

AN ABSTRACT OF THE THESIS OF

Claire E. Sahlberg for the degree of Honors Baccalaureate of Science in Biology
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Breast and Cervical Cancer Screenings in the Hmong population of Oregon

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Sheryl Thorburn

Hmong women in the United States have been shown to have low rates of breast and cervical cancer screening. The reasons behind these statistics are unclear. This study explored possible health literacy factors that may be affecting low screening rates for breast and cervical cancer in this population. A transcription of seventeen key informant interviews with prominent Hmong community members in Oregon was analyzed using content analysis. The participants' responses reflected their beliefs about the entire Hmong community in Oregon. Several main themes emerged. First, key informants reported that the majority of Hmong use their friends and family as sources for general medical information, as well as information specific to breast and cervical cancer. Secondly, Hmong individuals are reluctant to talk about breast and cervical cancer due to cultural values. Lastly, many Hmong may be unaware of the importance of breast and cervical cancer screenings. This study provides insight into an underdeveloped research area. These findings will be of use to future research that examines aspects of Hmong breast and cervical cancer screening in greater depth.

Key Words: Health Literacy, Hmong, Breast and Cervical Cancer

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Exploring Health Literacy Factors That May Affect Breast and Cervical Cancer
Screenings in the Hmong population of Oregon

by

Claire E. Sahlberg

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I understand that my project will become part of the permanent collection of Oregon State University, University Honors College. My signature below authorizes release of my project to any reader upon request.

Claire E. Sahlberg, Author

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TABLE OF CONTENTS

INTRODUCTION TO THE HMONG PEOPLE	1
HMONG CULTURE AND MEDICAL BELIEFS	3
<i>Family and Societal Structure</i>	3
<i>Belief System</i>	3
<i>Traditional Medicine</i>	4
LANGUAGE AND LITERACY OF THE HMONG	5
DEFINING HEALTH LITERACY	6
METHODS	8
THE HMONG BREAST AND CERVICAL CANCER PROJECT.....	8
ANALYSIS OF KEY INFORMANT INTERVIEWS.....	10
<i>Creation of the Codebook</i>	10
<i>The Coding Process</i>	11
RESULTS	12
HMONG POPULATION LANGUAGE, COMPREHENSION, AND LITERACY	12
SOURCES OF INFORMATION	14
<i>General Health Topics</i>	15
<i>Types of Information</i>	17
<i>Breast and Cervical Cancer; Cervical Cancer Screening</i>	17
BARRIERS	18
INFORMATION GATHERING.....	18
BREAST CANCER INFORMATION AND BREAST CANCER SCREENING	20
CERVICAL CANCER INFORMATION AND CERVICAL CANCER SCREENING	21
LANGUAGE AND LITERACY BARRIERS TO HEALTHCARE ACCESS	22
DISCUSSION	24
LIMITATIONS OF THE STUDY	26
RECOMMENDATIONS FOR FUTURE RESEARCH.....	27
CONCLUSION	28
BIBLIOGRAPHY	29

LIST OF TABLES

TABLE 1: HEALTH LITERACY QUESTIONS FROM THE KEY INFORMANT INTERVIEW GUIDE .	9
TABLE 2: POPULATION LANGUAGE, COMPREHENSION AND LITERACY PROFICIENCY AS INDICATED BY KEY INFORMANTS	13

Introduction to the Hmong People

The early history of the Hmong people remains hard to discern, but the summary by Duffy, Harmon, Ranard and Thao (2004) attempts to provide a clearer understanding of the past. The Hmong people of Southeast Asia likely originated from China over 2,000 years ago. Folktales of the Hmong people, which include allusions to ice and snow, have indicated possibly ancestry in Siberia (Duffy et al., 2004). Although difficult to trace, Duffy et al. (2004) explain that Hmong origins likely stem from southern China as evidenced by similarities in social organization. Mai Na Mm Lee (1998) states that China recognizes the Hmong people as the ethnic group Miao; this designation represents one of the 55 official ethnic groups recognized by the Chinese government. Today, the designation “Miao” or “Meo” is considered derogatory by the Hmong people because of its similarity to the Hmong word for “cat” and is rarely used outside of Southeast Asia.

Lee and Tap (2010) further explain the Chinese and Hmong have a bloody and violent relationship between the Hmong and Chinese. As a result of the significant cultural differences, the Hmong were considered barbaric by the Chinese. Historically, the Chinese government has accused Hmong people of hindering expansionism as early as the twenty-seventh century B.C (Lee & Tapp, 2010). As conflict continued, the Hmong were driven farther south and higher into the mountains around the sixth century. Hmong still residing in China can be found at these high altitudes. Conflict also forced many Hmong to begin emigrating to Laos and other Southeast Asian countries as early as 1800 (Lee & Tapp, 2010).

