A Qualitative Assessment of Community-Based Breast Health Navigation Services for Southeast Asian Women in Southern California: Recommendations for Developing a Navigator Training Curriculum

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Objectives. We identified key elements required for a training curriculum for Southeast Asian community-based health navigators (CBHNs), who help low-income, immigrant Cambodian, Laotian, Thai, and Vietnamese women negotiate cultural and systemic barriers to breast cancer screening and care in the United States.

Methods. We gathered the perspectives of 3 groups: CBHNs, community members, and their providers. We conducted 16 focus groups with 110 women representing different stages of the cancer care continuum and in-depth interviews with 15 providers and 10 navigators to identify the essential roles, skills, and interpersonal qualities that characterize successful CBHNs.

Results. The most important areas identified for training CBHNs were information (e.g., knowing pertinent medical information and how to navigate resources), logistics (transportation, interpretation), and affective interpersonal skills (understanding the language and cultural beliefs of patients, communicating with providers, establishing trust).

Conclusions. CBHNs serve a crucial role in building trust and making screening practices culturally meaningful, accessible, usable, and acceptable. Future research should focus on developing training curricula, policies, resources, and funding to better maximize the expertise and services that CBHNs provide and to expand our findings to other underserved communities. (*Am J Public Health.* 2011;101:87–93. doi:10.2105/AJPH.2009.176743)

Women of Southeast Asian (Cambodian, Laotian, Thai, and Vietnamese) backgrounds have some of the highest rates of breast cancer incidence and mortality in the United States,[1] yet they have the lowest rates of breast cancer screening among all ethnic groups in the country.[2,3] These women encounter enormous barriers to breast cancer screening and treatment services because of limited English proficiency, lack of transportation, high rates of poverty, and jobs that require long hours and leave little time for preventive health care.[4] In recent years, the importance of community-based health navigators (CBHNs)—outreach workers who improve access to and utilization of breast health services among underserved communities[5–17]—has increasingly been recognized.

Cancer health navigation can be defined broadly as services assisting individuals to overcome obstacles to timely cancer care, from screening to treatment and survivorship.[16] Many breast cancer studies describe hospital- or clinic-based health navigator programs.[18–21] Fewer studies have identified the skills and traits needed by health navigators in community settings, particularly among Southeast Asian communities in the United States.[22–27]

No nationally recognized curricula or certification or degree programs yet exist for training CBHNs. This gap prompted us to identify essential elements of community-based breast health navigation in 4 Southeast Asian communities in Southern California from the perspectives of multiple stakeholders. Our objective was to identify how CBHNs address cultural differences and systemic barriers to help low-income Southeast Asian women in Los Angeles County and Orange County, California (home to the nation's largest populations of Southeast Asian immigrants)[28] to navigate breast health services across the cancer care continuum.[29] Identifying core navigation elements is the first step toward developing a training curriculum that can be disseminated and replicated in other communities.

Three research questions guided our study: (1) What are the important individual, interpersonal, and community factors a breast health navigation program should address? (2) What types of culturally tailored strategies do CBHNs provide to support and enable Southeast Asian American women to obtain necessary services, from initial breast cancer screening exams through diagnostic, treatment, and rehabilitation–survivorship services or end-of-life care? (3) What specific training elements are needed in a community-based navigation program curriculum to prepare CBHNs to be effective in their role in promoting breast health?

We interviewed CBHNs, community members, and providers to assess the core elements of monthly CBHN training workshops conducted from 2000 to 2005 and to develop recommendations for a curriculum that could be culturally tailored and tested to increase CBHN effectiveness in diverse communities.

METHODS

CBHNs take a comprehensive approach to facilitating care beyond the formal health care system. The CBHNs in our study supported and guided community members in accessing numerous resources and medical and social service systems throughout the entire cancer care continuum, from initial screening exams through diagnosis, treatment, and end-of-life care.

We used theoretical concepts from the socioecological model and the social support literature to guide our overall study development. The socioecological model identifies 5 levels of influence for health-related behaviors: intrapersonal or individual factors, interpersonal factors, institutional or organizational factors, community factors, and public policy factors.[30]

The House model identifies 4 categories of social support,[31] as follows:

1. Informational–educational support: providing advice, suggestions, directives, referrals, and other information that a person can use to address problems.
2. Instrumental–logistical support: offering tangible aid and services, such as labor, money, and time, which directly assist a person in need.
3. Affective–emotional support: conveying empathy, moral support, love, trust, concern, and caring.
4. Appraisal support: giving affirmation and constructive feedback that is useful for the recipient's self-evaluation.

