

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

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### INTRODUCTION

This bulletin explores the cultural traditions of African Americans, Iranians, Somalis, and hard of hearing families grieving the loss of an infant. It summarizes a panel presentation from the **National Fetal and Infant Mortality Review Program's Fifth National Conference**, held August 2–4, 2007 in Alexandria, VA.

This bulletin is offered to assist perinatal and pediatric providers helping families from diverse ethnic and cultural backgrounds coping with fetal and infant loss. Readers are encouraged to review the three previous educational bulletins (Table 1). These bulletins provide insights for a variety of culture groups.

view may affect one's 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 many tools for self-assessment specifically for SIDS and infant death—including a cultural assessment tool specifically for local FIMR program use (<http://gucchd.georgetown.edu/nccc/selfassessment.html>).

### Recent Studies of Grief

What is the evidence to guide the grief support of families? What is the best approach? Do we know what assists families reach their

NFIMR Educational Bulletin	Culture groups
<i>Cross Cultural Expressions of Grief and Loss III: When an Infant Dies</i> (2007)	African American, Hmong, and Jewish family perspectives.
<i>Cross Cultural Expressions of Grief and Loss II: When an Infant Dies</i> (2003)	African American, French and English Caribbean, Hispanic/Latino, Chinese, and Objibwe cultures.
<i>When an Infant Dies: Cross Cultural Expressions of Grief and Loss</i> (1999)	Latino, Native American, African American, and Muslim populations.

Effective support of families 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 through their own cultural lens, and this

pre-loss level of functioning? Unfortunately we do not have rigorous data that informs us on these issues. We do not have the highest level of evidence, randomized controlled trials, to specify the most effective interventions. We do not have these studies because infant



This fourth bulletin summarizes a panel presentation at the National Fetal and Infant Mortality Review Program National Conference, held August 2–4, 2007, in Alexandria, VA. The panel and this Bulletin were produced in partnership with the Association of SIDS and Infant Mortality Programs (ASIP). NFIMR gratefully acknowledges their contribution in the development of this topic.



death is a relatively rare occurrence. Additionally, it is not ethical to withhold grief support for the control group while providing support to the experimental group. What we do know is from descriptive and qualitative studies. These studies give us information about specific populations with limited generalizability. The annotated bibliography at the NFIMR website provides details of recent studies.

We do know that it is critical that each provider be open to the needs of the family. Each family has individual needs. Our challenge is to listen to families and provide support for the needs of each family member. We must learn to be comfortable with the diverse needs of families that may be inconsistent with our own traditions and beliefs.

### 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 Somalis, Iranians, African Americans, and hard of hearing cultures. Each panelist describes their experience professionally and/or personally in working with bereaved families.

### Somali

Osman Mire provides interpreter services at Children's Hospitals and Clinics of Minnesota, Cross Cultural Care and Interpreter Services. He is from

Somalia and has been in the United States for over 30 years. He discusses the death of his child and traditions in the Muslim faith.

### Iran

Nazarine Farr is a doctoral candidate and holds a master's degree in Psychotherapy from University of San Francisco. Originally from Iran, she provides services to individuals and families the Centre for Living with Dying, Santa Clara County, California. Her work focuses on grief and loss. She reports on her family's experiences with grief and loss in Iran, as well as general knowledge about Iranian and Muslim culture.

### African American

Patt Young, Fetal and Infant Mortality Review (FIMR) interviewer for over 18 years in Oakland, California, has spoken to hundreds of women whose infants have died. These interviews provide insight into their grief and loss experience as they face the tragedy of their infant's death.

### Hard of Hearing

Margaret Widner-Kolberg is a nurse who became deaf as a young adult and now has a cochlear implant. She discusses the challenges and needs of hard of hearing individuals. She is a pediatric clinical instructor at Johns Hopkins University School of Nursing.

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## Summary

There are similarities and differences in the grieving process for families from different ethnic and cultural backgrounds. There are also significant variations even within a particular population. Broadly defined groups such as African American, Muslim or hard of hearing encompass people of considerable diversity in nationality, religion, history, culture, and politics. Service providers are challenged to appreciate 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 and father 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.

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## SOMALIA

*Based on the presentation of Osman Mire*

Somalia is on the east coast and the horn of Africa, bordered by both the Indian Ocean and the Red Sea. The country has a population of 9.5 million. Unlike many other countries, Somalia is largely composed of a single ethnic group that shares a common language, religion (Sunni Muslim) and culture. From 1991 through 1994, there was civil war in the country. Even today, the government is largely ineffective.

During the civil war, Somalis fled to neighboring African countries, such as Ethiopia, Yemen, and Kenya. Resettlement programs also made it possible for Somalis to emigrate to Germany, Switzerland, Finland, England and the United States. In fact, so many people have left the country that the median age is now only 17.5 years. An estimated 20,000 Somali refugees reside in Minnesota. Today, the Twin Cities have one of the largest populations of Somalis in North America. Other areas in the United States where many Somalis have settled include New York, Los Angeles, Washington, DC, San Diego and Seattle.

