard can result in feelings of anger or victimization. Finally, staff should assess the parent's ability to be assertive and confront others when they are unhappy with the way the loss experience is unfolding. This is important not only to ensure that parents' needs will be met but also to inform staff and family members of what is helpful during the loss experience. Hutti concludes by suggesting that health providers individualize care with effective social and professional support that matches the parents' needs and preferences.

Panel Overview

This bulletin is designed to help providers become more effective by lending insights into the grief response of families from a variety of cultures.

The papers are from a panel presentation on the grieving traditions of Hmong, Jewish, and African American cultures. Each panelist describes her experience professionally and/or personally in working with bereaved families.

Hmong

Nancy Vang provides an insightful account of the Hmong culture and grieving traditions. The Hmong are an Asian ethnic minority people who originated in China. Currently, there are an estimated 12 million Hmong in the world, including about 300,000 in the United States. The Hmong in this country initially came as refugees from Laos, but about 40% of those in the United States today were born here. Ms. Vang includes specific tips to help providers show respect and sensitivity to Hmong traditions.

Jewish

Bronya Shaffer describes the grieving traditions of Jewish families. Jewish law sets forth specific procedures for dealing with death and mourning, including the death of a fetus or infant. Mrs. Shaffer recommends that service providers pay a 'shiva call' to let family members know they are available to help. She also suggests resources that health care providers and Jewish families can use to answer questions about religious law in the areas of death and mourning, and to get legal opinions on controversial issues such as organ donation. She includes a case study highlighting some of the service issues that may arise in reaching out to Hasidic families.

African American

Khadijah Matin presents the African American perspective. She discusses historical and cultural influences on the individual's grief response, utilization of resources, and feelings toward service providers. She also explores the role of personal and family traits, religion, and knowledge. Reverend Matin recommends that service providers work with culturally/ethnically organized groups to learn about their values and practices and exchange information and concerns with colleagues.

HMONG BELIEFS AND TRADITIONS

Based on a presentation by Nancy L Vang

The Hmong People and Culture

The word 'Hmong' is an ethnic tradition, rather than a race or national origin. There is an estimated 12 million Hmong in the world. About 9.7 million live in mainland China, 1.2 million in Vietnam, 400,000 in Laos, 300,000 in Thailand, 300,000 in the United States, and 100,000 in Burma (Lao Human Rights Council, 2000). There is a substantial Hmong population in France as well. Until recently, most Hmong people lived in the mountains of Southern China, Laos, Thailand and Northern Vietnam. The Hmong people in the US mainly came as refugees from Laos. The Asian Hmong culture is agrarian with religious beliefs based in animism including the use of shamans for guidance, healing and other ceremonies.

The Hmong of Laos carried out U.S. military objectives in Southeast Asia from the 1950's through the 1970's. Once the United States pulled out of Vietnam, the North Vietnamese and the Communist government in Laos marked the Hmong for genocide. Many died or fled to the United States or refugee camps in Thailand. Starting in 1991, Thailand started a forced repatriation of the Hmong from their refugee camps back to Laos, where atrocious human rights abuses continued. Some of these Hmong refugees were able to emigrate to the US. In December 2003, the United States State Department agreed to resettle up to 15,500 Hmong from Thailand's last refugee camp. The largest number went to California and the second largest to Minnesota, which already had an established Hmong population.

While in the refugee camps, the Hmong began to learn the ways of an industrial society and new languages. The reality of living in the United States caused the Hmong to retain some and leave other traditions. The Hmong American generally have a positive view of their new country, and the younger generation tend to understand both cultures. About 40% of the Hmong in the United States were born here. The proportion of Hmong with personal memories of Laos is decreasing rapidly. Many have converted to Christianity and Hmong customs may not be practices in this group.

This bulletin will focus on traditional customs as practiced by Hmong today. For example, language is a great barrier to the elderly, many of whom could not read or write prior to coming to the United States. The handshake is a new concept to traditional Hmong people, especially for women. Traditional Hmong usually do not shake hands, greeting is verbal. Many Hmong women feel embarrassed shaking hands with a male or if the hand is held too tightly. (See Table 1 for more general etiquette for interacting with Hmong)

Tribes, Language, Clans, and Social Structure

Within the Hmong population there are various tribes or subgroups such as the White Hmong, Black Hmong, Flowery Hmong, Red Hmong, Blue or Green Hmong, and Striped Hmong. According to Hmong legend, these tribes were developed by ancient Chinese conquerors who forced the Hmong to divide into different groups and to identify themselves by wearing distinctive colors of clothes.

The language is called Hmoob (Hmong in English). It has many dialects. This language is tonal and related to the Sino-Tibetan language family. There are many dialects, including the Striped Hmong, Green or Blue Hmong and White Hmong. The dialects are mutually intelligible but differ considerably. The Hmong language, folktales, and traditions were passed down through generations by word of mouth for thousands of years. The Hmong language was not written down until the late 20th century. However, many Hmong still cannot read or write in their native language. Most Hmong in the United States speak White or Green Hmong. Older Hmong sometimes communicate by using metaphors. It is important to validate the information and ask if the information is understood.

Hmong people are organized into clans. There are 18 Clans all together, differentiated by family name. These names include Cha/Chang, Cheng, Chue/Chu, Fang, Hang, Her/Heu, Khang, Kong, Kue, Lee/Ly/Louie, Lor/Lo/Lao, Moua, Pha, Thao/

Thor/Thoj, Vang, Vu/Vue, Xiong, and Yang. Some of these are very popular and some of them are not, but when you hear one of these family names, you know the person might be Hmong. Clans are determined by ancestral lineage and the traditional ceremonies they practice. Families in the same Clan have the same ancestor and practice the same ceremonies to remember their ancestors. Clan leaders play an important role in the Hmong community. Decision-making is a collaboration between the head of household and the clan leaders. Clan leaders help the family when there is a problem, such as illness or death. When there is a death, the family feels lost, numb—they don't know what to do. The Clan leader will help to plan and organize the funeral, so it's not so overwhelming for the family. Many clan elders are gradually being replaced by younger leaders who are well-educated and fluent in English.