According to Duffy et al. (2004), the Hmong faced harsh rule under French colonial command in Laos. In 1918, driven by forced labor and extortion of taxation, an uprising known as the *Guerre du Fou* (“*Madman’s War*”) began. After two years of fighting the Hmong were finally allowed a measure of autonomy. Encouraged by the French government, the Hmong farmers began to cultivate opium, one of the major Laotian cash crops (Duffy, Harmon, Ranard, & Thao, 2004).

In the early 1960s, the Hmong figured prominently in the “Secret War” in Laos. Duffy et al. (2004) estimate that almost sixty percent of men from the Hmong population were recruited by the CIA to fight the communist North Vietnamese Army. Although initially used for intelligence gathering, the Hmong eventually fought in the ground war, rescued downed pilots, and flew in combat missions. Motives for participating in the war vary, but Duffy et al. (2004) suggest they may be attributed to anticommunism and fear of Vietnamese rule. More importantly, the Hmong believed that the United States would support the Hmong people during and after the Laos war even if Laos surrendered to communism (Duffy et al., 2004).

The Hmong sustained heavy casualties during the Secret War, losing an estimated 30,000 people from their population. Almost thirty percent of the Hmong became refugees as well (Duffy et al, 2004). Lee and Tapp (2010) suggest that the resettlement camps caused a severe loss off self-sufficiency for the first time in Hmong history. In these camps the Hmong interacted with many other ethnic groups, and encountered modern technology and a market economy. Once the war in Laos finally ended in 1973, many Hmong fled the country to bordering nations such as Thailand. Beginning in 1975, they entered the United States (Duffy et al., 2004). The U.S. Census Bureau (2010) states that

approximately 250,000 people of Hmong descent live in the United States today. They are most densely populated in California, Minnesota, and Wisconsin, but can be found throughout the entire country (Hmong National Development Inc.; Hmong Cultural and Resource Center, 2010). Oregon sustains a Hmong population of around 3,000, with the majority of the population Portland, Oregon (U.S. Census Bureau, 2010).

Hmong Culture and Medical Beliefs

The following sections briefly examine aspects of Hmong culture.

Family and Societal Structure

Traditional Hmong culture centers on the male, as noted by Kou Yang (1997). He states that “From childhood to old age, Hmong men assume many superior roles, and are perceived by family and society to be the breadwinners, protectors, leaders, and pillars of the family” (Yang, 1997, p. 3).

As described by McKinnis (1991), the basic societal units are the eighteen clans. All eighteen clans are present in the United States. Each clan has a leader with a large amount of responsibility who assists in problem solving and decision making. As mentioned previously, the clans are patriarchal. Only the men work and women are generally subordinate (McKinnis, 1991).

Belief System

A report compiled by the Center for Disease Control and Prevention (CDC) describes aspects of Hmong cultural beliefs (2008). The Hmong people are traditionally animist, believing in the spiritual world and the importance of living in harmony with nature. They believe the spirits inhabiting this world interact with humans, and represent both

good and evil forces. Traditional Hmong also believe that all individuals and natural objects have multiple souls, and soul-loss is a common cause of illness (Center for Disease Control and Prevention, 2008). By offending a spirit, a person risked retribution from a spirit in the form of illness and disease. Christine Owens (2007) explains that Hmong engage in rituals, animal sacrifice, and the use of amulets and tokens to prevent or reverse this soul-loss.

Traditional Medicine

In traditional Hmong society, the shaman is the center of the healing practice. As described by Plotnikoff, Numrich, Wu, Yang, and Xiong (2002), the shaman “diagnose[s] and treat[s] spiritual illness...receives all knowledge and wisdom for this role from the spiritual dimension...conducts healing ceremonies....and serves people of all ages and both genders with wide-ranging symptoms perceived as spiritual illnesses” (p. 30). For the Hmong people, healing is firmly intertwined with their spiritual beliefs. Plotnikoff et al. (2002) also explain that the Hmong believe that the disruption of “souls, spirits, and persons” can cause medical issues and disease, and that Hmong medical beliefs do not usually involve any chronic or long-term medical issues.

Lisa Capps (1999) discusses the many Hmong who came to the United States and converted to Christianity. Some American Hmong retained traditional beliefs, and merged cultural practices with Christian tradition. For example, the disease known as fright illness (*ceeb*) commonly affects Hmong children, and it is traditionally blamed on spirits, ghosts, or inauspicious omens (Capps, 1999). However, even Protestant Hmong Christians, according to Capps’ study, used shamans and traditional healers to combat *ceeb* (1999).