There are some Somali beliefs and traditions that are important to understand. Most Somalis have a strong belief in the after-life. Muslims believe that young people aged 15 years or younger are innocent and are not capable of committing any sins, so they automatically go to heaven. Also, there is the belief that illness and death are part of God's plan for everyone and the faithful have no control. It says in the Koran, "To Allah we belong and to Him we return" (the term Allah means God). So Somalis view dying in its religious context; it is considered to be a salvation and part of the cycle of life. When an adult

Somali person is terminally ill, the healthcare provider should tell the dying person because this is considered caring. For the terminally ill child, the provider tells the parents and the parent tells the child. When a death is imminent, there is a special portion of the Koran that is read or recited to the dying person. This is done for both adults and children. It is an important and necessary tradition. After death, the ritual washing of the body is done by the family, the funeral home or both. When the deceased is a child, either men or women can wash the body. When the deceased is an adult, however, only another woman can wash a woman's body and only a man can wash a man's body. This is done out of consideration for the privacy of the dead person.

Sometimes, Muslim religious rules may conflict with local customs or regulations. For example, under these rules when a child dies, cremation is not acceptable or permissible. Embalming and autopsy also are not acceptable, out of respect for the body. However, if something is required under local law, even if it's against the religion belief, it is permissible. So embalming and autopsy should not be done, unless they are required by law. Organ donation is permissible from the religious and cultural perspective. Parents can donate their child's organs, it is their choice. Burial should be done the same day, and there is no viewing the child's body in a coffin. Somalis usually seek support from relatives, friends, and religious leaders. The religious leader can provide comfort and explain religious traditions. Friends and families also are important sources of support and assistance. They will try to provide any comfort pos-

sible. For instance, friends may cook for the grieving family and other family members care for their other children. They don't want the grief-stricken parents to have any other burdens.

I will share my personal experience losing a child and the cultural aspects of how Somalis grieve this loss:

*Although grieving traditions vary among cultures, the deep sense of loss and sorrow is universal. So in that regard, losing a child is a universal tragedy that transcends cultural bounds. No one is ever truly prepared for the death of a loved one, even when the death comes after a long and serious illness. And when the loss is sudden and unexpected, as it was for me, the profound heartache and emptiness that you feel is accompanied by stunning disbelief. No matter the circumstances of the loss, there is always a crushing sadness that goes with it.*

*When we lost our child, my wife was a week from her due date. One day during the last week she went to the hospital for a regular checkup, and she took with her the youngest two children. The nurse prepared her for a sonogram and when she first looked at it, the baby appeared to be moving. But then she looked again and saw that the child actually was not moving. Well, she didn't want to give that news to my wife and said the doctor needs to review the sonogram. My wife suspected something was wrong when the nurse said she would call the doctor. When the doctor came and looked at the sonogram with the nurse, they saw that the child was not moving. So they took the two other kids and put them in another room so they could tell my wife the terrible news. She was alone when they told her that her baby was dead. They said she could be admitted to the hospital or return tomorrow to deliver the baby. My wife said, "I want to come back later because the child is dead and there is no reason to rush." So the next day we returned to the hospital and she delivered the baby. It turned out to be an umbilical cord death for the baby. And, actually, the sadness of that loss probably hit me harder than my wife. Even to this day, I don't want to see the pictures that we took that day.*

*As a Muslim, I have a deep faith in God and that God decides whether a person lives or dies. Even in great sadness, Muslims still have faith in God and believe in him. The Muslim faith and culture helped us through this terrible time.*

#### **The Holy Koran guides a sincere Muslim to bear trouble and affliction:**

*And we shall undoubtedly test you with something of fear and hunger, some loss of wealth and lives and fruit. But give glad tidings to the patient, who says when afflicted with calamity: "To God we belong and to Him is our return." They are those upon whom is God's blessing and mercy, and they are the ones who are guided. (2: 155–157)*

*Because I had moved to the United States from Somalia so long ago, I thought I knew how to make burial arrangements. I found out some things that I didn't know when we lost our baby. In the Muslim faith, there are certain procedures followed when a child dies. For example, you have to wash the body, you have to wrap it in a cloth, and then take it to the burial site immediately or at least within a day. In Somalia, when a child dies you can take the body to the morgue or funeral home right from the hospital. There are no restrictions or any other requirements that go with it. We went to get our baby's body from the hospital but were told we had to talk to the funeral home first. So I called the funeral home, and they told me, "You have to give us all the information and then we will come and pick up the baby." I conveyed this information to the hospital. The hospital did allow us to wash the body and wrap him in blankets and a white sheet, an important Muslim ritual. When the funeral home staff arrived at the hospital, I expected them to be able to take the baby immediately to the funeral home but this was not permitted. This was another delay and upsetting. I recommend that families be informed of these procedures immediately so they know what to expect. Our baby was buried in this country.*

In conclusion, care providers should offer interpreter services immediately and offer to contact an Islamic Center. Typically, Somali families are large and will need a space where they can mourn the child who died. If possible, arrange a place for the family and friends to gather. It is important to connect the family to the community as soon as possible, so they can get the support they need right away. Most Somalis prefer verbal communication to written communication. Even those who read and write



prefer information verbally, with important information written for later reference. Finally, remember that even if a provider does not know every aspect of the Somali grieving traditions, he can always ask the family what they need. The pain and sorrow of the loss is the same for everyone, regardless of their racial, ethnic, religious, or cultural backgrounds. And the mission is to help families cope with their grief in every way possible.

