

**Access to Adequate Healthcare for Hmong Women:  
A Patient Navigation Program to Increase Pap Test Screening**

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## **Abstract**

This paper describes the development and implementation of a Hmong Cervical Cancer Intervention Program utilizing a patient navigation model to raise cervical cancer awareness for Hmong women through educational workshops and to assist Hmong women in obtaining a Pap test. Out of 402 women who participated in a baseline survey, the Patient Navigation Program was able to enroll 109 participants who had not had a Pap test in the past 3 years and had never had a Pap test. Through utilization of outreach, an awareness campaign and patient navigation support, at least 38 percent of 109 participants obtained a Pap test. Overall, 21 workshops and 43 outreach activities were conducted by the Hmong Women's Heritage Association, leading to 63 percent of those enrolled in the Patient Navigation Program who could be contacted to obtain a Pap test.

**Keywords:** Hmong women, Pap tests, patient navigation

## **Introduction**

Access to quality health care is a continuing struggle for most Americans in the U.S. as reported by Families USA (2009). Not only is our nation struggling with the debate of how to achieve adequate and affordable healthcare coverage for all, but even those who do have adequate coverage may not be able to access appropriate care (Aston et al., 2003; Guidry et al., 1996). For ethnic minorities and underserved communities, it is more difficult to access even basic medical care due to various barriers such as lack of transportation, language difficulties, a lack of health insurance, systemic barriers and a lack of comprehension of the concept of disease prevention (Schwaderer & Itano, 2007; Special Service for Groups, 2001). For the Hmong, language and cultural barriers still persist as major barriers to accessing proper health care (Health Rights Hotline, 2006). Traditionally, the Hmong typically resort to healing practices such as shamanism and soul calling as a first step to preventing illness (Cha, 2003). This tradition is still practiced by many Hmong in the U.S., delaying their seeking of Western modes of medical services. This delay can pose a serious health risk as many studies have shown

that ethnic minorities and underserved communities are at the most increased risk of cancer and cancer related death (American Cancer Society, 2007; Oluwole et al., 2003).

In California, the lack of cancer screening for Hmong women is evident through data from the California Cancer Registry indicating the high incidence of mortality due to cervical cancer among Hmong women. Far worse than among other minority groups in California, cervical cancer for Hmong women is estimated to occur at a rate of 36.6 per 100,000, or three times as high as the total aggregated Asian and Pacific Islander American rate (11.8 per 100,000) and more than four times as high as that of Non-Hispanic White women in California (8 per 100,000) (Mills, Yang, & Riordan, 2005). With this unequal proportionality between Hmong women and Non-Hispanic White women, further empirical investigation and intervention programs are warranted.

The American Cancer Society (2010) has indicated that late stage cervical cancer is avoidable if Pap tests are done according to their current recommendations for Pap testing. Early Pap tests can detect early signs when this type of cancer is potentially curable and yet various Asian American ethnic groups are among the least likely to be screened for cervical cancer (Kem & Chu, 2007; Ponce et al., 2006), in particular, the newest Asian Americans from Southeast Asian countries. Therefore, Hmong women are at substantially increased risk of death from cervical cancer, and programs to increase the use of recommended Pap tests are indicated.

Since the early 1990s, there have been several studies and initiatives to assist underserved communities in obtaining cancer screening and cancer care through program models such as those associated with “promotoras” and patient navigation (Freeman, Muth & Kerner, 1995). Patient navigation services for ethnic communities are

tremendous assets to help patients face and overcome barriers that may impede their path to receiving health education and comprehensive early cancer care (Chyongchoiu et al., 2008). Patient navigators and promotoras are usually members within a community who work to send health messages to their community (Larkley, 2006). Scholars support patient navigation programs (PNPs) by explaining that these models provide “bridges,” and “culture brokers” between community members and health professionals (Bird, Otero-Sabogal, Ha, & McPhee, 1996; Eng, Parker, & Harlan, 1997; Landen, 1992; Love, Gardner, & Legion, 1997; McElroy, & Jezewski, 2000). PNPs are more available today in hospital settings and community based organizations; however, programs targeting specific ethnic populations such as the Hmong are limited in services and locations, if they exist at all (Bird et al., 1996; Chyongchoiu et al., 2008; Freeman et al., 1995; Larkley 2006; Ton-That, 1998).

