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The role of community education in increasing knowledge of breast health and cancer: Findings from the Asian Breast Cancer Project in Boston, Massachusetts

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Abstract

In the past decade, cancer rates have significantly decreased in the US, but breast cancer survival is lower in Asian American women, likely due to lower rates of screening behaviors in Asian Americans compared to other ethnicities, which could lead to later stage cancer diagnosis and increased mortality. This paper reports on the Asian Breast Cancer Project (ABC) a three phase peer-led community program designed to promote cancer prevention by improving breast cancer screening rates among Chinese and Vietnamese women in the Greater Boston area. The three phases of planning and coalition building, community health worker training, and the community workshop intervention are described. The workshop intervention was evaluated by comparing pre and post-workshop questionnaires evaluating knowledge about breast cancer screening and prevention. 252 women participated in the program across fourteen workshops. Each participant completed questionnaires about demographics, access to health care, and a 5-item self-administered questionnaire about breast cancer knowledge. Results showed the majority of the women had received a clinical breast exam or mammogram in the past 12 months (69% and 59% respectively), and older women were more likely to get a mammogram (85%) or clinical breast exams (74%) compared to younger women. 81% of women were interested in reminder systems. Baseline knowledge was high for three survey questions about mammograms and breast cancer risk (88–97%). For questions with fewer correct answers at baseline, knowledge about the meaning of lumps in the breast significantly increased (69% to 80% correct, $p<0.0001$), as well as knowledge about frequency of clinical breast exam (48% to 67% correct, $p<0.0001$). This pilot project indicated a partial effectiveness of the community workshop in a population with high baseline knowledge. The education workshop increased knowledge about breast lumps and clinical exam frequency. We also identified that reminder systems and appointment assistance are desired by this population. Our findings inform future cancer screening strategies for Asian Americans.

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Keywords

Breast; Asian; survey; cancer risk; survivorship; public health; health literacy; evidence-based practice

Introduction

During the past decade, cancer incidence and death rates have significantly decreased. Declining breast cancer deaths account for 34% of the overall reduction in female cancer mortality (ACS 2012). Despite the trends of decreasing cancer rates in the United States, non-Japanese Asian American women have demonstrated lower survival rates from breast cancer compared to Japanese American and non-Hispanic white women [1].

Even though breast cancer screening is proven to reduce breast cancer mortality [2], several studies have shown that Asian Americans have lower rates of mammography and other methods of breast cancer screening [3–6]. Surveillance, Epidemiology and End Results Program (SEER) and American Cancer Society (ACS) have shown that minority populations are more likely than non-Hispanic whites to be diagnosed at a later stage of disease [3]. Additionally, Warner et al. found Asian Americans to be diagnosed through symptoms rather than screening methods because of longer time to diagnosis [7].

Probable causes for the screening disparity between Asian Americans and other ethnicities are the numerous identified barriers to breast cancer screening specific to Asian Americans. Barriers have been recognized that make breast cancer screening more difficult for Chinese and Vietnamese populations. A positive doctor-patient relationship and a clear interpretation of the patient's expectations from the doctor have shown to improve proper treatment decisions [8, 9]. Several studies have also shown that a routine visit to the doctor increases likelihood of proper breast cancer screening practices [4, 10, 11].

Personal and financial resources are also a barrier to screening for Chinese and Vietnamese Americans. Women with access to health care and financial support from health insurance have shown greater ability to get mammography and other screening and treatment [4, 11–14]. Those with a higher income are also more likely to get proper screening [4, 15]. A language barrier or lack of English proficiency is also a barrier to screening for Chinese and Vietnamese Americans [8, 13, 16]. Living in the United States for an increased length of time also increases screening rates [13, 15].

Personal health beliefs and cultural factors can prevent mammography and other breast cancer screening. For example, not sharing a diagnosis because of cultural shame or embarrassment can cause a feeling of alienation, or a lack of trust in the Western medical system, and this can prevent the patient from pursuing medical treatment [9, 17]. Additionally, behaviors like smoking and other unhealthy lifestyle factors are associated with lower screening rates [4].

