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Recruiting Chinese- and Korean-Americans in Cancer Survivorship Research: Challenges and Lessons Learned

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Abstract

Purpose—This paper describes Asian-American recruitment experiences using data from the cancer survivorship study involving Chinese- and Korean-American breast cancer survivors specifically. The article discusses challenges to the successful recruitment of Asian-American populations for cancer survivorship research and provides recommendations for future recruitment efforts.

Methods—The study investigated the role of family communication in coping and quality of life for survivors from Chinese- and Korean-American groups diagnosed with breast cancer. Participants were primarily recruited through cancer registries and community outreach.

Results—A total of 157 breast cancer survivors (86 Chinese-Americans and 71 Korean-Americans) completed the final survey, yielding a final response rate of 62.8% of the accessible samples. Chinese-Americans were more likely to agree to participate but less frequently completed the survey, and Korean-Americans were more likely to refuse to participate. Common reasons for refusal were ‘too busy or too painful to recall,’ followed by ‘not interested,’ ‘too old,’ ‘distrust of the research’ or ‘health issue.’ Participants were more likely to be young and Korean-American compared to non-participants.

Conclusions—Cultural and linguistic barriers, distrust, and lack of awareness about cancer research should be considered to recruit more Asian-American cancer survivors. Community participatory research is required to ensure participation by sufficient numbers of ethnic minorities in cancer survivorship research.

Keywords

Cancer survivors; Chinese-American; Korean-American; Recruitment

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INTRODUCTION

Ethnic minority recruitment issues have attracted increasing attention as an important topic in health research since passage of the NIH Revitalization Act of 1993 [16, 7]. Increased focus on the participation of ethnic minority populations emerged with Healthy People 2010, which established the inclusion of ethnic minorities in health research as an overarching goal that is essential for ensuring the elimination of health disparities [22]. However, despite significant efforts, ethnic minorities are frequently underrepresented, and disparities in early detection, treatment, mortality, and survivorship related to ethnicity still exist [25].

More specifically, the participation of ethnic minorities such as Asian-Americans in cancer survivorship studies has persistently lagged behind that of Whites [11, 20]. Significant gaps exist in terms of health-related quality of life (HRQOL) and coping for ethnic minority cancer survivors and their family members. For example, Asian American subgroups have been combined under the umbrella category of 'Asian Americans,' or excluded from research or placed in the 'other' category. Fewer studies also showed inconsistent findings in terms of HRQOL experiences of Asian-American subgroups due to small sample sizes of ethnic subgroups [3, 13]. Furthermore, given that cultures might affect the coping and communication process between cancer survivors and their families [14], investigations which employ convenient samples with primarily white survivors may limit the generalizability of findings in coping and communication studies. Thus, recruiting more Asian-American populations into cancer survivorship studies is critical to allow for better interpretability of the findings.

Robinson and Trochim [19] noted the paucity of detailed information on the causes of the low participation rates of ethnic minority populations. Nevertheless, several studies have described a variety of factors that potentially affect recruitment among ethnic minority cancer patients. For example, language barriers, lower socio-economic status (SES), lack of health insurance and care, unstable employment status, and cultural factors impede the participation of Asian-Americans in cancer research [26, 10, 4]. Because of these challenges, researchers often perceive that Asian-Americans are less willing to participate in research or that Asian-American groups are difficult to reach [4].

To date, a variety of strategies specific for recruiting ethnic minorities have been tried. For example, Dignan and colleagues [5] developed the clinic-based recruitment plan collaboratively to work with the research team and the clinic staff, and provided incentive payments considering gas prices. Friedman and colleagues [6] suggested flexibility with scheduling, and engagement with community advisors using formalized process. Another study emphasized the development of a community-based culturally and linguistically appropriate educational intervention to increase health literacy in cancer communication [15]. Despite the gain in knowledge in this area, the lack of sufficient representation of Asian-Americans remains a challenge to improving cancer research and ultimately eliminating ethnic disparities in health outcomes.

In this paper, we utilize data from an outcome study that actively recruited Asian-American cancer survivors to describe ethnic minority recruitment experiences. Although this study

did not successfully recruit a large number of Asian-American cancer survivors, various strategies (e.g., the use of cancer registries, community outreach, trusted community members, contacts with participants from previous studies, and snowball sampling) were adopted to enroll and gain consent from participants. Based on our experiences, we discuss challenges to the successful recruitment of Asian-American patients in cancer survivorship research and provide recommendations for future recruitment efforts.

