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Minority Recruitment Strategies for the Breast Cancer Prevention Trial

by Gwendolyn Guy, Patsy Long, R.N., and Joseph Halperin, M.D.

The Pilot Minority Recruitment Program (PMRP) was initiated in July 1996 at The Moses H. Cone Regional Cancer Center in Greensboro, N.C., through the auspices of the Southeastern Cancer Control Consortium (SCCC). Funding by the National Cancer Institute through the National Surgical Adjuvant Breast and Bowel Project (NSABP) allowed the cancer center to hire a part-time recruiter to increase the participation of African-American women in the Breast Cancer Prevention Trial (BCPT). Also working on the project were a medical oncologist, research nurses, and a community outreach nurse educator.

The BCPT began recruiting participants in April 1992 and closed enrollment in September 1997. Criteria for the BCPT study were restricted to women who were 35 years and older, with a family history of breast cancer (first degree relative), atypical hyperplasia, early onset of menarche 12 years and younger, and first child born after age 30. According to the National Cancer Institute, of the 13,388 women on the trial, about 40 percent are ages 35 to 49, about 30 percent are ages 50 to 59, and about

30 percent are age 60 or older. About 3 percent of the participants are minorities, including African American, Asian American, Hispanic, and other groups. Five African-American female outreach coordinators in different areas throughout the Northeast and Southeast (Illinois, North Carolina, Pennsylvania, Texas, and Washington, D.C.) were employed to actively seek racial or ethnic minority women who met the study criteria for participation in the BCPT. Information about minority recruitment efforts in this article pertains only to the experience of the Greensboro site.

Six years after its inception, the Breast Cancer Prevention Trial shows a 45 percent reduction in breast cancer incidence among high-risk participants who took tamoxifen. As a result, investigators released the initial study results about fourteen months earlier than expected. They also notified the 13,338 women participants of the findings so these women who had been taking the placebo could consider starting tamoxifen therapy after consulting with their physicians. Participants will continue to be followed by the NSABP, with support from the National Cancer Institute. The majority of NSABP physicians, nurses, and other medical professionals are located at community cancer centers, allowing state-of-the-art research and cancer control trials close to home.

CHURCH AND COMMUNITY

Accrual to cancer prevention trials involves a dynamic that is different

from accrual to cancer treatment trials. The referral network in place for patients diagnosed with cancer is of little help in recruiting healthy individuals to cancer prevention trials. Accrual of minority patients to the breast cancer (as well as prostate cancer) prevention trials has been lower than desired from all NCI-supported institutions. Minority and poor patients cannot afford the luxury of worrying about preventing problems that are not likely to be a concern in the near future.¹

Key to minority recruitment efforts is community involvement. Members of the community must perceive that recruiters and outreach workers who come into their neighborhoods have a sense of concern and caring, commitment, and honesty. Outreach workers should be sensitive to community concerns and perceptions that may act as barriers to study participation. Such barriers may include unpleasant experiences in public hospitals, fear of being denied care because of inadequate financial support, fear that researchers will take advantage, and lack of understanding how trials can benefit participants. Many of these barriers can be overcome if the potential study participant and his or her family have good rapport with the health care providers.² Ensuring trust and maintaining credibility are critical in gaining the support of the minority community.^{3,4}

Minority recruitment efforts at The Moses H. Cone Regional Cancer Center began by seeking access to Greensboro's African-American community leaders, especially

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church ministers. Churches are influential institutions within the African-American community as well as the place where large numbers of women assemble. We hoped to bolster interest and possible participation in research trials, relying on church leaders as advocates for the study.

Talking to church leaders, however, was more difficult than originally thought. Many ministers were unavailable during the weekday and often too busy to receive visits or answer telephone calls. This predicament prompted development of an alternative and more successful approach for gaining entry into the ministerial hierarchy: We contacted women's ministries and women's committees within the churches.

In addition, the recruiter and outreach nurse made visits to local African-American businesses, women's civic organizations (such as local alumni groups of university sororities) and medical organizations (such as the Sickle Cell Disease Association of the Piedmont and a local chapter of a nursing association), and community health agencies. The purpose of these visits was to inform the groups about the research trial, provide an opportunity for their questions or concerns about the study, leave brochures and, hopefully, schedule presentations.

Name recognition of the study is the key to recruitment efforts. Local newspapers, television advertisements, and radio talk shows were all avenues for increasing name recognition as well as study support. Early on, our hospital public relations department contacted a local newspaper about our efforts to increase minority participation. The result was a widely read article about the study, which featured an interview with one of our African-American participants who stressed the importance and benefits of participation. In her own words, she described her family history of breast cancer and the feeling of security that the study fostered. "I know I am getting the best of care," she said in the article. "If anything is found, it will be found early." Endorsement by participants about the benefits of the study can improve credibility and trust. Indeed, approximately half the inquiries for study

participation resulted from this one newspaper article.

Overall, effective recruitment strategies evolved as a result of trial and error. For example, we found that presentations made at public housing sites had minimal success. Few attended, and the women who did come appeared to have more immediate concerns about other issues, such as housing, employment, and safety. We also found that outreach presentations that focused solely on recruitment did not generate an enthusiastic reception. What did generate interest were presentations by the outreach nurse educator about breast health issues, including breast cancer statistics, the necessity of doing breast self-exams and having regular mammograms, and early detection.

SUSPICIONS AND SUPPORT

Many women were reluctant to participate in the study because they were suspicious of clinical research, lacked information about the topic, and questioned the advantage of taking a placebo if the study medication was believed to be a prevention for the development of breast cancer. At a number of presentations, several women (generally older women) voiced lingering memories of the Tuskegee syphilis experiments in which minority patients with syphilis were given a placebo and died. On this topic we became proactive. We sought to ease concerns by explaining upfront—even before questions were raised—about these experiments. Still, many women 65 and older expressed a common sentiment that they had lived long lives without major illness and that participating in cancer prevention studies presented little personal benefit.

Through our efforts, about eighty African-American women voiced interest in participating in the BCPT. In the end, however, just three African-American women were enrolled. Unlike the women in the older age group, those who were most willing to participate in the research trial were between the ages of 35 to 49 and had a mother or sister with breast cancer. The women who had interest tended to have a high school or college education. Unfortunately, most of them failed to meet eligibility requirements for

the study and, thus, were ineligible to participate.

Many African Americans rely heavily on the counsel and advice of their primary care doctors. Because primary care physicians tend to be the bridge for many African Americans' willingness to embrace research, we tried to gain the support and involvement of area doctors. We conducted a dinner meeting with African-American physicians to open lines of communication between the area physicians and the hospital. Information about the BCPT was provided to physicians, who were asked to lend their support to this important study. This meeting was also an opportunity for physicians to voice their concerns about how the study would be implemented and what kinds of materials they would receive to educate their patients.

Medical institutions and local African-American physicians must develop a working relationship to promote and enhance patient access to the latest research techniques and studies. What's more, physicians from the African-American community need to become more involved with research proposals, study design, and actual implementation of the research. Such involvement could help the African-American community embrace and support treatment and prevention trials.

Outreach must continue long after studies are completed to build a relationship between the community and the study institution. The community must perceive a genuine concern about its overall well-being as well as the integrity and truthfulness of those who represent medical institutions. ■

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