Language and Literacy of the Hmong

There are multiple Hmong dialects representing many Hmong people. *Hmong Der*, or White Hmong, and *Mong Leng*, or Green Hmong, represent two distinct ethnic groups. Lee and Tap (2008) explain the intricacies associated with each group, as each group maintains its own cultures and customs. Controversy has arisen over whether these two groups should both be included under the Hmong designation; however, in many areas the groups frequently interact. To incorporate this exchange, Lee and Tapp (2008) suggested that the Hmong title represent both *Hmong Der* and *Mong Leng* in order to accommodate the globalization of the two groups.

The Hmong have a traditionally oral culture. As detailed by Lee and Tapp (2010), the Hmong highly value their oral language system. Their folk lore tells of the loss of their original writing system; historical tension with the literate Chinese majority has justified their oral culture. It was not until the 1950s, as noted by Xee Yang (Hmong Language, n.d.) that French missionaries developed a written Hmong based on English, German, and French characters. This alphabet, known as the RPA (Romanized Popular Alphabet), remains the most widely used method for writing in the Hmong language; however, many Hmong still remain illiterate in their language. A study researching Hmong diabetes knowledge reported that most Hmong surveyed could not read printed materials written in Hmong (Perez & Cha, 2007). Other studies have suggested similar findings (Tanjasi, et al., 2001).

The transition to English for Hmong immigrants to the United States remains challenging. According to the U.S. Census Bureau (2012), 90% of the Hmong population speaks a language other than English at home. Additionally, roughly half indicated that English was spoken less than “very well”. The lack of strong language skills has contributed to the English literacy difficulties.

The 2010 U.S. Census (2012) reported that around 45% of the Hmong-American population is under the age of eighteen. Only 25% of the entire U.S. population is under eighteen, demonstrating a drastic difference in the demographic. Several studies have assessed the language and literacy of the younger generation. In a study assessing factors affecting Hmong-American students in public school, Christopher Vang (2005) states that low literacy levels (as many as 85% of Hmong students are classified as Limited English Proficient) result in lower academic achievement. Cultural and language differences affect Hmong-Americans significantly, and literacy issues extend through the generations.

Defining Health Literacy

The U.S. Office of Disease Prevention and Health Promotion (2008) defines health literacy as “the ability to obtain, process, and understand basic health information and services to make appropriate health decisions.” Examples of health literacy include reading health-related materials, filling prescriptions, understanding health insurance forms, taking children to get vaccinated, or navigating Medicare and Medicaid (Kutner, Greenberg, Jin, Paulsen, 2003).

A study by the U.S. Department of Education (2003) found that only 12% of the nation's population could be considered "proficient" in health literacy, as assessed by health literacy related tasks. A proficient health literacy score indicated the ability to read and interpret complex texts, synthesize pieces of information from multiple texts, and solving multi-step quantitative problems (Kutner, Greenberg, Jin, Paulsen, 2003). The proficiency level is even lower for non-native English speakers.

A comprehensive review of health literacy literature summarizes the concept of health literacy and its main components: reading skills, numeracy skills, comprehension, using information to make health-care decisions, and being a successful health-care consumer (Speros, 2005).

Health Literacy and Disease

Some studies have already examined the link between health literacy and disease. For example, Lindau et al. (2002) researched the relationship between cervical cancer and health literacy abilities in 529 patients and found that health literacy was the best predictor of screening knowledge. A study by Sarkar et al. (2010) examined the relationship between health literacy and patient access to an online system in 14,102 participants. Those with the lowest perceived health literacy scores were found to be the least likely to use the online system. Additionally, Davis et al. (2001) suggested that low health literacy skills may be an overlooked factor in colorectal screening using small focus groups of 20 individuals. Many of these findings highlight the need for a closer examination of health literacy as it relates to specific groups, such as the Hmong population in Oregon.

Methods

This project involves the analysis of Key Informant interview data from the Hmong Breast and Cervical Cancer Project. In the next section, the Project is described. The sections following relate to the analysis of the Key Informant interviews.

The Hmong Breast and Cervical Cancer Project

The Hmong Breast and Cervical Cancer Project, funded by the National Cancer Institute, was an exploratory project aimed at identifying social, cultural, and health care system factors that affect Hmong women's breast and cervical cancer screening behavior in Oregon. Previous studies have indicated that Hmong women in the United States have low breast and cervical cancer screening rates (Kagawa-Singer & Pourat, 2000).

Additionally, they have a higher mortality rate than non-Hispanic whites (Chen, 2005).

This study aimed to understand factors that may influence breast and cervical cancer screening behavior. The Principal Investigator of this project is Dr. Sheryl Thorburn, PhD, MPH. Jennifer Kue, PhD, co-investigator and Karen Keon, MPH, research assistant also contributed extensively to the project.

