



Published in final edited form as:

J Natl Cancer Inst Monogr. 2005 ; (35): 102–105.

Participation of Asian-American Women in Cancer Treatment Research: A Pilot Study

Tung T. Nguyen, Carol P. Somkin, Yifei Ma, Lei-Chun Fung, and Thoa Nguyen

Vietnamese Community Health Promotion Project, Division of General Internal Medicine, Department of Medicine, University of California, San Francisco, CA

Kaiser Permanente Northern California, Division of Research, Oakland, CA

Department of Adolescent Medicine, University of California, San Francisco, CA

Chinatown Public Health Center, San Francisco Department of Public Health, San Francisco, CA

Abstract

Few Asian-American women participate in cancer treatment trials. In a pilot study to assess barriers to participation, we mailed surveys to 132 oncologists and interviewed 19 Asian-American women with cancer from Northern California. Forty-four oncologists responded. They reported as barriers language problems, lack of culturally relevant cancer information, and complex protocols. Most stated that they informed Asian-American women about treatment trials. Only four women interviewed knew about trials. Other patient-identified barriers were fear of side effects, language problems, competing needs, and fear of experimentation. Family decision making was a barrier for both oncologists and patients. Compared to non-Asian oncologists, more Asian oncologists have referred Asian-American women to industry trials and identified barriers similar to patients' reports. Our findings indicate that Asian-American women need to be informed about cancer treatment trials, linguistic barriers should be addressed, and future research should evaluate cultural barriers such as family decision making.

Few Asian-American women participate in cancer treatment trials, but little is known about the barriers involved (1–3). We conducted a pilot study with oncologists and Asian-American women to describe these barriers. Because trial participation is a complex process, we used the Pathways Model, a comprehensive framework that postulates that health-related behaviors require patients to negotiate a Community Pathway and providers a Medical Pathway, each with barriers and facilitating factors (4–5). The pathways interact through language and cultural concordance, system capacity, and patient education. We hypothesized that patients and physicians perceived different types of barriers, that both would identify language discordance as a barrier, and that Asian oncologists were more likely than non-Asians to identify barriers consistent with the patients' reports.

In 2003, using lists from the American Medical Association, the American Society of Clinical Oncologists, and hospitals (excluding Kaiser Permanente), we mailed anonymous surveys to all 132 medical oncologists in three Northern California counties. Items included sociodemographics, practice characteristics, proportion of Asian-American women with whom

Correspondence to: Tung T. Nguyen, MD, Box 0320, University of California, San Francisco, San Francisco, CA 94143 (e-mail: tung@itsa.ucsf.edu).

This study was funded by an Administrative Supplement to the Cancer Research Network, a consortium of non-profit integrated health care delivery systems and the National Cancer Institute (Grant U19/CA 79689). Dr. Nguyen was supported by the Asian-American Network for Cancer Awareness Research and Training (NCI Grant U01/CA 86322) and an American Cancer Society Cancer Control Career Development Award. We would like to thank Judy Dang, Leslie Lin, and Judith Luce, MD, for their help and Stephen J. McPhee, MD, and Edward Wagner, MD, MPH, for their support.

trials were discussed, and proportions of Asian-American women who were referred to and enrolled in trials. Using a 5-point scale, oncologists reported research attitudes, rated physician barriers, and assessed 23 barriers relevant to these women. Statistical analyses were performed using SAS (SAS Institute, Cary, NC).

Bilingual researchers conducted individual, face-to-face, semistructured interviews in Cantonese, English, or Vietnamese with 10 Chinese and 9 Vietnamese women with cancer from Northern California. The interviews were audiotaped, transcribed, and translated into English. Participants were asked whether they had heard of trials, whether trials were ever discussed, and whether they participated. Using open-ended questions followed by probes, the interviewer assessed research perceptions, attitudes, and barriers. Participants also rated 34 factors for their importance. Using standard techniques (6–7), two researchers independently coded transcripts using an iterative process and resolved differences by consensus.

