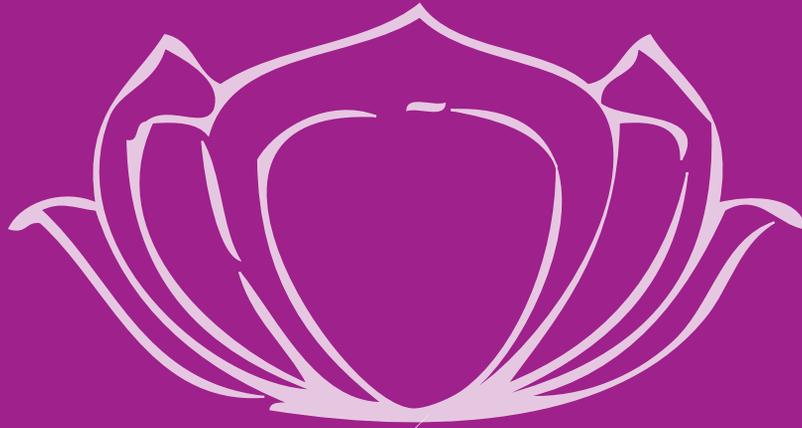


The Southeast Asian Breast Health Navigation Report



A Case Study of Health Navigation in the Cambodian, Laotian, Thai and Vietnamese Communities of Southern California





The Southeast Asian Breast Health Navigation Study

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EXECUTIVE SUMMARY

Southeast Asian (Cambodian, Laotian, Thai, and Vietnamese) women have the lowest rates of breast cancer screening among Asian and Pacific Islander women. Many Southeast Asian (SEA) women encounter enormous barriers to breast cancer screening and treatment services due to many factors. In recent years, there has been an increasing emphasis on the importance of employing community health navigators to improve health access and utilization for these communities.

This is the first community-based participatory research study to investigate community breast health navigation in four Southeast Asian communities in Southern California.

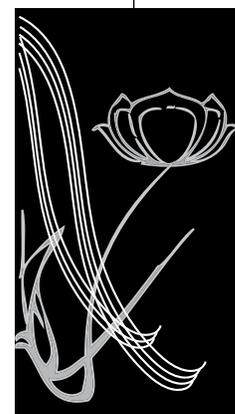
Our collaborative goal was to identify how community health navigators address cultural differences and systemic barriers to effectively navigate low-income Southeast Asian (SEA) women (Cambodian, Laotian, Thai and Vietnamese) in Los Angeles and Orange County to obtain breast health care services. We explored our research questions by studying the perspectives of three groups: community health navigators, Southeast Asian women/patients, and their providers.

We conducted focus groups with 110 SEA women, and qualitative, semi-structured, in-depth interviews with 15 providers and 10 community health navigators to achieve the following three specific aims corresponding to our research questions: 1) Identify how health navigation services enable Cambodian, Laotian, Thai, and Vietnamese women to seek breast health services, 2) Document and describe the roles, skills, and personal qualities of community health navigators, and 3) Analyze and synthesize the study findings to identify the essential elements needed to develop a future navigation model and training curriculum.

Overall, the focus group participants, navigators, and providers we interviewed all shared similar concerns about the complexities of the health care system and emphasized the value of having community-based health navigators in helping to bridge the gaps in this system. The list of potential topics that the three groups of respondents felt would be important to include in a training curriculum for future community health navigators working with Southeast Asian communities or other similarly underserved communities clearly contained significant overlap and agreement on the essential elements.

Community forums were organized in each of the four communities to provide study findings. All forum presentations and materials were bilingual, with the primary language tailored to each of the ethnic communities. All study participants were invited to attend the forums. Attendees completed evaluation forms at the end of the events.

The information shared from the focus groups and interviews more clearly defines the roles of a community health navigator and encourages conversations about boundaries for such work, training and continued education, as well as financial and policy implications. From all three perspectives, community health navigators appear to be the crucial links that help connect patients and providers throughout the complicated network of health care. The thoughts shared by all the participants clearly demonstrate how community health navigators are an important part of the health care delivery system, especially in serving tremendously diverse communities. However, in a field where resources are continually lacking and health needs are continually increasing, concerns were expressed on how to sustain community-based health navigation programs. More resources and funding are clearly needed to train community health navigators and maximize the services provided by these important individuals to improve access and care.



INTRODUCTION

Southeast Asian (Cambodian, Laotian, Thai, and Vietnamese) women have the lowest rates of breast cancer screening of all ethnic groups in the United States. Many Southeast Asian (SEA) women encounter enormous barriers to breast cancer screening and treatment services due to limited English proficiency; lack of transportation; high rates of poverty; employment in jobs with long hours and no time for preventative health care; and lack of information and resources for their communities. While there exist some studies on the lower screening rates among Southeast Asians, few studies and programs focus upon the Cambodian, Laotian, Thai, and Vietnamese communities in relation to cancer prevention and treatment. In recent years, increasing emphasis has focused on the importance of employing community health outreach workers and navigators to improve health access and utilization for these communities. However, while some studies have described health navigator programs using a hospital or clinic-based model, few studies have examined health navigator programs in community-based settings.^{1, 2} Our study focused specifically on community-based health navigators who support and guide patients throughout the entire cancer care continuum, from initial screening exams throughout diagnosis, treatment, and recovery or end-of-life.

Los Angeles and Orange Counties are home to the largest Southeast Asian populations in the nation, with community estimates far surpassing the total Census 2000 population count of 304,385. Hollywood is home to the largest Thai community in the U.S. Similarly, Long Beach has the largest population of Cambodians, and Orange County has the largest Vietnamese population in the nation.

This is the first research study to investigate community-based breast health navigation in four Southeast Asian communities in Southern California. We proposed a study to document and describe what community health navigators do and how they perform their work to help women in the Cambodian, Laotian, Thai, and Vietnamese communities to access and utilize breast health services. By identifying and understanding the essential elements involved in a community-based health navigation program, our long-term goal is to develop a formal curriculum that can be used to train community navigators to help women with breast health services in other underserved communities.

Our study objective was to identify how community health navigators address cultural differences and systemic barriers to effectively navigate low-income Southeast Asian (SEA) women (Cambodian, Laotian, Thai and Vietnamese) in Los Angeles and Orange County to obtain breast health care services. In particular, we posed the following three research questions, from the perspectives of health navigators, Southeast Asian women/patients, and their providers: 1) What are the important factors at the individual, interpersonal, and community levels that need to be addressed in an effective navigation program? 2) How do navigators culturally tailor their strategies to address these factors affecting the ability of SEA women to obtain necessary services from initial breast cancer screening exams through diagnostic, treatment and rehabilitation/ recovery services? 3) What specific training components are necessary in a community-based navigation program curriculum to effectively increase access to, and utilization of, quality breast health services? The study findings will help to develop and refine a theoretically-based model for navigation services in order to create a formal community-based breast health navigation curriculum that could be tailored to the needs and resources of SEA communities in California as well as other underserved, uninsured, low income, and low literacy immigrant and refugee communities. Our long-term research goals are to develop and test the effectiveness and impact of this curriculum.

¹ Nguyen TN, Tanjasiri SP, Kagawa-Singer M, Foo MA. Community Health Navigators for Breast and Cervical Cancer Screening Among Cambodian and Laotian Women: Intervention Strategies and Relationship-Building Processes. *Health Promotion Practice* 2008; 9(4): 356-367.

² Nguyen TN, Kagawa-Singer M. Overcoming Barriers to Cancer Care Through Health Navigation Programs. *Seminars in Oncology Nursing*, 2008; 24 (4): 270-278.

Our study is a community-based participatory research (CBPR) effort comprised of Families in Good Health/ St. Mary Medical Center (FiGH/SMMC), Orange County Asian and Pacific Islander Community Alliance (OCAPICA), UCLA Asian American Studies Department and School of Public Health, California State University Fullerton, Asian American Studies Program, and funding from the California Breast Cancer Research Program. The study was initiated in July 2006 and required 30 months to complete.

The study included focus groups with 110 SEA women and qualitative, semi-structured, in-depth interviews with 15 providers and 10 community health navigators. Our research team used theoretical concepts from the Social Ecological Model and the Social Support literature to develop the focus group and interview guides. The Social Ecological Model (McLeroy et. al., 1988)³ identifies five levels of influence for health-related behaviors: 1) Intrapersonal or individual factors; 2) Interpersonal factors; 3) Institutional, or organizational factors; 4) Community factors; and 5) Public policy factors.

According to House (1981)⁴, social support serves as a function in relationships that can be categorized into four broad types of supportive behaviors or acts:

- 1) **Affective/ Emotional Support** involves the conveyance of empathy, moral support, love, trust, concern, and caring.
- 2) **Instrumental or Logistical Support** involves offering tangible aid and services such as labor, money, and time that directly assist a person in need.
- 3) **Informational or Educational Support** involves providing advice, suggestions, directives, referrals, and other information that a person can use to address problems.
- 4) **Appraisal Support** involves giving affirmation and constructive feedback that is useful for self-evaluation purposes.

From December 2007 through September of 2008, our research team recruited focus group participants from the database of clients who received breast navigation services through the REACH 2010 Promoting Access to Health for Pacific Islander and Southeast Asian Women Program (PATH for Women).⁵ Focus groups were conducted with a convenience sample of consenting study participants in each of the four communities using the same focus group guide, translated into Khmer, Laotian, Thai, and Vietnamese. In addition, we conducted interviews with 10 navigators and 15 providers serving these four communities. All focus group and interview participants also ranked a checklist of potential topics that they felt were important to include in a training curriculum for community breast health care navigators (see page 36). Our research team developed this checklist based on a review of other health navigation studies.