These barriers that limit breast cancer prevention behaviors among Asian American women inhibit them from increasing their knowledge about the importance of breast cancer

screening and prevention, such as language barriers, clarity at the doctor's office, and the balance between personal and cultural beliefs and the Western medical system. Numerous studies have shown community interventions an effective method for decreasing barriers and increasing knowledge and screening activities for breast cancer in Asian Americans. However, none of them are in the greater Boston area, and several programs are not targeted specifically to Chinese and Vietnamese populations. Only two community programs have focused specifically on Chinese women and breast cancer. One program was a workplace intervention in China, which included an education intervention with motivational group education, dynamic interaction and role play, and the distribution of educational materials. The intervention was compared to a control condition with general health care education. They found the intervention significantly increased knowledge about breast cancer compared to the control group. They also found the intervention significantly increased feelings of confidence and capability to get a mammogram. The study also followed up after 6 months to evaluate screening rates, and they found those in the intervention group were significantly more likely to have a mammogram within the 6 months post-education.[18] A program for breast cancer in Chinese American women found that a culturally tailored video for Chinese Americans in the Metro Washington, DC area increased screening intentions, knowledge, and understanding of Western medicine and decreased fears about breast cancer [19]. A recent education program targeted multiple Asian American ethnic groups including Chinese and Vietnamese, in which women who were previously non-adherent were more likely to schedule yearly mammograms after the breast cancer education program [20].

Two programs in California for Vietnamese Americans have intervened in the community with outreach activities such as counseling, scheduling and educational materials. One showed a higher increased in breast cancer knowledge and increases in mammography receipt with the lay health worker outreach when compared to media exposure alone [21]. The other showed increased in education levels and plans to get clinical breast examinations after the outreach and educational activities [22].

This paper describes how a breast cancer survivor engaged the community, adapted an evidence-based intervention for Asian Americans, and implemented a community-level education intervention to increase the understanding of breast cancer among Asian American women in the Boston area. The community-level program was implemented in the context of the socio-ecological model (SEM), emphasizing the importance of individual behaviors, interpersonal relationships and community involvement.

Methods

Program Background

The Asian Breast Cancer Project (ABC) is a peer-led community-level program designed to promote cancer prevention by improving screening rates among Chinese and Vietnamese women in the Greater Boston area. A breast cancer survivor, Chien-Chi Huang, started ABC in January 2011 in response to her struggles and isolation during treatment and recovery. In starting ABC, Huang enlisted the help of an academic partner and a community-based organization, Massachusetts Asian Pacific Islander for Health (MAP). The development of

ABC occurred in three phases: Planning and coalition building, community health worker training, and a community level intervention with workshops.

Phase 1: Planning and Coalition Building

A coalition of fifteen agencies that serve the Chinese and Vietnamese community in the Greater Boston area were enlisted as partners for the project. Community-based organizations (CBOs) were responsible for outreach, securing space, and recruitment of Asian American women for the workshop. This coalition met twice over the course of the project. During the first meeting, coalition members talked about different ways to reach out to Asian women to encourage them to attend cancer prevention activities. The second meeting served as an opportunity to de-brief their experiences and talk through challenges they are facing.

Huang recruited a small, but diverse group of Asian women who were cancer survivors or experienced breast health problems to be peer leaders. They met monthly over the course of the project on Saturday mornings. A variety of community-building activities were used to foster mutual trust and support.

