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## Sources of Breast and Cervical Cancer Information for Hmong Women and Men

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### Abstract

Despite low breast and cervical cancer screening levels among Hmong women in the U.S. reported in the literature, understanding of the barriers to screening for Hmong women is limited. Health literacy issues may influence screening behavior for this population. This qualitative study explored sources of information about breast and cervical cancer including screening and identified barriers to seeking such information for Hmong women and men. We conducted semi-structured, in-depth interviews with 84 Hmong women and men living in Oregon, USA. Interviews were audio-recorded and transcribed. Transcripts of 83 usable interviews were analyzed using content analysis. Health care providers and the Internet were the most frequently cited sources of information about breast and cervical cancer including screening. Other sources were family, friends, and other media. Over half of the participants indicated that nothing would prevent them from seeking information about these topics. These findings suggested that health care providers and the Internet may be important sources of information about breast and cervical cancer screening for Hmong women. Additional research is needed to examine further Hmong women's health literacy needs and preferences with regards to breast and cervical cancer screening.

### Keywords

Asian; Hmong; sources of information; breast cancer; cervical cancer

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Like other Asian American women living in the United States (U.S.) (Ho & Dinh, 2011; Kawaga-Singer et al., 2007), Hmong women have been reported to have low breast and cervical cancer screening rates (Fang, Lee, Stewart, Ly, & Chen., 2010; Kagawa-Singer, Tanjasiri, Valdez, Yu, & Foo, 2009; Tanjasiri et al., 2001; Yang, Mills, & Dodge, 2006). Even so, few studies have examined factors associated with breast or cervical cancer screening behavior for Hmong women (Fang et al., 2010; Tanjasiri et al., 2001; Yang et al., 2006), and understanding of the barriers to screening is limited (Lee & Vang, 2010). A recent review identified low literacy, limited ability to speak English, and low cancer and prevention literacy as potential barriers to cancer screening for the Hmong (Lee & Vang,

2010). However, we found no studies that focused on the influence these factors may play in breast or cervical cancer screening for this population.

The Hmong, an ethnic minority from Southeast Asia, immigrated to the U.S. as refugees from the mid-1970s to 2006 (Hamilton-Merritt, 1993; Yau, 2005), and they are perhaps most known for their role fighting alongside the U.S. during the Vietnam War. Current census data show that the Hmong population has increased by 40% since 2000, with more than 260,000 Hmong currently residing in the U.S. (Hoeffel, Rastogi, Kim, & Shaid, 2012). The majority of Hmong refugees in the U.S. are from Laos, having fled to refugee camps in Thailand after the U.S. withdrew from Southeast Asia. In Southeast Asia, the Hmong led a traditional agrarian lifestyle, living in remote mountainous regions, raising animals, and growing crops for subsistence (Cha, 2003). The Hmong's cultural traditions, knowledge, and skills have been passed down orally from one generation to the next. It was not until the 1950s that the written form of the Hmong language was developed by missionaries (Dunnigan & Olney, 1985).

A number of language-related challenges exist in promoting early cancer detection with the Hmong such as the absence of Hmong words for terms like *cancer*, *cervix* or *cervical*, *Pap test*, or *mammography*. Furthermore, literacy is an issue for many Hmong, especially elders (Lee, Lytle, Yan & Lum, 2010). Nearly all Hmong refugees came to the U.S. not knowing how to speak, read, or write English (Allen, Matthew, & Boland, 2004). Older Hmong women and men living in the U.S. may not be able to read or write in English or Hmong, and many younger Hmong who can speak fluent Hmong may not be able to read or write in Hmong. Low literacy in one's native language can potentially increase barriers to cancer screening (Garbers & Chaisson, 2004), and low literacy is associated with poorer understanding of health information (Leyva, Sharif, & Ozuah, 2005) and poorer health outcomes (Sentell & Braun, 2012). Few studies on cancer-related information-seeking behavior among Hmong or other similar refugee groups, such as Vietnamese, have been conducted. Nguyen et al. (2010) found that older Vietnamese adults were more likely to use interpersonal sources, such as doctors, family members, and friends, for cancer and cancer screening information, and that those sources had a greater influence on their screening decision than did the Internet or print media. Another study identified a number of mental health literacy issues, including, but not limited to, language, that are perceived by mental health professionals to be barriers for elderly Southeast Asian refugees including Hmong (Lee et al., 2010). Although translating health materials into Hmong may be considered culturally appropriate and appreciated by the Hmong, it may not always be sufficient for communicating health or other information with Hmong patients or populations. Finding accurate and understandable health information can be a challenge for the Hmong. Despite these language and literacy challenges, our understanding of how these issues relate to breast and cervical cancer screening among Hmong women is limited. Knowing the sources to which Hmong women and men turn for information about breast and cervical cancer, as well as barriers to seeking such information, would be helpful for designing programs and interventions to increase screening in this population. For example, programs that use culturally acceptable information sources or that address key barriers to information seeking are more likely to be effective (Fisher et al., 2007). Our objective in this study was to conduct an initial exploration of sources of information about breast and cervical cancer, including screening, and identify barriers to seeking such information for Hmong women and men to provide direction for future research by suggesting information sources and barriers that may be particularly relevant for Hmong populations.

