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“Die Another Day”: A qualitative analysis of Hmong experiences with kidney stones.

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Abstract

Background: A chart review at a urological office revealed that Hmong patients present with higher rates of kidney stones, uric acid stones, and complications from kidney stones than non-Hmong patients. In order to ultimately redress this health disparity, a conference of Hmong and non-Hmong health care providers decided that we needed to first understand the pertinent social, cultural, economic, and biological factors contributing to the disparity. This research project sought to elicit Hmong patients and family members’ explanatory models, decision-making processes, and experiences with the health care system.

Methods: We conducted in–depth interviews with 10 Hmong kidney stone patients, 11 family members of 9 patients, and 4 traditional healers. All 10 patients had received urological interventions, including ureteroscopy (8), percutaneous lithotomy (5) and nephrectomy (2). Some patients had postponed medical assistance (6) and had refused procedures (4). We qualitatively analyzed the transcribed and translated interviews with an Excel spread sheet and N6 computer software. Results were discussed with patients and a community advisory council.

Results: Hmong concepts of kidney function and explanatory models of kidney stones are a blend of traditional and biomedical concepts. Kidney stones are understood as acute health problems caused by hard substances in water and food that stick to the kidney, which weak kidneys cannot excrete. Kidney stone sufferers do not know they have stones until they pass a stone or they see stones on X-rays, as pain or hematuria are non-specific symptoms. They prefer medications, including herbal medicines, to invasive urological procedures. In making decisions about urological interventions, Hmong patients balance fear of disease (pain and renal failure) with fear of doctors (complications from interventions and anesthesia). While patients have variable balance points to accept interventions, the basic philosophy of “die another day” captures people’s preference to act today so as to postpone “death” ---whether by disease or procedure – until tomorrow.

Conclusions: These findings identify Hmong patients and family’s experiences with this health disparity. This information could be used to increase the Hmong community and patients’ knowledge of the disease and decrease their fear of urological interventions. Urologists, primary care providers and community health educators could educate the Hmong community and patients about the recurrent and nearly asymptomatic but potentially life-threatening nature of kidney stones, and encourage early diagnosis of renal stones. health care workers should make institutional changes that could increase trusting relationships and decrease patients’ fears of providers and procedures.

Background:

Racial and ethnic disparities in health statistics are recognized and are targeted for elimination by the federal government’s Healthy People 2010 program (CDC 2000; NIH 2000). Many factors contribute to health disparities, including individual, institutional, environmental, and community factors. The effects of culturally discordant encounters in the healthcare system and the need for culturally competent care have been well documented in ethnically diverse groups, including the Hmong (Fortier & Bishop, 2004; Smedley, Stith, & Nelson, 2003). Physicians, patients, and families may all have different explanatory models regarding the nature of the disease, expectations about treatment, and evaluations of medical interventions, which could contribute to poor health care outcomes and health disparities (Kleinman 1980). Understanding patients’ explanatory models, perspectives, and experiences could assist providers in providing culturally appropriate care, which also could decrease health disparities (Kagawa-Singer & Kassim-Lakha, 2003). Several publications have documented Hmong patients’ views about disease etiology, mechanism, and treatment, which have differed from mainstream medical approaches, which may be contributing to health disparities in the Hmong community (Barret, Shadick, Schiling, Spencer, del Rosario, Moua & Vang, 1998; Cha, 2003; Culhane-Pera, Vawter, Xiong, Babbitt, & Solberg, 2003).

A two-year chart review (2000 - 2001) at a urological practice, which serves the majority of urological patients in the eastern metropolitan area near St. Paul, MN, revealed health disparities between Hmong patients and non-Hmong patients (Portis, Hermans, Culhane-Pera, & Curhan, 2004). Overall, Hmong patients presented to the urologist with higher rates of kidney stones (46% Hmong vs. 11% non-Hmong, $p < 0.001$).

Of those with kidney stones, Hmong patients had higher rates of uric acid stones (50% Hmong vs 10% of non-Hmong, $p < 0.001$); higher incidences of large stones in their kidneys called staghorn calculi (24 % vs 0%, $p < 0.001$); and had more invasive surgical procedures to remove the stones, including percutaneous nephrolithotomy (22% Hmong vs. 8% non-Hmong) and nephrectomy (5.8% Hmong vs 0% non-Hmong) ($p < 0.01$). Ten percent of Hmong patients refused surgical treatments for their kidney stones. It is not known what factors are contributing to this health disparity.

To identify potential reasons for this health disparity, 47 health care professionals including 16 Hmong providers attended a Hmong Kidney Stone Summit. In small groups and then in a large group, the participants explored four questions: Why do Hmong people have so many large kidney stones? Why aren't Hmong people benefiting from early diagnosis and treatment? What should be done to further investigate this problem? How can the Hmong community participate in the investigations?