### Some Somali Customs\*

#### Greetings

Somali warmly greet each other with handshakes, but shaking hands with the opposite sex is avoided.

Common verbal greetings include:

- ▶ Assalam Alaikum (Peace be upon you)
- ▶ Nabad miyaa (is their peace).
- ▶ Subah wanaagsan (Good morning)
- ▶ Galab wanaagsan (Good afternoon)
- ▶ Habeeb wanaagsan (Good night)

#### Names

Traditionally, Somalis have three names. The first is their given name and it is specific to that person. The second name is the name of the child's father and the third name is the child's paternal grandfather.

Women do not change their name when they marry. Therefore, that the husband and wife will have different names, while all of their children will have the same second and third name. The names of the father and mother will be different from the children.

#### Gestures

Somali use sweeping hand and arm gestures to dramatize speech. Many ideas are expressed through specific hand gestures:

- ▶ A swift twist of the open hand means "nothing" or "no".
- ▶ Snapping fingers may mean "long ago" or "so on"
- ▶ A thumb under the chin indicates "fullness".
- ▶ It is impolite to point the sole of one's foot or shoe at another person.
- ▶ It is impolite to use the index finger to call somebody; that gesture is used for calling dogs.
- ▶ The American "thumbs up" is considered very rude and offensive.

\*Adapted from Minnesota Department of Human Rights. Somali Culture and Customs. At [http://www.humanrights.state.mn.us/somali\\_culture.html](http://www.humanrights.state.mn.us/somali_culture.html) and the Centers for Disease Control and Prevention. Promoting Cultural Sensitivity: A Somali Guide. <http://www.cdc.gov/TB/EthnographicGuides/Somalia/chapters/chapter2.pdf>

## IRAN

*Based on the presentation of Nazarine Farr*

It is important to keep in mind that Persia (Iran) is an ancient culture—going back to 2000 BC. In the ancient times, for hundreds of years Persia was the most powerful regime and ruled most of the known world. Science, the arts (including poetry), and mathematics flourished under Persian rule. Iranians today are steeped in and proud of that 4000 year history and heritage. For example, the Persian poet Abolqasem Ferdowsi wrote his epic titled *Book of Kings (Shahnameh)* in about 1000 AD. The Book is credited with preserving Persian culture, history and language. It is often compared to Homer's Iliad. More to the point, many Iranians still today proudly own, display and cherish the book. Ferdowsi's tomb is still a popular tourist destination.

#### Book of Kings (Shahnameh)

*I've reached the end of this great history  
And all the land will fill with talk of me  
I shall not die, these seeds I've sown will save  
My name and reputation from the grave  
And men of sense and wisdom will proclaim  
When I have gone, my praises and my fame.*

Ending stanzas of the poem *Book of Kings* by Iranian poet Abolqasem Ferdowsi 930 AD–1020 AD. From *Abolqasem Ferdowsi: The Poet Who Rescued Iran* at [www.npr.org/templates/story/story.php?storyID=100397309](http://www.npr.org/templates/story/story.php?storyID=100397309)

Of all Muslim countries, only Iran is an official Shiite Muslim country. However, the country is home to many other faiths including Christian, Jewish, Zoroastrian, Bahaian and Sunni Muslims. All of these religions flourish without any government restrictions. In fact, Iran's Jewish population of about 25,000 is the largest community in the Middle East outside Israel.

In the western world today, Iran is frequently portrayed in a very negative light or is seen as a backward outpost. But the reality is very different. Here are some interesting and positive facts about Iran:

- ▶ Women constitute well over half of university students in Iran
- ▶ Iran's Sharif university is considered to be comparable to MIT, Caltech and Stanford
- ▶ Nine out of ten Iranians say that men and women should have equal legal rights
- ▶ Among Middle East nations, only Iranians held spontaneous candlelight vigils in sympathy with Americans after 9/11

Most Iranians are culturally Muslim—even if they may not actively practice their religion. When it comes to the funerals, the religion becomes part of tradition. Even if one was not a practicing Muslim, one would still follow traditional ways. For example, it is customary to bury a body on the very same day of the death. Therefore, autopsy may be a problem for some families.

Other days are also important after a death. In the Iranian community, very important days are the third, seventh, and 40th day after the death. It is traditional to go to the grave site as well as support the family on these dates. After the fortieth day, men usually have an afternoon tea or a lunch and they would shave. The women will wear black in mourning. If they are very sad, someone will buy them something new. If your outfit changes, it indicates moving on from grief. Often the first anniversary is the last time relatives and friends gather formally to acknowledge the loss. Everyone goes to the gravesite, but after that it's really up to family and friends to continue to acknowledge the death.

