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Hospice Patient with Gallbladder Cancer

A Case Story

Cher Xiong was a fifty-four-year-old woman with ten children ranging from eight to twenty-two years of age. She and her family had been living in the United States for fifteen years. Ever since she had delivered her last child eight years ago, she had had intermittent pain in her upper right side. Her doctors diagnosed gallstones and recommended an operation to remove the gallstones (a cholecystectomy), but Mrs. Xiong was uncertain that the invasive procedure could relieve her pain. She believed the pain had been caused by nurses who, after the delivery of her last child, had vigorously massaged her uterus over her objections.

Finally, unable to tolerate the pain any longer, she agreed to the operation. Following the procedure, the family was disappointed that the physician did not show them the gallstones, as he had promised he would. The doctor informed Mrs. Xiong and her family that she had cancer of the gallbladder and recommended chemotherapy. After long discussions, Mrs. Xiong and her family decided against accepting the doctor's recommendations for chemotherapy.

A year later, the cancer obstructed Mrs. Xiong's common bile duct, her skin became yellow, and she had abdominal pain. At this point the family asked the doctors for curative therapies, including surgery, chemotherapy, and radiation. But the physicians, understanding this to be an incurable terminal illness, offered only palliative therapies. For months the doctors tried to support her with medicines for pain control, an operation to drain bile, and a feeding tube with nutritional supplements. The specialists continued to be concerned that the family was not accepting Mrs. Xiong's terminal state. When the cancer infiltrated the beginning of her small intestine obstructing her stomach outlet, the family agreed to hospice care, including DNR/DNI (do not resuscitate/do not intubate).

Mrs. Xiong was transferred to a hospice unit, where for five days she experienced good pain control and no bleeding. She was drinking small amounts. A family member brought a video camera to record her statements; she talked about how she loved her children and wanted to be their mother forever.

On the sixth day, the patient was weaker. That night, shortly after the nurse gave her an intravenous antibiotic and flushed the line with saline and then heparin, she

became drowsy and barely responsive. Family members spoke with the nurse, but the communication did not go well. From the nurse's perspective, the family was upset about the patient's declining course and was not accepting her terminal state and her impending death. For their part, the family members interpreted the nurse's questions—"Why are you so upset? Don't you know she came here to die?"—and her tone of voice as meaning that the nurse wanted the patient to die. They became very upset, convinced that the nurse had harmed the patient—having poisoned or at least cursed her.

Mrs. Xiong's room filled with relatives. Her husband wanted to take her home, given that the hospice providers could not help her get better. The family wanted her to wear the ceremonial Hmong clothes she had made. They also wanted her to be with her children, to be available for family visits, to be home for Hmong New Year, to do Hmong healing practices, and to be protected from the nurses. The family took Mrs. Xiong home.

Once she was home, many people visited, including the family's Catholic priest. Family and friends kept a constant vigil around Mrs. Xiong's bed. They tried to persuade her to wake up, eat rice, and drink water, which they offered with spoons and cups. They pleaded with her not to die, saying they needed her. The Xiong house was filled with people day and night for seven days. The husband repeatedly expressed his anger that the nurse had tried to kill his wife.

A conference was held among four male family members, the family physician, and the head nurse of the hospice unit to address their concerns about the possible poisoning. After investigating, the head nurse determined that there had been a cross-cultural misunderstanding, but no evidence of poisoning.

Three shaman came to help Mrs. Xiong, performing ceremonies aimed at diagnosing and treating any lingering spiritual problems. Almost a week after coming home, she slowly woke up, to the delight of her family. Mrs. Xiong said that her dead mother had been holding her head under water; she could see and hear everyone in the room but was unable to answer them. The family rejoiced that the shaman had been successful at separating the grandmother's spirit from the ill woman.

About a week later, on the first day of the Hmong New Year, the patient experienced rectal bleeding and infection of the parotid gland. She and her husband agreed to hospitalization for blood and antibiotics as long as the nurse they distrusted was not allowed to take care of her. Two days later she again became lethargic. When her husband understood that the doctors could no longer do anything for her, he took her home. Two days later she died, surrounded by family members who wailed in grief.