The research team began the investigative study by conducting seventeen Key Informant interviews. In order to be eligible for the interviews, all participants had to be 18 years or older. Key Informants were members of the Community Advisory Board or other knowledgeable Hmong persons. The Community Advisory Board consisted of local Hmong leaders, community organizers, and other persons in health care related fields; they also represented five of the Hmong clans.

The Key Informant interviews were designed to assist in the creation of the interview guides for the In-Depth Interviews to be conducted in a subsequent phase of the project. All data were collected between July and August of 2009 by two investigators. Both males and females were interviewed during this process, and almost all interviews were conducted in English. Transcripts were created using audio recordings of the interviews for future analysis. The interviews used a semi-structured guide that dealt with beliefs about health care, health literacy, other cancers, Hmong population descriptions, and barriers to health care. Questions from the interview guide ranged from “When you think about Hmong people in Oregon, how much do you think they experience discrimination when getting health care?” to “What aspects of the health care system are barriers to screening for Hmong women?”, and “What do you think will be important things for us to tell potential participants in order to encourage participation?” The questions relating to health literacy are detailed in Table 1. Each question also contained several follow up probes.

Health Literacy Questions
Thinking about the Hmong women in this community... What do they usually do if they want to learn more about a health topic?
How much do Hmong women turn to other women for information? Why? Why not?
What sorts of things might stop Hmong women from seeking information about a health issue? Why?
Who would a Hmong woman turn to if she wanted information about breast cancer? Cervical cancer?
What sorts of things might stop Hmong women from seeking out information about breast cancer? Cervical cancer?
How does language or literacy pose challenges to accessing or using the health care system for Hmong women?
In what ways does language or literacy make it more or less difficult for women to get screened for breast or cervical cancer?

Table 1: Health Literacy Questions from the Key Informant Interview Guide

The interview guide from the Key Informant interviews assisted in the creating the in-depth interview guide, used in the second phase of the project. The second phase involved interviewing 84 Hmong women and men living in Oregon, using information gleaned from the Key Informant interviews. Those data are not included in this analysis.

Analysis of Key Informant Interviews

As stated previously, the data for this project came from the Key Informant Interviews of the Hmong Breast and Cervical Cancer Project. In total I worked with seventeen interviews, seven women and ten men. Because the focus of this project was on health literacy, I only used the sections of the interview relating to health literacy.

To assess the data from the interviews, qualitative content analysis was used. Content analysis tries “to attain a condensed and broad description of the phenomenon, and the outcome of the analysis is concepts or categories describing the phenomenon.” (Eto & Kyngäs, 2008). According to Krippendorff, the goal of content analysis is to make plausible, repeatable inferences from a given set of text (2004); the data analyzed in this research consisted of transcribed interviews.

Creation of the Codebook

The process began by creating a codebook. As described by Strauss and Corbin (1990), codes are developed from a variety of sources and ideas. They may “come from a pool of concepts that you already have from your disciplinary and profession reading”, or they might be “words and phrases used by the informants themselves” (p. 68-69). Initially, I scanned the interviews for recurring responses or topics from the participants. After completion, I began creating codes based on my expectations of the data. These included

codes like “Barriers to Screening”, “Information Gathering”, and “Types of Information Gathered.” My goal was to establish an overall direction before I created more detailed categories. I then resumed working with the interviews. Moving line by line through the transcriptions, I used both the interview questions and the responses to generate codes and sub-codes. As noted by Strauss and Corbin (1990), this is only one of the variations of open coding, in addition to paragraph and whole document analyses. While coding, it is imperative the codes represent the original research question in order for an accurate analysis to occur (Duncan, 1989). Codes I created ranged from emotional responses, such as “Pride”, to “Language Barriers” and “Transportation Issues”. Although the focus of this study was on health literacy, the interviewees often elaborated on other points. I tried to encompass all thematic aspects of the interviews while still focusing on the health literacy component. Including all these ideas allowed for the great amount of data to be coded; however, I was wary of being too specific in my codes for fear of limiting possible inferences and interpretations.

The first set of interview questions dealt with numerical responses; these questions were ignored for the purpose of the codebook.

The Coding Process

Today, many studies utilize computer software to analyze textual data (MacQueen & Milstein, 1999). For the purposes of this study, all coding was done by hand.

The process of coding allowed me to separate and categorize the large amounts of information present in the interviews. Working line by line, I assigned the interviewee’s responses to a code. In some instances, more than one code was assigned to a particular

sentence or thought. I continued this process throughout all seventeen interviews. Some sections of text were not assigned codes, because they did not contain any data that fit into the codebook. I modified the codebook several times to reflect ideas and themes missed in previous readings of the text. Areas of the text were also highlighted; these indicated particularly noteworthy responses or illustrative quotes.