Conference participants postulated there could be three major overlapping reasons why Hmong people are burdened with high rates of serious uric acid kidney stones: biological factors, health care system issues, and Hmong people's health care decision making. Biologically, Hmong people could have higher rates of uric acid stones. Perhaps they are predisposed to forming uric acid stones by genetic transmission of an impaired metabolic process. High levels of uric acid, such as in gout, can be caused by a genetic enzymatic deficiency in other populations (Kelley, Rosenbloom, Miller, & Seegmiller, 1968); the same or different enzymatic process could be affecting the Hmong. And perhaps people's behaviors could be contributing to high rates of uric acid stones, whether by low intake of fluid, or high intake of protein such as contained in organ

meats, or some other unknown process (Khatchadourian, Preminger, Whitson, & Adams-Huet, Pak, 1995; Ekeruo, Tan, Young, Dahm, Maloney, Mathias, Albala, & Preminger, 2004).

Given the presence of uric acid kidney stones, a complex interaction between Hmong people and the healthcare system could be impairing early detection and effective treatment of uric acid stones. In the healthcare system, physicians may not be accurately diagnosing the condition; specialists may not be providing culturally responsive healthcare; and there may be insurance or language barriers that impair patients' access to health care services. Hmong patients with indolent kidney stones may not be recognizing a serious health problem, either because they have a high pain tolerance, or few symptoms. Perhaps once they have symptoms, they may initially seek relief from traditional healing practices and then seek medical care late in the process. Once in the healthcare system, they may not accept medical or surgical recommendations early, or may reject invasive procedures and chronic medications. Perhaps patients and their families distrust physicians and are afraid of invasive urological procedures, similar to people's fears and concerns for other surgical procedures (Cha, 2003; Culhane-Pera *et al*, 2003; Johnson 2002; Mouacheupao 1999).

The conference participants decided that multiple studies were needed to investigate the health disparity, including genetic and metabolic studies for enzymatic deficiencies; epidemiological studies for population incidences of kidney stones and gout; clinical studies on interactions between health care providers and patients; and ethnographic studies of patients, family members, and providers' experiences.

This qualitative research effort is aimed at eliciting Hmong patients and families’ explanatory models of kidney stones, and decision-making processes about kidney stone treatments, including their experiences in the health care system regarding diagnosis and treatment of kidney stones.

The specific research questions are:

- What stories do Hmong people tell about kidney stones?
- What are their experiences and explanatory models about kidney stones?
- How do they decide to obtain treatment for their stones?
- Are patients rejecting physician’s recommendations for kidney stones? If so, what contributes to their rejection?

Methods and Analysis:

We, the two authors, conducted this qualitative research study by interviewing traditional healers, patients with urological stones, family members, urologists, primary care providers, and by conducting urological chart reviews. After our preliminary analysis, we discussed our results with patients, and our advisory council. We conducted the interviews in Hmong or English, as the participant preferred, as we both speak English and White Hmong and one of us understands Green Hmong.

Initially, to understand traditional concepts of kidneys, kidney diseases, and renal stones, we conducted in-depth open-ended interviews with 4 traditional Hmong healers (3 men and 1 woman) who knew magical healing (*khawv koob*), shamanic healing (*ua neeb*), and herbal medicines (*tshuaj ntsuab*). Three of the four traditional Hmong healers agreed to be audio-taped, and one agreed to have notes taken. The Hmong co-investigator translated and transcribed the audio-taped interviews into English, and another Hmong

research assistant checked the Hmong-to-English translations. The principal investigator coded the English transcripts and English notes with the assistance of N6 (a qualitative research software program from QSR), by three major categories: 1) Hmong concepts of kidneys, kidney stones, and gout; 2) Hmong preferences for treatments of kidney stones and gout; and 3) Hmong reactions to modern medical medicines and procedures. Both investigators reviewed the codes and made adjustments by mutual agreement.

To investigate patient and provider experiences, we contacted urological patients and their providers. At the urological office where the original chart review had occurred (Portis *et al* 2004), a Hmong nurse identified 28 Hmong patients with kidney stones from 2003; she was able to contact 16 people with accurate phone numbers, 14 of whom agreed to be referred to the researchers. Of these 14, 10 people agreed to be interviewed (2 were not available and 2 refused). Of these 10 patients, 9 gave us permission to talk with 11 family members.

We conducted 1.5- 2 hour open-ended in-depth interviews in the homes of these 10 patients and the 11 family members. The interview guide had four main open-ended questions and specific follow-up questions about telling their story; eliciting their explanatory model (etiology, mechanism, signs/symptoms, prognosis, and preferred treatment) (Kleinman 1980); pursuing their decision-making process; and recording demographic and biological information. We completed chart audits of the urological charts for 9/10 patients who consented.

We audiotaped all of the patient and family interviews. The Hmong co-investigator translated and transcribed them into English and another Hmong research assistant checked the Hmong-to-English translations. The principal investigator created

Excel spreadsheets for patients’ and family members’ stories to illustrate changes over time. The co-investigator reviewed the spreadsheets for accuracy and recommended changes to the investigator. The Excel spreadsheet had three major categories for each incident of kidney stones: 1) patients and family members’ explanatory models: ideas of etiology, patho-physiology, signs/ symptoms, course, and preferred treatment (Kleinman 1980); 2) reactions to the health care system, including providers and interpreters; and 3) medical decision making, including who was involved, what was discussed, when it was discussed or performed, and how decisions were made.

