

THE RECRUITMENT OF BREAST CANCER SURVIVORS INTO CANCER CONTROL STUDIES: A FOCUS ON AFRICAN-AMERICAN WOMEN

Kimlin Ashing-Giwa, PhD

Alhambra, CA

The recruitment of African Americans into cancer prevention and control studies has presented a major challenge to scientific investigators. Scientific findings, whether biomedical or behavioral, may not be appropriate and applicable to ethnic minority populations unless they are adequately represented as study participants. Moreover, the need to involve greater numbers of ethnic minorities is quite urgent due to the poor morbidity and mortality outcomes associated with ethnic minority group membership. Such is the case with breast cancer survivorship. The purpose of the study was to test a personalized recruitment strategy on response rate in African-American women. The response rate of 45% (n=117) African Americans and 64% (n=161) white subjects indicated only limited success in the recruitment of the African-American breast cancer survivors. The recruitment result suggests that culturally relevant recruitment strategies (eg, inclusion of African-American investigators, culturally consistent letter of recruitment) may be insufficient in adequately increasing research participation. Therefore, further studies on investigating factors that influence research participation (eg, type of incentives, and schedule of payment as well as type of stationery and stamps used) are needed. (*J Natl Med Assoc.* 1999;91:255-260.)

Key words: recruitment strategies

- ◆ breast cancer ◆ African-American women
- ◆ psychosocial oncology

The recruitment and retention of African Americans in research studies have been of major concern to scientific investigators. Scientific findings, whether biomedical or behavioral, may not be appropriate and applica-

ble to ethnic minority populations unless members of these populations are included in the subjects selected to participate. Moreover, the need to involve greater numbers of ethnic minorities is urgent as a result of the poor morbidity and mortality outcomes associated with ethnic minority group membership. The National Cancer Advisory Board and the National Cancer Institute conducted a conference in 1996 discussing the problem of ethnic minority recruitment and retention in cancer studies. The conference concluded that participation of ethnic minorities in clinical trials is fairly reflective of the proportion in the population. However, there exists a greater challenge to involve ethnic minority participants in cancer prevention and control studies.¹

The lack of ethnic minority participation in breast can-

From the California School of Professional Psychology, Alhambra, CA. This study was supported in part by a grant from the National Cancer Institute—CA63028. Requests for reprints should be addressed to Dr Kimlin Ashing-Giwa, California School of Professional Psychology, 1000 S Fremont Ave, Alhambra, CA 91803-1360.

cer research is no exception. Accordingly, there are significant gaps in the literature regarding ethnic minorities, particularly in the area of health-related quality of life. Breast cancer is the most common cancer in African-American and white women; the lifetime risks for each group are 1 in 11 and 1 in 9, respectively.^{2,3} Although the illness can be fatal, it is considered curable if detected and treated in the early stages. While breast cancer survivorship concerns have generated many studies, the research has typically included samples with inadequate representation of ethnic minorities.⁴ Furthermore, most studies included too few ethnic minorities to report on ethnic-specific results.⁵ Consequently, little is known about what factors influence well-being in African-American breast cancer survivors.

RECRUITMENT OF AFRICAN AMERICANS IN CANCER CONTROL RESEARCH

Cancer control that reports on psychosocial oncology with ethnic minority populations has been particularly lacking in research. In the past, research has focused primarily on middle- and upper-class white women, and efforts to recruit diverse ethnic groups have yielded unfavorable results.⁶ Many barriers have been noted including: 1) research barriers, such as failure to accept the restrictive nature of research protocols, 2) economic barriers, such as the lack of health insurance and poor health-care quality, and 3) individual barriers, such as perceptions of low or no risk.⁷ Additionally, African Americans, particularly those with low socioeconomic status, are more likely to have comorbid conditions that exclude them from the studies.¹ Moreover, scientists conducting studies may have a protocol that represents a Eurocentric model that can be alienating or inappropriate to members of ethnic minority groups.¹

Furthermore, systemic barriers exist. Individuals who are less educated, hold lower socioeconomic status, and are from ethnic minority groups have been excluded from appropriate scientific investigations.⁸ Moreover, these groups are often cautious about participating in research studies and are not responsive to traditional recruitment strategies.⁹ The history of discrimination in the health-care system toward ethnic minority communities and the experience of medical injustices such as the Tuskegee syphilis experiments still loom large in the African-American community.⁹

More importantly, the underrepresentation of ethnic minority individuals in the leadership of the research enterprise contributes to the lack of trust by minority participants.¹ These conditions create powerful responses that may impede open and willing participation in

research studies. Therefore, successful recruitment strategies are urgently needed to better understand cancer prevention and control with diverse ethnic communities.

