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Social-Cultural, Traditional Beliefs, and Health System Barriers of Hepatitis B Screening among Hmong Americans: A Case Study

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Abstract

Background—The Hmong experience a five-times higher incidence rate of liver cancer than non-Hispanic Whites and there is a low hepatitis B screening rate (24%) among Hmong adults compared to other Asian Americans. The purpose of this study was to examine the Hmong's perceptions on social-cultural determinants, traditional health beliefs, and health care system barriers that influenced community-based hepatitis B screening interventions.

Methods—A qualitative method was used, integrating a collective case study research design. In-depth interviews were used to collect data from 20 Hmong adults from the Greater Sacramento areas who participated in the Chen et al. (2013) study. A pattern matching analytic technique was used to analyze the data. The main core elements of Culture Care Theory were used to capture the key themes presented by the participants.

Results—Protecting a family's reputation; fear of doctors, medical procedures, and test results; lack of trust in medical doctors and medical care services; and using Hmong herbal medicines and practicing spiritual healing were identified as social-cultural and traditional health beliefs barriers to obtaining HBV screening. Health care costs, perceived discrimination, lack of transportation, linguistic discordance, and poor quality of care were identified as barriers to accessing high quality health care services and obtaining hepatitis B screening.

Conclusion—Providers, health policy makers, researchers, and community-based organizations will need to work together to develop intervention strategies to address the social-cultural, traditional health beliefs, and health care factors that influence obtaining hepatitis B screening in the Hmong community.

Keywords

Hmong or Hmong Americans; culture; hepatitis B; liver cancer; traditional beliefs

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INTRODUCTION

Hepatitis B infection is a global health issue. Over 1.34 million deaths were caused by viral hepatitis in 2015 worldwide, where approximately 257 million people were infected with chronic HBV, and the mortality rate from hepatitis has increased by 22% from 2000.[1] Although the incidence rate of acute HBV infection in the United States has decreased by 64% from 8,036 in 2000 to 2,895 in 2012[2], Asians and Pacific Islanders had the highest mortality rate for hepatitis B (2.7 deaths per 100,000 population).[2] Asian men have the highest incidence of liver cancer, double those among Non-Hispanic Whites (20.4 per 100,000 *vs.* 9.7 per 100,000).[3] Studies have indicated that Hmong Americans are disproportionally impacted by the hepatitis B infection and liver cancer when compared to Non-Hispanic Whites.[4,5]

There are limited studies that have been done to assess the Hmong Americans' knowledge, cultural and traditional health beliefs about HBV infection, as well as the challenges or barriers to getting screenings and vaccinations. One study conducted in Oregon reported that 96.4% of the Hmong research participants had heard of hepatitis B; fifty-three percent were screened, and 50% had been vaccinated.[6] Most of the Hmong people who were diagnosed with hepatitis B did not have a full understanding of the disease.[6]

In addition, there are fewer studies that have focused on the cancer rates, hepatitis B incidence and mortality rates among Hmong Americans. A study conducted in the San Joaquin Valley of California reported that 16.7% of the Hmong participants had presence of the surface antigen (HBsAg), an indicator of the chronic infection.[7] The study indicated that one out of every six Hmong appear to be infected with the hepatitis B virus. Another study found a prevalence rate of 3.41% among Hmong blood donors when compared with donors of all ethnicities at 0.06% rate.[8] The age-adjusted liver cancer incidence rate for Hmong males is $25.7/10^5$ compared to Non-Hispanic White males with an incidence rate of $3.7/10^5$ and $8.8/10^5$ for Hmong females compared to Non-Hispanic White females with an incidence rate of $1.5/10^5$.[5] Other investigators found a high proportional incidence ratio for liver cancer of 8.08 for the Hmong residing in Minnesota.[9] Another study reported that Hmong have the lowest median survival rate (only one month) among all California Asian American groups for hepatocellular carcinoma cases.[10] Overall, the Hmong experience a five-times higher incidence rate of liver cancer than Non-Hispanic Whites[4] and there is a low hepatitis B screening rate (24%) among Hmong adult participants in the Hmong community-based Hepatitis B Intervention for Hmong Adults Project.[4]