Results

The following sections present the results of the content analysis, and describe the major themes found in the health literacy portion of the Key Informant interviews.

Hmong Population Language, Comprehension, and Literacy

The questions in this section of the interview referred to the percentage of the Hmong population in Oregon that could understand, read, and write in both Hmong and English according to the Key Informants. Responses were categorized as either *Yes* or *No*, with *Yes* indicating proficiency (50% or more of the population) for Speaking English, Understanding English, and Reading English. Additionally, the category *some* was created when no percentage was given, but proficiency of the population was implied in the context of the interview. Lastly, the category *unknown* indicated the participant was unsure of the percentage and/or proficiency of the Hmong population in Oregon. This same categorization was applied to the questions that dealt with Speaking Hmong and Reading Hmong. Table 2 below summarizes the responses for all seventeen interviews.

Interview	Population Speaks English	Population Understands English	Population Reads English	Population Speaks Hmong	Population Reads Hmong
1	Yes	Yes	Yes	Some	No
2	Some	N/A	No	Yes	Yes
3	No	N/A	No	Yes	No
4	Yes	Some	No	Yes	Some
5	Yes	Yes	Yes	Some	No
6	Yes	Yes	Unknown	Yes	No
7	Yes	Yes	Yes	Yes	Yes
8	Yes	Yes	Some	Some	No
9	Yes	Yes	Some	Yes	No
10	Yes	No	No	Yes	No
11	Yes	Yes	Yes	Yes	Yes
12	Yes	Yes	Yes	Yes	No
13	Yes	Some	Yes	Yes	Yes
14	Yes	Yes	Some	Some	No
15	Some	Some	Some	Yes	No
16	Yes	Yes	Yes	Yes	No
17	No	No	No	Yes	No

Table 2: Population Language, Comprehension and Literacy Proficiency as indicated by Key Informants

Almost all of the Key Informants indicated that they believed the population spoke English proficiently. In some instances it depended on the age group. Many believed the younger Hmong population spoke English fluently and the older Hmong population spoke less English, as demonstrated below:

The older generation like grandmothers, very few speak- And then, there's people even my generation, you know, like in their forties, even those people they may be proficient in English for day-to-day, um, you know, conversation, and then, interaction...And even the younger people, the younger people may not have as much problems, you know, with the, uh, ability to access information and to research stuff. – Male

The comprehension and understanding of English was somewhat less, but 13 of the participants still indicated that the Hmong population mostly understood English.

I would say a pretty good percentage- I mean, I mean if they don't speak English, they would UNDERstand it...they would understand it enough to know what you're saying but may not be able to respond back, I would say most people...do speak some kind of English. – Female

When asked about speaking Hmong, all the Key Informants indicated that in general most members of the population speak Hmong proficiently. If the participant stated a lower percentage, it was because they believed some of the younger generation may not be as fluent. In contrast, the majority of Key Informants indicated that most of the population could not read Hmong. Because their culture has traditionally been oral, this may account for low levels of Hmong literacy. The quote below exemplifies this perception:

Reading Hmong is a myth. It's only a very small percentage, kay. Reading Hmong is a very small percentage. That's why a lot of time they ask me to do...Hmong translation. Uh I feel like maybe it's better to setup a section, then I go give them a talk for the whole afternoon, instead of, doing the flyer...they would not read it. – Male

Sources of Information

The participants were asked where they went for information about general health topics, breast cancer, and cervical cancer. They were also asked about sources of information

that they trusted, and how the responses differed between males and females. The following section summarizes the responses to these questions.

General Health Topics

Key Informants indicated that women most often looked for information from their peers, friends, and social circles, especially through their church. They believed women almost always spoke with other women, unless speaking with a family member such as their husband. One woman explains:

Talk to their friend and then get in touch with the resource or someone that they know and they trust. I don't think that a Hmong woman will just come in to your office and said, 'Tell me about this problem and issue'. They'd rather go and talk to someone that they trust and they say, 'You know, I think I have this problem'.

– Female

Some Key Informants also indicated that women would talk to their provider.

They would probably go to their providers if they are young enough to, to be open to, to go and see the provider. Um, older woman would probably seek, you know, other woman within the, the family. Uh, woman who are –woman who do go to church, probably, would have more resources. – Male

Other ways of information gathering included speaking to elders in the community, talking to other family members, and asking other types of medical providers.

