Published in final edited form as:

Contemp Clin Trials. 2010 July ; 31(4): 283–288. doi:10.1016/j.cct.2010.03.008.

Increasing Asian American Women's Research Participation: The Asian Grocery Store-Based Cancer Education Program

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Abstract

Background—Research study participants with diverse characteristics produce the most generalizable outcomes, but recruiting heterogeneous samples is difficult.

Methods—This pilot-study tests whether Asian women (N=1,079) with diverse language proficiencies, who were personally recruited to one study by a linguistically and culturally aligned recruiter, would enroll in another study with a single mailed invitation in English.

Results—The 134 participants in the second study represented 17.2% of those 779 women who had completed both baseline and follow-up surveys in the original study, making this characteristic the best predictor of future study participation. Of the 303 women in the first study who said they would be willing to participate in future studies, 17% (51) participated in the second study. Of the 733 who said they would not be willing to participate in future studies, 11% (83) participated. However, given the larger size of this group, researchers may recruit a greater absolute number of participants from it. While this rate of participation was less than the 25% rate achieved in the first

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study, the second study's single, mailed English language invitation were likely barriers to participation.

Conclusion—Securing IRB-approval to invite prior study participants from traditionally underrepresented communities to a new study is a strategy investigators can use to increase the diversity of their samples. Further research is warranted to determine whether Asian women who have participated in one study might also become effective recruiters for future studies.

Keywords

Asian Women; Clinical Trials; Education; Recruitment; Retention; Women's Health

Introduction

Research studies that include participants of diverse characteristics produce scientific findings with the broadest applicability.[1–3] With morbidity and mortality rates differing by such characteristics as race, culture, gender, age, income, education, behavioral characteristics, genetic factors, and stage of disease, the National Institutes of Health (NIH) Revitalization Act (1993) mandated the representation of women, elders, children, and members of minority communities in research studies.

Implementing this mandate has been difficult in the face of the many documented barriers to research participation. These barriers include, but are not limited to: lack of general health and disease-specific knowledge, language barriers, limited scientific literacy, lack of transportation to research sites, lack of family or community support for research participation, concerns that the study will interfere with the participants' family and/or work responsibilities, distrust of researchers, and concerns about the requirements and financial costs of the study.[1–9]

One of the most effective study recruitment strategies is via physician referrals.[10–15] This is self-limiting since not all patients have a regular physician and many see them infrequently. In addition, physicians have limited time to devote to helping scientists recruit study participants, and reimbursement for their time and expenses is rarely commensurate with actual costs. The ever increasing number of studies seeking diverse participants exacerbates these constraints and increases the competition for an already small pool of potential study participants. Clearly, other strategies are needed to secure adequate representation of diverse participants in the expanding number of research studies.

In 1956, Foot and Cone introduced the theoretical concept of “foot-in-the-door” and concluded that securing a small concession from a person is a predictor of that person's likelihood of conceding to a future request. This theoretical framework is potentially relevant to addressing the challenges of recruiting diverse participants to research studies. A growing body of scientific literature emanating from Foot and Cone's discovery would support this hypothesis: “A person who is recruited to one relatively simple study would be more likely to respond favorably to an invitation to participate in a subsequent study.”[16,17]

This raised the question of whether a research-focused institution might achieve greater diversity in its research samples by inviting people from underrepresented communities who had already participated in one study, to learn about another, and even to share this information with others in their social circle. To begin exploring this question, this pilot study explored the degree to which participants who had accepted an invitation to participate in one study would agree to participate in a second study. The study also explores how participants' responses regarding their willingness to participate in a future study is associated with their actual participation in a future study.

Methodology

As women were entering or leaving their Asian grocery store, bicultural, bilingual students who represented a clearly branded university outreach program, engaged these women in a brief conversation to ascertain their language preference. Then speaking in their preferred language, the students asked the women if they would be willing to participate in a brief health education program designed specifically for Asian women and if the women would be willing to help evaluate the program by completing a baseline and follow-up questionnaire written in their preferred language.