Religion, Marriage, Family, and Children

The traditional Hmong **religion** consists of ancestor worship and animism, both beliefs that the spiritual world co-exists with the physical world. Hmong believe that the spirits of the ancestors continue to influence the daily lives and welfare of their descendants, who in return continue to offer foods and observe the proper rituals to ensure that the ancestors are remembered and worshipped. The spiritual world is also believed to be inhabited by a wide variety of over spirits, many of which can influence the course of human life. These include house spirits, spirits residing in doors or other inanimate objects, spirits in nature as well as evil spirits. If someone offends one of the spirits, it can place a curse on the person, causing illness and even death.

In fact, US medical and social scientists have describe an “ethno-medical pathogenesis” in which hundreds of Hmong men have died from a cause know as sudden unexpected nocturnal death syndrome (SUND). The Hmong believe that an evil pressing spirit (*dab tsong*) comes for them in the night and paralyzes them, leading to death. Scientists say that the power of the Hmong belief in the evil

spirit is so strong, it may cause overwhelming fear and stress that actually leads to death.

To counteract evil or unhappy spirits, the Shaman is as a mediator between the visible world and an invisible spirit world and practices spiritual diagnosis and healing. Because ordinary humans cannot see the spirit world, Hmong use the Shaman to connect the real world to the supernatural. Common causes of illnesses that the shaman treats are 1) the soul wandering from the body lost because of injury, a loud noise, being unconscious, including anesthesia or feeling depressed which may be cured by a soul calling ceremony; or 2) hostile spirits, spells or violation of taboos which may be cured by an animal sacrifice.

The Hmong do believe in the sacrifice of animals, including chickens, pigs or cows to the spirits. The purpose of sacrifice is to protect a person from further harm or to have the animal's spirit take the place of sick person's spirit. Blood from the animal or amulets with parts of the animal (teeth, claws) may be attached in the person's clothing and should not be removed. Many Hmong are Christians and it is difficult to balance a modern world with traditional beliefs in the spirits.

Traditional Hmong belief holds that a person has several souls, usually three or four. When a person dies, one soul goes to heaven, one stays with the body and one is reincarnated. Sometimes one of the souls becomes separated from the person and needs to be recalled with a spirit calling ceremony. The Hmong believe that when a man dies he is reborn as a woman and when a woman dies she is reborn as a man, if she had fulfilled her childbearing destiny in this lifetime.

The souls of the dead live in the world of the supernatural. These spirits decide just how long a person will live on earth. When that time runs out, the person will die. These same spirits are also the souls of the Hmong people still waiting to be born. Someday these souls will reenter the earth in a new body.

Members of the same clan are not allowed to **marry**. Men and women with different last names may marry, even if they are first cousins. Young people meet potential mates at the New Year's

festival. Men generally marry between ages 18–30 years. Women often marry between 14–18 years. Hmong Americans believe that women should not marry until 18 years of age. Negotiations to arrange a marriage are common among Hmong Americans. The husband is considered the head of household and makes decision in consultation with clan elders. Women wield a great deal of power in the family since they are seen as having primary responsibility for the household. As chief care-givers for children, they can be extremely influential in their communities.

In the Hmong culture, the husband is the **head of household** and, traditionally, he is the one who makes decisions and is responsible for performing family religious requirements. The Hmong do not respect women less, but believe that one person should have the power to decide. Today, more and more mothers are becoming leaders in their community and make decisions, too. In younger families, both the father and mother make decisions. Hmong mothers nurture and take care of the children, and are responsible for the household. Although men usually make the health care decisions, they will ask the mother for advice because the mother often knows more about their children's conditions. Also, the mother will often be the one to talk with the health care provider.

Every **child** born is seen as a reincarnated soul in the Hmong people. After waiting until the infant has lived for 3 days, a Shaman evokes the soul to be reincarnated in the baby's body. At this time, the baby is also given a name. After identifying the baby by that name, the Shaman will call upon the ancestor to join the living, blessing and protecting the baby. Then the baby is given a silver necklace or a cloth necklace to keep the newly reincarnated soul from wandering around. Because this is an old tradition, Hmong people who are trying to adjust to the modern world may no longer follow it, but most people still do.

After delivery, the mother has to stay in her house for 30 days. She eats special food usually rice and fresh chicken and only hot liquids. She can only visit members of the same Clan or her husband's relatives. A woman in the postpartum

period is considered to be unclean and so is unwelcome to other Clans. This is because of the Hmong belief in the spirit world—the Hmong people themselves may not care about this, but the spirit world would be unhappy if new mother visited in the 30 days after giving birth. This might cause bad luck for the family or the woman.

Hmong families are 'child-centered' places where small children are regarded as treasures. Sons are valued more than daughters because they carry on the family name. The eldest son has a duty to perform the ancestor worship in the home. Gender segregation is common in social interactions. Parents are expected to exercise a high degree of control over their children and their future, as well. This may be in conflict with American beliefs about personal freedom and Hmong teen runaways have been a major problem among Hmong and Southeast Asia refugee groups.

Other Health Practices

Traditional Hmong methods for healing are not only based on shamanism, but also include use of ritual health practices and herbal medicine. Acupuncture and acupressure may also be used. Shamanistic health practices stem from the belief that illness is essentially spiritual in nature. The chief cause of illness is believed due to the loss of one's spirit or soul; illness can also result from natural causes. Fear, loneliness, separation from loved ones, and other emotional stresses can rip the soul away from the body.

