Wisconsin Hmong Experiences with Hemodialysis

by

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ABSTRACT

The purpose of this study was to explore the experiences of Hmong hemodialysis patients and the nurses working with them. Two Midwestern Wisconsin hospitals with hemodialysis units were used as data collection sites. All Registered Nurses working in the dialysis unit with Hmong hemodialysis patients were invited to participate. All Hmong hemodialysis patients were invited to participate. Cooperation and assistance was obtained by the Hmong community.

Questionnaires were distributed to the nurses and interviews were conducted with the Hmong hemodialysis patients. There were 17 nurses and four Hmong hemodialysis patients that participated in this study.

The results indicated nurses use a variety of methods to learn about Hmong culture on their own, but overall they felt there was a lack of training for them on Hmong culture. They felt the Hmong hemodialysis patients were less compliant with their medication regimen and dietary/fluid restriction but equally compliant with their hemodialysis treatment schedule compared to their non-Hmong hemodialysis patients. These nurses identified several patient barriers were present: transportation, finances, family support, depression, and anxiety. Cultural challenges that were identified in working with Hmong hemodialysis patients included: communication, Hmong beliefs about treatment, beliefs about illness, and fears about treatment.

The Hmong hemodialysis patients described experiencing profound sadness, weakness and uncertainty. They were sad that they had this chronic disease, that so much of their time was spent in dialysis, and that their lives were drastically changed. They described feeling fatigued and unable to participate in family, social, and clan activities. This also contributed to their sadness. Feelings of uncertainty and fear related to life, death, dialysis, the future, and kidney transplant were identified.

Recommendations to nurses, educators, administrators, and researchers were provided based on the results of this study. Future research is needed to explore this topic more completely.

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CHAPTER I

Introduction

The United States has long been known as a "melting pot" due to its culturally diverse population. Ethnic diversity is something that should be celebrated because it "contributes to the richness and creativity of society" (Hartog & Hartog, 1983, p. 911). This trend continues today, with the Hmong immigrants adding to the diversity since the 1970s. The Hmong, like other immigrants to the United States, have their unique cultural beliefs and practices that they bring with them. These customs affect their daily life in the U.S., as do their beliefs about health, illness, medicine, and healing. These will impact the Hmong's utilization and understanding or acceptance of Western health care services.

Nurses are health care professionals who understand the impact that culture has on an individual's and community's health. Providing culturally sensitive care is an important aspect of nursing curriculum. Nurses understand that in order to provide quality care, they must acknowledge and be prepared to incorporate their clients' beliefs and values into their nursing care plan. Despite this awareness, "there is a lack of research on caring for patients from diverse cultural backgrounds" (Shanahan & Brayshaw, 1995).

In their homeland, the Hmong often experienced acute and chronic illnesses such as tuberculosis, diarrhea, smallpox, and infections. In the United States they are also experiencing chronic diseases such as diabetes, cardiovascular disease, and kidney disease. These disease processes and their accompanying treatments may be new to the Hmong, so it is essential that nurses gain an awareness of Hmong experiences with these conditions in order to provide quality nursing care.

There are two main areas explored in the paper: Hmong and Hemodialysis. Therefore, the audience that would benefit from reading this paper would include those that are interested in learning more about the Hmong history and culture, and those interested in learning more about dialysis.

The present chapter will describe the statement of the problem and the purpose of the study. Assumptions inherent in the study will be identified. Terms will be defined and limitations of the study will be explored. The chapter will conclude with the methodology, a description of how the study was conducted.

Statement of the Problem

End stage renal disease (ESRD) is a chronic disease resulting from non-functioning kidneys. This disease, like any chronic disease, affects the individual as well as the family. The impact of ESRD is significant. The patient often feels fatigued, unable to fulfill typical roles and responsibilities, and unable to perform activities of daily living. The kidneys are vital to maintaining life, so when they shut down, an artificial kidney is required in the form of dialysis. In hemodialysis, blood is removed from the patient, filtered through an artificial kidney (a filter in the hemodialysis machine) and returned to the patient with toxic metabolites no longer present. These treatments typically last four hours each and are performed three days a week. The patient generally feels very weak afterward, and sometimes even the following day. The dialysis machine is filtering in four hours what the body would normally do in 48 hours. This shock to the system does not go unnoticed by the patient. This is a complex disease and treatment regimen which includes not only the dialysis treatments, but also strict restrictions in diet and fluid intake, and very often is accompanied by several medications taken throughout the day.

It is sometimes difficult for the nurse to help the patient fully understand the impact of this disease as well as the importance of following the treatment regimen. It is even more challenging when the nurse is working with a patient from a different culture than his or her own who then brings beliefs and values that may not always coincide with the medical plan. The Hmong have beliefs about health, illness, and treatment that will affect their understanding and perhaps compliance with such rigid medically prescribed treatment. The nurse will need to explore these issues with the Hmong hemodialysis patient as well as the family, because they too will be affected. Providing quality nursing care to the Hmong hemodialysis patient could be challenging partly because there is a lack of literature describing the experience of the Hmong hemodialysis patient.

According to the United States Renal Data System 2005 report, there has been a steady increase in incident counts of reported ESRD among the Asian population, of which the Hmong would be included. For example, in 1990 there were 1,180 new Asian patients with ESRD; 2,242 were reported in 1995; 3,073 in 2000; and 3,469 reported new cases of ESRD in the Asian population in the United States in 2003. The mean age at the start of ESRD therapy has also shown an increase over the past years. In 1990 the mean age was 55.8 years; in 1995 it was 60.1 years; 61.4 years in 2000, and 62.5 years in 2003. In addition, the prevalent counts (number of patients alive on December 31) have also increased substantially for Asian ESRD patients. In 1990 there were 4,413 Asians with ESRD; there were 9,538 in 1995; 14,999 in 2000; and 18,484 Asian ESRD patients in 2003.

These numbers indicate a growing need for nurses in working with the Asian population and ESRD. A specific treatment modality for ESRD is hemodialysis. Data reported by the Untied States Renal Data System Report of 2005 also included prevalent counts of Asian ESRD patients undergoing dialysis. Not surprisingly, these numbers are also on the rise. In 1990 there were 2,946 Asian ESRD patients receiving hemodialysis; there were 6,093 in 1995; 9,942 cases were reported in 2000, and 12,139 in 2003.

In summary, the Hmong population in the United States is experiencing ESRD and undergoing hemodialysis treatments. Nurses will be able to provide better care for these patients if they understand the cultural background, beliefs, and values, and incorporate this knowledge into the care for the Hmong hemodialysis patient. However, there is very little research on the Hmong experience with hemodialysis to assist the nurse in expanding his/her knowledge base to provide culturally sensitive nursing care.

Purpose of the Study

The purpose of this study was to explore the Wisconsin Hmong hemodialysis patients' experiences with end stage renal disease and hemodialysis. The experiences of hemodialysis nurses working with the Hmong patients were also explored. The broad goal this researcher hoped to achieve is to provide nurses with expanded knowledge of the Hmong hemodialysis patients' needs and concerns in order to improve nursing care for these patients. It is important to have this knowledge in nursing to be able to: 1) teach, support, and counsel the patient and families; 2) identify learning needs of the staff working with Hmong hemodialysis patients; 3) explore implications for educators in promoting cultural sensitivity in nursing education; and 4) to improve health care provided to the Hmong community. In addition, it is important that health care providers demonstrate a genuine interest in learning about and being respectful of the Hmong belief system and culture. This will potentially increase the trust the Hmong have in not only the health care system, but in the American population as a whole.

The research questions exploring Hmong hemodialysis patients' experiences were based on the following categories of data collection derived from the review of the literature: quality of life and relationships with others, stressors encountered and coping methods utilized, the role of traditional Hmong healing methods, and recommendations the participant had for health care providers. The following questions were asked of the participants (Appendix A):

1. How have kidney disease and hemodialysis affected your life?
2. How have kidney disease and hemodialysis affected your participation in family and clan activities?
3. How have kidney disease and hemodialysis affected your work and leisure time?
4. How do you feel others view you?
5. How do you view yourself?
6. What difficulties did you encounter initially when you started dialysis and how did you cope with these?
7. How do you cope with your current difficulties experienced because of hemodialysis?
8. Describe your relationship with your doctors and nurses.
9. Describe the role of traditional Hmong healing methods in your situation.
10. What recommendations do you have for health care providers?

The research questions exploring the nurses' experiences working with Hmong hemodialysis patients were also divided into separate categories. These included: professional education in learning about Hmong culture; comparison of compliance and rates of complications with the Hmong population compared to other hemodialysis patients; methods used to promote understanding with the Hmong patients; challenges and stressors encountered in working with Hmong hemodialysis patients; and rewards experienced while working with Hmong hemodialysis patients. Appendix B includes the actual questionnaire distributed to the nurses working in hemodialysis.

Assumptions of the Study

The study explored the experiences of two samples: the Hmong hemodialysis patients and the nurses working with the Hmong hemodialysis patients. It was assumed the Hmong hemodialysis patients understood the questions asked and responded honestly to them. It was assumed the interpreter relayed the questions and responses completely and honestly. It was assumed that the nurses who participated were honest in their responses.

Definitions of Terms

There are four terms that will be defined for the purpose of this study:

End stage renal disease is defined as kidney failure that is being treated with hemodialysis.

Hemodialysis nurse is defined as a registered nurse who works a non-specified number of hours in a hemodialysis unit.

Hemodialysis unit is a site for performing hemodialysis that can be for inpatients or outpatients.

Hmong is self-identified by the participant who identifies him/herself as either Hmong or Hmong-American.

Limitations of the Study

There were limitations to this case study. Generalizability may be limited based on the small sample size and only one city from which participants were chosen. Intracultural variations may exist: one cannot assume that all Hmong patients will experience similar changes in roles, responsibilities, challenges, and other effects. Furthermore, the questionnaire designed for this study lacks long established reliability and validity. However, summarizations and descriptions of experiences in an area where little literature is available will be useful to nurses, other health care providers, and nurse educators in caring for the Hmong dialysis patient and family.

Methodology

The main purpose of this study was to explore the lived experiences of Hmong hemodialysis patients. Data were collected via structured interviews with an interpreter present for participants who did not speak or understand English. Interviews were conducted with all consenting Hmong hemodialysis patients in a setting of their choice, and at a time of their preference. Interviews were conducted in June and July, 2007. Data was collected in a Midwestern Wisconsin city which has two medium-sized (250 bed) hospitals; each has a dialysis unit. Data from the interviews were analyzed using an inductive analysis approach following the guidelines described by Hatch (2002).

A second purpose of this study was to explore hemodialysis nurses' experiences working with Hmong hemodialysis patients. This data was collected via questionnaire and also took place during June and July, 2007. All hemodialysis nurses working with

Hmong hemodialysis patients in this Midwestern Wisconsin city were invited to participate. The questionnaire was designed specifically for this study. Data were reported using basic statistical analyses such as frequencies and ranges.

Chapter II

Literature Review

Professional nursing is the diagnosis and treatment of human responses to actual or potential health problems. Medicine focuses on disease, whereas nursing care focuses on illness. Kleinman, Eisenberg, and Good (1978) differentiated disease from illness. Disease is described as the physiological health condition affecting organ or body system function, whereas illness is the individual's response to this disease. Illness is "the human experience of being sick; the change in roles or behavior or ways of feeling because of the disease" and is "culturally constructed" (Kleinman *et al.*, 1978, p. 252). Culture shapes our beliefs about illness, how we respond, the types of care we seek, and the meaning of the illness (Warner & Mochel, 1998). Patient outcomes, compliance, and satisfaction will improve if we acknowledge and incorporate cultural values, beliefs, and variations into our treatment of illness (Pachter, 1994; Kleinman *et al.*, 1978). It is important to remember, however, that there are differences in beliefs and attitudes among individuals in the same culture (Rajan, 1995) and the effectiveness of our nursing care is impacted by the nurse's attitude, acceptance, and flexibility in working with multicultural patients (Gropper, 1998), which will help minimize coping and health problems among refugees (Carrington & Procter, 1995).

Carrington and Procter (1995) described the needs of refugees as a global nursing concern. They stated the "continued global population shifts and catastrophic events will inevitably lead nurses to become intimately more involved in the plight of refugees...nurses are ideally placed to develop meaningful healthy relationships with people who have endured a unique and complex struggle" (p. 10). Transcultural nursing is not an issue unique to America. Shanahan and Brayshaw (1995), for example, studied nurses in Australia, which has a health care system similar to that of the United States, and their awareness of Vietnamese patients' health care needs. In Australia there was a period of assimilation between 1947 and 1964 when immigrants were expected to quickly accept and acquire the dominant cultural practices. After 1973 the "White Australian Policy" was abolished in exchange for acceptance of a new policy of integration and multiculturalism. Despite this change in policy, their study, published in 1995, demonstrated that the Australian nurses had very limited knowledge of Vietnamese culture. In fact, most of the respondents, nurses working in home health, did not feel the needs of their Vietnamese patients were any different from those of their Anglo-Saxon patients. The majority, 12 of the 17, did not think their interventions were always culturally appropriate, and all the participants agreed they needed more education. An important message was sent, though, in that none of the nurses sought out this education on their own. Not surprisingly, it was found that nurses who asked their Vietnamese patients questions about their cultural beliefs had greater knowledge about their needs than the nurses who did not make these inquiries. In addition to asking the right questions, the nurse must demonstrate true empathy, curiosity and respect of her patients from other cultures (Carrillo, Green, & Betancourt, 1999). In summary, there is ample support for the need of research addressing cultural values, variations, and beliefs and its meaningfulness for nursing practice.

The Hmong are a group that may have cultural beliefs different from many of their Western health care providers. National data has been collected on a variety of cultural groups, including the Hmong, Vietnamese, Laotians, Cambodians, Thais, and

Koreans, to represent "Asian Americans," which inappropriately implies that these are all one racial group (Yu & Liu, 1992). Thus, it is relevant to explore these groups individually. Providing nursing care using a universal approach will not meet all clients' health care needs (Fuller, 1995) and so the aim of this project is to provide information to the nurse caring for a Hmong hemodialysis patient which may enhance the quality of care provided. Indeed, "even though Hmong refugees have been living in the United States for nearly 2 decades, many U.S. health care providers know little about the Hmong people practices" (Waters, Rao, & Petracchi, 1992, p. 642). Despite this claim, "no rationale is needed for planning and implementing culturally sensitive and competent care; there are no excuses for continuing to provide care that is insensitive and incompetent" (Davis *et al.*, 1992, p. 277).

This chapter will provide a review of the literature covering the history of the Hmong people, their family and social system, beliefs about health and illness, and barriers to obtaining health care in the United States. The chapter will also include a review of literature on the impact on the individual and family and their coping with hemodialysis and end stage renal disease.

Hmong History

The Hmong have been described as being strong and proud (Mattison, Lo, & Scarseth, 1994); capable of getting angry, yet not easily intimidated and more apt to flee, fight, or die than surrender (Fadiman, 1997); a patriarchal culture that has experienced a lifetime of change and adaptation (Duffy *et al.*, 2004); and possessing values they have tried to maintain despite their struggles. Some of these values include: respecting others; fulfilling obligations to the clan, religious obligations, and their role in society; being independent of non-Hmong groups and self-reliant; hard working; ensuring the family's welfare; behaving well; and tolerating others and avoiding conflict with others (Moore-Howard, 1982). The Hmong try to hold on to these values wherever they settle. An understanding of the Hmong plight "will help health care providers understand the source of Hmong people's mental anguish and distrust of Americans" (Culhane-Pera & Xiong, 2003, p. 19).

Historically, the Hmong were farmers. They used slash and burn farming where an area of trees and brush would be cut down, burned, and the ash used as fertilizer (Duffy *et al.*, 2004). They would farm the land until it yielded no crops, and then they would move on. The farm life of the Hmong in Laos was laborious. All family members engaged in the labor, and thus, large families were an asset to the Hmong. Khou Her recalled in an interview with Faderman (1998) the daily routine:

> Every morning we would be wakened up by the rooster crowing. The women would have to get up alone with their children. Each child had a different thing they were responsible for and they knew what that was. Some of the boys would go and get water, some would feed the animals, and the girls would help make the breakfast.
>
> As soon as we did everything we had to do around the house, we would all walk together to the farm. Sometimes it took an hour to make the walk, and sometimes- when the farm was far away- it could take maybe two hours. We would like to be there as early as possible, because that way we would get more done before we got too tired. We worked all morning, from around six o'clock until noon time. Then we would come back into a little house that we built on the farm and eat our

> lunch together. After that we would head back to the field and work until it was almost dark. Then we would all walk home together. (p. 37)

The Hmong tended to migrate to mountainous areas where they could be free and independent, but this also left them trapped in poverty, isolation, and without access to technology or education (Duffy *et al.*, 2004).

Some 300 years ago the Hmong left their mountainous homeland in Southern China to settle in Laos, Thailand, Vietnam, and Burma (Parker & Kiatoukaysy, 1999). They fought for their rights in the "Madman's War" from 1918-1921 rebelling against French rule (Duffy *et al.*, 2004). In the 1950's some Hmong that were in Laos fought against communism. Hmong soldiers ranged in age from 13 to 50 years. The three main groups of Hmong were the Green, White, and Blue. They were differentiated by language, dress, and custom, but maintained identity with the global Hmong community.

Perhaps the most life-altering events for the Hmong began with the Vietnam War. Americans recruited and trained the Hmong in the use of weapons and explosives (Mattison *et al.*, 1994). Chiu (2004-05) claimed "many of the West's most successful war efforts in the Laotian jungle were possible only after the CIA's recruitment of Hmong soldiers who had knowledge of and physical agility in their native environment" (p. 9). However, these new recruits were not taken care of very well. As Pa Chao Lo described, these soldiers wore Hmong clothes, had no shoes, hats or uniforms, and many were killed when they tried to pick up their uniforms when they were finally provided (Mattison *et al.*, 1994). The Hmong often refer to this period as the "Secret War". Mattison *et al.* (1994) described this as a time when the Hmong were fighting for the Americans, made gallant efforts to rescue and assist the Americans in battle, and suffered dire consequences of having to leave their homes, their crops, their animals, and eventually their entire livelihood. Chong Thao Xiong (Mattison *et al.*, 1994) explained "everything we had was destroyed or left behind" (p. 103). During this time more than 30,000 Hmong (10% of the Hmong population in Laos) were killed and 100,000 (30% of the Hmong population) became refugees (Duffy *et al.*, 2004). Tong Pao Moua recalled that many Hmong fled to the jungles during these years where they suffered miserably from famine, thirst, and loss. The Americans, he stated, tried to help by supplying weapons and food (Mattison *et al.*, 1994).

The withdrawal of American troops from Vietnam resulted in what has been called the "Great Exodus" from Laos to Thailand for the Hmong (Mattison *et al.*, 1994). The American government may have had legitimate reasons for its withdrawal, but the lives of the Hmong were forever changed. In another interview by Mattison *et al.* (1994), Tong Pao Xiong stated "The Americans threw everything away as if our country was of no value to them. They had a country which they went back to, and they threw us away like their baggage. They left us in misery" (p. 159) and Nhia Cha Vue stated his "country was broken and unlivable; that was when the American soldiers left" (p. 49). These perceptions have left the Hmong with a lack of trust in Americans. After the Americans left, the Hmong needed to flee the onslaught of the communists. They escaped to Thailand. However, according to Duffy *et al.* (2004) many Hmong who fought for the United States ended up in camps in Laos and never returned to their families. Cooper (1986) suggested there may also be economic reasons for the Hmong emigration from Laos. He used the term "population/resources imbalance" (p. 30) to describe the scarcity of resources, infertile land and possibility of famine. Culhane-Pera and Xiong (2003) described the situation in Northeast Laos as so badly damaged by bombings that agricultural efforts were fruitless, and thus, the Hmong would not be able to survive on their skills. Along with the threat of persecution from communist rulers, this led to the Hmong leaving what they called their homeland.

Words can barely begin to describe the exodus to Thailand. The Hmong experience was treacherous, tragic, and devastating to say the least. It took some families months, others years, to get through the jungles to reach the Mekong River (Fadiman, 1997). During this time they lived on insects and bamboo sprouts, tree buds, and roots (Mattison *et al.*, 1994). They suffered starvation, illness, injury, infection, separation from their families, and death. They needed to be quiet travelers. Sometimes parents would "put gooey opium in their babies' mouths to quiet them. Some died because of too strong a dose" (Olson, 1999, p. 87). Tong Pao Moua remembered "a married couple gave their oldest son an overdose of opium to kill him because they could carry him no further" (Mattison *et al.*, 1994, p. 89). The Hmong cherish their children, and to resort to these actions must have been heart wrenching. Bee Thao lived with his family for three years in the jungles of Laos before his father thought it would be safe enough to try to reach Thailand. He described his experience in an interview with Faderman (1998):

> So we became fugitives...you know, with very little food. Sometimes we lived in caves, and sometimes we lived inside a very...I would say a very small house that we would make from stuff we found in the jungle. But you can only live like that, at the most, two months. Then you have to move on to another place and build a new house again. If you live in one place longer than that, then for sure the communists are going to find you. (p. 48)

Once the refugees reached the Mekong River they found another huge hurdle to overcome. They needed to make rafts out of bamboo or swim across the river, which at some points was three miles wide. This was a deadly voyage for many Hmong. Those that reached Thailand were taken to the refugee camps. Moore-Howard (1982) described the camps as "atrocious" living quarters where "children play in ditches thick with raw sewage" (p. 34). There were no houses, just a large field where "we all lived and slept like animals" according to Tong Pao Moua (Mattison *et al.*, 1994, p. 89). The same river that was used for drinking water and washing vegetables was also used as the toilet because there were no outhouses or other facilities (Mattison *et al.*, 1994). There were 43,000 Hmong living in 3.9 acres, there was no school for the children, rodents were everywhere (Moore-Howard, 1982), and many Hmong lived in these camps for years before emigrating to other countries. Faderman (1998) provided accounts of Hmong immigrant experiences. An interview with Khou Her described the situation in the camps:

> A lot of the kids looked like those Ethiopian kids on TV. They were so sick that their eyes turned grey. There was nothing to eat almost. The food that was sent into the camp by trucks was only given twice a month. There wasn't enough food to last that long, so my family- we would buy like one bowl of rice noodles with the two or three *npaj* we saved. And we would take it home and give a little bit to each of the children to eat.
>
> We would wait and wait for the next truck to arrive. It was almost impossible to survive on what we got. Each time the truck came, they had like a bowl, and they would measure one bowl per a family member. So if you have six people in your

> family, you will be given six bowls for two weeks. I mean there is no way....I ate the food so preciously, not to waste a single rice grain. Most of the time I was still very hungry, but I had to give up whatever I could to my children. It was so sad and so hard. (p.71)

Hmong Family and Social Structure

The Hmong are a patriarchal, family-centered, clan-based ethnic group. There are 18 clans forming the unit of organization in the Hmong culture. Clan members are considered brothers and sisters (Duffy *et al.*, 2004) and marriage occurs outside of the clan. The woman keeps her own clan name but becomes a member of her husband's family and clan. The clan members act as a support system for each other. According to Duffy *et al.* (2004) the survival of the Hmong depended upon this group support. Olson (1999) described the clan leader as a respected member of the clan who acts as the head of all families in that clan. The clan leader acts as a mediator between Hmong and non-Hmong communities, helps to resolve conflict within the clan, and approves services before Hmong will participate, including some health care services. The clan leader is so well-respected that "if a member of the clan ignores the leader's advice, he will be completely shunned by all clan members" (Olson, 1999, p. 89).