While the educational program was open to all women who expressed an interest in participating, those who agreed to help evaluate the program (approximately one in four) completed the IRB-approved verbal consenting process. Potential participants were told they would be asked to: 1) complete a one-page baseline survey about their breast cancer knowledge, attitudes, and screening behaviors; 2) experience a short breast cancer education program of about five minutes duration or longer if they wanted to receive more information; and 3) be contacted to complete a three-minute follow-up telephone survey two months later to help evaluate the program. The participants were asked for a mailing address so the survey could be mailed to them, in case phone contact failed. The protocol included up to 10 follow-up call attempts. The baseline survey included two questions anticipated to predict the women's willingness to participate in future studies. The first question asked, "When we review the data we have gathered for this study, it is possible that we will need more information to understand the results. May we contact you should that happen?" The second question asked, "May we notify you about future studies that may be of interest to the Asian American community?"

Of the 1,203 Asian women, aged 20 years of age and older, who had consented to participate in the *Asian Grocery Store-Based Breast Cancer Education* demonstration project, 1,079 had provided mailing addresses that were presumed to be both accurate and complete.[18–30] The relative ease of directly reaching these 1,203 Asian women prompted the authors to contemplate whether this richly diverse sample might be receptive to an invitation to participate in other research studies and thereby help to expand the diversity of those samples. Further, not only were the women themselves possible candidates, but they each had circles of family and friends with whom they might be willing to share information about other studies.

With the goal of beginning to evaluate this idea, one year later, the IRB approved the delivery of: 1) a follow up letter of appreciation to those women for their participation in the prior study; 2) a copy of one of the previous study's published papers; 3) an explanation of the new study; 4) the survey documents for the new study inclusive of an IRB-approved re-consent statement; and 5) a stamped, self-addressed envelope in which to return the completed survey. The new survey focused on the participants' opinions about the effectiveness of *The Asian Grocery Store-Based Breast Cancer Education Program*, the amount of exposure each participant had to the grocery store displays, as well as their breast cancer screening activities during the past 12 months.

At baseline, 98% of the participants included in this study had expressed a preference to communicate in their native Asian language, regardless of their English language proficiency. For this follow-up pilot study, financial constraints prohibited the translation of the study's consent statements and survey questions into multiple languages (IRB then required medically certified translators). This was a constraint that was anticipated to limit at least some women's participation in the proffered study. While this was an unfortunate limitation of the present study, the reality is that among most United States' studies' eligibility requirements is "at least a working use of the English language." This protects is done to protect the participants from the risk of being unable to clearly communicate with the research team when the participant

confronts study-related problems. While some studies are focused on a specific community group and hence have staff members with language proficiency for that community, few research studies can afford to have staff with the linguistic skills needed to accommodate the wide diversity of Asian languages and dialects used throughout southern California. Thus although less culturally competent, this study's use of low literacy English documents was an appropriate compromise since most research studies have at least limited English language proficiency as a requirement. The financial constraints of this follow-up pilot study also determined that only a single invitation could be mailed to each participant. The invitations were mailed first class to gain an estimate of the number of undeliverable invitations.

Sample Description

Participants were all adult Asian women living in southern California whose presence at the grocery store and conversations with the student health educators demonstrated physical and mental capacity to conduct the activities of daily living independently. Of the 1,079 mailed study invitations, 43 (4.0%) were returned as undeliverable. It is possible that additional surveys were delivered to invalid addresses and discarded rather than being returned to the post office.

