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Medical Mistrust and Discrimination in Health Care: A Qualitative Study of Hmong Women and Men

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Abstract

Low rates of breast and cervical cancer screening among Hmong women have been documented. Mistrust of Western medicine and the health care system, as well as experiences of discrimination in health care, may be barriers to seeking health care for this population. In this study, we explored medical mistrust among Hmong women and men, their experiences with discrimination in health care, and how these factors may influence Hmong women's breast and cervical cancer screening behavior. We conducted semi-structured, in-depth interviews with women and men who were members of the Hmong community in Oregon. Transcripts of 83 interviews were analyzed using content analysis. Despite personally trusting Western medicine and the health care system, participants shared reasons that some Hmong people feel mistrust including lack of understanding or familiarity, culture, and tradition. Although mistrust was thought to result in delaying or avoiding breast or cervical cancer screening, more frequently trust was described as positively influencing screening. In addition, few participants reported being treated differently during breast or cervical cancer screening because they were Hmong. When discussing health care more broadly, however, some participants described differential (e.g., disrespectful or rude) treatment. Such experiences led to feelings such as anger and sadness and affected behavior, including willingness to seek care and choice of provider. Medical mistrust and perceived discrimination were not major barriers to breast and cervical cancer screening in this study. Additional studies are needed to assess whether our findings reflect the experiences of other Hmong.

Keywords

mistrust; discrimination; Hmong; cancer screening

Introduction

Remarkably low rates of breast and cervical cancer screening among Hmong women have been documented [1–4]. For example, a study of Hmong women in three locations in California found that only 51% had ever performed breast self-examination; among those aged 40 years or older, 52% had ever had a clinical breast exam, and only 30% had ever had a mammogram [3]. Screening levels at baseline and follow-up for Hmong women aged 40

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or older participating in a breast cancer screening education program in California were similarly low [2]. Reported rates of cervical cancer screening among Hmong have varied greatly. In a study in Fresno, California, less than 30% of Hmong women reported having received a Pap test [4]. More recently, in a study of Hmong women in Sacramento, California, 74% reported ever having had a Pap test [1]. In comparison, 53% of women in the U.S. reported having had a mammogram in the past year, and 78% reported having had a Pap test in the past 3 years [5]. Current screening guidelines recommend mammograms every year beginning for women at age 40 and Pap tests beginning 3 years after initiating vaginal intercourse, but no later than age 21 (recommened frequency varies according to multiple factors) [6,7]. Despite low screening levels among Hmong, few studies have examined barriers to screening for this population [8].

The Hmong are an ethnic group that came to the United States (U.S.) as refugees from Southeast Asia. They have a unique sociopolitical history and migration experience, including a long history of persecution [9, 10]. The Hmong are perhaps most known for their role in supporting the U.S. government in the “Secret War” in Laos [10]. From 1975 to 2005, more than 130,000 Hmong refugees resettled in the U.S. [11, 12]. Approximately 260,000 Hmong (defined as Hmong alone or in combination with other races) currently live in the U.S. [13]. California (91,224), Minnesota (66,181), and Wisconsin (49,240) have the largest Hmong populations. Oregon is one of 16 states that have Hmong populations ranging from 1,000 to 11,000 [13].

The Hmong Breast & Cervical Cancer Project is an exploratory study that examines social, cultural, and health care system factors that may influence breast and cervical cancer screening for Hmong women living in Oregon. The 2010 Census indicates that 2,920 Hmong live in Oregon [13]. No previous studies on breast and cervical cancer screening among Hmong have been conducted in locations with small to moderate-sized Hmong populations, where few, if any, resources and culturally specific programs for Hmong are available. Furthermore, although some research has examined the association between breast and cervical cancer screening behavior and sociodemographic and health care characteristics among Hmong women [1, 7, 8], understanding of the factors that may influence Hmong women’s breast and cervical cancer screening behavior is limited. Of particular interest here, some Hmong may mistrust Western medicine and the U.S. health care system, possibly due to traditional Hmong health beliefs and practices that conflict with Western medicine, lack of or negative experiences with medical providers in Laos, or historical factors [9, 10, 14–20]. In addition, negative perceptions of and experiences with the health care system, including discrimination, may be barriers to seeking health care [20, 21]. The purpose of the present study was to explore mistrust and trust of Western medicine and the health care system among Hmong women and men, their experiences with discrimination in health care, and how these factors may influence Hmong women’s breast and cervical cancer screening behavior.

