

How Patients With Limited English Proficiency Make Health Care Decisions: Hmong Patients' Perspectives

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ABSTRACT

Introduction: Information about how the limited English proficiency immigrants make their decisions to seek health care is not well understood. With acculturation, immigrants tend to shift their beliefs and practices towards the practices of their host country. Yet, little is known whether this holds true for the Hmong's health care decision-making.

Methods: To understand the health care decision-making process of limited English proficiency Hmong, we conducted semistructured interviews with 11 Hmong adults with limited English proficiency. Interviews were audio-recorded, transcribed, and analyzed using directed and conventional content analysis.

Results: We identified several themes: participants sought advice and information from family members who were proficient in English and Hmong and/or who had a health background for a treatment that they perceived to be potentially life-threatening. However, participants were more reliant on their own decision-making in medical situations that were time sensitive. Participants without immediate family asked for health advice from community members or peers who had personal experience with the health condition or treatment.

Conclusions: Our findings suggest a cultural shift in Hmong health care decision-making processes from relying on clan leaders and elders to seeking out the advice of adult children and spouses. Understanding this change in cultural decision-making dynamics will help health care professionals provide more culturally competent care in areas where the Hmong community have a prominent presence.

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INTRODUCTION

Efforts to reduce health disparities experienced by marginalized groups in the United States have not improved survival rates for minority patients compared to non-Hispanic White patients. One marginalized minority group often overlooked is the Hmong, a refugee group from Southeast Asia who first arrived in the US in the 1970s. The 2019 US Census estimates 327,000 Hmong living in the US, primarily concentrated in California, Minnesota, and Wisconsin, with growing communities across the country. Approximately 37% of the Hmong adult population speak English "less than well" or "not at all" (ie, limited English proficiency [LEP]).¹

Multiple factors contribute to health disparities experienced by the Hmong: limited access to resources, low educational attainment, lower-income status, low health literacy, and LEP.² Moreover, LEP Hmong members' reluctance to seek care is often connected to poor health care

experiences and poor-quality interpreter services.^{3,4} These factors are associated with lower screening rates for cancer,⁴ higher prevalence rates of type 2 diabetes,⁵ and overall lower rates of preventive health care.⁴

Health disparities also arise because the Hmong health belief system⁶ (based on shamanism where spirits influence health and well-being) often conflicts with the Western biomedical system. Consequently, the Hmong seek shamans to treat the soul and spirit before the physical body.^{7,8} Thus, when they do seek

Western health care, diseases are often at more advanced stages compared to non-Hispanic White patients.⁹

The Hmong organize in large, close-knit communities, known as clans. Traditionally, clan leaders and/or members of the clan (also called *kwv tij*)¹⁰ assist members with their decision-making, including medical decisions.^{7,11,12} As dictated by their culture, Hmong women consult their husbands before making final medical decisions.^{7,13} However, as the Hmong acculturate, it is important to reevaluate if these decision-making patterns still exist. With acculturation, immigrants tend to shift their beliefs and practices towards the practices of their host country.^{14,15} However, little is known whether this holds true for the Hmong's health care decision-making.

This study explored factors shaping the health care decision-making process of LEP Hmong. Our research questions were:

- (1) When do LEP Hmong seek health advice?
- (2) How do LEP Hmong make decisions to seek help?
- (3) Who do LEP Hmong consult when making health care decisions?

METHODS

This qualitative study was part of a larger study exploring barriers and facilitators to preventive cancer screenings for Hmong and Spanish LEP patients in a large Midwest health care center. It was approved by the University of Wisconsin's Institutional Review Board.

Sample and Recruitment

We recruited a convenience sample of participants. Eligibility criteria included self-identifying as having LEP, being a native Hmong speaker, being eligible for preventive cancer screening (women ≥ 18 and men ≥ 50), having no previous cancer diagnosis, and having had at least one primary care visit in the past year.

Recruitment strategies employed were posting bilingual (Hmong and English) flyers in clinics and local community centers, sending bilingual letters to potential patients, and attending cultural events. Participants were encouraged to refer family and friends. A bilingual Hmong research assistant screened interested participants.