Results

Of the 1,036 presumably delivered invitations, 134 (12.9%) surveys were fully completed and returned. Using the baseline ages of the 129 women who had given their age in the first study, their recalculated ages by the second study ranged from 21 to 75 years of age, with a mean age of 42.29 years ($SD \pm 11.3$). Seventeen (12.7%) of the 134 women had reported English language as their preferred language at baseline, accounting for 25% of the 66 women who had reported a preference for communicating in English in the baseline study. The remaining 117 (87.3%) Asian women had preferred to communicate in a language other than English at baseline, suggesting that they either had sufficient English language skills to complete the mailed survey in English or had someone who was able to help them. Table 1 shows the original 1,036 participants' distribution by ethnicity, language preference, and age for Study 1 and Study 2.

Table 1 shows the participants' demographic characteristics by the number of invitations mailed for the follow-up pilot study. It also shows the number of women willing to participate in future studies, the number of women willing to be called back with additional questions, and the women ($N=134$) who accepted the invitation to participate in the second study.

To test Foot and Cohen's theoretical model, the participation of women in the first study and second study was examined. Table 2 compares women's participation in the second study with their valid responses to questions about 1) their willingness to be called back if the research team had additional questions, 2) their willingness to participate in future studies, and 3) other baseline questions that might have been linked to participation in future studies, such as their perceived adequacy of their baseline breast cancer knowledge, adherence to recommended screening guidelines, and retention in the first study's two-month follow-up.

In relation to the first item, willingness to be contacted in the future with additional questions was not associated with participation in a new study. Interestingly, participants' response to the second item inquiring about their willingness to participate in a future research study was related to lower rates of participation (38.1% who said yes versus 61.9% who responded no at baseline). In the original baseline survey, 303 women reported that they would be willing to participate in future research studies. Of those who said they would be willing to participate, 17% (51/303) joined the second study. Of those who reported they would not be willing to participate in future studies, 11% (83/733) joined the second study. Chi-square analyses of the

women's responses at baseline and their actual participation in Study 2 showed that women who reported they would be receptive to being informed of future studies were significantly more likely to participate than those who said they would not be receptive ($p < .05$) (See Table 4).

In relation to items in the third category, Table 3 presents the comparison screening adherence reported for Study 1 and Study 2 and shows that women who reported adherence to breast self exam (BSE) and clinical breast exam (CBE) guidelines at baseline were also significantly more likely to participate in Study 2. There were no significant differences related to mammography screening.

Finally, it was noted that 100% of the participants in the follow-up pilot study had all completed the baseline survey and the two-month telephone survey for Study 1. There were no participants in Study 2 who had only completed the baseline survey of Study 1 (See Table 4).

DISCUSSION

Finding ways to recruit diverse samples faster is a key means of increasing the speed of scientific discovery. The Asian and Pacific Islander (API) community, which makes up 10.9% of California's population and is the fastest growing ethnic group in the State (U.S. Census, 2000), is not well represented in most clinical trials.[3,4,31] The heterogeneity within the API community adds to the importance of having strong representation from the Asian community within research samples.[18,21,32,33] The strategy pilot-tested in this study offers large research institutions one means of informing the Asian community of opportunities to participate in research studies in a culturally competent manner, making it worthy of further evaluation.

By conducting the recruitment for the first sample at a venue with a high density of Asian women, selecting a setting that was deemed to be an integral part of the Asian culture, and staffing the recruitment site with culturally and linguistically competent university students, it was possible to accrue the first large sample relatively quickly. Further, through the Asian grocery store venue, it was possible to reach women of diverse Asian cultures, linguistic preferences, levels of literacy in English and their non-English languages, socioeconomic groups, ages, degrees of acculturation, levels of education, and health status.

Based on Foot and Cone's foot-in-the-door theoretical framework, this study began with the hypothesis that, "A person who is recruited to one relatively simple study would be more likely to respond favorably to an invitation to participate in a subsequent study." [16,17] To be proven true, the participation rate for the second study would have had to have been more than 25%. This was not the case for the participants in general or for any subset of the original study's sample. In evaluating this outcome, it is important to remember that the eligibility criteria had narrowed for the second study, requiring English language proficiency which had not been required in the first study. Regardless of the explanation for the lower than hypothesized participation rate, this finding underscores the difficulties researchers face in recruiting representative samples of diverse characteristics within each cultural/racial group.