## Methods

### Design

This study was part of a larger project that explored the influence of social, cultural, and health care system factors on Hmong women's breast and cervical cancer screening. We used qualitative methods for this exploratory study because little research on breast or cervical cancer screening had been conducted with the Hmong, and no studies had focused on the specific topics of interest. The methods have been described in greater detail elsewhere (citation to be added after blind review). In the first phase of the project, the investigators interviewed 17 key informants who were members of the project's Community Advisory Committee or other knowledgeable persons from the local Hmong community. The data presented here come from the second phase of the project, during which we conducted in-depth interviews with Hmong women and men living in Oregon, as described below. The study protocol was approved by the Oregon State University Institutional Review Board.

### Participants and Recruitment

The target population included women and men aged 18 years and older. We included men because they have a major role in Hmong culture. Hmong society is kinship-based, divided into clans, and patrilineal. In traditional Hmong culture, the male head of household has a great deal of influence over family members' health and medical decisions (Cuhlane-Pera & Xiong, 2003; Faderman & Xiong, 1998; Johnson, 2002; Lee & Vang, 2010). Consequently, obtaining men's perspectives was important for understanding women's health issues. We selected a broad age range because women are recommended to begin clinical breast exams and Pap tests by their early 20s (American Cancer Society, 2011). In addition, men of all ages could potentially influence screening through their roles as husbands, sons, and fathers.

Our goal was to interview 20 women and 20 men in each age category (18–39 years and 40 years or older), with a target sample size of 80. Eligibility criteria were: (1) self-identified as Hmong, (2) aged 18 years or older, and (3) lived in Oregon. We sought to recruit a diverse sample with respect to clan, socioeconomic status, and acculturation. Accordingly, we recruited participants from the community using multiple strategies including placing printed materials (in English and Hmong) at popular community locations, making announcements at events and church meetings, talking with community members at informal gatherings, and receiving referrals. A recruitment script was used to provide additional information to individuals, determine their interest and eligibility, and schedule interviews. We completed eligibility screening with 86 individuals, of whom 84 were eligible. All of those who were eligible participated. A total of 84 interviews were conducted from December 2009 to May 2010. Because one interview was not useable, the final sample consisted of 83 participants (44 women, 39 men), representing 12 of the 17 Hmong clans in Oregon.

### Data Collection

One of the investigators (a Hmong woman) and trained Hmong staff conducted the individual interviews in Hmong, English, or both. Interviewers used an informed consent document to explain the study to participants, and participants gave oral consent to participate. The interviews, which were audio-recorded and lasted 45–120 minutes each, were conducted in participants' homes or offices, or in private rooms at a community-based center or other community location. Participants were offered \$25 for participation and up to \$10 each for childcare and transportation.

Of particular relevance, the semi-structured interview guide included the statement, “People turn to a variety of sources when they want information about a health topic,” followed by six questions: (1) What would you do if you wanted information about breast cancer? (2) What about screening? If you wanted to learn more about breast cancer screening, what would you do? (3) What sorts of things might stop you from seeking out information about breast cancer or breast cancer screening? (4) What would you do if you wanted information about cervical cancer? (5) What if you wanted to learn more about cervical cancer screening, what would you do? and (6) What sorts of things might stop you from seeking out information about cervical cancer or cervical cancer screening?”