Forty-four oncologists responded (response rate = 33.3%). Most had information about trials and had positive attitudes. The major Medical Pathway barriers included lack of staff, lack of time, effort to learn about trials, and eligibility criteria. Many (62.9%) had discussed trials with at least 5% of Asian-American women in the preceding 6 months.

Most Asian oncologists spoke an Asian language. Asian and non-Asian oncologists reported similar attitudes, physician barriers, and NCI trials behavior. More Asian than non-Asian oncologists had referred (75.0% vs. 9.5%, $P \leq .001$) and enrolled (40.0% vs. 9.5%, $P < .05$) Asian-American women in industry trials.

Few oncologists thought that Asian-Americans were reluctant to participate or that physicians were not informing them about trials (Table 1). The oncologists reported that the main barriers for Asian-American women were pathways interactions such as researcher–participant language discordance, lack of culturally relevant cancer information, and complex protocols. Family decision making was the main Community Pathway barrier.

Significantly more Asian than non-Asian oncologists chose as patient barriers lack of culturally relevant cancer information (64.3% vs. 32.1%) and fear of experimentation (50.0% vs. 20.7%) ($P < .05$). Although not statistically significant, more Asian oncologists chose lack of knowledge about research and family decision making as Community Pathway barriers.

All 19 patients were foreign born with ages ranging from 33 to 71 years. Most had limited English proficiency. Few had oncologists who spoke Asian languages. Only four had heard of treatment trials (Table 2). Fear of side effects was the main barrier to participation, followed by language problems, competing needs, and fear of experimentation or distrust. Family reluctance was also a prominent barrier. Many would consider participation if their physicians recommended it in a respectful manner.

Consistent with a prior study (3), oncologists and patients agreed that language was a barrier to trial participation for Asian-American women. Language discordance affects physician–patient communication among Asian-Americans (8–9) and research participation in other populations (10). In this study, Asian oncologists were more likely to speak an Asian language and to have enrolled Asian-American women in industry trials. This indicates that language and possibly cultural concordance can lead to more participation. However, many Asian-American women with cancer received care from non-Asian oncologists. To facilitate trial participation, these patients may need language and cultural support through interpreters or patient navigators.

An important factor identified by both oncologists and patients but not in the literature was the family decision-making process, which is important in other Asian-American health behaviors

(11). Even non-Asian oncologists identified this barrier, indicating that it is prevalent enough to be perceived by those from a different culture. This cultural factor deserves further investigation, but our finding indicates that family members should be involved in the discussion about trial participation. Oncologists and patients disagreed on other barriers. Most oncologists reported trial discussion with these women, but similar to findings in other groups, patients reported that they were not informed (12,13–14).

Oncologists and patients also differed regarding willingness to participate. The women would participate only under dire circumstances. Their reluctance is more marked than that reported in other groups (15–16). This may be a result of lack of knowledge about cancer and the research process, as people who knew more were more willing to participate (16). Distrust, a barrier among African Americans (12,17), was reported by some Asian-American women but not by oncologists.

Reflecting the views of the patients, more Asian than non-Asian oncologists identified as barriers lack of culturally relevant cancer information, fear of experimentation, and family decision making. As a result of having a shared background, Asian oncologists may have insight about barriers for Asian-American patients. Including ethnically concordant physicians in studies may lead to culturally appropriate interventions to increase participation (17–18).

Because of major limitations, the results of this pilot study are preliminary. The sampling frame and low response rate of the survey and the small number of foreign-born women interviewed limit the generalizability. Future studies could include physician–patient pairs to evaluate their interaction, and qualitative studies could evaluate cultural factors such as family decision making. Nonetheless, our findings indicate that more oncologists should discuss treatment trials with Asian-American women and that studies of linguistically and culturally appropriate recruitment methods are needed.