The majority of Key Informants indicated that men looked to other men for information about health topics. They almost never ask Hmong women for information, unless it is

their wife. Occasionally, participants responded that men might use the Internet to access information. For example:

I think Hmong men are very reserved about health care topics. Um, I think they would probably research themselves....I think they're not as, um, open to discuss it with other people...depending on the situation- I think they would talk to their friends or their brothers. – Female

A major theme about information gathering was the difference between the older and younger generations. Key Informants spoke about pride, education, and traditional beliefs as reasons for the difference in approach. Older Hmong might to be more “shy” and most of the Key Informants believed the older generation would be less likely to talk to the opposite gender. One woman stated:

I think that the younger um generation is more open in speaking to the women....be able to speak to them and relate a little bit more- rather than the older men. The older men tend to not even really believe that the woman will know the problem. The younger one will respect more and be more open to speaking to other people. – Female

Additionally, Key Informants believed the younger generation had an easier time navigating the Internet and using other resources. It was perceived that older Hmong relied on word of mouth, while the younger generation could look for information themselves.

With the younger ones, I- what I've seen is we're very in tune to, to what everyone else knows. We can, we can go get the information that anyone else gets

their hands on. Uh, through the doctor, through literature, through the Internet.

Uh, the older generation, it's all through word of mouth. – Male

Types of Information

One of the questions in the interview guide asked about the types of information that Hmong women would look for when searching for information. There was very little consensus, but several participants stated that the population just wanted general medical advice and understanding. A Key Informant answered:

They would ask about what the knowledge is, what they know about the disease.

Uh, some of the risk, what could they do, um, what kind of medication can help them with that disease process...with the disease. – Female

Additionally, participants thought women wanted stories about past experiences when talking to their friends.

Breast and Cervical Cancer; Breast and Cervical Cancer Screening

When looking for information about breast and cervical cancer, interviewees most often stated that women would either talk to their friends or talk to their provider. This man explains:

It's more likely um some of her female friend or relative probably have that experience or knowledge and will turn to them first. And- and or uh right now I think...there's only one Hmong doctor in town. Uh they probably will talk to their friends, and their friends will talk to somebody else- and then they will, by the time they get there will be second or third person. –Male

However, a major theme was that women would not ask anyone about breast and cervical cancer, including screening procedures.

I think the people don't ask about anything like that, no...because this kinda thing they don't have so much experience...they are not familiar with the thing, so they just, uh, don't feel like they have one or they need to check out or whatever. They don't- they won't ask anything. – Male

A few participants said they thought women could ask their provider about cervical cancer screening.

Yeah I- I think they- they can ask about the screening. They probably just uh, they probably feel freer to ask for screening because that- they still have the choice of whether to participate or not to participate. – Male

Barriers

The Key Informants were asked about factors that would prevent the Hmong population, especially women, from seeking out information about general health topics, breast and cervical cancer, and breast and cervical cancer screening. The major themes from these questions, as well as other responses relating to it, are discussed below.

Information Gathering

A major theme that emerged was the concept of a topic being too “personal” to be discussed. Most Key Informants spoke about the reluctance of the Hmong population to seek information about health issues, even if the issue was not considered taboo. For example:

Yeah personal or in uh personal things but yeah that's what I'm talking about I know that Hmong are if...if personal problem or personal issue or you know- they might not go. – Male

Other themes brought up relating to this included the importance of privacy, dignity, and being too shy or embarrassed to ask for information. A man notes:

Personal Dignity...very personal issue- very guarded issues. Uh, Hmong is, um Hmong community is very small. It's, you know, everyone knows everybody. So, it's not- you know, especially, you have some kind of a personal health issue like that, and they're very guarded. – Male

Another theme that was alluded to often was the idea of a reactive mentality. The Key Informants tended to think that the Hmong population would only seek information about a health topic after they were experiencing problems. An astute observation by one of the following Key Informants is described below:

And in these day we all will try to learn the word of prevention. My population and my people, we don't have the word of prevention is not really an active word that we use...put it in another term that we not really proactive, we only react...and so once that we, once that someone have problem then the whole community sad about it, angry about it, frustrated about it and we never really have anything to really look at it and say, 'what can we do to prevent so that it will not happen again?- Or when it over and then the mistrust coming in to place.
– Female

Several of the Key Informants mentioned that time might be a factor for seeking out information. These participants mentioned that work and the stress of children made health a lower priority. One woman said, “I think one thing is that people are so busy that-, that could be one thing that they might not have a chance to take care of themselves and seek information” (Female).

Breast Cancer Information and Breast Cancer Screening

Almost all the Key Informants talked about the ignorance in their population regarding breast cancer. The biggest problem, they implied, was a lack of knowledge about the importance of being screened.