## Data Analysis

Audio-recordings of the interviews were transcribed and, if conducted partially or entirely in Hmong, were translated into English. Interviews conducted in English were transcribed by either a transcription firm or project staff; these interviews were verified for quality and accuracy by the Hmong investigator and a research assistant. Interviews conducted predominantly in English with some Hmong language were transcribed, and the Hmong portions of the interview were simultaneously translated into English and transcribed by the Hmong investigator. Interviews conducted entirely in Hmong were simultaneously transcribed and translated into English by a Hmong employee at a transcription and translation firm. The Hmong investigator verified translation of the Hmong transcripts for translation accuracy by listening to 10 minutes of the beginning, middle, and end of the interviews. We communicated back and forth with the transcriptionist until we agreed on an accurate translation. We also consulted members of the Community Advisory Committee to clarify questions on translations.

We conducted content analysis using NVivo 8 (QSR International, Cambridge, MA). First, research team members independently reviewed a subset of transcripts to generate preliminary codes. Second, through a process of discussion, coding of additional transcripts, and refinement of codes, we finalized the list of codes. Next, entire transcripts were independently coded for content related to health literacy by at least two coders, including one investigator. One investigator and another member of the research team jointly reviewed the coded text, resolved any differences, and identified themes. Finally, we selected quotations to illustrate the themes and noted the participants sex and age by decade.

## Results

Most participants were born outside the U.S., preferred to speak both English and Hmong, reported reading English pretty or very well, and reported writing English pretty or very well (Table 1).

Many participants reported the same information sources for breast and cervical cancer (Table 2). In addition, participants generally identified the same sources of information for screening. As a result, the themes did not differ across these topics. For women and men, the most frequently cited sources for obtaining information about breast and cervical cancer, including screening, were health care providers and the Internet. Each of these sources was named by more than half of the participants (overall and by gender). Whereas these themes did not differ for women and men, we did, however, identify both similarities and differences in information sources reported by younger and older participants (Table 2). More specifically, both younger and older participants reported that they would seek information from providers. For example, a woman in her 60s said, “If I wanted to know about it, I would just ask the doctor.” Similarly, a man in his 20s shared, “In my opinion, the first thing is go through your doctor first, your primary doctor, and let’s see what she think,

if she can refer you, if or if she can get you information.” Many participants who said they would ask their provider identified other sources as well, especially the Internet.

In contrast, many participants simply said, “Internet” or “Google it!” without naming other information sources. A woman in her 20s reported, “I’d Google it! [laughter]....Internet is my first source, actually. Like, in sickness or anything, I always Google it.” A man in his 40s described the importance of the Internet as follows: “Nowadays, of course, we can’t trust everything that’s, on it, but the Internet is a great source for that type of information.” Many participants remarked that the Internet was the first place they would go to seek breast and cervical cancer information because there is a wealth of information on the Internet, it is easy to find information on symptoms and treatment options, and it is convenient. Participants who said they would search for information on the Internet were predominately under 40 years of age; nearly all of the participants aged 18–39 years said they would seek information about these topics on the Internet.

A small number of participants (mostly women) identified family, friends, or other media (e.g., pamphlets, books, magazines, TV) as sources for information about breast or cervical cancer. Some older participants reported that they did not know where to go for information; of those, some said they depended on their doctors to know this information, noted barriers such as language, or said they had not thought about it (some because they were asymptomatic).

The major theme related to barriers to seeking information was that many participants did not perceive barriers. Whether talking about breast or cervical cancer, over half of the participants indicated that nothing would prevent them from seeking information about these topics. This finding was similar for men and women and for younger and older Hmong in our study. For example, with regard to seeking information about breast cancer or breast cancer screening, a woman in her 20s said, “I don’t think anything would stop me if I wanted to know about it. Yeah. If I wanted to know about it, I would, I would find out. I don’t think anything would stop me.” For some participants, fear was a barrier to seeking information. Younger and older participants (mostly women) expressed fear of knowing they had the disease or fear of inviting it. As one woman in her 50s said, “Those bad diseases, if you don’t have it, you don’t want to know and you don’t want to hear [about] it.” Another woman (40s) remarked, “I don’t want to go see them [doctors]. I don’t want to talk about those kinds of things because I am scared and I shouldn’t go search for it [cancer information].”

## Discussion

Despite low screening rates, low literacy, and language barriers among Hmong reported in the literature (Fang et al., 2010; Kagawa-Singer et al., 2009; Lee & Vang, 2010; Tanjasiri et al., 2001; Yang et al., 2006), previous studies had not examined health literacy as it relates to breast and cervical cancer screening among Hmong women. In this study, we explored the information sources Hmong women and men would use in order to obtain information about breast and cervical cancer, including information about screening. Our findings pointed to health care providers and the Internet as key sources of information about these topics.