In 2006, a baseline measurement of Pap testing among Hmong women was conducted in Sacramento, California (Fang, Lee, Stewart, Ly, & Chen, 2010). Results from the baseline indicated that only 74% had ever had a Pap test, with 61% tested in the past 3 years, compared to 91% and 86%, respectively, of California women overall (Center for Health Policy Research, California Health Interview Survey, 2007). Additionally, 38% of the women who had never had a Pap test had never heard of a Pap test before, and 36% did not know that they needed the Pap test and/or had never thought about having one. The findings from this study indicate that Hmong women in the Sacramento region have very low rates of cervical cancer screening, and that most of the women who had never had a Pap test were unaware that they needed one.

As a result of the baseline study, we created the Hmong Cervical Cancer Intervention Program (HCCIP), which included a patient navigation program (PNP), educational workshops, and media and outreach campaigns.

In this paper, we first introduce the background of the Hmong and the barriers they face to preventive care. Next, we elaborate on the development of each of the three components of the HCCIP and our findings. Finally, we will discuss the lessons learned, including implications for future studies with a health promotion program utilizing patient navigators.

### **Background of the Hmong**

The Hmong are among the more recent of refugee groups as they began arriving in the U.S. in the mid 1970's at the end of the Vietnam-American War. The Hmong were America's strongest ally during the Vietnam War, as a result they faced political persecution and genocide due to their involvement with the Central Intelligence Agency (Fadiman, 1998). The U.S. Census Bureau's American Community Survey (2010) enumerated the increase of the Hmong population in the U.S. from 186,310 in 2000 to 236,434 in 2009. Demographically, the Hmong are a relatively young population (median age=20.5 compared to 36.8 years of age for the entire U.S. population) with an average household size of 5.16 members per household compared to 2.63 members per household for the overall U.S. population. Nationally in 2000, the per capita income for Hmong was \$10,837 versus \$26,668 for the U.S. as a whole; 25.7% of the Hmong had incomes below poverty versus 13.0% of the U.S. overall population; and 92.7% spoke languages other than English in the home, with 44.0% speaking English "less than very

well,” compared to 19.7% of the U.S. population as a whole who spoke languages other than English in the home, with only 8.7% speaking English “less than very well.”

As a preliterate society, prior to their arrival in America many Hmong were not exposed to the Western concept of healthcare, which often is a direct contrast to their traditional healing practices (Culhane-Pera, Her, & Her, 2007; Fadiman, 1998). In their traditional culture, the Hmong practice strong animistic healing rituals and ancestral worship beliefs. They do not have a grasp of preventive health as perceived by the West. The Hmong resort to traditional healing practices instead of seeking western medical physicians. Among the health issues confronting the Hmong are those that relate to acculturation such as experiencing changes in diet leading to more sedentary lifestyles (Yang & Mills, 2008); mental health issues (Ton-That, 1998) and chronic diseases, particularly diabetes (Culhane-Pera et al., 2007). Another health issue is cancer (Mills & Yang, 1997; Mills, Yang, & Riordan, 2005), especially cervical cancer, the cancer with the highest incidence among Hmong females (Yang, Mills, Dodge, 2006; Yang, Mills, & Riordan, 2004). These health issues are exacerbated by linguistic and cultural barriers, including unfamiliarity with Western health care systems.