Because this kinda thing they don't have so much experience and they don't have, um- No, they are not familiar with the thing, so they just, uh, don't feel like they have one or they need to check out or whatever. – Male

Participants felt that the general Hmong population would be unaware of the importance of acquiring information about breast cancer. If they did look for information, it would be because someone in their circle had an experience with breast cancer. A participant commented:

I don't think they would even contemplate it at all. Uh, unless they, they hear it from someone who had it- but even that won't encourage them to go and seek information about it...I'm afraid, most of the time, it's, it, they won't do it until it's too late. – Male

Lastly, a few of the female Key Informants remarked that fear of the actual screening process may be a deterrent for some women.

I think it just too afraid...yeah...that machine thing is too squeeze, they uh I think- I hear, I heard it hurts. – Female

Cervical Cancer Information and Cervical Cancer Screening

Like breast cancer, participants suggested that most of the population would be unaware of the need to get screened for cervical cancer. A main theme was once again simple unawareness of the issue. For instance:

But I think one of my most um...concern would be like, do they, if they know of such a thing. I mean, if they know such thing...it's like, do they really know there are such thing exists? – Female

Additionally, several interviewees brought up the idea that cervical cancer was too taboo and personal to be discussed. Those from the older generation might feel it was inappropriate to talk about it, even with a health care provider. Cultural differences may play a large role in their willingness to seek information or be screened. The remarks below illustrate this idea.

But when it comes to genitalia and private parts, it's just not a – and yeah, it's, it's a very taboo kind of discussion. – Male

There's some people who stick to the old culture and just, you know, or their...I don't know what-, their religious beliefs, stuff like that. – Female

As one participant pointed out, cervical cancer can sometimes be tied to sexually transmitted infections, which makes this topic even more uncomfortable in their culture.

People may not seek out information or be screened because of the negative connotations associated with the disease.

Yeah, the, the personal issue...the connotation of, you know certain things. Um, especially, like, you know, if, if you talk about, for example, cervical cancer, um, especially....it's construed- cervical cancer is tied to HPV for example, and that has to do with certain lifestyle. ...they're closely related to a taboo issue. – Male

A minor theme, as with breast cancer screening, was fear of pain because of the more invasive nature of the procedure.

Language and Literacy Barriers to Healthcare Access

Participants were asked how language and literacy affected the population's health care experience in areas such as transportation to appointments, making appointments, and communicating with doctors. Many of the Key Informants agreed that these could pose significant barriers, but did not elaborate on their reasoning. A major theme concentrated on the division of the Hmong into those that were literate, and those that were not.

Generally the participants, if literate and able to speak English fluently, did not expect there to be communication issues. However, those with fewer skills could find the health care system more difficult to navigate. One man stated:

So, there is a break between those who read and write English and there's those that don't. For the ones who read and write English, I don't think it's a problem. For the one who don't, um, and those are generally older- transportation, language, having interpreter for you, having someone there for you are, are some of the challenges for them...So, yeah, the language, for that generation is, is a

tough problem. But I don't think it's so much of a problem for the literate, uh, part, you know – in the Hmong community. – Male

The communication issues mentioned could be separated into several categories. First, most of the Key Participants touched on the issue of reading, understanding and completing medical forms, paperwork, and other written materials such as doctors' directions.

Sometime, the more you read, the more confused you get. And you don't understand half of your, what you read....or not even half, and it's just, uh, it's not interesting to, to you. Um, and so, you just don't read it....I used to go translated and I, my, myself, I have a hard time completing, answering medical question on the medical form. And given a person who has speak littler or write little, uh, is, it's challenging, is frustrated and um, so, it is a challenge. – Male

Secondly, another communication issue was speaking to the doctor. The Key Informants indicated that many Hmong use an interpreter, which is often a younger child in the family who speaks fluent English. Although this works, several participants mentioned that using family members for translation can be difficult because younger family members may not fully understand and be able to explain medical jargon. One man notes:

They cannot read and write and then it's I think uh the other thing is that um we don't have the uh interpreter who are- they can trust. And I think it will be easy if they can read and write then- they can you know...so if they don't have that then they need to have someone who can translate. – Male

For women without an interpreter, communicating needs to the doctor became very difficult. Additionally, the participants stated that setting up appointments and working with other members of the medical facility, such as the receptionist, could be stressful and problematic due to a lack of language skills. This participant's answer summarizes the perceptions:

Well, for the, uh, old women they- first they don't, uh, speak much English, so they don't know how to tell what they have or what they want to exam. For example, the breast cancer, they even don't know how to explain to doctor. When they want to make an appointment- uh, they don't know how to tell the doctor they want to take an exam like that, so why they don't know these things, they don't even, uh, make the doctor understand, so they don't bother to tell the doctor.