Background on the Hmong

The Hmong people immigrated to the U.S. as refugees at the end of the Vietnam-American War. The Hmong provided military support to the U.S. in Northern Laos. After the fall of Saigon in 1975, the majority of the Hmong people fled to the U.S.[11] The first wave of Hmong refugees have settled in the U.S. for over 40 years. The Hmong population in the U.S. was reported to be about 260,076 in 2010, a 175% increase from the year 1990 (94,439). Over 91,000 Hmong Americans reside in Californian followed by Minnesota (66,181) and Wisconsin (49,240).[12] In the State of California, Fresno (31,771) has the largest population of Hmong Americans followed by Sacramento (26,996).[12] Hmong Americans comprise 30 % of all Asian Americans in Sacramento and represent the second largest Asian American subgroup.[12] The Hmong in Sacramento have a high poverty rate (32.7%) when compared to the general population (9.5%); and about 51.7% of the Hmong in Sacramento have public health insurance.[12]

In the U.S., about 70 % of the Hmong still practice traditional animist, ancestor worship, and shamanism; while the other 30% have converted to Christianity.[13] Hmong animist tradition believes that all-natural things have spirits and they can influence a person's health.[14] There are ancestral spirits, spirits in nature, and house spirits. The Hmong practice ancestor worship and pay respect to their ancestors in the form of an offering, seeking protection and blessing for their family. The shamans maintain the communication between the living and the spiritual world.[14] Shamans perform rituals to determine the cause of sickness so that proper ritual ceremonies can be done to treat an illness.

Despite national health programs in the U.S. to eliminate the transmission of hepatitis B infection, Hmong continue to experience a higher rate of hepatitis B infections and a lower screening rate.[4–10,15] The purpose of this qualitative collective case study was to examine the Hmong's perceptions on social-cultural, traditional health beliefs, and health care system barriers that influence community-based hepatitis B screening interventions.

MATERIALS AND METHODS

We conducted a qualitative case study using a community-based participatory research (CBPR) approach to examine the Hmong's perceptions of social-cultural determinants, traditional health beliefs, and health care system barriers that influenced community-based hepatitis B screening interventions. The goals for case study designs are to explain, interpret, predict, and understand human behaviors. A collective case study was appropriate for this study as it provided an in-depth understanding of the cultural and system barriers experienced by Hmong adults when obtaining a hepatitis B screening. This study was framed using the Culture Care Theory (CCT).[16] The goal of the CCT is to explore the interrelationships between cultural care and professional care within diverse populations.

Community Collaboration

In 2006, Hmong Women's Heritage Association (HWHA) and the Hmong Cultural Center of Butte County (HCCBC) collaborated with the University of California, Davis (UCD) to implement the first hepatitis B intervention project focusing on promoting hepatitis B screenings among Hmong adults. It was a 5-year randomized controlled trial research project using a lay health worker intervention approach to support hepatitis B virus (HBV) testing by providing health education at home and patient navigation to 260 Hmong adults residing in the greater Sacramento area.[4] At the baseline screening interviews, 18% of the participants who were initially selected from each household reported having been serologically tested for hepatitis B. Based on this finding, the Hmong HBV screening rate appeared to be significantly lower when compared to Cambodian (45% male; 54% female), Chinese (48%), Koreans (56%), and Vietnamese (62%).[17–19] Though the lay health workers provided culturally and linguistically appropriate hepatitis B education, patient navigation, case management, and interpretation support, only 25 out of 105 individuals in the intervention group were tested. The Hmong hepatitis B intervention project demonstrated that there are significant social-cultural barriers within the Hmong community; therefore, in order to promote HBV screenings, further research was needed to better understand the cultural influences on screening practices among Hmong adults.

Data Collection

We collaborated with HWHA, HCCBC, and UC Davis to generate a list of 80 participants who were not tested for HBV in the Chen et al. study.[4] A purposeful sampling method was used to recruit participants from the Chen et al. study who were not tested for hepatitis B during the study period. We reviewed the participants' case files and recruited participants through phone interviews. The interviews took place either at the participant's home or at the HCCBC office from February to April of 2016.

The research instrument consisted of two parts: 1) orally administered questionnaire to collect demographic information and 2) a 60-minute in-depth interview using a semi-structured interview guide to collect data on how social-cultural, health beliefs, and health care system barriers influence hepatitis B screenings. Interview guides were developed and translated into Hmong by the first author. The interview guides were tested for validity with two male and two female Hmong lay health workers from HWHA and HCCBC. Two lay health workers were between the age of 18–40 years old and two were between the age of 41–55 years old. The lay health workers were credible sources because they were fluent in both English and Hmong, and they have over 10 years of experiences providing social and health education services to the Hmong community. The interview guide also was administered to two participants from the target populations for validity.