At the funeral home, the family asked the undertaker to remove the staples in her abdomen from the gallbladder operation. The family dressed her in multiple layers of traditional clothes and placed her body in a wooden casket made without nails or screws, lined with a white cotton shroud, and prepared for a four-day-long ceremony.

Questions for Consideration

Questions about Culture

How did the family's and the providers' perceptions and beliefs about etiology influence ideas about appropriate treatment?
Why did the patient and her family refuse treatment for gallbladder cancer initially and then ask for treatment later?
When are pain control measures considered appropriate? Why might an ill Hmong patient refuse pain medications?
Why did the family agree to hospice care and DNR/DNI?
How are the issues of death and dying handled and discussed in traditional Hmong families? In Christian Hmong families? In Anglo-American Christian families?
In traditional Hmong culture, what counts as a "good death" and as a "bad death?" What do U.S. hospice providers consider a "good death" and a "bad death?"
What cultural values and practices may provide barriers to Hmong families accepting hospice care? Which values and practices are congruent with hospice care?
What cultural beliefs underlie the practice of dressing the dying woman in her ceremonial clothes?
Why did the family request that the staples be removed from her body after death?

Questions about Cross-Cultural Health Care Ethics

Which behaviors of the U.S. providers did the most to damage the family's trust and which behaviors did the most to enhance it?
How are love, care, and concern expressed toward a dying person in traditional Hmong culture? How well does hospice's concept of "accepting" death fit Hmong beliefs about respectful treatment of the dying?
What cross-cultural differences arose regarding the disclosure and communication of health-related information?
In what way was the family's philosophy of end-of-life care in conflict with the philosophy of hospice? What accommodations is it reasonable to expect hospice to make? What accommodations is it reasonable to expect the family to make?

Questions about Culturally Responsive Health Care

What aspects of this case offer examples of a good cross-cultural relationship?
How might health care professionals prevent and respond to initial refusals for early treatment of cancer?
How might traditional remedies be combined with hospice care?
How might some of the barriers to Hmong understanding and acceptance of hospice be overcome?
What factors should health care professionals take into consideration when discussing a terminally ill patient's prognosis? When pronouncing a patient dead?
What type of grief counseling might be most welcome?
What can U.S. health care professionals learn from this Hmong family that might be helpful in their relationships with other patients?

Commentary

Cultural Complications in End-of-Life Care for a Hmong Woman with Gallbladder Cancer

Kathleen A. Culhane-Pera, M.D., M.A.

I am privileged to have known Mrs. Xiong. She taught me a lot. First, when I was a stranger, she invited me into her home for Hmong New Year, included me in her preparations for the feast, and explained the meaning of the soul-calling ritual. Later, when I became an acquaintance, she reached out to me at Hmong gatherings to include me in the events and shared with me her family's challenges in adjusting to life in the United States. And finally, when I became her primary care physician at the end of her life, she shared with me her physical sufferings, her struggles to find meaning in her illness, and her attempts to be cured so that she could continue to be a mother to her children. I am grateful to her for opening her home and heart and for sharing her last days with me. And I am grateful to her for the lessons she taught me about the importance of culture in illness. In this commentary, I describe what I learned about her health beliefs and about culturally responsive health care.

Abdominal Pain and Gallbladder Operation

Mrs. Xiong suffered with pain in her upper right side for years before consenting to a gallbladder operation. When I have told her story to physicians, some have asked me, "Why did she suffer rather than consent to a curative operation? Surely it would be better to have an operation than suffer from physical pain." These questions express the biomedical perspective—that pain is physically embodied and that operations can cure the pain by removing the physical source of pain. Mrs. Xiong had a different perspective.