Infants belong not just to the parents but the family at large. They are part of the greater community. The paternal grandparents, particularly, hold influ-

ence in the rearing of children. Therefore, the loss of an infant is mourned by not just the parents but the entire family.

Questions about who is to blame for the infant loss are common and often directed to the parents. The mother in particular is blamed and she may also blame herself. The husband's parents may be particularly critical of the mother. A grieving mother may carry the additional burden of explaining her actions to other family members, including her mother-in-law.

Blaming the parents occurs not only in Iran but the custom has been carried over to Iranian families leaving in the United States too. For example, an educated Iranian woman living in California, an Oxford graduate and engineer, lost her little girl in a car accident. With all the grief she was going through, she was expecting in-laws to visit. Her concern was how she was going to explain the death of her little girl to her mother-in-law. Dealing with her in-laws was an additional stress.

In regards to SIDS, even though nobody is to blame, the family focus again shifts back to the parents and their lack of parenting skills. Concerns regarding the safety of the child or exposure to the evil eye are brought up as well. In more traditional and conventional families, the woman may also have a sense of disgrace—especially if this is the first born or if the baby was a son.

An extremely important function for the health care provider is to convey to the family what is known about the cause of death and where possible, assure the parents that they could not have done anything differently or prevent it. This information can help them understand why the infant died and hopefully help parents convey accurate information to other family members.

The loss of a fetus is often grieved in silence. One reason for this would be that pregnancy is not publicized. Women do not talk about it publicly or among family. For example, a woman who was pregnant received different reactions when telling the news to her family. Her sister was very excited for her. Her brother, on the other hand, disconnected from the call when hearing her news. Additionally, he chastised her on more than one occasion for even mentioning it to him. Announcing a pregnancy is simply not

done. Therefore, if pregnancy is not talked about, the loss of it is even less discussed. The loss is not acknowledged and there are no specific rituals to deal with the loss.

In addition, there is a cultural fear of talking about the loss. Iranians may believe that if something bad happens and they talk about it, more bad things are going to happen, so best not to talk about it. With few opportunities to express their grief, the parents may experience helplessness, lack of trust and lose confidence, not just in themselves but in others as well. This may even expand to include the universe at large and their faith. Along with this, obviously, would come more suffering and sorrow.

After an infant loss, Iranian mothers and fathers tend to put on a stoic face and resume their normal life because it is expected of them. One woman reported that her child died of SIDS while in Iran. She reported that the way she worked through it was by trying to be normal. She said, *“I continued to work and that is how I coped. I did not really grieve my child’s death, I had to go on.”*

From a psychotherapist point of view, emotions eventually emerge if not expressed at the time of the loss. It’s not unusual for a physical manifestation of these losses. *I witnessed this in my mother. Throughout much of her life after her two children died of SIDS, my mother suffered from dizzy spells and at times, especially if she was under stress or she would hear of somebody who died, she would lose her coordination. The dizzy spells appeared after the first loss. Loss of coordination*

*appeared after the second loss. She never recovered from these symptoms.*

The FIMR home interview can provide an important service for Iranian bereaved mothers. During the interview, the mother finally has an opportunity to talk about her loss privately with a sympathetic, non-judgmental listener and to express her feelings about it. This is an opportunity she may never have in her own family and community. She also has the opportunity to ask questions about why the baby died and if appropriate, to be reassured that she did everything possible for the baby.

Finally, a uniquely Iranian support for the bereaved that can be provided is poetry. Iranians love and appreciate poetry and often use metaphors and poetry to provide solace. Many times poems and poetry describe the emotions parents are feeling but find it hard to express. Offering poems and prayers will be appreciated when it comes from the heart.

#### Excerpt from an Iranian poem: Self-Awareness

*To the memory of my son, a broken branch  
Whom shall I call... each day opening the window  
that ... framed your playful commotion?  
Whom shall I call without him coming?*

By: Manuchehr Atashi Iranian Poet 9/30/21–  
11/20/05. To read this beautiful poem in its  
entirety, go to <http://www.theliteraryreview.org/tlr-ira1.htm>

## AFRICAN AMERICAN

*Based on the presentation of Patt Young*

African Americans are about 12.2% of the total United States population. The state of New York has the largest black population followed by Florida, and Texas.

However, African Americans have a 2–3 times higher rate of infant mortality than the majority population in this country. Nationally, the urban, less affluent, and less educated African American mothers make up a large proportion of the women who experience infant loss. In spite of this higher mortality, information on the grief experience of these African American mothers is limited. Most bereavement

studies that have been done are qualitative and they provide perceptive insights into a specific community. It is equally important to remember that each woman’s experience is unique as she copes and learns to live with the death of her infant.