The traditional family unit for the Hmong may include several generations living together. Because the Hmong social system is patriarchal, the son will stay with his parents, and he and his wife will be responsible for taking care of his parents in their old age. A clan elder scolded a son for not taking care of his mother in a proper manner and stated that the Hmong culture would cease to exist if this filial responsibility was forgotten in this country. He feared that the strength of the Hmong family and community would disintegrate (Culhane-Pera, 2003). The eldest son will inherit family property and receive an education if it is available. The son learns from his father and uncles. The male is the decision-maker in the family, but he does accept the woman's input. The daughter learns her role and the culture from her mother, grandmother, and aunts. Once married, she has a limited voice in her parents' household and needs to earn her place in her husband's household (Duffy *et al.*, 2004). She is valued as a partner and coworker to her spouse, which Frye (1995) described as kinship solidarity.

Marriage typically occurred in children's teen years, sometimes as young as 12 years old (McInnis, 1991). As soon as the girl reached puberty she was considered an adult, ready to bear children and take on the female gender roles. Because of this, women tended to lack education. Women were considered inferior to men. At mealtime, men were served first. A woman walked behind her husband. Women were not allowed to participate in any legal proceedings. Girls typically did not have a voice in deciding whom they would marry. The male relatives of the female would "negotiate a marriage contract with the male's male relatives" (Faderman, 1998, p. 127). Kidnapping was common. This ritual brought the female to the male's household, where she would stay for several days while negotiations took place. She would then be considered taken as the man's wife and would rarely return to her parent's home (Faderman, 1998). It would be expected that the woman would become pregnant and start raising a family shortly after marriage.

Polygamy was acceptable in Hmong tradition. Generally a man would take another wife if the first was unable to bear children, if she needed assistance with her work, for a wealthy Hmong man to show his wealth, or for a clan leader to gain support of other clans. If a woman's husband died, sometimes the brother-in-law would marry her, whether he already had a wife or not (Faderman, 1998). If the woman chose not to remarry, the brother-in-law, uncle, or some other male member of the family might still be consulted as the decision-maker for the woman's family (Moua, 2003).

The male is the head of the household and makes the decisions. He tends to have more leisure time than his wife, who tends to work harder and performs the household chores (Moore-Howard, 1982). Ko Vang described to Mattison *et al.* (1994) the work of Hmong women. It was the woman's job to carry water, thresh and gather rice, grind corn, take care of the children, the garden and the house, kill chickens and pigs for guests, and boil water to clean her husband's feet. In the refugee camps in Thailand men often had difficulty finding work, and farming was no longer available to them. Women started to use their talents in embroidery and stitchery to earn money. This gave women their first real sense of independence (Faderman, 1998).

Children are highly valued in the Hmong family (Mattison *et al.*, 1994; McInnis, 1991). Not only do they carry on the family lineage, they are expected to take care of their parents in their old age or in ill health. In addition, the Hmong view children as proof of family worth (Reznik, Cooper, MacDonald, Benador, & Lemire, 2001). Children showed great respect for and honored their elders and the ill (Johnson, 2002; Mattison *et al.*, 1994) and according to McInnis (1991) were considered an economic asset. Parents were allowed, and indeed expected, to discipline their children in the manner they saw best fitting based on the child's behavior. Divorce was very rare, but if the parents did divorce, the children would stay with the father's clan (McInnis, 1991).

Ancestor worship has traditionally been an integral part of the Hmong value system as well (Duffy *et al.*, 2004). There is an "interdependence between the deceased ancestors and the living descendents" (p.15). The spirits of the ancestors will influence the descendents. Therefore, the descendents are expected to show proper worship, remembrance, and respect to the ancestors. This strengthens the Hmong identity and keeps family relations harmonious.

Traditional Hmong View of Health and Illness

The Hmong view of health and illness contrasts sharply with the beliefs of Western health care providers. When the Hmong seek health care, they do not necessarily want the physician to diagnose the problem; they want the symptoms resolved, usually with medication (Waters, Rao, & Petracchi, 1992). This was further supported by Johnson (2002), who conducted a study using participant observation, interviews, and focus group discussions with Hmong participants. He found that these Hmong participants had very little knowledge and understanding of body organs and systems. There were communication challenges identified because there are many terms used by health care providers that do not have an equivalent Hmong translation. The concept of a chronic illness that could be controlled but not cured was unfamiliar to the Hmong. When they were ill and sought Western medicine assistance, they expected medications to make them feel better immediately, but if there were unpleasant side effects, that would be cause for discontinuing the prescription. However, out of respect for the authority of the health care provider, these Hmong would not disclose their noncompliance. Rairdan and Higgs (1992) also described the Hmong highly valuing respect and being polite. Cha (2003) found that the Hmong in her study would stop taking their medications when their symptoms resolved, making the treatment of chronic health problems particularly challenging.

The Hmong traditional views of health and illness revolve around their belief in spirits and the possession of several souls, which can range from three to 32 depending on the source (Westermeyer, 1988). These souls and spirits need to be kept in harmony and satisfied with where they are (Frye, 1995; Tapp, 1989; Mottin, 1984). Illness is experienced because of soul loss (Tapp, 1989; Westermeyer, 1988; Bliatout, 1986). Some illnesses may not be caused by soul loss, but are just natural "usual hardships associated with life on earth" (Westermeyer, 1988, p. 775). Illness may also be caused by spirits being angry (Westermeyer, 1988) or unhappy or offended (Reznik *et al.*, 2001). Westermeyer (1988) also described the belief that illness could be caused by an accumulation of bad blood. This blood would need to be removed, but cautiously, because the Hmong believe the human body has only a finite amount of blood to last through their lifetime. Environmental events or stress can also cause illness. For example, Westermeyer (1988) found the Hmong believe if a cold wind enters the body the individual may suffer from an illness in the chest, back, or abdomen.

Mouanoutoua (2003) described the spirit belief system:

> The Hmong belief system deeply influences how people perceive and deal with physical and emotional problems. Hmong believe that benevolent tame spirits (dab nyeg) and ancestors' spirits (dab niam txiv) will protect the living if people treat them properly. Malevolent wild spirits (dab qus), spirits of people who died a violent death and spirits of people who did not receive a proper funeral, can make people sick, capture their souls, or take their lives. Another type of spirit,

> the good and powerful "neng spirits" (dab neeb) dwell with Hmong shaman, helping them diagnose illness, negotiate with and fight off offending spirits, and heal spiritual and physical ailments. (p. 218)

Bliatout (1986) described four types of spirits that affect mental health in particular: ancestor, nature, evil, and house. The state of disharmony or disequilibrium leads to suffering and can result from natural or spiritual causes (Frye, 1995). Some examples of natural causes include the environment or foods, working too hard, feeling angry, thinking too much, and grieving. Spiritual causes may be from malicious spirits entering the body, soul loss from fright, grief, or impaired skin integrity (such as with a surgical incision). The Hmong also believe in the "mandate for life" which states that each person has a predetermined length of life and illness and death will occur when their time is up (Thao, 1986). This may contribute to a reluctance of the Hmong to accept life-saving measures (Uba, 1992).

The management of an illness will depend upon its cause (Frye, 1995). Bliatout (1991) described three groups of Hmong healing practitioners. Diagnosticians may be an egg reader, bean or rice reader, ear reader, fortune teller, basket spirit caller, astrologer, or geomancer. Each of these healers would use a specific ritual to determine the cause of the illness or to help make recommendations for treatment.

The second group of healing practitioners is the non-spiritual healers, which includes the herbalist, massage therapist and acupuncturist. Women are typically herbalists, because "men are too careless" (Thao, 1984, p. 324) to prepare the herbs in the exact manner needed for healing. Cheon-Klessig, Camilleri, McElmurry, and Ohlson (1988) found in their interviews with Hmong living in a metropolitan area in the United

States that almost every Hmong household in this community had herbal plants used for medicine that would be shared among family and friends. Women in this study were also identified as being responsible for growing and preparing plants. Herbal medicine can be used for treating food poisoning or other ingestion illnesses, broken bones, or an energy imbalance (Duffy *et al.*, 2004). Acupuncture may be used for treating abdominal pain or headaches (Her & Culhane-Pera, 2004).

The Hmong may also use cupping and coining in the treatment of less severe physical illnesses. Cupping uses suction on the skin to draw out the fever or pain and coining involves scraping the skin with a coin to draw out evil spirits. McInnis (1991) cautions the reader that both of these rituals can result in bruising, which could be mistaken for physical abuse by a Western health care provider. The massage therapist might use oils, herbs, or ointments to relieve muscle pain, nervous discomfort, or abdominal pain (Cha, 2003). It is not uncommon for the Hmong to use special string or chains tied around the wrist or neck to prevent soul loss (Johnson, 2002; Westermeyer, 1988).

Bliatout (1991) identified the third group of healing practitioners as the spiritual healers. These include the soul caller and the shaman. The soul caller performs a special ceremony with the sacrifice of chickens and eggs to get a lost soul to return to the ill person and restore good health. Cha (2003) explained that the purpose of the soul calling ceremony during the Hmong New Year is "to prevent human souls from wandering away and becoming lost" (p. 78). She equated this practice with the Western practice of annual physical exams.

When a Hmong becomes ill, it is the responsibility of the family to seek treatment and a cure from his or her soul loss (Bliatout, 1986). The shaman is often consulted. Some have called shamanism a form of religion (Mottin, 1984), whereas others describe it as a way of healing (Lemoine, 1986). Spirits choose who will become a shaman, and once chosen, the shaman seeks training from an experienced shaman (Tapp, 1989). The shaman has the power to communicate with the spirits (Duffy *et al.*, 2004), and becomes an equal with the spirits so he is able to talk to the spirits, touch them, catch them, or liberate them (Mottin, 1984). The shaman is in control of his spirits rather than being "strictly possessed by them" (Tapp, 1989, p. 71).

The shaman has an altar in his or her home as a way of "announcing his or her expertise to individuals who seek help" and it "also symbolizes the shaman's devotion to the sick and suffering" (Thao, 1986, p. 366). The ceremonies performed by the shaman will vary depending on the illness, but in order for a cure to come about from this ritual, Thao (1986) asserts that the individual must truly believe in and have confidence in the shaman. After the shaman is consulted by the family an elaborate ceremony takes place which may involve sacrificing a chicken, cow, pig, or other animal, depending on the illness, the wealth of the family, and the shaman's recommendation (Westermeyer, 1988). This is evidence of the Hmong belief in Animism, the belief that animal spirits can be useful in curing the ill. The ceremonies may also involve incense and burning of spirit money (Tapp, 1989). According to Lemoine (1986) the first intervention by the shaman is to identify the cause of the illness. Three days will elapse, and if the person has begun healing, the shaman will meet this person, diagnose the situation and identify healing procedures. If after three days there is no improvement, it is believed that the spirits did not feel strong enough to deal with the illness and another shaman can be consulted. The shaman "restores the balance of the psyche by first identifying, then retrieving, the absent or lost parts of the self" (Tapp, 1989, p. 75).

According to Lemoine (1986) Hmong shamanism is frequently used for anxiety, psychic, and psychosomatic disorders. Bliatout (1986) stated that these traditional practices have successfully treated depression, forgetfulness, and loss of appetite. Plotnikoff, Numrich, Wu, Yang, and Xiong (2002) interviewed Hmong living in Minnesota and found they used the shaman for spiritual illness and the physician for physical illness.

Nao Kao Xiong called himself a "healer" who used his "*kher kong*" to relieve people of their illnesses (Faderman, 1998, p. 109). He shared a few examples of his healing that particularly impressed the doctors. One situation involved a woman who underwent surgery and postoperatively had uncontrolled bleeding. The doctors told the family that there was nothing more they could do, and she could die. The family called Nao Kao Xiong. He found that her arteries to her uterus were severed, causing the bleeding. He determined this by the blood flow appearance in her fingernails. He performed a healing *kher kong* and tied a *sher qeng* around her neck. The bleeding stopped and an x-ray the following morning confirmed to the doctors what Nao Kao Xiong had diagnosed. He shared a second case where he healed a woman's wound following a C-section delivery complicated by infection. Vicki Xiong (Faderman, 1998) told the story of a shaman healing her son after he had diarrhea and vomiting for almost a month and the Western doctors could not stop it.

In addition to the various healing practices, the Hmong have specific beliefs about the body systems. The liver is associated with emotions and personalities. Bliatout (1986) described the terms *siab phem* as ugly liver, meaning the person had destructive or abusive behavior and *nyaab siab*, or difficult liver, demonstrated by loss of sleep or excessive worry. Culhane-Pera and Xiong (2003) also identified Hmong specific beliefs about the body. The heart provides the body with blood and life, and the reincarnation of souls resides in the heart. The head has a soul that protects the body and governs the head. The head should not be touched. Blood is the sustainer of life. It is essential for health, keeps the body warm, and maintains balance (Cha, 2003). The Hmong believe they have a finite amount of blood that must last through their lifetime so they are very leery of having blood removed, even in the case of an accumulation of bad blood causing an illness (Westermeyer, 1988). Losing blood is thought to take away energy, but even with blood loss, Rairdan and Higgs (1992) explained that the Hmong are reluctant to consent to blood transfusion for fear of receiving the donor's spirits. The Hmong also distrust Western health care providers and fear that blood taken from them may be used to sell or give away (Ohmnas, Garrett, & Treichel, 1996).

Liamputtong (2004) described the special meaning of blood, in the form of menstruation, to women. Menstruation is essential to being a woman because it means she can bear children. It makes a woman healthy because it washes out the bad blood. The Hmong differentiate good menses from bad menses. Good menses are a sign of health, which means that conception will be good and are demonstrated by the discharge of bright red blood. Dark blood, or blood with clots, on the other hand, is seen as unhealthy and in this case the woman needs to avoid icy, cold food and liquids. Even though menstruation is a sign of health for a woman, she is embarrassed if others see blood on her clothes, and she is considered "dirty" and sex is avoided during this time. Menopause leaves a woman "clean, like men" (p. 165). During pregnancy a woman will not menstruate and the Hmong believe there are three possible reasons for this. The blood from menstruation may actually become a part of the baby and so menstruation will not resume until after birth. Another possible relationship between menstruation and pregnancy is that the blood from menstruation may be staying inside the woman to protect the baby by making a "protective dam" (Liamputtong, 2004, p. 161), which then gets set loose when the baby is delivered. The last thought is that the blood from menstruation is being used during pregnancy to feed the baby in the uterus. The menses become in a way the baby's food, and so menstruation would resume after delivery.

The Hmong understand that the kidney filters blood to make urine, which is stored in the bladder (Culhane-Pera & Xiong, 2003). Xiong (2003) explained the Hmong view of kidney disease would be exhibited by blood in the urine, or flank or abdominal pain, both of which would be treated with herbs. The typical signs and symptoms of kidney failure, such as swelling, fluid retention, and fatigue, would not be associated with kidney disease. When Mai Neng Moua developed fatigue and intermittent swelling in her face, kidney failure was not taken into account as a possible cause (Moua, 2003).

The Hmong "resist any procedure that physically changes a person, or the removal of any part of the body, even something like a tumor that should be removed" (Ohmans *et al.*, 1996, p. 27). They are uncomfortable consenting to any invasive procedure (Her & Culhane-Pera, 2004). One reason for this fear may be that they believe doctors are experimenting on them (Johnson, 2002; Cheon-Klessig *et al.*, 1988). Cha

(2003) explained that the Hmong believe that forecasted harm, such as when health care providers describe possible risks involved in procedures, can be predictive of the future. The Hmong would thus respond more favorably to the positive aspects of accepting treatment than the negatives of refusal. Waters *et al.* (1992) also explained that the Hmong believe the removal of a body part will result in missing that part when they are reincarnated, and according to Osborn (1992) surgery can upset the spiritual equilibrium, or a surgical incision could be a port of entry for an evil spirit (Waters *et al.*, 1992). True (1997) shared a story of a Hmong teen with abdominal pain who underwent surgery for what was thought to be appendicitis. When the surgeon opened her, he found she had a cancerous tumor on her ovary, so he removed the ovary and fallopian tube. The family was distraught about this and did not believe the diagnosis of cancer. Not only was she missing an important female organ, but also the chemotherapy the doctors recommended would most likely result in hair loss. The family feared this would "result in bad luck for the rest of her life, her next incarnation, and future generations of her clan, which then might lead to her being an outcast in the community" (p. 107).

Although depression is rampant among immigrant populations, the Hmong believe mental illness is shameful and should be hidden from others (Muecke, 1983). Rarely will they discuss their problems with an outsider, such as a health care provider (Cha, 2003). Dementia, however, is viewed as a natural part of the life cycle. The Hmong do not generally seek treatment for this condition (Olson, 1999). Reznik *et al.* (2001) explained that the Hmong view illness as manifested by the inability to perform daily activities and the existence of symptoms.

This section of the review of the literature shared readings from the Hmong history, their family and social structure and beliefs about health and illness. It is important for health care providers to have an understanding of the background of Hmong culture and beliefs in order to become more sensitive, understanding, and perhaps even more respectful of the Hmong living in the United States. Their traditional ways of life are being threatened by life in the United States, necessitating major changes in their lifestyle. The next section of the review of the literature will start with an exploration of what life is like for the Hmong in the United States.

Life in the United States

The Hmong may be considered "involuntary refugees" (McInnis, 1991, p. 571) who, according to Fadiman (1997) came to the United States fearing a loss of their self-sufficiency, desiring to resist assimilation, and to remain Hmong and maintain their ethnicity. In fact, Muecke (1983) identified four features that distinguish the Hmong from other immigrants:

- They have come to the United States by second, not first choice; their first choice was almost invariably to return to their native country if its political and economic conditions were similar to those that existed before the 1975 changes of government.
- They have come to the United States with little preparation, scant belongings, and no nest of compatriots to greet or help them.
- There is no realistic option for them ever to return to their homeland.
- They are survivors. Although statistics are not available, it is commonly estimated that for every refugee resettled, one died in flight. (p. 432)

Many of the elder Hmong continue to hold onto hopes of returning to Laos (Faderman, 1998). More recently, efforts have been made by churches and communities to greet the Hmong on arrival and set them up with resources and families from the community that will be a support and teacher for them, helping them to acclimate to their new society.

Initially, Hmong refugees were sponsored by church groups and settled in California, Wisconsin, and Minnesota (Mattison *et al.*, 1994). Because the family is "the most important influence in the life of the Hmong" (Olson, 1999, p. 88), groups of Hmong traveled within the United States to form larger Hmong communities. The first wave of refugees in 1975 tended to be well-educated, young, and Westernized (Muecke, 1983). The second wave, from 1979-1983, however, were less literate, had spent more time in the refugee camps, were less educated and less familiar with Western customs. This contrast added to the difficulty of the Hmong in being accepted and understood by their new country's citizens. Yang (2003) explained the third migration occurred in the late 1990's when many Hmong moved out of California to Minnesota and Wisconsin where they could find employment and a safe living environment for their families. Despite these attempts at finding a better life, Ko Vang was deeply affected by the traumas in her life as depicted in her statement that

> what troubled my heart was a life of drudgery...If I could come back, I would not want to be a Hmong. To be Hmong is to be very miserable. Maybe if I were born into a different race, life would be better. (Mattison *et al.*, 1994, p. 145)

Life in the United States is dramatically different than the traditional Hmong are accustomed. Their culture was passed on verbally from generation to generation; it has only been in the last 25 years that the Hmong have had a written language. "Hmong

Americans brought with them their unique cultural, historical and oppressed minority experiences that have no exact parallel with any prior ethnic immigrant group" (Yang, 2003, p. 7). The Hmong came to America with minimal to no understanding and exposure to electricity, automobiles and other forms of mass transit, shopping centers, schools, etc. There have been changes and impacts from their migration to America on the Hmong's economic viability, family structure, and their health.

It has been found that many Hmong have been living in poverty, overcrowded conditions, and in a situation of economic downward mobility since their resettlement (Dhooper & Tran, 1998). Although there are variations between and within Asian American groups, some typical experiences have included feelings of powerlessness, economic insecurity, unfulfilling work experiences, and lack of social support (Dhooper, 1991). Contributing to these issues was the immigration policy that separated Hmong clans and families and made them dependent on the American welfare system. Then, in the 1980's individual states started to reduce and eliminate public aid to the Hmong. This was emotionally distressing to elder Hmong who had no education and lacked skills for meaningful employment. On the other hand, an unfortunate consequence that Cha (2003) described for those Hmong who were becoming educated and successful is that these Hmong may become disengaged from their Hmong clan, adopt the Western view of ethnocentricity, and lose their Hmong cultural traditions.

The strength the Hmong community found in their families is now deteriorating. Large families were an economic asset and a sign of spiritual contentment in traditional Hmong community. In the United States, large Hmong families are considered an economic burden. A significant role change occurs when the children of the Hmong family become socialized to American society and are the link, the translators, between the teacher and the parent or the health care provider and the parent. According to McInnis (1991) the father in this situation may feel useless and dependent. Frye (1995) further explained that Hmong elderly are suffering from depression and isolation, which becomes exacerbated by the younger generation's assimilation to the American culture. The traditional respect of elders has deteriorated as children become the voice for the family and feel that they know more than their parents. One parent reported to Faung and Lee (1992) "I don't think I can depend on them [the children] for anything anymore" (p. 90). Cha (2003) found in her dissertation of Hmong Americans that the

> majority of Hmong American adults are not proficient in English, have a low level of education; have low socioeconomic status; and need the assistance of a cultural broker or translator when interacting with mainstream American service providers such as health care professionals. (p.15)

The children have come to view themselves as more learned than their elders.