Finally, we conducted 30-60 minute open-ended interviews with 5 urologists who had provided urological care for the 10 patients and 4 family physicians who provided primary care for 3 of the 10 patients; this article does not report those results, except as their information about patients influenced our understanding of patients’ medical histories.

The research was approved by the HealthPartners Institutional Review Board. Consent forms and HIPPA forms were translated from English into White Hmong, and back translated into English. For the majority who did not read Hmong or English, oral consent was obtained. The participants signed consent forms in English, and kept copies of the consent form in English or White Hmong, depending upon their preference.

Results:

The patients in this study were both men and women, with ages from 26 to 65 years, most of whom had little formal education and limited English language skills. See Table #1 for their complete demographic and medical information. The 11 family

members of 9 patients were 22 to 65 years of age, and included 5 spouses, 2 daughters, 1 mother, 1 father, 1 son, and 1 nephew.

The results of the study are presented in three parts. The first part describes patients and family members’ explanatory models. The second part presents Hmong experiences with urologists and urological interventions. The last section focuses on decision-making of urological procedures.

Patients’ and Family Members’ Explanatory Models

Combining the healers, patients, and families’ concepts of kidney stones, and explanatory models of kidney stone episodes reveals a general model about kidneys and kidney stones, which is a blend of traditional ideas and new biomedical concepts.

Anatomy/ Physiology: The healers said that in Laos, Hmong people knew that kidneys were essential to life (*txoj sia*), because they gave the body strength, but people did not ascribe specific functions to the kidney. Now people talk about how kidneys filter blood (*lim ntshav*), filter food (*lim mov*), filter water (*lim dej*), filter urine (*lim zis*), and make urine (*ua zis*). The healers think that people have obtained these ideas from interactions with medical personnel and teachings in this country. Patients’ descriptions of renal function fit with the healers’ ideas. However, concepts about internal anatomy were varied; some patients said that food goes from the stomach directly to the kidney to be filtered; some said that blood and urine travel to the kidney to be filtered; and others thought that the gallbladder and kidney are connected, so that stones in one organ can travel to the other.

Etiology: Patients, family members, and healers said that kidney stones form from natural causes. The most common etiology is cold, un-boiled and unfiltered water (*dej*

nyoos or raw water, as opposed to *dej siav* or cooked water) as it contains sediments (*zeb taub txuab*), that people can see as the hard gritty substance on pots and pans, which have held boiling water. This sediment can come from the earth or from water pipes. The second most common etiology is fatty pork, as the fat can congeal in the kidney to form stones, particularly if people eat pork with cold water. Other etiologies mentioned include pop, sugar, and any food with dirt. These substances can congeal in the kidney insidiously, but particularly if people drink cold water when their bodies are hot. Why some people develop kidney stones while others do not is attributed to the state of people’s bodily fluids; if people’s bodily fluids are poor (*roj ntshav tsis zoo*), they are more likely to develop stones. Ways to keep the bodily fluids healthy are to exercise and sweat. One woman said her stones formed because she had had untreated infections as a child; no one else mentioned this possibility. No one was sure whether families had predilections for stones. Despite the agreement about natural etiologies, there were some suggestions of supernatural etiologies. The traditional healers said that in Laos, both wild forest spirits (Dab Txeeb) or dragons (Zaj) could cause stones, but they are rare causes in this country. One patient thought that spirits might be involved in her stones; another person said a shaman found that her soul was sick; and one person thought that Jesus was testing her faith by allowing her to have recurrent stones and that she had bad luck because of something she had done in the past.

Patho-physiology: Patients, family members, and healers explained that as kidneys filter food and water, the sediments from food and water get stuck (*khub*) in kidneys of those with poor bodily fluids (*roj ntshav tsis zoo*). While small amounts of sediment can pass through the kidney, the sediment that gets stuck forms small stones

that get bigger over time, so that large stones stay in the kidney. If people’s bodily fluids are not good, and if the kidneys are weak (*tsis muaj zog*), then the kidneys cannot filter well and they cannot pump or squeeze or push the stones out into the urine. Or if people do not drink a lot of water, the water cannot push the stones out of the body. When the stones are stuck in the kidney, then the kidneys rot and fail, and then the urine overflows in the body, and the person cannot breathe and cannot live.

Signs/ Symptoms: Patient’s signs and symptoms of stones are variable. Pain could be extreme like an ax or childbirth, or a mild aching pain, or absent. Onset of the pain could be sudden and acute or intermittent or chronic and persistent. Location of the pain is variable, whether in their back, side, upper abdomen, lower abdomen, or urethra. Bloody urine could never happen or could occur intermittently. Also abdominal symptoms were variable, from severe pain to indigestion (*nchi nchi*), gastritis (*kem plab*), or extreme sharp pain (*mob ntxhia*). In addition, individuals described a range of other symptoms, including fevers, cloudy urine, vomiting, shortness of breath, swelling in their skin and abdomen (*tawv nruj nruj* or *plab zag*), feeling heavy, and not being able to urinate. Universally, people stated they did not know their pain was due to stones until the physician took an X-ray, or until they had passed a stone. Then, and only then did they label their illness as kidney stone (*mob txeeb zis* and *mob plawv zis*).