For Mrs. Xiong, health care workers had caused the pain and she was doubtful that an invasive procedure could remove the source of pain. She recounted that after she had given birth to her last child, the nurses had forcefully massaged her uterus and had caused permanent damage to her uterus and abdomen. Proscriptive and prescriptive behaviors *(caiv)* after childbirth are important for ensuring women's short-

term survival, long-term health, including fertility, and ability to produce breast milk. For example, postpartum bleeding is necessary to rid the uterus of old blood, so that the women's bodies are clean. If the old blood stays inside, women may develop infections, become infertile, and be bothered by multiple ailments for the rest of their lives. To ensure the blood flow and restoration of the uterus, women must not encounter wind, cold air, cold water, cold foods, intercourse, or rough handling of the uterus since these can cause the blood to congeal internally.

These concepts conflict with the nursing perspective that blood must stop flowing in order to prevent hemorrhage and the biomedical practice of massaging the uterus to express clots and make the uterine muscle clamp down. Hospital personnel focus on stemming the blood flow, while Hmong people focus on ensuring adequate blood flow. Nurses vigorously massage the uterus while Hmong women gently wrap the lower abdomen in a fabric binder. Compromises between these two positions can occur; for example, women can gently massage their own bodies, and nurses can accept more than the usual amount of uterine blood flow.

Mrs. Xiong tried to relieve her pain with home therapies, such as massage *(zaws hno)* and herbs *(tshuaj ntsuab)*, and sought assistance from a multitude of healers: Chinese acupuncturists and Asian grocers with their Thai and Chinese pharmaceuticals, as well as U.S. doctors and chiropractors. Finally, unable to tolerate the pain any longer, she consented to a gallbladder operation.

Still, Mrs. Xiong had fears about the operation that were similar to other Hmong people's concerns. After operations, some people have experienced long-term incisional pain and weakness that impair their abilities to return to a job, do housework, care for children, attend school, or make love for a year or more. Other people have experienced spirit loss from the fright of the operation or the "sleeping" medicine of anesthesia. Many people have been concerned that bodily mutilations can be carried into the next life. Finally, everyone has heard stories of doctors not taking good care of Hmong people and operating for their own benefit, such as learning, experimenting, or making money, or operating on Hmong people in order to harm them or kill them (Culhane-Pera, 1987; Mouacheupao, 1999). Because of these fears and concerns, Mrs. Xiong refused the operation for years, and they were still vivid in her mind when she finally agreed to have the operation.

Gallbladder Cancer: Initial Diagnosis and Considering Chemotherapy

Mrs. Xiong and her family listened to the news about the gallbladder cancer and the doctors' recommendations for chemotherapy but never went to see the oncologist. Physicians have asked me, "Why did they not act?" "Why did they refuse chemotherapy?" In fact, the patient and her family did act, but not in a Western biomedical way. They sought Hmong healers' opinions of her health and were reassured that she was healthy. In the patient's and family's explanatory models, Mrs. Xiong was not sick; she had no signs or symptoms to indicate that anything was wrong with her. There was no pain, no weakness, no X-ray finding, and no tissue that looked abnor-

mal. All they had was the doctor's word that she was sick. Also, they sought Hmong people's opinions of chemotherapy from their personal and familial experiences. Ultimately, the family decided they did not want her to experience hair loss, weight loss, vomiting, and profound weakness for an uncertain malady.

Symptoms of Gallbladder Cancer

When Mrs. Xiong did become sick with jaundice and an enlarged liver, her family queried the doctors about various biomedical therapies: operations, chemotherapy, radiation, and medications. Now that she had signs and symptoms that they identified as an illness, they sought life-saving treatments. Hearing that her doctors could not help her, and thinking perhaps that her doctors did not want to help her (after all, the doctors were angry that she had refused chemotherapy initially), they pursued other options: doctors at other hospitals, Catholic priests, and traditional Hmong healers. While they agreed with the doctors' serious diagnosis and the dire prognosis, they did not accept their physicians' view that seeking a cure was futile.