All focus groups and interviews were translated, transcribed and analyzed using codebooks developed by the research team. We entered and analyzed all data using the software programs Microsoft Word, Excel, and Atlas.ti. In reviewing the focus group data, key themes emerged in the following areas: general assistance needs and resources; knowledge of navigator services; navigation services provided; communication barriers and facilitators with providers; skills navigators should have; and areas or issues for change or improvement. The navigator and provider interview data yielded the following major themes: navigation services provided; outreach strategies; trust and respect; expectations from clients; common client problems; health navigator and provider expectations regarding navigator qualities; training skills navigators should have; and negative aspects and other issues of navigation.

This study received Institutional Review Board approval from California State University Fullerton, IRB #HSR-07-0186, Special Service for Groups, IRB#2006-04; and UCLA, IRB# G07-07-095-01.

³ McLeroy KR, Bibeau RD, Steckler A, Glanz K. An Ecological Perspective on Health Promotion Programs. *Health Education Quarterly* 1988; 15(4):351-377.

⁴ House JS. *Work Stress and Social Support*. 1981. Reading, Mass., Addison-Wesley Publication Company.

⁵ Tanjasiri SP, Kagawa-Singer M, Nguyen TN, Foo MA. Collaborative Research as an Essential Component for Addressing Cancer Disparities among Southeast Asian and Pacific Islander Women. *Health Promotion Practice* 2002; 3: 144-154.

RESULTS

FOCUS GROUP SUMMARIES

Focus groups were conducted among consenting individuals who had received services through a community health navigator from 2000-2005 via the REACH 2010 Promoting Access to Health for Pacific Islander and Southeast Asian Women Program (PATH for Women) for breast health services. The following are summary results from the focus groups for the four communities that participated in our study: Cambodian, Laotian, Thai, and Vietnamese.



Cambodian Community FOCUS GROUP FINDINGS



From February through May 2008, Cambodian interviewers conducted four focus groups with a total of 32 women regarding breast health navigation services. Women were recruited from a database of women served through OCAPICA's REACH 2010 PATH for Women Program. Focus group participants ranged in age from 26-80 years. Most women were married, spoke little to no English and had Medi-Cal or no health insurance. Two focus groups, totaling 24 women, focused on screening services; a third group of 6 women focused on diagnostic services; and a fourth group of 2 women focused on breast cancer survivors.

I. GENERAL HEALTH NEEDS

A. Medical Needs

In response to the question asking about the types of help focus group participants needed for health care in general, only a few answered, and the responses were for navigation services, and not health care needs, except for a general check-up. The fact, however, that they are aware of the need to go in for a general check up is noteworthy, and belies the usual assumption that this population will only go to the doctor when they are not feeling well. This finding supports the need for more research regarding the concept of "well" check-ups and their meaning in the Cambodian community.

B. Lack of Language Services, Transportation, Insurance, Appointments, Paper Work, Follow Up

One of the top needs across the focus groups was

having bilingual providers or interpreters for health care appointments. Participants felt that when the providers or an interpreter was available, they felt the providers understood them better, they understood what the doctor was explaining to them and asking of them, and they could make informed decisions. As one woman noted, "*She [the health navigator] help me to fill out the forms, and translate with the doctor, pick me up. Without her, I don't know nothing.*"

One clear intangible service outcome for the navigators was the emotional support they provided for the women. The Cambodian women responded with words like "thrilled, happy, confident" to be able to ask all their questions of the doctor they needed. Many women in the screening focus groups said that if it were not for the navigators, they would just not go see a doctor for anything. The women were also forthcoming in telling the focus group facilitator what they felt like when no interpreter, or only their children (as either minors or adults), who spoke limited Khmer, was available. They used words like "*stupid, deaf, frustrated, ignorant, and frightened.*"



II. BREAST HEALTH CARE ASSISTANCE RESOURCES

Many women in the screening focus groups mentioned that they went in for general check-ups or annual check-ups. This, in itself, is a major service of the navigators, because it supports more general health than just breast health.

III. KNOWLEDGE OF NAVIGATION SERVICES

Participants learned about the breast health navigation services provided by PATH for Women health navigators through Cambodian media ads; friends/word of mouth/ referrals; and health fairs at community venues; and, noting the dedication of the navigators, at chance individual meetings at restaurants and at the temples. Health navigators provided women with:

- General health education information,
- Instruction on breast self exam,
- Assistance in making appointments,
- Transportation,
- Assistance with paperwork and forms,
- Interpretation,
- Understanding their visit and test results,
- Reminders about appointments,
- Psychosocial support,
- Finding a health care provider, and
- General explanations of health care information

We discuss each of these navigation services in more detail below through specific themes that emerged from the analysis of the focus group data.

IV. NAVIGATION SERVICES PROVIDED

A. Informational/Educational Navigation Assistance

Women felt that navigators were important helping them to understand what preventive screening methods were necessary and helped them to keep informed about the latest health information. Many focus group participants felt that community health navigators were extremely helpful to new patients who did not know the health system, the providers, or the health issues. They also made it clear that they would not go to the doctor without the navigator now, because they would not be able to ask their questions or understand what the doctor was trying to tell them. They also stated it was essential to have well trained bilingual community health navigators to assist the women and their families on a regular basis, and at the hospitals, 24 hours a day.

One of the informational services noted by one woman was spending time in the home before the first medical encounter, to “get to know me.” Part of the result is building trust and empathy, but the other aspect is “client assessment.” In order for the navigator

to do the most effective work for the client, s/he must know the needs of her clients, prioritize them, and assess the relationship between the symptom and the rest of the woman’s life as well as the most appropriate medical care needed.

B. Logistical Navigation Assistance Knowledge of the health care system

The participants felt that having a bilingual community health navigator, who was well trained and knew the health care system well, would be ideal. They prioritized having someone who knew the health care system well, and had adequate knowledge about the diseases and general health information.

Filling out forms

One woman noted “I would not understand anything if I go to see the doctor by myself without the health navigator. I do not know how to read English. I have difficulties to fill out the forms. Without the health navigator, I would rather stay home instead of going to see the doctor...”

Appointment scheduling and reminders

Participants wanted assistance in appointment scheduling, reminders, and filling out difficult paperwork. Many times the client needed the navigator to change appointments as well. From a logistical point of view, this is important in building rapport with the doctor’s office to minimize the “no show” problem that creates a negative mind-set for the office staff. It seems navigators were also proactive in obtaining appointments for the women they served.

One woman said: “The health navigator contacted me for an appointment to see the doctor.”

Interpretation and support

All the women participating in the focus groups identified the need for interpretation and support. One participant gave the example of not having an interpreter available in the emergency room and not understanding why they did not do more for her son: “If I had a health navigator with me, she can translate for me and then I can understand what they are saying and they can understand what I am saying.”

Another woman noted: “Without health navigators working in the hospital, it would be very difficult for me. It happened to me when my husband had a heart

attack. I had a very hard time at the ER because I don't speak English. I cried so bad because I'm so worried about my husband and I cried because I don't know anything that they were going to do to my husband. My daughter was with me, but she cannot explain to me in Khmer language to me. I would like to request to have a Cambodian translator in the hospital."

Transportation

Every woman who spoke during the focus groups said that transportation provided by the navigator was essential. These women said they did not drive, and if it were not for the community health navigator, they would not go to the appointment because they could not get there – not because they did not want to go.

Emotional or Interpersonal Navigation Assistance

Many women noted that the health navigator provided social support by being there with them for their medical visits. This support made the women feel at ease and pleased with their medical visits:

"...the health navigator provides me with mental and emotional support. They helped me feel confident and much less worried. The mental aspect, I think is very important."

"Able to ask questions of the doctor I am frightened to ask"

"Just knowing the navigator is available, I feel comfortable getting checked."

"With health navigator, I'm not afraid at all, because she knows how to speak with me and makes me feel normal."

"I was so happy to learn that the health navigator always keep my confidentiality. I fully trust her and feel very comfortable to tell her all my problems with no doubt."

Appraisal or Affirmation Navigation Assistance

Health navigators in the Cambodian community also helped women to understand their medical visits and to follow up with test results.

V. COMMUNICATION WITH PROVIDERS

All participants felt that health navigators were important in facilitating communication and promoting providers' understanding of the women's cultural beliefs and practices, because none of the doctors noted spoke Khmer. Community health navigators also helped to explain each step of the medical appointment and helped the women comprehend the health information provided and the meaning of the test results. Many women mentioned that they spoke little to no English and the navigator helped them to communicate with their provider in ease:

"(Doctor) cannot answer my question or explain anything to me unless the health navigator interprets for him.... I have questions in my mind about my breast, but I'm scared to ask. I turn to the health navigator for help. She asked the doctor for me, then clearly told me what the doctor said."

"I cannot see the doctor without the health navigator. I might just go back home."

"All participants are more comfortable with female doctors. It is a taboo in Cambodian female world. Besides their spouses, they feel so shy to discuss female problems with male doctors. They don't want to disclose any private issue directly to male doctor."

"Without the health navigator, the conversation between the doctor and I will be fruitless. I am not able to describe my problems for him to help. He would not get any information from me either. Treatment may not be possible."

Participants felt that community health navigators could improve understanding and communication with providers and wanted them available regularly during providers' hours. They understood that health navigators would not be available 24/7 but felt that they were only needed during regular clinic hours.

VI. QUALITIES/ SKILLS DESIRED FOR NAVIGATORS

Participants wanted their health navigators to be professionally trained and have health knowledge, specifically in regards to breast and cervical health, as well as keep up to date on the latest health information. They wanted their navigators to be bilingual and bicultural and not only interpret for them, but also explain the situation so that they could have a better understanding. Gender was essential to discuss “women’s” issues. They would not do so if the navigator was a man.

Only one woman explicitly noted it, but she was extremely comforted that the navigator kept her information confidential.