Prognosis: Patients and healers understood kidney stones as an acute and non-life-threatening problem, which needed treatment to relieve the pain. Only some people were concerned about stones leading to kidney failure and dialysis. But most were also concerned about recurrent stones. Patients’ and healers’ main preventive strategy was drinking boiled and filtered water. All patients either bought bottled water from stores, or

obtained spring water from wells in the city, or boiled and then filtered the city tap water in their homes. They did not routinely ingest herbs or prescribed medicines to prevent stones. In addition, patients and healers said it was important to exercise in order to keep the kidney, body and bodily fluids strong, as breathing heavily and sweating keeps the body fluids moving, and keeps the organs working, including the kidney. They described how the lack of balance in diet and exercise, and the lack of sweating out impurities that are ingested in foods, are causing many diseases, particularly diabetes mellitus and hypertension, but also kidney stones.

Treatments: All ten patients received urological procedures (see Table #2); reactions to procedures and decision-making are discussed below. The timing of accepting urological procedures *vis a vis* onset of symptoms was variable. One person sought care without any symptoms, because of an incidental ultrasound finding of renal disease, and ultimately agreed to removing a non-functioning kidney. The other nine people all sought emergency care for relief of severe pain. Four people had not known they had stones, while 5 knew they had stones from previous episodes. Five patients had postponed urological care for days to years, using herbal medicines and massage, and 3 had refused urological interventions, including one man in acute renal failure. Ultimately, 8 patients accepted ureteroscopy with stent insertion and stent removal; 5 accepted percutaneous lithotomy with or without laser lithotripsy and with or without stent insertion; and 2 agreed to nephrectomy. (See Table 1 for explanation of procedures.)

Eight patients used Hmong herbal medicines (specifically *ntoo daj*, *txiv muag nas*, *ntoo zeg qaib*), which they obtained from relatives, herbalists, the market, or their own gardens. They took the herbs to dissolve their stones or help the stones leave their body,

both before seeking medical assistance as curative therapy for their ailment, and after receiving urological procedures, to dissolve stones so they would not have to have another procedure. The herbs were known to be effective, but were also criticized as not being able to dissolve large stones, taking a long time to work, tasting bitter, being expensive, and not being as effective as in Southeast Asia. A ninth person received herbs from her family, but had the operation before she could take them, and the tenth person did not mention herbs. Four people received abdominal massage to relieve their pain, and one person drank Coca-Cola.

Seven people turned to traditional supernatural therapies either before surgery to prevent complications from the operation, or after surgery to continue their healing process, or both before and after the operations. These therapies include soul-call (*hu plig-2*), ancestral (*laig dab-1*), wrist-tying (*khi tes-1*), magical healing (*kawv koob-2*) and shamanic ceremonies (*ua neeb -3*, and *fiv yeem/ pauj yeem-3*). The one Christian patient prayed to Jesus and tried to accept God’s plan for her.

Hmong Experiences with Urologists and Urological Interventions

Several patients and family members stated that they were not afraid or concerned about the providers, the procedures, or the care they received, asserting they needed the urologists’ help, the urologists knew what they were doing, and they and their family members trusted the urologists. Other patients and family members expressed fears and concerns about the procedures. They were concerned that the procedure would not cure the stones, as the stones would return anyway; and the procedures would not cure their renal failure, so they would need dialysis anyway. They were afraid of the pain from the procedure; afraid of complications, such as the incision in the kidney not

healing; afraid of the adverse effects from anesthesia, such as brain damage and not waking up from the procedure; and afraid of death from the procedure.

Many patients and family members’ descriptions of their experiences with urologists were positive. They said that the urologists were nice, helpful, and respectful; the urologists explained the diagnosis well by showing X-rays and stones, and explained the procedure well by drawing pictures. They stated they believed the doctors, trusted the doctors, and were not afraid of the doctors, as the doctors had studied and had known what they were doing. However, other patients and family members complained about urologists, stating the surgeons were rude, mean, disrespectful, impatient, were rushed, did not explain the procedure well, and took advantage of people who did not speak English.

“Doctors—there are some nice ones and some mean ones. I’ve gone to get treated several times, so I know American’s hearts now. One time I went to get treated, (the doctor) lied to me.”

“So like (another patient) said, you are afraid because you don’t know the language; they can do whatever they want to you, so you are afraid. Now we have interpreters and people who work in the hospital so if there is anything (we need), we can communicate with them.”

“We may be stupid (uneducated) like this, but our children are able to work and translate... so they know. If we are not treated well, our children know that they are not doing right.”

