ABSTRACT

The purpose of this ethnographic study was to explore the perception, care, and preferred treatment of Hmong American elders with chronic confusion (i.e., dementia). We conducted this study over 30-months in Minnesota and Wisconsin, using participant observation and in-depth interviews with 25 Hmong Americans (family caregivers, traditional healers, community leaders). Traditionally, the eldest son has the primary responsibility for his aging parents, with his wife providing the actual care. Conflicts with this norm are emerging due to changing circumstances of Hmong living in America. Caregiving was viewed as reciprocal for the love and care given by the elder generation and a model of traditional values for the younger generation. The role and spiritual orientation of the informant influenced the
perceived cause of chronic confusion. However, the traditional spiritual needs of the elder became the primary factor in determining health-seeking behaviors. Overall, informants were opposed to nursing homes and viewed the care of elders as a family responsibility. We encourage the use of these findings for the development of family-based education programs within the Hmong-American community.

Key Words: Hmong, dementia, chronic confusion, family caregiving, shamanism

INTRODUCTION

The United States is becoming increasingly more diversified with growing numbers of older adults. The U.S. Census Bureau (2000) reports that of 274 million persons living in the United States, 62 million (22.6%) are from an ethnic minority group. These changing demographics are accompanied by an increased recognition that cultural values and beliefs about dementia that are held by elders and their caregivers affect help-seeking and caregiving behaviors (Janevic & Connell, 2001; Yeo & Gallagher-Thompson, 2006). Ethnogeriatric research primarily focuses on large ethnic groups with a long-standing presence in the United States. Other groups, such as Hmong Americans, have been a neglected focus of research. An increased understanding of Hmong elders with dementia and their family caregivers could facilitate the development of culturally relevant programs of care. Valle (1998) emphasizes the need to consider both the cultural and historical background when working with a specific ethnic minority group. Throughout history and across geographic locations, family/clan structure and spirituality have provided the Hmong people with an important means of maintaining cultural identity and providing the solidarity, support, and networking necessary for adapting to new life experiences and situations (Keown-Bomar, 2004). We begin by providing a brief overview of the historical background of the Hmong. This is accompanied by a description of the family/clan structure and traditional spiritual orientation that also influence the perception and care of elder Hmong with chronic confusion (i.e., dementia). Chronic confusion is defined as “an irreversible, long-standing and/or progressive deterioration of intellect and personality characterized by decreased ability to interpret environmental stimuli, decreased capacity for intellectual thought processes, and manifested by disturbances of memory, orientation, and behavior” (North American Nursing Diagnosis Association, 1999, p. 119).

Historical Background of the Hmong

The Hmong are an ethnic minority from China and Southeast Asia who have fought throughout history to maintain their independence and cultural identity.
Those living in the United States originated in the remote highlands of Laos where they lived in small villages with extended patrilineal households and were able to maintain their cultural heritage and agrarian lifestyle. During the Vietnam War, those living in Laos, were recruited by both the Communist Pathet Lao and the U.S. Central Intelligence Agency (CIA). Those serving the U.S. effort monitored the Ho Chi Ming Trail, gathered intelligence information for the CIA, and rescued U.S. pilots who had been shot down by the communists. Following the communist takeover of Laos in 1975, the Hmong who assisted the United States were forced to flee their homeland or suffer persecution and/or death by the communist Pathet Lao. Many escaped by crossing the Mekong River, fleeing to refugee camps in Thailand until resettlement opportunities became available in other countries such as the United States, France, Canada, and Australia (Hamilton-Merritt, 1993). Hmong refugees began arriving in the United States in the mid-1970s and constitute a growing proportion of the U.S. population. The 2000 census reports 186,310 Hmong people living in the United States, a 97% increase from the previous decade (Lee, Pfeifer, Seyig, Todd, Grover, Vang, et al., 2004). Leaders within the Hmong community believe these statistics to be a 50% to 60% under representation, primarily due to the language barrier confronting the Hmong when completing the census report (Doyle, 2001). More recently, the 2006 American community survey estimates 209,000 Hmong living in the United States (U.S. Census Bureau, 2006). However, the Hmong National Development in Washington D.C. believes the actual population is closer to 275,000 (Lee & Pfeiffer, 2007). The largest number of Hmong are living in California, Wisconsin, and Minnesota, with the highest concentration in the St. Paul/Minneapolis area (Lee et al., 2004).

Family/Clan

An understanding of the family/clan structure has important implications for the care of Hmong American elders. Traditionally, family units are patriarchal with strong family bonds based on interdependence. Within the family, members have well-defined roles and responsibilities. The family unit is part of a larger clan structure that provides the basic social organization for the Hmong community. Membership into a clan is achieved by birth. Hmong practice exogamy, requiring persons to marry outside of their own clan. Upon marriage a woman leaves her clan and joins the clan of her husband. In the United States, the Hmong community is organized into an 18-clan structure. To support this clan structure, populations of Hmong are concentrated in enclaves throughout the country (Cha, 2000, 2003; Faderman, 1998).

Spirituality

Traditionally, the majority of Hmong practice a combination of animism and ancestor worship. These spiritual beliefs are strongly linked to concepts of health,
illness, and care of elders. In this belief system each human has multiple souls. While reports range on the exact numbers of souls, most agree that there are three souls of primary importance (Cooper, 1998; Rice, 2000). A basic element of the animistic belief system is that these souls must remain in harmony to sustain health. Spiritual illness occurs when one or more of these souls separate from the physical body. Some illnesses, particularly those that are less severe and non-life threatening, may have a biological cause requiring treatment with herbs or organic substances (i.e., animal parts) (Bliatout, 1991); these remedies may be used alone or in combination with spiritual healing. For a detailed description of the traditional beliefs and treatments (i.e., shamanic healing ceremonies, herbal remedies) specific to Hmong elders with chronic confusion who are living in Laos refer to Gerdner, Xiong, and Cha (2006).

Based on beliefs of ancestor worship, there is strong interdependency between living family members and deceased ancestors (refer to Gerdner, Cha, Yang, & Tripp-Reimer, 2007). For example, a xwm kab (house spirit altar) is constructed in the home of the eldest male family member. Rituals are performed on this altar throughout the year to appease the ancestral spirits, in return these ancestral spirits will guard and protect the living. Non-adherence to these established rituals may cause the ancestral spirits to become dissatisfied and cause harm (e.g., sickness, death) to living family members. Belief in ancestor worship has implications for the care of elders as they approach the end of their life.

Chronic Confusion

Research on dementia among the Hmong is very limited. There are no statistics on the prevalence of dementia within the Hmong community. One ethnographic study conducted at the Ban Miao Meto refugee camp in Thailand documented a healing ceremony, performed on a 62-year-old Hmong male suffering from “senility” (Chindarsi, 1976). Cha (2000) conducted a multi-method study including a focus group, in-depth interviews, and a survey to explore health problems reported by Hmong Americans (ages 20-86 years) living in Colorado. Results from the health survey (n = 40) revealed that 40% of elders reported significant problems with forgetfulness. In addition, during an in-depth interview, a Hmong mental health therapist reported knowing a large number of Hmong elders who suffered from signs of dementia but preferred to be seen by a shaman.