Methods

We chose to use qualitative methods for this exploratory research project because little research on breast or cervical cancer had been conducted with the Hmong, and no studies had focused on the specific topics of interest. Throughout the project, a community advisory committee consisting of six Hmong community leaders and three additional community members who were interested in the project provided input and support. In addition, in an initial phase, the investigators (one of whom was a member of the local Hmong community) interviewed 17 key informants. The key informants included members of advisory committee and other knowledgeable persons from the local Hmong community. The purpose of the key informant interviews was to inform the development of the interview guide and the recruitment and data collection plans for the primary data collection effort. In this article, we present data from in-depth interviews with Hmong women and men living in Oregon. The study was approved by the Oregon State University Institutional Review Board.

The target population included women and men, as well as younger (aged 18–39 yrs) and older (aged 40+ yrs) community members. We included men because they have a major role in Hmong culture and were expected to influence Hmong women's health-related attitudes, decision-making, and behavior. More specifically, Hmong society is kinship based, divided into clans, and patrilineal. Traditionally, medical decisions are made by male household members, and individuals and families may seek consultation from extended family members and/or clan leaders before making a medical decision. According to Johnson [14], women generally do not have the autonomy to make important medical decisions about their own health; their husbands must be consulted before final medical decisions are made. Consequently, obtaining men's perspectives is 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 [22]. In addition, men of all ages could potentially influence screening through their roles as husbands, sons, and fathers, etc.

Our target was 20 participants per age group for both women and men, in order to capture a range of perceptions and experiences within each sex/age subgroup. Eligibility criteria for the in-depth interviews were (1) self-identify as Hmong, (2) aged 18 yrs or older, and (3) live in Oregon. To recruit a diverse sample with respect to clan, socioeconomic status, and acculturation, we used 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. In total, 84 interviews were conducted. One interview was not useable, resulting in a final sample of 83 participants (44 women, 39 men), representing 12 of the 17 Hmong clans in Oregon.

One investigator (a Hmong woman) and trained bilingual, bicultural Hmong staff conducted the interviews between December 2009 and May 2010. Interviews 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. Depending on participant preferences, interviews were conducted in Hmong, English, or a combination of both. Interviews were audio-recorded and lasted 45–120 minutes. Men and women's versions of the semi-structured interview guide included questions and probes about participants' trust of Western medicine and the U.S. health care system, why some Hmong people mistrust Western medicine or the health care system, and how trust and mistrust affect breast and cervical cancer screening. Questions also asked about participants' negative health care experiences, including experiences of being treated differently when seeking or getting health care because they are Hmong. Similarly, participants were asked about positive and negative experiences with breast and cervical cancer screening; for these questions, women were asked about their personal experiences, and men were asked about the experiences of women in their family. Interview questions also covered a range of other topics (e.g., health care system barriers to screening, health literacy).

Interviews were transcribed and, if conducted partially or entirely in Hmong, were translated into English. We conducted content analysis of the transcripts using NVivo 8 (QSR International, Cambridge, MA). Research team members independently reviewed a subset of transcripts to generate preliminary codes. Then, through a process of discussion, coding of additional transcripts, and revision, we finalized the list of codes. Entire transcripts were coded for content related to trust/mistrust and discrimination by at least two coders, including one investigator. The two investigators jointly reviewed the coded text, discussed any differences in how text was coded, assessed their agreement with the codes, revised coding where appropriate, identified major themes, and selected illustrative quotations. We examined differences in themes by sex and age. Because younger (aged 18–39 years) participants were more likely to have been born in the U.S.; understand, read, and write English; and have completed four years of college or higher (data not shown), we used age as a proxy for acculturation. For each quotation, we noted the participant's sex and age (by decade).

Results

Table 1 presents the characteristics of the in-depth interview participants. As shown, the majority of participants were married. Their educational attainment varied. More than half were born outside the U.S. When asked about language preferences, most participants reported that they preferred to speak both English and Hmong, rather than only one or the other. The majority of women had been screened for breast and cervical cancer.

In the following sections, we present the major themes that emerged related to mistrust and trust, their effects on breast and cervical cancer screening, and discrimination in health care.

Personal Mistrust

Although most participants indicated that they trusted Western medicine and the health care system in the U.S., some participants shared feelings of mistrust. No major themes emerged as to why they *personally* mistrusted Western medicine and/or the health care system, but for a number of participants mistrust in health care reflected a lack of trust in doctors. For example, one man in his 40s talked about mistrusting the doctor because of fears of being studied, and another man in his 60s talked about differences in race and language barriers. A woman in her 30s stated, "I don't really feel that they can relate to me.…You know my doctor, when I share information with her, I don't always feel like she really understands that I feel like she's sometimes a little bit dismissive." Reasons for mistrust also included negative beliefs about Western medicine or, conversely, a belief in traditional medicine as reasons for mistrust. For example, when talking about reasons for mistrusting Western medicine, the same woman above explained that her mother's preference for traditional medicine made her hesitant to give her children medications and influenced her to only use Western medicine as a last resort.