Hmong Decision-making about Urological Interventions

Overall, patients’ decision-making process was an engagement of balancing two fears: balancing fear of the disease, particularly pain and renal failure, with fear of the procedure, including the provider, and anesthesia.

If their pain was mild, people avoided medical care, including medications and urological interventions. However, if their pain was severe, they sought medical care quickly. Once at the hospital, if medications relieved their distress, they were satisfied. But if their pain persisted, or they felt their kidneys were in danger, they accepted the urological interventions and praised the providers. If they had moderate pain, or recurrent pain, and herbal medicines and other therapies did not relieve their symptoms, they eventually consented to various urological procedures.

This balancing was mediated by a philosophy of “die another day”. (See Figure 1). “Die another day” captures people’s preferences to act today so as to postpone “death” ---whether by disease or procedure – until tomorrow. If they felt they could “die” today from the kidney stone, they would accept the procedure. If they felt they could “die” today from the procedure, and not “die” today from the stone, they would not agree to or would postpone the procedure.

“If you can still live...they say that if you are not going to die today, you’d rather postpone it until tomorrow. Hmong people say that, right? So today, I still feel well, so I will live another day, but if I do not feel well tomorrow, then I will go (die) tomorrow. Isn’t this right? Hmong have this idea, so they are very afraid.”

“We are afraid. We are very afraid, so we don’t really want to go to the doctor, until we are going to die and we are in severe pain, and Hmong meds will not

help. When we go, they may say that you have cancer and other things and want to treat you.”

Patients’ age and English fluency, family members’ evaluations, and health care providers’ actions were important influences on the decision-making process. For the youngest two patients who spoke English and had graduated from high school, their fear of impaired kidneys tipped their balance of accepting procedures (including a nephrectomy) quicker than other patients. The older non-English speaking patients looked to their English speaking family members for assistance. Indeed, family members were important in accepting procedures; in 3 cases, the patient and spouse made the decision; in 3 cases, patient and nuclear family made the decision; in 4 cases, patient and extended family made the decision. Family members influenced the patients; seeing their family members in severe pain or renal failure, speaking directly with the providers, evaluating the X-ray and laboratory results, they decided whether they trusted the providers, and whether the severity of the stones were worth the risks of the procedures. Healthcare providers’ actions also influenced the process. If providers were polite, patient, and respectful, patients and families were less fearful of the procedure and provider; but if providers were rude, mean, and impatient, patients and families were more fearful of the procedure and provider.

Different aspects of the patient’s EMs also influenced the decision about urological procedures. The presence of severe signs and symptoms and serious prognosis of kidney damage increased their fear of disease, which influenced them to accept the procedure. And prior experience of not improving with herbal medicines or of improving with urological procedures decreased fear of the procedure, which facilitated their

accepting the procedure. Only one patient stressed the importance of exhausting traditional resources prior to or during the western treatments or procedures in order to arrive at a successful outcome, and he postponed the intervention until he had nearly died from renal failure. In general, the other two domains of EMs (assessment of etiology and pathophysiology) seemed to have no influence; for most patients, natural remedies were needed for naturally occurring stones.

Ultimately, all ten patients agreed to urological interventions when the interventions were necessary to help them postpone death another day. They agreed because they assessed their problem as being serious (5 with severe pain, 1 with large stone, 2 with renal impairment, and 2 with renal failure), and because their fears of the providers and procedures were calmed (either because they or their relatives assessed that the providers were trustworthy).

Although all ten patients ultimately accepted urological interventions, eight patients postponed seeking medical help or refused urological procedures. Four people refused procedures at some point during their decision-making process; 6 people postponed seeking medical care; and only 2 people seemed to accept without postponing or originally refusing. Although there were variations in individuals’ “tipping point” –at what point they agreed to the procedure-- they all balanced fear of the disease, pain or renal failure, with fear of the provider and procedure.

Three of the four patients who refused interventions were overwhelmed with their fear of the provider and/or procedure such that the pain and fear of disease and renal failure that had driven them to seek medical care diminished in comparison. One patient rejected stenting despite showing up in the emergency department in renal failure because

he did not want to undergo dialysis from a catheter in his neck vein (which he thought went beyond the necessary treatment for his condition) and because he was appalled that the operating crew was ready to take him before he had made his decision. He left the hospital, and one week later sought help at another hospital because he feared he would drown in the urine that was building up in his body. The second patient’s husband refused a stent because he was not familiar with the way that the procedure was being explained to him and did not trust the provider; he eventually consented after another provider took time to explain and show him the x-rays. In addition, he was concerned about a spiritual causation of her stones, and performed three spiritual treatments before consenting. The third patient refused to have another ureteroscopy to remove her stent because after 4 urological procedures for stones she was tired of having the procedures (which did not cure her problem) and anesthesia (which made her weak). Also, she was upset because the doctor who placed the stent was “mean”: he lied; he didn’t do what the interpreter said he was going to do; and he didn’t really care for old people like herself who don’t speak English, so she didn’t trust him. The fourth patient had already improved after a procedure, but she also had an atrophied non-functional kidney that could have been removed. Since she was asymptomatic and did not assess that as a problem, she decided to forego nephrectomy and was happy that her provider “understood Hmong culture” and respected her decision.