Phase 2: Community health worker training

Ten bilingual/bicultural Asian American women were trained as peer health educators. The Women's Health Network at the Massachusetts Department of Public Health provided two trainings for the peer health educators, "Helping you take care of yourself" (HYTCY) and "Communicating Across Cultural Boundaries" (CACB.) The National Asian Women's Health Organization (NAWHO) developed CACB, an evidence-based, culturally competent curriculum, which transfers applicable knowledge about the needs of and barriers facing Asian American women as they seek breast health/breast cancer services, as well as practical skills for better communicating with Asian American women and reaching Asian American communities on breast health/breast cancer issues. CACB is a health education intervention that increases cultural competence, knowledge, and skills—developed by the Division of Cancer Prevention and Control and the Centers for Disease Control and Prevention (CDC). HYTCY was developed in 2006 to educate women in Massachusetts about breast, cervical and cardiovascular health, using PowerPoint presentations, flip charts, and hands-on activities. The curriculum was developed for low-literacy populations and was available in several languages [23]. HYTCY is a curriculum providing basic information about cancer risk factors, physiology, signs, symptoms, screening, and tests. The underlying framework is that education will increase knowledge and awareness, leading to early detection and reduction in cancer mortality. The curriculum has been applied to different cancers, including a knowledge workshop for prostate cancer in 2012.

Phase 3: Community-level Intervention

Because of the short time-frame for the grant period, ABC did not have the time and adequate resources to develop a new curriculum. Instead, ABC elected to adapt two evidence-based programs as the basis for its cancer prevention activities; The Witness Project (TWP) and Helping you take care of yourself (HYTCY). The programs were adapted by stakeholders with expertise in community education, breast cancer, and the

development of a culturally competent curriculum. The community-level level intervention workshops consisted of an hour-long training of HYTCY by a peer health educator, with a peer leader who told her story of breast cancer and breast health-based experiences.

TWP is an evidence-based intervention that has been shown to increase cancer screening rates in the African American community. TWP utilizes the power of storytelling to encourage women to engage in cancer prevention activities. TWP has been designated a "Research-tested intervention program" by the National Cancer Institute. It is a community-based intervention program that has proven results in improving cancer screening rates (breast and cervical) among African American women. To train the breast cancer survivors to tell their stories, ABC used an adapted "The Witness Project" (TWP). Peer leaders played an important role in the project. The peer leaders accompanied the peer trainers and told their personal stories and struggles with breast health problems or breast cancer.

Community workshops

Training took place at community sites throughout the City of Boston. Trainers used the same curriculum developed by DPH. Each training lasted two-hours. Over the course of twelve months, fourteen community workshops were conducted in the Greater Boston area targeting Chinese and Vietnamese women. The locations of the workshops included a hospital, two senior centers, a corporation, and several community-based organizations. The workshop was one hour long and included a PowerPoint presentation with time for questions and answers. The workshops were conducted in Chinese, English and Vietnamese, depending on the preferred language of the group. Workshop participants were given handouts in English and Asian languages, Komen shower cards (cards to hang in the shower with information about risk, screening, and self-exam instructions) in Chinese and Vietnamese language and Komen breast cancer stickers. In some instances, a clinician was present to answer participants' questions.

Program Evaluation Design

The outcome of interest in the evaluation of the community-level intervention is the workshop participants' knowledge about breast cancer screening and prevention. Participants in the workshops completed a five-item, true/false, self-administered pre-post test at the beginning and end of the workshop to assess change in knowledge about breast health and cancer prevention. These questions were:

1. If a woman discovers a lump in her breast, she absolutely has breast cancer.
2. Starting at the age of 40, women should get a mammogram once a year.
3. Mammograms cause breast cancer.
4. As women get older, their risk of breast cancer increases.
5. Women need to have a clinical breast exam done by a healthcare provider every five years.

Human subjects approval was granted by the Tufts Medical Center Institutional Review Board.

Statistical Analyses

Descriptive statistics using frequencies and percentages were reported for the age, ethnicity, and background screening behaviors of the participants. Pearson's Chi-Square test was used to compare screening behaviors by age group. The six-level age groups were collapsed to binary age strata of 50 and older vs. ≤49 due to sample size constraints. McNemar's Chi-Square test for categorical variables was performed on the five yes/no survey questions about breast examination to determine whether there were significant changes from pre to post-intervention to evaluate the workshop's effectiveness to increase breast cancer knowledge. Analyses were performed with SAS, version 9.2 (SAS Institutes, Cary, NC).