Mrs. Xiong and her family wondered about the cause of her cancer. They knew that cancer was caused by the chemicals in U.S. water and food, but they routinely boiled their water and bought animals from a local Hmong farm in order to avoid these chemicals. They wondered about the staples in her abdomen from the operation; perhaps the metal had caused a serious reaction like cancer. They considered whether anyone had cursed her. They consulted their priest, went to church, and wondered whether God was punishing her for her sins. And they wondered about a spiritual cause that Christianity could not elucidate. Consulting a Hmong shaman, they learned that Mrs. Xiong's husband's father's soul was unhappy. Their father had died during the war without a funeral, without having a song to guide him to the land of the ancestors, and without a burial. Thus, his souls were in limbo, unable to fulfill their destinies of reaching the land of the ancestors, being reincarnated, and guarding over the buried body.

The family responded to Mrs. Xiong's problems, seeking to cure her as well as make her comfortable. They sought Hmong healers, gave her herbal medicines *(tshuaj ntsuab)*, massaged her swollen abdomen (*zaws*), and tied strings on her wrist after calling her soul *(khi tes hu plig)*. They conducted a shaman ceremony *(ua neeb)* to try to rescue their father's souls. They saw doctors and gave her Western medicines for diabetes, nausea, and pain. They worked with the home nurses to create a bedroom on the first floor, complete with hospital bed, commode, and an electric nasogastric pump to administer nutritional supplements through a nasogastric tube.

In short, her family was very active in her care. Mrs. Xiong was raised in a social system that conceives of individuals as an integral part of their families, not as separate social beings. At every phase of Mrs. Xiong's illness, the men of her family—her husband, married son, husband's older brother, and husband's adult nephews—were her therapy management group. They listened to the doctors' explanations and recommendations, enlisted the assistance of Catholic priests and Hmong shaman, weighed the possible etiologies and the pros and cons of each treatment regimen, and considered whether to resuscitate her and whether to enter hospice and eventually decided to take her home from hospice. Mrs. Xiong expected and trusted her family members to make the best decisions about her care, and as far as I could tell, Mrs. Xiong agreed with her family's decisions.

Considering Resuscitation

From her initial hospitalization for the metastases to the hospitalization for the duodenal bleeding, health care providers had recommended that Mrs. Xiong not be resuscitated or intubated, since she had a noncurable terminal illness. But the family refused these recommendations because they wanted the doctors to save her life. At one hospitalization, the doctors raised this issue again. They wanted to speak directly with Mrs. Xiong, but because she did not speak English and because a trained Hmong interpreter was not available, the doctors inquired about her desires through her married son. Her husband and son answered the question: they wanted everything done for their wife and mother. Unsatisfied, a doctor pressed them to ask Mrs. Xiong about her desire. Her son translated the doctor's question and their answer, and she replied that she agreed with her husband and her son. The doctors left the room, feeling uncertain they had heard Mrs. Xiong's true desires.

On several prior occasions, I had talked with Mrs. Xiong about her physical pain, her emotional suffering, and her desire for a cure. Mrs. Xiong had expressed ambivalence, wanting to live so her children would have a mother and wanting to die so that her pain and suffering would be over; but mostly she wanted to be cured and be a mother for her children. While she did not express any ambivalence in that hospital room, I believe that she had expressed her feelings and desires to her husband at other times.

A month later, after an episode of vomiting blood and after a CT scan indicated that a mass was invading her small intestine, the family talked about resuscitation again. Mrs. Xiong's male family members surrounded her bed, evaluated the gravity of the medical assessment, and considered their options. She turned to me, asking with begging eyes to tell her I could cure her. My heart sank. I wanted to answer her in the affirmative, as Hmong custom seemed to demand. How could I be medically accurate and not give her false information, as medical custom demanded? The family discussed the situation and ultimately decided that since neither medicines nor operation could cure her, they wanted her to receive the best supportive care that we could provide. At that bedside, the men decided to enter Mrs. Xiong in the hospice program, which included not resuscitating her. Mrs. Xiong was quiet with the solemnity of finality on her face.

A Good Death

Through the choices they made, the actions they took, and the feelings they expressed, Mrs. Xiong and her family revealed one version of a "good death." They rejected hospital care when the hospital could no longer provide any curative assistance, and they

rejected hospice care when it seemed dangerous. They decided to take care of her at home instead.