METHODS

The original study intended to investigate the role of family communication in coping and quality of life for Chinese- and Korean-American breast cancer survivors (BCS). The study employed a culturally responsive model [2] for ethnic minority inclusion in survivorship research to maximize Asian-American recruitment. The study was approved by the institutional review board at the study sites.

Participants

Study participants included 157 Chinese- ($n=86$) and Korean-American ($n=71$) BCS living in LA. Eligibility criteria for inclusion were as follows: (1) self-identifying as Chinese or Korean, (2) being within 1–5 years of a breast cancer diagnosis (stage I–III), (3) having completed active treatment, (4) being 18 years old or older, and (5) being able to speak Chinese, Korean, or English. Survivors of a more advanced stage of cancer (i.e., stage IV), those with other cancer diagnoses, and those with other major medical (e.g., heart disease, stroke) and psychiatric (e.g., major depression, schizophrenia) conditions were excluded because their medical characteristics (e.g., disease progression and prognosis) were significantly different from their study counterparts.

Recruitment

Prior to the recruitment of participants, all materials (i.e., flyers, questionnaires) were provided in both English and Chinese/Korean, because most Chinese- and Korean-Americans have limited English proficiency. Using a rigorous “forward-backward” translation procedure, the English versions of the materials were translated and back-translated into Chinese and Korean by independent bilingual translators. The panel of translators then compared the two English versions to ensure that they were equivalent. Corrections were made until equivalence was achieved.

Participants were recruited mainly from the California Cancer Surveillance program (CSP), specifically, the LA, Desert Sierra, and Orange sites, and from local LA hospital cancer registries from October 2009 to April 2011. As the largest county in California, LA County is a diverse urban and suburban area with a population exceeding 12 million. The 2010 census documented that LA County consisted of approximately 15% Asian-Americans. Of all Asian Americans living in LA County, Chinese-Americans comprised 27% and Korean-Americans comprised 16%, indicating greater percentages compared to those in other areas [21].

According to the CSP-designated procedures, a letter to each patient’s physician was first sent to notify the doctor of the study and invite his/her patients to participate. Invitation

letters were then sent to each potential participant identified by the CSP if her physician did not respond within two weeks indicating that she should not be contacted for health/medical reasons. This mailing also included a patient response form to allow the patient to express interest in participating in the study or to request more information. If the patient response form was returned indicating interest, the potential participant received a screening telephone call. If the patient response form was not received within two weeks of mailing, the potential participant received telephone calls from a trained ethnically and linguistically matched research assistant (RA). During this conversation, the RA indicated that an invitation letter had been mailed, the study was described, any questions regarding the study were answered, and the informed consent form was mentioned. If the potential participant was interested, then the RA conducted a screening over the phone to assess eligibility. Otherwise, reasons why they do not want to participate were asked simply. Eligible participants were mailed a questionnaire and consent form and were asked to return them in an enclosed prepaid envelope within 3 weeks. If survivors had not returned the survey after the third follow-up phone call, they were considered non-respondents.

Additionally, community-based recruitment approaches were employed to identify more Chinese- and Korean-American BCS. For Chinese-Americans, participants were recruited through community organizations and support groups where the principal investigator (PI) has well-developed, strong, and mutual trusting relationships. Korean-American participants were drawn from local LA hospitals, Korean doctors' offices, support groups, and community organizations. The PI has previously collaborated with physicians, nurses, and staff in these agencies and they agreed to serve on a community advisory board as well as assist in recruiting Chinese- and Korean-Americans. Recruitment letters indicating study purpose, eligibility criteria, procedures, and contact information were mailed directly to potential participants by the agency staff to comply with patient privacy and HIPAA regulations. Flyers describing the study were also distributed to agencies. Collaborators in the community agencies were involved in recruitment, the development of culturally and linguistically appropriate materials, and the interpretation and dissemination of the findings.

Recruitment through newspapers and word of mouth (snowball sampling) was also employed. We identified a variety of events in the Chinese- and Korean-American communities and sought permission from the organizers to attend and speak briefly about our study. We distributed flyers at the events describing the study to potential participants. Women who did not immediately decide to participate received a follow-up telephone call if they provided their contact information.

Finally, we directly contacted BCS from our previous studies who indicated an interest in participating in future research studies. They were recruited mainly through a local hospital registry, community organizations, and support groups.