### **Methods**

In this HCCIP, we used the exploratory research approach to describe the process and report findings from the intervention phase, media campaign and educational workshops and outreach. We chose the theoretical concept of social support through the health navigator as a framework for the program’s implementation. Nguyen, Tanjasiri, Kagawa-Singer, Tran and Foo (2008) found that social support that utilizes health navigators appears to be effective in getting Vietnamese women screened for cervical

cancer. House (1981) outlined the four main behaviors or acts of social support to be: (1) emotional support, which involves showing empathy, moral support, love, trust, concern and caring; (2) instrumental support, which offers services such as labor, money, and time to directly assist a person in need; (3) informational support, which includes giving advice, suggestions, directives, referrals, and other information that can help a person to solve the problem at hand; and (4) appraisal support, which gives affirmation and constructive feedback that is useful for self-evaluation purposes. These behaviors are keys to building trusting relationships to reach communities. Since there has not been a known empirical validation regarding the effectiveness of a PNP with Hmong Americans, this study represents a new approach to reduction of health inequities among Hmong women. The findings from this study can be utilized in future research projects to determine mechanisms to improve health access and reduce cultural barriers to obtain Pap tests for Hmong women.

Below, we briefly highlight some of the events that led to the development and implementation of the PNP program at Hmong Women's Heritage Association (HWHA). The Hmong Cervical Cancer Intervention Program began in January 2007 and ended in June 2009. This study is a community-based intervention program that was developed and implemented by several Hmong community activists including the first four authors of this paper; we also explain the procedures we used to validate our intervention model.

Based on the high incidence rate for cervical cancer among Hmong women and the baseline study, HWHA's HCCIP was developed (Fang et al., 2010). The HCCIP aims included: (1) culturally appropriate and linguistically specific cervical cancer education for the Hmong community in the greater Sacramento region; and (2) education and

increased cancer awareness through early detection with Pap testing. We speculated that cervical cancer education would increase knowledge and awareness of cervical cancer screening and the intent to seek care for cancer or cancer prevention when medically appropriate. The HCCIP program had three components: media and outreach; educational workshops; and the PNP. The media, outreach and educational workshop segments were aimed at increasing awareness and knowledge of cervical cancer. The PNP was aimed at increasing Pap testing of those women who self-reported on our baseline survey that they had not had a Pap test in the past 3 years or had never had a Pap test. All three components were conducted simultaneously.

HWA patient navigators collected data for the HCCIP program. Raw counts were recorded in the form of the number of workshops, attendees in each workshop, and navigation services provided. Individual files were also created for participants who needed more intensive services from HWA staff. Below are illustrations as to how each component was developed and implemented. Figure 1 shows the tracking of each Hmong woman from the baseline study and Figure 2 depicts the flow of the HCCIP.