Recently, ethnic minority patients have been successfully recruited from tumor registries.¹⁰⁻¹² The recruitment strategy used by Bastani et al¹⁰ involved an oversampling of ethnic minority women to increase the number of potential subjects.

In addition, the Witness Project¹¹ and Smith et al¹² used culturally consistent methods such as normative health beliefs, church or community-based sites, appropriate learning and linguistic styles including ebonics, "witnessing" (the cultural-religious style of teaching and educating), and interconnectedness (the cultural value that defines individual identity via relationships and group context). The Erwin et al¹¹ and Smith et al¹² studies also included African-American researchers. These studies concluded that cancer registries contain demographic and clinical information, including the treating physician, that can be used as avenues for recruiting ethnic minority participants.

Additionally, researchers have found success in recruiting community-based populations from traditional gathering places, eg, church, beauty parlors, and barber shops. Penn¹³ reported two successful studies with African-American women who were recruited from church membership. One study recruited 500 women to complete a one-time survey, and the other study retained 159 women for a nine-month, long-term follow-up study. Other investigators have recruited successfully from places with large numbers of low-income, ethnic minority populations, eg, Head Start programs¹⁴ and Public Health clinics.¹⁰ The role of the investigator was further emphasized in understanding the sociocultural context of the ethnic minority community.^{13,15} Further underscored was the importance of a multidimensional approach: 1) community assessment, 2) preparation of the target community (where possible), and 3) reciprocity (giving back to the community).^{14,15}

The research described in this article attempted to address increasing the recruitment of African-American women for an investigation on the impact of breast cancer on quality of life. We report on the outcome of our recruitment strategy in a mailed survey research with long-term African-American and white breast cancer survivors. The recruitment process and response rates across the two groups of women is described. The purpose of this component of the larger study was to test a personalized recruitment strategy on response bias by ethnicity. The quality of life results are discussed elsewhere.⁵

MATERIALS AND METHODS

Subjects

The participants were recruited from a sample of African-American and white breast cancer survivors who participated in a larger study.¹⁰ These patients were originally identified from the California Tumor Registry and were diagnosed between 1989 and 1990. Their participation in the study by Bastani et al¹⁰ required the survivors to provide the names of first-degree female relatives who were cancer-free. Only subjects who responded to the previous study were selected. These breast cancer patients were contacted in 1996 for participation in the current study; therefore a four-year period had passed between their involvement in the two studies.

Equal numbers of African-American and white women were sampled to have adequate numbers for statistical comparisons. Three hundred eighteen African-American women were selected (these were the total sample of responders in Bastani's study) and 303 white women were randomly selected (from a total available sample of 583) for inclusion in this study.

Procedure

Potential subjects were contacted by mail and invited to participate in the study. Two letters were included in this mailing; the first letter of invitation was from Dr Bastani, and the second letter was from the investigator. The investigator's letter was personal, sharing the investigator's concern about issues affecting breast cancer survivorship and emphasizing the pervasive impact of breast cancer. Two versions of this investigator's letter were created: one version presented the researcher as a health psychologist, and the second version was tailored specifically for the African-American woman and presented the researcher as a woman of color, as well. The tailored letter also emphasized the lack of research addressing issues relevant to African-American breast cancer survivors and appealed to the African-American value of interconnectedness by noting that their participation would generate knowledge that may benefit other African-American breast cancer survivors. Additionally, the details outlining the study were described with special attention given to confidentiality and the voluntary nature of participation. The survey instrument also was included in this mailing. Expected survey completion time was approximately 40-50 minutes, and subjects received a \$5 gift certificate for their participation.

Instrumentation

The survey instrument assessed selected treatment issues related to breast cancer. The content areas

included: type of surgical and adjuvant breast cancer treatment, quality of health care, health beliefs, quality of social support, stress, and health perception. Subjects were required to report retrospective and current information about their medical treatment and the quality of their relationship with their doctors. The questionnaire included several standard measures of quality of life (CARES-SF, SF-36 General Health Perceptions Scale) as well as some new items developed specifically for the study. New items (social support, interconnectedness, and spirituality) that possessed face validity also were included in the survey instrument. The instrument primarily contained closed-ended items; open-ended items were used to elaborate on specific topics.