Only one study specifically addressed the issue of dementia within the Hmong-American community. Olson (1999) interviewed 10 Hmong-American formal and informal leaders living in Milwaukee, Wisconsin. All but one of the interviews were conducted in the English language. Responses were based on the informant's general impressions about dementia rather than personal experience in caring for a family member with this condition. Findings suggest a reportedly low prevalence rate of “dementia.” Since the cause was attributed to a “natural part of old age,”
there was no perceived benefit in seeking treatment from either traditional healers or physicians. A serious limitation of this study was the exclusion of interviews with family caregivers and traditional healers.

The proper diagnosis and care of Hmong elders with dementia are important and timely issues. This need is illustrated by an incident that occurred during the summer of 2005 when an elder Hmong American with "memory problems" wandered from his home in Wisconsin and was unable to find his way back home. After 21 days of intensive searching the man was found 2 miles from his home and suffering from dehydration (Moua, 2005).

Because of the limited information in this area, the purpose of this focused ethnographic study was to provide an in-depth exploration of the perception, care, preferred treatment, and use of community resources for elder Hmong Americans with chronic confusion (dementia). Research findings will foster development of culturally responsive programs of care.

**METHODS**

**Setting**

Data were collected over a 30-month period through participant observation and in-depth interviews with Hmong-American family caregivers of elders with chronic confusion, traditional healers, and community leaders. The study was conducted in St. Paul/Minneapolis, Minnesota (Hmong pop. 40,707*) and Eau Claire, Wisconsin (Hmong pop. 1,920*) (Lee et al., 2004).

The 2000 U.S. census data reports that in Minnesota, 97.3% of the Hmong population resided in the St. Paul/Minneapolis area. Of those Hmong living in Minnesota, 41.7% have no formal education and 33% are below the poverty level. The enclave of Hmong Americans living in the St. Paul/Minneapolis area is fairly self-contained, with Hmong telephone directories, grocery stores, clothing shops, community resource centers, funeral homes, newspapers (Hmong Times, Hmong Today), health clinics, pharmacies, and a radio station.

The Hmong-American population of Wisconsin is distributed within five cities scattered throughout the state. In Wisconsin, 46% of the Hmong have no formal education and 26% have incomes below the poverty level (Lee et. al., 2004). Since Eau Claire has a smaller population of Hmong Americans than the St. Paul/Minneapolis area, there are fewer resources dedicated to the needs of this group. Because of its close proximity to the St. Paul/Minneapolis area (approx. 85 miles), residents of Eau Claire maintain strong networks to the people and resources available there. The rural area surrounding Eau Claire is more suitable to the agrarian life style that has been historically significant to the Hmong. It is here, in the rich farmland, that they are able to grow a variety of vegetables (i.e., Thai eggplant, yu choy, bitter melon, squash), spices (i.e., jalapeño chili peppers), herbs (i.e., lemon grass, cilantro) and raise chickens, hogs, and cattle.
Field Entry/ Participant Observation

Leaders of the Hmong community were consulted early on when the purpose and design of the study were being conceptualized. Later the study was publicly endorsed by a major Hmong American organization. Initial fieldwork included participant observation in community activities (i.e., Elder Hmong New Year celebration, weekend markets where elders sold traditional remedies for a variety of health conditions). As rapport was established, a community liaison became instrumental in introducing the principal investigator (PI) to informal family gatherings such as shamanic healing ceremonies and family visits to a nursing home. An explanation of the study and its purpose was provided to community members during informal interactions at these locations. Detailed field notes were kept to describe observational and participatory experiences. Participant observation of adult day services and a unit of a long-term care facility dedicated to serve Hmong and other Southeast Asian minorities have been published previously (refer to Gerdner, Xiong, & Yang, 2006).

In-Depth Interviews

The first formal in-depth interview was conducted 8 months after initial field entry. Community entry was further facilitated by a second Hmong-American liaison, who was a trusted member of the community. She took the lead in the initial recruitment efforts of key informants. A leader of a major Hmong-American organization also assisted with recruitment efforts. With permission of potential informants, informational meetings were scheduled between the potential informant, community liaison, and PI. The community liaison (a certified healthcare interpreter) assisted with the communication process when Hmong was the preferred language. The purpose of the study and the informant’s role was explained. Potential informants were encouraged to ask questions. In return, questions were asked of potential informants to assess their understanding of the study including their role and rights as an informant. Consent forms were available in both Hmong and English to accommodate their preferred language. Written consent was obtained from those who volunteered to participate in in-depth interviews with the understanding that they could decline to answer any question they chose and they could withdraw from the study at any point. This process was approved by the institutional review board at the University of Minnesota.

Guided in-depth interviews were conducted in the informants’ preferred language to explore the topics of interest in this focused ethnographic study. Key informants included Hmong-American adults providing in-home care for family members with chronic confusion, traditional healers, and community leaders living in St. Paul/Minneapolis, Minnesota and Eau Claire, Wisconsin.

Interview guides were developed for each category of informant (family caregiver, traditional healer, community leader). All were asked the perceived cause of chronic confusion, preferred treatment and its effectiveness. In addition,
family caregivers were asked to describe the role of family and clan in caregiving, the experience of caregiving, and the use of community services (medical doctor, adult day care, nursing homes). Interviews with community leaders addressed issues of prevalence and community concern. Probes were used to more deeply explore topics elicited from informants.

Each informant participated in a single interview at a time and location of their choice. The average interview lasted approximately 2 to 3 hours. With permission, all interviews were audio-taped. Following the interview, each informant received a $25 gift certificate redeemable at a popular Hmong-American grocery store.

Informants for In-depth Interviews

In-depth interviews were conducted with 25 adult Hmong Americans. The majority of these interviews \((n = 17)\) were conducted in the Hmong language with the assistance of a community liaison who, as described earlier, was a certified health care interpreter. All of the informants were born in Laos and came to the United States as refugees. Fifteen of the informants were in-home caregivers of family members with chronic confusion. Family caregivers included: two spouses, three adult grandchildren, one daughter, five daughters-in-law, and four extended family members (e.g., three nieces and a second cousin) who had served in this role for a mean of 5 years (range: 8 months to 12 years). Two of the informants cared for more than one family member. A grandson cared for both of his grandparents, and an extended family member cared for her husband’s aunt and uncle. Comparison data were collected from five Hmong community leaders, all of whom knew elders with chronic confusion. In addition, five traditional healers were interviewed, including one \(poj\) \(maub\) \(chauj\) (medicine woman) and four \(txiv\) \(neeb\) (shamans). Two shamans served multiple healing roles (i.e., \(khawv\) \(koob\) [magic healer], herbalist). All of the traditional healers received their training while living in Laos and had between 22 to 31 years experience as a healer. Additional demographic data are displayed in Table 1. The initial plan to obtain data on annual income was abandoned after consultation with both community liaisons who cautioned that it was considered too personal of a question.