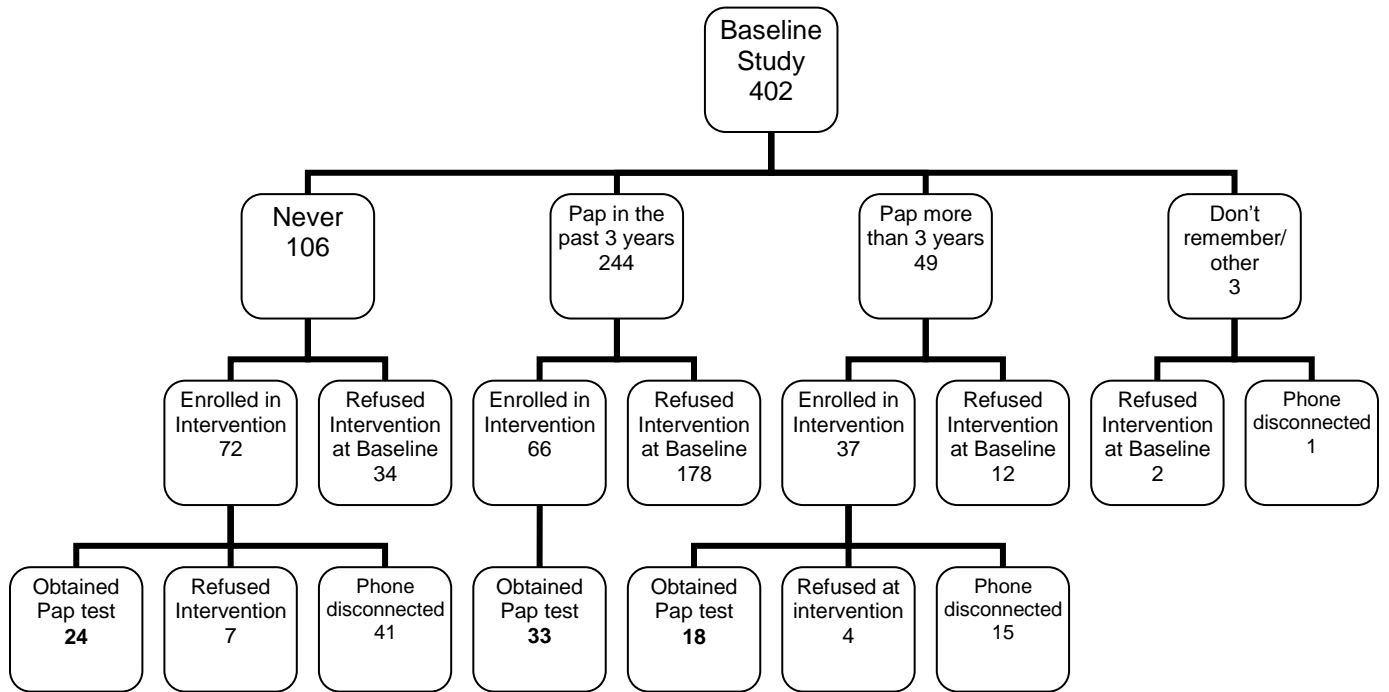
#### *Media and Outreach Component*

In this component, we began a media and outreach campaign aimed at increasing awareness of cervical cancer and thus increase the Pap test rate for Hmong women. Two Hmong public service announcements (PSA) containing cervical cancer information that included our contact information for assistance were made on a short band local radio program hosted by a Hmong-speaking radio personality. Hmong radio is the main channel for Hmong community news in Sacramento County. The radio programs ran in November 2007 and April to June in 2009.



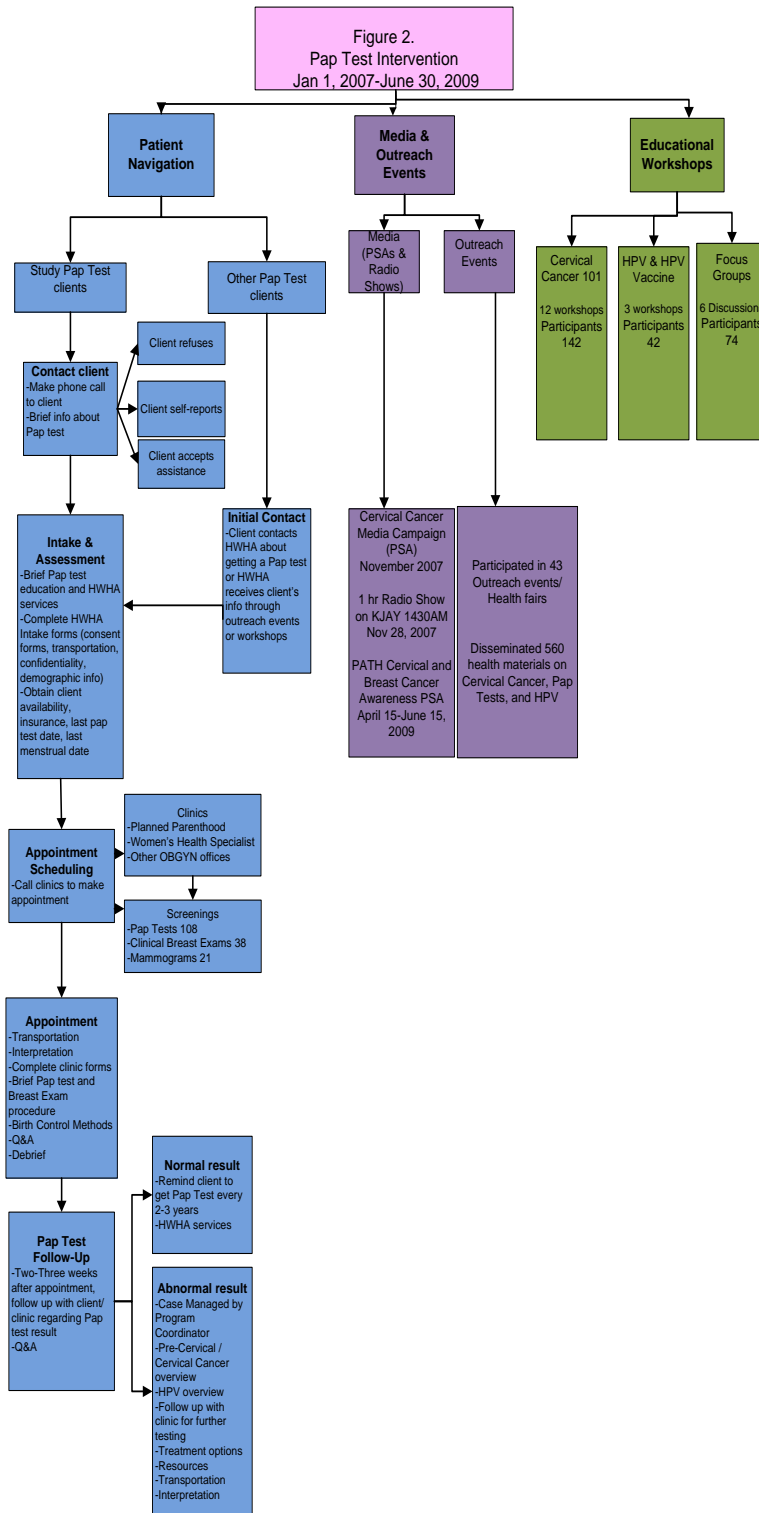
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Figure 1. Tracking of Hmong Women Pap Testing from Baseline Study