VII. CHANGES/ IMPROVEMENTS

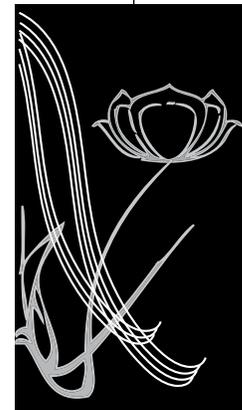
Participants were emphatic and almost pleading to keep the program available. Several stated clearly that if there were no community health navigator, they would not go to their doctor.

Overall, women were very satisfied with the services currently provided by community health navigators. They felt that it was important to have all of these services: assistance with making appointments, appointment reminders, assistance with paperwork/ forms, interpretation, social support, education about health issues, and transportation. *“This program really saves lives of women who don’t have Medi-Cal and need free screening.” “We would like to (give) thanks to this program for helping our community and please continue to help Cambodian women.”*



Laotian Community FOCUS GROUP FINDINGS

Between January and March 2008, three focus groups and a survivor interview were conducted with a total of 30 Laotian women regarding the breast health navigation services they received through OCAPICA's REACH 2010 PATH for Women program. Of the three focus group sessions, two consisted of 24 women who had received health navigation support in the screening stages of the cancer continuum of care and one session totaling 5 women consisted of individuals in the rehabilitation/recovery stage of the cancer continuum. The ages of all participants ranged from 42 to 70 years with an average age of 54 years. Most of the women were in their 50s. All women had children and were monolingual, and most had no health insurance



I. GENERAL HEALTH NEEDS

A. Medical Needs

When focus group participants were asked about the types of help they needed for health care in general, many mentioned that they needed medical care for breast health (mammograms), cervical health (Pap smears), blood pressure, and, cholesterol checks.

B. Lack of Language Services, Transportation, Insurance, Appointments, Follow Up

All women mentioned a common set of issues that needed to be addressed to access health care services. They stated a need for interpretation, help with making appointments, help with completing paper work/forms at the doctor's office, transportation, dealing with health care costs and lack of insurance issues, and help understanding the health care system (for instance, health navigators' understanding of the health care system seemed to make it easier and quicker for the women to get through the system).

II. BREAST HEALTH CARE ASSISTANCE RESOURCES

Health navigators were a resource that many women found helped them to access and utilize health care services, especially for breast and cervical health. Most of the women in the Lao community met their health navigators at community outreach events or health fairs at local gathering sites such as the temples.

III. KNOWLEDGE OF NAVIGATION SERVICES

Health navigators provided women with health information, instruction on self-breast examination, assistance in making health appointments, transportation, assistance with paperwork/forms, interpretation (including providing assistance in understanding the medical visit and test results), help to remind about appointments, and support by being with women during the doctor visits.

IV. NAVIGATION SERVICES PROVIDED

A. Informational/Educational Navigation Assistance

Women felt that community health navigators were important in helping them to understand what preventive screening methods were necessary. In some instances, navigators even provided instructional education by showing women how to conduct self-breast examinations. One woman stated "...in my country, I never know what a Pap smear or mammogram is.....; however a navigator help me understand."





B. Logistical Navigation Assistance **Knowledge of the health care system**

All women felt that the logistical navigation knowledge of health navigators helped them to connect the fragmented elements of the health care system. Women also felt that a navigator's knowledge of the health care system made it easier and quicker for them to facilitate the health care system; on their own, they felt that things would be harder and take much longer.

Appointment scheduling and reminders

Health navigators provided assistance in setting up medical appointments and also provided reminders so that women did not miss their appointments.

Interpretation and support

Most women who participated in the focus groups spoke very little to no English, as a result, communicating with their health care provider was challenging. Health navigators provided interpretation services at health care visits. Not only did they provide interpretation, but they also helped women to better understand the information that was conveyed in a medical encounter; as a result, women felt that they better understood the medical care. While health navigators attending medical appointments were there to provide language support, many women also felt that this same opportunity allowed for social support. They felt that they had someone to support them and be with them through this experience. One woman stated, "... if we have the navigator go with us we are not afraid." Another woman expressed, "A health navigator helps me the most are be there for me and comfort me...."

Transportation

Every woman mentioned how health navigators were pivotal in providing transportation to and from medical appointments. Reliance on health navigators to pick up women for appointments, ensured compliance with their appointments and therefore access to care. One participant shared that health navigators are "...very helpful when they pick us up and they help us check in after that they drop us home thank you very much."

C. Emotional or Interpersonal Navigation Assistance

Many women noted that the health navigator provided social support by being there with them for their medical visits. This support made the women feel at ease and pleased with their medical visits:

"A health navigator helps me not to be nervous every time when I go to doctor office"

"...when I went the very first time, of course I was afraid because I don't know the language so the navigator helps me feel comfort."

"I'm so happy that I see the navigator go help us; I feel less afraid."

"In the Lao community, all the navigators were women. This helped to bridge cultural discomfort in seeing a male provider alone for a medical visit."

"...if we have the interpreter to go with us we might feel comfortable - yes we are shy, but if we had a female doctor it might be ok."

"... the doctor was asking me are you shy - she [the patient] said no but I want the female because we are the same gender."

"...in our culture we want only women to know about our body parts because we are shy."

Follow-up discussions with the navigators helped to explain that while some of the women mentioned feeling shy, embarrassed, modest, and/or uncomfortable about their breast examinations, they felt all of these aspects could be overcome with the support of a navigator who made them feel at ease and comfortable by explaining to them what to expect during the exams. Many women expressed that they felt capable of returning and getting the examination in the following year by themselves. This sense of self-empowerment was a goal that all the navigators wanted to achieve with the women they navigated.

D. Appraisal or Affirmation Navigation Assistance

Health navigators in the Lao community also helped women to understand their medical visits and to follow up with test results.

"Yes, the navigator was very helpful and explained every detail about all the situation."

V. COMMUNICATION WITH PROVIDERS

All participants felt that health navigators were important in facilitating communication and promoting providers' understanding of the women's cultural beliefs and practices. Navigators also helped to explain each step of the medical appointment and helped the women to comprehend the health situation and results. Many women mentioned that they spoke little to no English and the navigator helped them to communicate with their provider in ease:

"I need the people to help me with interpretation with the doctor because I don't understand English."

"...yes when we went with the navigator, they explain to the doctor that in our country we never had check up like this."

Women felt that community health navigators not only helped them to understand their medical visits better, but their presence also encouraged doctors to be more responsive to their questions, as well as to take more time to explain what was going on during the medical visit. If they wanted to convey something, participants felt doctors were more responsive if interpreters were with them.

"...since I went to see my primary doctor, when they came to do the exam, they don't really pay attention much. If the navigator went with us, they might explain more."

"...if we want the doctor's help with pain here and there, we have people that help us there- it is easier."

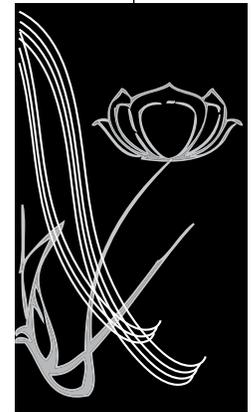
VI. QUALITIES/ SKILLS DESIRED FOR NAVIGATORS

Women wanted their community health navigators to have health knowledge, specifically in regards to breast and cervical health. They wanted their navigators to be able to speak English and not only interpret for them, but also explain the situation so that they could have a better understanding. Some women said that the most important quality or skill of a navigator is one who could understand their situation and then support them to get their needs addressed. Health care knowledge and health care system logistics were important. However, basic logistics were most important, for example, providing transportation support.

VII. CHANGES/ IMPROVEMENTS

Overall, women were very satisfied with the services currently provided by community health navigators. They felt that it was important to have all of these services: assistance with making appointments, appointment reminders, assistance with paperwork/ forms, interpretation, social support, and transportation. They did not feel that anything needed to change except that there needed to be many more community health navigators available in all health care facilities and available at all hours, so that patients coming in at any time of day or night would have appropriate access. They felt that if they knew that every doctor had a community health navigator, they would feel more comfortable attending their doctor appointments. Lastly, they hoped that the PATH for Women program would continue and be available to help more people in the community.

Thai Community FOCUS GROUP FINDINGS



From December 2007 through March 2008, Thai interviewers conducted six focus groups with a total of 36 Thai women regarding the breast health navigation services they received through OCAPICA's REACH 2010 PATH for Women Program. Of the six focus groups, one consisted of 12 participants and another with 6 participants, who had received navigation assistance for initial breast health screening services; one with 4 participants and another with 2 participants who had received assistance with diagnostic breast cancer services; one with 3 participants who had received assistance with treatment services; and one with 9 participants who had received assistance with rehabilitation and recovery from breast cancer. The ages of all participants ranged from 42 to 87, with the majority being in their 50s. Most participants were monolingual and had no health insurance.

I. GENERAL HEALTH NEEDS

A. Medical Needs

When focus group participants were asked what types of help they needed for health care in general, many mentioned that they needed medical care for such common ailments as diabetes, high blood pressure, back pain, cholesterol, and dental care. Participants wanted access to free or low-cost exams and blood tests for these major medical areas.

B. Lack of Language Services, Transportation, Insurance, Appointments, Follow Up

One of the top needs across all focus groups was having an interpreter for their health care appointments. One participant mentioned: *"An interpreter is an issue. We don't have knowledge about the interpreter. The healthcare providers should not only give us the advice. We should be able to ask them questions as well as whether we can do this or that, not just listen to them. We should be able to ask them what we can do, not just for them to advise us."*

Other needs or challenges in accessing quality health care included lack of transportation and insurance; not knowing where to go for services; and difficulty in scheduling appointments (due to language issues and long wait times). For those women who received diagnostic breast cancer screening exams, some had to wait a long time to get results. Some women, not knowing the protocol, anxiously waited for months to hear the exam results before asking their navigators to follow up. Those women who had received treatment for breast cancer shared that, their Medi-cal benefits through the Every Woman Counts Program (Breast Cancer Early Detection Program, federally) were discontinued after 18 months, after which time they could no longer afford as many doctor appointments or treatment medications. One woman expressed, *"Now I have to pay \$75 every time I see a doctor. I also have to pay for the medication. Last time I paid \$43 for Tamoxifen and Vitamin C and Vitamin D."* Many women discontinued or reduced their medical care due to reasons of cost.