All study procedures were conducted in the participants' preferred language (e.g., English, Chinese, or Korean) by ethnically and linguistically matched RAs (Korean and Chinese). Participants received an incentive payment of \$40 for completing the survey.

Data Analysis

We outlined the flow of potential study participants from the initial recruitment pool to the number of participants. Next, we determined the number of individuals who were accessible (i.e., those who were directly contacted by RA) and not accessible and the proportions of individuals who refused to participate, who were ineligible to participate, who agreed to participate but did not complete the survey (called ‘passive refusal’), and who participated. We then compared the available demographic and medical characteristics of participants and those who were accessible but not participated. We also compared the available variables of all participants and non-participants (regardless of accessibility). These comparisons were conducted using chi-square and independent sample t-tests. Finally, descriptive statistics, such as the mean and standard deviation, were used to describe the study samples. Independent sample t-tests and chi-square tests were conducted to investigate whether demographic and medical variables varied by ethnicity. The data were analyzed using SPSS 20.0.

RESULTS

Of the 619 potential participants to whom recruitment letters were mailed, 535 Chinese- and Korean-American BCS (86.4%) were identified from the California CSP and hospital registries. An additional 13.6% of participants were recruited from previous studies ($n=63$), public events ($n=16$), and support groups ($n=6$). Approximately 60% of the total potential participants were not accessible ($n=369$). Most did not respond to the letters or follow-up telephone calls, and some were not reachable due to incorrect contact information.

A total of 250 potential participants, or 40.4% of participants to whom recruitment letters were mailed, were accessible. This accessible group included 155 Chinese-Americans and 95 Korean-Americans; approximately 40~41% of potential participants were accessible, regardless of ethnicity. Among the accessible Chinese-Americans, 19 refused to participate (12.3%), 10 were not eligible to participate (6.5%), 40 agreed to participate but did not complete the survey (25.8%), and 86 participated (55.5%). Among the accessible Korean-Americans, 7 refused to participate (7.4%), 1 was not eligible to participate (1.1%), 16 agreed to participate but did not complete the survey (16.8%), and 71 participated (74.7%). Thus, a total of 157 BCS (86 Chinese-Americans and 71 Korean-Americans) completed the final survey, yielding a final response rate of 25.4% of the identified samples and 62.8% of the accessible samples (see Figure 1). More specifically, 64 of 399 people who were identified via California CSP (16.0%), 37 of 136 people via a local registry (27.2%), and 39 of 63 people via previous studies (61.9%) participated in the study. In a community-based approach, approximately 77% (17 of 22) completed the final survey.

Of individuals who were accessible but did not participate in the study (refusal + ineligibility + passive refusal; $n=93$), Chinese-Americans were more likely than Korean-Americans to agree to participate but not complete the survey, whereas Korean-Americans were more likely than Chinese-Americans to refuse to participate in the study. For both ethnic groups, the most common reasons for refusal were ‘too busy or too painful to recall,’ followed by ‘not interested,’ ‘too old,’ ‘distrust of the research’ or ‘health issue.’

Available demographic and medical characteristics were also compared for participants ($n=157$) and those who were accessible but not participated ($n=93$). Age, years since diagnosis, and cancer stage were not significantly different between the two groups, indicating that age, years since diagnosis, and cancer stage were not associated with whether accessible cancer survivors participated in the study. However, ethnicity showed a significant difference, indicating that Korean-Americans were more likely than Chinese-Americans to participate.

Comparisons between participants ($n=157$) and non-participants ($n=464$; 93 who were accessible but not participated + 371 inaccessible individuals) regardless of accessibility were then conducted using the available demographic and medical characteristics. Although years since diagnosis and cancer stage were not significantly different between participants and non-participants, age and ethnicity varied. Participants were more likely to be young ($t=-2.54, p < .05$) and Korean-American ($X^2=6.31, p < .05$) compared to non-participants (Table 1).

Table 2 shows participants' demographic and medical characteristics. The mean age of all participants was 55.3 years ($SD=9.7$). For most demographic characteristics except for education, Chinese- and Korean-American BCS showed similar patterns. Korean-Americans were more likely to have obtained higher levels of education than Chinese-Americans. Significant differences existed between the two groups in terms of cancer stage and years since diagnosis. Chinese-Americans were more likely to have been diagnosed with stage II breast cancer, and Korean-Americans were more likely to have been diagnosed with stage I breast cancer. More years had passed since diagnosis for participating Korean-Americans (Mean=3.9; $SD=1.4$) than for participating Chinese-Americans (Mean=3.24; $SD=1.8$).