References

1. Alexander GA, Chu KC, Ho RC. Representation of Asian-Americans in clinical cancer trials. *Ann Epidemiol* 2000;10:S61–7. [PubMed: 11189094]
2. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA* 2004;291:2720–61. [PubMed: 15187053]
3. Summary Report of Needs Assessment. Oakland, CA: Association of Asian Pacific Community Health Organizations; 2000. Capacity-Building Initiative for Asian-American and Pacific Islanders to Participate in Clinical Research Studies.
4. Hiatt RA, Pasick R, Perez-Stable E, McPhee S, Englestad L, Lee M. Pathways to early cancer detection in the multiethnic population of the San Francisco Bay area. *Health Educ Q* 1996;23:S10–S27.
5. Green, L.; Kreuter, MW. *Health Promotion Planning: An Educational and Environmental Approach*. 2nd ed.. Mountain View, CA: Mayfield; 1991.
6. Strauss, A.; Corbin, J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Newbury Park, CA: Sage Publications; 1998.
7. Pope C, Ziebland S, Mays N. Analysing qualitative data. *Br Med J* 2000;320:114–6. [PubMed: 10625273]
8. Weech-Maldonado R, Elliott MN, Morales LS, Spritzer K, Marshall GN, Hays RD. Health plan effects on patient assessments of Medicaid managed care among racial/ethnic minorities. *J Gen Intern Med* 2004;19:136–45. [PubMed: 15009793]
9. Ngo-Metzger Q, Massagli MP, Clarridge BR, et al. Linguistic and cultural barriers to care. *J Gen Intern Med* 2003;18:44–52. [PubMed: 12534763]
10. Napoles-Springer A, Grumbach K, Alexander M, et al. Clinical Research with Older African Americans and Latinos. *Res Aging* 2000;22:668–91.
11. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: “You got to go where he lives. *JAMA* 2001;286:2993–3001. [PubMed: 11743841]

12. Roberson NL. Clinical trial participation. Viewpoints from racial/ethnic groups. *Cancer* 1994;74:2687–91. [PubMed: 7954287]
13. Finn R. Surveys identify barriers to participation in clinical trials. *J Natl Cancer Inst* 2000;92:1556–8. [PubMed: 11018085]
14. Lynch GF, Gorelick PB, Raman R, Leurgans S. A pilot survey of African-American physician perceptions about clinical trials. *J Natl Med Assoc* 2001;93:8S–13S. [PubMed: 11798063]
15. Advani AS, Atkeson B, Brown CL, Peterson BL, Fish L, Johnson JL, et al. Barriers to the participation of African-American patients with cancer in clinical trials: a pilot study. *Cancer* 2003;97:1499–506. [PubMed: 12627515]
16. Ellis PM, Butow PN, Tattersall MH, Dunn SM, Houssami N. Randomized clinical trials in oncology: understanding and attitudes predict willingness to participate. *J Clin Oncol* 2001;19:3554–61. [PubMed: 11481363]
17. Pinto HA, McCaskill-Stevens W, Wolfe P, Marcus AC. Physician perspectives on increasing minorities in cancer clinical trials: an Eastern Cooperative Oncology Group (ECOG) Initiative. *Ann Epidemiol* 2000;10:S78–84. [PubMed: 11189096]
18. Sheppard VB, Cox LS, Kanamori MJ, Canar J, Rodriguez Y, Goodman M, et al. Brief report: if you build it, they will come: methods for recruiting Latinos into cancer research. *J Gen Intern Med* 2005;20:444–7. [PubMed: 15963169]

Table 1
Factors related to clinical trials participation of Asian-American women as reported by oncologists (N = 44)*

