Perception and Care of Elder Hmong Americans with Dementia

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Background

• Ethnic minority from Southeast Asia
• Assisted U.S. effort during Vietnam War
• Communist takeover of Laos in 1975
• Fleed to refugee camps in Thailand
• Began arriving in U.S. -- mid-1970s

2010 U.S. Census

• 260,000 Hmong Americans living in U.S.
• 3.1% were 65 years or older
Family Role / Decision Making
- Organized into an 18-clan structure
- Family is a sub-component
- Members have well-defined roles & responsibilities
- Patriarchal, strong family bonds based on interdependence
- Any life decision that affects one family member will have direct / indirect impact on all
- Decisions made as a group under the leadership of eldest male
- Clan leader consulted only with unresolved dispute

Spirituality
- Traditionally the Hmong practice animism and ancestor worship
- These beliefs are strongly intertwined with beliefs related to health and illness.
- Spiritual Illness / shaman
- Within this belief system some illness may have a biological cause / herb or organic substances

Spiritual Beliefs
- Influenced by religious beliefs of dominant cultures in Laos, Thailand, US (Christianity, Buddhism)
- Animism / Ancestor Worship (estimated 70%)
- Self-identified Christians may retain traditional beliefs to varying degrees
- Spiritual status may change over time
Heterogeneity

- Spiritual Beliefs
- Level of Education
- Ability to Speak English
- Country of Birth
- Degree of Acculturation

Dementia in Hmong Elders

- Has been a neglected issue.
- Until recently little is known about the perception, prevalence, and preferred treatment.
- Important and timely issue
Historical Context


**Tem Toob**

- *Ntoo laus ntoo khoob, neeg laus neeg tem toob* (Blia Lo, personal communication)
- Compares an elder who has memory impairment with a tree that has been hollowed with age.
Needlework: Mai Lee
Artist: Teng Xiong; Consultant: Sia Her Xiong

Ethnographic study to systematically explore the impact of living in the U.S. on these traditional views

Methodology
- Focused ethnographic study involving 2.5 years of participant observation and in-depth interviews with Hmong American family caregivers, traditional healers, and community liaisons to explore:
  - Perception & cause of chronic confusion / dementia
  - Family caregiving experience
  - Access and use of Western health care services
  - Use of traditional healers.
Setting
- St. Paul / Minneapolis, Minnesota (Hmong pop. 40,707). Largest enclave in U.S.
- Eau Claire, Wisconsin (Hmong pop. 1,920)

Access and Recruitment
- Began by obtaining support from Hmong American leaders during the design of this study
- Study was publicly endorsed by Lao Family Community who also assisted with recruitment
- Research team included a Hmong nurse
- PI became immersed in the Hmong American community (community activities, family gatherings)

Data Generation
- Interviews conducted at a time and location convenient to the participant
- Majority of interviews conducted in the Hmong language with assistance of a certified health care interpreter
- With permission all interviews were audio-taped.
- $25 gift certificate for groceries at Hmong American grocery store.
- Extensive field notes
Data Analysis

• Taped interviews transcribed
• Supplemented with field notes
• Data content analyzed using ethnographic analytic procedures described by Kirk & Miller (1986).
• Major categories identified

Demographic Data

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<th>N</th>
<th>Mean</th>
<th>Range</th>
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<td>19.8</td>
<td>9-24</td>
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<tr>
<td>Age</td>
<td>Mean</td>
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<td>53-89</td>
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<td></td>
<td>Range</td>
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<td>9-24</td>
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<tr>
<td>Time in U.S.</td>
<td>Mean</td>
<td>63</td>
<td>34-92</td>
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<tr>
<td></td>
<td>Range</td>
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<td>14-27</td>
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<td>55-85</td>
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<tr>
<td></td>
<td>Christian</td>
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<td>75</td>
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<td></td>
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<td>75</td>
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<td>75</td>
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<td></td>
<td>Traditional Healer (n=5)</td>
<td>3</td>
<td>75</td>
<td>55-85</td>
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</table>

Labeling Chronic Confusion

• Most used the term tem toob
• "When people get old there are so many things on their mind, [they] forget things. Too many things too focus on so their mind doesn’t work."
• Only 6 reported receiving a dx. for this condition, with one adding, "but many of us do not know what that [diagnostic term] means."
• Dementia: "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."
Perceived Cause

- Traditional healers (i.e., shamans) attributed the elder’s condition to soul loss.
- Hmong Christian minister: "unfulfilled emotionally," he added, "their spiritual side is empty so they have no hope for the future…the emotional effects the physical."