The majority of interviews were conducted in the informants’ homes. There were wide variations in living situations ranging from an older wood-framed rental home located in a lower middle class neighborhood to a family owned brick home in a new housing addition. Many families lived in multigenerational homes where an elder was living with a married adult child and young grandchildren. Photos of family members and Hmong military leaders (i.e., General Vang Pao, Touby Lyfoung) were often displayed on living room walls.

It was not uncommon to see a \(xwm\) \(kab\) (house spirit altar) in the home of those families who retained the traditional beliefs of animism/ancestor worship. The entrance of one home was protected by \(ntaj\) \(neeb\), a talisman that is created from three pieces of wood that are each carved into a knife shaped figure. Charcoal is
used to decorate the blades of each knife with a series of diagonal stripes. The knives are hung from the top of the door in an effort to protect the home and its occupants from evil spirits.

The home of each shaman contained an elaborate altar, generally constructed of two shelves draped with spirit paper. The items displayed on an altar vary but generally include: a candle or small oil lamp, small bowls of water, and a bowl of rice with a raw egg resting in the center surrounded by sticks of incenses.

Two of the care recipients were shamans, although they were no longer able to practice healing ceremonies, their altars were maintained in a place of honor in the

<table>
<thead>
<tr>
<th>Table 1. Demographic Data</th>
<th>Caregiver (<em>n</em> = 15)</th>
<th>Community leader (<em>n</em> = 5)</th>
<th>Traditional healer (<em>n</em> = 5)</th>
</tr>
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<tr>
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<tr>
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<td>63 years</td>
<td>75 years</td>
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<tr>
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<tr>
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<td>5</td>
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<tr>
<td>College (4 years)</td>
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<td>0</td>
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</table>

*Birth dates are not recorded in the Hmong villages of Laos and birthdays are not celebrated as they are in the United States. Informants provided the year of their birth to the best of their ability. This data should be considered approximations.
home. Another care recipient was a medicine woman and had an altar to honor *dab tshuaj* (spirit of medicine).

**Data Analysis**

Audiotaped interviews were reviewed by an interpreter who did not assist with the interview process. The purpose of this review was to determine the accuracy and completeness of interpreted responses by the informants. These audiotapes were transcribed verbatim. Transcripts were read repeatedly, then examined line-by-line, underlying phrases and assigned tentative category labels in the margins. Labeled passages were then clustered into larger units.

Field notes were also examined carefully, reflected upon, and coded by major topics of exploration. These topics were subsequently linked with interview data. Findings are presented by major topics: labeling chronic confusion, caregiving structure, caregiving experience, perceived cause, preferred treatment, and use of community resources.

**RESULTS**

**Labeling Chronic Confusion**

Because there is no word(s) in the Hmong language for the concept of dementia, we began the interview by asking caregivers what term they used to describe the elder's condition. Most caregivers used the Hmong word that most closely describes elders with chronic confusion, *tem toob*. A community leader explained that there is no direct English translation for this word, but described it as “when people get old there are so many things on their mind, [they] forget things. Too many things to focus on, so their mind doesn't work.” Only six caregivers reported receiving a formal medical diagnosis for this condition, with one adding, “but many of us do not know what that [diagnostic term] means.” Later during the conversation this caregiver stated,

> In America, they give this diagnosis [dementia] to crazy people, but I don't think she is crazy—it is her memory. She doesn't remember when she has eaten. She doesn't remember what people have told her or what people have done for her—so her memory is not there.

Concern was raised that a negative stigma would be inflicted on the elder as a result of the symptoms associated with the elder's condition. Consequently, several caregivers expressed the need to protect the elder from the “critical eye” of the community, as exemplified in the following comment,

> Her memory isn't there any more, she doesn't know that she is going to be embarrassed. People don't like her. But as family we keep her close to home. She is not in public anymore. We would never take her grocery shopping because her talking doesn't make sense—we don't want people to judge her wrong.
Consistent with these concerns, as the interview continued there was an overall reticence on the part of the family members to discuss specific behavioral and psychological symptoms associated with the elder's condition.

**Caregiving Structure**

The inherent importance of family life was apparent by the extensive collection of family photos that were hanging in each of the homes of family caregivers. An understanding of the family/clan structure has important implications for the care of an elder with chronic confusion. This was explained by one community leader through use of a visual model composed of five concentric circles. The first or inner circle represents the nuclear family comprised of husband and wife. When a woman marries she joins her husband’s clan (kvvvij) leaving behind her clan of birth (neejtsa). The second outward circle symbolizes the husband’s family. The third circle represents the wife’s family. The fourth circle represents the entire clan, and the fifth circle represents the Hmong community as a whole. A married woman’s first priority is to her husband and children. As a wife, her next responsibility is to meet the needs of her mother-in-law and father-in-law.

Within this structure, traditional norms hold that the eldest son has the primary responsibility for his aging parents, with his wife providing the actual hands-on-care. If inherent problems occur with this arrangement, the responsibility is usually passed to the youngest son. One caregiver noted this norm is beginning to change due to adjustment to life in the United States: “Families are beginning to assess the [individual] situation to determine which son, or more importantly, which daughter-in-law is more willing and capable of taking care of the elder.”

However, conflicts do arise when there is a deviation from cultural norms. For example, the eldest son of one woman had a job that required him to move every 2 to 3 years, preventing a stable residence. It was therefore decided that the elder would live with and be cared for by her married daughter. Some members of the Hmong community viewed these arrangements as a neglect of the eldest son’s responsibilities. Consequentially, the care recipient reportedly felt a sense of shame and felt obligated to defend her son when members of the community inquired about her living situation.

The caregiver also explained that traditional norms prevent her mother from “accepting anything from her son-in-law (caregiver’s husband) in terms of personal chores, least it bring shame upon her. It was enough that he had allowed her to stay in his home.”

Negative consequences may occur when a son is forced to provide care even though another family member is more willing and capable:

> When she [grandmother] came to the U.S., she getting sicker and older, her son took her into his home, and his wife is the one who took care of her. But the care was not adequate, that is why she got very weak and sick. The doctor
was concerned that she had malnutrition. The son refused to allow anyone else to care for her, but his wife became pregnant and said that she could not take care of his mother any more.

The elder woman was subsequently placed in a nursing home, “but she cry all day long, she did not like it.” As a result, the clan leader was consulted and it was decided that the elder would be cared for at home by her granddaughter.

Several care recipients had no close living relatives. Under these circumstances, cultural norm dictates that a patrilineal extended family member assumes the caregiving responsibility. For example, a niece by marriage was caring for her husband’s aunt who had been preceded in death by two husbands and four children. A second example involved an elder couple who was being cared for by their cousin’s wife, following the recent death of their son. The caregivers appeared to be satisfied with these arrangements and were fulfilling the daily needs of the care recipients.