	Physician Ethnicity		
	Asian (N = 14)	Other (N = 30)	Total (N = 44)
A. Medical Pathway: Provider			
Mean Age in years [†]	41.2	50.1	47.2
Mean years in practice [†]	8.6	18.1	15.1
		%	
Male	57.1	75.9	70.0
Asian place of birth [†]	46.2	0.0	14.3
Speak an Asian language [†]	71.4	0.0	22.7
U.S. medical school training	92.3	96.6	95.5
Private practice	57.1	34.6	42.5
Teaching hospital affiliation	69.2	88.9	82.5
Proportion of Asian-American patients in practice	22.5	19.8	20.7
Have at least 10 Asian women with active cancer diagnoses	46.2	52.2	50.0
Have at least 10% of Asian women eligible for trials	54.8	47.6	50.0
Patients are not interested in trials	35.7	23.3	27.3
B. Community Pathway: Asian-American Women's Barriers			
Knowledge		% agree	
Lack of knowledge about research and its concepts	57.1	27.6	37.2
Lack of knowledge about cancer	35.7	17.2	23.3
Attitudes and Beliefs			
Fear that experimental is inferior to standard treatment	50.0	24.2	32.6
Fear of experimentation [‡]	50.0	20.7	30.2
Belief that cancer is fatal or incurable	21.4	20.7	20.9
Lack of interest in contributing to science or community	28.6	13.8	18.6
Socioeconomic Factors			
Fear of loss of time from work	35.7	24.1	27.9
Social Support			
Deference of decision making to family	64.3	44.8	51.1
Deference of decision making to physicians	42.9	28.6	33.3
Fear of racial or ethnic discrimination	0.0	3.5	2.3
Culture			
Reluctance of Asian-Americans to participate in trials	21.4	27.6	25.6
Access			
Lack of transportation	35.7	13.8	20.9
Lack of adequate health insurance	7.1	13.8	11.6
My Asian-American patients are not eligible for trials	7.1	6.9	7.0
C. Pathways Interaction			
Cultural and Linguistic Concordance		% agree	
Researchers do not speak the same language [‡]	53.9	48.3	50.0
Lack of culturally relevant cancer information [‡]	64.3	32.1	42.9
Patient Education			
Trial protocol or informed consent too complex	50.0	50.0	50.0
Physician effort and time for informed consent	28.6	26.7	27.3
Physicians do not inform Asian-Americans about trials	7.7	3.6	4.9

* N for each cell may not equal N for the column due to missing values.

[†] Cochran-Mantel-Haenszel test comparing Asian and non-Asian oncologists, $P \leq 0.01$.

[‡] Cochran-Mantel-Haenszel test comparing Asian and non-Asian oncologists, $P < .05$.

Factors related to clinical trials participation of Asian-American women as reported by Vietnamese and Chinese women with cancer (N = 19)

Table 2

Category	N	Participant Quotes
Knowledge and Practice Heard of cancer clinical trials Participated in cancer clinical trials	4	"There was a medication being tested at the time and it should be good for me. When he (treating oncologists) told me that it was good for me, I had to trust him."
	2	
Barriers Fear of side effects	11	"If everything had failed [on me] and it was the only hope, the only chance, I might try it. However, even if it were the only hope, I would still need to know if it would cause lots of uncomfortable feelings."
	6	
Fear of experimentation or distrust	6	"The idea of an experiment scares me. The experience from taking estrogen, which caused my cancer cells to grow, has already made me very fearful and I lost the courage to try any medication."
		"There were reports stating that it (hormones) was good for us. Now, they are confirming that the hormone is bad for us. I have no confidence in those researchers..."
Family is against trials participation	7	"Being guinea pig worries me a lot. The care in clinical trials is not always the best care. It is a 50-50 chance to get into the right or best treatment."
		"First of all, her husband is not very supportive to her condition... If she tries the new medication, it must take her more time to see the doctor, right? Who would give her a ride there? Her closest person is not willing to help her and she does not want to ask others for help."
Language Childcare, work, or transportation Facilitators Physician recommendation	11	"If the doctors can convince me when I was being offered the opportunity for participation, I would join in... If they give me facts and that it would help me with my situation, I would participate."
	12	
Recommendations by cancer survivors or others	10	"I think people are rather fearful to try this. It might have to do with the fact that they are more conservative and that they need to see actual personal experiences before they can have courage and faith. Often time, in my support group, some needed extra confirmation from others, who had gone through the treatments, to reassure them before they could make the decisions."
	4	
Offering physician is knowledgeable and respectful Wish to help others or science Quality of care in cancer clinical trials	14	"The doctor followed me more carefully and more regularly while I was in the trials... If there were any problems, I just called, get a good explanation, and got blood test or get seen right away."
	12	
	7	