Our community-based participatory research effort involved several community organization partners. We designed the study as an inductive–qualitative evaluation of 1 component of the Racial and Ethnic Approaches to Community Health 2010 Promoting Access to Health for Pacific Islander and Southeast Asian Women (PATH for Women) Program,[32] which focused on addressing breast and cervical cancer disparities among Southeast Asian and Pacific Islander communities in Southern California. The CBHNs in our PATH for Women Program participated in monthly workshops totaling approximately 400 to 500 hours on various topics over 5 years (2000–2005), as well as continuous job development training. Over this period, our CBHNs conducted outreach to 60 350 Southeast Asian men and women (approximately 95% were women), educating them about breast and cervical cancer screenings, and helped 3309 Southeast Asian women to receive mammograms and Papanicolaou tests.

Recruitment and Data Collection

From December 2007 through September of 2008, we conducted focus groups with 110 Southeast Asian women recruited from the pool of past PATH for Women participants. We also conducted qualitative, semistructured, in-depth interviews with 10 of the 12 PATH for Women Program CBHNs (the 2 other CBHNs had moved and were not available). These 10 CBHNs then referred us to 20 providers with whom they had worked closely during the Racial and Ethnic Approaches to Community Health 2010 PATH for Women Program. Fifteen of the 20 providers agreed to be interviewed for our study.

We developed focus group and interview guides that incorporated themes and concepts from the socioecological model and social support literature. The focus group guide was translated into Khmer, Laotian, Thai, and Vietnamese languages. All study participants were asked about general breast health needs and resources, navigation services, communication between patients and providers, and what skills were needed by CBHNs. Participants were also asked to rank (in descending order) the skills provided by CBHNs and a list of topics for inclusion in a training curriculum for CBHNs. We compiled the list of topics from reviews of previous PATH for Women training workshops. Individual rankings of topics were then aggregated and counted to arrive at the top 5 topics for each ethnic group and type of respondent (patient, CBHN, provider).

Focus groups were conducted with a convenience sample of 110 consenting study participants who had received navigation services at different stages of the cancer care continuum: screening, diagnosis, treatment, recovery, and end of life. We conducted 16 focus groups (each averaging 1.5 hours) among the 4 Southeast Asian communities. All focus groups and interviews were transcribed verbatim and translated into English by trained bilingual and bicultural study staff and volunteers.

Analyses

To minimize response bias, we employed study recruiters and interviewers who were trained bicultural and bilingual program staff and who had not provided the community health navigation services to the women in the databases. We analyzed all focus groups and interviews with codebooks developed by the authors through an inductive and iterative process that focused on identifying major themes.[33,34] We organized data with ATLAS.ti version 5.[35]

Each researcher independently analyzed the focus group and interview data and noted major themes and domains of analysis through interrater consensus development, with the emergent codebooks serving as guides. All 4 researchers, along with the community organization partners, then met over several sessions to discuss our independent analyses and to identify similar associations between major themes and coded segments of text, as well as to identify new themes not previously noted in the preliminary codebooks. Any discrepancies or disagreements in interpretations of certain codes or themes were further clarified through our discussions to confirm the validity of the findings.[36,37]

RESULTS

We contacted 240 community members, and 110 agreed to participate in the focus groups, yielding an average response rate of 46%. However, the response rates differed among the 4 communities (Table 1). We had more difficulty recruiting women in the cancer stages of diagnosis, treatment, and recovery from the Cambodian, Laotian, and Vietnamese communities than we did from the Thai community. The 10 CBHNs we interviewed were all Southeast Asian women aged 40 to 64 years who lived in the communities they served. The 15 providers (13 women, 2 men) we interviewed were mainly non–Southeast Asian health care providers (except 4 who were Vietnamese), and most spoke only English. These 15 providers included 8 physicians, 4 nurses, 2 mammography technologists, and 1 medical assistant.

The focus groups and interviews yielded key themes in navigation that coincided with the 4 areas of social support: informational–educational, instrumental–logistical, affective–emotional, and appraisal services. Our major findings from the community, navigator, and provider perspectives are summarized in Table 2.