In less serious illness, parents or other family members may perform rituals needed, e.g., if a baby cries in the night, an adult family member may go to the door and swing a burning stick back and forth to light the way for the baby's soul to return. The 'Soul-caller,' who could be a family elder or a shaman, is one of the most important roles of traditional Hmong health care experts.

Hmong have specific healing practices that have been misunderstood and misdiagnosed in western cultures as child or spousal abuse. These include the following:

- ▶ **Cupping:** cotton or tissue is burned in a small glass jar. After the flame is out, the jar is placed

over painful area and remains until air within the jar has cooled, producing a vacuum and a round ecchymotic area. The purpose of cupping is to equalize body imbalances and/or to draw out evil spirits that may be causing illness. This practice is also used among other Asians, Latin Americans and some Europeans and is generally used only on adults.

- ▶ **Coining/coin rubbing:** using a spoon or coin with a balm or salve, the skin over the affected area is rubbed and stroked lightly until an ecchymotic area appears, an oval bruise with an irregular border. The purpose of the coining is to draw out the illness from the body. Coining is done to treat such illnesses as colds, vomiting, headache, other sources of pain and seizures. This technique may be used with both children and adults. This practice is also common among many Asian cultures.
- ▶ **Pinching:** skin is pinched over a symptomatic area, causing an ecchymotic area. Commonly a pin or sewing needle is then used to prick that area. The purpose of pinching/pricking is to remove the toxin causing the illness. Some minor illnesses treated by this procedure include local pain, fever, coughs and fainting. This treatment is used with children and adults. The practice is also common among some other Asian cultures.

Death and Funerals

One distinctive set of Hmong rituals are those related to death. Some American funeral homes are now making it possible for these customs to be observed. A Hmong person has to be given elaborate funeral rites, otherwise the soul of the dead person is believed to remain in limbo, unable to join the ancestors in the other world or to be born again. For this reason, all the important steps of a proper Hmong funeral have to be observed. Four different reed pipe ritual music/songs must be played: showing the way chanting, last breath reed music, helping the person mount the horse for the heavenward journey, and raising the body to get it on its way to the spirit world just before burial. Depending on the age and importance of the deceased, many animal sacrifices may also be

offered. The deceased should be buried in traditional Hmong clothes, not western clothes.

Hmong who follow traditional religious views believe that **death** is merely a phase people go through when passing from this plane of existence to the next. Because life is considered a continuous journey, death is a part of life, not the end of it. People are destined to live to a certain age, and when that age is reached, Hmong understand it is time for the person to depart. However, the spirit will reincarnate in a new baby.

The Hmong do not talk about death; this is one reason it stays in their hearts for so long. Death is not discussed because of the belief that spirits are all around, and if death is discussed, the spirits will hear it. The spirits will make other relatives sick and they'll cause more death in the family. This belief has been part of the culture for so long that it's hard to eliminate it.

If a baby dies within three days after birth, no funeral is held for that baby. This is because the Hmong believe a baby has no soul until it is three days old, when the shaman invokes a soul calling ceremony so that a soul can be reincarnated into its body. American clinicians may have trouble dealing with this Hmong custom. They do not understand when a young couple whose baby has died says, "You do whatever you have to with it."

One family that I worked with told the social worker, "You cremate the baby—do whatever you need to—we don't have anything to do with it." I don't know how parents can grieve in that situation. I think all they do is be silent and let time heal them.

The death of a son is considered a greater loss. It is the traditional Hmong belief that when a male dies, he is reborn as a woman and when a woman dies she is reborn as a man if she has fulfilled her childbearing destiny in this lifetime.

My Personal Story

I would like to share with you a little bit about my own life experience.

I never knew my father and was told by my Mom that he passed away when I was a baby, same as my Grandma. I never knew what they looked like or who

they are. There were no pictures, either. So, it's hard to imagine, but when I was around 14 years old I had a baby myself. No clinicians, no doctors to help me. I had the baby by myself.

At the age of 14, I suffered a great deal because my very first baby died when he was five months old. I felt it was my fault—I was too young and did not know. When my baby got sick, we went to the hospital in a bigger town—it was a long trip in taxi. On the first evening there, my baby looked different to me. I went to the nurse—she was Thai—and asked her to take a look at the baby. She said, “Your baby is already dead. I cannot help you. You waited too long to bring your baby in.” She sounded like she was blaming me for it. I felt so bad already. I remember feeling like I was floating—I could not cling on to anything. So this baby's death was devastating. I looked at the clinicians in the hospital, the families there, and everyone look like mannequins to me, because no one understood me. No one could bring my baby back. Although it has been 25 years, I can still recall these feelings.

My advice to clinicians is that if you don't know what to say, just give the patient and family a little time. Some general guidelines for interacting with Hmong are described in Table 1. And don't be afraid to ask if there anything you can do to help. I know this is what Americans do best. Health care in the United States is more than gold to me.

After I came to the United States in the late 70s, I had my second boy. In Hmong families, boys are considered more important than girls because boys are the ones who carry the family name and pass on family rituals. When I had my second son, I had excellent care from an Asian doctor. I could not talk with him because I did not speak English at that time. To this day, I still don't know his name or nationality, but I remember that the health care I received was so much better than the care in my country. That's why we need to learn from each other—so when we go home after a day's work, we can say, “Yes, I've done my job.”

Finally, I had been working in health care for about 10 years, and I had seen families lose their child. One family cried as if their only child had died and they had many children at home. Allowing a soul calling ceremony for the families that are in this situation may help ease the fear and emotional pain.