The Hmong traditionally did not have a period of adolescence that is experienced in the United States. They married young and took on parental responsibilities. In America, the Hmong are finding education as a necessity and this is changing their traditional teen experiences. McInnis (1991) suggested "this change and the influence of the peer group during the teen years have presented new challenges to the Hmong parents, who have no role models and no personal experience with American adolescent development" (p. 577). Mattison *et al.* (1994) interviewed Hmong living in LaCrosse, Wisconsin and found a common theme these elders expressed: they want their children to be educated and to continue to uphold traditional Hmong customs. Education is seen as essential to the generations of immigrants in order to succeed in America. Faung and Lee (1992) also assert "the need for overcompensation is very strong" (p. 97) as evidenced in the following statement during an interview in their study of Asian immigrants:

> I'm nobody unless I excel or do really well. Then I am accepted by the main society, as a peer, on an average level. Nobody will pay any attention to me unless I do something extraordinary, and then I'm not at the level of extraordinary with Americans, but on the level of commoners. (p. 97)

Ko Vang described the new challenge in raising children in America: "modern children have harsher mouths" and "if parents speak harshly to modern children, the children say that they will run away and join gangs" (Mattison *et al.*, 1994, p. 145). The youth are struggling with becoming socialized and belonging in American society; they want to be like others their age, yet they know their parents want them to retain their heritage (Duffy *et al.*, 2004). According to Xiong (2003) when the young Hmong do not follow traditions or advice of the parent, the parent typically believes it is because the children do not love the parent. "The challenge is to understand and appreciate the cultural disparities that the elder generation is experiencing as they reconcile conflict or seek to balance old beliefs and traditions with new practices and values" (Naftali & Thao, 2003, p. 149).

As mentioned by Mattison *et al.* (1994), gang membership is a particular concern. Faderman (1998) interviewed several teens about their gang involvement. These kids did not always view themselves as gang members, or gangsters, but rather as kids just getting together to have fun, fight boredom, drink beer, and sometimes to use drugs. After a while, stealing became a common activity as a way of earning money, showing strength and courage, and having fun. As the presence of gangs grew, their exposure and access to weapons also increased. This resulted in drive-by shootings, gangs fighting gangs, and a lot of fear among Hmong family members. Parents had lost control. The Hmong children wanted to feel a part of a family, and they found this camaraderie in their gang. They also felt a sense of respect and prestige as gang members. Once a member, the only way to get out of the gang was to get married. Some boys married exactly for that reason.

Intergenerational conflict has resulted in homicide, suicide, and domestic violence (Her & Culhane-Pera, 2004). Tong Pao Moua (Mattison *et al.*, 1994) suffered miserably in his family's flight from Laos, but life in LaCrosse, Wisconsin, was difficult for him as well. He could not drive and mostly stayed in the house "broken hearted" and felt "If no one comes to take us touring, I do not want to live" (p. 91). Dhooper (1991) claimed not only is the traditional hierarchical structure being challenged, the traditional roles of men and women in the family structure are changing. Women are becoming educated and experiencing a social life, and the men may become jealous because they may no longer be the breadwinner of the family (Faung & Lee, 1992). According to Cha (2003), Hmong women still feel inferior to men, despite becoming professionals. They are generally not allowed to be in leadership positions in the clan. One of the dilemmas they encounter is that Hmong men and elders want things to stay the same, while the Hmong women and children see the possibilities in America and want their community to change in acceptance of these.

The story of Mia Neng Moua (Moua, 2003) illustrates challenges Hmong families face in the United States. Mia was a college student when she developed some feelings of fatigue and intermittent swelling in her face. She attributed these to the stress of school and working. When she went to the doctor for a routine physical in preparation for a trip, she was found to have high blood pressure. Upon further investigation, blood tests revealed her kidneys were failing. The doctor asked her to come to the hospital, which she did, mostly against the advice of her mother and uncles. They were afraid. She wanted to know what was causing the kidney problem, so when the doctors suggested a biopsy, she was in agreement, but again her mother and uncle were not. They were afraid of the doctor's intentions, and they believed that traditional herbs and Hmong healing methods would suffice. She was not ill in appearance. She did not seem to have any problems until the doctor put her on medication. She was able to carry on her daily activities. Thus, they really did not believe the doctor's claim that this was an emergency situation. Mia agreed to the biopsy, and later consented to dialysis when her kidneys had failed completely. She wanted to be able to take care of herself and be independent, but her mother wanted to show her love for her daughter by taking care of her. This was a difficult time for the family. There was conflict between the generations, conflict regarding the treatments, and conflict regarding decision-making. Mia wanted to make the decisions, but she also wanted approval from her family. She stated "My whole family, nuclear and extended, is mad at me for having gone through with the biopsy and having chosen dialysis. They'd rather I try herbal medicine and if I get worse, then do dialysis" (Moua, 2003, p. 192). She was eventually placed on the waiting list for a transplant, but was sad to hear that her own family would not be tested for compatibility. Her mother was too afraid of having another child of hers become ill. Mia lived on her own, performed her own peritoneal dialysis, and eventually received a transplant from a friend.

Hmong Health and Illness in the United States

Initial health concerns when the Hmong arrived in the U.S. were tuberculosis, hepatitis B, malnutrition and malaria (Dhooper & Tran, 1998). In exploring the health status of Hmong refugees, Catanzaro and Moser (1982) found that 15% of the Hmong in their sample had positive reactions to the peripheral test for tuberculosis, 18% had hepatitis B, 75% had positive stool cultures, and 30% suffered from anemia. Emerging conditions of concern in the Hmong population are chronic conditions such as hypertension and diabetes (Dhooper & Tran, 1998), asthma (Brainard & Zaharlick, 1989), kidney disease, arthritis, and cancer (Cha, 2003). Mental illness in the form of depression and posttraumatic stress disorder are prevalent (Cha, 2003; Kinzie, 1994; Barrett *et al.*, 1998). Westermeyer, Neider, and Vang (1984) found in their study of Hmong refugees that these Hmong had greater depression than the general population at 1.5 years postmigration, and although the scores improved at 3.5 years postmigration, they were still high. High scores of depression were associated with poor English proficiency and dependence on welfare.

Other immigrants' experiences might be helpful in identifying areas of possible concern for the Hmong. For example, Masuda, Lin, and Tazuma (1980) explored life change event scores in Vietnamese refugees and found these scores were very high in their first year after migration. They suggested the "continued high life change indicates a continued need for psychosocial readjustment" (p. 448). Some of the areas that the immigrants experienced as life change events were financial, life-style, work, spouse, school, and troubles with the law. The Hmong have experienced these life change events as well, indicating a potential need for health care intervention. Cha (2003) found mental health problems to be prevalent in the Hmong in Colorado: 20% experienced anxiety or restlessness, 40% were forgetful, 32% had feelings of worthlessness, 45% admitted to worrying too much, and 32% often felt like they would like to die.

Kinzie (1994) likened the trauma of the Hmong experiences to Holocaust victims of World War II. The Hmong were involved in years of warfare, escape for them was dangerous, and they were singled out because of their ethnic, religious, or social affiliations. Even after years of being in the United States, the Hmong may still be haunted by their experiences.

Mental health services would be appropriate, but as stated previously, the Hmong feel shame in this illness and will not usually seek out services. However, some services are available. For example, the psychiatric clinic for Southeast Asian refugees at the University of Oregon has as its goal to provide treatment in a culturally sensitive manner (Kinzie,1994). The Kajsiab House in Madison, Wisconsin, also provides services to Hmong, particularly war veterans, who not only suffer from emotional and psychological problems, but also need assistance in living in the American culture successfully (http://www.mhcdc.org/Services/KHSEA.html, retrieved March 7, 2005). The services provided at the Kajsiab House are meant to improve the lives and promote the well being of the Hmong in Dane County, Wisconsin, through the following services: cultural brokering and case management (counseling, translation, advocacy), Hmong sister group (counseling and support group for Hmong women), psychological, psychiatric, and alternative medicine services (individual and family therapy and medication consultation), social and recreational activities, meals (breakfast and lunch), Hmong, English, and citizenship classes. Transportation is provided. Services are provided to the

Kajsiab House clients' children in need of academic and/or social support. The Kajsiab House is a site where the non-Hmong community can learn about Hmong culture, needs, and services.

The Kajsiab House was started in 2000, and in March, 2005, there were approximately 40 to 50 Hmong who came to the facility daily (personal communication, Doua Vang, Associate Program Manager, March 9, 2005). Unfortunately, at the time of that conversation there was concern among the program administrators that funding would end and the Kajsiab House would need to close. Indeed, even at the national level there lacked support for Asian American health care services. There were only eight objectives for Healthy People 2000 that addressed Asian Americans in particular, while there were 48 for Black Americans, 31 for Native Americans, and 27 for the Hispanic American population (Dhooper, 2003).

The traditional Hmong view of illness causation may persist in the United States. For example, Brainard and Zaharlick (1989) found the Hmong in Franklin County, Ohio, used Western medicine as a last resort and retained their belief in spirit-caused illness. After an outbreak of measles in 1990 in St. Paul, Minnesota, Henry (1999) explored the Hmong view of immunization, services utilized, and cause of the measles. She concluded that "Hmong parents appear particularly vulnerable rather than stubbornly traditional" (p.48), most of the parents lacked education and understanding of immunizations and many felt the benefits of immunizations were "unpredictable and negligible" (p. 35). Henry (1999) found that these Hmong used both Western and traditional Hmong healing methods; two-thirds of the parents brought their children to a physician. Unfortunately, three children died during this outbreak, and all of them were Hmong. Henry (1999) interviewed 19 sets of parents who had been living in the United States from five months to ten years about their view of the cause of measles. The causes identified were summarized as: a time of seasonal change or weather condition, or as evil spirits that were "afraid of and offended by odors produced by cooling and by burning animal fur; as living in uninhabited areas; as frightened by noise and the technology produced in the city of St. Paul, and as dangerous to people" (p. 40).

In a recent study of Hmong with kidney stones, Culhane-Pera and Lee (2006) found these patients had a variety of explanations for the etiology of stones: cold, unboiled water; fatty pork; pop, sugar, food with dirt; poor bodily fluids; spirits; sick soul; and a test of faith. Eight of these ten patients used Hmong herbal medicine, seven used traditional supernatural therapies, and all ten eventually underwent urological procedures.

There is some evidence that shamanism may be going out of favor among the Hmong community as many of the Hmong in America and Thailand are converting to Christianity (Capps, 1994). In a study of the Hmong in Kansas City, Capps (1994) found that the conversion to Christianity has resulted in changes in ideas about illness causation. They have come to disregard soul loss and spirit illness; they do not believe in the ancestral or nature spirits as causes of illness and thus, "concepts of health and the treatment of illness have undergone dramatic change with the abandonment of shamanism and ancestral worship" (p. 161). The Hmong in Kansas City also felt that even if they did want to participate in shamanism they could not out of fear of being ostracized from their Christian community. The one exception found was in treating fright illness. These Hmong did not attribute this to soul loss, however, but to blood circulating too slowly.

Not all Hmong are converting to Christianity, nor are they all accepting of the abolishment of shamanism. Shone Yang was born in Laos and came to the United States when he was a teenager. He was interviewed by Faderman (1998) when he was 25 years old. He is educated, having earned a Bachelor of Science degree in chemistry. He recalled missionaries trying to convert Hmong to Catholicism before the Vietnam War. Some Hmong, then and now, practice both shamanism and Catholicism. Shone Yang explained his view:

> But I think less and less people here are believing in shamanism because of the churches and all the doctors and nurses who say they have knowledge and skills to cure people. I think for those who are living in the U.S. now, in ten years they won't be practicing the shaman religion anymore. That is very bad because that is a part of our tradition that is being destroyed. Not only that, it is the *main* core of our culture. (p.116)

Vang and Xiong (2003) claimed that conversion to Christianity may not mean the person no longer believes in the animist views of souls and spirits. They may also not believe in Jesus and God as one would expect in Christianity. Thus, it might be helpful to inquire if the Hmong person practices old religion or new religion. Not only will religious beliefs affect decisions on causes and treatments of illness, but they also affect beliefs about suffering (Boehnlein, 1987).

Cha (2003) discovered in a sample of Hmong in Colorado a variety of healing services were utilized: 47% were patients of a shaman, 42% were patients of a Hmong herbalist, 95% used massage therapist services, and 50% were a patient of Western physicians and nurses. She found the majority, 70%, were not knowledgeable in the use of the health care system in the United States. However, the more educated, younger Hmong did seek medical care from a physician rather than a Hmong healer for a variety of reasons: they thought the illness was serious; they were skeptical of the Hmong healer's ability; there was a lack of scientific evidence in support of Hmong herbal remedies and their chemical makeup; they had converted to Christianity and had lost faith in shamanism; or they thought the Hmong massage therapist could harm them due to a lack of training. Osborn (1992) suggested in order to provide greatest benefit, collaboration should be encouraged because then "Hmong healers receive the respect that is their due and Western health care providers gain credibility and acceptance in the Hmong community" (p. 319).

Plotnikoff *et al.* (2002) remind health care providers that "one Hmong person's beliefs, values, and practices may differ from another's" (p. 32) and proposed several pertinent questions for health care providers to ask their Hmong patient: Do you practice the new ways or the old ways? Are you working with any other healers? Are you using any herbs for your condition? What do you call your sickness? What do you think has caused the problem? Why do you think it started when it did? What do you think the sickness does? How does it work? What kind of treatment do you think you need? What do you fear most about the sickness?

Barriers to Health Care in the United States

The Hmong have historically been a minority wherever they have lived. They feel vulnerable and discriminated against and are quick to become suspicious (Cha, 2003).

These feelings were somewhat supported with the American involvement in the Vietnam War and the promises made to the Hmong during those years and in their early migration experiences. The immigration rules separated Hmong from each other. Many Hmong living in America now distrust government authority, and claims of improving life are not trusted. Trust in health care providers has been slow to develop. This lack of trust often results in the Hmong delaying seeking treatment, sometimes to the point where it is too late to achieve desired outcomes (Uba, 1992).

Making this trust even harder to attain have been the stories of health care providers notifying child protection service agencies about noncompliance in the medical regimen and the subsequent removal of children from their homes and placement in foster homes. Fadiman (1997) shared the story of a little Hmong girl diagnosed with a seizure disorder. She was removed from her parent's home when the physicians suspected they were not correctly administering the medications to her. When a teenager and her parents refused to consent to chemotherapy treatment for ovarian cancer, the physicians notified Child Protective Services, she was removed from her home and forced to receive the treatment (True, 1997). Another situation involved a nine year old with end stage renal disease requiring dialysis. The mother did not speak English, and the child was taken out of the home due to a fear of noncompliance with therapy (Reznik *et al.*, 2001). As one might expect, these types of situations are devastating to a family. In each of these cases the health care providers felt they were doing what was best for the child, and they thought the problem was noncompliance. However, in each of these cases the parents thought they were not only doing what was best for the child, but what was best for the family and clan as well. In Hmong culture, the needs of the group take precedence over the needs of the individual (Willgerodt & Killien, 2004; Reznik *et al.*, 2001). In retrospect, there seemed to be significant lack of understanding, misunderstanding, and miscommunication on both the parts of the health care providers and the Hmong families. Furthermore, these actions indicated a lack of tolerance for Hmong cultural beliefs. Rajan (1995) claimed "health care professionals frequently demonstrate ethnocentrism and tend to rely on unicultural professional values and rules" (p. 452). If nurses show respect for the Hmong culture, trust will be enhanced, and compliance and understanding may be forthcoming (Rajan, 1995).

Several suggestions have been made to increase the trust between the Hmong and their health care providers. Gervais (1996) implied that trust can be built by health care providers providing thorough explanations to their Hmong patients. Falvo and Achalu (1983) found in their study of Indochinese refugees that 72% of the participants felt they were not given enough information. The Hmong feel interrogated when asked many questions during a health history, so providing an explanation of the purpose of these questions will build trust (Cha, 2003). The Hmong question the health care provider's competence when many tests are ordered (Osborn, 1992) or many questions are asked (Waters *et al.*, 1992). They also fear being experimented upon (Gervais, 1996). Thus, an explanation of why tests and questions are necessary will enhance trust. Trust can also be established through a kindly manner. Barrett et al. (1998) stated the Hmong want their providers to be happy, kind, and caring. In fact, "basic human kindness" (p. 181) was identified as the most important health care provider characteristic for the Hmong. Culhane-Pera and Lee (2006) found in their study of Hmong patients with kidney stones "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" (p. 14).

The lack of trust of Western health care providers may well be an underlying theme for other barriers to health care as well, but these will be discussed separately. Mokuau and Fong (1994) identified three criteria by which health services could be evaluated. The barriers to health care are inherent in these criteria. Availability is described as "adequate facilities, trained personnel and the resource capacity to handle those persons in need" (p. 26). Accessibility includes the location of health care services, cost, and hours available. Acceptability is the "degree to which services are compatible or congruent with the cultural values and traditions of a group" (p. 27)

The most prevalent health care barrier in terms of availability may be communication problems and a lack of trained interpreters. Obviously, if the health care provider speaks English and the patient speaks Hmong, it will be challenging to communicate effectively. In these situations, a translator is needed. Children and young adults have often been utilized as translators because of their English proficiency (Cha, 2003). Not only does this violate the hierarchical and authority structure of the Hmong (Frye, 1995), but the Hmong find it disrespectful (Waters *et al.*, 1992) and embarrassing (Osborn, 1992). There are also sensitive topic areas that would be inappropriate to discuss in front of the child. These include sexually transmitted diseases, medical procedures and examinations of the genitalia, and conditions such as HIV/AIDS that are associated with a stigma (Parker & Kiatoukaysy, 1999). Poor communication between the health care provider and the Hmong patient also results in the patient feeling like the provider is hiding something or is trying to hurt the patient (Shiva Bidar-Sielaff, manager, interpreter services/minority community relations, UW Health, personal communication, May 19, 2005).

There is a lack of trained interpreters (Warner & Mochel, 1998) and a deficiency in training programs (Cha, 2003). Falvo and Achalu (1983) found the majority if their Indochinese study participants felt communication was a major problem at their doctor appointments. Significant problems resulted for Foua Yang and her family due to a lack of interpreters (Fadiman, 1997). More recently, in a study of Hmong Americans in Colorado, Cha (2003) found that 65% of the study participants required a translator and 62% used a family member or friend to translate. Only one used a trained interpreter. She also found that only four out of 12 interpreters had received formal training and four of the study participants had translators that were not effective. She explained further that interpretation takes time, something that health care providers are often lacking. Other problems with lack of proper training could occur. For example, "interpreters may distort information because of their own values" (Hartog & Hartog, 1983, p. 913), the translator might not relay information he or she believes is irrelevant or embarrassing, or the interpreter might use his or her own personal interpretation of what was said rather than exactly what was said by the health care provider, distorting the messages (Cha, 2003). Furthermore, there are some medical terms and conditions that cannot be directly translated in Hmong (Cha, 2003; Yang, 2003; Barrett *et al.*, 1998). Cha (2003) suggested interpreters should be trained in a variety of fields and:

> there is a very real need to develop a standardized health care translation training course, manual, and qualifying test. The core of this course, and of its course materials, must be that body of Hmong and English words or terms that express

> Hmong and Western conceptualizations of health symptoms and illnesses, cross-listed, one with the other, in order to train Hmong American interpreters effectively. (p. 145)

Communication barriers are also detrimental to making appointments, accessing health care services, understanding directions (Parker & Kiatoukaysy, 1999) and reading prescriptions (Fadiman, 1997). One further issue with communication involves confidentiality. American health care providers follow strict guidelines for disclosure of health information to anyone other than the patient. The Hmong want to involve the clan elders and family, and sometimes more of the community, in the decision-making process. Health care providers need to reconcile these differences.

Communication barriers can result in problems with autonomy and decision making as well. Health care providers have an ethical obligation to ensure their patients understand the treatment options, risks, benefits, and alternatives. This is informed consent. "Clients can give consent only if they have first received sufficient information on which to base a decision" (Barnes, Davis, Moran, Portillo, & Koenig, 1998, p. 413). It also means they need to understand the information provided. Barnes *et al.* (1998) studied informed consent from a multicultural perspective in cancer patients. They found health care providers would often provide teaching but were unable or chose not to evaluate understanding of what was taught. Some providers would not discuss all options, but rather just the one they thought was best for the patient. Some patients were comfortable leaving the decision to the health care provider "because the professional knew best" (p. 419). It is important to overcome communication barriers for nurses to uphold their code of ethics.

Accessibility is the second criterion used to evaluate health care services. The Hmong elders typically do not drive, so transportation to and from health care services will be an issue for them. They need to depend on others, something which leaves them feeling worthless and isolated (Duffy *et al.*, 2004). Brainard and Zaharlick (1989) found Hmong refugees in Franklin County, Ohio, had the lowest utilization rates of physician, hospital, and clinic services compared to other Laotian refugees. Uba (1992) identified a lack of financial resources, inaccessible services, and a lack of knowledge of available services as barriers to health care for Southeast Asian refugees. More recently, Cha (2003) found lack of access and transportation were barriers for the Hmong in Colorado, in addition to the cost of services. Traditional treatments from the shaman would be paid by a variety of methods, and would be based partly upon the ability of the family to pay. Kunstadter (2003) claimed the Hmong "deeply distrust providers who they believe are in the business of making money, will experiment on them, or will provide inferior care to patients on welfare" (p. 84). Certainly, these views would affect the utilization of health care services.

