

Providing care to Hmong-Americans

Disclosure Statement: The following is a guide for healthcare providers to learn about the Hmong culture with emphasis on Hmong End-of-Life care beliefs. This guidebook should serve only as a general reference in relevant cases. It is the belief of the creator of this reference booklet that every Hmong patient is an individual with individual ideas that may or may not reflect these generalizations on traditional Hmong culture.

The purpose of this guide is to:

- Introduce Hmong traditional health and healing beliefs in relation to death and dying
- Provide culturally sensitive tips, suggestions, and practices to help increase trust and alleviate cross-cultural misunderstandings
- Help healthcare providers become more aware of personal bias, stereotypes, assumptions and anxieties that may be contributing to insensitive care practices

General

Religion

Although an estimated 70% still practice traditional Hmong religion, a significant number are Christians. Many have a combined system of beliefs.

Spirits

Dab is the general term for spirits in the world and can cause a wide variety of illnesses through various means. Telling Hmong patients directly that they are dying is taboo, for a dab may overhear the conversation, realize the patient is weak, and steal the weak patient's soul.

Body

The Hmong view the body as a whole, with each body part having a soul that interconnects with the souls of the other body parts. If one part of the body is sick, this sickness may spread throughout the body to affect the whole body. Illnesses may be caused by natural phenomena—germs, changes in weather, accidents, or emotions, or supernatural forces—fate, soul loss, ancestral spirits, or evil spirits.

Family Dynamics

Clan

The central unit of social organization in Hmong communities is the clan. Thus, collective identity is central to the Hmong way of life.

Decision-Making

Many Hmong regard "the family group" as more important than "the individual," for making health care decisions. Extended male family members and clan leaders are often involved in difficult decision making processes.

Usually, no one person makes a decision; rather, the group discusses the options with certain members holding more respect or weight in the conversation. The group then comes to an agreement such that the group is then responsible for the outcome of the decision. Some people believe that it is better to do nothing than to interfere with fate and be responsible for the result of interfering.

It is important for physicians to realize that decision-making in the traditional Hmong community can be a timely process, but the time is important for creating a trusting and therapeutic relationship.

Health

Life Circle

Traditional Hmong believe that the physical world co-exists with and is connected to the spiritual world. Life and death are joined in a circle in which the person rotates with reincarnation bringing the soul back to life. The person's fate, whether born as an animal or person, and how much one suffers, depends on the type of life they lead in a previous life, as energy is carried further into future lives.

Healer

A ritual healer is a person who performs healing rituals to cure various illnesses. The healer, usually a man, learns his gift and receives his connection with healing spirits from other healers. The healer calls spirits with incense and then directs spirits to help the patient by using a bowl of water and silver coins, a metal knife, or his own breath. Healers are consulted for specific problems and are thought to solve physical problems, emotional problems, and spiritual problems.

Traditional treatments

- Herbal remedies
- Food intake
- Animals are sacrificed for different reasons for various healing and religious purposes. If a sick patient's soul was stolen and taken to the spirit world, a shaman might exchange the animal's soul for the human soul

Nontraditional treatments, which are deterrents for many Hmong patients

- Immunization
- Blood transfusions/organ donation
- Surgery

Communication

- Verbal
 - Value small talk
 - High context communicators

- Non-verbal
 - Avoid prolonged eye contact
 - Use engaging body language
 - Recommendations: *use a soft gentle voice, make indirect eye contact or brief direct eye contact, and convey a sense of patience*

Recommended tips for relaying an illness:

1. Talking about the possibility of a terminal diagnosis

- When you are anticipating that a diagnostic test may result in a terminal diagnosis, you could say:
 - *"I am unsure what this test will show. I am concerned that it could be a severe illness. If it is not serious, we will all be joyful for you. But if it is serious, who would you like me to talk with? We could have a family conference; which family members would you want to be present?"*

2. Talking about death and dying

- Prior to death, it is inappropriate for practitioners to directly say
 - **To the patient:** *"You will die",*
 - **To the family:** *"Your mother only has two weeks to live."*

Although it is common practice to explain to families about the life expectancy of a loved one, it is disrespectful to give an approximate time frame unless specifically asked.

To convey that a person will not have long to live, a Hmong person might say:

- "Nws txoj sia tsis ntev" (Her/ his thread of life is not long, or s/he will not have long to live);
- "Tej zaum nws nyob tsis taus ntev" (Probably s/he does not have long to live)
- "Nws nyob tsis taus txog 120 xyoo". ("She cannot live to be 120 years old.").

This phrase is derived from a Hmong folk tale that identifies 120 years as the ideal age before the soul begins its journey to yeeb ceeb for reincarnation (Gerdner, Cha, Yang, & Tripp-Reimer, 2007).

To convey that medical and nursing actions can no longer keep patients alive, providers can say, "The sky is getting darker and darker and the sun seems to be setting more and more."

All of these expressions can convey the same meaning as talking about death directly without making patients and families feel that providers want death to occur.

End of Life

Varying wishes

- Making decisions for patients at the end of the patient's life varies from patient to patient and from family to family. Most Hmong adults have not

created living wills, as it has been taboo to make plans for future adverse events.