On the positive side, another criterion for evaluating this response rate was the cost of recruiting participants to the second study. Whereas the first study's sample recruitment was time consuming and incurred relatively intense labor costs, display costs, and mileage expenses, the second study's sample was recruited with only the time and cost of mailing a single letter to each potential participant. Thus, while the uptake was not as high as that achieved with the first study's face-to-face invitations to study participation, this slightly lower response rate may still be viewed favorably because of its low cost. For most studies, this response rate would have been sufficient to achieve a representative sample. Further, there are ways of increasing

the number of responses that were not employed in this second study, such as reducing language barriers, offering participant incentives, sending a second mailing, or following up the mailings with a personalized phone invitation. These additional facilitators of participation will likely be of even greater importance when the subsequent studies ask greater demands of participants and thereby introduce greater barriers to participation.

It was also notable that even among the participants in the first study who said they would be unlikely to participate in a future study, 11% (83) accepted the invitation to participate in the subsequent study. That was a rate considerably higher than would have been expected based on the marketing data for cold calling, where a one to three percent response rate is the norm. Of even greater importance for researchers is the observation that, since this group was considerably larger than the group that said it would be interested in being contacted again, the absolute number of positive responses was considerably greater than the number derived from the group that responded favorably to this question. The degree to which this 11% participation rate is simply a reflection of people's normal capacity for cognitive inconsistency or the direct result of their positive experience with their first study participation is worthy of further research. Hence, not only should this group be included in future invitations, the very act of getting them to participate in a first study may have exerted a positive impact. As a result, such questions need to be worded carefully so as to be hypothetical questions about one's likelihood of engaging in a subsequent study, not questions seeming to seek permission for making future contact. If worded as permission questions, it is possible that researchers' Institutional Review Board would not permit subsequent mailings to be made to this group.

While prior research using the foot-in-the-door model would suggest that people who completed all facets of one study would be more likely to be receptive to an invitation to participate in a second study, it was not anticipated that this characteristic would describe 100% of the participants in the second study. This knowledge could have saved the study the cost of mailings to the 410 baseline participants who did not take part in the two-month follow-up study, thereby producing a substantial cost savings in recruitment costs for studies that only need to recruit a relatively small number of participants from this community.

Besides direct recruitment of participants at Asian grocery stores, researchers can also enlist shoppers' help in recruiting to studies via snowball sampling techniques. Researchers can have their culturally competent research staff members provide study information to shoppers and ask the shoppers' help to identify other members of the Asian community who might be interested in learning more about their study.[34] In this manner, researchers can raise the community's awareness of their need for Asian American study participants and thereby accrue more diversity among study participants.

Providing information about research studies and the related health information required to explain the studies can benefit the Asian community through better access to health information and ultimately, through the ability to generalize research findings. This can also help the research community to fulfill its Federal mandate to recruit representative samples.

A limitation of this study was the addition of the English language requirement for participation. This confounded the evaluation of the true impact of participating in a first research study on later decision making related to future study participation. For future studies, it would be helpful to test the efficacy of this strategy by recruiting only participants who could already meet the requirement of possessing at least moderate English language proficiency. An alternative study would be to test the strategy by sending the second study invitation in the participants' stated preferred language. Both studies would help to assess the true impact of the language barrier to subsequent study participation. Other studies should also be undertaken

to assess the impact of adding recruitment facilitators to determine if the associated incremental increases in cost are justified by incremental increases in recruitment.

The results from this study suggest that increasing Asian American women's access to opportunities to participate in one minimally invasive study could help increase the accrual of Asian women to other studies. If researchers can identify IRB-acceptable ways to create a database of Asian women with prior exposure to research study participation, this could lead to an increase in the recruitment of Asian women to future research studies.