General Mistrust

Regardless of whether they reported personal mistrust, all participants gave reasons that Hmong people, in general, mistrust Western medicine or the health care system. Participants often talked about multiple and interrelated reasons for mistrust. Broad themes regarding the sources of mistrust included lack of understanding or familiarity, as well as culture and tradition.

Lack of Understanding or Familiarity—A major theme for why Hmong people mistrust Western medicine and the health care system was a lack of understanding or familiarity, as well negative impressions of Western medicine or the health care system. Familiarity with and confidence in traditional medicine were also considered, especially by younger participants, to be important reasons for why Hmong people do not trust Western medicine. For example,

> They don't really understand it. You know, they're, they're used to the old ways, so they don't, you know, they're not used to change, really, you know, so. I think that's the main reason why they don't trust it. – man in his 30s

> They're used to their traditional medicine, they're used to their own, you know, getting better with whatever they're supposed to do in their country, or stuff like that. You know, the Hmong way. So then they come to the United States and they're like, you know, "I've been living this long so I don't really need to do it." – woman in her 20s

Culture and the Older Generation—In a similar vein, culture and tradition were thought to be important contributors to mistrust, especially for older Hmong. This belief was voiced more frequently in interviews with younger participants and men. For example,

> The Hmong in this country, they, it's like they don't trust in that, they *coj kev cai qub* [they still practice the old traditions or beliefs].…They [elders] don't really trust the system because they *coj kev cai qub*… – man in his 30s

> There are still some…people, they still believe in animism more, so they still think it is due to evil spirits or ancestors. We all know that the reason they don't have trust is because of that, right? – woman in her 50s

Other Reasons—A smaller number of participants, especially older ones, thought mistrust resulted from negative experiences with the health care system, including discrimination. The patient-provider relationship and language issues (e.g., lack of communication and understanding because of language) were also mentioned. In addition, some participants indicated that Hmong people mistrust Western medicine because they are afraid of it due to unfamiliarity, negative impressions about it, or negative experiences when getting health care, including discrimination. They also expressed that some Hmong fear being studied by providers.

> So if you go get screened for things like that, they're afraid that they're just being studied.…a Hmong person's thinking is that it's just to be done for studying purposes and not something that is done to help them. So then if they go get screened, they get the news that they have the cancer, then maybe the doctor isn't able to help treat the cancer, this will cause Hmong people to be even more scared. – man in his 50s

Trust

As noted above, the majority of participants reported that they generally trusted Western medicine and the health care system in the U.S. The main themes revolved around believing in Western medicine and the health care system and the providers themselves.

Belief in Western Medicine and the Health Care System—Although some attributed their beliefs to growing up in the U.S., both younger and older participants cited their belief in Western medicine, familiarity with it, and past experience as reasons for trusting it. They also discussed that Western medicine produces results, is science-based, and utilizes technology. For example,

> As for the medication in this country I think that I trust almost about 100 percent. Uh huh, because they [doctors] have finished their studies about giving medicine and knowing your sickness so they can know what medication to give you. They have to give you the right medication, then you trust in eating the medicine, as for me, it's not hard when it comes to giving medicine in this country. I trust in it 100 percent. – woman in her 40s

> I think, well, the reason why I would trust.…Western medicine is because of technology. I would say technology and also, because it's really, it's, you know, Western medicine is more science-based. It's more based on, actual facts versus, beliefs and religion or culture. – woman in her 30s

Similarly, when sharing their reasons for trusting the health care system, participants talked most often about their confidence in both the health care system and Western medicine. They believed that if you are ill and seek care, your health care needs will be met. One participant described it this way:

> The things I have trust in are, like, illnesses, when you get sick you think it is due to evil spirits and other things, but it really is due to your body system or an illness in your body system causing you to get sick.…This part of it should go to… the doctors in order to get better. Because they are the ones that can test to find out why and what kind of medicine to help to remove that sickness. – woman in her 50s

Providers—Some participants indicated that they trusted the health care system, and to a lesser degree Western medicine, because of providers. They noted providers' education and knowledge and having had positive experiences with providers.