Table 1*
Etiquette for Interacting with the Hmong

- A. The handshake is a new concept to the traditional Hmong person. This is especially the case among women. Traditional Hmong usually do not shake hands with women. Many Hmong women feel embarrassed shaking the hands of a male. Traditionally, handshakes do not occur. Persons greet one another verbally. Holding hands too tightly during a handshake will embarrass Hmong women.
- B. When conversing with a Hmong family, one should always ask for the head of the household which is usually the father.
- C. When speaking to a less assimilated Hmong person whether through the telephone, in person, or through using an interpreter, one should use simple terminology. Many Hmong possess a limited vocabulary in English.
- D. Hmong teach their children to be well behaved in the presence of guests. Typically, in cases where their children are interrupting or not behaving well in the presence of guests, Hmong parents do not send their children away or discipline them. Discipline is usually administered after the guests have left.
- E. When talking to a Hmong person, he or she may not look directly at you or give eye contact. The person you are speaking to may look down or away from you. Traditionally looking directly into the face of a Hmong person or making direct eye contact is considered to be rude and inappropriate.
- F. Displaying a smile is considered to be indicative of a warm welcome and friendship when meeting with a Hmong person. On the other hand, laughing or making rough comments in the presence of a Hmong person may be considered to be a sign of insincerity and rudeness.

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- G. Traditionally, it is considered inappropriate for the opposite genders to sit too close to one another when conversing. To avoid misinterpretations, a male should keep a distance between himself and a female when in conversation or in any type of encounter.
- H. When entering a Hmong home, a seat or chair will be offered. If the visitor does not sit on the family's furniture, family members might assume that the visitor thinks that their furniture is messy, contagious with disease, or that the visitor assumes that he or she is of a higher status than they.
- I. Most traditional Hmong elders, especially men, do not want strangers to touch their heads, or those of their children, due to their religious beliefs and personal values.
- J. Most traditional Hmong men take on an adult name after they have married and had their first child. The adult name is added to the first name. It is intended to signify the maturity of the person. After the naming, it is thought that the recipient will be blessed with good fortune. Most Hmong men prefer to be called by their adult name. It is common for Hmong men and women to have the same names.
- K. It is very common for Hmong families to visit one another without setting up an appointment. Sometimes a family will just show up at the door without warning, and expect a warm welcome. It is considered rude and inappropriate to tell the visiting party that you do not have time to visit with them.
- L. Hmong people tend to be humble. They usually do not want to show or express their true emotions in front of others. Often, they will say: "maybe" or "I will try" instead of giving a definite positive or negative reply. Sometimes they might say "okay" or "yes" which actually means "no", when they feel pressured. When talking to less assimilated Hmong persons always repeat questions and allow them some time to think about their responses.
- M. When it comes to decisionmaking, it might take Hmong persons a while to come up with a response to a particular situation. Usually the father makes most of the decisions for the family. But sometimes, the male head of the immediate household may involve relatives including uncles, cousins, or even clan leaders in important decisions. Before making a decision, most Hmong elders like to receive a second opinion. This is because they do not want to be held solely accountable for what might turn out to be a wrong decision.
- N. When dealing with a Hmong family, confidentiality is considered to be a very important issue. However, within the family itself, confidentiality may not be thought of as all that important. Family members share their experiences and seek support from one another.
- O. When a Hmong person offers you a drink you should not simply decline it. This is considered to be impolite or rude. So as not to offend him or her, just take the drink or the offered object and hold it for awhile before placing it back on the table or a nearby surface. The same goes for offered gifts. Refrain from quickly saying "No". Explain why the gifts cannot be accepted.
- P. When entering a Hmong home during mealtime, guests will be invited to join the family in eating. Whether the guest wants to eat or not, he or she should take part in the meal. He or she does not have to eat much; taking just a bite or two will make the family happy. Otherwise, the family will stop eating and will talk to the guest until he or she has left.
- Q. It is considered quite embarrassing and rude when outsiders assumingly label the members of a Hmong family as man or wife. If one does not know the family or the relationships between family members, one should ask.

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- R. Most traditional Hmong families do not enjoy hearing direct comments about their children, especially infants and babies. A comment such as “your child is cute” is not looked upon favorably. Hmong believe that if a bad spirit hears such comments, it might come and take the child’s soul away.
- S. There are many unusual physical marks which might be found on the body of a Hmong person. These are commonly the result of a home treatment for traditional healing and health problems such

as colds and headaches. These marks may involve bruises or redness from cupping, spooning, or coining on the neck, shoulder, back, chest, forearms, and forehead. Hmong also may wear unusual accessories such as red necklaces made from silver and brass, white cloths around their wrists, and red or white strings on their wrists, necks, or ankles. These accessories may be worn for health and religious purposes.

*Reprinted with permission from The Hmong Center, St Paul, MN online at www.hmongcenter.org/etforinwitle.html

TRADITIONAL HASIDIC JEWISH BELIEFS AND TRADITIONS

Based on a presentation by Mrs. Bronya Shaffer

Introduction

Within the Jewish community there is a very broad spectrum of ethnic and political backgrounds, traditions, degrees of religious observance, and levels of acculturation.

It is important to recognize, however, that despite such differences all of Jewish life is governed by Jewish law. For the most part Jews, wherever they live, have incorporated or adapted to the majority culture in terms of behavior, profession, and non-sectarian social mores. Nonetheless, everything in Jewish life is governed by Jewish law. Life and death, their definitions, determinations, and attendant rituals are firmly rooted in Jewish law and tradition. This discussion will provide an overview and highlight beliefs and traditions concerning death. Today’s venue precludes the topic’s deserved scope; far more information is available and the reader is encouraged to visit the websites listed for a better understanding of Jewish practices in death and mourning.