Interviews were conducted in the Hmong language and digitally recorded. The interview audios were transcribed into Hmong and then translated to English by the first author. The first author had over 20 years of experience in translating and interpreting in Hmong for the Hmong community and over 14 years of experiences in the area of research, community health education, and community outreach to reduce health inequities and disparities. In addition, the first author served as the Program Manager/Research Director for Hmong Women's Heritage Association, for the P01 "Liver Cancer Control Interventions for Hmong Adults" a collaborative effort with the University of California, Davis, San Francisco, and Los Angeles.[4] The first author is currently a Cultural and Linguistic Consultant for Health Net/Centene, and her roles are to develop strategies and policies to deliver cultural and linguistic services to Health Net/Centene's members.

Human Subject Protection

The IRB application (IRB ID 216987-5) to conduct the research was approved by the University of California, Davis on December 17, 2015 under No More than Minimal Risk and by the University of Phoenix IRB on December 31, 2015 under Exempt Review.

Analysis

The data review and analysis were done in conjunction with the data collection. The interview scripts were read and coded independently by two people, the first author and a colleague researcher. The first author and a colleague researcher met to discuss themes that did not fit under the identified categories, establishing new categories, if necessary. Findings also were verified by HCCBC. After 20 participants were interviewed data saturation was achieved. Participants' responses to social-cultural, religious, and health care systems barriers no longer provided new data, themes, and coding. Pattern-matching analytic technique was used to analyze the data. A pattern-matching analytic technique compares an empirically based pattern to the findings from a current study.[20,21] To capture the key themes presented by the participants, the main core elements of the Culture Care Theory (CCT) frameworks (kinship and social factors; cultural values and beliefs; and health care factors) were used.[22–23] Once the key themes were identified, they were categorized under the core concepts of the Culture Care theory. Interview transcripts were uploaded to the appropriate node created for each of the categories. Once the transcripts were uploaded, coding was used to categorize emerging themes and sub-themes into limited categories.

RESULTS

Participant Characteristics

We made phone calls to seventy participants. Forty-one of the participants' phone numbers were disconnected. Seven participants refused to participate in the study. Two participants were tested for HBV; therefore, were ineligible to participate in the study. Twenty participants out of the eighty individuals in the Chen et al. study who were in the intervention group and were not serologically tested for HBV during the study consented to take part in the study. Table 1 shows the participants' characteristics. Sixty percent were female and over half of the participants were between the ages of 41 and 64 years old. Ninety-five percent of the participants were born outside of the U.S., and over half of the participants had the equivalent of a high school education or lower, and the majority were married.

The data collected were organized into the following three categories: social-cultural factors, traditional beliefs factors, and health care system factors. The social-cultural factors and health care system factors were identified as the two categories with the most coding. Table 2 shows the themes and subthemes emerged under the Culture Care Theory framework.

Social-Cultural Factors

The lack of family support; the man of the household making health decisions for the family; protecting a family's reputation (by not getting health screening); fear of doctors and test results; lack of trust in medical doctors and medical care services were identified as cultural barriers to obtaining HBV screening and seeking health care services. The following are selected excerpts from participants sharing social-cultural barriers.

> "I personally think that the family is trying to protect their family due to prejudice or discrimination from other families, especially if they have sons and daughters. They don't want other families to not want to marry into their family."

> "Our Hmong, we would feel ashamed. For example, if I have hepatitis B, people would consider me as an unclean person. So, there is prejudice. I think in our community people don't want to be known as having bad genes…No one wants to be known to have any kind of illness. It is all comes back to shame."

Most of the participants are afraid to go see the doctors and they also fear their medical test results. The following are selected excerpts from participants.

> "We have a lot of fear when we go see the doctor because there are some good and some bad doctors. For example, some people's health conditions are not serious, but doctors make the person sicker. For some people, they live normal, but when they go see the doctor, they don't come back (meaning they die). There were a few cases like these that have occurred, so we have fear and do not want to go see the doctor."