The last group of barriers to health care fall under the category Mokuau and Fong (1994) called acceptability; the degree to which the health care providers are accepting and tolerant of cultural variations. The Hmong have felt discriminated against, believing Western health care providers have not been accepting of their traditional healing practices, being instead hostile in their attitude toward the Hmong (Cha, 2003). Being treated in this manner is detrimental because the Hmong share their negative experiences with their community, and boycotting a physician or even a hospital has resulted (Cha, 2003; Cheon-Klessig *et al.*, 1988). The Hmong are fearful of hospitals. They are not viewed as places of healing (Fadiman, 1997), but rather as a place one goes to die (Parker & Kiatoukaysy, 1999). The Hmong often want many family members to stay with the hospitalized patient as an expectation of the familial role (Cha, 2003), as a sign of love for their ill family member (Culhane-Pera & Xiong, 2004), and because they fear that spirits will come to the hospital at night (Johnson, 2002). Liberal visitation should be allowed and appropriate accommodations provided (Fadiman, 1997). Health care providers also need to understand the Hmong view privacy as very important (Reznik *et al.*, 2001; Dhooper, 1991), and modesty results in women being uncomfortable answering questions or being examined by male providers (Cha, 2003; Parker & Kiatoukaysy, 1999).

Culhane-Pera and Lee (2006) found the decision making process in their study of Hmong patients with kidney stones was based on the fear of disease versus the fear of the procedure. If pain was minimal or mild, health care would be postponed. If pain was severe, medical care was sought promptly. These researchers labeled this balancing of fears as “die another day”. If the patient felt he would die today from the stone, treatment would be accepted. If he thought he could live without the treatment, it would be postponed. If the patient thought he could die from the procedure today, and not from the stone, treatment would be postponed. In essence, death would be postponed until tomorrow.

Overcoming Barriers to Health Care in the United States

Claims have been made that health care providers have not been responsive to the cultural variations and needs of their patients (Dhooper, 1991). Falvo and Achalu (1983) explored Indochinese refugees’ health status and needs from the perspective of the refugee and the physician. They found the "majority of the physicians stated that, aside from communication, health care approach to Indochinese patients could be the same as for American patients" (p. 23). Unfortunately, a more recent study by Culhane-Pera and Vawter (1998) found that some health care professionals participating in a study regarding their treatment preferences for a Hmong woman intubated because of swelling from a thyroid cyst rupture stated "they did not respect MH's cultural and spiritual beliefs" (p. 184) and this affected their decision-making. Frye (1995) identified health care providers' lack of understanding of Hmong beliefs, customs, and culture as a barrier to obtaining health care. A lack of understanding is not the same, however, as a lack of respect. Understanding can be enhanced through education. Respect for other people, on the other hand, cannot be easily learned from a textbook or at a conference. This lack of respect can affect the Hmong's acceptability of health care providers and the quality of care provided. Part of being respectful to the Hmong means taking the time to develop "a personal connection with the patient before turning to health-related matters" (Vawter, Culhane-Pera, Babbitt, Xiong, & Solberg, 2003, p. 311). The Hmong have felt that their physicians lack bedside manners and in general, do not spend enough time with them (Cha, 2003). Americans might be accustomed to this as ordinary, but one could understand where the Hmong might feel this is discrimination or lack of respect.

Developing a good, caring relationship may in fact help to "overcome any cultural misstep" (Hartog & Hartog, 1983, p. 910). Additional suggestions for improving the acceptability of health care services, particularly through showing respect, have included: allow family visitation and the performance of special healing ceremonies (Fadiman, 1997); provide same gender health care providers for Hmong patients (Parker &

Kiatoukaysy, 1999; Barrett *et al.*, 1998; Fadiman, 1997); include the family and clan elders in decision-making (Barrett *et al.*, 1998; True, 1997; Osborn, 1992) and respect their choices by incorporating these into their care (Willgerodt & Killien, 2004); be curious and ask questions regarding the Hmong patients' view of the illness, causes, and treatment (Carrillo *et al.*, 1999) and be nonjudgmental (Capps, 1999). Berlin and Fowkes (1983) used a LEARN mnemonic to teach about cross-cultural health care

> *Listen* with sympathy and understanding to the patient's perception of the problem
>
> *Explain* your perceptions of the problem
>
> *Acknowledge* and discuss the differences and similarities
>
> *Recommend* treatment
>
> *Negotiate* treatment (p. 934)

Fadiman (1997) identified the paradox: the Hmong believe what they do is right, the health care providers believe what they do is right. This writer believes that perhaps in order to provide culturally sensitive health care to the Hmong, we need to accept that what we both do is right.

End Stage Renal Disease

End stage renal disease (ESRD) is a chronic illness that impacts all aspects of an individual's life. It can also have a multitude of effects on the family. When the kidneys cease functioning, as in end stage renal disease, medications, diet, and fluid restriction will help to optimize the patient's health and well being, but dialysis or kidney transplantation also need to occur. The kidneys are responsible for filtering and excreting wastes from the blood. Without proper functioning, toxic waste products will accumulate and the patient will die. The kidneys are vital to maintain life.

Federal funding for ESRD patients requiring dialysis or transplantation began in 1973 with passage of Public Law 92-603. Hemodialysis can be performed in a clinic setting using internal blood access and a machine acting as an artificial kidney. Peritoneal dialysis is often done at home through a catheter in the abdomen. Hemodialysis typically is performed three times a week for four hours each treatment. Peritoneal dialysis can be performed several times throughout the day or during bedtime hours. It allows the patient and family more freedom in terms of traveling distances and participation in social activities. With either type of dialysis, cure is not possible. Rather, the goal is to relieve symptoms, maximize functioning, and maintain quality of life. Kidney transplantation offers hope for a cure, but along with this procedure comes life-long medication therapy and the risk of rejection.

Effect of Hemodialysis on the Individual

Furr (1998) thoroughly summarized the impact of renal failure on the patient:

> On the one hand, the physiological effects of ESRD and its treatment interfere with patients' psycho-social functioning. The disease affects behavior, mood, cognitive processing, and participation in social and economic activities. Furthermore, ESRD can cause changes in appearance, affect sexual desire and performance, impair memory functions, and can lead to changes in social status by limiting opportunities and affecting the ability to perform roles. Patients often experience a loss of previous family status, an increasing dependence on others, a decline in socioeconomic status, financial stress, familial tension, and marital

> discord. Psychologically, patients may experience low self-esteem, insecurity, poor body image, frustration, anxiety, and depression. (p. 98)

Numerous other studies have led to similar claims. Siegal, Calsyn, and Cuddihee (1987) found depression and anxiety were prevalent in their sample of end stage renal disease patients. Chronic renal failure in Hong Kong patients was found to result in fluctuating feelings, role reversal, financial difficulties and alteration in body image (Mok, Lai, & Zhang, 2004). The family has been identified by some renal disease patients as the most important source of social support (Siegal *et al.*, 1987).

Caress, Luker, and Owens (2001) explored the meaning of illness in 405 renal disease patients. Illness was seen as multidimensional for these patients. Illness was viewed as value because for some people chronic illness increased their psychological strength or resulted in a change in their attitudes. It seemed to make them value their life. Illness as enemy was present because of the loss these patients experienced. They felt the struggle they endured was unfair and unexpected. For some, the illness was viewed as a punishment. Others described it as physical and psychological weakness, and yet others described their chronic illness as a relief. They were relieved to not suffer from mental illness. Illness as loss was identified as its own category because of the significant losses experienced: body function, social life, normalcy, lifestyle, and future.

O'Brien (1983) described the personal strength it takes for a renal failure patient to accept hemodialysis:

> …the thought of total life dependency upon a machine may become overwhelming. The early hemodialysis patient sees in somewhat "hazy" relief a future in which previous family or career goals may have to be abandoned, life

> activities modified, and relationships are endangered. The prospects are not reassuring; the outcomes uncertain; the path lonely, but a choice must be made. One must accept or reject the fearful yet sustaining therapy made possible by advanced medical technology. The decision is awesome and only the courageous give assent. (p. 129)

There are numerous stressors hemodialysis patients encounter. Baldree, Murphy, and Powers (1982) sampled 35 hemodialysis patients and found 25 of them reported from 11 to 25 stressors out of a total of 29. Stressors can be either physiological or psychological and contribute to patient outcomes (Kimmel, 2000).

Physiological effects from dialysis that may produce discomfort for the patient include: hypotension, nausea, vomiting, muscle cramps, headaches, loss of muscle tone, and change in skin color (Suet-Ching, 2001; Gurklis & Menke, 1995). Fatigue is a common problem identified by hemodialysis patients (Lok, 1996). In a study of 307 hemodialysis patients of varying cultural backgrounds, Curtin, Bultman, Thomas-Hawkins, Walters, and Schatell (2002) found the most frequently occurring symptom was lack of energy or feeling tired. Gurklis and Menke (1988) had similar findings in their study of 65 hemodialysis patients. Polaschek (2003) found in a sample of six Caucasian males undergoing home dialysis that lack of energy was the most significant problem these patients experienced. Campbell and Campbell (1978) wrote of their personal experience with renal disease, dialysis, and transplantation. They identified lack of energy as a significant problem. O'Brien (1983) found in her study of 126 dialysis patients that fatigue and exhaustion following dialysis were common. Fatigue was identified as a main stressor in Korean hemodialysis patients as well (Chang, Lee, Kim,

& Kim, 2003). One hemodialysis patient stated "In reality I only have a 4-day week because the dialysis days don't count because I am too tired to do anything" (Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001, p. 199). Moua (2003) described an episode of fatigue "There were days I was so sick I just wanted to crawl into a warm corner somewhere and sleep. I didn't care who saw me, looked, or stared. Just as long as they didn't step on me" (p. 195).

Adding to the fatigue from treatment is the frequent sleep disturbances and insomnia that occur as a result of the disease, treatment, and medications (Polaschek, 2003; Curtin *et al.*, 2002; Gurklis & Menke, 1988). Fatigue may also affect a person's ability to carry out their normal activities. Thomas-Hawkins (2000) found functional status, the ability to perform activities, was significantly lower on the second dialysis day of the week compared to baseline, as well as the preceding and subsequent nondialysis days. Thus, there may be variability in feelings of well being in relation to the dialysis cycle (Polaschek, 2003).

Psychosocial effects are also commonly reported. In addition to resulting from fatigue, isolation is common due to the time commitments at the dialysis center. Personal and professional relationships often suffer (O'Brien, 1983). Welch and Austin (1999) found in their study, which included 50% African Americans, that the most frequently identified stressor was the inconvenience and missed activities from the amount of time spent on dialysis. This required lifestyle modifications. Polaschek (2003) also found that socialization for home dialysis patients was minimal.

In addition to social isolation, dialysis patients have also expressed a loss of freedom, feelings of dependency on a caregiver, and disrupted marital and family life

(Hagren *et al.*, 2001). Reduced libido and impotence also may affect the couple's relationship (Curtin *et al.*, 2002; O'Brien, 1983). Changes in family roles and responsibilities need to be addressed because the dialysis patient may not be able to fulfill his or her roles (Gurklis & Menke, 1988). There may be a sense of loss of control. Moua (2003), a Hmong college student with renal failure described the "mourning" over the loss of her body:

> The scariest thing about being on dialysis is that I feel I have not control over my body. That's hard. To feel disconnected from myself. It's strange to think my own body now is a stranger to me. I am not longer intimate with my body. I cannot get attached to it because I know I will lose more of it. (Moua, 2003, p. 191)

Another category of stressors from dialysis include the restrictions imposed because of the illness. Strict food and fluid restrictions can be challenging for the patient and family (Welch & Austin, 1999; Gurklis & Menke, 1995; Gurklis & Menke, 1988; Baldree *et al.*, 1982). Some patients do not express stress or concern about food and fluid restrictions, and this may be because of noncompliance in this area (Welch & Austin, 1999). The access device for dialysis can also pose problems or stressors for the patient. In O'Brien's study (1983) it was not uncommon for the patients to be familiar with the staff and their abilities. Therefore, when certain nurses were assigned to them, the patient would readily know how smoothly the hemodialysis session would run. Some nurses were better than others at accessing the site and reducing complications. Multiple attempts at accessing the site can be stressful for the patient (Gurklis & Menke, 1995), as well as fear of infection, clotting, malfunctioning, and bleeding at the site (Welch & Austin, 1999).

Unemployment rates tend to be high among these patients due to the extreme fatigue, time required for treatments, and side effects experienced from the illness and treatment. There may be considerable time away from work due to frequent hospitalizations (Gurklis & Menke, 1988). Both of these situations can greatly impact a family's financial situation.

Despite the fact that ESRD treatment may be covered by Medicare, Campbell and Campbell (1978) found that obtaining financial assistance was very difficult and time consuming. The forms required some knowledge of writing, math, and record keeping. It was common for the couple to spend ten hours per week just on bookkeeping. They also felt an invasion of their privacy. They had to depend on family and friends as sources of financial support. Insurance premiums skyrocketed. Ferrans and Powers (1993) found in their sample of 349 hemodialysis patients that financial independence was very important to them, but they were only slightly satisfied with their ability to meet this need. Evans *et al.* (1985) found only 37.2% of the in-center hemodialysis patients in their study had the ability to work part or full time. Kutner, Brogan, and Kutner (1986) found the percentage of in-center hemodialysis patients that were employed was lower than transplant or home dialysis patients, and the employment rate also decreased over time.

Additionally, financial trouble may contribute to noncompliance. Dobrof, Dolinko, Lichtiger, Urbarri, and Epstein (2001) found among low income African American and Latino renal disease patients, those with financial problems or difficulty coping were more likely to miss dialysis treatments compared to those without these problems. Patel, Shah, Peterson, & Kimmel (2002) stated the "reliance on a chronic life-sustaining treatment and the reduction in employment potential place considerable psychological and social demands on hemodialysis patients" (p. 1013). These researchers used a variety of measurement tools in evaluating a sample of 53 hemodialysis patients. Although the majority of the sample was African American (86.8%), there were some Caucasian (9.4%) and Asian (3.8%) patients included. Their results revealed the following: men had higher depression scores compared to women; older age correlated with higher depression scores and lower activity of daily living scores; spirituality and religious involvement scores correlated with greater satisfaction with life; higher perception of quality of life and lower depression scores, and spirituality correlated with low perception of burden of illness. In addition, they found the nephrologists played a crucial role in the patient's perception of their quality of life, whereas the nursing staff contributed to feelings of social support but did not appear to affect quality of life perception for these patients.

The quality of life in ESRD and hemodialysis patients has come into question because there is debate on the fiscal responsibility of the government to pay for treatment for all ESRD patients (O'Brien, 1983). Studies of quality of life for ESRD and hemodialysis patients have revealed scores that are only slightly lower than the general population (Ferrans & Powers, 1993; Evans *et al.*, 1985). Dialysis patients in Israel also were found to have a lower quality of life score than the general population (Frank, Auslander, & Weissgarten, 2003). However, when Evans *et al.* (1985) compared quality of life scores between transplant, incenter hemodialysis or home dialysis treatment groups, they found incenter hemodialysis patients had the lowest scores on the three subjective measures of quality of life: well being, psychological affect, and life satisfaction. In contrast, younger, white, more educated patients had higher subjective quality of life scores compared to their counterparts. Molzahn, Northcott, and Dossetor (1997) found that transplant patients had higher quality of life scores compared to dialysis patients, and a positive outlook contributed to quality of life. Lok (1996) found the total stressor score had a negative correlation with total quality of life. This means that as stressors increased in this sample, quality of life was perceived to be lower. In fact, only 28.5% of this study's participants reported feeling satisfied with their life. Effective coping methods are needed to combat these negative feelings.

The adjustment to hemodialysis has been described by researchers. Reichsman and Levy (1972) identified three stages a dialysis patient typically goes through. The honeymoon phase occurs in the first few weeks of undergoing dialysis when the patient initially feels physical and emotional improvement and has feelings of hope and happiness. This stage may last six weeks to six months. The second phase, disenchantment, and the third, discouragement, generally lasting three to 12 months, occur as the patient develops feelings of sadness, hopelessness and helplessness. Suet-Ching (2001) added a final stage of long-term adaptation to describe the patient's acceptance of the disease, its treatment and limitations. O'Brien (1983) conducted a longitudinal study with renal failure patients and divided the phases into early and long-term adaptation to hemodialysis.

Coping Methods Used by Individuals on Hemodialysis

There is evidence that hemodialysis patients engage in a variety of coping methods in dealing with their disease and its effects. In a recent study of Korean hemodialysis patients, Chang *et al.* (2003) identified four categories of coping methods these patients described using: realistically focused, positive re-confrontation, passively withdrawn, and pessimistic renunciation. The group described as realistically focused tended to be the youngest and had experienced the shortest time on dialysis compared to the remainder of the participants. These patients identified stressors similar to those previously discussed: economic problems, inability to earn money, and physical fatigue. The main coping strategies utilized were looking for help from others, hoping for a kidney transplant, and participating in other treatments along with hemodialysis that may be helpful. Campbell and Campbell (1978) described a period of denial prior to dialysis, and once it was initiated, they felt "there were times of sharing, friendship and thankfulness for extended life and its meaning and pleasures. There were also times of despair, crisis, pain and weariness" (p. 386). Although they looked forward to a kidney transplant as a cure, once the transplantation occurred they "realized that transplantation was no instant panacea and that, in many respects, it was like trading one set of problems (dialysis) for another set (transplantation)" (p. 387). They were not prepared for the complications following transplantation. This realization may also occur with the Hmong. They have built trust with their health care provider by this point, and they expect that transplantation will make everything better (Shiva Bidar-Seilaff, personal communication, May 19, 2005).

Support from family and friends has been found to result in better outcomes for the dialysis patient. Furr (1998) found less anxiety and depression and better self esteem in dialysis patients who had a social support system. Siegal *et al.* (1987) found in their study of ESRD patients that the family was the most important source of social support, and Gurklis and Menke (1995) found that over 90% of their study participants received social support from immediate family members. Interviews with renal failure patients in

Hong Kong revealed an overwhelming theme of the importance of the family and family support. Family was a motivator for these patients (Mok *et al.*, 2004). Indeed, adequate social support may contribute to long-term survival of the dialysis patient (O'Brien, 1983).

Nursing staff and other dialysis patients have also been identified as sources of support for the hemodialysis patient. Bordelon (2001) asserted that supportive relationships among dialysis patients can improve quality of life and provide the opportunity to share experiences that might help them to solve problems. The Hmong, particularly those who do not speak much English, may not benefit from these types of relationships. Although some hemodialysis patients felt "the large open ward produces uncomfortable feelings of watching, seeing sickness and being watched" (Giles, 2003, p. 36), O'Brien (1983) found a different perspective from her longitudinal study of dialysis participants. These patients found in the dialysis unit that they were no longer differentiated by cultural or socioeconomic backgrounds. These patients developed close relationships despite their differences. They also tended to watch out for each other and provided support to each other. This can produce fear and pain when a dialysis patient dies. One patient reported reluctance in developing close relationships with other dialysis patients because of the emotional trauma associated with death:

> I'm just not going to get close to these patients again. I really have with several. I've sat next to several patients that have passed, and the last one was very bad because we had gotten to know each other real well- for a couple of years. It really hurt when it [the death] happened and it's scary. I got despondent. So I just decided, no more. (O'Brien, 1983, p. 33)

O'Brien's (1983) study also explored patient-nurse relationships and found that for many nurses, developing more than a strictly professional relationship occurs, particularly because of the amount of time spent together. Other nurses felt that this personal relationship could be detrimental to the nurse's judgment, especially if the patient became very ill. The majority of patients develop good relationships with their nurses as well as doctors. Sloan (1999), however, found that patients had difficulty distinguishing the technicians from the nurses in the dialysis unit. In Sloan's study of five hemodialysis patients, three stages of guarded alliance relationships were described. Naïve trust occurred initially when the patient trusts the health care provider. Disenchantment occurs later, mostly because of setbacks in well being and because the patient perceives a lack of empathy by the dialysis staff. The guarded alliance stage is almost inevitable according to Sloan because of the long-term nature of the patient-staff relationship. This stage is more positive and includes different types of relationships. The hero worship relationship is when the patient thinks the nurse is great; resignation is characterized by the patient understanding he or she needs dialysis to live; minimal involvement in this realm is when the patient is knowledgeable and independent; and team playing is achieved when trust is developed.

The second group of coping skills described by Chang *et al.* (2003) are positive re-confrontation. Patients described as using positive re-confrontation as a coping method were identified as having a belief in a "supernatural being" (Chang *et al.*, 2003, p. 46), finding value and meaning in life and keeping a positive outlook. These patients had the lowest stress perception scores of the four groups. Keeping a positive attitude was also identified by hemodialysis patients as a major coping method characterized by staying active, not letting dialysis run or ruin their lives, and keeping a sense of humor (Gurklis & Menke, 1995). Prayer, faith in God, and trust in God were also identified as coping methods by Gurklis and Menke (1995) and Baldree *et al.* (1982). O'Brien (1983) examined dialysis patients' perceptions of religious faith and its relevance to acceptance of their condition. Upon initial interviewing, the patients were fairly evenly distributed, with 33 believing their religious faith had no relevance to accepting their condition, 27 said it was sometimes relevant, 31 responded it was usually relevant, and 35 felt it was always an important contributor to their adjustment to chronic renal failure and dialysis. Three years later, 18 patients reported an increase in the degree of importance religious faith played in their lives, and one patient changed his response from a positive to a negative perception of the importance of religious faith. Other researchers have found that religion did not contribute much to coping and adjustment (Siegal *et al.*, 1987).

The main coping strategies utilized by patients in the positive re-confrontation group included: comparing themselves to others who were more seriously ill, enjoying their social life within the boundaries of their physical limitations, maintaining hope, complying with the treatment regimen, and being optimistic about their present and future. Complying with the medical plan is similar to the coping method Gurklis and Menke (1995) described as maintaining control of one's health care. These patients took their medications appropriately, were active in learning about ESRD and hemodialysis and in monitoring themselves, and participated in decision-making. An internal locus of control, the belief that events are the result of an individual's actions, has been found to be associated with better compliance and greater acceptance of renal disease compared to those patients with an external locus of control, the belief that events are beyond the individual's control (Poll & De-Nour, 1980). Although control and independence were sometimes exhibited by noncompliance (Calvin, 2004), Polaschek (2003) urges health care providers to view these activities as adaptation in the best way the patient can, based on his or her beliefs and values. Maintaining hope and a possibility for the future were coping methods used by other hemodialysis patients (Rittman, Northsea, Hausauer, Green, & Swanson, 1993).