*I have been a FIMR interviewer since the early 1990s and have interviewed hundreds of women—mostly African American women who had low income and had low educational levels in Oakland California. Today, I would like to share with you what I have learned from these women about their experience of grief and loss and*



*how the FIMR interviewer can make a difference. My experience may not be typical of all communities in the United States but I believe that there are some common threads of knowledge that will assist all FIMR interviewers to better understand the women that they serve.*

The women in Oakland often feel terribly isolated in their communities and don't have anyone to talk to. When women of any background, but particularly African Americans, achieve a higher level of education, it is easier for them to articulate their needs. Less educated, lower income women often express a sense of isolation and a lack of support in coping with their loss. An infant death is unexpected and so there may be no rituals or traditions passed along to support grieving parents through the tragedy. Also, grieving parents typically have no access to the understanding and empathy that can only be provided by others who have also experienced the loss of a child. Bereaved women do not know other African American women who are also grieving the loss of their babies. Therefore there may be no potential network of supporters. Mothers tend to internalize their pain, in part because they feel that they are the only ones that were experiencing such loss.

Funds for burial are also an issue. Most women want to have a burial, but they cannot afford it. Some hospitals offered free cremation, but in most cases it is a group cremation of several people. Generally, the women are unable to recover their own baby's ashes and so they prefer to have a burial. Occasionally, a funeral home or a community member will donate services but most mothers must settle for a group cremation. This is another source of pain because their baby is lost again—cremated with other people.

Different issues arise when a fetal or infant loss occurs in the hospital. Even though the mother may feel very isolated in her community after she has gone home, at the hospital, relatives and friends arrive to be supportive. Hospital staff should provide adequate space to accommodate the visitors. Regardless of family functioning, all the relatives will visit. Even though they haven't seen each other in years, the word goes out that a baby has died and all of these family members are going to show up to give support. They will all be quite distraught, yet they will be an important source of support to the mother and to each other.

The few days or so after a woman loses an infant or a fetus in the hospital, there may be much support. The hospital staff may have given her a bereavement packet with some information. If she delivered between 8:00 and 5:00 on a weekday, possibly a social worker talked to her. Friends and family visit to express condolences and share the grief. However, after awhile, hospital staff have moved on and family members go their own way and return to their routines. Then, the mother is left alone with no one available to discuss her feelings. Consequently, the woman has no one who understands her experience of grieving the loss of a child. She doesn't have any resources or language skills to express her needs. She is locked inside of herself with her pain. The ability to articulate her emotions may be limited. Consequently, staff may think, "*Well, she's stoic. You know, she's internalizing this and does not need help.*" In reality, she just has difficulty expressing her emotions. As health professionals, it is important to remember that lack of emotional expression may not reflect the emotional state.

The black church historically has been a very important source of support and comfort for bereaved African Americans. However, it would be a mistake to assume that everyone in the African American community belongs to the church. Many of the younger women who have lost an infant in Oakland are not connected with any church. Many of them may never have gone to church at all and are not involved in any congregation. The lack of this resource added to their sense of isolation. However, most of these women had a Christian foundation and a very strong belief in God, even if not attending formalized religious services. They also tended to believe the baby was in heaven and this was comforting to them. They often referred to the baby as an angel, and this seemed to console them.

Another observation is that most if not all women who lose a baby have a certain sense of guilt. Almost any mother feels responsible for their child's welfare, and she tends to feel guilty over every bad thing that happens to them, including death. Many mothers will feel responsible for the loss, no matter what cause is listed on the death certificate. Some women blame themselves for the death of their child as some form

of punishment, and some women blame their social and economic circumstances.

Some women believe that not everything was done for their infant because they are poor and African American. One woman who said that she was sure her child did not receive the care he needed. It was her sixth child, and she was on Medical Assistance. She said, “*They thought I had too many children.*” However, the infant’s very large and detailed medical record clearly documented that the hospital personnel had tried everything to keep the infant alive. The interviewer can listen to these emotions, validate the feelings but remain non judgemental. If appropriate, an important part of the role of the FIMR interviewer is to reassure the mother that everything possible was done for the baby. Otherwise, without that feedback, women may internalize these negative feelings and the feelings may affect all future contacts with the health care system.

In the early 1990’s, Oakland had high rates of African American infant mortality but the least number of African American bereavement supports. The bereaved women in Oakland generally lacked familial support, partner support, and a social support system. There were no support groups and it was difficult to start one because women distrusted the ‘system.’ So, interviewers today may still find that there is a huge and unmet need for culturally appropriate and sensitive groups in the African American community, especially for lower income families.

*We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly.*

*Martin Luther King, Jr. Letter from a Birmingham Jail, 1963*

An emotional component of infant loss is that babies are the hopes and dreams of their parents. This is true for everyone—no matter the circumstances, new parents feel on top of the world when they have a baby. They have hopes and dreams for the baby’s future—that their child will have more than they have. Women of less affluence have the same aspirations for their children.

*“When a parent dies, you have lost your past.  
When a child dies, you have lost your future”*

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

On the other hand, these women also have a long history of multiple personal losses, not just infant loss but many other kinds of cultural, economic and social losses as well. So the loss of the infant, while it is devastating and heart wrenching, may not be the worst thing that has happened to them. Sometimes it isn’t even the most current pregnancy loss that was the most devastating loss. It may have been a pregnancy that happened three years ago. At times, a FIMR interviewer may find such a diminished reaction to the loss surprising and difficult to accept. The interviewer should keep in mind that the degree of grief and loss may depend on what other crises were going on in the woman’s life at that time and what she has experienced in the past.