> "I had a son who was attending Chico State and the doctor said there was a problem with his liver. The doctor insisted to do a biopsy. After the biopsy, they said my son only had a few months to live. This is something that we Hmong people fear the most."

Traditional Health Beliefs and Healing Factors

Most of the participants (n= 11) believed that most of the illnesses had spiritual causes. If there was a health condition, they would call on the Shamans to *ua neeb*, (perform a spiritual healing). Participants over the age of 50 voiced that they relied on spiritual healing, so they did not go see the doctor and seek health care screenings. A majority of the participants expressed that the hepatitis B screening procedure went against the Hmong belief on health and the way of life. The following are selected excerpts from participants explaining Hmong health beliefs.

> "When someone is not doing well, we ask our ancestors for blessings. Another is to call the Shaman to perform rituals to bring our wandering spirits back to our bodies. For example, if we were diagnosed with hepatitis B, the doctor may help take care of the virus and the physical problem, but we still need our spirits to stay with our bodies to help us heal. What Hmong people are scared of the most is when our spirits refuse to come back."

> "Hmong have a saying that, *txhob moog cem pobzeb tsaam pum tsaub tsis*. (Direct translation "do not lift the rock, or you will see a crab.") This means that if you don't have any symptom, you should not go ask the doctor for screening. If you go ask the doctor, they will tell you that you have this and that health problem."

The older participants who practiced the traditional religion (ancestral worship) often seek spiritual and herbal medicinal healings before seeking care from a doctor. Going to the doctor was secondary to seeking traditional healings.

> "If the health problem is not able to be cured from traditional healings, then we will seek medical care. Medical care service is only used when everyone says that there is no other alternative. If it is a matter of life or death, then we will go see the doctors or hospitals."

> "We are not use to receiving care from doctors. We normally use herbal medicines and perform a spiritual healing. When we know that we are going to die if we do not seek medical care, then we will go to see the doctor."

Barriers to Health Care Services

Health care cost, perceived discrimination, lack of transportation, linguistic discordance, and poor quality of care were identified as barriers to hepatitis B screening and accessing quality health care services. Most of the participants (n= 16) have Medicaid as their health insurance. A few of the participants (n= 7) have experienced discrimination and unprofessional behaviors by the doctors. The following are selected excerpts from participants.

> "Not having medical insurance is very difficult for us. We may be able to afford to pay for the screening, but if we were diagnosed with hepatitis B, we will not able to pay for the treatment. Knowing that you have the disease and not being able to receive treatment is very stressful. We rather not know."

> "We have seen doctors who speak very negative about us and have discriminated against us. Doctors would say, 'If you don't take this medication, you will die in the next few days.' Phrases such as this make Hmong patients lose hope and not want to go see the doctor anymore."

> "…a few years ago, I had really bad shoulder pain and they sent me to see a specialist. The doctor was very rude and did not have good communication. After this experience, I just didn't go to see the doctor anymore…He thought that I had faked my pain, so that I can apply for SSI…Ever since this experience, I really don't like to go see doctors."

Linguistic discordance was identified as a major barrier to accessing health care services. Most of the participants (n=12) depended on their children and relatives to interpret for them. Below is a selected excerpt from one of the participants.

> "It is difficult for me if the staff in the doctor's office does not speak my language. My two older kids are now working, so I don't have anyone that can interpret for me. For example, the place where they draw blood, they don't have an interpreter. Sometimes, I have to reschedule my appointment because I can't find anyone to interpret for me. There were a few times that I had to take my twelve-year old to interpret for me."

DISCUSSION

Implications

Social-cultural factors are important influences that affect how people view their health issues and decide whether to obtain health screenings.[23–25] In a traditional Hmong family, the father usually makes decisions related to any immediate family issues.[11] The in-depth interviews revealed that most of the participants asked for permission from either their husband or father prior to obtaining a health screening. These are important indicators that community-based hepatitis B screening interventions may need to include the person who makes health decisions for the family.