Health care providers were an important information source for both men and women and for both younger and older Hmong. Providers were the most frequently cited information source for Hmong aged 40 years or older, suggesting that interventions that involve working with providers may be a culturally appropriate strategy for reaching older Hmong women. The importance of providers as a source of information could, however, reflect that many of

the women in this study had received provider recommendations for screening, and most had been screened. On the other hand, because male participants also indicated that they would seek information from providers, the preference for obtaining information from providers cannot be entirely explained by previous experience with screening. Thus, our findings suggested that providers can play a critical role in education about breast and cervical cancer for Hmong.

The finding that many participants would search the Internet for information about breast and cervical cancer was unexpected given that the literature emphasizes low literacy and acculturation levels and portrays the Hmong as holding onto traditional beliefs and practices (Lee & Vang, 2010; Cha, 2003; Culhane-Pera & Xiong, 2003). Our results suggested that the Internet could be an important venue for Hmong, particularly the younger generation, to find information about breast and cervical cancer screening. The Internet may be a favorable source of information for those Hmong who feel that they do not have time to go see a doctor or feel that doctors do not spend enough time with them. Furthermore, our findings have implications for future health promotion programs. Promoting targeted health messages or programs through social media or web-based campaigns could be innovative ways to reach some Hmong women and men.

The participants were selected using a purposive sampling strategy and may not be representative of other Hmong in the U.S. For example, the screening levels reported by women in this study were higher than the screening rates found in other studies with Hmong women (Fang et al., 2010; Kagawa-Singer et al., 2009; Tanjasiri et al., 2001; Yang et al., 2006). Given their greater experience with screening, the participants could have been more comfortable interacting with health care providers about breast and cervical cancer screening than may be the case for other Hmong women. In addition, participants may have been more acculturated and computer savvy than other Hmong. Future research should assess the extent to which the Hmong, in general, are familiar and comfortable with searching the Internet for health information and how successful they are at finding websites that provide credible and accurate information.

In addition to the aforementioned limitation, in this study we asked a relatively small number of questions concerning health literacy. We did not ask participants to report on their past experiences obtaining information about breast or cervical cancer, and their reports of what they *would* do may not reflect their actual behavior. Furthermore, neither the ability to read and critically analyze information about breast and cervical cancer screening nor the ability to act on such information was examined. Studies that conduct a more comprehensive examination of health literacy related to breast and cervical cancer information are required to better understand the needs and preferences of Hmong women. When considering the present findings, it is also important to note that in a separate analysis of health care system barriers to breast and cervical cancer screening from the same project, language issues were among the major barriers to screening identified, especially for older Hmong.

In conclusion, this qualitative study was an initial exploration into health literacy issues for Hmong women and men related to seeking breast and cervical cancer information. The findings suggested that two frequently used sources of information regarding health topics – health care providers and the Internet - may be appropriate sources for Hmong to obtain information about breast and cervical cancer screening. The findings provide direction for future research.

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TABLE 1

Participant Characteristics ( $N=83$ )

Characteristic	Total $n$ (%)
Sex	
Women	44 (53)
Men	39 (47)
Mean age in years (SD)	38.8 (13.2)
Women, age in years	
18–39	25 (57)
40	19 (43)
Men, age in years	
18–39	20 (51)
40	19 (49)
Born in U.S.	32 (39)
Language preferences ( $n=76$ )	
Hmong only	18 (24)
English only	4 (5)
Both	54 (71)
Read English pretty well or very well	60 (72)
Write English pretty well or very well	58 (70)
Ever had clinical breast exam, women ( $n=44$ )	33 (75)
Ever had mammogram, women aged 40+ ( $n=19$ )	15 (79)
Ever had Pap test, women ( $n=44$ )	37 (84)
Received recommendation from doctor or health care provider for:	
Clinical breast exam, women ( $n=44$ )	32 (73)
Mammogram, women aged 40+ ( $n=19$ )	17 (90)
Pap test, women ( $n=44$ )	34 (77)

**TABLE 2**

## Sources of Information about Breast and Cervical Cancer including Screening by Age

Themes	Aged 18–39 years (n = 45)	Aged 40+ years (n = 38)
Sources of information about breast cancer		
Health care providers	25	28
Internet	44	4
Family and friends	9	5
Other media	6	7
Don't know	0	11
Sources of information about cervical cancer		
Health care providers	26	28
Internet	41	7
Family and friends	10	2
Other media	6	4
Don't know	0	14