Data Collection

All participants reviewed study information and were interviewed at home. A semistructured interview guide ensured consistency across interviews. In this study, we asked about LEP Hmong participants' thought processes around health care decision-making, specifically who they turned to for health care advice and the factors that influenced their health care decisions. For example, we asked "When you make a decision about your health, do you consult with others or seek information outside the clinic? [Probe:] Who/What?" This guide was written in English and translated into Hmong by a bilingual study team member and then back-

translated from Hmong into English by another bilingual study team member to ensure accuracy and capture the meaning rather than a literal translation. Any discrepancies were discussed until group consensus was reached. Interviews were conducted in Hmong with at least two bilingual study staff attending all interviews. Consistent with the Hmong collectivist culture, participants welcomed having more people in the conversation.¹⁶ Interviews were collected from July to December 2013, lasted between 45 and 120 minutes, and were audio-recorded. All participants received a \$50 honorarium.

Data Analysis

The audio files were transcribed verbatim in Hmong and translated into English using a group translation method to focus on meaning rather than literal interpretation for data validation.^{17,18} Group translation involves people with cultural and linguistic skills working together to translate and review the materials with one adjudicator present to determine final translations.^{17,18} We focused on capturing meaning because there are Hmong phrases and concepts with no English equivalent.¹⁸ Disagreements in translation were resolved as a group, discussing all possible interpretations that most closely corresponded with what participants intended to convey.

We used directed and conventional content analysis¹⁹ to analyze the data. Directed content analysis works well with predetermined categories of questions (eg, health care decision-making and barriers to seeking care). These predetermined categories were derived from empirical research.^{4,8} Hence, we generated categories from prior research to guide the data analysis. For example, "I make my own health decisions" was coded as health care decision-making. Conventional content analysis was used for responses that did not fall within the predetermined categories. For example, "If I feel like I am going to die, I'm going to go to the doctor immediately" was coded as "making decision by self." Through an iterative process, codes were grouped into categories. Data saturation, when no new themes emerged, occurred prior to the final interview. We used NVivo 10 (QSR International) to manage the data. Two study team members coded interviews separately, met to review codes, and added codes when they identified new content that did not fit within the predetermined categories. All codes and categories were brought to the larger interdisciplinary research team for confirmation. Discrepancies were discussed until consensus was reached. Data saturation (ie, no new themes emerged²⁰) was reached by the 8th interview, and we continued data collection until the 11th participant. Four themes resulted from our data analysis.

RESULTS

There were 11 Hmong participants (6 females, 5 males) with an average age of 55 (range 34 to 70 years). More than 80% of the participants had less than a high school education or none. Nine

participants were publicly insured and two were privately insured. All had been in the US from 8 to 33 years.

We identified 4 major factors playing a role in participants' decision-making processes: (1) the type of medical care, (2) the seriousness and/or urgency of the participant's health condition, (3) the participant's English language proficiency and health knowledge, and (4) the participant's personal experience with the illness.

Type of Medical Care

Most participants shared that their decision to seek advice depended on the type of medical care they needed: primary care visits versus surgical procedures. These categories were driving factors regarding whom they would allow to influence their medical decisions.

Primary care visits. Nine participants across both sexes reported that with routine primary care visits, they make their own medical decisions. One woman shared about her own decision-making that because others do not have enough medical experience to help make an informed decision, the decision ultimately depends on oneself: *"That, it depends on you only. They can't make the decision for you [...] So I make the decision on my own."* Male participants conveyed similar sentiments about their health care decision-making: *"If you need to go, you don't talk to anyone."*

Surgical procedures. In contrast, some participants shared that for surgical procedures, they sought advice from their immediate family members—adult children, parents, siblings, and spouses. For surgical procedures that participants perceived to be invasive and/or life-threatening, seeking advice from family was a way to decide whether to proceed with the treatment and follow the physician's medical expertise. For instance, this participant expressed that she would talk to her family before making the decision to have surgery:

[About] surgery [...] I think that if [I] have an illness, I will first talk to my mother, father, brothers, husband, and children before I go [...] If they say 'if you do this, then maybe it will be good too' then I will go do it. If you make your own decision, then you might make mistakes [...]

Some participants shared that they also gathered information from extended family who had past experiences with the recommended medical treatment. They wanted to educate themselves about the experience and about any potential high risks associated with surgical interventions. For example, one man stated that requiring a bypass heart surgery necessitated him to seek medical advice from extended family members because his family would shoulder the burden if he became disabled or died:

"To do something like that [surgery] to your heart, it is dangerous [...] Something like this, you have to talk with your family so that they can help you make the decision to see which option is best."