DISCUSSION

Asian-Americans typically display low levels of participation in cancer research due to language barriers [24]. In many studies, the ability to understand and speak English is a criterion for inclusion [4]; thus, the language barrier may be a formidable obstacle to recruiting Asian-Americans who have limited English-language skills. Indeed, in this study, approximately 90% of all participants replied that their primary language is Chinese or Korean; thus, only 10% ($n=15$) were fluent in English. Given that the immigration history of Asians was relatively short, and breast cancer typically occurs after age 30, eligible participants are likely to be first-generation immigrants over age 50, thus most of current Asian BCS may have limited English skills. As a result, studies that target Asian-American BCS should provide qualified bilingual staff and prepare bilingual materials for successful recruitment. Both the PI who is bilingual in Korean and English, and an aide who speaks Chinese and English were actively involved in recruiting Korean- and Chinese-American BCS, respectively, resulting in the successful recruitment of 86 Chinese-American and 71 Korean-American BCS. Meanwhile, a similar study which PI conducted in other area focused only on English-speaking Asian-Americans due to the complex procedures for the recruitment of non-English speaking Asian-Americans; however we failed to recruit a significant number of Asian-Americans. These results imply that it may be difficult to recruit sufficient Asian-American participants without including non-English-speaking

Asian-American BCS. Nevertheless, when second-generation Chinese- and Korean-Americans reach the age of 50 (perhaps in a decade's time), we expect that language issues in recruiting Chinese- and Korean-American BCS may be reduced.

In this study, the percentage of accessible individuals (40%) was relatively lower than in other studies [4], indicating that a large proportion of Chinese- and Korean-American cancer survivors moved after they had been entered into the cancer registry. Asian immigrants may have less stable living circumstances, making them more likely to move. Diverse recruitment strategies improved the accessibility to Chinese- and Korean-American participants. More specifically, contacts with participants from previous studies as well as a community-based recruitment approach, including support groups and Chinese/Korean doctor's office visits, were effective for recruiting Chinese- and Korean-American BCS; their participation rates were relatively high compared to contacts via registries. This finding implies that long-term and personal relationships through a multifaceted approach may facilitate the recruitment of and participation by Asian-American BCS. Nevertheless, given that a few of eligible participants in community agencies exist, recruitment through a community-based approach requires significant investment of time and efforts. Additionally, we should not overlook the demographics in specific regions. A greater percentage of Chinese- and Korean-Americans live in California, whereas only a few may live in other area such as Ohio. Expansion of the recruitment region beyond the original region may be helpful to successfully recruit Asian-American samples in the Midwest region, where few Asian-Americans reside. Consistent collaboration built on trust with Asian agencies is also necessary to actively recruit Asian-American cancer survivors, given that many Asian subgroups are likely to utilize Asian agencies due to language and cultural barriers.

We demonstrated that differences in ethnicity emerged between participants and non-participants. Korean-Americans were more likely than Chinese-Americans to participate in the study. To date, few studies have included Korean-Americans who speak Korean compared to those who speak Chinese; such that Korean speakers have been purposely excluded from many studies due to the high costs of translation and transcription. We found that the refusal rate of Korean-Americans is relatively high, but participants who agree to enroll in the study are likely to continue to participate, which suggests that employing Korean-English bilingual researchers to recruit Korean-Americans may be helpful. Meanwhile, Chinese-Americans were likely to agree to participate, but they did not complete the survey, which suggests that it may be necessary to incentivize completion of the survey or to oversample Chinese-Americans, considering the number of passive refusals (no direct written or verbal refusal). As a result, culturally tailored strategies that are effective for recruiting Asian-American subsamples may be necessary because their responses and attitudes toward research participation vary.

Challenges and Suggestions for Researchers

Decades of ethnic minority inclusion research have identified a set of challenges and obstacles that researchers face in recruiting minority populations, such as Asian-Americans. Challenges that researchers frequently confront include stereotyping and researchers' perceptions that ethnic minorities might be less willing to participate in research or that

minority groups are difficult to reach [23, 4]. Economic factors have previously been cited as reasons why researchers often exclude minorities or experience barriers in recruiting underrepresented populations [17]. The obstacles include costs associated with transportation, establishing a relationship of trust with underserved communities [8], and costly media advertisements [9]. Additional difficulties may occur during planning and preparation because the research requires a more elaborate and lengthy process. For example, the complexity of forms, the validation of measurements, translation procedures, and recruiting and training bilingual personnel have been identified as major obstacles to including and recruiting ethnic minorities [17, 11].