Jewish law prescribes very particular procedures for dealing with a death, a process that begins the instant that it is determined that death has occurred, and that continues through several stages. In the body of Jewish law dealing with health, healing, illness and death, there is a very definite and unambiguous line between life and death...laws concerning the care of the dying

are scrupulously observed. At the instant that death is pronounced the focus of the law is immediately shifted to preserving the dignity of the deceased, and the process of preparation for burial. Since the definition of ‘life’ in Jewish law is not contingent on quality of life, or length of life, the procedures followed to ensure the utmost dignity and respect for the deceased are no different for an infant from that of an adult. Fetal death does have its specific qualifications. In every instance of fetal death, the mother, family and professional providers involved should consult with an expert in the laws and traditions of fetal death practices.

Death and burial customs

All those present as death is occurring are encouraged to remain present until the pronouncement of death is made. This applies to family and friends; medical personnel, are exempt from this custom. The greatest respect afforded a soul is to actually watch over it as it passes from this life to the next. When the death is noted by medical personnel, attendant family or friends should be notified immediately. At that point, the relatives/friends of the deceased should be allowed to perform the duties incumbent upon them in preparation for the funeral and burial. Among these are closing the eyes of the deceased, and covering the face. One of the more poignant traditions, even for

infants, is that family and friends will ask forgiveness of the deceased for anything that they may have done to cause pain or discomfort of any kind. This is one way of bringing closure to the relationship in this life.

Out of respect for the deceased, burial usually takes place within 24 hours. Arrangements are usually made by immediate family members but it is acceptable for family friends to handle this. Under circumstances that would not allow for family, friends to be present for an immediate funeral, the funeral may be delayed. This provides friends and family an opportunity to pay their final respects. For example, with sudden death, family may not be immediately available.

A basic tenant of Judaism is that every soul has its purpose. There is a reason for every soul to be—whether this soul survives in a human body for several minutes or many years, there was purpose to that soul. This is something that is strongly felt. While knowledge of this soul's completed mission is a comfort, the pain and grief are no less real. It is unlikely that you will hear even the most devoutly religious person saying: "...how wonderful, this soul has just completed its mission on earth is now departed..." The belief in a soul's purpose does not remove the pain of grief. It is important, therefore, that grieving parents, siblings, have the support they need.

The deceased is not left alone from the moment of death, until burial. In a city with a sizeable Jewish population, the family will notify the burial society who will then see to the specific arrangements. This includes a 'shomer' who is a person present with the deceased at all times. A family member or friend may stay with the deceased. These individuals say prayers and recite psalms during the time from death until burial.

Stages of grieving

There are three stages to grieving in the Jewish tradition. The first stage is called "shiva." After the burial, the family returns to the shiva house to begin a seven-day period of intense mourning. Shiva is from the word "sheva," which means seven. This week is called "sitting shiva" and it is a time for the family to be together in their mourning. During this week, friends and loved ones come to share memories and comfort the grieving family with short visits called "shiva calls." A family sits shiva after having lost a parent, spouse, sibling, or child.

The seven-day period of mourning begins immediately after the burial. Thus, the day of the burial is the first day of shiva, and then it continues for six more days. However, if a Jewish holiday such as Rosh Hashana falls during the seven days, shiva ends the afternoon just prior to the holiday. Mourners usually do not leave the house during this time, even to go to work. In recent years, there has been a trend to sit shiva for only three days, although nothing in the Jewish tradition supports this. The number seven in Judaism is significant for it symbolizes completion in this world, as in the seven days of creation. The concept of sitting for only three days comes from the mistaken belief that making the period of mourning shorter will somehow make it easier.

Every shiva experience is a different because every loss is different. If the bereaved is someone you had been close to but hadn't seen much of recently, the period of shiva is a good time to reestablish the relationship with the family. It is a most appropriate time to visit the parents of a child that was lost. It is greatly appreciated when a health care provider calls on the family during this period. It is very comforting to families just to know that all the help that was possible was given.

The second stage of mourning encompasses the first 30 days following the burial and is called "shloshim," from the word meaning "thirty." This period includes the shiva, but most restrictions that apply to mourners during the seven-day shiva period are lifted after that week. For the next 23 days, mourners can leave the house and return to work, but they should limit social engagements and avoid festive outings.

After completion of the shloshim, the official mourning is ended for all mourners except those who have lost a parent. Those who have lost a child or other loved one can now resume activities without restriction. Those who have lost a parent have a third stage of mourning which lasts a total of one year from the day of death.

Cultural issues

There are some culturally-based differences in the expression of grief among Jewish families. Among orthodox Jews, for example, there is a tremendous sensitivity to modesty, including physical acts of affection and love between husband and wife. Therefore, do not be surprised if you see husband and wife embraced

and held by friends and family, but not by each other. In fact, at happy times, such as when a child is born, you won't find religious Jewish couples showing their joy by hugging or kissing each other. They hold that in check, and their expression of love and affection, and that of solace and comfort, for one another is verbal, it's not shown physically in public. Upon hearing that a child has died, the husband and wife often don't fall into each other arms in grief. A physical distance is maintained in the presence of others and the child's parents will not relate to each other physically in the presence of others. In private, they are as comforting and loving to each other as they express their grief.

The Jewish law against autopsy is stringent to preserve dignity and respect for the deceased. There are certain circumstances when an autopsy may be acceptable. An autopsy may be accepted if it provides immediate benefit to a living person.

My father was killed in a car accident where the state law required an autopsy in cases of accident. Jewish law, on the other hand, forbade any desecration of the body unless it was for immediate benefit to someone's life—certainly not the case in this instance. I had the opportunity to meet with the medical examiner, who then consulted as well with a rabbi expert in Jewish law and state law, and was able to persuade the state to allow for the dignity of my father's passionate commitment to Jewish law.