At home after she left the hospice unit comatose, Mrs. Xiong wore her traditional Hmong clothes *(khaub ncaws laus)*. When people die they travel to the land of the ancestors, live as ancestors, and relate to living people as ancestors. Wearing ancestral clothes is symbolic of this status change. At home, her family members encouraged her to eat and drink and thus expressed their love by providing for her. At home, her children cried and told her they did not want her to leave them, because she was the only mother that they had, and who would take care of them and love them if she left? At home, relatives and friends filled the house, to encourage her to get well, pay their last respects, comfort the family, and find solace for their own grief. Also, people stayed at the bedside to hear Mrs. Xiong's last words, for a dying person's last words convey wisdom and blessing on those who hear them.

The family provided her with more than just culturally appropriate supportive care, however. They also continued to seek cures from herbal therapies, from Christian prayer, and from shaman rituals. And they were rewarded in their efforts when, after many days, she woke up from her coma and lived with them for another week. When she failed again, her family and friends once again gathered around her. At the very instant that Mrs. Xiong died, the throng at her bedside began to wail *(hniaj)*, expressing their grief, all in their own words and in their own musical tune. Mingled, the voices created a powerful symphony of human emotion.

As heart wrenching as her passing was, Mrs. Xiong's death could be considered a "good death." A "bad death," in contrast, is one where a person dies alone with no one to mourn, wail, or appropriately take care of the body; where a person dies in an accident, since souls will stay at that place and take other victims in the future; where a person dies in physical agony from a violent mutilating death, which carries bad luck into the next life; or where a person commits suicide, which condemns a soul to wander in limbo for eternity.

Hospice

The conflicts in the hospice in-patient unit were due to the nurses' and the family's different concepts of optimal care of the dying person. For the hospice nurses, optimal treatment included making Mrs. Xiong physically comfortable, telling her she was dying, verbally giving her permission to go, and not feeding her when she was comatose. These ideas conflicted with the family's cultural norms about how to care appropriately for Mrs. Xiong. To the hospice nurses, the dying patient's needs were not being met, but I suspect that Mrs. Xiong's needs were being met, since she had been socialized into her own cultural norms about appropriate behaviors toward sick and dying people. To the hospice nurses, the family was in denial; I believe that the family understood she was dying but were responding to her final days in a manner appropriate for Hmong culture. While the nurses tried to understand the Hmong concept of end-of-life care so they could adjust their care, they had difficulty embracing the Hmong approach, which, on one hand, agreed with supportive care and rejected aggressive therapies but, on the other hand, held out hope for finding a cure.

Does this mean that hospice care is inappropriate for traditional Hmong people? I do not think so. I think it means that the hospice team needs to provide support to the family and to the patient in ways that the family and the patient define as supportive, which can include taking care of a dying patient without directly communicating about dying and continuing to provide some therapies that might extend life.

Distrust and Vulnerability

Several issues contributed to the distrust Mrs. Xiong and her family felt toward health care providers. At times their requests and desires were in direct conflict with health care providers' actions. The obstetrical nurses continued to aggressively massage her uterus after childbirth despite her protests. The surgeons did not show her the gallstones, as they had promised. The doctors refused to give her any treatment when she had symptoms from her cancer. The doctors repeatedly inquired about not resuscitating her. And the hospice nurse had wanted her to die. Distrust was fueled by communication problems. There were few trained interpreters available in the hospitals and clinics where she was seen, and when there were interpreters, providers had poor skills in working with them.

The distrust between providers and patients goes beyond the micro-level of doctor-patient communication and relationships; it extends to the macro-level of political and economic systems. As a refugee woman, Mrs. Xiong's life had been dramatically influenced by forces far beyond her control. International geopolitical and economic issues—which resulted in the Vietnam War, recruitment of Hmong soldiers, withdrawal of U.S. military forces, interim refugee camps in Thailand, and, finally, resettlement in the United States—caused feelings of vulnerability to and alienation from mainstream U.S. society.