O'Brien (1983) found that patients with positive attitudes had self-perceptions of wellness rather than sickness. This attitude also results in better adjustment to chronic illness such as ESRD. Brown, Feins, Parke, and Paulus (1974) found distinct differences in home dialysis patients that were well-adjusted compared to those that were less well-adjusted. The well-adjusted patients minimized their losses, emphasized their abilities, were achievement oriented, accepted their limitations and maintained interest in hobbies and activities. In contrast, those patients that were less well-adjusted led lives that revolved around dialysis, letting it become their main focus in life. They tended to have more mood swings, loss of friendships and less participation in activities.

An individual's adjustment and acceptance of chronic renal disease and dialysis may also contribute to long-term survival, which O'Brien (1983) identified as seven to 12 years of dialysis in her longitudinal study of dialysis patients. Those patients who survived tended to be "less alienated, more active socially, possessed more social support systems, and more positive about the quality of their social interactions with family and friends" (p. 152). In further support of these claims, Evans *et al.* (1985) found close correlations of psychological affect and well being, life satisfaction and well being, and psychological affect and life satisfaction among their 859 participants with renal disease. One social worker summarized the importance of acceptance:

> Patients have to accept dialysis. If they agree to the treatment and if they decide, yes, they want to be on dialysis, then somehow they have to get integrated into a new life. I think it is the only way they are going to survive. If they can somehow come to terms with it in an emotional kind of way, then they can manage the physical and the dietary and all the rest of it. But they have to somehow accept on an emotional level, that this is how it's got to be if they're going to be a survivor. (O'Brien, 1983, p. 153)

Keogh and Feehally (1999) found hemodialysis patients had lower scores on the Acceptance of Illness Scale compared to other patients suffering from chronic illness such as diabetes, cancer, hypertension, and arthritis. Caucasians also scored significantly higher than Indo-Asian patients in their study. In contrast, Mok and Tam (2001) found Hong Kong middle aged married men undergoing hemodialysis used acceptance as a major coping method.

The last two groups described by Chang *et al.* (2003) were more pessimistic and used avoidance as a coping method. Those who were passively withdrawn identified two dominant stressors: change in physical appearance and perception of their illness as endless. They felt their present life was meaningless and they avoided socialization because of feelings of inferiority. O'Brien (1983) found that food for many participants posed a dilemma. Dietary restrictions for the dialysis patient are severe, and food for many people is associated with socialization. Most participants in her study admitted to cheating on their diets. This cheating was in the mild form where the patient knew and accepted his or her limitations, to the binging patient who did not control his or her cravings. She also observed that many of the participants felt a stigma attached to renal disease and dialysis such that they would not tell others about their disease, would not eat in front of other people, and felt embarrassed by their appearance, lack of energy, and need for dialysis. Hagren, Pettersen, Severinsson, Lutzen, and Clyne (2005) also found pessimistic themes in their study of 41 Swedish hemodialysis patients' experiences. These themes included struggling with time consuming care, feeling that life is restricted, a sense of emotional distance, and feeling vulnerable.

The final category of coping method was termed pessimistic renunciation (Chang *et al.*, 2003) and characterized patients who viewed hemodialysis as their destiny and no longer feared death. Their main stressors were similar to the other groups: grief over loss of kidney, fatigue, change in physical appearance, and a disease process that was endless. They did not use similar coping methods, however. This group gave up searching for meaning in life, felt hostility and anger about their lives, were pessimistic, and gave up looking for alternative or supplemental treatments.

Fear of death or dependence on a machine to maintain life does not have to result in pessimism. Calvin (2004) found that hemodialysis patients were realistic in their knowledge that they would die, but remained optimistic in their outlook, considered themselves feeling good or healthy, and thought they might even beat the odds if they were able to maintain physical functioning. These "patients admitted that their bodies were failing, but they made adjustments so that they could retain as much independence as possible" (Calvin, 2004, p. 562). Hagren et al. (2001) also found that although "the fear of death was both implicitly and explicitly expressed" (p. 200), these hemodialysis patients made adjustments in their lives to cope effectively.

Other researchers have explored coping in the dialysis population. O'Brien (1983) classified three types of dialysis patients: career dialysis patient, part-time dialysis patient, and the free-lance dialysis patient (p. 163). The career dialysis patients center their lives around dialysis. Dialysis becomes their main source of socialization, and these patients enjoy and look forward to their dialysis treatments. Part-time dialysis patients may consider their treatment as their part-time job. They have life responsibilities outside of dialysis, but are acutely aware of the time demanded for dialysis. These patients try to maintain family and work lives as best they can. The free-lance dialysis patients vacillate between compliance and noncompliance in diet and dialysis treatments. They can be quite challenging to the dialysis nurse.

Problem-focused and emotion-focused coping have also been explored as methods of adjusting to renal disease and dialysis. Problem-solving coping methods are attempts to solve problems, whereas the emotion-focused methods are directed toward relieving the emotional distress that accompanies the stressor (Baldree *et al.*, 1982). Several researchers have found problem-focused coping methods were used more commonly than emotion-focused ones. Lok (1996) found problem-focused coping methods were used among patients on dialysis for three to four years, while Blake and Courts (1996) found patients on hemodialysis eight or more years rated problem-solving coping higher than emotion- focused coping methods. They also found no correlation between gender and coping methods. Problem-focused coping methods were used more frequently than emotion-focused in a study of 35 hemodialysis patients (Baldree *et al.*, 1982), a Canadian sample of 30 male dialysis patients (Cormer-Daigle & Stewart, 1997), 68 patients on dialysis from three to 200 months (Gurklis & Menke, 1988) and 103 dialysis patients studied by Walch and Austin (2001).

Emotion-focused coping methods were used more often by patients aged 50 to 60 years and by those hemodialysis patients with an education less than twelfth grade (Blake & Courts, 1996). Sadly, they found coping scores in this sample were lower than those from a sample in 1988. This would support the claim by Poll and De-Nour (1980) that "although the methods and techniques of haemodialysis have improved greatly, the patients' adjustments have not changed and have remained unsatisfactory" (p. 156). Felton, Revenson and Henrichsen (1984) found that emotion-focused coping methods were associated with poorer adjustment to chronic illnesses such as hypertension, diabetes, rheumatoid arthritis, and cancer.

Effect of ESRD and Hemodialysis on the Family

Campbell (1998) was a spouse of a renal failure patient. She claimed "no family escapes care burdens and major life adjustments when a member has ESRD" (p. 100). Ziegert and Fridlund (2001) stated the family often vacillates between hope and despair. They interviewed 12 hemodialysis patients' next-of-kin and summarized their findings into several themes: a feeling of confinement, a feeling of social isolation, a feeling of a changed life world, a feeling of security in life, a feeling of a threatening future, and promoting health.

Feeling confined was described as needing to always be available, having to plan one's day, and being preoccupied with the disease. A wife interviewed by O'Brien (1983) expressed her preoccupation with her husband's renal failure:

> At first when he went on dialysis I only half-slept at night. But it's still a constant worry. I go to bed with him on my mind and I wake up the same. It gets harder as you go on. They [the patients] kind of get tired. He'll say, "If I just didn't have to go in to that unit today, I could make it. I just don't feel like goin'." I'm the one who has had to really support him over the years. It's been hard. A lot of things you would love to do, but you just couldn't leave. (p. 63)

Campbell (1998) also felt that her life revolved around the disease her husband had.

A feeling of social isolation occurs from the loss of social life and active leisure time (Ziegert & Fridlund, 2001). Campbell (1998) felt isolated and lonely at times. Initially in the illness family and friends rally around the couple, but as the disease progresses and with the chronicity of ESRD, family and friends start to drift away. As one patient claimed "You find out about real friends when there is trouble" (O'Brien, 1983, p. 16). It is likely that with the reduction in socialization there would be a concomitant reduction in social support. Social support is important to coping for the family, just as it is for the individual. Daneker, Kimmel, Ranich, and Peterson (2001) found that spousal level of depressive affect inversely correlated with levels of perceived social support; those with greater social support had lower depression scores. South Koreans, Mexican Americans and Anglo Americans were compared in a study of family resiliency by White, Richter, Koeckeritz, Lee, and Munch (2002). The South Korean caregivers were younger than the other two groups, and they experienced the greatest illness demands, while perceiving themselves low in relative/friend support and family resiliency. Anglo American caregivers reported a significantly higher perception of support from the community than the South Koreans or Mexican Americans. The researchers concluded there are ethnic differences in response to the dialysis experience. No studies were found that addressed specifically the Hmong experience with end stage renal disease and hemodialysis.

The feeling of a changed life world (Ziegert & Fridlund, 2001) was characterized by a loss of a life companion, lack of future visions, having to adapt themselves, carrying a greater workload, and a changed relationship. Knafl and Gilliss (2002) described the impact "when a family member has a serious illness families are confronted with the possibility of making major changes in their usual routines to accommodate illness demands and are challenged to face the possibility of a radically altered future" (p. 186). There is some evidence that the burden on the caregiver is less with patients who are independent in performing their activities of daily living (Harris, Thomas, Wicks, Faulkner, & Hathaway, 2000). These researchers also found no significant difference in burden between young and old caregivers. McGee (1981), however, found that older spouses and those married longer tended to resent dialysis less compared to younger, more recently married couples.

Wicks *et al.* (1997) found that caregiver burden was significantly related to quality of life. In their sample of 96 family caregivers of patients waiting for kidney or pancreas-kidney transplant, the majority (60%) stated they felt little or no burden, whereas only 5% felt a moderate to severe degree of burden. 80% of these caregivers rated their quality of life as either excellent or good, with only 2% rating it poor or very poor. One factor that could contribute to these results, however, is that 56% of the patients were independent in their activities of daily living. The sample was composed of Caucasians (46%) and African Americans (54%). Whereas studies of quality of life of

ESRD patients have yielded fairly optimistic results, Lindqvist, Carlsson and Sjoden (2000) found Swedish hemodialysis spouses to have a significantly lower quality of life than an age-matched general population in Sweden. One patient described the role change his wife encountered:

> Anne experienced considerable role conflict. Whereas before dialysis she had been a wife, lover and companion, she now was sometimes thrust into the strange role combination of nurse, mother and sister. During dialysis she became a "nurse" and often had to respond to crises of pain, shock or malfunctioning of the machine. At other times she was like a mother and gave comfort and strength when self-esteem was low, and at still others, she became a sister or friend because of changes in our sex life and the lack of time to enjoy each other during the week. (p. 387)

McGee (1981) compared home peritoneal dialysis patients and patients receiving hemodialysis in the hospital setting. He found home dialysis spouses felt the patient was more dependent on them, and wives were more likely than husbands to be satisfied with home dialysis. Chowanek and Binik (1989) explored the marital relationship and psychological well-being among renal failure patients and their spouses at various points during the progression of renal disease. They found that women patients and women spouses had higher psychological distress than the males, and dialysis couples had less overall happiness and more somatic difficulties than nondialysis couples. They also found that marital role strain was a significant predictor of psychological well being, particularly the solidarity subscale, which assessed the couple's reciprocation in areas of intimacy, cohesion, companionship, and affection. Family members often felt they needed to adapt to the mood swings and changing personalities of the dialysis patient (Schneider, 2003; Campbell, 1998). O'Brien (1983) found depression, alienation and dependency were also frequent complaints. A wife of one dialysis patient expressed the impact of her husband's personality change:

> I was ready to adapt and adjust our lives if necessary but I was not expecting what happened. I was not expecting the personality change. For him to become as demanding, I mean really demanding, as he is. He will not ask anybody else to do anything for him except me. He really had mood swings. Sometimes he's up and everything's fine and other times he really gets irritable. When I learned that the disease caused it, I could accept more of the personality changes and things that go with it. He's very definite in a lot of things that he thinks he remembers, but he gets them mixed up- but he doesn't think so, and he gets upset if I correct him. (O'Brien, 1983, p. 14-15)

Feeling secure in life included trust in the health care team, financial security, and a feeling of being well informed (Ziegert & Fridlund, 2001). This theme is in contrast to what other researchers have found. In one study, family members did not have much contact in general with the hemodialysis staff (O'Brien, 1983), and some patients in other studies did not necessarily trust their health care providers (Calvin, 2004). They were able to identify those staff who had expertise and were competent and those who were not competent (Hagren *et al.*, 2001). Financial concerns were as real for family members as they were for the individual.

A feeling of a threatening future was characterized by a fear of death and living with a constant worry (Ziegert & Fridlund, 2001). O'Brien (1983) found the following:

> Many family members suggest that the most difficult stressor that they encounter is the uncertainty of the patient's condition and prognosis. A mother commented that her daughter's illness condition was a constant worry and that whenever the phone rang she feared that it might involve the kind of rush trip to the emergency room that she had experienced several times. (p. 63)

Uncertainty related to the patient's health, dialysis, potential loss, and availability of a kidney for transplant was a major source of stress for family members of individuals living with ESRD (Pelletier-Hibbert & Sohi, 2001). Starzomski and Hilton (2000) also found uncertainty to be a major stressor in family members of patients awaiting kidney transplant.

Promoting health was the last theme described by Ziegert and Fridlund (2001) and was identified as taking initiatives, being bothered to do things, and being knowledgeable. O'Brien (1983) suggested the size of the family and the involvement of the extended family will affect decision-making and roles and responsibilities. In a small family the tasks may become the burden of one person, whereas in a larger family, or if the extended family is involved, these duties may be shared. Some families reported the illness and treatment brought them closer together in their support of each other. Taking on extra responsibilities can result in fatigue (Schneider, 2003). Campbell (1998) agreed when she explained "the price of keeping all aspects of life balanced and provided for is often exhaustion" (p. 101).

Interviews with dialysis patients and their spouses yielded six major emotional needs: the need for identity due to the loss of roles and poor self-concept, the need to grieve, the need for safety and control of the environment, particularly because of potential complications during dialysis, the need for communication, especially with the health care providers, the need for love, and the need to establish one's optimum level of wellness (Santopietro, 1975). It is imperative that health care providers assess the family's needs and concerns in order to intervene appropriately. Wagner (1996) found there were discrepancies between the nurse's view and the family's perception of family needs. Family members indicated that psychosocial needs were more important than the ranking given by nurses. Family members felt the need for information and comfort were important, as was the dialysis staff caring about the patient. Nurses thought it was important that they be able to handle emergencies, but family members did not view this as so important. Nurses could be mistaken if they make assumptions about family needs.

Coping Methods Used by Families with a Member on Hemodialysis

Family support groups have been helpful in coping with renal disease (Winkes, 1983) and encouraging a variety of coping methods. Being optimistic was the most widely used coping style among a Swedish sample of spouses of ESRD patients (Lindqvist *et al.*, 2000). Pelletier-Hibbert and Sohi (2001) found in focus group interviews with 41 family members of individuals with ESRD that the following coping strategies were utilized: living each day as it comes, finding positive meaning in the illness, hoping for a kidney transplant, and faith in God. Lastly, Flaherty and O'Brien (1992) interviewed 50 family members of individuals with ESRD at four different periods of time: six to eight months after initiating dialysis, and then at 12, 16, and 24 months. Their interviews yielded five styles of family coping. The remote family style was described as ESRD not interfering or changing the life of the family. The patient in these families was very independent. The enfolded family coping style resulted when the family worked together and found the illness strengthened their relationships. The altered family coping style was characterized by major changes in family members' daily activities and an increased patient dependence on the family. The distressed family style was identified when the family experienced sorrow or grief about ESRD, concern for the patient, feelings of hopelessness or negativity, and when family members felt that ESRD had a great impact on the family. The last coping style described was called receptive family coping, and this was characterized by acceptance and adjustment. In this study, the remote family style was used most frequently, and the in-center hemodialysis family members had the highest percentage of remote family style and the lowest in distressed family styles. O'Brien (1983) found some families coped by normalizing their lives despite dialysis. This concept was termed routinization and tended to be used most commonly with long-term coping in dialysis.

Summary

In conclusion, the review of the literature has provided several insights into the Hmong culture, their views of health and illness, end-stage renal disease, and hemodialysis as a treatment modality. The Hmong in this country are facing diseases and medical treatments that are foreign to them. They did not experience these in their homeland. There are barriers to health care that many Hmong encounter. In order to provide quality nursing care to the Hmong patients, nurses need to understand these barriers, design interventions to overcome these, and evaluate the effectiveness of these interventions. In order to provide quality nursing care to the Hmong hemodialysis patients, in particular, the nurse needs to have an understanding of the patients' experiences, feelings, stressors, coping methods, etc. The nurse develops a plan of care to address these issues, implements the interventions, and evaluates their effectiveness. Assessment is the first step in the nursing process, and gaining knowledge and understanding is an important part of this step.

There were no studies found that explored specifically Hmong experiences with hemodialysis, nor were there any studies found that explored hemodialysis nurses' experiences with Hmong hemodialysis patients. This researcher hoped to provide an initial description of both of these areas that have yet to be explored.

CHAPTER III

Methodology

The main purpose of this qualitative study was to explore the lived experiences of Hmong hemodialysis patients. The perspective of the hemodialysis nurses working with the Hmong patients was also studied. This chapter will describe in detail the methods and rationale used for sample selection, data collection methodology and procedure, and data analysis. The chapter will conclude with a discussion of limitations of the study.

Subject Selection and Description

The experience of the Hmong in the United States and the health care system has been described, but not in relation to chronic renal failure and hemodialysis in particular. This study was meant to provide an initial description of the experience of Hmong hemodialysis patients' experiences. Following approval from the researcher's affiliated institution's and hospital's Institutional Review Boards, the entire population of Hmong hemodialysis patients in a Midwestern Wisconsin city were identified by the staff of the hospital hemodialysis units. There are two medium-sized hospitals (250 beds) in this city, and each holds a hemodialysis unit. The entire population of Hmong hemodialysis patients, N=7, was approached and invited to participate in the study.

In order to demonstrate respect, increase trust, and enhance communication between the researcher and the participants, a respected member of the Hmong community was invited and agreed to assist with explaining the study to the Hmong hemodialysis patients. Polit, Beck, and Hungler (2001) explained that researchers often need to gain access to informants through a key person to ensure cooperation. In regard to the Hmong, specifically, Shadick (1993) stated that enlisting the assistance of leaders in the Hmong community would increase participation and cooperation in health education programs for the Hmong. The member of the Hmong community that assisted the researcher in the project also recruited a respected and trustworthy translator for the interviews conducted. This translator has worked with these Hmong hemodialysis patients and has developed a trusting relationship with them.

The criteria for participation in the study were as follows: hemodialysis patient self-identified as Hmong, over 18 years of age, and able to communicate either verbally or in writing or designate a surrogate to assist with the interview. The Hmong translator contacted the hemodialysis patients via telephone, explained the study, and invited the patient to participate. The patients who agreed to participate were asked to identify a place, date, and time of their preference for the interview to be conducted. Some studies have been conducted during dialysis treatments, but this also adds the risk of participant fatigue, which could alter the degree of responses to questions. The researcher also wondered if conducting the interview during dialysis, in the presence of the staff, would somehow contribute to the responses by the informants. Thus, the researcher felt it would be appropriate for the patient to decide when and where to conduct the interview. Giles (2003) claimed interviewing in an environment of the participant's choice "increased the contextual validity of the interviews" (p. 35). In addition, Hatch (2002) described the ideal environment for an interview as quiet, private and comfortable, both physically and in terms of comfort in answering questions. The researcher anticipated the participant would choose a setting he/she was comfortable in for the interview.

The registered nurse sample was a convenience sample of nurses working in the hospital hemodialysis unit from the two hospitals of similar size (250 beds) in the

Midwestern Wisconsin city. The nurses met the following criteria: work with Hmong hemodialysis patients, over 18 years of age, able to read and write English. Although Hatch (2002) stated that the convenience sample is the most common but least desirable of the sample selection types, this researcher felt it would be appropriate for an area that has yet to be explored.

Instrumentation

A structured interview was designed for exploring the Hmong hemodialysis patients' experiences. A structured format was chosen in order to provide clear guidelines and elicit cooperation from the Hmong community members that were assisting with this project. The questions were designed to explore different aspects of the Hmong hemodialysis patients' experiences. According to Hatch (2002), effective questions for a qualitative study will explore the participants' perspectives, be clear, open-ended, neutral, respectful of the participants' knowledge, and generate answers related to the objectives of the research. The questions asked of the participants in this study met these criteria. The researcher attempted to use language that could be translated and would be familiar to the Hmong hemodialysis patients. The questions were clear in the sense that they did not ask too much at once. There were no leading questions or biases in the questions. All of the questions were related to the objective of the study and the review of the literature. The following questions were asked in the structured interview with the Hmong participants:

1. How have kidney disease and hemodialysis affected your life?
2. How have kidney disease and hemodialysis affected your participation in family and clan activities?

3. How have kidney disease and hemodialysis affected your work and leisure time?
4. How do you feel others view you?
5. How do you view yourself?
6. What difficulties did you encounter initially when you started dialysis and how did you cope with these?
7. How do you cope with your current difficulties experienced because of hemodialysis?
8. Describe your relationship with your doctors and nurses.
9. Describe the role of traditional Hmong healing methods in your situation.
10. What recommendations do you have for health care providers?

Quantitative measures of quality of life (Ferrans and Powers Quality of Life Index), stressors (Hemodialysis Stressor Scale), and coping methods (Jaloweic Coping Scale) have been utilized by researchers with hemodialysis study participants and described in the review of the literature. These tools, however, would require translation into Hmong, and could potentially limit the extensiveness of data obtained when exploring this population. For example, these measures may be largely based on experiences from other ethnic groups, and therefore they might not reflect the true experience of the Hmong hemodialysis patients. Because very little is known about the experiences of the Hmong hemodialysis patients, qualitative data collection would be particularly relevant (Polit *et al.*, 2001).

Health related quality of life generally includes physical, psychological, and social domains (Valderrabano, Jofre, & Lopez-Gomez, 2001). The open-ended question asked in this study to explore quality of life for the Hmong hemodialysis patient was: How have kidney disease and hemodialysis affected your life? According to Ferrans and Powers (1993), the Ferrans and Powers Quality of Life Index-dialysis version asks specifically about the satisfaction and importance of leisure time activities and time spent with family and friends. The Chinese dialysis Quality of Life Scale (Valderrabano *et al.*, 2001) also explores the individual's role in his/her family. Therefore, if the participant did not address these two areas specifically in answering the first question, the next two follow-up questions were: How have kidney disease and hemodialysis affected your participation in family and clan activities? And How have kidney disease and hemodialysis affected your work and leisure time?