Six patients stayed home treating their initial episode of kidney stone pain or recurrent kidney stone symptoms with traditional massage or herbs and postponed seeking medical assistance for hours, days, or even one week before finally seeking medical assistance for relief. They did so in order to treat themselves with less invasive,

less costly, and more familiar treatments. If the symptoms went away, then they could avoid seeking medical assistance from a health care provider with whom they were unable to communicate well due to their limited English. Additionally, if their symptoms were alleviated prior to seeking medical attention, perhaps the severity of the disease would be lessened, thereby decreasing their chances of having to undergo invasive procedures.

Only two people seemed neither to postpone nor refuse medical or surgical assistance. The first was a young English speaking patient who was afraid her damaged kidney would contaminate the other kidney, was ill from a serious kidney infection, and did not want to alienate the urologist, so quickly agreed to a nephrectomy. The second was an older non-English speaking patient whose wife had done well after a nephrectomy years before, who quickly accepted a ureteroscopy.

Discussion:

These in-depth interviews with traditional Hmong healers, patients and family members reveal similar explanatory models about kidneys, kidney function, stone formation, and stone treatment, and a general decision-making approach to urological procedures, which could help health care providers communicate with and respond to Hmong patients who suffer from kidney stones.

Patients and families’ explanatory models indicate that stone disease is a natural disease caused by substances in food and water, which can coalesce in anyone’s kidneys, but are more likely to form in weak kidneys of people who have engaged in risky behaviors, such as eating a lot of fatty pork, not exercising, and drinking cold water when their bodies are hot. These mechanisms are similar to mechanisms of developing other

chronic diseases in the U.S., such as diabetes and hypertension (Culhane-Pera, Her & Her 2007). As a naturally caused problem, people generally turn to natural treatments to treat kidney stones, such as herbal medicines, biomedicines, and surgical procedures.

However, some patients use supernatural therapies to relieve kidney stones, fortify patients against the pain, and guard against the complications from invasive procedures.

Patients and families’ EMs are relevant in their decision-making about urological interventions. People accept the interventions if they are in severe pain (signs/symptoms), if they project dire futures (prognosis), and if other therapeutic alternatives are not available or efficacious (treatments). And they reject the interventions if the opposites are true. In contrast, concepts about causation and pathophysiology of kidney stones do not seem to influence their decision.

While patients and family members’ cognitive processes are active in their decision-making processes, emotional issues are just as relevant. It is clear that people’s fears, concerns, and lack of trust in medical providers, surgical interventions, and anesthesia influence their decision-making process. It seems that social forces---patients’ and family members’ ages, English speaking abilities, and levels of formal education---greatly influence patients’ emotional experience of the medical care system, level of comfort with the providers, and evaluation of their need for an invasive procedure. These social forces seem to influence overall treatment preferences and decision-making more than cultural beliefs.

Anthropologist Linda Garro’s reviews of medical decision-making theory and cognitive anthropological approaches make several points that are relevant to this study, and illustrate limitations (Garro 1998a; Garro 1998b). One, people may operate within

their constructed simplified cognitive models, but these models may not account for the full complexity of people’s reality, including psychological issues (Simon 1957 cited by Garro 1998a) and macro-level social-economic factors (Sargent 1982, cited by Garro 1998a). Our schematic graphic may depict people’s simplified decision-making processes while the real complexity of people’s decision-making processes may lie beyond people’s awareness, beyond our data results, and beyond our decision making model (see Figure #2).

Two, there is a difference between normative and descriptive models of decision making, a difference between what people should do and what they chose to do (Abelson and Levi 1985 cited in Garro 1998a). We attempted to identify what people chose to do and not what they felt they should do, and thus, we did not inquire about differences or potential conflicts between what culture dictates they should do and what they did. As such, we may have missed a point of tension within Hmong culture in St. Paul MN or a point of conflict between Hmong and American biomedical cultures.

Three, power dynamics may influence the medical options offered and considered, the framing of the pros and cons for that decision, as well as the making of the decision itself (Kayer-Jones 1995). Certainly, the Hmong patients and family members in this study are aware of the doctor-patient power differential, are concerned about whether the providers’ recommendations are really the best for them, and cautious about whether providers have their best interest at heart. It is for this reason that non-English speaking and non-formally educated patients particularly look to their English speaking and educated family members for assistance and guidance. However, we did not

explore other aspects of the power differential, and our schema may not fully represent the power differences between patients and providers.

Four, rather than pitting emotional processes against cognitive processes in decision making, emotional can be seen “as integral to cognitive processes” (Garro 1998a:324, who cited cognitive anthropologists such as D’Andrade & Strauss 1992). Certainly in our simplified decision-making model, people describe roles for both emotion and thought in making their decisions. Indeed, the emotional process is ultimately supreme since the balance is between two fears. The cognitive processes are background for the emotions, which is really the basis for the “fulcrum”, tipping the balance towards or away from the procedure, because of fear of the disease or fear of the procedure.