RESULTS

Subject ages ranged from 32-90 years. The mean age for African Americans was 61.8 years, and the mean age for whites was 64.8 years ($P=.000$). The educational background ranged from high school graduates to doctorates, 75% of African-American and white women had some college education. More than 42% were currently working outside the home; 28% of the African-American women and 32% of the white women had professional careers. Sixty percent were married, 21% were widowed, and 19% were single. There were significant differences by ethnicity; African-American women were more likely to be unpartnered with less household income than their white counterparts. Forty-eight percent ($n=56$) of African Americans and 67% ($n=108$) of whites were partnered; 52% of African Americans and 33% of whites were unpartnered ($P=.000$). The annual household income ranged from <\$15,000 to >\$100,000; 56% of African-American and 79% of white households earned >\$25,000 ($P=.000$). The demographic and medical results are presented in Table 1.

The overall response rate was 278 (54%). One hundred seventeen (44%) of the African-American women who were originally recruited and 161 (65%) white women who were originally recruited participated ($P=.000$). The recruitment results are presented in Figure 1.

DISCUSSION

This article describes the recruitment process and participation outcome in two ethnic groups. This study was designed to involve equivalent numbers of African-American women so meaningful conclusions could be drawn separately for each ethnic group. More importantly, the study attempted to address the challenge of

Table 1. Demographic and Medical Information

| Variable | No. (%) Total Sample (n=278) | No. (%) African American (n=117) | No. (%) White (n=161) | P Value* |
|--------------------------------|------------------------------------|--|-----------------------------|----------|
| Age | | | | .038 |
| Mean (yr) | 63.6 | 61.8 | 64.8 | |
| <50 yr | 36 (13) | 20 (17) | 16 (10) | |
| 50-64 yr | 112 (40) | 46 (39) | 66 (41) | |
| ≥65 yr | 130 (48) | 51 (44) | 79 (49) | |
| Relationship status | | | | .001 |
| Partnered | 164 (59) | 56 (48) | 108 (67) | |
| Unpartnered | 114 (41) | 61 (52) | 53 (33) | |
| Education | | | | .105 |
| ≤High school | 70 (25) | 31 (26) | 39 (24) | |
| Some college | 133 (48) | 63 (54) | 70 (44) | |
| College graduate | 75 (27) | 23 (20) | 52 (32) | |
| Income | | | | .000 |
| <\$25,000 | 80 (30.5) | 47 (44) | 33 (21) | |
| \$25,000-\$45,000 | 80 (30.5) | 33 (31) | 47 (30) | |
| ≥\$45,000 | 102 (39) | 27 (25) | 75 (49) | |
| Occupation | | | | .001 |
| Professional/Manager | 83 (30) | 32 (28) | 51 (32) | |
| Technical/Admin/Sales | 60 (22) | 30 (26) | 30 (19) | |
| Service or other | 51 (19) | 30 (26) | 22 (14) | |
| Homemaker | 80 (29) | 23 (20) | 57 (35) | |
| Type of surgery | | | | .173 |
| Mastectomy | 144 (52) | 62 (53) | 82 (51) | |
| Mastectomy with reconstruction | 54 (19) | 17 (15) | 37 (23) | |
| Breast conservation | 80 (29) | 38 (32) | 42 (26) | |
| Mean years since diagnosis | 7 | 6.49† | 7.36‡ | .000 |

*To calculate the P values, chi-square tests were used for the percentage comparisons and t-tests were used for the mean comparisons.
†n=115.
‡n=160.

recruiting adequate numbers of African-American women into cancer control research.

The results of this study and previous research suggest that sample selection is a critical component to successful recruitment. We used documented strategies that were successful in other studies (eg, the tumor registry database provides a good selection of ethnic, age, and economic diversity, and previous study responders are probably more likely to participate). Additionally, a personalized recruitment letter was specifically designed for the African-American patients (the content as well as the tone of the invitation letter to participate was personal and culturally consistent). This letter informed the perspective African-American participant that the principal investigator was also a woman of color.

This study achieved only limited success in recruiting ethnic minority participants into a cancer control study. Although the study implemented culturally consistent methods of recruitment and highlighted the involvement of an African-American investigator, significantly more whites participated than African Americans. Additional factors may influence research participation (eg, type of incentives, incentive schedule, type of stationery, and stamps). Therefore, further research must investigate specific factors that influence African-American participation into cancer control research.