Another issue is the real or potential loss of the relationship with the baby’s father. In many cases, the woman’s only connection to the father was the baby, and that connection may end with the death of the baby. The isolation for this mother is greater as she faces the devastation of two losses. Her expressed grief may be greater for the loss of the relationship with the baby’s father. The FIMR interviewer should remember that no one really has any control over how she will react to certain losses and be non judgmental about what the woman says and feels. The point is that the death of a baby is one part of an ever-changing landscape of the woman’s life. So her reaction is shaped by the many contextual factors that surround the loss.

After two to six weeks, family and friends may decide that the best way to support the mother is to avoid talking to her about the death. They may also expect the mother should be able to stop grieving, “move on” and return to normal. When the FIMR interview is initiated 2–6 weeks after the death, the mother may say that she feels something is wrong with her because she cannot stop grieving the loss. The FIMR interviewer can validate the

mother's feelings, give her permission to express her emotions and offer support and referral, as needed.

In summary, in the Oakland African American community, bereaved women who suffer an infant loss lack understanding about the process of grief, guilt over the baby's death, and a largely unfilled need for culturally appropriate support. These women need someone to focus on their needs. A

FIMR interviewer can help and is very well received in Oakland, in part because mothers say no one but the interviewer is there listening to their feelings. Even if the interviewer doesn't know the cultural norms or rituals, she can let the mother tell her story. The interviewer's greatest gift is to listen from the heart. She can provide the compassionate support these women so desperately need and they will appreciate it always.

## THE DEAF AND HARD OF HEARING CULTURE

*Based on a presentation by Margaret Widner-Kolberg*

*Today, I will discuss general issues about the deaf and hard of hearing culture related to interactions between hard of hearing patients and medical providers and some specific needs of families during pregnancy, the birthing process and in the postpartum period. Deaf and hard of hearing families have their own traditions. Hearing loss is superimposed on existing traditions. When the deaf and hard of hearing come in contact with an unprepared health care system, hearing loss may exacerbate feelings of isolation, stress and exhaustion for these families. This section provides some suggestions for working more effectively with families with hearing difficulty.*

Hearing loss exists in all age groups and affects all cultures. The exact number of people with hearing impairment is unknown, but the British Medical Research Council Institute of Hearing Research estimates that the total number of people suffering from hearing loss worldwide (greater than 25 dB) will exceed 700 million by 2015. In the developed world alone, the number of hearing-impaired people will reach 215 million by 2015.

Surveys based upon the American population have estimated:

- The number of hearing-impaired in North America today is more than 36 million people,
- By the year 2030, the number of hearing-impaired people in North America will reach 78 million,
- In the Baby Boomer population, one in six people has hearing loss,
- Between the ages of 29 and 40, what we refer to as the X generation, one in fourteen have hearing loss,
- In the population under 18 years of age, there are 1.4 million children that have hearing problems.

Hearing loss is defined as: a decrease in sound, silence. Hearing loss is indeed a "loss" and can reduce the quality of one's life in many ways. The impact of hearing loss is an individual one, and can only be defined in individual terms. Every person is affected differently by hearing loss as defined by their own particular personalities, their life histories and their social situations.

A person's cultural heritage strongly shapes their individual values and beliefs. A cultural group can be defined as people who share a common origin, language, customs, style of living and sense of identity. People with hearing loss develop individual variations like language, communication, and sense of identity. This fact, by definition, makes them a cultural group. This **invisible disability** greatly impacts a person's life and their interactions with others. Only by recognizing and understanding a families' specific culture can we incorporate and tailor our interactions to effectively help these families. We do this not only with our actions but most importantly with our communications skills.

Individuals who have good hearing usually take it for granted. Untouched by hearing loss, we do not realize the impact it can have on everyday life. Normal hearing allows full participation in all types of communication. Consider how much information we receive daily from conversations, listening to others, from radio and television. Most importantly, every day we rely on hearing for our interaction with those around us through the expression of ideas and feelings in conversation. Unthinkingly we rely on our hearing for the signals that shape daily lives—the

sound of door bells, telephones, alarm clocks, car horns, fire alarms.

Try imagining a life without sound, a world devoid of music, voices, or laughter. Now imagine hearing only partial sounds, distorted and muffled. This is the world experienced by a person who is hard of hearing. Exacerbating the impacts of hearing loss are the feelings of frustration, depression, isolation and exhaustion felt by a person with hearing loss.