In addition, the assessment of risk has to be considered. Because all medical decisions are made under uncertainty and inherently involve risk, an individual’s attitude toward risk may also influence medical decision-making (Rosen, Tsai, & Downs 2003). A difference in risk attitude across race and education has been found to be one factor in explaining the underutilization of health care services as certain groups may be more risk tolerant and willing to live with the risks of their underlying disease and undergo fewer procedures (Rosen *et al*, 2003). This patient population assessed risk of disease and risk of procedure, and when they felt they could no longer live with the risks of their disease, they sought help. It was then that many patients from the study group turned to their family members to help assess their risk and to help reduce their risk or decide which risk could be better tolerated given the situation (risk of morbidity or dying from disease vs. risk of morbidity or dying from procedure). The role of the patient, the family, and

physicians in treatment decision-making has been found to differ by racial/ethnic groups, with family influence playing a bigger role in certain groups and contributing to racial/ethnic group differences in treatment received (Maly, Umezawa, Ratliff, Leake 2006).

Other studies of Hmong people’s interactions in the health care system, and decision-making for or against medical and surgical procedures reveal similar issues and concerns as discovered here (Cha, 2003; Culhane-Pera *et al*, 2003; Johnson, 2002; Mouacheupao 1999; Vang 2006; Lee, 1991; Xiong 1995). These studies document that Hmong people’s negative experiences with the Western medical system are common within the Hmong community and contribute to people’s fear of the hospital and mistrust health care providers. They are afraid that they will be used for practice and that treatments are not for their benefit but rather for the benefit of the physician who needs to practice procedures. This lack of trust significantly affects the patient-physician relationship and may lead to delayed care or unmet health needs (Mollborn, Stepanika, & Cook 2005). All of the studies describe Hmong people’s cognitive beliefs about their illnesses, their wealth of treatment choices including traditional healers and medical providers, and their cautions about accepting medical and surgical interventions. While none have described the salient decision-making force as “die another day”, it seems that our results are similar to theirs: people do not quickly accept medical and surgical interventions if there are other, less-risky, less-invasive and effective alternatives, or if they are not so seriously ill that only the risky invasive procedures will help them.

The Hmong community may not be unique in this assessment. A study of 180 kidney stone patients (93.5% White and 6.5% Black) who had undergone previous stone

removal procedures perceived invasive procedures as less desirable than the non-invasive long-term preventive medical therapy, and shock wave lithotripsy, unless they had long pain free periods (Kuo, Aslan, Abrahamse, Matchar, & Preminger, 1999). While their study used a quantitative utility measure and did not explore qualitative cultural, social, and emotional issues, it seems that even mainstream patients who do not have language or cultural barriers to form trusting relationships prefer to avoid invasive procedures for recurrent stone disease. Nonetheless, when language and cross-cultural issues are present, they may render it more difficult to overcome people’s fears and concerns.

Study Limitations:

We do not know to what extent people’s decision-making processes were revealed to us in discussions after their urological interventions. People’s descriptions could be limited by the time between their decision and our discussion (from 1 month to 1 year), lack of willingness to detail their experiences, or lack of trust in us as researchers or in the research process. They may be looking back favorably on these experiences and downplaying any fears that they may have had during the decision-making process now that they are over and there were no major complications from their decisions. In some cases, we found out important information about the sequences of events from family members, the charts, and providers, which provided additional information about their experiences and their decision-making processes.

Future Developments:

Future studies could test this decision-making model in prospective studies of Hmong patients with kidney stones, both with interviews and with developing validated quantitative instruments to evaluate decision-making. The social-cultural factors that

seem to influence the fulcrum of decision making, such as age, English fluency and literacy, formal education, acculturation, and desire for traditional treatments could then be quantitatively measured. Once robust, the model could be tested in other clinical settings with other diseases and decision-making processes. In addition, further research is needed to identify other contributors to the health disparity--the high rates of uric acid stones and their complications in the Hmong population--including biochemical studies, epidemiological studies, and observational studies that can study the interactions between healthcare providers and Hmong patients.

Clinical application:

This information about patients’ cultural beliefs and medical decision-making process could help medical providers and community educators as one important aspect in correcting this health disparity. Health care providers need institutional assistance to provide care to non-English speaking people. Health care system changes could increase Hmong people’s knowledge about kidney stones and decrease their fears of urological interventions. Possibilities include hiring and effectively working with Hmong bilingual-bicultural workers and medical interpreters; designing and implementing educational videotapes about renal function, renal stones and urological procedures for stones in Hmong dialects; and forming alliances with Hmong primary care providers and urologists. In addition, community health education could provide information about kidney function, stone formation, and complications from stones and could stress the recurrent and nearly asymptomatic but potentially life-threatening nature of kidney stones. Fortunately, many of these activities have been started in an effort to improve

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healthcare to Hmong sufferers of kidney stones. Other studies could evaluate the effect of these actions upon the health disparity.