Mrs. Xiong's own ideas about the etiologies of her cancer suggest how her suffering and her sense of vulnerability in her new country contributed to her distrust. She blamed her husband's dead father, who had not received his proper burial. The wandering soul's perpetual suffering that could not be repaired is an apt metaphor for the loss of cultural certainty that occurred when the war uprooted people from Laos and for the sense of powerlessness refugees feel. She blamed the contaminated food and water of the United States, which contrasted sharply with the untainted food the Hmong had grown and pure water they had used in Laos. She had tried to isolate herself from the contamination by boiling water or eating foods that came from Hmong farms, just as she had tried to protect herself and her family from other hazards of U.S. society; but she was unsuccessful. Perhaps sensitive to the interjection of aspects of U.S. life that are foreign, unnatural, and ultimately harmful to the Hmong people, she blamed the metal left in her body from the gallbladder operation. And by blaming the operation, which she had avoided so long, she expressed the vulnerability she felt to the potential hazards of Western health care and her fear that, after all, the surgeons may purposefully be harming Hmong people with their interventions.

Mrs. Xiong's story of suffering exemplifies the value of attending to people in the context of their lives and responding to their cultural needs as health care professionals continue the struggle to prevent and treat cancer.

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Commentary

The Husband's Plea for Provider Honesty

Phua Xiong, M.D.

In 1980 when we arrived in this country, we were approached by Americans who came to our home and told us to stop having children. They said they had medicine they wanted us to take. We did not know what they were talking about or why they wanted us to stop having children. We were new. At that time we had eight children. Back in Laos, having many children was a blessing. The bigger a family, the better life was.

When we had our ninth child they came back again saying we must do something about having too many children. But we Hmong, we do not do things like Americans. We prefer natural family planning. Then we had our tenth and last child. My wife never had any problem with any of her pregnancies or deliveries. But this time, things did not go very well.

After the delivery, the nurses massaged my wife's uterus very hard, causing a lot of pain. Then she had a lot of pain with her bladder. She could not urinate, her urine path was swollen. She had so much pain in her bladder and abdomen. Her abdomen got bigger and bigger and she felt like she was going to die. Then the doctors put a plastic tube into her urine path and bladder. The urine came out and the pain went away.

Right before we left the hospital, they gave my wife a shot. They did not tell us what the shot was for or why they felt she needed it. When we got home, she started having urinary pain again. Oh, she was in pain, a lot of pain. Nothing we did would take the pain away. The pain started in her lower abdomen, then gradually radiated to her upper abdomen and continued into her chest. She was very sick, pale, and suffering much pain. We took her to the doctors and after some tests we were told it was her gallbladder that caused the pain.

We summoned several shaman, herbalists, and other Hmong healers to help my wife. They came and did their best. My wife got better, but the pain recurred. After much consideration, we decided she should have the surgery to take out her gallbladder. We agreed to the surgery on two conditions, that the doctors genuinely do

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This commentary is based on Dr. Xiong's interview of the patient's husband.

their best to save my wife and that we get to see the "diseased" gallbladder. The doctors promised; they gave us their word. We believed they were "men of their word." We waited patiently as they rolled my wife into the operating room. Several hours passed. We were told she would be out by 1 P.M. We waited until 1 P.M. Then 2 P.M. 3 P.M. And 4 P.M. Finally, the doctors came out and said, "Everything's okay. Don't worry."

We were relieved to hear they were finally done and that she was okay. But the doctors did not let us see her right away. When she was taken upstairs we finally got to see her. She was in a lot of pain. We asked to see the gallbladder. The surgeon told us they were still examining it. "Later," he said. But later that night, we saw no gallbladder. The next morning, we asked again. We wanted to see the "thing" that caused so much pain for my wife. They told us we needed to fill out some papers before we could see it. We filled out the papers and signed our names. Still, they did not show it to us. We asked again. They replied, "Oh, we chopped it up into tiny little pieces and placed them in a glass jar. Whether you see it or not, you won't know the difference. You won't be able to tell it's a gallbladder anymore."