Psychosocial effects from kidney disease and hemodialysis have been evaluated quantitatively with The Illness Effects Questionnaire, used by Patel *et al.* (2002), and the Haemodialysis Stressor Scale, used by Lok (1996). In the latter questionnaire the psychosocial subscale addresses role reversal with spouse and children and how the individual views him or herself. The next two questions in this research project were asked to explore the psychosocial perspective: How do you feel others view you? And How do you view yourself? These questions also help the reader understand what it might be like for the Hmong when they are chronically ill.

Stressors and coping methods were explored by Welch and Austin (1999), Cormer-Daigle and Stewart (1997), and Gurklis and Menke (1995). The first group of researchers mentioned (Welch and Austin, 1999) used the Hemodialysis Stressor Scale in their study of hemodialysis patients at an initial period and again three months later. Gurklis and Menke (1995) used a structured interview as well as the Hemodialysis

Stressor Scale and Jaloweic Coping Scale. Cormer-Daigle and Stewart (1997) examined illness related stressors, hemodialysis related stressors, and administered the Ways of Coping questionnaire to a group of Canadian hemodialysis patients. Stressors and coping methods were explored in this study by the following questions: What difficulties did you encounter initially when you started dialysis, and how did you cope with these? And How do you cope with your current difficulties experienced because of hemodialysis?

Health care team members have been identified by some hemodialysis patients as a source of support (Patel *et al.*, 2002; Siegal *et al.*, 1987). In order to explore the Hmong hemodialysis perspective, the following request was made: Describe your relationship with your doctors and nurses.

The last two questions in the structured interview explored the use of traditional Hmong healing methods and recommendations for health care providers. These questions were asked to elicit specific information that would be helpful to health care providers in improving the quality of care for the Hmong hemodialysis patient.

In summary, the structured interview questions were designed to explore effects of hemodialysis and kidney disease on the Hmong patients' quality of life and relationships, stressors encountered and coping methods, role of traditional Hmong healing methods, and recommendations for health care providers.

The questionnaire for the hemodialysis nurses was developed specifically for this study. It explored several areas of interest. These included: professional education obtained to learn about Hmong culture, comparison of Hmong hemodialysis compliance and participation in treatment with other hemodialysis patients, actions taken when there are communication barriers, and challenges and stressors of working with Hmong hemodialysis patients. In order to explore rewards nurses experience working with Hmong hemodialysis patients, this was left as an open-ended statement for the nurses to write a response. A space was provided for other comments, and limited demographics were collected, such as age, years in nursing, education level, and years of experience in hemodialysis. The questionnaire was reviewed by an experienced hemodialysis nurse who provided feedback and changes were made in the tool based on this feedback.

Data Collection Procedure

A meeting was arranged with the respected member of the Hmong community mentioned above. The purpose of the study was explained by the researcher and the study questions were shared. The Hmong contact expressed interest in the study and a willingness to call hemodialysis patients, explain the study, and request participation on behalf of the researcher. This Hmong contact also identified a respected, trustworthy translator who would be available to translate during the data collection.

Following approval from the Institutional Review Boards from the University and two hospitals with hemodialysis units, the researcher contacted the nursing directors of the two hospital hemodialysis units to obtain names and phone numbers of all Hmong hemodialysis patients. The Hmong interpreter telephoned the patients, explained the study, the risks and the benefits, and upon agreeing to participate, the patient identified a date, time, and location where he/she would prefer to be interviewed.

Upon meeting the participant, the researcher explained the study, the risks and benefits, and the translator presented this information to the participant. A consent form was signed after this was also translated to the participant. All interviews were tape recorded and the researcher took field notes as well during the interview. The tapes and notes were secured in a safe, private location by the researcher. Clarification of misunderstandings or confusing responses was attempted during the interview process. Immediately following the interviews, the recordings were transcribed verbatim by the researcher. The field notes were referred to when clarification in the recording of the interview was required. No participant names or other identifying information was recorded. Appendix D includes the cover letter and consent form for the Hmong hemodialysis patient participant.

Data was collected from hemodialysis nurses via questionnaire developed for the purpose of this study. (Appendix B) A list of all nurses working with the Hmong hemodialysis patients was obtained from a staff member. In attempt to achieve a high participation rate, the suggestions made by Dillman (2000) were followed. Initially, a personalized correspondence in the form of a brief letter was placed in each nurse's individual mail slot at their place of employment. This letter explained that in a few days they would be receiving a questionnaire. The purpose of the study and the importance of returning the completed questionnaire to the researcher were explained. The following week the questionnaire was delivered and placed in each of the nurse's mail slots. A self-addressed, stamped business-sized envelope was included for returning the completed survey to the researcher. A returned questionnaire implied consent. There was a separate postcard included with the questionnaire that offered the nurse the opportunity to express an interest and willingness to participate in a follow-up interview if it was deemed necessary to expand or clarify components of the questionnaire. This card asked for the nurse's name and means of contact, and was stamped and addressed to the researcher.

This card was kept separated from the questionnaires to ensure confidentiality and anonymity in the returned questionnaires.

The following week a postcard was delivered to the nurses' mail slots thanking them for their participation and if they had not returned the questionnaire, a gentle reminder requesting them to do so. All returned questionnaires were secured by the researcher. No names or other specific identifying data was obtained. The returned postcards with expressed interest in interviewing were kept in a secure place until the study was completed. At that time they were shredded. Appendix C includes the letters provided to the nurses.

Data Analysis

Analyzing qualitative data can be very challenging. Polit *et al.* (2001) describe the process of data analysis in qualitative studies as involving "clustering together related types of narrative information into a coherent scheme" (p. 44). Hatch (2002) provided guidelines for the novice researcher conducting inductive analysis. "Inductive data analysis is a search for patterns of meaning in data so that general statements about phenomena under investigation can be made" (Hatch, 2002, p. 161). It includes the following steps (Hatch, 2002):

1. Read the data and identify frames of analysis.
2. Create domains based on semantic relationships discovered within frames of analysis.
3. Identify salient domains, assign them a code, and put others aside.
4. Reread data, refining salient domains and keeping record of where relationships are found in the data.

5. Decide if your domains are supported by the data and search data for examples that do not fit with or run counter to the relationships in your domains.
6. Complete an analysis within domains.
7. Search for themes across domains.
8. Create a master outline expressing relationships within and among domains.
9. Select data excerpts to support elements in your outline. (pp. 162-178)

Once the interviews with the Hmong hemodialysis patients were transcribed, the responses were read thoroughly to identify initial themes. As each interview was added to the data set, the researcher read all the interviews again, looking for new insight. Categories were developed that described parts of the data. The researcher was careful to mark data with codes so that the examples of the categories or domains could be retrieved later. Step number five required the investigator to continue to read the data and identify if the categories were supported by the data or if there were parts of the data that did not fit within the categories identified. The researcher then looked for themes across the categories or domains and attempted to make sense of it all by describing similarities, differences, connections between domains, and what it all meant. Lastly, in reporting the data, it was important to include excerpts from the interviews that supported the data analysis.

The data from the questionnaires the nurses completed were reported in frequencies and ranges. A correlation analysis was used for a section of the data. There were no other analyses performed. A summary of the results was provided, along with recommendations for improving nursing care for the Hmong hemodialysis patient based on the questionnaire responses.

Limitations

Two obvious limitations to this study are the small sample size and the lack of experience the researcher had in qualitative data analysis. Other studies have been reported with a sample of five hemodialysis patients (Sloan, 1999) and another with four in-home dialysis patients (Giles, 2003). Both of these studies were conducted via interviews with the participants. Although the primary investigator lacks experience in data analysis, every attempt was made to maintain integrity, objectivity, and openness in evaluating the data.

Generalizability of the results is not appropriate. However, the reader does reach an initial understanding of an area yet to be explored. Other limitations need to also be considered in terms of culture, language, and communication barriers. The investigator trusted the translator to not self-interpret or alter the questions or responses, but rather to relay them in their entirety. One must also consider the extent of full disclosure of the participants' feelings and concerns.

Chapter IV

Results

The purpose of this project was to explore the experiences of Hmong hemodialysis patients and the nurses who care for them. This chapter describes the results from the questionnaires the nurses returned and the interviews of the Hmong patients. Because the sample size is small the results need to be interpreted carefully. However, this study does provide some data for a newly explored area in nursing. The results will be separated into two main sections: Nurses' experiences in working with Hmong hemodialysis patients and Experiences of Hmong hemodialysis patients.

Nurses' Experiences in Working with Hmong Hemodialysis Patients

The data collected regarding nurses' experiences working with Hmong hemodialysis patients will be discussed based on the following subsets: professional education in learning about Hmong culture, comparison of compliance and rates of complications with the Hmong population compared to other hemodialysis patients, methods used to promote understanding with the Hmong patients, challenges encountered in working with Hmong hemodialysis patients, and rewards experienced while working with Hmong hemodialysis patients. Stressors encountered will be discussed with the professional education. This section will begin with a description of the sample, or the demographics.

Demographics

All of the Registered Nurses working in hemodialysis with Hmong patients from two Midwestern hospitals were invited to participate in this study by completing a questionnaire that was placed in their mailbox at their unit of work. Questionnaires were returned to the researcher by 17 of the 23 nurses, a response rate of 74%. All the nurses were female. The nurses ranged in age from 24 to 56 years (mean 44 years). Over two-thirds, 70%, of the sample was over 40 years old. This sample of nurses varied in their years in nursing from two years to 33 years (mean 19 years). There were 12 respondents (70%) who had been in nursing for 10 years or more, while over half (56%) had been in nursing for 20 years or more. Only four (23%) had been in nursing for less than five years. Although this sample had been in nursing for many years, the majority of these nurses had five years or less experience in hemodialysis (n=11, 65%). The range for the number of years working in hemodialysis was two to 24 years, with 29% (n=5) working in hemodialysis for ten years or more. In terms of educational preparation, eight of the respondents (47%) were Associate Degree graduates, eight (47%) were Baccalaureate Degree graduates, and one nurse had earned a Master's Degree in Nursing.

Professional Education in Learning about Hmong Culture

The nurses were asked about the number of hours they spent learning about Hmong culture outside of their work in the hemodialysis unit. The nurses varied greatly in their effort to learn about Hmong culture. One respondent wrote in "minimal" for hours of discussion with health care providers and Hmong community/family members, and had no hours identified for any of the other options. Four (24%) nurses admitted to two hours or less in total hours spent learning about Hmong culture, while six (35%) indicated they had spent a total of four to 20 hours, four nurses spent from 30 to 50 hours and one nurse each estimated a total of 73 and 170 hours learning about Hmong culture.

The most frequently used method of learning about Hmong culture was informal discussion with Hmong community members and/or family members of the patients. There were 14 respondents (82%) that indicated they used this avenue to learn about Hmong culture. The next most frequently used method, by 11 (65%) nurses was discussion with other health care providers. Approximately half the participants (n=8, 47%) read journals or articles about Hmong culture. Five nurses read books, three nurses took University courses, and two respondents attended a conference or seminar to learn more about Hmong culture.

Even though 14 of the respondents indicated they learned about Hmong culture through informal discussion with Hmong community members and/or family members of the patients, nine (64%) of these nurses admitted to five hours or less learning with this resource, while the other five respondents indicated they spent from ten to 60 hours in these discussions. Thus, a greater percentage of nurses spent five hours or less learning about Hmong culture with this method. The results were similar in the other areas as well. For example, six (55%) of the 11 nurses who had discussions with other health care providers indicated spending five hours or less in this activity, while the other five (45%) nurses identified ten to 30 hours were spent in these discussions. While five nurses indicated they read books, three (60%) of them read for five hours or less; the other two read 10 to 20 hours total. Eight nurses indicated they read journal articles, five (62.5%) of them with five hours or less and three (37.5%) spent ten to 20 hours learning about Hmong culture in this format. Overall, there was not a great amount of time spent by these nurses learning about Hmong culture.

Based on the time spent learning about Hmong culture, the responses to the following question were not surprising. All of the respondents either disagreed (n=15) or were neutral (n=2) with the statement “I am knowledgeable about Hmong herbal medicine”. What may be surprising, however, is that only one nurse agreed to the statement “I feel I am at risk from a legal standpoint when I am working with Hmong patients”. The remaining 16 were split evenly between feeling “neutral” and disagreeing with the statement. The respondents did not feel they were violating their ethical standards either. Three nurses were “neutral” while 14 disagreed with the statement “I feel my ethical standards are in jeopardy when I am working with Hmong patients”. The nurses were divided in their willingness to encourage herbal treatment if they knew more about this. Five nurses agreed, eight were neutral, and four disagreed with the statement “If I knew more about herbal treatment I would be willing to encourage its use for my Hmong patient”.

There was no correlation between total hours of time spent learning about the Hmong culture and years of working in hemodialysis (r= -.23) or highest degree earned (r= .28). A mild inverse relationship was found between the total number of hours spent learning about Hmong culture and years of nursing experience (r= -.423). This would indicate that as a nurse gained years in experience, the likelihood of the nurse spending time outside of work learning about patients from other cultures decreased.

Comparison of Compliance and Rates of Complications

The nurses were asked several questions comparing their experiences with Hmong hemodialysis patients and non-Hmong hemodialysis patients. The majority (n=13, 76%) of the nurse respondents viewed the Hmong hemodialysis patients as less compliant with their medication regimen than their non-Hmong counterparts. The other four respondents felt the Hmong patients were just as compliant with their medication regimen compared to the non-Hmong hemodialysis patients. In terms of compliance with dietary/fluid restrictions, 11 (65%) respondents identified their Hmong patients were less compliant, while six (35%) felt the Hmong hemodialysis patients were just as compliant as the non-Hmong patients.

There were seven nurses who viewed their Hmong hemodialysis patients as less compliant with their dialysis treatment schedule while ten respondents viewed their Hmong hemodialysis patients just as compliant with their dialysis treatment schedule compared to their other hemodialysis patients. Based on the number of nurses indicating their Hmong patients were less compliant with their medication regimen and dietary/fluid restrictions, one might anticipate these patients experiencing more complications. The respondents in this study did not indicate this, however. Only four (24%) nurses thought their Hmong hemodialysis patients were more likely to experience complications from dialysis, while the majority, 76%, thought these patients were just as likely as their non-Hmong hemodialysis patients to experience complications. This might indicate that complications from dialysis result from factors not identified in this study.

Patients receiving hemodialysis tend to be treated with a multidisciplinary approach, including social workers, physicians, dieticians, and nurses. The majority (n=10, 59%) of the respondents felt their Hmong hemodialysis patients were less likely to be a participant in this multidisciplinary plan of care, while five (29%) felt they participated the same and two (12%) felt the Hmong participated more in the multidisciplinary plan of care compared to the non-Hmong hemodialysis patients.

Methods Used to Promote Understanding with the Hmong Patients

The questionnaire asked the nurses to identify ways they handle situations when they are uncertain of their Hmong patients' understanding of teaching and recommendations made by the nurses. Using a trained interpreter was "sometimes" used by 13 (76%) of the respondents and "always" used by 4 of the nurses. The respondents were almost evenly divided by the frequency of using an adult Hmong family member. Eight of the respondents chose "always" and nine of the respondents chose "sometimes" in response to this item. Sometimes an adult family member might not be present to help translate. In this case, the nurses indicated they would use a minor family member "always" (n=3), "sometimes" (n=11, 65%), while three nurses indicated they would "never" use a minor to help with translating.

A few nurses also wrote in their own way of trying to ensure understanding by their Hmong patient. Three nurses indicated other Hmong patients who spoke English and Hmong would be asked to translate. Another nurse identified the unit she worked at tried to ensure understanding by having an interpreter available regularly, albeit not frequently: "We schedule monthly care conferences, then call the interpreter with the care conference schedule. We schedule all our 'Hmong patients' on the same day".

Challenges Encountered in Working with the Hmong Hemodialysis Patients

In this study there were three categories of challenges, patient, institutional, and cultural, that had subheadings for the nurse to identify the frequency of this challenge as either very common, sometimes a problem, or not a problem. The patient challenges were transportation, finances, family support, depression, and anxiety. The majority of respondents indicated each of these patient challenges was sometimes a problem.

Transportation was seen as very common by two nurses, sometimes a problem by 12 (71%) and three nurses felt transportation was not a problem. Finances were seen as a common problem by four nurses, sometimes a problem by nine nurses (53%) and not a problem by three nurses. One nurse was unsure of the Hmong patient financial situation as indicated by her response as a question mark. Family support was seen as a common problem by three of the respondents, sometimes a problem by nine (53%) and not a problem by five nurses. The majority, n=12 (71%) of the respondents identified depression as sometimes a problem for their Hmong patient, while three thought it was very common and two felt it was not a problem. The majority of the nurses thought anxiety was sometimes a problem, n=11 (65%), two indicated it was very common, and four felt it was not a problem.

By combining the responses of "very common" and "sometimes a problem" it is clear that these nurses viewed the patient challenges as barriers to care. Fourteen (82%) indicated transportation was a problem for the Hmong patient, thirteen (81%) indicated finances was a problem, twelve (71%) thought family support posed a problem, while 15 (88%) indicated depression was a problem for the Hmong hemodialysis patient.

Institutional challenges that were included in the study were lack of trained interpreters, lack of adequate time with patient, lack of training on Hmong culture, lack of availability of interpreters, and agency policy on use of interpreters. Seven nurses responded that the lack of trained interpreters was sometimes a problem and seven thought it was not a problem. The remaining three respondents felt it was very common to have a lack of trained interpreters. This lack of trained interpreters did not seem to be as common a problem as the availability of interpreters. Twelve nurses felt the availability of interpreters was sometimes a problem, and two felt it was very common to have a lack of available interpreters. Only three respondents felt the availability of trained interpreters was not a problem. These nurses did not view the agency policy on use of interpreters as a problem: 12 nurses felt this was not a problem, two felt it was sometimes a problem, one thought it was a common problem, and two respondents did not answer this item. The majority (n=12, 71%) of these nurses felt having a lack of time with the patient was sometimes a problem, while five felt it was not a problem. All of the nurses agreed that there was a lack of training on Hmong culture, and this either was a very common problem (n=11) or sometimes a problem (n=6).

There were four cultural challenges explored: Hmong beliefs about illness, Hmong beliefs about treatment, Hmong fears about treatment, and communicating with the Hmong. Four nurses expressed they thought Hmong fears about treatment and Hmong beliefs about illness were very common problems, while five nurses felt Hmong beliefs about treatment presented a very common problem. Ten (59%) of the respondents felt Hmong beliefs about illness and beliefs about treatment were sometimes a problem, while nine felt Hmong fears about treatment were sometimes a problem. Two nurses felt Hmong beliefs about treatment were not a problem, three felt Hmong beliefs about illness were not a problem, and four nurses identified Hmong fears about treatment were not a problem. Ten nurses identified communicating with the Hmong was a very common problem, while seven nurses believed it was sometimes a problem. One of these respondents added the comment that communicating with the Hmong was not a problem when interpreters were used.

Combining the responses of "very common" and "sometimes a problem" dichotomized the response to this challenge as either a problem or not a problem. The results showed that all the cultural challenges identified were barriers. All of the respondents felt communication was a problem, 15 (88%) felt Hmong beliefs about treatment were a problem, 14 (82%) identified Hmong beliefs about illness as a challenge, and 13 (76%) nurses believed Hmong fears about treatment created a problem for the Hmong hemodialysis patient.

Rewards Experienced While Working with Hmong Hemodialysis Patients

The nurses were asked to identify rewards they experienced while working with their Hmong hemodialysis patients, and any other comments they would like to add were encouraged. The majority (82%) of the nurses wrote comments in this section. The rewards of working with Hmong hemodialysis patients can be explained by three categories: learning the culture, being recognized for care provided, and the role of the family. Several nurses indicated that being exposed to and learning about a new culture was rewarding. One nurse also added she has more respect for different cultures. Several nurses described their Hmong patients as loving and caring. One nurse indicated sometimes this was shown after a relationship had developed: "when gain their trust are very loyal, friendly, and loving; one person always comes and gives us a hug".

The nurses in this study indicated it was rewarding for them when their Hmong patients recognized the care provided. A typical response in this category was "the patients are courteous and thankful for the care given them".

Another nurse wrote in: “helping them to feel better and having them understand how dialysis helped to do that; when they call me by name, seeing them after they’ve received a transplant”.

These respondents also found working with and getting to know families was rewarding for them. Family members, especially wives of the male patients, often came along to stay during the dialysis treatment. One nurse noted families with younger generations who were speaking English and Hmong tended to ask more questions and seek out information about health care. This was rewarding for her. One nurse was able to describe the uniqueness of each family within the Hmong culture:

> Although the Hmong culture is, I would imagine, somewhat the same with each family Through working with these patients over the years. They each have very different personalities and each family is very unique. Different families-some want to really be involved with the patient/family members others don’t

One nurse summed up her feelings of reward working with the Hmong by expressing her joy of nursing: “I love working with all my dialysis patients”.

Nurses’ responses on the questionnaires indicated all of them felt communication was at least sometimes a problem, but the majority indicated it was a very common problem. The comments written by the nurses certainly supported and provided evidence of communication barriers. One nurse stated the Hmong were at a disadvantage because of this barrier. Another nurse provided specific examples of this challenge in her comments:

> When communicating (teaching, asking questions) through an interpreter its difficult to get a “feel” for what the Hmong patient is trying to communicate. For

> example reminders to limit fluid intake- any troubles with alternatives to drinking fluids- answer is always "no" or would you like for me to give you suggestions or these are things you can do to quench thirst- they respond with "no" and yet will come into ER with CHF

Communication barriers affect teaching moments as well as the ability to get to know the patient and develop relationships, as one nurse explained: "Difficult to get to know them personally through an interpreter Ex. would like to know more about their personal lives- ex. what did you do yesterday. Casual questions".

It may be challenging to communicate if the direct translation of words does not relay the message intended. Another nurse provided an example: "'tired' really means they are ready to pass out 'went swimming' really means took a shower".

One comment written by a respondent did not necessarily relate to the challenge of communication directly, although it may be a component. This nurse made note of the challenge that can arise when a Hmong patient with kidney disease is told dialysis is needed: "starting dialysis can be time consuming, as they usually do not make the decision as to whether they can start- it is determined by others and not always immediate family".