- Some families will want everything done for their loved ones, while others will carefully accept some interventions while rejecting others.
- Some families embrace hospice and palliative care while others continue to pursue multiple therapies in the hopes of a cure.

Hospice care

- Many Hmong patients want to have immediate family as well as clan members present when a family member is sick in the hospital. Families tend to be large, and it is culturally important that the extended family show their respect by being present for a family member's serious health problems.
- While many hospitals have policies surrounding how many people can visit patients, bending this rule can both show respect for the patient's culture as well as facilitate the Hmong family decision-making process.
- Having all members present may speed this process when time is of the essence and decisions need to be made quickly.

Advanced directives

- When discussing advance directives the most culturally responsive approach is to arrange a care conference with family members and a cultural interpreter who can act as a cultural broker. It may be helpful to acknowledge the sensitive nature of the topic and explain the obligation that health care providers have in understanding elder's wishes (Gerdner, Cha, Yang, & Tripp-Reimer, 2007).
- Since Hmong elders come from an oral culture, it may be more culturally appropriate and meaningful to use an audio recorder instead of written consent of wishes (Reid, 2007).
- "In addition, it may be helpful for providers to explain that they're trying to empower the family by converting their family-based decision making process into an American medical and legal document, which will insure that family's desires are respected when the time arises"(Standford, 2012)

Post-mortem care

- Helpful phrases:
 - ***b pas nqus tsis tuaj***: "One [more] breath doesn't come"
 - **Tas sim neej lawm**: "S/he has reached the end of life"
 - **Nws tsis nyob nrog peb lawm**: "S/he is no longer with us"
 - **Nws xiam lawm**: "S/he is lost or gone"

Quick tips:

- Build trust by engaging in small talk
- Avoid prolonged eye contact

- Refrain from asking a woman to disrobe (if possible)
- Determine communication preferences for decision-making prior to any treatment
- Use an interpreter, but remain engaged with the patient
- Explain, explain, explain!

Reflective exercises:

- Are you aware and mindful of your own cultural beliefs, values, and behaviors?
- How do these affect your interactions with patients?
- If you cannot manage your biases for the sake of the patient, do you recognize that limitation and defer to a colleague?
- How do we adapt to the needs and preferences of our patients?
- Are we open to different approaches to the same problem?

Patient Stories (Johnson, 2002)

Misunderstanding:

In Laos, Hmong individuals did not have exposure to modern medicine or education, so the complexities of the human body were generally unknown to them. When asked if they understood the anatomy of the human body, all informants indicated they had no idea what organs were in the body or how the organs functioned. When health care providers would tell them they had a disease or malfunctioning organ, they were at a loss and had difficulty comprehending the situation. Most of the medical and anatomy terms that were used by Western medicine had no words or terms in the Hmong language. Explaining about a malfunctioning kidney would require that the interpreter use a lengthy paragraph to say what could be said with one word in the English language.

Nurses story:

I was working in the emergency room one night and a Hmong family brought in a patient who had been vomiting blood. We immediately put in an N/G [nasogastric] tube and bright red blood was flowing from the catheter. The family members went crazy. They tried to pull the tube out and take the patient out of the hospital. We had to call security and they took the family members away. They thought we were killing the patient and we thought they were trying to kill the patient. If we had known about the belief in the "Pool of Blood," we could have been more understanding of their reaction. (The belief was that in the chest there was a pool of blood that was vital to life. If a person lost this pool of blood, he or she would die.)

Emergency Room Experience:

One elderly woman tearfully shared an experience she had when going to an emergency room. She said she had a terrible pain and thought that she was going to die. She was extremely upset, crying and writhing in pain. She could see the American doctor checking other patients in the room, and he treated them respectfully. When he came to her, he began to mock her distress by mimicking her facial expressions and crying sounds. She felt humiliated and cried as she said, "Why did the doctor treat me so badly when he was nice to the other patients?"

Miscommunication:

This is a story of Hmong parents whose 15-year-old daughter was diagnosed with metastatic terminal ovarian cancer. The parents had been told prior to her surgery that she had appendicitis and she would be fine after the surgery. After giving the parents the terrible diagnosis of metastatic cancer, the physicians asked the parents to give consent for the daughter to receive palliative chemotherapy. They gave the parents the information that the chemotherapy would not save their daughter's life but may help to prolong it. They also said that there were potentially serious complications of receiving the chemotherapy including nausea, vomiting, weight loss, hair loss, and possibly death. The parents were asked to give consent for this procedure, and they assumed that they had the right to choose. They refused the chemotherapy; they thought if their daughter was going to die, they did not wish her to suffer more due to the treatment. The physicians became angry and told the parents, "If you aren't going to let us help your daughter, you may as well take her home." The parents took this comment as an instruction and took their daughter home. They were very shocked the next day when police came to their door and forcibly took their daughter to the hospital where she was given chemotherapy against her parents' and her wishes. The physicians had obtained a court order saying the parents had removed their daughter from the hospital "against medical advice." The court order gave them permission to return the child to the hospital and force the child to have a treatment that even they had deemed to have marginal effect. The parents were frightened and heartbroken. They could not understand why they had been asked to give consent for the chemotherapy treatment when, in fact, they had no choice. They could not understand why their beloved daughter was being forced to have the terrible treatment that they perceived as torture.