Whether we could tell it was a gallbladder or not, whether it was whole or chopped up into pieces, we still desired to see it. We insisted. The doctors refused. We argued with the doctors, but we were powerless. The specimen was in their hands and they kept possession of it, refusing to let us see it. We never got to see the gallbladder, the organ they claimed was the cause of my wife's pains. After much frustration and anger, we knew we had no chance. And with resignation and anger in our hearts, we gave up the fight to see the gallbladder. But, why wouldn't they let us see it? Had they done something harmful to my wife while they were in her body?

They told us they took out the gallbladder along with about three fingerbreadths of stomach. They said she had cancer. They wanted her to see the cancer doctor after she recovered from the surgery. The cancer doctor told us that with the cancer drugs, she would get weaker, her hair would fall out, and she would be sick for two months to a year. If she got better then it would mean she might be okay, but if she got worse, then it would mean, "*tag les*" (that's it!).

She had suffered so much already. We had to wait until she regained her strength so she could withstand the cancer drugs. While waiting we sought Hmong medicine to help her get better. She got better. For four months she had no pain.

Shortly after that she complained of pain in her abdomen again. We thought about possible reasons. Perhaps she lifted something heavy that caused the pain to recur at the surgical site. But she hadn't. Perhaps the pain was from the surgical scars. Or perhaps from the metal staples the doctors used.

The pain got worse and worse over the next three to four days until she could not stand it any more. We took her to a different hospital this time. We no longer trusted the doctors at the first hospital and did not want to go back to them. At this second hospital, the doctors took some X rays and told us her liver had turned into pus. "Whatever you have, wear it. Whatever you crave, eat it. Whatever you desire to do or see, do it. All that is left for you is death. You have no chance at life," they said. We all cried and begged them to help her. But they stated they had no way to make her better.

Why had the liver turned into pus? I believed it was the staples. She had twenty of

them inside her. After she died, we took them out. I still have them. Twenty staples! The doctors did not use suture material. Instead, they used metal staples during her surgery. Whether the doctors had good or bad intentions, I don't know. But, I know that metal in the body can cause pain and illness. Doctors might say that staples do not cause problems, but we Hmong, we believe differently. We do not like metal in the body. We know from experience that metal can cause infection, create pus, and lead to necrosis of that part of the body. Metal in the body can cause a lot of pain, redness, and swelling and can "protrude out of the body" in your next life *(mob txhav dab)*. All metal must be removed from the body before burial to prevent this from happening.

The doctors did not tell us ahead of time they were going to use staples. They were not honest with us. They lied to us, over and over again. Frankly, I still don't really know exactly what caused my wife's abdominal pain. In my opinion, I fear that what might have happened in the operating room was this: they injured the liver while inside her body. They then turned around and told us the gallbladder and stomach had cancer, blamed the whole thing on the cancer, so that in the end, it would appear they had done nothing wrong.

Why do I say this? Because in the beginning when they took the X rays, they did not mention anything about cancer of the liver. If it truly was cancer in the gallbladder, they would have shown it to us as we requested. I am most angry with the surgeon. He did not tell us the truth and did not show us the gallbladder. If the stomach had cancer in it and they took part of it out, they should have shown it to us and let us see how it looked. Without seeing the gallbladder it is difficult to believe they actually took it out. Perhaps it was never taken out. The second set of X rays showed nothing wrong with the stomach or gallbladder; it was just the liver. It is very hard to trust the doctors. When a man gives his word, I expect him to live up to it. They made promises they did not keep. Why would they hide the truth from us? Perhaps they made false promises to placate us so we would let them use her, operate on her, study her, and make money on her.

Finally, her family doctor recommended hospice care because they could watch her closely, give intravenous fluids and medicines that would make her comfortable, and she would not suffer so much pain. Hospice was in the same hospital that she had her surgery.

She was there for three or four nights and felt okay. I went and watched her all the time, day and night. On the fourth night, when the evening nurse left, another nurse came on duty. I was tired and settled myself into the chair in the room. My wife told me she wanted to go to the bathroom. Since the nurse was in the room, I asked her to help my wife up, but the nurse said she wouldn't. "I gave her a shot of medicine already," the nurse said. I looked over to where she was and saw that the nurse had just picked up three needles to throw away. My wife told me the nurse gave her three shots of medicine into her IV. I got up from my chair and went over to my wife. Suddenly, she became nonresponsive. She did not respond to my voice or my touch. There was no answer from her.