There are many prejudices directed toward people who are hard of hearing. Some stigmas include:

- ▶ Almost all people with hearing loss are old people.  
*This is not true. About half of people with hearing loss are working age or young people*
- ▶ People with hearing loss are less intelligent than people with normal hearing.  
*This is not true. There is no connection between hearing impairment and intelligence. The range of intelligence of people with hearing loss is equal to intelligence across the general population.*
- ▶ People with hearing loss are almost always mentally ill.  
*This is not true. People are not mentally ill if they suffer from hearing loss. But psychologically it is difficult to be hard of hearing.*
- ▶ People with hearing loss hear what they want to hear.  
*This is not true. Hearing loss is not equal to selected hearing. The ability to hear depends on the degree and kind of hearing loss and the conditions and surroundings in the hearing situation.*
- ▶ If people with hearing loss cannot hear, they just have to wear hearing aids or turn up the volume.  
*This is not true. It is not that simple and even though hearing aids help they do not make one's hearing normal.*

People who suffer from untreated hearing loss often find it extremely difficult to participate in social activities, even with their own families. Some common social problems and consequences for people with untreated hearing loss are:

- ▶ Isolation and withdrawal
- ▶ Inattentiveness
- ▶ Bluffing
- ▶ Problems communicating with children/grandchildren
- ▶ Distraction/Lack of concentration
- ▶ Problems at work—may have to give up working/retire

- ▶ Problems participating in social encounters and reduced social activity

- ▶ Loss of intimacy

People who are deaf or hard of hearing use a variety of ways to communicate. These people might rely on sign language interpreters, assistive listening devices, speechreading and/or written messages. Many can speak even though they cannot hear. Under the American Disability Act (ADA), the method of communication and the services or aids the hospital must provide will vary depending upon the abilities of the person who is deaf or hard of hearing and on the complexity and nature of the communications that are required. Before deciding how to communicate most successfully to the family, health care providers should first ask the family how best to communicate with them.

It should be noted that many in the deaf community champion their unique situation and take pride in being a deaf person who only communicates through signing, using American Sign Language (ASL). This cadre of ASL signers share a feeling of belonging in the same milieu. They pride themselves as being the true deaf “culture”. They also differentiate themselves from those who are deaf but try to participate in the hearing world by speaking or communicating in other ways.

The United States enacted the ADA in 1990. Under the ADA, hospitals must provide effective means of communication for patients, family members, and hospital visitors who are deaf or hard of hearing. Hospitals cannot charge patients or other persons with hearing disabilities an extra fee for interpreter services or other communication aids and services. Effective communication is particularly critical in obstetric health care settings such as the prenatal care clinic or labor and delivery units where miscommunication may lead to misdiagnosis and improper or delayed treatment. As a general rule, it is always inappropriate to ask family members or other companions to interpret for a person who is deaf or hard of hearing. Family members may be unable to interpret accurately in the emotional situation that often exists in medical situations.

There are several ways other than signing in which a health professional can communicate with a person that is hard of hearing. One of these is **speechreading (lipreading)**. Health professionals can help



speechreading communication with people that are hard of hearing in conversation by following a few basic rules. These rules coupled often with technology make a difference in being understood. The rules are:

- ▶ Find a well lit environment away from noise to conduct the conversation
- ▶ Get the person's attention before beginning to speak
- ▶ Face the person when speaking to them
- ▶ State the subject matter up front
- ▶ Keep food, gum, hands away from the mouth, so that the patient can more easily speechread
- ▶ Speak normally, perhaps slow down a fraction, don't speak louder
- ▶ If the patient misses what is being said, repeat it in different words

These rules sound simple but remembering them and using them consistently take practice. It takes effort by both parties to the conversation and more importantly, assertiveness by the person with the hearing difficulty to ask for what they need. One problem with lip reading is that only 30 to 40% of English sounds are readily visible on the lips. People who are deaf and hard-of-hearing report misunderstanding words when lip reading, especially when the health care provider wears a beard, speaks rapidly, does not look directly at them or speaks with a foreign accent or an impediment. Of course, during delivery or for other obstetric procedures, providers and staff wearing masks make lip reading impossible. Both deaf and hard of hearing individuals describe fear when they have no means of communication with clinicians or technicians during physical examinations or procedures when the providers are masked.

Some individuals who are deaf or hard of hearing rely more on **written communication**. However, writing may not be an accurate communication medium. It has been estimated the reading level for some people who are deaf and hard of hearing may be at the fourth grade level when they graduate from high school. Thus written information about diagnosis, medications and medical procedures can be easily misinterpreted or misunderstood. It is also important to understand that even through a deaf or hard of hearing individual is proficient in American Sign Language, she may not be as proficient in reading English or in speechreading.

For **telephone communications**, many people who are deaf or hard of hearing use a teletypewriter (TTY)

rather than a standard telephone. These devices have a keyboard and a visual display for exchanging written messages over the telephone. The ADA established a free nationwide relay network to handle voice-to-TTY and TTY-to-voice calls. Individuals may use this network to call the hospital from a TTY. The relay consists of an operator with a TTY who receives the call from a TTY user and then places the call to the hospital. The caller types the message into the TTY and the operator relays the message by voice to the hospital staff person, listens to the staff person's response, and types the response back to the caller. The hospital must be prepared to make and receive relay system calls, which may take a little longer than voice calls. For outgoing calls to a TTY user, simply dial 7-1-1 to reach a relay operator.

For more complicated and interactive communications, such as a patient's discussion of symptoms with medical personnel, a physician's presentation of diagnosis and treatment options to patients or family members, or a group therapy session, it may be necessary to provide a **qualified sign language interpreter** or other interpreter. (See Table 1) In the US, this usually means someone that excels at American Sign Language (ASL). However, foreign born patients or those whose first language is not English may use another form of signing. In fact, ASL is not exactly the same as British Sign Language (BSL).