Experiences of Hmong Hemodialysis Patients

There were seven Hmong hemodialysis patients invited to participate in the study. The Hmong interpreter who agreed to assist with the interviewing contacted each Hmong hemodialysis patient, except for one. This patient spoke and understood English and was thus approached by the researcher and invited to participate. Three patients declined participation. One had just recently been started on dialysis (within three months), one had been struggling with an acute illness during the data collection period, and the other had just been diagnosed with cancer and was undergoing treatment for that as well. It is conceivable that these three patients could be experiencing an inordinate amount of stress, making their situations perhaps more unique than the other hemodialysis patients' experiences.

The four patients who participated agreed to be interviewed during their dialysis treatments. One patient was very hard of hearing and did not speak well and requested that his wife be allowed to answer the questions with him. Each interview was audiotaped and transcribed verbatim after the interview was completed. Notes were taken during the interviews as well. The interviews lasted from 20 to 31 minutes each. The ages will not be disclosed due to the possibility of anonymity being violated. Each participant was male. The length of time each participant had been on dialysis was eight months, one year, two years, and four years. They also varied in their length of time in the United States. One patient was born in the U.S. His parents came from Laos, but he was not sure how long ago. The other participants have been in the U.S. for three, 15, and 20 years. The results from the interviews will be categorized in the following groups: quality of life and relationships with others, stressors encountered and coping methods utilized, role of traditional Hmong healing methods, and recommendations for health care providers.

Quality of Life and Relationships with Others

There was an overwhelming sense of sadness evident throughout the interviews with the Hmong hemodialysis patients. Three of the four participants specifically used the term "sad" numerous times, one included "depressed", and one used the term "stressed". Feeling sad or stressed resulted from several aspects of being a hemodialysis patient. Weakness, inability to perform or fulfill roles, inability to participate in activities, and feelings of uncertainty, worthlessness, and fear were all described and brought back to feeling sad.

Weakness was described by all of the patients as affecting their lives. One participant stated:

> I started on dialysis. I feel weak. I am unable to do anything. I am too tired. I can't babysit. I can't help my wife around the house. If they have work to do I can't help. I'm very sad I am unable to do any of these things. My appetite is not good so that leads to weakness…I'm so sad that I'm weak and have to go through all of this.

Another patient experienced similar problems: "I'm very weak, need help walking. Somebody sometimes has to stay there to help me walk all of the time. I have a cane, but I feel very weak all the time."

This patient's wife added:

> He never gets up to do anything. He will either lie down or sit on the couch most of the day and there's really nothing that he can do to help that. Even though he tries to eat more so that he gets stronger it doesn't do much good. He doesn't have much of an appetite anyways.

The inability to participate in activities resulted in feelings of sadness for these participants. One patient was especially sad that he could not enjoy his life in the United States. He stated:

> I am very sad that I have this disease, that I have to come here to do dialysis. I am very sad that I have this disease. I can't enjoy this country the way that I thought I

> would. I can't go to the places I wanted to go see… I'm just very upset that I came to this country and not being able to do, I'm unable to do anything. I know the hospital is helping me as much as they can but I still am sad that I am not able to do anything.

The inability to do what one desires caused hardship for this patient, who wanted to sightsee around the U.S. Another patient also expressed the sadness in not being able to do what he wanted, but from a different standpoint:

> Having kidney disease has stopped me going to family and joining in clan activities; whether they are having parties, feasts, festivals, even funerals, too, I can't do that anymore…I can't help out in the home doing chores…I used to go squirrel hunting and like to go fishing. Now I can't do any of that as well and it saddens me a lot that being a person and you are not able to help out your family at home, especially when you are a head of household, you're the father and you can't do anything to help your family anymore.

This patient spoke of not only missing out on life's activities, but also the inability to fulfill roles and responsibilities. Another patient expressed the impact on his psyche:

> I'm very sad that I have this disease and on dialysis. All I know is that, about myself, is that if I'm on dialysis my life is only 50/50. It's not complete anymore. I feel that I cannot help myself, my family, my clan, my family members, my relatives. I feel that has brought me down to a lower level than others around me… What I mean by that is I can't do what others can do anymore as a normal person can do, like eating the types of foods I enjoy eating most or doing things I

> enjoy doing the most, helping out friends and family. I can't do anymore so that's why I see myself as lower than them.

Each of the patients discussed the inability to participate in activities. All four identified this was related to weakness and fatigue, three discussed the dietary restrictions, and one patient related it directly to the fistula for dialysis as well:

> It is taking a lot out of my health wise. It is kind of a little but stressful to wake up by five in the morning and come here for four hours three days a week. It gets kind of stressful to wake up so early, and then after dialysis I'm really tired. I don't want to do much afterward.
>
> My brothers and them, they go canoeing or something with a bunch of their friends and I don't really participate in them because of dialysis I guess. My left hand has a fistula in it so canoeing requires a lot of rowing and my left hand is very weak and it kind of hurts after dialysis days. I can't carry much weight on the left hand so I can't do a lot of activities with my brothers and stuff.

Another patient stated:

> It has affected my participation in family and clan activities due to the fact that the food that they eat. I'm on a special diet and I can't eat what they eat at the activities or at the festivals or the feasts.

These restrictions made another patient sad: "The doctors have told me that I should not eat certain foods. The food that I want to eat they told me not to eat and I'm sad that I'm not able to eat those."

And another patient stated: “It is kind of hard for me to stay away from a lot of certain foods and I’m limited to how many cups of water I can drink each day, liquids I can drink.”

One participant indicated a fear of traveling to attend family or clan activities because if something happened and he got sick, he was afraid his insurance would not cover the treatment.

In addition to the inability to fulfill roles and responsibilities in the home, one patient described the challenge in finding and keeping meaningful employment, which affected his quality of life from a financial perspective:

> I want to get a job, but then a job will require that I be there. And really I take a lot of medications. I’m on so many kinds of medications. I’ve developed other problems from the kidney dialysis. I’ve developed sleep problems, RLS, restless leg syndrome. I have problems with my digestive system now. If I had a job then all of these things would get in the way of me trying to get a job. I have to take these medications constantly.

Quality of life has been affected by being a hemodialysis patient, as previously described. There is physical weakness, inability to fulfill roles and responsibilities, and an inability to participate in activities. There also is an emotional impact on these patients. Hopelessness, worthlessness, fear, and uncertainty were identified by these participants.

Two patients specifically mentioned their desire for a kidney transplant, but neither felt hopeful that this would happen. One patient stated:

> People, doctors say that because I’m younger that I’ll probably be towards the top of the list. There’s so many people out there that need a transplant too so I don’t

> really see myself getting one anytime soon. I don't really feel like I'm going to, don't really feel like I'm getting it… The list doesn't mean very much.

The other patient thought receiving a kidney transplant would solve his health problems: "That is the only thing that can make my life better."

The participants all shared their frustrations with not being able to participate in activities. For some, this led to feelings of worthlessness. One patient described this as a vacillating emotion:

> Sometimes I feel sad and I feel that my life is worthless. That's usually at the times when I'm generally very sick, can't do anything to help out with family and I feel that it's probably time for me to go. I'll leave it up to God to make the decision whether or not it is time to go or if I should live longer. And then on other days when I'm feeling much stronger I feel that I feel stronger, I want to help out my family as much as I can. So I really look forward to that day and on those days I feel that I'm not worthless; that I have a family, have children, that I have to love them to the most that I can.

Another patient described the desire, but the inability to do what would normally be expected:

> It can be pretty tough. You have to be at the hospital a lot of time. Sometimes it can be kind of stressing because I'm such a young person…A young person on dialysis is very difficult. I feel more like I should be out there playing a game of basketball or getting exercise. It's hard to do that when you have so many things going on with your body and you're tired most of the time. So it can get pretty tough.

Feelings of fear and uncertainty were described in relation to dialysis treatments themselves and in terms of the patients' future. Complications, such as fainting during dialysis, caused one patient to worry that it could happen to him, and another patient actually did faint, three times, which also left him fearful and uncertain:

> If it's the machine that's not working properly then it's okay, I would be able to help myself and recover it myself, but if it's something because my blood isn't good or something went wrong inside of me and I passed out like that I feel like if somebody doesn't wake me up I feel that that could be the last time that I'll see anybody else...That's why I have my wife here all the time... I don't know for sure even if it's me that is not feeling well, I don't know if I faint if I will ever get up again.

This same patient expressed the uncertainty of life and death as a dialysis patient:

> I feel pretty sad because everybody in this world they just want to live, they don't want to die. They want to be healthy. They don't want to get sick. So I feel pretty sad that I'm sick. I don't know when I'm going to die so that worries me a lot. I don't know if, I know, I hope, I will still be alive today but I don't know if I will be alive tomorrow.

One patient said: "I don't know how long my life is going to last, maybe months, years, I don't know."

Another patient described the response he and his wife tell others when they ask about his condition:

> We know I am getting sick, I am getting older. So the best thing for us to look forward to the next day. Hopefully by tomorrow that we are both still alive and that I am still alive. That is what we look forward to the most.

Sadness, fear, and uncertainty were intertwined emotions.

In addition to the quality of life being affected, relationships with others are affected by being a dialysis patient. As already described, there is a decreased ability to perform expected roles within the family, as well as a decreased attendance to activities. The Hmong patients all described their family and friends as understanding of their situation, but because of their condition, sometimes they are not asked to participate in outside activities, and other times out of respect they will be asked, but will decline. Two patients described the reaction of their friends as noticing a change. One patient explained:

> Others see me as one who has changed. My strength, my personality, my speech, not able to attend most meetings with clan members, family members, because of my situation, health condition. Others tend not to call me any more. Not that they don't want me there, it isn't that, because they understand what I am going through and would rather have me rest than come to discuss matters within the community.

A patient's wife described the questions that arose because of the change family members noticed after they had been separated for many years:

> One of his relatives came and found that he has changed a lot and she was telling them how come he has changed so much? He used to be so active, so outgoing, so

> strong, was able to do everything, but then now how come everything has changed so much?

The wife acknowledged the change in her husband:

> When he was younger, back in his country in Laos, he was a highly ranked official with Hmong army during that time, before the Vietnam War… He was a very strong man, very outgoing, very strong man, could do a lot of things. It's just that ever since he started dialysis that everything has changed a whole lot for him.

She also expressed her belief that some people who did not know her husband might think he has always been weak like this. She does not let this bother her, though: "I'm not going to let that get in the way of my love for my husband."

The wives of each of the married patients were always present during their dialysis treatments. The reason for this was twofold: to monitor for complications and get help quickly if needed, and to love and support their husbands.

Stressors Encountered and Coping Methods Utilized

In addition to the changes in quality of life and relationships with others, dialysis treatments themselves were stressors for these patients. Three of the participants expressed frustration with their medications not helping, and in some cases, their medications made them feel worse. This led one patient to question whether he should continue with the medication or not:

> The thing that bothers me is the medicine they give me to help me but then I take them and they should make me feel better and have a better appetite but I don't feel better and I'm just sort of worried about that. And if the medicine that will help me doesn't help me I don't want to take it anymore…Sometimes they put

> some medicine in the dialysis and it makes me weak, makes me sick and I just don't like that the medicine in the dialysis makes me drowsy, makes me weak and I can't do anything the rest of the day. I have headache, dizzy, vision is blurred and I wish for them to help so I would not have to go through all these.

In addition, this patient stated it was difficult for him to communicate his concerns to the staff. Two other participants also shared their stressors while being on dialysis, both of them related to complications, but one led to a great amount of fear:

> First when I was on dialysis I was pretty scared and nervous. I didn't know what was going on. The first few times I had actually blacked out or fainted about three times when I was on dialysis. I guess it was just something different my body just couldn't take it.

This patient also fears passing out and never waking up. Death was a fear for another patient as well: "On dialysis the medicine they put into the dialysis makes me feel weak, makes me feel sick and sometimes I feel like I'm going to die."

Another patient described boredom as a stressor in addition to more sources of discomfort:

> You get pretty stressed just sitting here for so long. If I have a lot of things going on while you're on dialysis like I get really itchy or your arm might hurt or you might be really tired, you might have a headache, you might have a leg cramp or a spasm, need something to help pass the time.

The coping methods utilized were very few and not detailed. Three of the patients really depended on the prescribed medication to help relieve their symptoms and help them feel better. One patient shares his concerns with his sisters, who are supportive and listen when he wants to talk about his feelings. Another patient stated he tried to exercise and spend time gardening or fishing so he could stay as healthy as possible. Two of the patients felt more energetic and less symptomatic on non-dialysis days, so they tried to enjoy those days. The other two patients felt the same weakness and fatigue on dialysis and non-dialysis days. None of the patients shared specific coping methods utilized in handling changes in quality of life or relationships with others.

Role of Traditional Hmong Healing Methods

All of the patients in this study agreed that Western medicine and treatments were appropriate and necessary, whereas there was not a role for the traditional Hmong healing methods. One patient stated his family "aren't people to do that kind of thing... They just let the hospital do whatever they need to do." Another patient stated he was a Christian and relied on prayer and faith rather than traditional Hmong healing methods. The other participants also explained that traditional Hmong healing methods would be appropriate for spiritual problems, not physical ones, such as kidney failure. A typical explanation was provided:

> The traditional Hmong healing is not something for this situation. If it's something that is disease, health related or due to kidney, heart, lung, brain even, our traditional customs or rituals are not able to help with this sorts of situations. If it's spiritual, then there are methods, there are ways for helping that person. But in my situation there's nothing that we can do to help with that.

Recommendations for Health Care Providers

The Hmong hemodialysis patients varied somewhat in how they described their relationships with the doctors and nurses. Three of the participants stated they had a good relationship with their health care providers. One example is the following: "My relationship with the nurses and doctors here are pretty good. Whatever I need they'll give me. So I listen to them, they listen to me and it works out well." Another patient who also felt he had a good relationship with the doctors and nurses added:

> Whatever we need, blankets, food, whatever, even, not for the patients but just for the patient's visitors too. The doctors and the nurses were willing to provide and give us all the assistance that we need while we are here at the hospital.

Two of the patients felt the doctors and nurses loved them and were helping them, even though one patient admitted to having difficulty communicating with the health care providers.

One participant in the study was not as pleased with his relationship with the doctors: "They just come once in a while. They check on me to see if the problems are getting better, to see if you're following the stuff you're supposed to and that's basically it." This same patient did feel the nurses made attempts to help him while he was on dialysis:

> People who work here a lot are really nice. A lot of them try to talk to you, try to talk to you and get you talking so you're not so bored all the time-you have to sit here so long.

This patient also felt that the nurses did have an understanding of what he was going through because they had worked with so many other patients, even those that had died. They knew what could happen to dialysis patients.

These patients appreciated the work the nurses and doctors did for them and felt they were trying to help the patients to feel as good as possible. They did have some recommendations for their health care providers. One patient, however, was leery of making recommendations:

> I don't have any recommendations. One thing is that I can't really express my concerns or recommendations to them. I feel that if a person like me expresses something like that that it might upset the health care providers or the clinic so I don't think that there is any recommendations to the health care provider.

One patient requested the staff help in finding ways to pass the time. Watching television was not effective in relieving his boredom. Another patient wanted the staff to "be more prompt to get them off the unit" when he was finished with his treatment. This patient attributed delays to understaffing or the nurses working too slowly. When he was finished with dialysis, this patient wanted to be unhooked from the machine right away so he would not have pain.

The final recommendation was for the hospital to have more doctors and nurses for the safety and protection of the patients. Two patients felt more staff were needed. One explained:

> The reason why I say that is because we need more doctors to tend to patients because there are only certain types of doctors that know about heart disease, there are certain types of doctors that only know about kidney, and there's some

> nurses that are here and some that aren't and if something is to happen to patient and the particular doctor is not here that other doctor cannot help that person right away so I recommend that they have staff on here all the time to help patients all the time so they are never short on staff, especially with doctors.

This patient had expressed serious concerns about fainting while on dialysis and feared that he would die if someone did not respond quickly. One other patient witnessed a fellow dialysis patient faint, and that was bothersome to him as well. Hearing about these episodes was also frightening:

> I spoke with … and he was out for a little while. He didn't remember anything. He didn't know what time it is. He blacked out. He wasn't here for a while. That's all I have to say about that.

Of special note, three of the participants in this study expressed gratitude for the opportunity to share their experiences and were hopeful that this research might even help other dialysis patients.

Chapter V

Discussion

This study was an exploration of experiences of Hmong hemodialysis patients and the nurses who work with them. The data was collected via questionnaire from the nurses and through face-to-face interviews with the Hmong patients. An interpreter was used for three interviews because these patients did not speak English. One patient did speak and understand English so the interpreter was not needed for that interview. The response rate from the nurses returning the questionnaires was quite good at 74%. Four of seven Hmong hemodialysis patients agreed to participate. The results of the data collected were presented in the previous chapter. An extensive literature review was conducted prior to data collection and was described in Chapter II. This chapter will summarize the results and address correlations to what was found in the literature. Limitations to the study will be addressed. The chapter will conclude with recommendations by the researcher.

Nurses' Experiences in Working with Hmong Hemodialysis Patients

Two medium-sized (250 bed) Midwestern hospitals with hemodialysis units were used as data collection sites. There were 23 nurses working in these two units who were invited to participate in this study by completing a questionnaire that explored their experiences working with Hmong hemodialysis patients; 17 nurses responded. The majority of the responses were provided in Likert-scale format, although there was one item that was fill-in-the-blank, and there was an open-ended question for the nurses to write in their feelings and experiences. There were seven hemodialysis patients during the data collection period that these nurses cared for, but that number does fluctuate as new patients are added and others are discontinued from the dialysis treatment protocol. The majority of these nurses had a vast number of years in nursing, but less than five years of experience in hemodialysis. It is possible that these nurses worked in units other than hemodialysis where they also took care of Hmong patients. The questionnaire was focused specifically on the Hmong hemodialysis patient, but it is conceivable that some of these nurses included their previous experiences with Hmong patients in responding to the questionnaire. It is uncertain if this would be a limitation or add richness to the data.

It can be challenging, stressful, and yet rewarding simultaneously when caring for patients from other cultures, especially those who do not speak English when that is the native language of the health care provider. Communicating with the Hmong patients was seen as a barrier to care by these nurses. While just over half (59%) of the nurses felt there was a lack of trained interpreters, 82% felt availability of interpreters was a problem. In 1998, Warner and Mochel claimed there was a lack of trained interpreters. This was supported by Cha's research in 2003, who also suggested there is a need for formal training programs for the Hmong interpreters. The results of this study corroborate these suggestions. Cha (2003) also found that family members were frequently used to translate. The nurses in this study identified that the use of family members was also common. What was troublesome, however, is that family members, even if minors, were used as interpreters, as well as other Hmong patients. This poses concern for confidentiality, especially when using other patients to translate. Frye (1995), Waters *et al.* (1992), and Osborn (1992) suggested using minors would violate Hmong views on authority, be disrespectful, and embarrassing for the elder. While these were not specifically addressed in this study, the potential exists when nurses use young family members for interpreters for these feelings to arise.

Uba (1992) and Cha (2003) found transportation and finances can be barriers to care for Hmong patients. The nurses in this study agreed that these were challenges for their patients. These nurses also felt Hmong beliefs about illness and treatment were challenges. This was somewhat surprising considering these nurses did not, overall, spend a lot of time learning about Hmong culture. However, there is ample description in journals and books about the traditional view Hmong have of illness, especially in terms of spirits and disruption of harmony. There also has been a fair amount written about herbal treatments, Shamanism, and other Hmong traditional treatments. These were illuminated in the review of the literature. It is possible that this is what these nurses have come to understand and believe about the Hmong, and applied this to their patients in particular. None of the Hmong hemodialysis patients in this study implicated their beliefs about treatment or illness were challenges. Indeed, these patients felt dialysis was the only appropriate treatment for them, aside from kidney transplant.

The majority of these nurses (76%) felt their Hmong hemodialysis patients were less compliant in their medication regimen than their other hemodialysis patients. Almost two-thirds (65%) felt the Hmong patients were less compliant with dietary and fluid restrictions than the other hemodialysis patients. Although the questionnaire did not request details about this, the reader might wonder how the nurses know there is less compliance. Perhaps they assume there may be less compliance if they believe their Hmong patients' views of treatment and illness are different than the western view. These nurses did not indicate the Hmong patients experience more complications; in fact, the responses on the questionnaire indicated they felt the Hmong patients experienced similar complication rates to their other dialysis patients. This could be interpreted to mean other factors not included in this study contribute to complications, non-compliance was not severe enough to result in complications, or the Hmong patients may be more resilient and able to handle non-compliance better. These conclusions would be speculations only and further research is required to determine the compliance and complication truth. One might surmise that rates of compliance in reality are the same for the Hmong as non-Hmong hemodialysis patients, which is why complication rates are similar.

Another component of care for hemodialysis patients is the multidisciplinary approach. Despite one agency including a Hmong interpreter at the care conferences, the majority of these nurses still felt their Hmong patients did not participate in the multidisciplinary plan of care as much as the non-Hmong patients. While no explanations for this were provided, there could be a variety of reasons for this. One nurse did provide an example of the difficulty in communicating with the Hmong patients, and not knowing for sure if they understand, because they tend to agree to what is recommended and ask no questions. Some of the Hmong participants also alluded to their belief that what the doctors recommended was what was best and they would go along with this. Barnes, Davis, Moran, Portillo, and Koenig (1998) suggested this passivity may be a cultural value. It is possible that these patients listen in care conferences but offer little to no comments or questions, whereas the non-Hmong patients might be more active participants. However, one Hmong patient did state that there is a mutual respect between the doctor and the patient and that the doctor listens to him just as he listens to the doctor. There also could be concern that the use of the interpreter in care conferences is not the same as the patient participating. There has been concern by researchers that interpreters could distort messages or instructions (Cha, 2003; Hartog & Hartog, 1983).

There has been ample evidence in the research describing the emotional impact of dialysis on the patient and family. Depression and anxiety are two such manifestations that patients frequently experience (Furr, 1998; Siegal *et al.*, 1987). The nurses in this study felt their Hmong hemodialysis patients experienced depression and anxiety as well. This was also supported in the interviews with the Hmong patients in this study. It was interesting that the majority of nurses felt family support was a problem for these patients, considering the wives of the married patients were always present during dialysis treatments. This researcher observed several loving gestures the wives displayed, such as gentle touch, covering the patient with blankets, rubbing the hand or the head, and sitting close by to their husbands.