Spiritual Cause

1. "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."
2. 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."
3. "Evil spirit takes the person’s soul and tortures it, causing the person to become crazy and forgetful."

Perceived Cause

- Majority of family caregivers attributed memory impairment to aging process.
- Majority of community liaisons identified stress as the cause.
Family/Clan Structure

Five concentric circles [beginning with a description of the inner circle & describing outward]
1. Nuclear family comprised of husband/wife  
   (when woman marries joins husband clan)  
2. Husband’s family  
3. Wife’s family  
4. Entire Clan  
5. Hmong community as a whole

Caregiving Structure

• Traditionally, the eldest Hmong son has primary responsibility for his aging parents, with his wife providing the actual hands-on care.  
• Conflicts with this tradition are emerging due to changing roles and lifestyles of Hmong living in America.

Caregiving Role

• Return of the love and care given by the elder  
• Model of traditional values for younger generation.  
• Overall, female caregivers were pleased to devote time and attention to care of a family member and took pride in this endeavor.  
• More difficult for those who were forced to juggle a career outside of the home along with the role of traditional wife and mother.
Ancestor Worship
Belief: 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.

Preferred Treatment
• Regardless of the personal beliefs of caregiver, traditional healers were sought when the elder retained beliefs of animism/ancestor worship.
• Shamans used to promote spiritual and family unity.
• The religious leader recommended that Christian Hmong seek spiritual assistance when initially confronted with memory impairment.
• Christian Hmong may use an adapted version of healing ceremony performed by a minister.
• Because the majority of family members viewed the elder’s condition as a normal part of aging, they did not seek treatment from a physician, unless accompanied by a health crisis.

Support Groups
• Local Chapter of the Alzheimer’s Association was unsuccessful initiating a support group in the Hmong American Community
• One community member was puzzled as to why a family would seek the assistance of “strangers” to discuss such a sensitive issue.
• 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 caregivers were selective about whom they chose to confide in regarding the elder’s condition.
Nursing Homes

1. Have Hmong speaking staff
2. Serve foods that are culturally appropriate
3. Be located in close proximity to family to allow frequent visits.
4. Provide flexibility with a friendly environment that is welcoming to families.
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.

Conclusions

• With an increase in life expectancy there is an increased risk for dementia
• Caregiving of elders with dementia is posing new challenges for the Hmong American community.
• Role of family and spirituality are primary factors in determining care for Hmong elders with dementia.
• Roles of family members are well-defined based on gender, generation, and kinship (Keown-Bomar, 2004).
• Specific to this study, these roles define caregiving responsibilities of elders with dementia and extend outward to the use of community services.
• Spiritual orientation influences perceived cause and health seeking behaviors.

Conclusions (cont’d)

• Study participants identified dementia as a "neglected issue within the Hmong community".
• There is a critical need to develop culturally and linguistically appropriate family caregiver training program.
• The Hmong community relies heavily on family and clan for support and information. Outreach efforts should include these authority figures.
Implications

- Health needs assessment must be conducted on an individual basis.
- Health care interpreter and/or cultural broker
- Honor individual expression of culture and accommodate the associated variation of needs
- By tradition, holistic perception of health that includes spiritual well-being.
- Western medicine can never replace spiritual healing
- Traditional beliefs accommodated whenever possible

Linda, this slide was not in the webinar handout. It’s included here for you to decide if you’d like to use it. This came from your Ppslide draft v5-5.

Reference