A caregiver’s age imposes restrictions on their authority. For example, a grandson served as the primary caregiver for his cognitively impaired grandparents. When grandparent’s behaviors became unmanageable and required a firmer approach, the grandson consulted a male elder (uncle). The grandson explained, “It is best to ask someone who is older than you to come and talk [to grandparents], if I go directly to them [grandparents]—it is not right—to them it is disrespectful.”

**Caregiving Experience**

Caregiving was viewed as a reciprocal act for the love and care received by the elder generation. For example, a grandson stated, “my grandparents loved me so much as a kid . . . now I have to treat them with love and respect because that is how they cared for me when I was little. It is like giving back to them.”

The majority of female caregivers did not speak English or work outside of the home, adhering to the traditional role of women in the Hmong culture. These women expressed satisfaction in devoting their time and attention to caring for their loved ones and took enormous pride in the outcome. This viewpoint is reflected in the following statement:

> I am happy that I am her caregiver and can help her go through this . . . I take care of her, cleaning and washing. I do 24-hour care for her and many people around my house say that I do perfect care for her. She is clean, she is eating right, she has nutrition. But before, someone else was taking care of her and she was weak, very tired, not eating, just sleeping most of the day.

Fulfillment of the caregiving role was more difficult for a female informant who had a career outside of the home and was forced to juggle this role with that of traditional wife and mother. This caregiver made an important distinction between “a Hmong woman living in America” and a “Hmong American woman.” This distinction refers to the degree to which women either adhere to
cultural norms or become acculturated. She provided the following narrative as further explanation:

I feel good about having that responsibility [caregiver] but sometimes it is frustrating because I am not able to do what I think I should be doing. I am a mom and I have children of my own. I am a full-time employee. My mother worked all of her life but she had flexible hours where she could do the kinds of things that she needed to do. . . . There are times when I feel, “why can’t I do as good a job as she would be able to do for her elders? I keep thinking, why can’t I do that? I should be able to do that, I should be able to deal with this—but I just can’t. . . . When your kids start reminding you of things that you should have done or that you are being mean or that you don’t spend as much time with your mom, you really start to wonder, what are they seeing, what am I teaching them? Can I just be reckless and selfish sometimes and not feel like I have to pay for this sometime in the future? It goes along the way of parenting—you know care of the elderly—I just keep making the comparison between the two. It is exactly the same thing. No matter what I do, if I don’t do it right, I am going to be paid back somehow.

The competing demands imposed by life in America was preventing this caregiver from upholding the high standards that she believed were expected. Consequently, she was also concerned that she was not serving as a proper role model for her children.

A second caregiver, who worked outside of the home, provided additional insight into to the care of elders in the villages of Laos compared to urban United States.

The very traditional people would have the wife of the eldest son care for her in-laws. But it is so hard to do that in this country now. We can do that easily in Laos because everybody is doing the same thing, like if you have ten sons—everybody would live together and help doing the farm, so the whole family has one goal, one purpose. But right here in the United States lots of struggle, because you have your own life, your own family, your own job, different schedules, so it is very hard right now for our people. Truly, I am suppose to take care of her [care recipient] but because of my job, my place where I live, it is not fit for her, so it is hard to put her to where she is suppose to be.

A community liaison for this study later reported that informal discussions about the study with a number of female caregivers had revealed that they lived in daily conflict with the competing roles of wife, mother, and caregiver along with the financial need to work outside the home. However, these women were “afraid” to discuss their concerns because of the “perceived” shame that it may bring to their family and themselves.

There was concern that these competing demands would jeopardize the provision of care. One caregiver explained that improper care of an elder may result in
a “curse” or “lack of blessings” by either the ancestral spirits or the elder’s spirit upon death. This view was retained by a Christian caregiver as well.

In general, little girls are taught their future role as family caregivers by observing and assisting their mothers in this role. One daughter described the new challenges posed by the increased longevity of Hmong Americans that may be accompanied by debilitating chronic illness (i.e., chronic confusion).

Although our parents and their parents were used to caring for their own elders, I have to say that it is going to be harder for my generation . . . we will be taking care of a frailer, older population than my mother or her mother’s generation ever had to deal with. Because of medical care, people will live longer but not necessarily healthier . . . so even when I listen to my mother or my mother-in-law talking about caring for their elders—it is not frail elders with memory loss. If they are frail . . . they don't last a long time. When they are talking about very old, they are talking about 60 [years of age]. . . We are faced with another skill that we need—that we have not received—even our parents have not [acquired] any skills in . . . assisting someone who is frail with memory loss.

Traditionally, males did not assume caregiving roles. However, a formal interview with a male spouse revealed that he was the primary caregiver for his wife who was afflicted with vascular dementia. His unmarried daughters provided very little assistance with their mother’s care due to other commitments. This spousal caregiver was seeking a second wife to assume the primary caregiving role of his first wife. The care recipient was aware that her husband was pursuing a relationship with another woman and was greatly distressed by this. Although he would be violating U.S. law, traditional Hmong norms would have allowed him to accept a second wife during a traditional Hmong wedding ceremony.

**Perceived Cause**

The perceived cause of chronic confusion was explored through a variety of vantage points including family caregivers, community leaders, and traditional healers. Within these groups, the role and spiritual orientation of the informant influenced the perceived cause. Primary explanatory models included advanced age, spiritual cause, and emotional stress.

Seven caregivers attributed memory impairment to the aging process. One caregiver simply stated, “when you get old your brain is not working anymore.” Another qualified this answer by adding, “elders do not have as much blood as when they were young, so the blood is diminished and the brain does not get a lot of blood.” Traditionally, it is not uncommon for Hmong persons to believe that the adult has a fixed amount of blood that is not capable of being replenished if lost (i.e., injury, surgery, blood draws).

The belief that chronic confusion is a natural part of aging was supported by the following proverb that was told to us by one community member: *Ntoo laus ntoo*
to qhov. Neeg laus neeg hnem hnov. Ntoo laus ntoo khoob. Neeg laus neeg tem toob. The English translation is “As a tree ages, it has a hole. As a person ages he becomes forgetful. An old tree is hollow. An old person has memory loss or impairment.”

Six caregivers attributed the elders’ chronic confusion to a spiritual cause. More specifically, one husband stated, “the shaman said that the spirit of my wife’s deceased sister came and took her spirit.” Similarly, another caregiver believed that ancestral spirits had captured one of the care recipient's souls as a means of seeking appeasement through “money or food.”

Traditional healers elaborated by identifying three spiritual causes for this condition. First, “in the U.S. . . . many elders live in loneliness . . . they getting sad and lonely—don’t want to stay near this body anymore so that is why they wander around.” Second, it was believed that an evil spirit may invade or attach itself to the person’s body. More specifically, one shaman said, “an evil spirit could block the elder’s mind so that he or she doesn’t know how to think clearly.” A third cause occurs when an “evil spirit takes the person’s spirit and tortures it, causing the person to become crazy and forgetful.”