Community Perspectives

Community members were specific about the different types of support they received from the CBHNs. A key challenge faced by

TABLE 1—Characteristics of Southeast Asian Focus Group Participants and Community-Based Breast Health Navigators and Providers: Southeast Asian Breast Health Navigation Study, 2006–2008

				Stage of Cancer Continuum			
	Participants Contacted, No.	Actual Participants, No.	Response Rate, %	Screening, No.	Diagnosis, No.	Treatment, No.	Recovery, No.
Community focus groups							
Cambodians	39	32	82	24	6	0	2
Laotians	70	30	43	25	0	0	5
Thais	71	36	51	18	6	3	9
Vietnamese	60	12	20	12	0	0	0
Total	240	110	46	79	12	3	16
Interviews							
CBHNs	10	10	100	. . .	. . .	. . .	. . .
Providers	20	15	75	. . .	. . .	. . .	. . .
Total	30	25	83	. . .	. . .	. . .	. . .

Note. CBHN = community-based health navigator. Ellipses indicate category not applicable.

these women was informational: learning about the different parts of the fragmented health care service system, which required them to go to different locations to receive screenings and tests. Community members also noted that CBHNs provided women with information on screening exams and how to conduct breast self-examinations. One woman stated, “[I]n my country, I never know what a Pap smear or mammogram is . . . however, a navigator help me understand.”

Community members also noted that the CBHNs, with their bicultural backgrounds, health knowledge, and interpretation skills, played a key role in improving patient–doctor communications and helped patients make informed and culturally acceptable decisions regarding their health and treatment. One participant said, “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.”

Other elements were categorized as logistical support: scheduling appointments and identifying community resources and clinic sites for care; navigating the health care system beyond the medical encounter, including organizational and systemic policies and procedures (e.g., insurance coverage); and helping patients navigate community resources that linked to the mainstream health services (e.g., immigration issues and other family or social services).

Community members emphasized the emotional–affective support that CBHNs provided. Many women felt that the support and physical presence of CBHNs provided them with the confidence to engage in their own health care: “[T]he 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.” Another respondent said, “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.”

Having follow-up appraisal support also helped these women to better understand their visits and test results and empowered them to seek additional care and resources. For example, constructive feedback from CBHNs on health education and where to get services helped women to better understand preventive health and to seek access, as a participant explained: “Yes, the navigator was very helpful and explained every detail about all the situation.”

Navigator Perspectives

CBHNs shared similar thoughts on the types of services and support that they provided to community members. They spoke about the importance of outreach and education and building trust within the community. Educational outreach was often the first step in increasing community knowledge and awareness about breast health, as well as building trust in breast health programs. One CBHN stated,

> Well, one of the things we’ve been doing is 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. . . . Now we know each other well, that trust is right there, you know. And so now when . . . 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.

Like the focus group participants, the CBHNs felt that the most important logistical navigation services they provided were translating and interpreting, explaining exams and procedures, making appointments and filling out forms, applying for insurance or other financial assistance and explaining coverage of services, preparing patients and accompanying them to doctor’s appointments, providing transportation to and from appointments, and explaining test results and follow-up procedures.

CBHNs from all 4 ethnic communities agreed with community respondents in highlighting the services they provided throughout the entire cancer screening and care process, including helping patients to link to mainstream health services. Many CBHNs noted that because they knew the health system and other resources in their communities so well, they were often able to steer the women and their families through their appointments much more quickly and effectively because they knew when and where to go, whom to see, and how to access specific services. Moreover, the staff at the various agencies also knew the

TABLE 2—Navigation–Social Support Services Identified by Community-Based Breast Health Navigators, Providers, and Patients: Southeast Asian Breast Health Navigation Study, 2006–2008

Type of Support	Services Provided
Informational–educational	General health education information
	Instruction on breast self-exam
	Assistance in finding a health care provider
	General explanations of health care information
	Outreach and education at community sites
	Advocacy for patients
Instrumental–logistical	Assistance in making and changing appointments
	Transportation
	Assistance with filling out paperwork and forms
	Interpretation
	Reminders about appointments
	Assistance in applying for insurance or financial assistance and benefits programs
Affective–emotional	Trust building
	Improvement of relationships with providers
	Improvement of cultural understanding
	Maintenance of confidentiality
	Assistance with other emotional issues beyond health (e.g., family concerns, stress)
Appraisal	Affirmation that preventive screenings are healthy behaviors
	Assistance with understanding content of medical visits, test results, and care plans
	Expansion of patient confidence and readiness for care through opportunities to talk with others who share the same experiences
	Reinforcement of logistical information (e.g., encouraging women to make their own appointments and schedule follow-up care)
	Assistance in involving family members and friends in patient's care
	Encouragement of community members to be their own advocates by building their skills and giving them constructive feedback

CBHNs and helped facilitate scheduling and other aspects of the women's clinical experience.