II. BREAST HEALTH CARE ASSISTANCE RESOURCES

Many women in the screening focus groups mentioned that having the mobile mammogram services at the Thai temples was very useful and convenient for them to get exams. One participant expressed, *"What makes it easier for us is to provide us with the mobile screening at Wat Thai."*

Another participant added, "At Wat Thai because we don't have to take off work as it offers services on Saturday or Sunday which is convenient for us."



Participants from all six focus groups also mentioned the importance of having a health navigator/interpreter who knows the health system to guide them through the cancer care process.

III. KNOWLEDGE OF NAVIGATION SERVICES

Participants learned about the breast health navigation services provided by PATH for Women health navigators through newspaper ads and stories; mail notification; friends/word of mouth/referrals; self-introductions by navigators at mobile mammogram events and health fairs at the Thai temples and other community venues; and staff referrals from community-based organizations such as the Asian Pacific Health Care Venture or APHCV (this last channel was especially prominent for those Thai women who were treated for breast cancer, since staff were very helpful in referring them to treatment services).

IV. NAVIGATION SERVICES PROVIDED

In the Thai community, one particular health navigator provided most of the navigation assistance for the majority of women participating in the focus groups. Many participants mentioned that this navigator took care of “everything.” One woman noted, “She takes care of all our problems.” The navigation services listed by the women fit into all four categories of Social Support outlined in the “Methods” section above and noted below.

A. Informational/ Educational Navigation Assistance

The navigators functioned as an information resource or consultant – someone who could give answers to their questions and give suggestions about where

to go and who to see for information and resources, or what to do after diagnosis and treatment (e.g. what foods to eat, what medications to take, how to deal with symptoms, side effects from treatments, etc.). One woman who went through treatment for breast cancer shared, “When I ask her to ask questions for me, she will. When I have certain kinds of questions or problems, I ask for her suggestions and follow her advice. She is also a consultant... Yes, when we first got a diagnosis of the disease, we were confused. Whom can we turn to... In the beginning she introduced someone with the same symptoms to me.”

B. Logistical Navigation Assistance

The navigator provided:

- Assistance with **making appointments and filling out forms**. The navigator knew exactly what to do to make things most convenient and efficient.
- **Assistance in applying for Medicare** and explaining coverage of services.
- **Explaining to patients what would occur at the visits and accompanying them to the doctor’s appointments** (e.g. one woman mentioned, “Usually, she (the navigator) suggested that we shouldn’t wear lotion or perfume” for the doctor and mammogram exams.”
- **Translation/ Interpretation** (since most of the women were monolingual). One woman expressed, “For example, when the doctor wanted me to sign something, I would like to have the Thai translation under the English version. At that hospital, there might be something like that, but it was not clear. There were Chinese and Spanish translations, but there was no Thai translation. As in the case when they sent us for mammogram and the film was not clear and they sent us there for the second time. I would be able to sign the paper if there was a Thai translation. I would not need an interpreter then because I could understand some English. But I couldn’t write. When they asked me to fill the blank, I didn’t know.” Another participant expressed, “We would be mute without an interpreter.”



- **Transportation** to and from appointments. One woman expressed, *“It takes over an hour to wait for the medication. It is difficult for people who live far away and can’t drive, and the children have to go to work.”*

C. Emotional or Interpersonal Navigation Assistance

Many women consistently emphasized the importance of having the navigator provide moral support during the doctor appointments and exams and help to comfort and ease their worry and anxiety. One woman mentioned that *“She made us feel warm and comfortable just like going with the children or grandchildren.”*

D. Appraisal or Affirmation Navigation Assistance

Following up and discussing test results was extremely important in explaining the purpose of the tests, reassuring the women with the results, educating them about the medical system, their health status, and health care needs.

Helping with other follow up or next steps in care.

Many women mentioned that they appreciated the navigator doing extra things to help them, such as introducing them to others going through the same problems, or calling to check in on their health and ask about their families. Many women in treatment or recovery from breast cancer also greatly appreciated that the navigator would cook and bring meals for them during their care.

V. COMMUNICATION WITH PROVIDERS

Participants also mentioned the importance of having the community health navigator serve as a

facilitator in their interactions and communications with providers. The navigator helped to explain confusing things to the patient, such as interpreting medical terminology. One woman mentioned, *“I might understand the Thai or Chinese doctors. But I need an interpreter to interpret what the Caucasian doctors say because I don’t understand them.”* Some participants said they understood basic English and could speak and listen, but one patient expressed, *“It is not the same as when we have an interpreter. The medical terminology and speaking language are not the same.”* Others mentioned that if they didn’t have community health navigators for appointments, *“We wouldn’t know anything. If we go to see a doctor on our own, we wouldn’t know anything. It would be very difficult.”* One participant shared a story of how she had asked a friend to interpret for her during a doctor’s appointment and her friend mistakenly told her that the doctor said she would die that year. Having a community health navigator, who is also a trained health interpreter, would help to avoid such devastating misunderstandings. One woman noted, *“We want to know what the doctors said to us and what symptoms we have. We knew some of what they said but not well enough. We were not confident of understanding what the doctors said. We would like to make sure of what the doctors said and didn’t mistakenly understand it the other way around. This is important.”*

Many women also mentioned that having a community health navigator helped them to *feel more “confident” and “brave” to ask the doctor questions*, especially questions that the patients were usually shy about asking – such as issues regarding female organs or sexual activity (*“sleeping with husband or boyfriend”*). One woman who had appointments without a navigator or interpreter in the past shared, *“Sometimes when I was listening to the doctors, they spoke so naturally that I was afraid to ask them. They might think that I am stupid if I ask them. As a result, I just said ‘Yes. Yes.’”* Many participants also noted that they felt less worry and stress because the navigators would know what questions to ask. One woman expressed, *“For example, because she went with us enough times and got suspicious and asked the doctor what was wrong with us and it was dangerous, what stage, and whether or not the doctor can tell us what was wrong with us. She sort of knew what the questions were. Then the doctor answer her.”* Another participant noted that navigators become well-equipped for

guiding patients because *“she or he will learn from our problems and asks the doctors about those problems. That was how she/he will accumulate the knowledge and pass on to future clients.”*

Participants also appreciated that the navigator helped the doctors understand their cultural backgrounds and histories. One woman expressed: *“They asked about our history, ancestors, and whether or not it is genetic. Did it happen to your parents? Sometimes, our parents didn’t have that symptom, but we did. What caused the problem? We have to tell them.”* Another participant mentioned, *“In our Thai culture, for instance, we are shy when we get mammogram and Pap smear. That is our culture. I believe that before we came to America, we all didn’t get Pap smear in Thailand due to the difference in our cultures. That is one reason, isn’t it? That is our culture. In Thailand, women do not want to get mammogram or Pap smear because they are shy. That is the number one reason.”*

VI. QUALITIES/ SKILLS DESIRED FOR NAVIGATORS

When the participants were asked about what makes a breast health navigator helpful and what kinds of information and skills an ideal navigator should have, all the different types of navigation assistance mentioned above in section IV were mentioned. Women wanted navigators who were knowledgeable and could provide accurate information about breast cancer and the process of getting care and access to health resources. This was especially important for those women in the treatment and rehabilitation/ recovery stages. Participants across all focus groups also wanted someone who could help them with the logistics of getting care (including being able to interpret, help with doctor appointments, transportation, etc. as mentioned above in Section IV.B.). However, the most often- mentioned categories or types of qualities and skills participants wanted to see for their navigators were the emotional/ interpersonal and appraisal/ affirmation characteristics mentioned above in Sections IV.C. and IV.D. Some of the adjectives participants used to describe their ideal navigators included: sincere, well-rounded, friendly, attentive, trusting, warm, nice, comfortable, efficient, prompt, patient, understanding, and caring. One woman nicely summed up these characteristics by saying, *“Good people skills and can communicate well. That is the most important.”* Many

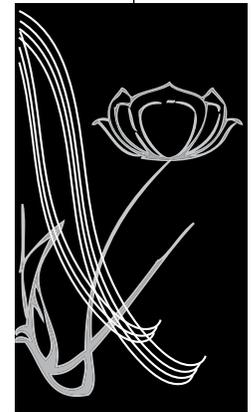
participants noted the importance of having the health navigators affirm them as not only patients or clients but as individuals with families whom the navigators truly cared about. This is reflected in one woman’s comment about the closeness she felt with her navigator, *“She knows my whole family, from my children to my husband...she is very friendly.”* Another participant mentioned her desire for a navigator who is sincere: *“It is hard to find a person who is sincere to you. We are far away from our hometown and have limited education. Someone who has education is fine and can get treated. But someone without education and power would get no treatment or had nowhere to go or no one to turn to. It will be good if we can get help in this matter.”*

When asked about whether the gender of the navigator was important, some participants said they did not care as long as the navigator could help them. But most mentioned that they would prefer to have a female navigator for the reasons noted in the following quote: *“Sometimes a female health navigator might know more about female issues and we won’t feel uncomfortable with her in some matters.”*

VII. CHANGES/IMPROVEMENTS

Overall, participants were very satisfied with the navigation services they received. They wanted access to more navigators and navigation services for the Thai community. Some women proposed establishing a health center in North Hollywood because they felt the Thai community was in “dire need” for more quality breast and general health care services. One participant wondered about her navigator: *“Is it tiring for her? I don’t know. Sometimes I was wondering and would like to ask whether or not she is tired or has a lot of patients. Often times we don’t want to bother her too much, but we need her.”*

Vietnamese Community FOCUS GROUP FINDINGS



From January 2008 through May 2008, Vietnamese interviewers conducted three focus groups with a total of 12 Vietnamese women regarding the breast health navigation services they received through OCAPICA's REACH 2010 PATH for Women Program. The three focus groups consisted of women who had received navigation assistance for breast health services. The ages of the 12 participants ranged from 45 to 63. Most participants were limited English proficient and had no health insurance.