CONCLUSION

The importance of targeted and personalized recruitment strategies that reflect the cultural competency of

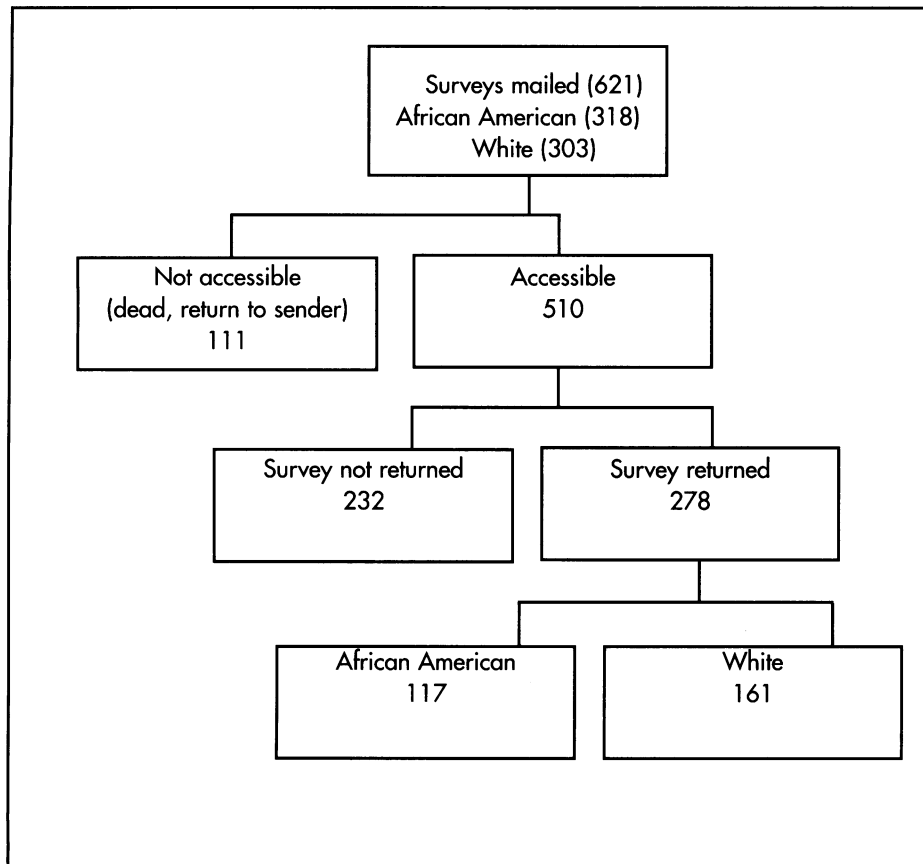


Figure 1.
Recruitment results.

the investigators cannot be overemphasized. The content of the solicitation letter should demonstrate the researcher's commitment to the target population and acknowledge the dearth of information regarding this population with the specific illness. This letter must demonstrate the potential benefits of the individual's participation to the African-American community as a whole and the inclusion of ethnic minority involvement in the actual research process. These content areas reflect the cultural value of many African Americans. These areas appeal to the cultural value of interconnectedness in the African-American community.^{5,16,17} Additionally, the invitation letter and the actual questionnaire should be easy to read and in clear, simple language.

These recommendations are further supported by the Conference on the Recruitment and Retention of Minority Participants in Clinical Cancer Research.¹ The conference summary highlighted the need to tailor recruitment approaches to the culture and needs of the community, and engaging ethnic minority health professionals in the research process.

Literature Cited

1. Benson A. Institutional perspectives on minority population recruitment to cancer clinical trials. In: *Recruitment and Retention of Minority Participants in Clinical Cancer Research: Conference Summary*. Washington, DC: The National Institutes of Health and The National Cancer Institute; 1996:4-5.
2. *Cancer Facts and Figures for African Americans, 1996*. Atlanta, GA: American Cancer Society; 1996.
3. Wingo P, Bolden S, Tong T, Parker S, Martin L, Heath C. *Cancer Statistics for African Americans*. American Cancer Society; 1996.
4. Ashing-Giwa K, Ganz PA. Understanding the psychosocial and quality of life impacts of breast cancer in African American survivors. *Psychosocial Oncology*. 1997;15:19-35.
5. Ashing-Giwa K, Ganz PA, Petersen L. Quality of life in African-American and white long-term breast carcinoma survivors. *Cancer*. 1999;85:418-426.
6. Baquet C, Hunter C. Patterns in minorities and special populations. In: Greenwald P, Kramer B, Weed D, eds. *Cancer Prevention and Control*. New York, NY: Marcel Dekker Inc; 1995:23-36.
7. Benson A. Institutional perspectives on minority population recruitment to cancer clinical trials. In: *Recruitment and Retention of Minority Participants in Clinical Cancer Research: Conference Summary*. Washington, DC: The National Institutes of Health and The National Cancer Institute; 1996:20-23.
8. Nickens H. A compelling research agenda. *Ann Intern*