CBHNs felt that the foundation for their effectiveness was the trusting and respectful relationships they formed with the women and with leaders in their communities. This cultural relationship building involved educating not only patients but also their families and community leaders (e.g., through churches and temples) to establish a network of support services for women at different stages of the cancer care continuum. The affective–emotional support built through these relationships ensured follow-up after the educational support, leading to improved screening access.

Several CBHNs also discussed the importance of helping women to be self-sufficient so that they could eventually learn to navigate, and help others to navigate, the health care system by themselves. As one CBHN explained,

> 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 [on their own].

Provider Perspectives

Despite their different disciplines and areas of expertise, the providers consistently echoed the responses of the community members and CBHNs. All the providers we interviewed emphasized the importance of understanding the cultural beliefs and health practices of their patients. The CBHNs bridged the language and cultural barriers between patients and providers by providing bicultural and bilingual interpretation services.

Providers also acknowledged that CBHNs were pivotal in linking community members to programs and services for screening support. The CBHNs helped to ensure access to care by providing information on available services and where to access them. Providers also noted that CBHNs provided logistical assistance beyond the clinical visit and care plan. "[W]ith her navigation skills, it's really opened my eyes to some of the challenges even outside of our own system and . . . the real gaps in coverage," a provider said about her CBHN's help with insurance and financial coverage. Another provider said that CBHNs were valuable and helped

> to keep people from falling into the cracks. . . . [T]hey 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.

Many providers described how CBHNs improved health care visits by providing affective–emotional support as well as appraisal support to the women. One provider said,

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

All the providers noted the important roles played by CBHNs in facilitating the patient–provider interpersonal relationship, thereby ameliorating the challenges for providers of working with diverse communities. Overall, the providers were positive about the CBHNs and considered them to be integral to achieving an efficient and effective health care visit with their patients. CBHNs served as cultural and linguistic interpreters, helping providers to communicate clearly and coherently with their patients and ensuring appropriate medical understanding, confidentiality, and follow-up health care.

In ranking a list of training topics required to produce effective CBHNs, our study's providers, CBHNs, and community participants were in substantial agreement (Tables 2 and 3). The skills mentioned in the interviews and focus groups were those skills ranked most essential for a training curriculum. Community members from 3 of the 4 ethnic groups, however, ranked 2 skills—knowing how to be effective interpreters and knowing what women can do to live healthier lives—much higher than did providers or CBHNs.

DISCUSSION

From multiple perspectives, CBHNs were seen as the crucial links between patients and providers throughout the complicated network of health care. In particular, 4 distinct types of social support (informational–educational, instrumental–logistical, affective–emotional, and appraisal) captured key aspects of the resources CBHNs needed to develop trust in a community and enable patients to understand, practice, and maintain breast health behaviors. Although much of their work occurred at the individual and interpersonal levels of the socioecological model, the CBHNs' knowledge of their communities and formal health care systems was reported to be important to their effectiveness.

Many of the top-ranked training topics for a curriculum were either informational–educational or logistical–instrumental. These groupings demonstrate a common recognition among the CBHNs, providers, and their patients that a great need exists for more outreach and education on breast health among new immigrants and low-income communities to increase early detection of breast cancer and decrease mortality rates for these communities. This is an important finding, and one that is not well documented in the research literature or addressed by navigation services that focus only on patients who have been diagnosed with breast cancer. Clearly, just informing women about the need for mammograms will have little impact in these communities if the barriers addressed by CBHN programs are not removed first.

TABLE 3—Training Curriculum Topics Ranked in Importance by Community-Based Breast Health Navigators, Providers, and Southeast Asian Focus Group Participants: Southeast Asian Breast Health Navigation Study, 2006–2008

Training Topics	Top 5 Rankings by Focus Group Participants[a]				Top 5 Rankings by CBHNs[a]	Top 5 Rankings by Providers[a]
	Cambodians	Laotians	Thais	Vietnamese		
1. Knowing about the women's breasts and about breast cancer (e.g., how does it develop, what causes it, can we prevent it).			1	1	3	1
2. Knowing what women can do to live healthier lives and lower their chance of getting breast cancer (e.g., diet/nutrition, physical activity, dealing with stress).		2	3	3		
3. The cancer care process: affective: what to expect from screening exams; if a person is diagnosed, what are her treatment options; and surviving and recovering from cancer.			4	2	5	2
4. Knowing the language, 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).	2	1			2	5
8. Protecting patient confidentiality: protecting any private information about the patient.	5					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				
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?).						

Note. CBHN = community-based health navigator.