# Access to Adequate Healthcare for Hmong Women: A Patient Navigation Program to

## Increase Pap Test Screening



The first PSA in Hmong used this message:

*Did you know that cervical cancer is the leading cause of cancer death for Hmong women? According to the National Cancer Institute and Richard Yang it appears that the Hmong women have the second highest incidence of cervical cancer among all U.S. racial/ethnic women. Hmong women experienced three to four times higher mortality rates of cervical cancer than API and non Hispanic white women. Cervical cancer is a preventable disease if detected early. The recommendation from the American Cancer Society is to get a Pap test done every 2 years. If you would like to get a Pap smear test done or need more information, please contact Hmong Women's Heritage Association.*

The second PSA, in Hmong, used this message:

*Did you know that cervical cancer is the leading cause of cancer death for Hmong women? A study conducted by the Hmong Women's Heritage Association in 2006 found that only 74% had ever had a Pap test, with 61% tested in the past 3 years. Hmong women experienced a higher mortality rate than other API and non Hispanic white women due to our lower screening rate. The recommendation from the American Cancer Society is to get a Pap test done every 2 years. If you would like to get a Pap smear test done or need more information, please contact the Hmong Women's Heritage Association.*

We also participated in an hour-long program focusing exclusively on cervical cancer hosted by a local Hmong-speaking radio personality through the same station during the study period. The program was an interactive, informative show with the audience being able to call in with questions.

For the outreach component, we participated in various community health events throughout 2007 and 2009, such as Hmong Family Healthy Day, Florin Technology Health Day, Birth and Beyond Health fair and school events such as health & safety health fairs where cervical cancer brochures were distributed and onsite education was provided to the community. The major outreach events for the Hmong community occurred twice a year at the annual Hmong festival in Sacramento during Hmong New Year and the summer Southeast Asian Games (SEA games). Both of these events drew thousands of Hmong from the surrounding communities. The Hmong New Year festival is typically attended by an estimated 40,000 people across California and elsewhere in the United States.

#### *Educational workshops*

We developed materials and PowerPoint presentations on cervical cancer with the assistance of physicians associated with the Asian American Network for Cancer Awareness, Research and Training (AANCART) and called those workshops Cervical Cancer 101. The workshop covered basic information on cervical cancer such as signs and symptoms, preventive strategies and care and treatment options. All materials were designed by the second author as culturally and linguistically tailored to be sensitive and appropriate for Hmong men and women and were translated by HWAH. All workshops were open to Hmong women, men, and youth.