A Hmong-Christian minister contends:

The brain is very difficult for our people [Hmong] to understand, so anything about the brain, the thinking part, the feeling part—is [viewed as] related to the spirit. Anything that you can not see or imagine or are [not] educated about, they would say, “it is from the dab or the spirit.”

The Hmong-Christian minister personally believed that chronic confusion in elders was caused from being “unfulfilled emotionally,” he added "their spiritual side is empty so they have no hope for the future . . . the emotional effects the physical.”

Four family caregivers and the majority of community leaders identified emotional stress as either a contributing factor or the primary cause of chronic confusion in elders. For example, one informant stated, “we [Hmong] believe that because you cried a lot, you worried a lot, you suffered a lot, then you just lost your memory.” Similarly, a granddaughter attributed the life-long accumulation of stress to the onset of her grandmother’s memory impairment. Another caregiver stated, “My mother-in-law thinks a lot about her children in Laos and she would always cry over them and worry about them. This makes her really sad and depress[ed] and this may have lent to her illness.”

Preferred Treatment

The perceived cause was closely related to the choice of health seeking behaviors. The majority of family members viewed the elder’s condition as either a normal part of aging or attributed their condition to a spiritual cause. Consequently, they did not seek treatment from a physician, unless accompanied by a
health crisis (e.g., cerebral vascular accident). Regardless of the personal beliefs of the family caregiver, traditional healers were consulted when the elder retained beliefs of animism/ancestor worship. All but one of the care recipients practiced animism/ancestor worship. A community leader explained:

When my mom is sick I call the shaman. My belief is to help her emotionally. I know that she believes the shaman and every time the shaman do something to her . . . she will feel better. But to me, I know that it [shamanism] is a psychological belief, so I have to do something to make her happy and then she feel better.

_Ua Neeb Kho_

All four shamans reported treating numerous elders for chronic confusion through _ua neeb kho_ (healing ceremony). Healing ceremonies have basic similarities but vary based on the individual circumstances surrounding the lost or abducted soul. The shaman enters a trance enabling travel to “the other world” to negotiate for the return of the afflicted person’s soul. The negotiation process involves burning incense and spirit money and usually an animal sacrifice (e.g., chickens, pig). One shaman described the negotiation process for a wandering soul:

When the body getting older, the second soul getting sick—getting really sad—very lonely—it [the second soul] is looking around for reincarnation . . . a new body, so they have a new life again in a different body. That is why they have that memory loss and they dream they just say things that are not right. As a shaman, my job is to call this spirit and I say “don't be sad, don't be lonely, come back to your body. Your daughter-in-law, son-in-law, daughter, and son are here—everything that you need is right here. My role as a shaman is to go calling this spirit to don’t go away to just feel better and feel good and come back home and stay.

The shaman, after successfully retrieving the lost or abducted soul, will loosely tie a red or red/white entwined string around the neck or wrist of the afflicted person. The string must be worn “for a long, long time . . . I [shaman] suggest forever . . . some people get tired [of wearing it] after a couple years and I recommend that they just tie it under the bed [on the bed frame].” The purpose of this string is to protect the soul from _dab_ (evil spirits) and secure the soul to the body. A number of care recipients were wearing a loosely tied red string around either their wrist or their neck. In homes where these ceremonies had been performed we often saw spirit paper or other artifacts hanging on the front door in an effort to protect the home from evil spirits.

Caregivers had mixed feelings about the effectiveness of _ua neeb kho_ as reflected in the following statements:

We tried [shamanic healing ceremony] a month ago and two weeks ago, but it didn’t work. I believe in it, that they will cure for it, but now-a-days, it is hard to find a true shaman, like my grandpa [who was a shaman prior to the deterioration of his health] to care for those people.
We did several shaman performances. In November, we did twice for the husband. This included an offering of food and money for the ancestors and the sacrifice of a cow to call the soul to return to the body. . . . After each shaman ceremony he wake-up and do better, walk around and be happy again for two to three weeks, but then he get sick again.

Another caregiver declared, “we had five *ua neeb kho* performed for my wife—I think they helped.” The following case example describes the behaviors of one elder Hmong woman and the traditional treatment that was prescribed.

*Case Example*—An elderly Hmong woman lived with her son and daughter-in-law. One day while her family was at work, the elderly woman heard a knock on the door, looked through the peep hole and saw her husband who had died over 20 years ago. The elder became frightened and reported the incident to her family when they returned home.

Throughout the subsequent 18 months, the elder’s cognitive abilities deteriorated requiring her daughter-in-law to quit her job to assume a full-time caregiving role. As the elder’s condition advanced she was unable to recognize family members, was no longer able to prepare meals, and placed objects in inappropriate places. On one occasion, she buried all of her money in her garden (a common practice in Laos during the war). The elder began isolating herself in her bedroom for long periods of time and would not allow family members “to come near her—not even to feed her.” The elder subsequently “lost a lot of weight” and her physical health began to deteriorate.

The family reported taking the elder to a number of physicians who were not able to “find anything wrong with her.” Based on the family’s animistic beliefs, they also consulted a shaman who performed a healing ceremony. The ritual involved the sacrifice of a goat and a quail. Following the ceremony, the shaman made two talismans from selected parts of the sacrificed animals. The first was hung on the door where the elderly woman had reported seeing her husband. The second talisman was hung on a coat hook just inside the kitchen door.

Following the ceremony, family reported that the woman’s condition began to improve. She became more responsive to family members, was able to assist in meal preparation, regained her ability to converse coherently and welcomed guests into her home. The family stated that she was “back to normal” and attributed this to the shamanic healing ceremony. Upon further inquiry the family vaguely stated that the elder woman was also taking “some medication” that had been prescribed by her physician.

Ntxiv Ntawv

Two shamans emphasized the need to perform *ntxiv ntawv* (a ceremony to extend the person’s “life visa”) in conjunction with or subsequent to *ua neeb kho* (healing ceremony). It is believed that each person is given a “visa” that determines their “mandate of life” or length of time they will reside on earth.
during this lifetime. At the completion of *ntxiv ntawv*, pieces of red, black, and white cloth are cut and appliquéd in a unique configuration on the back of the person’s shirt.

One caregiver explained the supplemental use of *ntxiv ntawv* as follows:

We perform a lot of shaman ceremonies for her. We do shaman ceremony several times but it is to support her spirit. With old age like this, you have the shaman come in and look but usually nothing cause it. When you get old, we believe that the shaman perform to add years to your life. That is the kind of ceremony we perform for her.

**Khawv Koob**

Two shamans in this study were also practitioners of *khawv koob* (magic healing) and employed this technique in the treatment of elders with chronic confusion. As explained by these traditional healers, *kawv koob* is indicated when an evil spirit invades the elder’s body or blocks the elder’s mind. *Khawv koob* can be performed by anyone versed in this technique, it does not require a spiritual calling. The practitioner of *kawv koob* recites various incantations, burns incense, and sprays magic water on the afflicted person as a means of frightening the evil spirit away. One healer emphasized that it is essential to treat as soon as possible “when the evil spirit comes into the mind . . . or the person gets memory loss, and it gets worse and worse and usually can not cure.”