Results

Participants

A total of 252 women participated in the workshops. Complete demographic data was available for 234 participants and intervention evaluation data was available for 238 women. Demographic characteristics from the participants are reported in Table 1. The majority of those who answered the question about having a primary care physician did have one (89%), but 124 of 243 (53%) were missing data. The age range of the population was from < 39 to > 80 years old.

Screening and Preventive Behaviors

Participants were asked about self-breast examinations, clinical breast examinations, and mammography. The participants were equally likely to perform and not perform a self-exam in the past month (52% vs 47%). Of the 121 who did perform a self-exam, few reported the frequency, but the most common answer was "monthly" (n=25). 69% of the study population reported having a clinical breast exam and 59% of the study population reported having a mammogram in the past 12 months. Of the 96 who did not receive a mammogram in the past year, 63 did not answer why. The most popular answer for those who did was "not needed yet" (n=9) and many of them were under 39 years old.

We analyzed the screening behavior by age group to see if age had an effect on screening behavior. When stratified by age, those ages 50–80+ were statistically significantly more likely to have a mammogram ($p<0.0001$) and a clinical breast exam ($p=0.003$) in the past 12 months compared to those under 49 years of age (Table 2). The distribution of those who reported a self-exam in the past month, interest in reminders, or willingness to have a mammogram was not statistically significantly different across age groups (Table 2).

Willingness of Future Action

Participants were asked if they were willing to receive a mammogram as well as willing to receive reminders about future appointments. Of the 192 participants who answered the question about willingness to get a mammogram, the majority (88%) were willing to receive one. Of the 149 that answered the reminder question, 121 (81%) were willing to receive a reminder in 3 months. For the open answer question "how may we help you get your test scheduled and keep your appointment?" 210 (90%) did not answer the question. Of those

who did, most suggested reminders for the appointment such as letters, emails, calls, or assistance with making the appointment.

Workshop Evaluation

Evaluation of the workshop showed statistically significant differences in correct responses between pre- and post-intervention for two of the five breast examination questions (Table 3). At baseline, knowledge was high for survey questions 2, 3, and 4 (97.7%, 92.3% and 88.8% respectively). The questions that had high correct response rates at baseline did not show a statistically significant increase in knowledge about breast examination after the community workshop. Question 1, “if a woman discovers a lump in her breast, she absolutely has breast cancer” showed a statistically significant increase in correct answers from 69% to 80% correct ($p=0.0003$). Question 5, “women need to have a clinical breast exam done by a healthcare provider every five years” showed a statistically significant increase in correct answers from 48% to 67% correct ($p<0.0001$). The number of missing values for each question was less than 10% and did not vary by question. Additionally, the missing values were evenly distributed among the ten locations and the five questions (data not shown)

Discussion

The development and evaluation of a three-phase program for breast cancer screening and prevention in Asian American women has been described. The results of the intervention evaluation indicate a partial effectiveness of the community workshop. Among the five items on the community workshop evaluation questionnaire, there was only a statistically significant change in knowledge from pre- to post-intervention for the question about the correspondence of discovery of lumps to breast cancer (question 1) and about clinical breast examination frequency (question 5). The non-significant change in knowledge for the other questions is likely due to the high baseline knowledge of the participants. Additionally, many of them were compliant to breast cancer screening, indicating higher involvement with community and health resources. The ABC intervention fits in the context of health behaviors in the framework of the socio-ecological model (SEM), which emphasizes the importance of individual behaviors, interpersonal relationships, community involvement and overarching society-level policies. The community workshops encompassed the SEM framework by increasing knowledge about breast cancer prevention for individuals and expanding interpersonal interactions by connecting the participants with the peer health educators. The workshops can expand community engagement and utilization of resources to maximize healthful breast cancer prevention behaviors by Asian American women.