I. GENERAL HEALTH NEEDS

A. Medical Needs

When focus group participants were asked what types of help they needed for health care in general, many mentioned that they needed medical care for women's health care such as, breast and cervical health, as well as osteoporosis, diabetes, arthritis, and other common screenings. Participants wanted health care clinics where they could get all their screenings and results at one location rather than having to go to different clinics and centers, because it requires too much time off from work. Some indicated that when they received screenings at different sites, their primary care physician never received the results so they felt that their care was not coordinated well. In addition, many were uninsured and utilizing MSI (Medical Services for the Indigent) because they did not yet qualify for Medicare due to age. Some seemed to be waiting to obtain Medicare so they could seek care.

B. Lack of Language Services, Transportation, Insurance, Appointments, Follow Up

One of the top needs expressed by the women was to have bilingual providers or interpreters for their health care appointments. Participants felt that when the providers or an interpreter was available, they felt the providers understood them better and they could make informed decisions. One participant indicated that when they go to an "American clinic," *"the doctors do not talk much and do not have the closeness that Vietnamese doctors would have."* However, another participant indicated when she went to an "American Hospital" and *"they had a translator, they were very sincere and allowed me to see the mammogram films, other places don't do that."*

Other needs or challenges to access quality health care included lack of insurance; not knowing where to go for services, and wanting one permanent location to be able to go for services; long wait times; having to go to multiple locations; and not being able to take time off from work.



II. BREAST HEALTH CARE ASSISTANCE RESOURCES

Many women in the screening focus groups mentioned that it would be good to have one site to get all of their breast health and other care to avoid confusion and save time. One participant said, *"I wonder why we only are covered for breast treatments but not for the other lower parts of the body. Why is the service only offered for a certain body part but for not all?"* Another participant commented, *"That's why I'd like to have all tests done at the same place since it's very confusing to*



have many different testing places. Right now, it is good that we are offered free screening services; however, sometimes, we get sent to different places for our tests. It is very time consuming. Our mammogram films might be placed at different places, so it's hard for the doctors to keep track and compare the results. Hence, I suggest that we keep everything at one place so that when we need help we know where to go to. It is easier to keep track of our processes that way."

Another participant said, "That's why sometimes we have received requests from two or three different places regarding our breast examination. It is not centralized. I might get tested at one center this year and at another next year. Therefore, like you said earlier, our mammogram films might be scattered at different places."

Having services and tests centralized at one site was discussed at length among one of the Vietnamese focus groups. Another participant said that having breast screenings and diagnostic tests at one location would help everyone know where to go, as well as women could refer friends and families to this permanent location.

III. KNOWLEDGE OF NAVIGATION SERVICES

Participants learned about the breast health navigation services provided by PATH for Women health navigators through Vietnamese media ads and radio; friends/ word of mouth/referrals; and health fairs at community venues.

IV. NAVIGATION SERVICES PROVIDED

Informational/Educational Navigation Assistance

Women felt that community health navigators were important in helping them to understand what preventive screening methods were necessary and could help to keep women updated on the latest health information. Many focus group participants felt that community health navigators would be extremely helpful to new patients who did not know the health system, the providers, and the health issue. Once a patient was familiar with the health care provider/system and interpreters were available, then many patients could navigate by themselves. Other participants felt that due to the confusion of the health care system and the lack of coordination between screening services, treatment, and primary care services, well- trained bilingual health navigators would still be essential to assist the women and their families on a regular basis.

Logistical Navigation Assistance

Knowledge of the health care system

The participants felt that having a bilingual navigator who was well trained and knew the health care system well would be ideal. They prioritized having someone who knew the health care system well, over the navigator's gender.

Appointment scheduling and reminders:

Participants wanted assistance in appointment scheduling, reminders, and filling out difficult paperwork. One participant discussed the process of scheduling for some of the exams can be "lengthy and troublesome," thus having a navigator that was regularly available during provider hours would be very helpful.

The focus group facilitator mentioned that while transportation is an important issue in the Vietnamese community, this topic was not mentioned during the focus group, perhaps because patients often rely on public transportation or their family and friends to provide the transportation for them.

Interpretation and support

All the women in the focus groups identified the need for interpretation and support. Even if the women have Vietnamese health care providers, the need for interpreters in screening, diagnostic, and treatment services are needed. One participant gave the example of not having an interpreter available in the emergency room and not understanding why they didn't do more for her son; *"If I had a health navigator with me, she can translate for me and then I can understand what they are saying and they can understand what I am saying."*

Emotional or Interpersonal Navigation Assistance

Many women noted that the health navigator provided social support by being there with them for their medical visits. This support made the women feel at ease and pleased with their medical visits:

"...the health navigator provides me with mental and emotional support. They helped me feel confident and much less worried. The mental aspect, I think is very important and helpful for us during the course of the medical care."

"A professional health navigator must be trained to address all the issues that a patient may have. ...he or she must know how to be friendly so that the patients would not have to feel ashamed for having to depend on others."

Appraisal or Affirmation Navigation Assistance

Health navigators in the Vietnamese community also helped women to understand their medical visits and to follow up with test results.

"Usually the navigator took care of everything for us. Then they gave us the address and contact information so we could make the appointment. They often require us to contact and let them know after we are done. In case there is something wrong, they will contact us about the test's result. In my case, after doing some tests, they suspected ovarian cancer and sent me to (hospital) for further tests. Fortunately, they found out it was normal and they (navigators) were very happy to let me know the news."

"As I did not know anything, having someone there to guide and help me was certainly assuring."

V. COMMUNICATION WITH PROVIDERS

All participants felt that health navigators were important in facilitating communication and promoting providers' understanding of the women's cultural beliefs and practices, especially when the provider was not Vietnamese. Navigators also helped to explain each step of the medical appointment and helped the women comprehend the health situation and medical care results. Many women mentioned that they spoke little to no English and the navigator helped them to communicate with their provider:

"If there are Vietnamese translators, we will not be afraid to ask for help. When there are no Vietnamese we keep on being afraid and not asking anyone for help. Even if we ask and they answer, we do not understand. This has happened to me before as well. Luckily I know a little English, but it does not always flow smoothly."

Participants felt that navigators improved understanding and communication with providers and wanted them available regularly during providers' hours. They understood that health navigators would not be available 24/7 but really appreciated having them during regular clinic hours. *"A health navigator should be present daily, during the same working hours as the doctors. For patients who have the experience, they don't need the health navigators. For new patients without the proper understanding, health navigators can be there to help them."*

VI. QUALITIES/ SKILLS DESIRED FOR NAVIGATORS

Participants wanted their navigators to be professionally trained (e.g. trained on medical terminology and other areas to provide the best quality service available), have health knowledge, specifically about breast and cervical health, and to keep up to date on the latest health information. They wanted their navigators to be bilingual and bicultural and not only interpret for them, but also *explain* medical terminology so that they could better understand their health situation. Gender was not an important issue unless it related to women's health, then participants felt more comfortable having female



navigators. Participants wanted their navigators to be empathetic and nonjudgmental so they would not be ashamed of their illness.

“A health navigator must know how to be multilingual and be able to help with issues that patients may be scared of. A navigator must be caring, gentle and provide care thoughtfully so that patients can feel like they are not so bad or scared about their sickness no matter how sick they may be.”

Another participant felt that the health navigator *“must have the knowledge and be up to date with health information; if there is a new illness or a new food, inform everyone so everyone would know to improve their health.”*

Participants also wanted the community health navigator to help them understand how to navigate the health system and had numerous suggestions on coordinating care at one or a few facilities to increase the knowledge of the Vietnamese community on where to obtain services. Some participants asked about health care financing and how insurance works, and wanted the navigators to also understand this so they could explain to patients why certain screenings are covered and other screenings and treatment are not. Participants felt that navigators could help reduce confusion and misunderstandings by explaining to them more about their appointments and the way the health care system works. Finally, participants also saw the health navigators as advocates, helping patients to stand up for their rights and be able to make informed decisions about their treatment options and medicines.

VII. CHANGES/ IMPROVEMENTS

Overall, women were very satisfied with the services currently provided by patient navigators. They felt that it was important to have all of these services: assistance with making appointments, appointment reminders, assistance with paperwork/ forms, interpretation, social support, education about health issues, and transportation. They wanted screenings and services to be more coordinated and that full services, from screenings to results, would be made available at a single facility so they did not have to go to so many different sites and take so much time off from work. They also felt that health navigators were very important to utilize and that clinics and health care providers should have them available at regular hours, so that patients could receive appropriate care. Participants felt that once they learned the health care system, about their health needs, and had language access through interpreters, they would be more able to navigate the health system themselves so that health navigators could focus upon new patients who are more challenged in accessing care.

INTERVIEWS WITH NAVIGATORS

From January through December of 2008, a total of 10 female community-based health navigators (at least two to three navigators each from the Cambodian, Laotian, Thai, and Vietnamese communities) were interviewed regarding their experiences and perspectives on community-based navigation for breast health services. All navigators were part of the REACH 2010 PATH for Women Program between 2000 – 2005. Each navigator was interviewed once, and all interviews were conducted in English or Vietnamese. The average interview time was 1 ½ hours, although a few interviews exceeded two hours in length. All interviews were audio-recorded and transcribed verbatim by research staff and volunteers. A 13-question semi-structured interview guide was used to interview all the navigators.