> I do have to trust them and I respect that they, they have gone through the educational system to train them to be doctors and in that profession, and in all aspects from the receptionist to the nurse or the doctor, to the, to the policy writers and stuff, that they all got a critical understanding of what, what they must do in their own worlds to help move the system along, so. Even though I'm of a ethnic background, I can trust them to be able to do their job. – man in his 20s

A few participants also indicated that, due to communication barriers, trusting providers was the only option due to an inability to understand or question the provider's judgment or diagnosis.

Effects of Mistrust and Trust on Breast and Cervical Cancer Screening

Almost two-thirds of the women and half of the men reported that mistrust/trust had no effect on whether or not they (women) or the women in their family (men) get screened for breast or cervical cancer. In contrast, lack of trust in Western medicine or the health care system resulted in some women, particularly older women, delaying or avoiding breast and/or cervical cancer screening. As one man in his 20s said, "Well, if they don't trust the system, they just won't get it. Won't get the screening." More frequently, however, trusting Western medicine, specific providers, or technology was described as having a positive influence on screening. For example,

> I trust Western medicine so I always get screened. Um, I guess if I didn't, I probably wouldn't, but I do. – woman in her 30s

> If my wife is willing, then I trust it enough for her to go get screened. And I will encourage her to go get screened because the doctor is able to find it when it's small, it will still be curable. But when it gets bigger, then it will be difficult. I would like for everyone to go get screened. – man in his 50s

Discrimination in Health Care

Among women who had been screened for breast or cervical cancer and men who reported family members with breast or cervical cancer screening experience, very few reported differential treatment when getting breast or cervical cancer screening on the basis of being Hmong. One woman in her 40s shared an experience when getting screened for breast cancer during which she felt that she had to wait longer in the waiting room and, later was treated differently in the exam room because she was of a different race. As a result, she changed doctors. She said that she knew that she was being treated poorly on the basis of her race because her non-Asian co-workers described being treated better. She went on to say that the experience made her not want to get clinical breast exams anymore "unless it is a really good doctor that I trust that I can feel comfortable going to."

When discussing negative health care experiences more broadly, however, some participants described situations in which they and/or family members were treated differently because they are Asian or because of their culture, language, education, or insurance. When asked more specifically if they had ever been treated differently when seeking or getting health care because they are Hmong, most participants responded that they had not, although others described being treated disrespectfully, unfairly, insensitively, or rudely. For example,

> I think that they see you are a person from another country, someone who is *plaub hau klub* [someone with black hair, another race] so you are Asian so they don't, so they said disrespectful things to you, and also they think you don't know English so they will say, will say things like they don't respect you. – woman in her 50s

> I don't know if it's because I'm Hmong, but it's, I would say more, more because I am, different.… in that I'm Asian…there's been occasions where, I would be sitting in the waiting room and, I might as well be a part of the furniture, because I'm not being noticed until I actually, I've, I've actually learned to be assertive to get the service that I need, because people are blind when they [see] someone who is different. – man in his 40s

These experiences of discrimination affected behavior such as willingness to seek care, its timing, and choice of provider. For example, when one participant was asked how her experiences with discrimination made her feel, she responded:

> You know, it makes me think that I don't need to see them anymore. I will try to find a different method, finding another way of health care or looking back into our Hmong medication that is better off.…Yes, I would first find medicine for it to see if will heal and then when almost dead, then will go to the ER. – woman in her 40s

Participants also described a variety of emotional responses to discrimination including anger, sadness, frustration, and feeling ignored.

Discussion

Part of a larger project exploring factors that may influence breast and cervical cancer screening for Hmong women in Oregon, the present analyses focused on the potential role of medical mistrust and discrimination in health care. We found that these factors did not characterize the breast or cervical cancer screening experiences of most participants. Even so, some participants reported that medical mistrust does negatively impact breast and cervical cancer screening. In addition, participants described situations when discrimination affected health care utilization. Further research on these topics is needed. In particular, quantitative studies that identify subgroups for whom mistrust and discrimination are significant barriers to breast or cervical cancer screening could inform the design of screening programs for Hmong women.

Beyond the findings related to breast and cervical cancer screening, we hope the insights gained from this study will help inform future research on barriers to health care that Hmong communities experience more generally. Consistent with the literature [9, 10, 14–20], all in-depth interview participants shared reasons why some Hmong people mistrust Western medicine or the health care system. The reasons for mistrust generally concerned unfamiliarity with Western medicine, cultural and traditional practices, as well as negative experiences with the health care system and providers and fear of being studied, as reported elsewhere [14–20]. Future research could examine these potential barriers to health care in greater depth. Importantly, many of the reasons for mistrust reported here could be addressed in educational programs for the Hmong community and/or in provider training.