These data might also prompt research-focused institutions to test whether their organization's overall ability to recruit members of underrepresented groups to research studies might be enhanced by creating community-based research opportunities that demonstrate how research can directly benefit their community. These studies could simultaneously serve as a hands-on learning laboratory for participants because time is allocated to incorporate research-related learning activities for participants. If this is effective in increasing a community's participation rates in future research studies, then the ultimate outcome could become a dynamic tipping point as increasing numbers of community members discover the potential benefits of participating in research studies.[35]

CONCLUSION

Using Foot and Cone's theoretical foot-in-the-door framework, this study examined the recruitment of Asian women to research studies and demonstrated both the challenges of recruiting participants to studies and some possible strategies for more successfully accomplishing this goal.

Acknowledgments

This project was funded by a San Diego and Imperial County Breast Cancer Early Detection Regional Partnership Grant, a Susan G. Komen Breast Cancer Foundation Special Populations Grant, and multiple years of funding from the San Diego Affiliate of the Susan G. Komen for the CURE; the National Cancer Institute Grants: R25 CA65745, P30 CA023100, U54 CA132379/U54 CA132384, and U56 CA92079/U56 CA92081; and the National Institutes of Health, Division of National Center on Minority and Health Disparities-sponsored (P60 MD000220) UCSD Comprehensive Research Center in Health Disparities. The content is solely the responsibility of the authors and does not represent the official views of any of the funding agencies.

The authors wish to thank the hundreds of UCSD undergraduate students who participated in the realization of this project and the owners and managers of the following Asian grocery stores who shared the common vision of enhancing their community's health: 66 Ranch Market, 79 Supermarket El Cajon, 79 Supermarket Mira Mesa, 79 Supermarket San Diego, 99 Ranch Market, Diwali Festival, First Korean Market, Hing Long Market, India Sweets and Spices, Manila Seafood Market, Neema's Sari Palace, Nijaya Market, Philippine-American Expo, San Diego Supermarket, Seafood City Chula Vista, Seafood City National City, Vien Dong, Vien Dong III, Vien Dong IV, Yaohan Mytsuwa, and Zion Market.

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Table 1
Ethnicity, Linguistic Preferences, and Age Distribution among Study 1 and Study 2 Participants

Characteristics	Completed Study 1 baseline survey (N=1,190) N (%)	Completed Study 1's 2-month follow-up (N=779) N (%)	Number of Study 2 surveys delivered (N=1,036)	Willing to participate in future surveys (N=733) N (%)	Willing to be contacted with additional questions (N=798) N (%)	Participated in second study (N = 134) N (%)
Ethnicity						
Chinese	302 (25.4%)	203 (67.2%)	255	56 (21.9%)	218 (85.5%)	52 (20.4%)
Filipino	248 (20.8%)	171 (68.6%)	217	80 (36.8%)	188 (86.6%)	17 (7.8%)
Indian	125 (10.5%)	72 (56.6%)	111	38 (34.2%)	98 (88.3%)	7 (6.3%)
Japanese	47 (3.9%)	29 (61.7%)	42	13 (30.9%)	26 (61.9%)	16 (38.1%)
Korean	123 (10.3%)	94 (76.4%)	120	44 (36.7%)	95 (79.2%)	19 (15.8%)
Vietnamese	275 (23.1%)	178 (64.7%)	233	70 (30.0%)	197 (84.5%)	18 (7.7%)
Other	70 (6.0%)	32 (45.7%)	58	28 (48.3%)	51 (87.9%)	5 (8.6%)
Native Language						
Chinese	251 (21.1%)	168 (66.9%)	213	44 (20.6%)	184 (86.4%)	40 (18.8%)
English	78 (6.6%)	50 (64.1%)	66	24 (36.4%)	51 (77.3%)	17 (25.8%)
Indian Dialects	108 (9.1%)	63 (58.3%)	96	35 (36.5%)	87 (90.6%)	6 (6.3%)
Japanese	40 (3.4%)	26 (65%)	37	13 (35.1%)	23 (62.2%)	15 (40.6%)
Korean	119 (10.0%)	90 (75.6%)	116	44 (37.9%)	91 (78.4%)	18 (15.5%)
Tagalog	228 (19.2%)	156 (68.4%)	198	72 (36.4%)	173 (87.4%)	11 (5.5%)
Vietnamese	271 (22.8%)	177 (65.3%)	228	70 (30.7%)	197 (86.4%)	18 (7.9%)
Other	95 (8.0%)	49 (51.6%)	82	27 (32.9%)	67 (81.7%)	9 (10.9%)
Age Groups						
20 to 39	498 (41.8%)	341 (68.5%)	438	140	384 (87.7%)	63 (14.4%)
40 to 49	295 (24.8%)	203 (68.8%)	261	89 (34.1%)	228 (87.3%)	37 (14.2%)
≥50	235 (19.7%)	163 (69.4%)	207	74 (35.7%)	180 (86.9%)	29 (14.0%)
Unspecified	162 (13.6%)	72 (44.4%)	130	26 (20.0%)	81 (62.3%)	5 (3.8%)