Med. 1996;125:237-238.

9. Jenkins B, Lamar V, Thompson-Crumble J. AIDS among African Americans: a social epidemic. *Journal of Black Psychology.* 1993;19:108-122.

10. Bastani R, Maxwell A, Bradford C. A tumor registry as a tool for recruiting a multi-ethnic sample of women at high risk for breast cancer. *Journal of Registry Management.* 1996;23:74-78.

11. Erwin D, Deloney L, Dai H, Erkman L. The role of the cancer registry in building outreach programs: the Witness Project example. *Journal of Registry Management.* 1996;23:79-85.

12. Smith S, Trapido E, Richman S, Jean-Francois A, Lojko S, McCoy C. Use of tumor registry data in minority health programs. *Journal of Registry Management.* 1996;23:86-95.

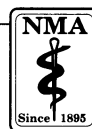
13. Penn N. *Conference Summary: Recruitment and Retention of Minority Participants in Clinical Cancer Research.* Washington, DC: The National Institutes of Health and The National Cancer Institute; 1996:80-81.

14. Sanders-Phillips K. Correlates of health promotion behaviors in low-income black women and Latinas. *Am J Prev Med.* 1996;12:450-458.

15. Millon-Underwood S, Sanders E, Davis M. Determinants of participation in state-of-the-art cancer prevention, early detection/screening, and treatment trials among African Americans. *Cancer Nurs.* 1993;16:25-33.

16. Akbar N. African roots of personality. In: Smith W, Burlew K, Mosely M, Whitney W, eds. *Reflections on Black Psychology.* Washington, DC: University Press of America; 1979:79-87.

17. White J. *The Psychology of Blacks.* Englewood Cliffs, NJ: Prentice-Hall Inc; 1984.



JOURNAL OF THE

National Medical Association®

Coming this summer . . .

A Preliminary Study of African-American Physician Involvement in the Care of Human Immunodeficiency Virus-Infected Patients

M. Keith Rawlings, Richard M. Grimes, and Irene Easling

This article examines the patterns of care for human immunodeficiency virus (HIV)-infected African Americans. Questionnaires were mailed in 1995 to National Medical Association members. Of the 709 respondents, 63% were primary care physicians, pediatricians, or obstetricians-gynecologists; 72% had 0-10 HIV-infected patients, while 9% had >90 patients HIV patients; and 12% had been treating HIV patients for >10 years. The majority of these patients were African American; male-to-male sex and injecting drugs were the two major risk factors. Complexity of HIV care and lack of reimbursement were the principal barriers to providing HIV care. African-American physicians are actively involved in the care of HIV patients. The burden of providing this care is borne by a relatively small number of physicians. Programs are needed to increase the number of African-American providers of HIV care and to provide appropriate reimbursement.

A Survey of the Ethnic and Racial Distribution in Orthopedic Residency Programs in the United States

Richard E. Grant

This study examined the racial and ethnic composition of orthopedic training programs in the United States. A questionnaire was mailed in 1995 to the chairperson at each of the 159 orthopedic programs in the United States. Eighty-nine (56%) responses were received. The distribution of orthopedic residents and fellows was as follows: white non-Hispanic, 84.2%; Asian, 6.6%; African American 3.6%; Native American, 2.2%; Puerto Rican, 1.2%; Mexican American, 0.8%, and other Hispanic, 1%. African Americans and Hispanics were underrepresented among orthopedic training programs compared with their numbers in the general population. The percent ages of residents in these two minority groups were also below goals established by the Council on Graduate Medical Education and the US Government's *Healthy People 2000* report. Native Americans and Asian, by contrast, were overrepresented. If racial balance is to be achieved in orthopedics, new incentives must be created to encourage more African Americans and Hispanics to enter orthopedic residency training programs.