Three areas of concern that are relevant to administrators specifically are that these nurses did not feel they had adequate time to spend with their patients, they did not have adequate knowledge of Hmong culture, and this is an aging workforce. The first and last items have been issues for many years in nursing, and in fact, have been implicated as reasons for the nursing shortage. Nurses are aging. As these nurses reach retirement age, the potential exists for the nursing shortage to worsen. It has also been reported repeatedly nurses leave the profession because of lack of time with the patient and the inability to provide quality care because of this. There also needs to be concerted effort to improve the educational opportunities for these nurses. Formal seminars and conferences would be a chance for these nurses to learn more about their Hmong patients. Newsletters, research reports, and conversations with Hmong patients could be published and distributed to the staff. Staff meetings could incorporate learning more about Hmong culture.

Despite their admittance of a lack of knowledge, communication barriers, and concerns about compliance, these nurses did not feel their ethical standards were being violated, nor did they feel they were in legal jeopardy. A concern that could be brought forward is that of informed consent. Autonomy, the right to make decisions, is inherent in informed consent, just as is adequate knowledge and understanding. Informed consent has been described as an "ethical obligation" and "when the health care provider and the patient do not share the same first language, there is an immediate barrier to informing the patient of his or her clinical situation and the available choices" (Barnes *et al.*, 1998, p. 412, 416). These nurses did indicate a need for more information about their Hmong patients. They identified several barriers to care as well as concerns about compliance with treatment. These nurses also described rewards they experienced in caring for Hmong hemodialysis patients.

Experiences of Hmong Hemodialysis Patients

Face-to-face interviews using a structured format with four Hmong hemodialysis patients were conducted. Although the questions were predetermined, during the interviews if the responses were unclear or confusing to the researcher, further exploration was attempted. An interpreter was used for three of the interviews as these patients did not speak English. All of the interviews took place during the participant's dialysis treatment.

The most prevalent themes were feelings of sadness, weakness, and uncertainty. All of the participants described feeling sad that they had kidney failure, were on dialysis, were weak, missed out on family and clan activities, and could not fulfill their roles and responsibilities. Weakness was a major contributor to each of these. Uncertainty about their future, complications they might experience, and the potential for a transplant were discussed. Studies by Siegal *et al.* (1987) and Furr (1998) included descriptions of depression resulting from being a hemodialysis patient. It is unclear in the results of this study if sadness in these patients could be equated as depression. While it seemed that weakness and fatigue contributed most to the other issues these patients experienced, it is possible that sadness could also be a component.

Weakness and fatigue were common in these patients. The literature is replete with evidence of these effects from dialysis as major stressors for the dialysis patient. For example, Lok (1996) found fatigue was common in hemodialysis patients, Curtin *et al.* (2002) found feeling tired was the most frequently occurring symptom in their sample of hemodialysis patients, Polaschek (2003) found lack of energy was the most significant problem experienced by hemodialysis patients, and O'Brien (1983) found fatigue and exhaustion were common. Other researchers found similar results: Chang *et al.* (2003), Moua (2003), and Hagren *et al.* (2001), all found fatigue and weakness common problems in their studies of hemodialysis patients.

Feelings of weakness and fatigue often contributed to the inability to participate in activities. Both previous research as well as the results of this study indicate these are problems for dialysis patients. Studies by Baldree *et al.* (1982), Gurklis and Menke (1988), and Welch and Austin (1999) showed the inability to participate in activities was a common stressor for hemodialysis patients. Being able to see the United States was important, but not achievable, by one participant in this study. Mattison *et al.* (1994)

found in their research that something Hmong immigrants looked forward to was sightseeing.

One patient in this study also described other health problems he was experiencing, such as sleep problems. Gurklis and Menke (1988), Curtin *et al.* (2002), and Polaschek (2003) also described this in their research. Fluctuating feelings of well being were described in this study as well as by Polaschek (2003). Dietary and fluid restrictions were stressors for this sample of Hmong hemodialysis patients. These have been found to be sources of stress for other hemodialysis patients as well (Welch & Austin, 1999; Gurklis & Menke, 1995; Gurklis & Menke, 1988; Baldree *et al.*, 1982).

Physical discomforts such as headaches, muscle cramps, and hypotension were described in the research by Gurklis and Menke (1995) and Suet-Ching (2001). In this study, these complaints were identified, with hypotension being exhibited by feelings of dizziness. One patient in this study also described his fistula causing weakness and pain in his arm and hand. Welch and Austin (1999) found this to be a stressor as well in their study.

Evans *et al.* (1985) found few hemodialysis patients in their study were able to work full or part time. Kutner *et al.* (1986) found incenter hemodialysis patients had lower employment rates than transplant or home dialysis patients, and Gurklis and Menke (1988) found unemployment to be a significant problem for hemodialysis patients. In this study, the inability to find meaningful employment was identified as a stressor resulting from the fatigue, treatment schedule, and medication regimen.

Family support and support from the nursing staff have been shown to be effective and important coping mechanisms (Mok *et al.*, 2004; Bordelon, 2001; Furr, 1998; Gurklis and Menke, 1995; Siegal *et al.*, 1987). One patient in this study did express the support he received from family members but he did not find the nursing staff particularly supportive or people that he would confide in, but he did feel the nurses had an understanding of what he was going through, and at times they did try to talk with him to help him pass the time while he was on dialysis. The other participants in this study did feel supported and cared about by the nursing and medical staff.

Previous research in coping with dialysis has shown that hoping for a kidney transplant was a strategy used by Korean hemodialysis patients (Chang *et al.*, 2003). Two patients in this study expressed a desire to receive a transplant, but neither were feeling it would happen anytime soon. Both thought a transplant would make their lives better, just as Campbell and Campbell (1978) did, but this couple later found out it was not necessarily the cure they had anticipated. Shiva Bidar-Seilaff, the manager of interpreter services/minority community relations at UWHealth in Madison, Wisconsin, expressed the same concern about Hmong patients feeling a transplant would cure their problems.

Research has also shown that support from family and friends has been instrumental in hemodialysis patients' coping and relieving stress, depression, and anxiety (Furr, 1998; O'Brien, 1983). Although this sample of hemodialysis patient did not share family support as a coping mechanism, one patient did say he talked with his sisters about his feelings and the other patients all had wives that were present and attentive during their treatments. Perhaps the wording of the question in the interview needs to be changed. The researcher asked "What difficulties did you encounter when you started dialysis and how did you cope with these?" and "How do you cope with your current difficulties experienced because of hemodialysis?". It is possible that these questions were difficult to understand and the term "cope" was not familiar to the Hmong patients.

The use of prayer and faith in God has been shown in some studies to be a coping mechanism (Gurklis & Menke, 1995; Baldree *et al.*, 1982) but other researchers found religion did not contribute to coping (Siegal *et al.*, 1987). One patient in this study expressed faith was a means of dealing with his illness. He prayed and many of his friends and family members prayed for his health.

Trying to stay as active as possible was one way a patient in this study coped with dialysis. Previous research has shown this to be a coping mechanism of dialysis patients (Chang *et al.*, 2003; Gurklis & Menke, 1995). A study by Culhane-Pera and Lee (2006) of Hmong patients with kidney stones revealed "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" (p. 10).

Giles (2003) found that the large, open ward atmosphere could be frightening for hemodialysis patients. There were two patients in this study who described similar feelings. Watching other hemodialysis patients experience complications left them fearful. They wanted more nurses and doctors available, especially for these times.

The patients in this study also expressed feelings of uncertainty and fear related to life, death, dialysis, the future, and kidney transplant. These types of concerns have been previously identified as sources of stress for family members of hemodialysis patients (Pelletier-Hibbert & Sohi, 2001; Ziegert & Fridlund, 2001; Starzomski & Hilton, 2000; O'Brien, 1983).

In summary, the Hmong hemodialysis patients in this study are experiencing many of the same stressors described in the literature. Sadness, weakness, inability to perform roles, inability to participate in activities, and feelings of uncertainty and fear were all described. The Hmong patients used compliance with medications, support from family members, faith in God, and trying to stay active as their main methods of coping. They felt their nurses and doctors were trying to help them, but they also felt more staff was needed, particularly to prevent complications or to deal with these complications promptly.

Limitations

The most obvious limitation to this research is the small sample size. Only one city was used for data collection, with four Hmong hemodialysis patients and 17 hemodialysis nurses participating. The results cannot be generalized to other populations, but this study does provide the reader with a beginning understanding of what these patients are experiencing and what their needs may be. There has been no previous research on the Hmong hemodialysis patient experience. The results also help us to understand the experiences of these nurses and what their needs are as well.

Whenever an interpreter is used, there is a potential for meanings to be distorted, messages to be lost, or words to be misunderstood. It is important that the participant trust the interpreter in order for them to disclose their true feelings. The interpreter used for this research has been working with the Hmong hemodialysis patients for many months, and attends care conferences with them. It was hoped that there was a trusting relationship developed prior to this data collection.

Another limitation is that it is unclear how the experiences of these participants would compare to those nurses and Hmong hemodialysis patients who declined participation. Their experiences may be quite different.

Furthermore, although this novice researcher attempted to maintain authenticity, methodological rigor and trustworthiness, she admits that coding, data analysis, and development of themes was challenging. These criteria are important in evaluating qualitative research (Fossey, Harvey, McDermott, & Davidson, 2002). Lastly, the questionnaire distributed to the nurses lacks long established reliability.

Recommendations

Based on the findings from this research, recommendations can be made to the following professionals: nurses, educators, administrators, and researchers. The data indicated that nurses have not been self-motivated to learn more about the Hmong culture. Although this study did not explore the barriers to educating oneself, some potential reasons for this lack of learning about the Hmong culture could be time constraints, lack of resources, lack of finances to attend learning activities, or other learning needs of higher priority. Employers could be of assistance by offering more seminars and speakers to share the Hmong culture with the staff, assist the nurse with financial reimbursement, and provide adequate time for the nurse to attend educational programs. The data also indicate the Hmong hemodialysis patients would like prompt attention following completion of the dialysis treatment and a variety of distraction techniques during dialysis treatment. Nurses also could assist the Hmong hemodialysis patients to explore current coping mechanisms and support systems, implement nursing interventions to enhance these coping mechanisms, and collaborate with other professionals to enhance these coping mechanisms and support systems.

The results of this study have implications for nurse educators. Curriculum should include cultural diversity and transcultural nursing concepts. Nurse educators can be role models for student nurses as well as practicing nurses in providing quality care to Hmong patients, not just in hemodialysis, but in all areas. Nurse educators also should be attending seminars or other learning activities to enhance their knowledge and understanding of Hmong culture.

Administrators can also use the results of this research to respond to the needs of nurses and patients. The nurses working with the Hmong hemodialysis patients indicated more time is needed to spend with the patient and more knowledge is needed on Hmong culture. The Hmong patients also noted that more staff is needed for patient support and to promptly handle complications. The workforce is aging and this will create staffing challenges in the future for hemodialysis units. It is important to work closely with the Hmong community to have trained, professional interpreters readily available to the staff. Administrators should promote lifelong learning in nursing by encouraging and financially supporting attendance at conferences on multicultural nursing. Staff meetings could incorporate information on Hmong culture or have a speaker from the Hmong community available for questions during a time when staff are most readily available. Recent research and general articles regarding Hmong culture should be made readily available for staff as well.

There are also some recommendations for future research based on the results of this study. More research is needed on the Hmong hemodialysis patients' experiences, particularly in terms of coping methods. Research is needed to explore what would be helpful to the Hmong hemodialysis patients in coping with their illness. This study did not examine the impact on the family, and this is an area that could be explored. Compliance was identified as a problem by the nurses in this study, but the researcher did not address this with the Hmong hemodialysis patient. Although a qualitative method was used to collect data from the Hmong hemodialysis patients, there are numerous tools available to measure the concepts identified in this study. Research is needed to explore the applicability of these tools to the Hmong population.

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APPENDIX A-Questions for Hmong Participant Interviews

1. How have kidney disease and hemodialysis affected your life?
2. How have kidney disease and hemodialysis affected your participation in family and clan activities?
3. How have kidney disease and hemodialysis affected your work and leisure time?
4. How do you feel others view you?
5. How do you view yourself?
6. What difficulties did you encounter initially when you started dialysis and how did you cope with these?
7. How do you cope with your current difficulties experienced because of hemodialysis?
8. Describe your relationship with your doctors and nurses.
9. Describe the role of traditional Hmong healing methods in your situation.
10. What recommendations do you have for health care providers?

APPENDIX B-Questionnaire for Registered Nurse Participants

Nurse Experiences with Hmong Hemodialysis Patients

In order to understand the needs of health care providers and the issues and challenges in working with Hmong hemodialysis patients, please respond to the following items as directed. This survey should take approximately 5 minutes to complete. Thank you for your participation.

Professional Education

In addition to your professional work with Hmong hemodialysis patients, how many hours have you spent learning about Hmong culture?

_____ hours of reading books
_____ hours of reading articles and/or journals
_____ hours of attendance at conferences or seminars
_____ hours of discussion with other health care providers
_____ hours of informal discussion with Hmong community members and/or family members of my patients
_____ hours of University courses taken

Compliant Comparison

In comparison with the majority of my other hemodialysis patients, I find my Hmong hemodialysis patients to be:

Circle the response which most accurately reflects your perception

compliant with medication regimen	More	Less	Same
compliant with dietary/fluid restrictions	More	Less	Same
compliant with dialysis treatment schedule	More	Less	Same
likely to experience complications from dialysis	More	Less	Same
a participant in the multidisciplinary plan of care	More	Less	Same

Being Understood by the RN

When I am uncertain if my Hmong patient understands my teaching or recommendations, I do the following:

Circle the response which most accurately reflects your perception

Use a trained interpreter	Always	Sometimes	Seldom	Never
Use an adult Hmong family member if present	Always	Sometimes	Seldom	Never
Use a Hmong family member, even if a minor	Always	Sometimes	Seldom	Never

Other (please write in how you handle this situation):

Challenges Working with the Hmong

What do you see as the biggest challenges in working with the Hmong?

For each of the following lists of potential challenges, identify if each item is
1. very common 2. sometimes a problem 3. not a problem

Patient Challenges:
Transportation ____
Finances ____
Family Support ____
Depression ____
Anxiety ____

Institutional Challenges:
Lack of trained interpreters ____
Lack of adequate time with patient ____
Lack of training on Hmong culture ____
Lack of availability of interpreters ____
Agency policy on use of interpreters ____

Cultural Challenges:
Hmong beliefs about illness ____
Hmong beliefs about treatment ____
Hmong fears about treatment ____
Communicating with Hmong ____

Stress with Working with Hmong Hemodialysis Patients

For each of the following statements, please circle the response that most accurately reflects your feelings.

I am knowledgeable about Hmong herbal medicine	Agree	Neutral	Disagree
I am confident my Hmong hemodialysis patients can communicate to me about the specific plants or herbal remedies they are using to treat their illness	Agree	Neutral	Disagree
If I knew more about herbal treatment I would be willing to encourage its use for my Hmong patient	Agree	Neutral	Disagree
I feel my ethical standards are in jeopardy when I am working with Hmong patients	Agree	Neutral	Disagree
I feel I am at risk from a legal standpoint when I am working with Hmong patients	Agree	Neutral	Disagree

Rewards working with Hmong Hemodialysis Patients

Please write in the rewards you have experienced while caring for Hmong patients.

Do you have any other comments about working with Hmong hemodialysis patients?

Demographic Data

Age in years ______ years
Years in nursing ______years
Years in hemodialysis nursing ______ years
Highest nursing degree earned ______ (Diploma, ADN, BSN, MSN, PhD, etc.)

This concludes the questionnaire. Thank you for your time and participation. You may place the questionnaire in the enclosed envelope to return to the researcher.

APPENDIX C-Letters to Registered Nurses

Introductory Letter

Dear Registered Nurse,

You are being invited to participate in an exciting project exploring Hmong hemodialysis patient experiences and the nurses who work with them. My name is Linda Krueger and I am a nursing instructor at Chippewa Valley Technical College, as well as a per diem staff nurse at Luther Hospital. In fulfilling requirements for my Education Specialist Degree, a field study is required. I am inviting you to participate in this study. Next week you will receive a questionnaire that will explore your perceptions and experiences with working with Hmong hemodialysis patients. It should take only 5 minutes of your time to complete the questionnaire. I would like to thank you in advance for your consideration and participation in the study.

Cover Letter

Dear Registered Nurse,

I am a nursing instructor at Chippewa Valley Technical College and am currently working toward my Education Specialist Degree. I am a staff nurse at Luther Hospital as well. A field study is required as part of my degree requirement. I am conducting a study on Hmong hemodialysis patient experiences, as well as hemodialysis nurse experiences working with Hmong patients.

I am inviting all registered nurses working at the hemodialysis units in the Chippewa Valley who work with Hmong hemodialysis patients to participate in this study. Participation in the study involves responding to questions from the questionnaire that is included in this packet. Completion of the questionnaire will take approximately 5 minutes of your time and would be greatly appreciated.

The results of this study will be useful to nursing administration, nurse educators, and nursing staff working with Hmong patients and in hemodialysis to understand the challenges of working with diverse cultures, provide education in areas of need, and to promote nurse satisfaction and comfort with caring for patients from varied cultures.

The proposal for this research has been approved by the Institutional Review Board of the University of Wisconsin-Stout and the facility by which you are employed. The study follows the guidelines they have determined are appropriate for protecting human subjects of research studies. Your participation will be completely confidential. Your name will not appear on the questionnaire, nor will it appear in any of the results discussed.

Completion of the enclosed questionnaire is completely voluntary. Returning the questionnaire is considered consent to participate in this study. You may return the questionnaire in the envelope provided.

There may be an opportunity to participate in a small group interview to further explore the needs of the nurse caring for Hmong hemodialysis patients. If you are interested in participating in this process, please fill out the enclosed form and return it to the researcher in the envelope provided. These will be kept completely separate from the questionnaires and the interviews will also be kept confidential.

You will be provided the results of the study upon request. If you have any questions about this study, please feel free to contact the following:

Linda Krueger RN MSN	Dr. Bruce Pamperin	Sue Foxwell
Researcher	Research advisor	Research Administrator
CVTC nursing instructor	UW-Stout faculty	UW-Stout
835-4204	232-1508	232-2477

Thank you for your time and participation.

Follow-up Letter

Dear Registered Nurse,

Last week you received a questionnaire in your mailbox asking for feedback on your experiences working with Hmong hemodialysis patients. I would like to thank you for your participation in this study if you responded. If you have not yet responded, I would ask that you please consider completing the questionnaire. It will take approximately 5 minutes of your time.

I hope to use the results of the tool to enhance the knowledge of health care administrators, educators, and providers in understanding the challenges, barriers, and rewards with working with Hmong hemodialysis patients. I hope to identify suggestions to these groups as well so that, together, we may improve health care services to the Hmong community.

If you have already completed and returned a questionnaire, I would like to take this opportunity to thank you for your time and consideration. Please do not complete the questionnaire again. It can be discarded. If you have not completed the questionnaire, I have enclosed a copy of the questionnaire and an envelope that can be used to return the completed questionnaire. Thank you for your participation in this project.

APPENDIX D-Cover Letter and Consent Form for Hmong Hemodialysis Patient Participant

Dear Patient,

I am a nursing instructor at Chippewa Valley Technical College and am currently working toward my Education Specialist Degree. I am a staff nurse at Luther Hospital as well. A field study is required as part of my degree requirement. I am conducting a study on Hmong hemodialysis patient experiences, as well as hemodialysis nurse experiences working with Hmong patients.

I am inviting all Hmong hemodialysis patients to participate in this study. Participation in the study involves responding to questions from the researcher regarding your experiences of living with hemodialysis. The interview may take 30 to 60 minutes. You may choose to be interviewed during your hemodialysis treatment or at another time and location of your choice.

The results of this study will be useful to nurse educators and nursing staff working with Hmong hemodialysis patients to improve the quality of nursing care provided and to add to the health care team's understanding of Hmong experiences.

The proposal for this research has been approved by the Institutional Review Board of the University of Wisconsin-Stout and the hospital in which you receive hemodialysis. The study follows the guidelines they have determined are appropriate for protecting human subjects of research studies. Your participation will be completely confidential. Your name will not appear in any of the results discussed.

If at any time during the interview you feel ill or do not wish to continue, the interview will stop. The care you receive from the nurses will not be affected in any way whether or not you choose to participate. An interpreter may be present and the conversation may be recorded to help the researcher in communicating and remembering your responses to the questions asked.

You will be provided the results of the study upon request. If you have any questions about this study, please feel free to contact the following:

Linda Krueger RN MSN	Dr. Bruce Pamperin	Dr. Howard Lee
Researcher	Research advisor	Director EdS program
CVTC nursing instructor	UW-Stout faculty	UW-Stout
835-4204	232-1508	232-1251

Thank you for your time and participation.

Consent Form

Title of investigation: Wisconsin Hmong Experiences with Hemodialysis

Principal investigator: Linda Krueger RN MSN

This document is to certify that I ______________________________, hereby freely agree to participate as a volunteer in a study of Hmong experiences with hemodialysis as part of the educational requirement for the Education Specialist Degree at the University of Wisconsin-Stout.

- The research project and my role in the study have been explained to me by Linda Krueger, RN MSN, and I understand her explanation. A copy of the procedure of this investigation has been provided to me.
- I have been given an opportunity to ask questions and they have been answered to my satisfaction.
- I understand that I am free to refuse to answer any question in the interview.
- I understand that all data will remain confidential with regard to my identity.
- I understand that participation is voluntary and the care I receive from the hemodialysis nurses will not be affected
- I understand that if I have any questions about this study I may contact the investigator by writing or calling:
  Linda Krueger
  815 Plum St.
  Eau Claire WI 54703
  835-4204
- I understand that I may also contact the following individuals if I have questions or concerns about my treatment as a participant in this study by writing or calling:

Dr. Bruce Pamperin	Sue Foxwell
UW-Stout Faculty	UW-Stout Research Administrator
715-232-1508	715-232-2477

- I understand that I am free to withdraw my consent and discontinue my participation at any time.

_____________________ ____________________________

(Date) Signature of Participant

I, the undersigned, have defined and fully explained the investigation to the above participant.

____________________ __________________________

(Date) Signature of Investigator