Implications for providers

In many schools for health care providers, the traditions of mourning are not part of basic school curriculum. It is not until a death occurs that we realize the importance of cultural traditions. As health care providers, we can guide and assist families during this crisis. The grieving individual needs to know that there are certain procedures to follow in the Jewish religion, and there are resources available to help them learn about those procedures.

Recently, I read a story by a New York Times journalist in the New York Times magazine section. The author, a young woman living in Japan, had become pregnant after waiting a long time to conceive a child. And then she discovered that her so very beloved and so long awaited unborn child was no longer alive and she experienced enormous grief. I read the story with tears;

I'd experienced this grief myself and knew the pain. This writer described her feelings of loss, and confusion, and her search for a meaningful way to deal with and to express her grief. She wrote that knowing there was nothing in her own (Jewish) tradition, she turned to a Hindu friend who told her about the Hindu practices of women who miscarried. And I remember reading that, and just being absolutely heartbroken for her. Because she just didn't know—of course there is a Jewish response to it, but she'd never learned that; she just wasn't aware of it. And had she contacted somebody who was knowledgeable, she would have found that her pain as a Jewish woman was addressed in her very own history and tradition.

You, the service provider, can help by offering to call the family's local rabbi who can give the family the education they need to process the death. There are also websites that offer information and answer questions about Jewish traditions.

Many issues arise after the death of a child. Many of the current issues require Jewish legal expertise. For example, it is possible to save lives by harvesting organs from people who are technically dead even though there is still respiration. In the Jewish legal community there is no consensus on this issue. The traditional view has always been that both autopsy and organ harvesting are absolutely prohibited. Today, it's important for everyone to be aware of the ability to save lives by donating organs. It is recommended that the family discuss this issue with their Rabbi or/and Jewish legal advisor. Many Jewish legal experts find that organ donation is permissible under certain circumstances, but many do not agree. The prohibition is unclear and a matter for each individual consulting with their own Rabbi.

FIMR home visit question

One FIMR program in New Jersey has a home visiting component. The nurse makes home visits and provides bereavement counseling. A few Hasidic families have lost children and live in the service area. The visiting nurse, Paula, is Jewish and has tried on many occasions to reach out and provide services. She is not sure if her help would be welcome, or even if she would be allowed in the home during the mourning period.

Paula would certainly be allowed in the home. The week of shiva is when people come to the house to

mourn. Usually Hasidic families have a very strong support system. In New Jersey or New York, the family and/or the community are present for support. There is a tremendous amount of encouragement to talk about feelings, to work through feelings according to the established process. For the first few days, the most intense period of grief, the mourning family members may not even talk. During the seven days of shiva, the mother of the home does not prepare meals or cook—someone comes in and assumes those responsibilities. The mother, father, and siblings have no responsibilities during this time.

During the rest of the shiva and even more so during the 30-day period of shloshim, the family will open up more to share memories of the deceased and express their feelings. As the grief diminishes, they resume normal social activities and involvement. So what Paula can do, most of all, is express her willingness to be of help. That is always appreciated. Let them know that bereavement counseling is available, and perhaps other services as well, should they want them. It is a tremendous help to just reach out. When you put your hand out it's not always taken, but sometimes much, much later the person remembers, "Oh, that's someone that I think can help me now." So Paula can just let them know that she is there for them, should they ever need her. Shiva is a very appropriate time for her to do this because that's when it is sort of an "open door policy."

Paula could make a shiva call to pay her respects and let them know she is available. She should mention, too, that she is a trained professional. Sometimes people find it easier to express their feelings to someone who is not part of the family or the community. Paula could just slip a note to the mother saying, "If you ever want to talk to me, I'm available," and be sure to include her telephone number. It can be very comforting just to know that help is available if needed.

I would like to conclude with the words of Isaiah, where he says, "May God swallow death forever and may He wipe tears from all faces." (Isaiah 25:8) And may it be so.

Selected Web Sites

www.Chabad.org.

Information about Jewish life, traditions, and history; "Ask the Rabbi" feature to answer questions about Jewish religious philosophy and traditions.

www.hods.org

Halachic Organ Donor (HODS) Society, disseminates information about Halachic (Jewish law) issues and Rabbinic opinions concerning organ donation.

www.AskMoses.com.

This site offers live advice 24 hours a day, 6 days a week (closed on Shabbat); Hasidic Rabbi's available online or referral to expert.

EXPRESSION OF GRIEF: AFRICAN AMERICAN PERSPECTIVE

Based on a presentation by Reverend Khadijah Matin, MS

Introduction

For African Americans in the United States, despite significant gains in many key health indicators, infant mortality and racial disparity in quality health care remain critical issues plaguing the population. Several issues remain at the forefront of the national dilemma:

- ▶ Disparities in the health of African American women, infants, and children continue to affect community life. This issue needs to be addressed across the entire continuum of health care, not just upon the death of an infant or when a mother is in crisis.
- ▶ Although the health community is making strides in moving from cultural awareness to diversity to

competence, with the eventual goal of achieving both proficiency and high levels of patient satisfaction, we still need to make a greater effort to incorporate culturally competent practices into the spectrum of care.

- ▶ There remains a paucity of social research on issues related to fetal and infant death in the African American community. We need to further examine how the intersection of varied cultures, mores, and habits is manifested in our communities. The definition of what is actually African American is ever evolving with African and Caribbean traditions, as well as influences from the dominant culture, all playing a part.

- ▶ The African American experience is not static—it is a changing dynamic need to be re-visited often.