I. TYPES OF NAVIGATION SERVICES PROVIDED

When asked about the kinds of services navigators provided to their patients, navigators mentioned services in all four categories of Social Support outlined in the “Methods” section above: Information/Education; Logistical/Instrumental; Emotional/Affective Interpersonal; and Appraisal/ Affirmation Navigation Assistance.

A. Informational/ Educational Navigation Assistance

Since the community health navigators worked with many women in the Southeast Asian communities who were newer immigrants and from low-income backgrounds, all navigators felt that outreach and education were key aspects of their work. Educational outreach was often the first step in increasing

community knowledge and awareness about breast health. In order to do the outreach, all of the navigators talked about the importance of establishing trust with community members and leaders. One navigator expressed, “Well, one of the things is we’ve been doing outreach - like temples and churches and all of that because of that building trust and relationship and, you know, between the sites and our agency, especially since like me, now we know each other well, that trust is right there, you know. People receive the services from our agency...and so now when we want to do something or we want to do some outreach for other programs, it makes it much, much easier for us to go out there and then they support you and the needs that you want to do your job: things like that. It really helps make it easier to perform your job.”

Navigators from the Cambodian, Thai, and

Vietnamese communities also felt that ethnic media (i.e. in-language newspapers, radio, TV) was one of the most effective ways to conduct outreach. All navigators also felt that word of mouth and outreach to stores, businesses, temples/ churches, community-based organizations, as well as at health fairs, were particularly effective outreach strategies.

B. Logistical/ Instrumental Navigation Assistance

The most important logistical navigation services provided by the navigators included:



- **Translation/Interpretation** and explaining procedures in general
- **Making appointments and filling out forms** (because the navigator would know exactly what to do to make things most convenient and efficient).
- **Applying for insurance or other financial assistance** and explaining coverage of services.
- **Preparing patients and accompanying them to doctor's appointments**
- **Transportation** to and from appointments.
- **Explaining test results and follow up procedures.**

The Vietnamese health navigators felt that translation and interpretation services were not as critical for their clients due to the availability of Vietnamese-speaking providers. They still felt, however, that they acted as “interpreters” in explaining the medical terms and procedures, as some doctors did not have time to provide these explanations.

All community health navigators felt that the education and outreach they conducted helped them to achieve one of the most important outcomes of their job: to get the women to go to the doctor

“If you give them only information and they never see the doctor, that’s like useless information, and that’s why I say just to bring, to get them physically to see the doctor, that’s the most important service.”

Oftentimes, community health navigators from all four ethnic communities also emphasized how they supported their patients throughout the entire cancer screening and care process. Many of the navigators noted that because they knew the health system well in their communities, they were often able to navigate the women through their appointments much more quickly and effectively by knowing when and where to go, who to see, and what to do for specific services. The health navigators also noted that they provided logistical help not only to their clients, but also sometimes to the clients’ families and support networks as well. One navigator expressed, *“there’s a lot of things that you do, you not just go there, interpreting, and then you’re leaving. You bring the patient in there, you really have to hold hands, take the patient to the provider sites, and help client fill out their medical history forms, and especially since we’re talking about breast health here, there’s many women who don’t*

have any health insurance, and they have to apply for the BCEDP programs, then they have to fill out all these requirement forms...our time, you know, you really have to be flexible, to earn the client or the patient’s trust, so our time has to be very flexible, you know, not just the individual patient that you’re helping with, but you have to be kind of flexible for the patient’s family, that means, you know, can be husband, children, grandparents: whoever needs the health information. Then you have to be there and ready to provide the information to them.”

C. Emotional or Interpersonal Navigation Assistance

Most of the community health navigators felt that the emotional and interpersonal aspects of patient navigation were some of the most important services they provided. They felt that the trusting and respectful relationships that they formed with the women and leaders in their community were the foundation for their effectiveness. One navigator mentioned, *“And then for the women, you know, the most important is building trust – if you give them good service, they always... – because I still have patients been with me for 5 years, and even the program end,... I work here for 9 years and those women are still coming.”*

One health navigator explained how she established this trust through her body language and knowing the customs and cultural expectations of her clients: *“In terms of speaking with the women, you use your tone of voice, and your gestures to them, for example...if you like, distance yourself from the, and make them feel like, ‘Oh maybe I’m not healthy enough (for her to) want to sit next to me – or maybe I’m dirty or poor or not clean enough or poor or whatever.’ Because that body language, it shows, you know, it shows. To do that is not, it’s a no-no. For me, I talk to them, I sit close to them and also to build a relationship I’m always talking to them, asking them questions about their family, their life...”*

Usually, all the health navigators took great care and invested a lot of time and effort in getting women to be comfortable with them and to trust them. One navigator mentioned, *“I talk to them because I use quality time. When you have a chance to sit with somebody, your family, one person, its more than you talking or presenting for many people because once they start with you, she will never go away and she’s going to keep (coming to you) and she will refer somebody, and she’s (gonna)(also) encourage somebody to you.”*

D. Appraisal or Affirmation Navigation Assistance

In addition to the emotional and interpersonal navigation assistance, many of the navigators mentioned the importance of following up with the patients, to see how they were doing after their appointments. One navigator expressed, *“First we try to make them feel a little bit comfortable and know us, and we call and, you know, like chat a little bit, and so, like one or two times... and then later on they grant their trust to us and then when the appointment comes we call them again, and after we finish with the appointment and everything, we have to follow up with them again ... you know, did the doctor send you any note, or any, like any result for the test or anything...”*

All community health navigators emphasized the importance of guiding women throughout the cancer care continuum and not only navigating them through the screening exams, but also through diagnosis, treatment, rehabilitation, and any other issues, if needed. One navigator noted, *“Okay, the most important thing is not just like get screened and it gets done, but I have to work all the way through: they need referral when they need help, when they need treatment, everything, it’s not just for herself, for her family, her children, whatever they need help, I refer them or I find the service for them.”* Other health navigators talked about the importance of having support groups: *“From the support group I have them call, talk to other survivors who have similar experience. When they say ‘you have breast cancer, you gonna get surgery and you gonna get chemotherapy’ before that I have them listen to the people who have the experience so that don’t feel so scared, to be ready.”* Another navigator mentioned, *“I always invite a cancer survivor coming with me to the presentation and let the cancer survivor express herself, sharing her experience, telling her story to the audience, and that works very positively with the audience.”*

Many of the health navigators not only helped the women with breast health concerns, but also followed up with them and their families on many other issues, such as immigration, social services, and/ or general life issues. One navigator mentioned, *“You know, sometime I’m not just helping for the cancer prevention. Sometime you have something in the family, I help too. Yeah, sometime they have problem with the bill or something, I help too. That’s why they know me, they pass to other people.”* Another navigator mentioned, *“These days, in the community, everything has changed, you know? Women now, the older women, they’re alone.*

Husbands left them, for younger woman... Oh, so many things going on the community now, stress. So that’s why when you see them, you provide service to them; it’s not just bring them to the doctor. You provide them counseling and encouragement.”

A few of the navigators mentioned that one of the challenging aspects of their job was that they often had to deal with these additional issues because their clients did not know where else to turn for help. While all the navigators were able to refer their clients to the services they needed, they wished that they could do more to help the women with their complex problems.

Several navigators also discussed the importance of teaching their clients to be self-sufficient so that they could eventually learn to navigate, and help others to navigate the health care system by themselves. One navigator expressed that *“There are always newcomers to the country that need those (navigation) services... but for the next generation that have been here, we need to see in the perspective of the future that we give them the tools, we give them all the information, we try to motivate and guide, and let them try.”*

II. QUALITIES/ SKILLS DESIRED FOR NAVIGATORS

When the community health navigators were asked about what they thought made a breast health navigator helpful and what kinds of information and skills an ideal navigator should have, all talked about the different types of navigation assistance mentioned above: being able to provide all the educational and logistical assistance and having interpersonal skills (e.g. being kind, friendly, patient, caring, culturally sensitive and understanding, professional, etc.). In addition, some talked about the gender of the navigator as being important. One navigator said, *“I think being a woman. I don’t know if they assume that that might be the case, or maybe that’s just the way our culture is... but in terms of breast and cervical cancer, I would feel more comfortable if - I’m trying to imagine myself in the patient’s shoes. I would want to talk to someone that’s female... That, another thing is to just be honest, to be knowledgeable, to be polite and professional...”*

Many navigators also talked about the communication skills that navigators should have in working with the providers, and being able to establish mutually beneficial relationships. One

navigator gave an instance of talking with a provider: *“He didn’t know that we are also there as a resource for them. So I think, in a way, if we kind of make the doctors aware of that, that we are also there as a resource for them, and their patients, so that it’s a continuum of care, that it’s not just a one way referral and that’s all.”*

III. TRAININGS AND CONTINUING EDUCATION OPPORTUNITIES

When asked about the types of training that all navigators should have, navigators consistently mentioned the following top training areas: Interpretation and translation – especially for medical terminology

- Knowledge about breast health and breast cancer
- Continuing education on the latest medical developments in the breast health field (e.g. new technology such as digital mammograms)
- Knowing about available resources and where to refer women for health services
- Knowing the roles, responsibilities, and boundaries for navigators (what they should and should not provide in terms of services).
- Knowing about patient confidentiality and ensuring we protect this.
- Diversity training and knowing how to work with different cultural communities.

Most of the interviewed community health navigators also mentioned the importance of receiving some type of certification as trained health navigators. They felt that having a formal certification or training process/ degree program would help

them to be better acknowledged and valued by both providers and patients. Some felt that being certified might also help to increase their pay because their services and the high quality would be more formally recognized and utilized.