**Christianity/Prayer**

The religious leader recommended that Christian Hmong elders seek spiritual assistance when confronted with chronic confusion. He emphasized that spiritual fulfillment is key to positive self-esteem, emotional wellbeing, and hope for the future; all of which serve to support physical health. In addition, he believed that prayer provided the emotional strength to “handle a physical illness.”

We had the opportunity to attend a healing ceremony that had been adapted for a Christian Hmong family. The ceremony was performed for a 92-year-old man who had practiced traditional spiritual beliefs (animism/ancestor worship) throughout the majority of his life. He converted to Christianity shortly after his arrival in the United States 27 years prior. Currently, he suffered from mild memory impairment and confusion. He also had medical diagnoses of hypertension, congestive heart failure, and pulmonary edema. To supplement the elder’s medical care, his family organized a prayer ceremony. In preparation for this ceremony, a cow had been sacrificed as an offering to God. A key component of the ceremony involved a minister leading the family in prayer. This was followed by an adaptation of the traditional string tying ceremony (*ntxawm paj ntaub*). This ritual began by the minister blessing a large quantity of white strings approximately 8 inches in length. He did this by holding the strings in one hand and a Bible in the other while reciting a prayer. Afterwards each family
member was given two strings, one to tie loosely around the wrist of the afflicted elder. The second string was tied to the wrist of his wife. As the strings were tied, the family member recited a personal blessing (i.e., I wish you good health). Following the ceremony a feast was served to family that included dishes made from the meat of the sacrificed cow.

A second important example illustrates the use of prayer. The caregiver's mother experienced nightmares that were so frightening that she sought comfort from her daughter in the middle of the night. Traditionally nightmares are attributed to the influence of an evil spirit. In this example, both the daughter and mother were self-identified Christians and would pray together until the mother felt better. The daughter explained, “once you have prayed, the Holy Spirit is with you and protecting you, then the evil cannot touch you.” The daughter concluded, “but if she continues to have that kind of nightmare then I would have to call upon a shaman to come in and find out what is going on, because maybe I am not strong enough to get rid of the spirit.” Similarly, a community leader explained that it is common for members of a Christian Hmong congregation to inform their minister of a “bad nightmare” so that a prayer can be said on the person’s behalf.

Herbs

There is widespread use of medicinal herbs in the Hmong community. These are indicated when the health condition is believed to have a biophysiological cause. Only one traditional healer knew of and used an herbal remedy for the treatment of chronic confusion in elders. This was the same healer who had acknowledged that chronic confusion could have a physiological cause. This informant was a shaman as well as an herbalist. He explained that when treating an elder he usually began with the herbal remedy. The remedy was prepared in one of two ways: 1) boiling the herb in water as a tea, or 2) chewing the herb, ingesting the juice, and then “spitting the leaves out.” The herb was to be administered one time daily, if positive effects were not seen in two to three days, he recommended a shamanic healing ceremony.

Although the majority of caregivers and community leaders had gardens where medicinal herbs were grown, none knew of any herbal remedies available in the United States for elders with chronic confusion. Throughout our fieldwork we attended numerous celebrations where we encountered elder women selling herbal remedies but none knew of a remedy for the treatment of elders with chronic confusion.

Community Resources

With an understanding of informal care structures and perceived cause, we advanced the interview to explore the use of community resources such as medical care, support groups, adult day services, and nursing homes.
Western Medicine

Because chronic confusion was not viewed as having a biophysical cause, family saw no perceived benefit in consulting Western medicine for treatment. The informants in this study limited their use of hospitals to emergency care. The majority of elders were reported to view hospitals with varying degrees of mistrust.

Support Group

At the time of this study we learned of a local chapter of the Alzheimer’s Association that had aggressively tried, but was unsuccessful in starting a support group for Hmong families of persons with dementia. One community leader was puzzled as to why a family would seek the assistance of strangers to discuss such a sensitive topic. This is consistent with the perspective of a caregiver who emphasized, “you need to talk it over with someone in the family . . . you have to keep it in the family.” Overall, family caregivers were selective about whom they chose to confide in regarding the elders’ condition.

Adult Day Service

At the time of this study, an Adult Day Service was available in Ramsey County, Minnesota. This program enabled Hmong family to place their frail elders in a culturally appropriate environment while they were at work. The elders were opposed to referring to this service as day care (which they associated with child care). Noon meals were catered from a local Hmong restaurant. Walls were decorated with posters of Hmong villages and other familiar scenes from Laos. Craft activities were based on Hmong culture (i.e., paj ntaub), traditional music, and videos of Hmong folk tales (The Tigers Steal Nau Plai’s Wife, Ntxawm). At the time of this study there were 15 frail elders utilizing this service, but we were told that only three of these persons had chronic confusion.

One caregiver in our study used this service to supplement the care of his grandfather. The grandson believed that the activities and social interaction with other Hmong elders helped to alleviate his loneliness. Another caregiver enrolled in our study had made arrangements for her mother to visit the Adult Day Service program, in hopes that she could place her mother there during the hours she was at work. Following their visit, her mother bluntly stated, “it really is a place for people whose children have abandoned them . . . I just want you to know that I am not going there.” The caregiver added:

She [mother] is just not going to participate because she has her children that are taking care of her and she is not like all of these people who don’t have anybody. I think that part of it is a status thing. If I am able to be on my own, I am telling the world that I am well taken care of, but if I need
anybody’s help [outside of the family] that means that my children are not able to [care for me] or do not love me.

When asked about the use of community services such as adult day care, one caregiver said, “I don't trust any community service. I take her along with me if I go someplace.” When referring to paid caregivers in general, a grandson said, “elders [would] . . . rather have a close family member (i.e., son) take care of them [rather] than an outsider, because they [paid caregiver] don’t take care of them as good as the son.” Another caregiver said, “to them [paid caregivers] it is all about getting paid, it is all about money and to me it is not, because whether they pay me or not it is my duty, it is my job . . . . You don’t do it for the money, for me I do it because I am repaying them [grandparents] for what they did for me when I was little.”

Nursing Homes

Nursing homes were identified as a relatively “new concept” within the Hmong-American community, whose members were generally opposed to the use of these services. A community leader relayed the following Hmong proverb to convey the responsibility of adult children in the care of their aging parents, “You grow crop, just get ready for the hungry. You raise kids to prepare for when you get old, your children will take care of you.” Similarly, a second community leader shared this proverb, “You raise a horse to carry a load, you raise children and a daughter-in-law to take care of you when you are older.”

One caregiver strongly believed that American society contradicted these traditional beliefs. “In America children grow up, leave the home, live by themselves, lead their own life, leave the elder behind, and eventually place their elder parent in a nursing home.” This 34-year-old informant admitted a “constant fear” that in advanced age he would be forced by his son to be placed in a nursing home.