Table 2

Contrast of Responses in First Study with Actual Participation in Second Study

First study question and first study screening adherence status	First study response options	Response in 1 st study	Participation rates in 2 nd study
		N=1,190 N (%)	n=134 N (%)
May we call you back with additional questions?	Yes	861 (72.4%)	107 (79.9%)
	No	329 (27.6%)	27 (20.1%)
Willing to participate in future study	Yes	317 (26.6%)	51 (38.1%)
	No	873 (73.4%)	83 (61.9%)
Had enough breast cancer knowledge	Yes	404 (33.9%)	43 (43.9%)
	No	425 (35.7%)	55 (56.1%)
Adherent to BSE at baseline	Yes	379 (31.8%)	68 (50.7%)
	No	758 (63.7%)	66 (49.3%)
Adherent to CBE (only 40 and over) (N=692 for Study 1, N=71 for Study 2)	Yes	322 (46.5%)	47 (66.2%)
	No	344 (49.7%)	24 (33.8%)
Adherent to mammography (only 40 and over) (N=692 for Study 1, N=71 for Study 2)	Yes	256 (37.0%)	36 (50.7%)
	No	409 (59.1%)	35 (49.3%)
Completed the 2-month follow-up survey	Yes	779 (65.5%)	134 (100%)
	No	411 (35.5%)	0 (0%)

Table 3

Reported Adherence to Screening Guidelines at Study 1 versus Study 2

		Time 2	
		Yes	No
		N (%)	N (%)
Time 1 BSE adherence	Yes	32 (76%)*	10 (24%)*
	No	36 (40%)*	53 (60%)*
Time 1 CBE adherence	Yes	29 (83%)**	6 (17%)**
	No	17 (49%)**	18 (51%)**
Time 1 Mammogram adherence	Yes	18 (60%)	12 (40%)
	No	17 (42.5%)	23 (57.5%)

* significantly different, $\chi^2=14.6$, $p<0.0001$

** significantly different, $\chi^2=9.13$, $p<0.005$

Table 4

Participation in Study 2 by their Responses or Behaviors in Study 1

		Actual Participation in Study 2	
		Yes	No
		N (%)	N (%)
Time 1 Receptive to future research studies	Yes	51 (38.1%)*	252 (27.9%)*
	No	83 (61.9%)*	650 (72.1%)*
Time 1 May we contact you in the future?	Yes	107 (79.9%)	691 (76.6%)
	No	27 (20.1%)	211 (23.4%)
Time 1 Completed follow up survey	Yes	134 (100%)**	603 (66.9%)**
	No	0 (0%)**	299 (33.1%)**

* significantly different, $\chi^2=5.77$, $p<0.05$ ** significantly different, $\chi^2=62.44$, $p<0.0001$