Cultural influences

African Americans have a story to tell. Our history is unique and imbued with a rich cultural heritage that remains despite transplantation to the Americas. We need to be aware of this and find ways to retain those traditions that inspire us and contribute to long life. The strength of the African American cultural heritage is reflected in the endurance of some ancient cultural patterns, the re-interpretation of others, and the adaptation of even more. Fortitude was born of the multiple experiences of the African American people. Their experiences range from those of slaves to free-born persons arriving as workers in the United States, many of whom migrated from the south to northern cities. The diversity of occupations including trades people, farmers, homesteaders, military personnel, and professionals and contributes to the diversity within the African American community.

The history of the African American family is the story of a struggle to rebuild stable family institutions and fill the emotional, cultural, and spiritual void that was the legacy of slavery. African culture has helped shape family patterns in language, music, art, housing, dance, traditional religion and healing practices, and other faith-based activities. Some of the most influential values in this culture include strong kinship bonds, work orientation, and adaptability of family roles. There are various forms or definitions of extended family and who is included, reflecting the influence of African, European, Native American, and Caribbean heritages and the associated political and economic dynamics.

Multiple manifestations of racism have been another stressor throughout the lives of African Americans. Social injustice (e.g., inequality in health care), societal inconsistency, and the feeling of personal impotence are part of their daily existence. All of these factors affect the individual's grief response, utilization of resources, and feeling of trust/distrust of service providers.

Stories are used to describe the experience of families experiencing a perinatal loss or infant death. These stories provide a window into the family's experience. Implications for providers are also included.

Interview with an African American Social Worker

As African Americans, we are often able to better cope with miscarriage, abortion, and infant death because we try not to exercise or wallow in “blame”—the loss of a baby is generally not seen as an opportunity to sue someone, but in most cases viewed as God’s will. Though devastated, we see the death as part of the cycle of life. The stillborn is delivered and named, as if he or she had a life, and then buried. Often, the mother will try to get pregnant soon after. Moving on, moving on, because the family must survive and we gotta keep the job...demands that we move on. We may be quiet, and only share with a small circle. No explanations are given—we can’t afford to stop living. “Go on, move forward girl, it’s a natural life cycle. It’s not a cause to stop breathing.”

Class affects the ability to cope. Some of us, due to economic status or where we live, are removed from traditional familial supports and therefore struggle to bridge the gap. When we don’t exist in a nuclear family, we are even more stressed. In these cases, it is important to seek support from non-traditional sources. We can start by developing social networks and reinforcing the notion of social support, defined as caring, fellowship, love, affection, and instrumental support. Each member of the network is both open to receiving support and available to provide support when needed. This mutuality engenders feelings of self-worth and self-esteem as individuals recognize their role in the collective group.

Kavanaugh and Hershberger identified economic stressors as theme for African American low-income parents. Many mothers felt that this overall feeling of being stressed out during the pregnancy contributed to the pregnancy outcome.

Interview with a Lay Midwife and Akan Priestess

I’ll speak of personal experience and what I’ve been told by friends and patients. From the traditional African perspective, when there is an infant death a ritual is held so that the soul does not repeat this experience in the next life. The premature death is seen as part of the spiritual cycle and God’s way

of addressing one who was not ready or in good enough health to survive in this life.

One patient, after losing two children due to congenital problems, conducted research on her own to fully understand why, because the providers were vague in their explanation. Once she understood why it was ill advised for her to try again, she then decided to look within her extended family network. She took in children of other women (not blood kin) who were having difficulty caring for them, and raised them as her own. She also created a children's storybook, with one of her own daughters as the heroine of the story as a way to acknowledge her passing in this life.

The old folks say that when woman miscarries, it is nature's way of handling something that went wrong. When a baby is born and appears healthy, we wait seven days before naming the child to make certain he or she is here to stay. No baby showers are held before the birth, and the mother borrows basic necessities until after the seven days. Then she can receive gifts and have the naming ceremony.

When my child died, soon after his father's death due to critical illness, it was perceived as the father wanting the child with him. Although the hospital social worker repeatedly tried to counsel, I chose to seek solace with my community and religious advisors. I knew the child was in a good place. I had older children, and I saw this as a time to re-interpret my role as mother. So I began to teach and to work as a midwife and librarian.

Interestingly, other family members soon began to share similar stories of difficult births, miscarriages, or early death. It was as though I had to experience one of these ordeals first-hand before being allowed into this "sisterhood" or special circle. Family shared on a 'need-to-know' basis.

The child's death was not spoken of freely—not as if the infant wasn't seen as a valued member of the family, but not dwelled upon so as not to bring that energy forward and affect future generations' outcomes.

This story is rich with information on the mother's perspective on the life and death of her child. The importance of putting the life and death in a spiritual context is noted. The mother accepted her inability

to successfully bear a child and invested her energy in helping other women's children.

This story is consistent with recent research on the grief response of African American women. In all studies, spirituality was found to provide important support. Inner resources were used to develop self-help strategies to cope with reactions following the loss of a child.

Interview with an African American Father

The following is an excerpt from an interview with a father of six who is of African American and Native American descent, and is a Muslim.

It all started with a dream that our next child (this is my second marriage and therefore sixth child) would be a boy. So when my wife became pregnant and carried near to full term, we expected a boy. The baby was a girl. She took one breath and then died.

My teachings as a Muslim told me that when this happens, it means the person would immediately go to paradise. And so we were somewhat consoled. I also remembered stories from my mother, who would talk of life having its cycles and not all of us coming the same way.