Several lessons that have implications for recruiting Asian-American cancer survivors have emerged. First, cultural and language barriers should be addressed to successfully recruit ethnic minority populations. Utilizing culturally and linguistically competent research personnel who should be adequately trained may help overcome linguistic and cultural barriers. Culturally and linguistically appropriate materials and instruments should be also created after considering the unique cultural dynamics and cultural nuances of the study target populations. Given that language and culture provide the experiential context for the capacity to obtain, process, and understand health information [1], health literacy issues may be also related to the recruitment of Asian-Americans. However, the current study did not demonstrate the impact of health literacy on research participation because health literacy related variables (i.e., education) were not available. Future study is required to further explore how culture, language, and health literacy issues influence study participation.

Second, distrust issues may influence Asian-American cancer survivors. To address distrust issues, it is necessary to actively recruit ethnic minorities using community-based participatory research and to sustain long-term and personal relationships with participants. Collaboration with community physicians and partnership with community organizations may allow researchers to use existing networks and gain greater access to targeted individuals or groups. Given that ethnic minority cancer survivors maintain strong bonds to their communities, the recruitment of cancer survivors must start with the community based on trust.

Third, the lack of awareness about cancer research is widespread among ethnic minority populations [12, 18]. Educational materials should be provided to increase the awareness of the benefits of cancer research in ethnic minority populations. The development of community health programs to deliver health education would also be helpful. Advertising and educating about the research benefits to minority communities would facilitate the resolution of distrust issues and the successful recruitment of ethnic minority populations.

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Figure 1.

Study 1: Flow Chart of the Recruitment

Note: CA=Chinese-American, KA=Korean-American

Table 1
Comparisons of Demographic and Medical Variables between Participants and Non-Participants

Variables	Identified Samples (N=619)			χ^2 or <i>t</i>	
	Accessible (N=250)		Inaccessible (<i>n</i> =371)		
	Participants (<i>n</i> =157)	Those who were accessible but not participated (<i>n</i> =93)			
Age (M, SD)	55.9 (10.4)	57.3 (14.6)	58.8 (12.8)	-0.67	-2.54 *
Years since diagnosis (M, SD)	3.9 (1.9)	4.0 (1.5)	4.2 (1.4)	-0.27	-1.12
Cancer stage					
I	36 (34.9)	36 (38.3)	153 (41.2)	3.45	4.19
II	55 (53.4)	40 (42.6)	167 (45.0)		
III	12 (11.7)	17 (19.1)	51 (13.7)		
Ethnicity					
Chinese-American	86 (54.8)	68 (73.1)	236 (63.6)	9.24 **	6.31 *
Korean-American	71 (45.2)	25 (26.9)	135 (36.4)		

* $p < 0.05$,

** $p < 0.01$

Table 2

Demographic and Medical Characteristics of Study Participants

Variables	Chinese-Americans (n=86)	Korean-Americans (n=71)	χ^2
	N (%)		
Age(M, SD)	55.2(9.7)	55.5(9.7)	-.19
Cancer stage			16.01**
I	32(37.2)	35(50.0)	
II	45(52.3)	23(32.9)	
III	9(10.5)	12(17.1)	
Education			10.05**
< high school	16(18.6)	2(2.8)	
high school graduate	11(12.8)	14(19.7)	
> High school	59(68.6)	55(77.5)	
Household income			1.65
Under 25K	35(43.8)	22(33.8)	
25K–45K	13(16.3)	12(18.5)	
45K–75K	14(17.5)	12(18.5)	
Over 75K	18(22.5)	19(29.2)	
Employment status			1.54
Unemployed	42(50.0)	42(60.0)	
Employed	42(50.0)	28(40.0)	
Marital status			.04
Married	17(19.8)	15(21.1)	
Other	69(80.2)	56(78.9)	
Health insurance			1.17
Private	38(48.7)	27(44.3)	
Public	35(44.9)	27(44.3)	
No insurance	5(6.4)	7(11.5)	
	Mean(SD)		<i>t</i>
Years since dx	3.2(1.8)	3.9(1.4)	.43*
# of pat comorbidities	2.1(2.3)	1.8(2.3)	.94
# of current comorbidities	3.8(3.3)	3.0(3.4)	1.48

* $p < 0.05$,** $p < 0.01$.