Another caregiver [an adult grandchild] recognized the importance of modeling traditional values for his own children:

I don't want to . . . send her [grandmother] to a nursing home because when you do that you are showing your son that when you get older they are going to do the same thing to you.

Hmong elders commonly fear being placed in a nursing home. This fear is reinforced when it is learned that another elder has been placed in a nursing home. A spousal caregiver recounted that her husband, who was blind, was afraid of being physically or verbally abused by nursing home staff. The grandparents of one caregiver threatened to commit suicide if placed in a nursing home.

A community leader emphasized that nursing home placement negatively effects both the elder and the family. The elder feels “rejected and worthless . . . and just waits for death.” The community perception of the family is:
... you don’t love your parents ... you threw them away, you put them aside, you forget how they raised you, you have not paid respect. It is a disgrace for the family line to put their parents in a nursing home. Your sons and your grandsons will have a hard time looking for a spouse ... because people will say 'that your family put their elderly people in a nursing home—so don’t have a connection with them, at least through marriage. Everyone will avoid marriage line through your family.

Similarly, another caregiver [daughter] described placement of an elder in a nursing home as a “double jeopardy.” Placement results in “feelings of guilt” and “goes against our [Hmong] tradition because we are suppose to be able to take care of them [elders].” She added that this “tradition” is becoming unrealistic in the United States for Hmong women who have a full-time job and are supporting a husband and children. She described the criteria that she believed essential to a nursing home:

1. have a Hmong speaking staff;
2. serve food that is culturally appropriate; and
3. be located in close proximity to family to allow frequent visits.

Two additional criteria were identified as being optimal, but not essential:

4. provide a flexible, friendly environment that is welcoming to families; and
5. allow residents to practice traditional ceremonies such as hu plig (soul calling) for those who retain animistic beliefs and prayer ceremonies for those who are Christian.

She concluded, “if my mother has to go to a nursing home, I hope that I would be able to find a place such as that to make it a little easier—maybe for me, more than for her.”

The need for nursing homes to be culturally and linguistically competent in the care of Hmong elders was echoed by three other caregivers. One of these caregivers emphasized that “without the language competency there is no way for an elder Hmong to express their basic needs (i.e., I hurt here, I sick, I want this or that).” Another of these caregivers elaborated:

At this moment the nursing homes are not sensitive enough to the culture and beliefs. I came to America without a career so I can take care of my grandmother. But I can see that the children and grandchildren of other families, who have good jobs, may put their family member in a nursing home because they care about their career. ... My grandma tried to live in a nursing home once, but she cried all day long, she did not like it. ... We choose to keep her at home because she does not like American food.

One informant concluded, “a nursing home is good if you don’t have any more family left.” However, a community leader adamantly believed that there
would always be a family member available for care even if it were a distant relative or clan member.

DISCUSSION

All of the informants in this study were born in the remote highlands of Laos. The care of Hmong elders in urban America is much different than previous generations experienced in caring for elders in small villages in Laos. With an increase in life expectancy, there is an increased risk for chronic illness such as dementia. Caregiving of elders with dementia is posing new challenges to the Hmong American community.

Informants in this study identified the roles of family/clan and spirituality as the primary factors in determining the care of Hmong elders with chronic confusion (i.e., dementia). The strong interdependence between the individual, family, and clan provides the structure for this care. As previously reported, this interconnecting relationship was described by one informant through the use of concentric circles, beginning with persons in the nuclear family and expanding outward to the Hmong community as a whole. Roles of these members are well-defined based on gender, generation, and kinship (Keown-Bomar, 2004). Specific to our study, these roles define caregiving responsibilities of elders with chronic confusion and extend outward to the use of community services. In addition, spiritual orientation influences the perceived cause of illness, care of elders, and health seeking behaviors.

Transition to life in the United States has influenced both the family/clan structure and the spiritual orientation of its members. We proceed by discussing our research findings within the context of the ongoing transition to life in the United States.

Personal Meaning Attributed to Chronic Confusion/Tem Toob

Throughout recent history, interaction with people of Laos, Thailand, and the United States have exposed the Hmong to differing lifestyles and religious faiths (i.e., Christianity), all of which have had varying influences on the retention of traditional cultural and spiritual beliefs. It is estimated that 70% of the Hmong population in the United States continue to practice the beliefs of animism/ancestor worship (Pfeifer & Lee, 2005). It is also important to recognize that some Hmong who self-identify as Christians may, to varying degrees, continue to believe in the influence of spirits on their lives and health.

The findings of this study indicate that the spiritual orientation of informants influenced the perceived cause of the elders’ condition. The majority of those who retained animist beliefs identified chronic confusion/tem toob as a spiritual illness.
that required intervention by a spiritual healer. Similarly, the Christian-Hmong leader identified a lack of spiritual fulfillment as a cause for dementia that required divine intervention through prayer.

Almost half of the family caregivers attributed advanced age to the onset of chronic confusion. A long-standing Hmong proverb, relayed orally from one generation to the next, has reinforced this belief. When chronic confusion was viewed as a natural part of aging, family members did not see a need for either spiritual or medical intervention. However, because the majority of elders retained traditional beliefs of animism/ancestor worship, their wishes took precedence. Under these circumstances, despite the beliefs of the caregiver, a shaman was often consulted to satisfy the spiritual needs of the elder. This finding is in conflict with that of a study conducted by Olson (1999) in which informants denied the need for spiritual intervention. However, our findings are consistent with the traditional health seeking behaviors of Hmong elders with chronic confusion, or tem too, who are living in Laos (Gerdner, Xiong, & Cha, 2006) and Hmong refugees living in a camp in Thailand (Chindarsi, 1976). It is also consistent with the findings of a study that explored the health problems and preferred treatment of Hmong Americans living in Colorado (Cha, 2000).

Approximately one-fourth of the family caregivers and the majority of community leaders identified stress as the cause of chronic confusion. Elder care recipients had been exposed to numerous stressors throughout their life. All of the elders in this study lived in Laos during the war and escaped to Thailand where they lived in refugee camps under substandard conditions until relocating to the United States. Throughout this time many, if not all, experienced the death and separation by geographic location of nuclear and extended family members. Compared to other immigrant and refugee groups, adjustment to life in the United States has been especially difficult for elder Hmong who, like the care recipients in this study, spoke Hmong as their sole language and lacked a formal education. As a result, elder Hmong are more likely to contend with low socioeconomic status, have insufficient means of transportation, and become psychologically challenged by social isolation, enforced role change, and threats to cultural heritage (Parker, 1996; Thao, 2002).