In-depth interviews revealed that most Hmong did not want to get screened for hepatitis B because they did not want to be known as an unclean person and having a bad gene. In addition, participants felt that there would be discrimination within the Hmong families. For example, one participant feared that other families would not want to marry into their family if they were diagnosed with hepatitis B. Protecting a family's reputation is a cultural barrier to hepatitis B screening, which is also seen in the Turkish and other Asian cultures.[24–26]

Distrust and unfamiliarity with Western medicine were identified by the majority of the participants as other barriers to getting tested for hepatitis B. A study focused on barriers to cancer screening among Hmong Americans found that the Hmong had experienced many negative health care services in the U.S. that led the Hmong community to not trust and have a fear of going to see the doctors.[27] Our study indicated that there is a need for more education on preventive care and health screenings in the Hmong community. In addition, cultural competency trainings should be offered to physicians as well as medical students who provide care for the Hmong community.

Strengths and Limitation

This study was a follow up study to the first randomized, controlled, longitudinal study to promote hepatitis B screening for Hmong Americans.[4] The study had several strengths. First, we collaborated with the original partners in the Chen et al. study, which included the University of California, Davis, Hmong Women's Heritage Associates, and Hmong Cultural Center of Butte County. Secondly, the interview guides were translated into Hmong by the first author and were reviewed as well as approved by the Community Board Advisory Committee at the HWHA. Thirdly, our study was the first to use the Cultural Care Theory to examine the Hmong's perceptions on social-cultural determinants, traditional health beliefs, and health care system barriers that influenced community-based hepatitis B screening interventions. However, one of the limitations was that we focused on hepatitis B services for the Hmong community and the findings may not be generalizable to the general population. We recruited participants from the community-based Hepatitis B Intervention for Hmong Adult project completed in September of 2011[4]; therefore, some of participants have moved out of the area or have changed their phone numbers.

Future Study

Our study was the first to examine the cultural-social, traditional health beliefs, and religious and health care system barriers to obtaining a hepatitis B screening for the Hmong. The participants were limited to the Hmong participants who were randomized in the intervention group in Chen et al. study and most of them were not community leaders, spiritual healers, and had no educational background. Future studies should target: the person who makes health decisions for the family, spiritual healers, community leaders, and Hmong educators. This would allow them to examine strategies on how to overcome the identified cultural-social, religious, traditional health beliefs, and health care system barriers.

Conclusion

Our study indicated that Hmong Americans have many social-cultural, traditional health beliefs, and health care barriers to obtaining hepatitis B testing. In order to reduce some of these barriers, there is a need for collaboration between clan leaders, physicians, community-based organizations, and county health programs to create culturally appropriate hepatitis B intervention strategies and deliver culturally congruent care services. Culturally congruent care is defined as "actions and decisions that fit with people's ways of life to support satisfying health care and promote well-being or dignified death.[16(10)]" There are three actions and decision modes: "culture care preservation and/or maintenance; culture care accommodation and/or negotiation; and culture care repatterning and/or restructuring.[16(192)]" These actions and decisions guide the establishment of congruent care.

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TABLE 1

PARTICIPANT CHARATERISTICS

	N=20		
Characteristic	**Label**	**N**	**%**
Age (year)			
	18–40	9	45
	41–64	11	55
Gender			
	Male	8	40
	Female	12	60
Country of Birth			
	Laos	16	80
	Thailand	3	15
	USA	1	5
Marital Status			
	Currently Married	13	65
	Widowed	5	25
	Separated	1	05
	Single, never been married	1	05
Highest Level of Education Completed			
	No Formal Education	12	60
	Elementary School	2	10
	Some High School or Vocational School	1	05
	High School Graduate	2	10
	College Graduate	3	15
Speak English			
	Well	2	10
	No So Well	5	25
	Poorly	4	20
	Not at All	9	45
Employment Status			
	Employed Full Time	3	15
	Employed Part Time	2	10
	Unemployed	10	50
	Retired	5	25
Health Insurance			
	Medicare/MediCal	16	80
	Private	4	20
Primary Care Doctor			
	Yes	20	100
	No	0	0

Table 2

CATEGORIES, THEMES, AND SUBTHEMES EMGERGED UNDER THE CULTURAL CARE THEORY

Category	Themes	Subthemes
Social-cultural factors	Care supporters	
	Cultural barriers	
		Family reputation
		Fear of doctors, medical procedures, and test results
		Lack of trust in medical doctors and medical care services
	Health decision maker	
Traditional health belief & healing factors	Cultural belief on cause of illness, values, and lifeways	
	Spiritual healing and Hmong herbal medicines	
Health care system factors	Barriers to health care services	Health care cost Perceived discrimination Lack of transportation Linguistic discordance Poor quality of care