Other educational intervention studies to improve breast cancer knowledge and screening behaviors in Chinese Americans have similar and contrasting designs and findings. Lee-Lin et al. (2013) also conducted a one-group pre-post test questionnaire to evaluate knowledge about breast cancer in Chinese Americans before and after a teaching and counseling intervention [24]. They also used a convenience sample from partner agencies in the community. However, the study took place in Oregon on 44 women, the questionnaire was 93 questions, the population only included women who did not have a mammography in the

past year, and they included individual counseling in addition to a group teaching session. They also found limited improvement in knowledge, with significant improvements in information about breast cancer susceptibility [24].

Additionally, Wang et al. used a video intervention to improve breast cancer screening and knowledge in Chinese Americans [19]. They also used a pre-post questionnaire to evaluate the effectiveness of the video intervention. Their questionnaire included broader topics such as screening intentions, views of cancer, and barriers. Their knowledge section included ten questions, and they found significant increases in nine out of ten of the survey items after viewing the video. However, like Lee-Lin et al., they also recruited women who did not receive a mammogram ever or in the past two years. Their sample size was 44 women recruited with flyers and websites in the Chinese community of the DC area [19].

A consideration for the low effectiveness of the educational workshop intervention and the high baseline screening behavior in the study population is the growing network for cancer awareness, treatment, and prevention for Asian Americans in the Greater Boston area. Boston is one of 9 sites of the National Cancer Institute's Patient Navigation Research Program, and it is one of two that support the Asian population specifically. Patient Navigation supports and guide persons with abnormal cancer screening or new cancer diagnosis, assist in accessing the cancer care system, and overcoming barriers in a culturally sensitive way [25, 26]. Battaglia et al. (2012) have evaluated the effectiveness of the Boston Patient Navigation Research Program for breast and cervical cancer at six community health centers for multiple minority ethnicities, including Asian American. They found the patient navigation an effective method to improve cancer screening activities across all ethnicities of study [26]. There is a strong network in the Boston area for Asian Americans, with many initiatives, including patient navigation, to assist community members in different phases of the cancer continuum, including screening, treatment, and survival. There were patient advocates in many locations in the Boston area, from major hospitals to small clinics, with the intentions of assisting patients/community members in need. The ABC program did not pre-screen women about their breast cancer screening behavior or connection to medical resources. Based on our results, it seems the women participating in the program were connected to the community, and they also seemed connected to medical resources. This method of community outreach did not reach the Asian American population in Greater Boston that is not connected to resources.

Limitations

There were several limitations to the pilot study and the evaluation methods. The program did not reach the appropriate population, because by reaching out to participants in community organizations, the participants are already in the community network receiving guidance and direction on screening behaviors and recommendations. The project was exploratory, so there were no eligibility criteria for workshop enrollment. The population in this study is not representative of the non-adherent, hard-to-reach population. However, it is an important finding for future programs that the women connected to the community organizations that the CBOs used for recruitment exhibited health-seeking behavior and higher breast cancer screening knowledge than expected. An additional limitation was that

the demographic data on age, ethnicity, breast cancer screening history, and primary care physician status (Table 1) was not linked to the individual survey answers on the evaluation questionnaire (Table 3), so adjustment for potential confounding by demographic characteristics could not be made in the intervention evaluation. Additionally, there were minor differences in the baseline questionnaires across locations, some including all questions while some were missing the question about having a primary care physician. This accounts for some of the missing data on the primary care physician question. Also, some of the answers were written in non-English languages and data entry was performed by an English-speaking investigator, so any non-English open answers were reported as missing data.