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Table # 1: Demographic and Medical Information for 10 Patients

Gender	4 men/ 6 women
Ages, mean and range	41 (26-65) years
Marital status	8 married, 1 divorced, 1 widowed
Religious affiliation	8 Hmong animists 1 Christian 1 both Animist and Christian
Years in US, mean and range	16.2 (10-23) years
Formal education	2 High School graduates 8 English as a Second Language or none
English language skill	1 excellent 3 good 2 fair 4 poor to none
Employment	6 unemployed 4 employed (fastfood, assembly, billing)
Insurance	1 private insurance 8 public assistance insurance 1 uninsured
Housing	3 home owners 4 home renters 3 public housing assistance
Family history of kidney stones	3

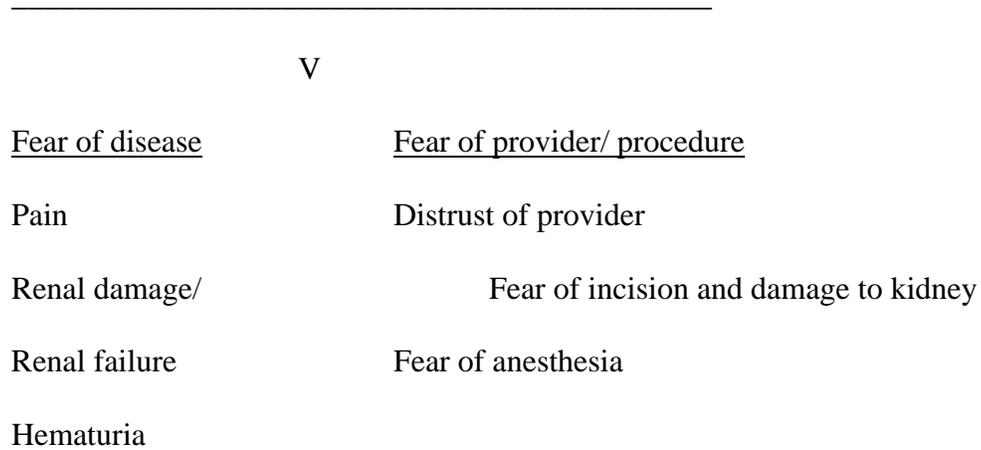
Family history of gout	2
Urological diagnoses	<p>4 Renal staghorn calculi</p> <p>2 Kidney stones, other</p> <p>9 Ureteral stones, obstructing</p> <p>3 Acute renal failure</p> <p>2 Chronic renal insufficiency</p> <p>3 One non-functioning kidney</p> <p>3 Kidney infection</p> <p>3 Gout</p>
Urological procedures	<p>5 Percutaneous nephrolithotomy*</p> <p>8 Ureteroscopy & stent placement/ removal***</p> <p>2 Nephrectomy***</p>

*Percutaneous nephrolithotomy: A small incision is made through the back into the kidney and then an endoscope is passed into the kidney to visualize the kidney stones that are too large to pass through the ureter into the urinary bladder. Wire baskets are then placed through the scope to remove the kidney stones. If the stones are too large, they may first be broken up with sound waves, or lithotripsy.

**Ureteroscopy & stent placement/removal: A thin lighted tube (ureteroscope) is passed through the urethra into the bladder and up into the ureters and towards the kidneys in order to visualize and remove stones. A stent is a small tube that is placed in the ureter to help drain urine from the kidney to the bladder, which later must be removed.

***Nephrectomy: A surgical procedure that removes a kidney.

Figure 1: Decision-Making Process of “Die Another Day” as a Balance, with a central fulcrum.



Process of Balance:

If more fearful of disease than provider or procedure, accept intervention.

If more fearful of provider or procedure than disease, refuse intervention.

Influencing factors:

Age: If younger, patients less fearful of procedures and providers and more fearful of diseases and consequences of disease

Gender: No apparent influence

Language, education: If English speaking with high school education, patients more fearful of disease and less fearful of procedure

Family members: If in favor, patients less fearful of provider/ procedure

Providers: If speak respectfully, take time, show X-rays, explain, have interpreters, then patients less fearful of provider/ procedure. If speak rudely, impatient, not show X-rays, then patients more fearful of provider.

Religion: Little variation to assess influence; one Christian woman accepted, refused, and postponed multiple procedures.

Insurance: Little variation to assess influence; one woman without insurance more fearful of long-term consequences of disease that could cause death or disability, which could influence family’s financial situation.

EM, Etiology: Little variation to assess influence.

EM, Patho-physiology: Little variation to assess influence.

EM, Signs/ symptoms: If severe pain, recurrent pain, swelling or shortness of breath from renal failure, patients more fearful of disease.

EM: Prognosis: If renal failure, patients more fearful of disease.

EM: Treatments: If herbal medicines or massage failed, patients more fearful of disease

If previous urological intervention unsuccessful, patients more fearful of procedure.

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