#### *Patient Navigation*

We had a total of 106 women from our baseline study that had never had a Pap test. From those 106 women, we enrolled 72 women into PNP. Thirty four women of the 106 refused follow up contact at the time of the survey by refusing to provide their

phone number, email, or home address. We had a total of 49 Hmong women that were not current with Pap testing according to the recommended guidelines for testing within three years. Of these 49, 37 were enrolled into the PNP. We had an additional three women who did not remember their last Pap test date; however, none of the three were enrolled in PNP. A total of 109 Hmong women were enrolled in the PNP (72 who had never had a Pap test and 37 without a current Pap test).

The Hmong women who self-reported never having had a Pap test or not being current were asked at baseline whether or not they would like to be enrolled in the PNP, which meant they would be contacted and provided assistance to obtain a Pap test during the study period. The patient navigation process began at baseline. If consent was given to enroll in the PNP, a trained bi-lingual patient navigator (PN) contacted each woman with a phone call to give a brief explanation of the Pap test procedure and then set up an appointment for intake. Each woman was given a choice to decline to participate at intake. Those that declined participation were given Pap test brochures, an agency brochure and a list of free or low-cost women's clinics as a reference if they wanted to obtain assistance at a later date.

Those women who consented to participate in the PNP were called and given a brief overview of the agency services and completed routine agency consent forms for service, confidentiality agreements and a transportation liability waiver. The PN also obtained basic information about medical history, client availability, type of insurance, last Pap test date, if any, and last menstrual period date. The PN assessed each woman's needs and concerns and then proceeded to schedule an appointment with a local women's clinic or personal gynecologist if she had one at time of intake. Once the appointment

was set up, the appointment was given to the woman and on the appointment day, the PN provided transportation, interpretation, and assistance with completing clinic forms. The PN interpreted for each woman and explained the procedure and forms thoroughly at the clinic. The PN also talked with each woman to comfort and lessen her anxiety through an explanation what to expect.

After the appointment, the PN debriefed each woman about any concerns and questions and followed up with each woman after two to three weeks concerning Pap test results. Those with normal results were encouraged by the PN to get a Pap test in another two to three years. Women who had abnormal Pap test results received more intensive patient navigation services. For these women, the PN continued with services by contacting the clinic or gynecologist for detailed information regarding the next steps to get complete care such as helping each woman understand her results, treatment options and procedures, talking to her family and coping with her diagnosis. Each woman received one-on-one assistance until she finished treatment and care or declined further assistance.

Approval for human subject participation was provided through the University of California, Davis.

## **Results**

### *Media and Outreach*

The PSAs have been effective in stirring the interest and concerns of Hmong women and also, surprisingly Hmong men. More than thirty women called expressing their symptoms and a desire to get a Pap test but said they could not due to language barriers, a lack of transportation, or not knowing where to go and who to ask for medical

services. Many were not aware that they could ask for assistance from their own primary care physicians. Hmong fathers called with concerns for their daughters and asked how they could help their daughters avoid a human papilloma virus (HPV) infection and cervical cancer.

In addition to the media campaign, we participated in 43 outreach events including health fairs, adult education and public school events, and other community events. Through these events, we disseminated over 560 health materials on cervical cancer, Pap tests and human papilloma virus infections. Our health materials were also made available through the internet on our website for public access. Staff in the program also provided educational sessions regarding cervical cancer to the community in both Hmong and English. We have shared our findings and efforts with more than fifteen professional audiences such as physicians, researchers, college-aged students, and other Hmong community leaders and shamans.

#### *Educational Workshops*

We hosted a series of twelve cervical cancer 101 workshops, reaching 142 men and women ages 18 and above. Additional workshops on HPV and HPV vaccine were also conducted with more than forty women and teens. To assess cervical screening barriers and behaviors, we also conducted a series of four focus groups which included 74 participants aged 18-64 from various backgrounds, such as college aged women, Hmong cultural traditions practicing women, working women, and women practicing the Christian faith. From these workshops and focus groups, we were able to understand the needs of our community and hear what each participant had to share regarding their own health experiences in the U.S.