In evaluating the topics that should be included in a training curriculum, navigators consistently ranked the following as priority areas:

1. Knowing the language, customs and beliefs of patients
2. Knowing the different roles of the health navigator and what services they can provide (e.g. transportation, making appointments, filling out paperwork, giving advice, etc.)
3. Knowing about the women’s breast and about breast cancer (e.g. how does it develop, what causes it, can we prevent it)
4. Knowing how to talk with the doctor to help the patient
5. The cancer care process – what to expect from screening exams; and if a person is diagnosed, what are her treatment options; and surviving/ recovering from cancer.

INTERVIEWS WITH PROVIDERS

From January through December 2008, a total of 15 health care provider interviews (including physicians, nurses, radiologists/mammography technologists, and medical assistants) were conducted about their experiences and perspectives in working with bilingual and bicultural health navigators serving the Cambodian, Laotian, Thai and Vietnamese communities for breast health services. Providers were identified via a network of health navigators from the PATH for Women program, serving the four Southeast Asian communities in Southern California. Each provider was interviewed once using a semi-structured interview guide consisting of 19 questions that was developed by the research team. All interviews ranged from 30 minutes to 90 minutes, with an average interview time of 35 to 45 minutes. All interviews were audio-recorded and transcribed verbatim by research staff and volunteers. Most interviews were conducted in English, while a few were conducted partially in Vietnamese. All of the interviews were transcribed and analyzed in English.

I. DEFINING COMMUNITY-BASED NAVIGATION

All the providers have worked with or have been exposed to health navigators at one point in time and spoke of the importance of understanding cultural beliefs and health practices of their patients. Most importantly, interpretation was identified as essential to provide quality health care. All providers noted that due to the diverse communities in Los Angeles and Orange counties, they were challenged to be able to provide high quality health care to all. For many, health navigators helped to address these challenges and helped to bridge the language and cultural barriers between patients and providers.

The following represents the various roles of health navigators as described by the interview participants:

A. Information/Educational Navigation

- Link community members to health care services
- Help community members understand where and how to get services
- Provide information on what services are provided

B. Logistical/Instrumental Navigation

- Make appointments and help to fill out forms/paperwork
- Help to apply for insurance/financial assistance and benefits programs

- Prepare patients for health appointments by helping to explain what to expect
- Provide interpretation and language assistance for patients and providers
- Provide transportation for patients to and from the appointments
- Advocate for the patients in the health care system, beyond the care plan and the clinical obligation of the provider
- Help to remind patients of appointments and follow through on care plans

A navigator and interpreter "...helps a lot in communication. It makes me [the provider] understand them, their problems better, and it helps communicate what I want to provide care to them better..."

A provider responding to a question about how a health navigator impacts communication between a patient and provider noted, *"I think the communication has been good, really effective, and the instructions and the information given to the patients translated to the patients. I think it's been very effective."*

C. Emotional/Interpersonal Navigation

- Provide support, including emotional support – help people (particularly those seeking health care) not to feel alone
- Serve as a familiar face patients can identify with
- Help to build trust with providers



One provider mentioned: *"I see them as very caring people, you know, they sit with the patient, explain with the patient, whatever help them...just like their own family members."*

Many providers felt that navigators helped to make their jobs easier by creating trust with the patients: *"By all means, it really, it really does help, because you know, if you have a patient who trusts you because they trust their navigator, and then they realize we are on their side, if you have a patient relationship established and there is mutual trust, the patient is more likely to believe you...they will follow through with the plan...and they'll be much more compliant and the outcomes is much better. And then if you have a patient who doesn't understand you, or doesn't trust you, who doesn't feel their needs are met, they will not follow you."*

Another provider spoke about how a health navigator helps to create comfort for and with patients: *"You know, because you get a patient who doesn't know what's happening, they just get rigid and then you're fighting...you know...it's very difficult."*

D. Appraisal/Affirmation Navigation

- Help to increase patient confidence and willingness to participate in their health care
- Increase a patients' readiness to obtain breast screening and treatment services
- Help to identify gaps in the health care system

A provider speaks about how the patient feels having a health navigator with them in health care visits, *"I think it builds confidence, in us too, I think it totally builds [the patient's]... confidence in us and their willingness to participate in treatment, in the recommended treatments*

or tests that are being recommended because...because it becomes easy to understand what...what we're trying to say and what the value and importance of that is."

Another provider spoke about how health navigators assist beyond the clinical visit and care plan, *"...with her navigation skills, it's really opened my eyes to some of the challenges even outside of our own system and the...the real gaps in coverage [speaking specifically about insurance and financial coverage]."* A navigator is valuable and helps *"...to keep people from falling into the cracks...they get to them in a timely way, to get the treatment that is available, to empower [the patient] with the information they need to make the best decisions about their life."*

Providers shared varying experiences of working with health navigators, but all noted the values and challenges of working with diverse communities and the roles health navigators played in facilitating the patient-provider relationship. Overall, the providers spoke very positively about the health navigators with whom they had worked, and noted that they were integral in creating a seamless health care visit with their patients. Health navigators served as cultural and linguistic brokers, helping the provider to communicate clearly and coherently with the patient, and ensuring appropriate medical understanding and confidentiality for health topic discussions. Most importantly, health navigators made communication between the patient and provider easier and more efficient, allowing for a better health care visit. Navigators also helped providers to better understand their patients' problems and concerns, and enabled them to provide better care.

II. QUALITIES/ SKILLS DESIRED FOR NAVIGATORS

The interviewed participants discussed the following qualities and skills that they wanted to have in a health navigator:

- Patient, kind, and empathetic in explaining the health process
- Know how to communicate between the patient and provider
- Know and understand the paperwork process
- Know protocols and programs such as Every Woman Counts
- Know the language and the culture of the patients

- Proficient in both English and the patient’s language
- Provide social support, care, and empathy
- Be knowledgeable of the health screening process, as well as treatment and recovery
- Be knowledgeable about breast cancer screening techniques/methods and treatments
- Know medical terminology
- Build a relationship with patients and create trust between the patient and provider
- Understand the health care system
- Be professional and not get emotionally involved

7. Training on medical terminology
8. Training opportunities through city college programs
9. Navigators should receive certification for their trainings and hours of service learning
10. Opportunities to develop better institutional systems of training

III. TRAININGS AND EDUCATION OPPORTUNITIES

As a result of the discussion on qualities and skills that a health navigator should have, all interview participants were also asked questions about the types of training and education that health navigators should have. Many of the skills mentioned above were also skills providers felt were imperative for a training curriculum for health navigators.

Providers consistently ranked the following as top priority areas that should be included in a training curriculum to keep navigators up to date on the latest information:

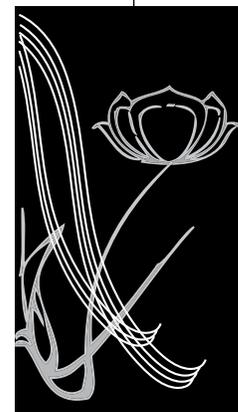
1. Knowing about the women’s breast and about breast cancer (e.g. how does it develop, what causes it, can we prevent it)
2. The cancer care process – what to expect from screening exams; and if a person is diagnosed, what are her treatment options; and surviving and recovering from cancer
3. Knowing the language and customs and beliefs of patients
4. Protecting patient confidentiality – protecting any private information about the patient
5. Knowing the different roles of the health navigator and what services they can provide (e.g. transportation, making appointments, filling out paperwork, giving advice, etc.)
6. Understanding all the programs that provide health care in the community and when to send patients to the right ones

While all providers noted that some form of training was important to providing services as a health navigator, most stated that their hospitals or private offices did not have such training programs in place. Many felt that such training programs would be important, but were not sure what resources were available to provide this training.

All providers interviewed discussed the value of a health navigator, but they also discussed key challenges in creating a system of health navigators for health care services, including recruiting and retaining individuals to serve as health navigators. In many cases, community-based navigators are volunteers and are not compensated for their time and efforts. Providers spoke about finding resources to support navigators and their time. While many recognized the added benefit of these services, their sites (e.g. practices, clinics or hospitals) did not have the financial resources to support such services. Many sites had existing bilingual clinical staff who also served as on-site interpreters, but if such staff were not available, providers lacked other affordable options. All providers mentioned the telephone language services as a resource, but many shared that face-to-face interpretation services were preferred and overall, were better services. Outside of these existing resources, means to develop or fund health navigators were minimal to none. Lastly, while health navigators are important and have a great deal of knowledge about the health care system and health resources, providers emphasized that there needs to be clear roles and responsibilities; the health navigator is not the health care provider and should never provide medical advice.

Community FORUMS

Community forums were organized in each of the four communities to provide study findings for community members. In addition, presentations were made by invited guests such as doctors, nurses, and other health professionals regarding the importance of getting regular health check-ups as well as the services available to help community members obtain care. All forum presentations and materials were bilingual, with the primary language tailored to each of the ethnic communities. All study participants were invited to attend the forums. Attendees completed evaluation forms at the end of the events.



The Vietnamese community forum was held on November 15, 2008 in Westminster, CA. Over 70 people attended the forum. For many, it was their first time attending such a health forum. The age range of attendees was 26-78 years old, with the majority in their 50s and 60s.

The Cambodian community forum was held on December 11, 2008 in Long Beach, CA. Close to 100 people attended the forum, with a third of the audience composed of men who had attended along with their wives, daughters, and friends. The attendees ranged in age from 17 to 75, with the majority being in their 50s and 60s.

The Thai community forum was held on December 13, 2008 in North Hollywood, CA. Over 90 people attended the forum, including many breast cancer survivors. The age range of attendees was 29-89 years old, with the majority in their 50s and 60s.

The Laotian community forum was held on December 14, 2008 in Long Beach, CA. Over 70 people attended the forum, including some community members from the Cambodian and Thai communities who had worked with Families in Good Health and OCAPICA in the past. The participants ranged in age between 31-74 years old.