– Male

Discussion

The study aimed to explore possible reasons for low breast and cervical cancer screenings in relation to health literacy. Data from the U.S. Census Bureau indicates that the Hmong population in the United States tends to have low English literacy skills, especially when compared with other groups (U.S. Census Bureau, 2012). The data from this study corroborate with those findings, as the Hmong in Oregon were believed to have some English skills but not be entirely proficient. This also supports the data that claim almost all Hmong speak Hmong at home (U.S. Census Bureau, 2012), since every Key Informant indicated that Hmong is the dominant language of their population in Oregon. The low levels of Hmong literacy complement findings from previous studies as well.

Tanjasiri et al. (2001) and Perez and Cha (2007) both noted low levels of healthy literacy during their studies with Hmong populations.

The project's findings indicate that most Hmong are perceived to talk to friends and family as their main source of information. In general, the communication was thought to be limited within the gender except in the case of spousal relationships. It is relevant to note that Key Informants did not suggest women would look to men for information, as traditionally described in their patriarchal system (Yang, 1997). This contrasts the established Hmong societal practice of relying on the male figure for guidance. The tight social network of the Hmong population became apparent by the sharing of information between peers, so programs or projects working to educate the population might focus on utilizing the word-of-mouth communication so often mentioned by the participants.

Many of the Key Informants highlighted the role of the physician when gathering information. The importance of trust was continually mentioned, emphasizing the importance of the doctor-patient relationship within this Hmong population. Further studies might more closely examine the link between physician and patient as it relates to their health knowledge.

Another aim of this study was to explore possible health literacy barriers that may be affecting low breast and cervical cancer screening rates. As stated in the results, there were a variety of barriers present, and one of the main issues was the belief that the population would find a topic too "personal" to discuss. The unwillingness to pursue information, especially breast and cervical cancer information, greatly speaks to Hmong

cultural values. Privacy and dignity are highly regarded; attempts to educate the population must be aware of these principles.

Ignorance on the subject of breast and cervical cancer screening could be attributed to a variety of interwoven factors. Since Hmong value discretion, topics relating to sex (such as breast and cervical cancer) would not be discussed. This lack of dialogue, as described earlier in this study, may contribute to limited knowledge. Additionally, language and beliefs may affect this trend. Hmong medical beliefs do not incorporate long term illness (Plotnikoff et al., 2002), and this study also showed a lack of Hmong words for medical terminology. Combined, these factors may all contribute to the issue of limited knowledge as a barrier to screening.

Most Key Participants commented that they did not think language and literacy issues would affect the younger generation, but may be more problematic for the older generation. Of the variety of scenarios brought up in the interview (such as transportation, making appointments, etc.), few seemed to significantly stand out as major problems. Instead, the responses focused on the literacy level of the patient, which usually related to age. Future research might concentrate on this division to better target these sub-groups within the population.

Limitations of the Study

A primary concern in my analysis was the lack of objectivity that could have occurred with only one coder. Because of the complex nature of both creating and implementing the codes, incorrect interpretations and a lack of consistency could be present. Because I was the only coder for this analysis, I had to find another way to maintain reliability and

consistency. This was accomplished by completely recoding the entire set of data a second time. I waited several weeks between each coding, in order evaluate the data more objectively and somewhat mimic the effect of multiple coders.

The study is also limited by the sample size and demographic area. There were only seventeen Key Informants, and all of them were from the Oregon area. The second phase of the Hmong Breast and Cervical Cancer Project interviewed many more participants, but any future studies might include Hmong populations outside of Oregon.

Another factor influencing the results was the subjectivity of the Key Informants. As knowledgeable members of the Hmong community and part of the Community Advisory Committee, these individuals strived to represent the community as a whole; however, their answers reflect their beliefs about the population and may not accurately portray all attitudes of the population.

Recommendations for Future Research

This exploratory study focused on the role of health literacy plays breast and cervical cancer screening. It did not attempt to suggest strategies to increase breast and cervical cancer screening rates. Research should be continued that addresses the main themes from this study, such as the peer interaction and the lack of knowledge on the subject. Further studies might make use of Hmong social interactions as a possible method to encourage screening. Additionally, research into education that utilizes the community structure might be beneficial as a way to address the limited understanding of the meaning and importance of cancer screenings.

Conclusion

This study reveals perceptions, beliefs, and concerns of Hmong community leaders about health literacy and breast and cervical cancer. The strengths of the Hmong Breast and Cervical Cancer study include collecting information from male and female participants and utilizing respected community members as participants and advisors in the process. The findings elaborate and provide information to an area of Hmong health lacking in-depth research. Conclusions from this study may be used to further address low screening rates in the Hmong community.

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