### *Patient Navigation*

The PN contacted each woman who reported on the baseline survey that she had never had Pap test or was not current. Although 109 Hmong women enrolled in the PNP, the final retention rate was only 48.6 percent. Approximately half of the enrolled women had either moved out of the county or could not be contacted through a phone number or address. At the conclusion of the PNP, our patient navigators assisted 42 Hmong women of the 109 enrolled, which was 38.5% of those who had never previously had a Pap test or were late in getting their Pap test. Through the PNP intervention period, we had an additional sixty-six Hmong women who obtained a Pap test with a PN. Half of these women were from the baseline study, who self-reported as having had a Pap test in the past three years but needed to be screened again because the Pap test exceeded the recommended ACS recommendation during the intervention period (American Cancer Society, 2010). The other thirty-three women were not a part of our baseline study but self-referred from workshops, Hmong radio PSAs or from outreach events and had contacted our PN for assistance. In the thirty months of PNP intervention, we assisted 108 Hmong women.

### **Discussion**

Our study is the first that we are aware of that has attempted to systematically examine factors associated with cervical cancer screening (Pap testing) among Hmong women and follow these same women longitudinally with an intervention plan to increase their screening rates. This is also the first study to implement a patient navigation program for Hmong women in seeking early cancer screening. It is difficult for each Hmong woman to proceed through the ideal routine of obtaining a primary physician



referral to a gynecologist for a Pap test or for a woman to request a Pap test, due to language and cultural barriers and a lack of knowledge about early cancer screenings.

We have also found through workshops and focus groups that Hmong women not only came to learn about cervical cancer but also for social and emotional networking and support. The more the women met together to learn about cervical cancer, the more comfortable they became to share their own symptoms, fears, and perceived barriers due to perceptions of a stigma. For example, some women felt that frequent Pap testing was associated with and possibly suggested that a woman was taking part in promiscuous activities and therefore, always in need of constant women's examinations. Through the workshops and discussions, the women learned that a Pap test is an early screening for cervical cancer and does not necessarily correlate with promiscuity. In addition, many women had the impression that Pap tests were only a part of pregnancy and childbirth in America. If a woman was not pregnant, she thought it was not necessary to have a Pap test. Most women were not aware of the recommended guidelines. Through educational workshops, Hmong women talked together about their concerns, understandings, misunderstandings, and myths and were able to build on common beliefs and most importantly, build a relationship of trust with each other and patient navigators. Some women teamed together and asked to get their Pap tests on the same day.

Many of the Hmong women also did not know where to go to get a Pap test or who to ask to get a Pap test. They did not know that their primary care physician could refer them to a gynecologist. It is not that Hmong women do not want to get screened to prevent cervical cancer, they are unaware that screening is available because they never heard of Pap tests in Laos and Thailand. We have also found that if a PN is available to

help lessen their anxiety by overcoming barriers such as language, transportation, setting an appointment and communicating with each health professional's office, most Hmong women are ready and willing to obtain a Pap test. This process requires trust and understanding between the PN, the woman, and the physician.

Through our educational workshops and patient navigation model, we have found that Hmong women are very concerned about their well-being and health. Most Hmong families seek health care from a shaman or traditional treatment through herbs or natural healing methods. Cancer prevention is an unfamiliar concept in the Hmong community. It takes a bi-cultural and bilingual PN to intervene and be the bridge to link Hmong families with western health care.

### **Challenges and limitations of the Study**

One challenge we encountered was in facilitating access to quality care even with bilingual Hmong-speaking healthcare providers. Women who had a bilingual and bi-cultural Hmong primary physician still were not getting referred for a Pap test. Patient navigators are essential in coordinating and educating each woman. They are advocates and serve as a resource for support, knowledge and empowerment. The PN answers questions and concerns before, during and after appointments. Most physicians may not take the time to talk to each woman when she is in the office especially Limited English Proficiency (LEP) women because appointments with LEP women require time and effort through the utilization of interpretation services. Additionally, many physicians may not have the time or patience, or lack culturally responsiveness. Limited English Proficiency women may also be more hesitant in asking a physician questions because of fear, shyness, intimidation, and a lack of communication or language skills.