Conclusions

We found that participants recruited for the ABC program that were involved in the community were also connected to medical resources and exhibited screening behavior. In our evaluation, we found significant improvement in breast cancer knowledge for lumps in the breast and clinical breast exam frequency, two questions with low correctness at baseline. We also found that reminder systems and appointment assistance are desired by this population and can help improve screening and appointment adherence. The study population was adherent to breast cancer prevention guidelines for self exams, clinical breast exams, and mammograms, especially those ages 50–79 and individuals that reported having a primary care physician. Future program development for the Chinese American and other Asian American populations should incorporate engaging educational activities, as well as interactive assistance such as appointment reminders, scheduling, and other tangible assistance. In the future, the educational workshop will be most effective for those who are less aware of breast cancer screening guidelines and are in need of the education intervention. It is likely that the most effective interventions will be those that are given to participants who have lower rates of breast cancer knowledge at baseline.

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Table 1.

Demographic and baseline characteristics of participants (N=234)

Variable	N Missing	N (%)
Age (yrs)	11	
<39		43 (19)
40–49		21 (9)
50–59		35 (16)
60–69		53 (24)
70–79		54 (24)
≥80		17 (8)
Ethnicity	12	
Chinese		181 (77)
Vietnamese		24 (10)
Mixed		16 (7)
Other[a]		1 (.5)
Primary Care Physician	124	
Yes		12 (11)
No		98 (89)
Self exam in past month	8	
Yes		119 (53)
No		107 (47)
How often do you perform self exam[b]	173	
Daily		7 (3)
Weekly		9 (4)
Biweekly		4 (2)
Monthly		25 (11)
Every two to three months		7 (3)
Yearly		2 (1)
Other[c]		7 (3)
Clinical breast exam in past 12 months?	5	
Yes		157 (69)
No		72 (31)
Mammogram in past 12 months?	4	
Yes		135 (59)
No		95 (41)
Willingness to receive mammogram on regular basis	42	
Yes		169 (88)
No		23 (12)
Interested in reminder	85	
Yes		121 (81)
No		28 (19)

Variable	N Missing	N (%)
How may we help you get your test scheduled and keep your appointment?	210	
Reminders		13 (6)
Assistance		6 (3)
Other		6 (3)

[a]Other races/ethnicities included Hispanic, Korean, Caucasian, and Native American

[b]If frequency was between categories, it was rounded down to the next lowest frequency

[c]Other frequencies included often, always, once in a while, and less than monthly

Table 2.

Differences in screening behavior in past 12 months by age group

	Age		P value[a]
	50–80+ years	<39–49 years	
N (%)	159 (71)	64 (29)	
Mammogram			**<0.0001**
Yes	117 (53)	13 (6)	
No	40 (18)	50 (23)	
Clinical breast exam			**0.003**
Yes	116 (53)	35 (16)	
No	39 (18)	29 (13)	
Self-exam[b]			0.21
Yes	84 (39)	28 (13)	
No	70 (32)	34 (16)	
Willingness to receive mammogram regularly			0.31
Yes	121 (66)	40 (22)	
No	15 (8)	8 (4)	
Interested in reminders			0.60
Yes	88 (61)	29 (20)	
No	19 (13)	8 (6)	

[a] P value for Pearson's chi square test, statistically significant at $p<0.05$

[b] Self exam in past month

Table 3.

Change in knowledge about Breast Cancer screening and prevention (N= 238)

	Question	Correct Answer	N missing	Correct, pre-education (%)	Correct, post-education (%)	P value[a]
1	If a woman discovers a lump in her breast, she absolutely has breast cancer.	No	15	154 (69.1)	180 (80.1)	**<0.001**
2	Starting at the age of 40, women should get a mammogram once a year.	Yes	14	219 (97.7)	218 (97.3)	1.000
3	Mammograms cause breast cancer.	No	17	204 (92.3)	205 (92.8)	1.000
4	As women get older, their risk of breast cancer increases.	Yes	15	198 (88.8)	208 (93.3)	0.0755
5	Women need to have a clinical breast exam done by a healthcare provider every five years.	No	17	106 (47.8)	148 (66.7)	**<0.001**

[a] P value for McNemar's test, exact P values reported, statistically significant at $p<0.05$