Seriousness and Urgency of Health Condition

Participants shared that the seriousness and/or urgency of their perceived symptoms influenced whether or from whom they would seek medical advice. There were 2 qualifying conditions: (1) immediate life or death decision-making and (2) low urgency.

Immediate life or death decision-making. All participants reported that if they perceived their lives to be endangered and needed immediate medical care, they would make their own health care decisions. This is a default decision once cultural and spiritual healing practices failed to yield any medical improvements. For example, a participant shared that when she could no longer withstand the physical pain and believed herself to be very sick, she made her own decision:

Because if you are super sick then you have to go. If you are super sick and you cannot talk with them [family], then you can go on your own and that's fine [...] And if they say that if I don't do the surgery, I will die, then I will make the decision on my own.

Low urgency. In contrast, if Hmong participants perceived their medical conditions to be of low urgency, then they included immediate family members in their health care decision. One man replied that he and his wife made decisions together: *"After getting checked up and if they say 'oh, I see this and it's like this, we have to schedule another appointment for you to come back and we will treat it like this,' then you have to discuss it with your wife and family before you go."* Another female gave a similar statement about how she and her husband decided together for him to undergo a colonoscopy without involving other family members: *"Yeah, we were the two [participant and her husband] that made this decision for them [doctors] to take an x-ray inside the colon and the stomach to see if there is any illness in there."*

English Language Proficiency and Health Knowledge

All participants reported that because of language barriers and their unfamiliarity with Western medicine, they deferred their medical care needs to English-proficient family members, usually their adult children. Some also sought advice from family members whom they perceived to be knowledgeable about the health care system and/or involved in health-related professions. One female explained how she trusted her adult children's advice regarding her medical needs because of their English proficiency:

I trust my family more. For example, it is my children and my husband. Because my husband, I trust him, but he doesn't know English. So even if I trust him, if it involves American people then he doesn't know English, so it's my children I trust.

One man also explained that his daughter helped with his medical decisions because she is bilingual and a nurse: *[...] the daughter has had some schooling in nursing [...] She knows English better. Every medication, she knows. If they want me to take it, she knows how.*

Personal Medical Experience

Eight participants shared that community members were also key informants for medical-related decisions. Before a medical procedure, if no immediate family member could provide information, participants asked members of the community for their medical opinions. One man shared the importance of accessing health care advice from his peers who were familiar with medical procedures or know people who have been diagnosed with certain diseases. The information gained from his peers was more trustworthy than the medical advice from his provider: *“I talk to my friends and see what they say to me. If they say it’s ok for me to go then I will go seek care and see how they [doctors] can help me, so that I can be happy.”*

Another participant shared her personal experience with obstetric care with her friends and sister-in-law. She said they were pleased with the accurate descriptions of the entire process of routine prenatal care, including different types of medical procedures:

“You have to think that it is a way to check up and protect yourself from getting sick and to help you know early and to help your child. This is something good for you.” That’s what I say to them, and they say “ok.” After they go [for a] checkup, they say, “Oh yeah, it’s like you said.”

DISCUSSION

To the best of our knowledge, this study is the first to investigate factors motivating LEP Hmong in their health care decision-making processes. We found participants first identify their needs as surgical versus nonsurgical or dangerous versus nondangerous and then decide whom to seek medical advice from. Bilingual family members—especially those with a health background—are ranked as the most desirable, but only for decisions involving surgical interventions or dangerous treatments like chemotherapy. Extended family members become involved when the entire clan can be affected negatively if the participant has a high probability of becoming disabled or dying. Friends become relevant when family fails to provide medical information. Our finding regarding who participants consult about their health is consistent with existing research.²¹ However, this ranking is irrelevant when participants perceive their symptoms as potentially harmful and life-threatening. Then participants are motivated to make their own decisions and trust their health care provider.