My family, as African Americans, is very close, with few secrets, sharing struggles and accomplishments. This is how we were raising all of the children. So in explaining to the older children, we talked of their sister, Saediqua, who was now in paradise. We planned for a Muslim funeral, after explaining to the hospital staff the need for this to occur within 24 hours. They were very cooperative. Following Islamic etiquette, I offered the jannazah prayer with my two sons before wrapping her for burial. They looked at her and acknowledged her as their sister. The next day she was placed in a plain casket and, with the community's assistance, offered a full funeral service.

Prior to this, my wife had experienced two miscarriages. And so we dealt with this death in the context of her personal reality. As a young father I did not know enough to articulate all of my feelings. Looking back, I realize a lot of what I understood was based on all the things I'd been told growing up. This collective knowledge got me through. I

called upon the social group for support. And I was comforted by the dream and the close relationship with my sons—these helped me bridge the grief and move forward. We did not have much money, so soon I had to return to work. I felt comforted, wrapped up in my dual culture. The following year, a son was born, and we named him Ali Sadeq.

This family found comfort in religious traditions. Mutual caring and support by family members helped sustain them in this difficult time. This father's response is somewhat similar to that of McCreight who reports that a father's response to pregnancy loss may be very personal and emotional. It is suggested that fathers have limited support available to deal with the tragedy they have experienced. Many undergo self-blame, loss of identity; and the need to appear strong and to hide their feelings of grief and anger. In O'Leary and Thorwick phenomenological study, fathers suppressed their anxiety and fear in their desire to protect the mother. They also report societal pressure to be strong and this inhibited the need to get support. Lack of recognition of their pain was also identified. They report that fathers may not report their own anxiety and fear because of the desire to protect the mother. Pressure to 'be strong' interferes with getting support. While FIMR focuses on maternal interviews, fathers are an important dynamic in maternal and family grief response.

Interview with an African American Labor and Delivery Nurse

African American and Caribbean patients are open to sharing and being consoled. The family plays a big part in providing care—in some instances, multiple generations come to provide solace. Spirituality is very important and is reflected in the language of coping and understanding the outcome. The parents may ask for a cleric to perform baptism or for advice before making final decisions. They will ask to hold the child, when possible. The death is seen as a part of the cycle of life, and the child is recognized as a member of the family. The parents grieve as if the baby had lived its full life. They appreciate it when we cry with them.

Religion/spirituality

Each interview describes the tragedy of infant death and how a family deals with this loss.

Spirituality is at the center of the experience. This may not be associated with church attendance but with a belief in a higher power.

For many African Americans, the place of worship serves as the center of community life. African American congregations constitute a network of sub-communities within the larger, secular world. The religious community may be Christian, interfaith, Moslem, Buddhist, Hindu, traditional African (e.g., Akan or Yoruba), or politically based. All offer refuge, connection, resources, and the strength to cope with death and remember the 'missing' member of the family.

The nature of knowledge for African Americans includes what is known both through the physical senses and through extrasensory perceptions. "Spirit" gives essence to the life form, which in turn provides concreteness to the spirit; the two are one. Rituals, symbols, and language are vehicles by which knowledge is transmitted from generation to generation. Life experiences are given depth and meaning through the realization of their interrelatedness and significance in the life and existence of the group.

Death, however early, is viewed as a 'rite of passage' with clear meaning for the entire family. The health care provider can assist in coping by allowing a principal relative, elder, or advisor to come and work with the patient. This will facilitate a sense of place and belonging for the individual and other family members.

Implications for providers

Health care providers working with bereaved African American families need to bear in mind the historical, cultural, and social factors that help shape these families' grief responses and needs. Issues to be mindful of include:

- ▶ historical distrust
- ▶ culturally linked concept of family structure and the decision-making process
- ▶ diverse communication styles
- ▶ the perception of health as physical, with a moral/spiritual balance
- ▶ a code of ethics that is different, but not wrong or inferior

In working with a bereaved family, it is important to ask what would be helpful. Facilitate the process for families, but don't decide for them. It is also important to consider the whole person in a non-judgmental approach.

Other tips for providers include:

- ▶ Go into a community that you would like to learn about.
- ▶ Work with culturally/ethnically organized groups—ask about specific issues and practices but understand that they may not share all. Potential resources include religious leaders of different faiths, herbalists, shamans, churches, mosques, temples, patient advocates, and peer counselors in community-based organizations.

- ▶ Exchange information and concerns with colleagues, collectively strategize, and work in collaboration, not isolation.

Conclusion

Service providers working with bereaved families must be mindful of the unique history, values, and traditions of the communities they serve. A family's reaction to the death of a child and the kind of support they find helpful will vary across cultures, communities, and individuals. Understanding the backgrounds and traditions of different racial/ethnic groups is important, but it is just as important not to stereotype all people within a particular group. The African American experience continues to change, and it may differ from family to family.

ABOUT THE PANEL

Based on a presentation by Reverend Khadijah Matin, MS

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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 Johns Hopkins University School of Nursing.

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Reverend Matin is of African American and Cherokee descent. She is a mother, educator, interfaith chaplain, and self-described "wild woman who does not sing the blues." Reverend Matin converted from the Episcopal religion to Islam. She is an ordained interfaith minister. She is the Associate Director, Organizational Learning at Lutheran Medical Center, New York. She has spoken extensively

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Mrs. Bronya Shaffer is a scholar for , an online resource of qualified men, women, and rabbis offering answers to questions about Jewish law and traditions. She is a noted lecturer on Jewish women's issues. In addition to conducting regular classes, Mrs. Shaffer serves as facilitator for several women's self-awareness and support groups and leads workshops on child-rearing and relationships.

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Mrs. Vang is a member of the Hmong, an Asian ethnic minority people that originated in China. Her son Chai died when Nancy was 14 in Thailand of a gastrointestinal problem. She is the mother of seven children and a grandmother.

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