Because of the accompanying behaviors associated with the elder’s condition, several informants expressed concern that some members of the Hmong community would label the elder as being “crazy.” Consequently, they made an effort to protect the elder’s dignity and respect by shielding them from potential criticism. This may explain the reticence of informants to discuss the elder’s condition with persons outside of the family. When the cause is viewed as stigmatizing (i.e., as was the fear of the community perceiving the elder as crazy), the shame may be seen as related to the entire family not just the individual. Respect for and duty toward the elder may prevent external help seeking (Tempo & Saito, 1996).
Factors influencing Caregiving

Hmong elders have traditionally been provided with a high degree of respect. This has been and continues to be accompanied by a strong commitment to the care of family elders. This is viewed as reciprocal of the love and care that elders provided to subsequent generations. Caregivers who had children of their own emphasized the need to preserve these values for future generations by serving as role models. There was concern that this value system would be diminished or lost through the subsequent generations of Hmong as they became “Americanized.”

Characteristics of the caregiver—such as sex, familial relationship (i.e., daughter vs. daughter-in-law), and age/generational cohort (grandson vs. son)—influenced individual caregiving roles and responsibilities. The Hmong are a patriarchal society. Traditionally, the eldest son has the primary responsibility for his aging parents, with his wife providing the actual hands-on care. Conflicts with this prescribed norm are emerging due to changing roles and lifestyles of Hmong-American citizens. Women, in particular, are confronted with multiple competing roles. However, only two caregivers identified this as a concern. As previously mentioned, we learned of other female caregivers who shared these views to varying degrees but declined to be interviewed. The potential shame that could be brought to family members by merely verbalizing these concerns may have served as a self-censuring mechanism for potential informants. Ultimately this may have biased the sample.

Male caregivers were also faced with unique challenges. For example, we learned of a husband who was seeking a second wife to care for his wife. Historically, in Laos, many Hmong people practiced polygyny, allowing the male to marry more than one wife. This practice is not legal in the United States, but has been known to covertly occur through a traditional Hmong marriage ceremony, which is not recognized as a legal union in the United States.

The age and generational status prevented a grandson from directly confronting the challenging behaviors exhibited by his grandparents. Cultural norm required deferment to a male elder even though the grandparents were living in the home of the grandson who was married and had children of his own.

Overall, in-home care of elders was viewed with devotion and pride. The quality of care was reflective of how the family as a whole was perceived by other members of the Hmong community. A perception of improper elder care or neglect may bring long-standing shame to the family and its individual members.

Ancestor worship also has important implications for the care of elders. The premise of this belief system is that ancestral spirits continue to influence the lives of living family members. For example, an elder must be cared for and respected during the final years of life to prevent harm from befalling the family when the elder dies and joins the ancestral spirits. It is not uncommon for Christian Hmong to retain beliefs, to varying degrees, regarding the influence of ancestral spirits on their daily lives.
Interdependence in Decision Making and Treatment of Elders

Family structure is based on interdependence rather than independence (Hall, 1990, Keown-Bomar, 2004). Consistent with this view, major health care decisions are traditionally made by the family unit under the guidance of the eldest male (Cha, 2000). Although the literature indicates that this is changing with younger generations of Hmong Americans, overall informants in this study adhered to this traditional norm with care decisions for elders being made under the leadership of the eldest male. However, regardless of the personal beliefs of the primary decision maker, the traditional spiritual needs of the elder became the primary determining factor for health seeking behaviors. This is consistent with research findings that emphasize the importance of adhering to traditional norms for the care of elders despite acculturated belief systems within other family members (Rick & Forward, 1992).

Spiritual healing ceremonies promoted family interdependence by treating the family unit as a whole with emphasis on the needs of the elder, rather than treating the elder in isolation of the family. Shamanic healing ceremonies were therefore used to promote spiritual and family unity. Similar to the shamanic healing ceremony, Christian-Hmong use an adapted healing ceremony, performed by a minister to promote spiritual and family unity.

Security in Solidarity/Interface with Dominant Culture

The family is part of a larger clan structure that provides the basic social organization for the Hmong community. Dunnigan (1986) observes that experience throughout history has taught the Hmong people that “security depends on solidarity.” He explains that reliance on persons outside of the Hmong community threaten this unity. Therefore, it is not surprising that Hmong informants were reluctant to use community services outside of these enclaves.

Informants did not usually seek Western medicine for the treatment of an elder with chronic confusion, since there was no perceived benefit. Overall, hospitals were reserved for emergency care. Some elders had a fear of physicians and hospitals. This is consistent with findings of previous studies that have explored the experience of Hmong persons utilizing the Western health care system (Johnson, 2002).

Admission to a LTC facility was associated with negative stigma for both the elder and their family. Care of the elder was viewed as being the responsibility of the family. LTC facilities were viewed as being culturally and linguistically deficient in the care of Hmong elders.

Since their arrival to the United States in 1975, the Hmong community and its elders have focused much of its efforts on educating its youth to promote economic independence for the next generation (Hutchinson & McNall, 1994). The knowledge and expertise acquired through advanced educational degrees is viewed as a means of empowering the Hmong-American community as a whole.
This training includes health professionals who are sensitive to the unique health care needs of the Hmong-American community. Some members of the Hmong community have expressed concern that these needs have taken precedence over the smaller elder cohort. Hmong community leaders identify the concept of dementia in its elders as an important but neglected need. The Hmong community in St. Paul/Minneapolis is beginning to recognize the need for culturally competent services for Hmong elders who are frail and/or cognitively impaired. The motivation is to provide services to assist family caregivers, particularly those who have jobs outside of the home. This includes several adult day service programs and meals-on-wheels. One LTC facility has developed a unit specifically for the care of Southeast Asians. At the time of this study, approximately 60% of the 39 residents were Hmong (refer to Gerdner, Xiong, & Yang, 2006).

CONCLUSIONS/IMPLICATIONS

This focused ethnographic study is the first to provide an in-depth exploration of the perception and care of chronic confusion (i.e., dementia) within the Hmong-American community. Transition to life in the United States is posing new challenges for the care of elders with dementia. There was a reticence on the part of some caregivers to discuss these challenges for fear that it would cast a negative stigma on the family. There was also a tendency to shield the chronically confused elder from the judgmental eye of others. There is need for the development of culturally appropriate family-based education programs within the Hmong-American community to alleviate the misconceptions and negative stigma that is associated with dementia. It is recommended that these programs be designed and implemented in consultation and support of prominent Hmong American organizations such as Lao Family Community.

As a beginning effort, general themes from the life experiences of the family caregivers in this study were used to develop a culturally sensitive, bilingual (English/Hmong), illustrated book for Hmong American children and their families entitled, Grandfather’s Story Cloth (Gerdner & Langford, 2008). The educational value of this book is augmented with discussion questions and answers that support a family-based approach to learning. This supplemental material may be obtained complementary from the author at lgerdner@gmail.com or the publisher at www.shens.com. A grant from Extendicare Foundation of Milwaukee, Wisconsin has provided funds for the purchase and distribution of 1000 copies of the book Grandfather’s Story Cloth to select organizations in geographic areas where there are high concentrations of Hmong Americans living. This will be accompanied by a series of speaking engagements by the first author (Linda Gerdner) in an effort to promote awareness and understanding of dementia within the Hmong American community. This is being initiated as an impetus for the development of more comprehensive family-based educational programs.
REFERENCES


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