#### Situations where an interpreter may be required for effective communication:

- ▶ discussing a patient's symptoms and medical condition, medications, and medical history
- ▶ explaining and describing medical conditions, tests, treatment options, medications, surgery and other procedures
- ▶ providing a diagnosis, prognosis, and recommendation for treatment
- ▶ obtaining informed consent for treatment
- ▶ communicating with a patient during treatment, testing procedures, and during physician's rounds
- ▶ providing instructions for medications, post-treatment activities, and follow-up treatments
- ▶ providing mental health services, including group or individual therapy, or counseling for patients and family members

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- ▶ providing information about blood or organ donations
- ▶ explaining living wills and powers of attorney
- ▶ discussing complex billing or insurance matters
- ▶ making educational presentations, such as birthing and new parent classes, nutrition and weight management counseling, and CPR and first aid training.

From US Department of Justice, Civil Rights Division. ADA Business Brief: Communicating with people who are deaf or hard of hearing in hospital settings. October 2003 <http://www.ada.gov/hospcombr.htm>

Families who are hard of hearing and deaf face unique challenges during pregnancy, labor and delivery even in the best of circumstances. Much of what has been reported about the deaf experience during pregnancy comes from sources in Britain. The UK Disability Act of 1995 seems to have spurred families, advocates and providers to begin to address the needs of deaf mothers. The vignettes below are excerpts adapted from Sabina Iqbal's book *Pregnancy and Birth: A Guide for the Deaf Woman*, which was published by RNID in the UK in 2004. They describe the isolation, lack of resources and information encountered by deaf women in the health care setting:

*"It was difficult to access information about pregnancy or parenting from any bookshop or library because of the high level of English and I had to rely on my husband or someone to translate the information from English into British Sign Language (BSL)."*

*I missed out on a lot of information in antenatal classes. I saw a video about preparing for labor and delivery but it had no subtitles and no BSL on the video. I would have preferred to go to antenatal classes for deaf parents so that I was in a signing environment. Instead I was the only deaf parent in the class. I was so isolated and felt left out from the friendly conversations among the class."*

*"I put in big capitals on my birth plan that I was hard of hearing and how they could help me. I think that helped a bit, but when the crunch came, nobody told me what was going on. I was cut when I didn't want to be and I did feel ignored. When the baby was born, they told my husband it*

*was a baby girl—and I was lying on the bed exhausted and forever asking whether I had a baby girl or boy."*

*"The midwife came for a check of me and the baby. I made sure that my own hearing mother wasn't around because then the midwife would only talk to my mother and not me."*

*"During the first night after my baby was born, the vibrating baby alarm wouldn't work as the ward had many crying babies and the alarm kept going off. So I told the nurse to alert me if my baby cried when I was asleep—but she didn't. Instead she woke me and angrily asked me why I was not taking care of my baby who was crying. I had to remind her that I was deaf."*

These experiences point out the importance of awareness and importance of clear communications with mothers and families during pregnancy and child birth. These clear communications become immeasurably more important when faced with a perinatal loss or infant death. The fear and stress of the situation can be compounded because of communication difficulties. Poor communication between hearing providers and families who are deaf and hard of hearing may create an atmosphere of mistrust in the system, depression, further isolation, and guilt. Families may never get to ask all the questions about the infant's death that they want to or the questions that they do ask may be misunderstood. This lack of knowledge affects future relationships between the husband and wife; between parents and surviving children and between parents and the entire family.

After validating the best method for communication with the family, the FIMR interviewer can use that method to make a difference for these families that will last a lifetime. The FIMR interviewer can provide accurate information about what happened to the infant. As appropriate, the interviewer can reassure the parents that they could not have done anything to prevent the death and that everything possible was done to save their infant. The FIMR interviewer can listen to the story of the mother's loss. Finally, the mother may be unaware of care she should receive to improve the outcome of subsequent pregnancies and this can be communicated as necessary through assistive hearing support. The FIMR interviewer can explain the need and refer the patient for any such care needed.

The FIMR team can also be an advocate for families who are deaf and hard of hearing. The team can take action to ensure that the services and resources mandated by the ADA are actually available to childbearing families in their community. The team can also act to ensure that the needs of deaf and hard of hearing families who have lost an infant are addressed, their questions are answered and that they are not alone in their time of grief and sorrow.

In summary, serving any patient community requires clear and appropriate communications. Serving the patient who is deaf or hard-of-hearing is about communication. Important life saving and

emotional support is not possible unless the health providers communicate information to the patient effectively. Assistive devices and assistive efforts permit patients and families who are deaf or hard of hearing to “hear”. However, hearing loss is not the same for any two individuals. What works for one person may not work for another person. The varying degree of hearing loss among patients requires a broad array of available resources to effectively serve this special patient population. There is one common denominator. The deaf and hard-of-hearing patient population deserves the same quality of care as other patients.

## ABOUT THE PRESENTORS

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