In contrast to the data on why Hmong people in general experience mistrust, when asked about their own level of trust, most in-depth interview participants reported they *do* trust Western medicine and the health care system. We discussed these findings with members of the project's community advisory committee, and they suggested that when Hmong people think of the health care system, in general, they trust it; when they recollect specific situations and personal experiences, however, mistrust becomes an issue. Another possible explanation is that participants may have felt more comfortable talking about others rather than about their own beliefs and feelings of mistrust. A limitation of this study was that we did not ask participants about the differences between their own feelings of trust and their comments about Hmong people more generally. Interestingly, younger participants tended to identify culture, tradition, and belief in traditional medicine as reasons for mistrust among older Hmong, whereas older participants did not discuss these issues as frequently. Younger participants may have perceived these factors to be more important to older Hmong than they actually are; alternatively, older Hmong may have been less willing to discuss these issues with interviewers. Additional research that examines medical mistrust and its impact on health care seeking behavior and interactions with the health care system, especially among older Hmong, could help inform programs serving Hmong populations and be useful to providers.

Literature on discrimination and health among Asian Americans is limited [23], and no previous studies have examined how discrimination in the health care context affects the Hmong. As presented here, participants in this study shared experiences of discrimination when interacting with the health care system; furthermore, they indicated that those experiences could affect subsequent health care utilization. Of relevance to future research, participants were not always certain if they were treated differently because they are Hmong or for some other reason, which points to potential challenges of attributing the causes of discrimination. The nature of participants' experiences (e.g., disrespectful and rude treatment) corresponds with how interpersonal discrimination has been measured by some researchers [e.g., 24–27], suggesting that future quantitative studies could adapt existing measures for use with Hmong populations. In general, more research is needed to determine the extent to which Hmong women and men experience discrimination in health care settings and the impact of such discrimination on attitudes and behavior.

This study has important strengths and limitations. Strengths include the sample's relatively large size for a qualitative study, inclusion of women and men, and heterogeneity with respect to age and other characteristics. In addition, community engagement in the project (i.e., members of the community participated in the research team and the advisory committee) enhanced the project's credibility in the community, cultural sensitivity, and ability to recruit, as well as the interpretation of findings. We also want to note that the larger project examined other aspects of and potential barriers to breast and cervical cancer screening; those data are beyond the scope of one article and will be presented elsewhere. Like most qualitative research, a limitation of this study is that participants were not randomly selected and may not be representative of all Hmong women and men in Oregon. The findings are not generalizable and may not reflect the full range of views or experiences shared by non-participants. In particular, those with the greatest mistrust may not have participated. In addition, most women had received breast and cervical cancer screening, and their experiences and views may differ significantly from those who had not. Moreover, some Hmong are reluctant to discuss cancer for fear of inviting it, which could have affected both participation and responses to interview questions. Our bilingual and bicultural research team members, the participation of the advisory committee, and the use of culturally appropriate procedures may have offset these potential limitations to some degree. Another important point is that when participants were asked to report on their own perceptions and experiences, they sometimes talked about other people or used language that suggested a hypothetical situation. Potential explanations for those responses include that the topics may be sensitive and that those responses reflect the Hmong's collectivist culture [14, 17, 19].

In conclusion, medical mistrust and perceived discrimination do not appear to have been major barriers to breast and cervical cancer screening for study participants. The extent to which their experiences reflect those of other Hmong is unknown and is a topic for future research.

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Table 1

Characteristics of In-Depth Interview Participants (N=83)

Characteristics	**n (%)**
Women	44 (53)
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)
Currently married	68 (82)
Education	
Never attended school or only kindergarten	11 (13)
Grade 1–11	10 (12)
Grade 12, GED, or high school graduate	20 (24)
Some college (1–3 years) or technical school	25 (30)
4 years of college, or bachelor’s degree or higher	17 (20)
Born in U.S	32 (39)
Language preferences (n=76)	
Hmong only	18 (24)
English only	4 (5)
Both	54 (71)
Has ever had a clinical breast exam (women only)	
Aged 18–39	17 (68)
Aged 40+	16 (84)
Has ever had a mammogram (women only)	
Aged 18–39	1 (4)
Aged 40+	15 (79)
Has ever had a Pap test (women only)	
Aged 18–39	20 (80)
Aged 40+	17 (90)