The second challenge is the lack of resources for college aged Hmong women. From our baseline study (Fang et al., 2010), most college-aged, educated Hmong women, most of whom were U.S. born (fluent in English), had never had a Pap test, and some had never heard of a Pap test. We provided outreach and educational workshops to this group of younger Hmong women but found that they were not as responsive to enrolling in our services. Many refused services at the time of the survey. This finding supports our understanding that second-generation Hmong women lack knowledge and understanding of early cancer screening because their parents did not have the information. Present and future patient navigation programs should not only focus efforts in helping monolingual middle aged and older Hmong women but also U.S.-born Hmong American women.

In addition to the challenges, a limitation of our study was the low retention of Hmong women due to relocation and possibly the increased use of cell phones instead of land lines, which prevented us from reaching many participants by phone. Of those who had never had a Pap test, we enrolled 72 women, but 41 were no longer reachable, accounting for 56.9%. Of the not current group, we enrolled 37 women, but 15 were not reachable, accounting for 40.5%. Many of the Hmong women were new refugees. The high mobility rate may have been due to housing opportunities and relocating to be closer to relatives. For future studies, we recommend incorporating questions asking for an additional contact person or a nearby relative's contact number to be reached in the event that participants' cannot be contacted through their phone number.

We did not have a control group to compare with our intervention group. The availability of a control group would have strengthened our findings. We could

incorporate control and intervention groups in future studies to better understand the impact of patient navigation services.

### **Conclusions**

Overall, in our intervention time frame from January 2007 to June 2009, we were able to increase the awareness of cervical cancer throughout Sacramento, California through Public Service Announcements (PSAs), radio shows, health events and workshops. This is evident through the thirty-three Hmong women who contacted us to assist them in obtaining a Pap test. Our goal to increase the Pap testing screening rate among Hmong women in Sacramento, California was achieved because we were able to increase our baseline screening rate from 61% to 71%, an increase of 10 percentage points (See Figure 1). Additionally, we assisted 63% (75 out of 119) of those enrolled in interventions to obtain a Pap test who were involved in the baseline study and could be contacted.

Hmong women are experiencing new health care that was not readily available, accessible, and affordable to them in their country of origin. While learning to adapt to these changes, they are also facing other environmental, social, physical, and mental stressors in life which may be the cause of their delay in obtaining early cancer screenings.

Patient navigators are essential to meeting the needs of underserved minority women who have language and cultural barriers to accessing western health care services. Patient navigators can make a difference and are critical for cancer survival and preventing cancer mortality. If PN are involved at first diagnosis, they can link and directly assist the patient and families to resources, treatment options and care. Patient

navigators can also assist patients with appointment keeping and compliance with treatment or medications. Hmong patients with language, cultural, and transportation barriers cannot survive the cancer journey by themselves. Patient navigation programs lead to higher Pap test screening rates (Levine, Becker, & Bone, 1992; Levine, Becker, Bone, Hill et al., 1994; Witmer, Seifer, Finocchio, Leslie, & O'Neil, 1995).

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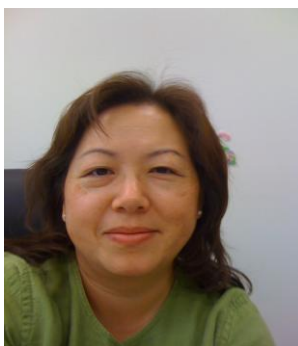
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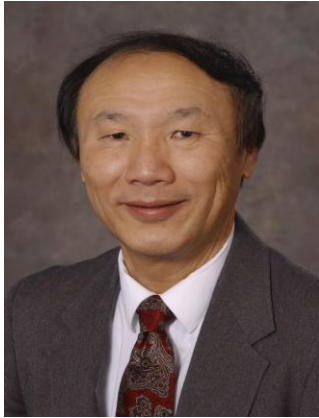
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