[a] Respondents were asked, "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 5 topics, with number 1 being the most important."

All study participants emphasized the importance of not only informational and instrumental resources, but also the interpersonal or affective–emotional aspect and the appraisal aspect of health navigation. The CBHNs provided much more than translation and interpretation services; they worked to establish trusting relationships and improve communication between patients and their providers. Combined with the informational and logistical aspects of health navigation skills, the ability of CBHNs to build trusting interpersonal relationships appeared to be the key to making navigation activities culturally meaningful and relevant for their community patients, motivating them to obtain the important breast-screening exams that lead to earlier detection of cancer as well as to more timely and optimal treatment and recovery.

Although the list of essential training topics ranked by the 3 groups of respondents had significant overlap and agreement on core training curriculum elements, the majority of community members ranked 2 skills—knowing how to be effective interpreters and knowing what women can do to live healthier lives—much higher than did providers or CBHNs. Also, the focus group participants from all 4 communities and the CBHNs ranked knowing how to talk with the doctor to help the patient among their top 5 skills; the providers did not rank this skill in their top 5. These different rankings may reflect the different assumptions about expected navigator communication skills, as well as about the role of the patient, that are held by providers and their patients from Southeast Asian communities. For example, some providers might assume that CBHNs possess interpretation and communication skills as part of their background or because their job requires those skills, whereas patients and CBHNs may believe that professional training in these areas is an important part of a curriculum. These findings, also noteworthy, have not been documented in the literature, and therefore warrant further research.

We recommend that CBHN programs include culturally tailored training components with strategies for establishing trust and various follow-up social support services in particular communities. We also recommend further research into the appraisal support that CBHNs provide, because we detected some overlap between this category and the emotional–affective types of social support. Further research would help to clearly define the relative importance of the different types of social support provided by CBHNs as well as to explain the dissonance between the providers and the other 2 groups regarding the importance of communication skills needed during the patient–provider encounter.

The transitions along the breast cancer care continuum are complex. The ideal process is an iterative cycle of screening and normal results, but some patients will encounter suspicious findings that place them on a more complex path, especially if they are unfamiliar with how different health systems work. The knowledge and training CBHNs are given enable them to understand the institutional and community contexts through which their community's patients must navigate. By using culturally grounded approaches to build trust and respect, CBHNs are able to deftly guide and support patients through the maze of institutional and community barriers. Such navigation skills appear to go beyond the roles of hospital- or clinic-based health care navigation detailed in previous studies.[8,11,12,16,18–21]

No nationally recognized certification or degree programs exist for training CBHNs.[38] Our identification of the specific types of support and training areas needed by CBHNs provides the core elements for developing a formal curriculum to replicate in other communities the access created by CBHNs in Southern California for breast health services. Beyond essential topic training areas, we are examining other factors that may influence the effectiveness of training curricula, such as the number of training hours, the utility of different models of health navigation, the trainers who conduct the training, and the types of follow-up training that should be developed.

Limitations

Our findings provide valuable contributions to advance research on patient navigation; however, some limitations may affect their applicability to other contexts. We were successful overall in recruiting the targeted number of women for participation, but response rates significantly differed across ethnic groups. Contacting women was more difficult in some communities than in others, and participation in focus groups was limited in some cases by conflicting work schedules. As a result, our response rates may have reflected important self-selection biases and did not provide enough information across the 4 communities at each stage of the cancer care continuum to clearly delineate differences in the experiences of women in each ethnic group.

Furthermore, because our focus was on training curricula, we cannot (and do not) make any claims of tested program success beyond the results presented here. Our qualitative assessments identified key areas of work for CBHNs, but further experimental studies are needed to truly assess the effectiveness of CBHNs in increasing access to care and timely screening, diagnosis, and treatment for community members.

Conclusions

Despite increased efforts on many fronts in the past few years to fund, develop, and evaluate the important work of CBHNs,[7,8,11,12,39,40] much more work is needed to advance knowledge, research, and practice in this growing health sector. Understanding the health navigation process may enable medical practitioners, community women, and community groups to be better advocates for policies, resources, and funding to train CBHNs and maximize the expertise and services provided by these important individuals to eliminate health disparities. ■

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Contributors

T.-U.N. Nguyen led and supervised the overall development, writing, and revisions of the article. J.H. Tran contributed to writing and reviewing significant portions of the article. M. Kagawa-Singer and M.A. Foo helped to write and edit key parts of the article. All authors helped to conceptualize ideas, oversee the study implementation,

complete analyses, interpret findings, and review drafts of the article.

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