I asked the nurse what medicines she gave my wife. She said she had not done anything wrong and rushed out the door. I believe the nurse purposely tried to kill my wife with bad medicine. The nurse thought my wife had a bad illness *(mob phém)*,

and she wanted to make her die faster. I could tell by the way she treated my wife. The first nurse was kind, gentle, and friendly. This nurse was rough, hostile in her manner and her words.

Americans, they do that to us because they do not like us. We are refugees; we do not speak the language. We come here and depend on them, their money, so maybe they purposely do things like this to us. They see our people have a lot of children and do not like that, so they give us shots to stop having children without our consent. My wife never had problems with any of her children. Why did she have so many problems this last time? All the things that doctors and nurses did to my wife, I could not be sure they were done with any good intentions, without malice.

When they gave my wife the shot before we left the hospital with our tenth child, my wife never menstruated again. They never told us what the shot was for, but we figured it out. We had an aunt who was also given a shot after the birth of her twelfth child. When she got home, she started bleeding profusely and almost fainted. She went back to the hospital and they told her it was from the shot she received. They gave her another shot and that stopped the bleeding. My wife must have received the same shot except my wife never bled. The medicine interfered with her body's natural cleansing system and stopped the blood flow. After delivering babies, women need to bleed some to release all the dead blood from the uterus. If she had been able to bleed, her body might have reacted differently and she might not have had so many problems. The shot to prevent her from having anymore children harmed her. It made my wife suffer a lot, she had a lot of pain and she died.

We ask that the doctors and nurses treat us the same way they treat themselves because we all are human beings. When they help, we ask them please to help with honesty. If the situation were reversed, we would help them with all our heart. If they make a mistake we ask that they be honest with us, tell us the truth, do not keep it from us, do not make up something else to cover for their errors. When they tell us they will do something, we expect them to keep their word. Promises made from one adult to another, no matter what color you are, should be fulfilled because that is how we can trust one another. We Hmong should not have to suffer because of doctors' dishonesty, mistakes, and prejudices.

14

Pregnant Woman with a Brain Hemorrhage

A Case Story

Mao Her, a forty-year-old woman who was thirteen weeks pregnant with her eleventh child, developed a severe headache after attending a funeral. Her husband, Toua Lee Her, massaged her head and did *khawv koob,* a healing ritual, which did not relieve her headache. Recognizing the seriousness of her condition, he prepared to do *fiv yeem,* a spiritual healing ritual that promised to make an offering to the gods of the four corners of the world in return for assistance with her headache. Before he could do the ritual, Mrs. Her suddenly lost vision in one eye, and vision in her other eye began to blur. Mrs. Her's family called 911 for an ambulance to take her to the hospital.

Her husband reported that once they were in the emergency department, they waited between thirty and sixty minutes before anyone looked at his wife. Finally he prevailed on a nurse to come look at her. The nurse noticed Mrs. Her's unequal, nonreactive pupils and called a doctor. Mr. Her and his family were angry about the lack of prompt attention in the emergency department and the absence of a Hmong interpreter. They wondered whether they received poor and slow care because they were Hmong.

A CT scan of Mrs. Her's head revealed an intracerebral hemorrhage with a massive swelling that was putting pressure on the brainstem. The doctors showed the family the CT scan and recommended a cranial operation to release the pressure and remove the intracerebral blood clot. They predicted that without an operation, she would surely die, and with an operation, she would have only a 50 percent chance of living.

Her husband and her husband's male relatives (some of whom spoke English well, but none of whom had any medical training) listened to the doctors, considered their options, and decided to permit the operation, feeling that only "technology" could help her now. Once she was taken to the operating room, her husband called more of his family members and his wife's brothers to tell them about her grave condition and their decision to allow the doctors to operate. The operation proceeded without complications. The neurosurgeons found no explanation for the cause of her hemorrhage; there was no evidence of an aneurysm, a tumor, or a vascular malformation, and she