Interestingly, we found several instances where it appears that there may be a shift in Hmong health care decision-making. First, no participants mentioned seeking advice from clan leaders traditionally sought for medical advice.^{7,10,11} Second, decision-making was shifted to spousal decision-making when traditional Hmong family structure dictates that men make decisions for all important matters, including health care.^{7,10}

We found that male participants valued their wives’ opinions on their illnesses. All participants stated seeking spousal advice, especially for subsequent testing and procedures needed for diagnosis or treatment. This type of marital partnership does not conform to the patriarchal health decision model found in previous literature on the Hmong.^{7,11,12} However, our most unexpected finding was that Hmong women expressed autonomy in health care decision-making instead of deferring to their husbands. Although we did not explore the impact of acculturation on Hmong people’s health care decisions, it is plausible that it may have influenced this shift. Future research could explore to what extent acculturation affects health care decisions to better inform health care practices about the dynamic process of caring for their patients.

Our results demonstrate that for high-risk or invasive surgical procedures, LEP Hmong individuals sought medical advice instead of making the decision on their own. This is likely motivated by the Hmong’s clan structure, whereby all members unite to provide social and financial support to individuals.^{7,11,12} Therefore, the opinions and advice from extended family weigh heavily on Hmong individuals’ decision-making processes. Including extended family members may mitigate any consequences from unexpected mortality or morbidity. Previous research supports this finding regarding family involvement when having to make decisions about important medical procedures.^{7,12}

It is important to note the interesting dichotomy in the participants’ decision-making processes. Health care advice from others is only relevant when the time-sensitive component is removed. For time-sensitive care, decision-making becomes self-dominant. This finding is consistent with a current hepatitis B screening study among Hmong who will make their own decisions in situations that they perceived to be emergencies.²² This self-reliance regarding health decisions or reliance on others highlights complexities within health care decision-making processes that exist among LEP Hmong. Involving family members early in any health discussions may be key to helping LEP Hmong individuals receive appropriate and timely medical care. Future research also could study communication strategies that clinicians could use to be inclusive of Hmong family members in health care discussions, such as key Hmong phrases to support and empower family members’ involvement.

Lastly, we learned our participants consulted with friends and peers in the Hmong community when family members were not available to provide medical advice. Their connections and/or personal experience with similar procedures provided insights into quality-of-life after medical intervention. Community members bring community buy-in, which may prevent delays in care thereby improving health outcomes. Multiple studies on social networks show that strong social support improves health outcomes.²³⁻²⁵ A systematic review of shared health care deci-

sion-making in minority groups found that prior experiences of friends and family members significantly influenced the decision-making of patients to seek or forgo treatment.²⁶ Therefore, knowing key informants and the factors used to qualify who patients ask for medical advice can lead to timely and effective medical interventions.

Lastly, our study uncovered a role reversal between parents and children regarding health care-related decisions. Participants sought medical advice from and expressed value in their adult children's opinions because of their English proficiency and health knowledge. This finding contradicts previous research findings that children/young adults do not participate in the health care decision-making processes of older Hmong adults.²⁸ Language barriers may account for this reliance on their children compared to English-proficient Hmong adults. Future research could explore Hmong families' navigation of this role reversal as another insight into acculturation into the American health care system. These cultural shifts in Hmong health care decision-making are similar to other immigrant groups acculturating into the dominant culture of their host country.^{28,29} Our findings highlight the importance of understanding and appreciating evolving cultural norms and including family members and friends during medical encounters, which could facilitate better health care-seeking behaviors in the LEP Hmong population.

This study has some limitations. First, because health care decision-making was not the larger study's main focus, we may not have fully captured all the conditions informing LEP Hmong participants in their health care decision-making processes. In addition, we were unable to explore the impact of acculturation, religion, and immigration on health care decision-making among Hmong participants because this study was focused on cancer screening. Because we used a convenience sample, there is some potential for bias to occur. Also, we were unable to explore situations where participants decided not to seek care. Lastly, because this study focused on LEP Hmong participants, our findings are applicable only to LEP patients. More research is needed in the area of medical anthropology to understand the shift and role of decision-making over time in the Hmong-American community.

CONCLUSIONS

We found that the process by which LEP Hmong adults decide when and from whom to seek advice is complex. They consult family, friends, and community, but whom they consult depended on the type of decision required: diagnostic testing, procedures, or high-risk surgeries. However, participants were more self-reliant if the treatment was time sensitive. These results suggest a shift regarding from whom medical advice was traditionally sought and have significant implications. Understanding the decision-making process among LEP Hmong can help clinicians provide more culturally competent care and develop strat-

egies to increase medical compliance, thereby reducing health disparities in the LEP Hmong population.

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