Overall, we received overwhelmingly positive comments regarding all the forums. Of the 177 evaluation forms collected from the four forums, close to 100% of the participants noted that the forums helped them to understand the importance of getting mammograms and Pap smears and that they would be more likely to encourage other women to get these screening tests. Almost all of the participants expressed that they learned something new from the forum and would be more likely to use and encourage others to use the navigation and interpretation services available for breast and cervical

health. Of those who had participated in the research study (focus groups or interviews), all commented that they felt their experience in general was “very good” or “good.”

Participants were also invited to write additional comments regarding any aspects of the forum or research study. A few of these comments are highlighted on the next page:



"The forum today was very good in educating the people in our community, especially in letting them know that they have a lot of resources and supportive people to help with their health care. I hope that your program will continue to provide these services for a long time, especially for older people. I support your programs wholeheartedly."

"The forum today was very good and helped me to learn and understand more about breast and cervical cancer, as well as the importance of having a health navigator and professional interpreter. I support your public health programs for Asian Pacific Islander women."

"I'm very interested about this program, and thank you about your explanation – very clear about health."

"This meeting benefits the ones with less education, giving them the chance to take care of themselves. I would like to thank everyone who arranged this meeting."

"I would like to see this kind of meeting more often in the future. People can exchange the information among each other."



CONCLUSIONS

Overall, the focus group participants, navigators, and providers we interviewed all shared similar concerns about the complexities of the health care system and discussed the value of having community-based health navigators in helping to connect the fragmented services of breast health care. In our study, participants described community health navigators as individuals who assist and support clients to access, utilize, and understand breast health services. Community health navigators also served as interpreters and educators who helped to explain medical terminology and procedures. Beyond these skills, community health navigators also provided social, logistical, and emotional support to enable clients to understand, practice, and maintain healthy screening behaviors. Community health navigators did not just help to steer clients through the health care appointment and health care system, they also helped clients to navigate community resources so that health services were readily accessible.

Training Curriculum

The list of potential topics that the three groups of respondents felt would be important to include in a training curriculum for future community health navigators working with Southeast Asian communities or other similarly underserved communities clearly contained significant overlap and agreement on the essential elements.

Similarities

The topics ranked as being the most important included the following that are listed in no particular order (see page 36 for rankings by group):

1. Knowing about the women's breast and about breast cancer (e.g. how does it develop, what causes it, can we prevent it, etc.).
2. Knowing what women can do live healthier lives and lower a woman's chance of getting breast cancer – e.g., diet/ nutrition, physical activity, dealing with stress, etc.
3. The cancer care process – what to expect from screening exams; what to do if diagnosed with cancer, what her treatment options are; and how to survive and recover from cancer.
4. Knowing the language and customs and beliefs of patients.
5. Knowing how to talk with the doctor to help the patient.
6. Knowing the different roles of the health navigator and what services they can provide (e.g. transportation, making appointments, filling out paperwork, giving advice, etc.).

7. Protecting patient confidentiality – protecting any private information about the patient.
8. Be trained and skilled in high quality and appropriate interpretation.
9. Knowledgeable about all the programs that provide health care in your community and when and how to send patients to the right ones.

Differences

Only one topic differed among the three groups interviewed: Knowing how to be good interpreters. While focus group participants from three of the communities ranked this as one of the top five topics, neither the navigators nor the providers ranked this topic in their top six. This is a noteworthy finding that warrants further research.

Another interesting finding is that while the focus group participants from all four communities and the navigators included the topic of "Knowing how to talk with the doctor to help the patient" in their top five, the providers did not rank this same topic in their top six. This may reflect certain assumptions being made by the providers that are not similarly assumed by the navigators or their clients.

Many of the top ranked topics from the checklist across all groups included informational/ educational areas, such as knowing the medical information on breast cancer; knowing what women can do to live healthier lives; and knowing about the entire cancer care process. This demonstrates that there is a common recognition among the navigators, providers, and their patients that a great need exists for more

outreach and education on breast health in these newly immigrated and low-income communities. Training health navigators in these areas is crucial to raising community awareness and decreasing the breast cancer incidence and mortality rates for these communities.

Important Qualities of the Navigators

Many of the focus group participants and all of the navigators emphasized the importance of the affective or interpersonal aspects of health navigation: knowing how to talk with the doctor to help the patient; knowing the language, customs, and beliefs of patients; knowing the different roles of the health navigator and what services they can provide; and protecting patient confidentiality. Combined with the informational and logistical aspects of health navigation skills, the ability to establish and build trusting interpersonal relationships seems to be the key in making navigation activities culturally meaningful and relevant for the community members they navigate.

Our study identified what seem to be the essential elements that should be included in developing a community-based breast health training curriculum. Key tasks common to community health navigators are: 1) assisting with making appointments, 2) filling out forms/ paperwork at appointments, 3) assisting with financial assistance and benefits programs, 4) translation and interpretation, 5) transportation, 6) logistical navigation and 7) emotional support. The information shared from the focus groups and interviews helps to more clearly define the roles of a community health navigator and encourages conversations about boundaries for such work, training and continued education, as well as financial and policy implications.

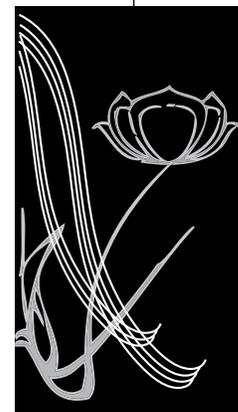
Our initial study proposed looking at the cultural differences that impacted access to health care. After reviewing the study data, we conclude that it is not the ethnic differences but rather the challenges in navigating the health care structure that creates barriers to access. Since the mainstream health care system is a manifestation of the dominant culture, it is not surprising that languages, health beliefs and health practices different from the western biomedical model compound the barriers of understanding and navigating the health care system. This is why community-based health navigators are especially

valuable in being able to bridge these language and cultural differences to help guide and support patients throughout the health care system and cancer care process.

From all three perspectives (navigator, patient, and provider), community health navigators appear to be the crucial links that help connect patients and providers throughout the complicated network of health care. These bilingual and bicultural community health navigators provide so much more than translation and interpretation services; they work to establish trusting relationships with community members to motivate them to get the important breast screening exams that lead to earlier detection and consequently, more effective treatment and recovery.

Unfortunately, no nationally recognized certification or degree programs exist for community health navigators. While there have been increasing efforts from many fronts in the last few years to fund, develop, and evaluate the important work that health navigators do, much more work is needed to advance the knowledge and practice in this growing health sector. Part of sustaining this health sector would also include developing a comprehensive roadmap that explains the various steps for navigating through the healthcare journey and the value of community health navigators in helping to navigate this road. This roadmap should ideally be developed with the input of patients, providers, and navigators (as we have begun to do with this study) so that all understand their roles in affecting the multi-faceted factors that impact access and utilization of health care services.

In a field where resources are continually lacking and health needs are continually increasing, there were high concerns expressed on how to best create equitable access to quality health care, particularly with health navigation. The thoughts shared by all the participants clearly demonstrate how community health navigators are an important part of the health care delivery system, especially in serving tremendously diverse communities that face extensive challenges to access and utilization; however, there were also concerns expressed about the maintenance



and sustainability of such programs. Important to note is the tremendous amount of time the health navigators and providers we spoke with spend on caring for diverse and underserved communities, including volunteering their time outside of their clinical and work hours. More resources and funding are clearly needed to train community-based health navigators and maximize the expertise and services provided by these important individuals and systems of care.

In conclusion, we thank all the study participants, including the focus group attendees, the navigators, and the providers who agreed to be interviewed for our study. We thank everyone involved for sharing their thoughts not only about navigation but also about breast health services in the Cambodian, Laotian, Thai and Vietnamese communities. Through all the focus groups and interviews, it was made very clear that it is not any one part that makes the system complete. All of us (community members, health advocates, navigators and providers, researchers, funders, and policy-makers) must work collectively to reduce cancer disparities and ensure improved health and well-being in our communities.

Please rank each topic below and let us know how important you think it is to include each topic in the training of community-based health navigators. Please circle the number corresponding to your answer for each topic. Then please rank the top five topics, with number 1 being the most important.

	Camb	Lao	Thai	VN	CHN	Provider
1. Knowing about the women’s breast and about breast cancer (e.g. how does it develop, what causes it, can we prevent it)	6		1	1	3	1
2. Knowing what women can do to live healthier lives and lower a woman’s chance of getting breast cancer. - e.g. diet/nutrition, physical activity, dealing with stress, etc		2	3	3	6	
3. The cancer care process – what to expect from screening exams; and if a person is diagnosed, what are her treatment options; and surviving and recovering from cancer			4	2	5	2
4. Knowing the language and customs and beliefs of patients	3			4	1	3
5. Knowing how to talk with the doctor to help the patient	4	3	2	5	4	
6. Knowing how to support the patient and their family when they are worried or upset						
7. Knowing the different roles of the health navigator and what services they can provide (e.g. transportation, making appointments, filling out paperwork, giving advice, etc.)	2	1			2	5
8. Protecting patient confidentiality – protecting any private information about the patient	5				6	4
9. How to manage support groups for survivors and caretakers						
10. Knowing how to work with cancer patients and their families when the end is near (End-of-Life Care)						
11. Knowing how to be good interpreters	1	5	5			
12. Knowing about kinds of health insurance – where to get it, what it covers, etc.						
13. Understanding all the programs that provide health care in your community and when to send patients to the right ones.		4				6
14. Patient rights – knowing about cancer legal and policy issues and how they affect patients						
15. Knowing where to get cancer information (internet, library, hospital) that the patient can understand and use						
16. Knowing about clinical trials (what are clinical trials and how do patients get involved?)						



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