Mounting Research Addressing Issues of Race/Ethnicity in Health Care

Recruitment and Retention of Subjects for a Longitudinal Cancer Prevention Study in an Inner-City Black Community

Daniel S. Blumenthal, John Sung, Ralph Coates, Jackie Williams, and Jonathan Liff

Recruiting and retaining subjects for longitudinal prevention trials is challenging. The inherent difficulties are compounded when the trial is to take place in a low-income minority community, since prevention is a low priority among residents of such communities, and research is viewed with suspicion. We present our experiences in attempting to recruit and retain low-income black women living in inner-city Atlanta for a trial of an educational intervention to promote screening for cancer. The intervention was conducted in the home by trained lay health workers. We found that recruitment was more successful when we recruited directly from the community than when we recruited from the patient registry of a primary health care center. The attrition rate over an 18-month period was high. Among members of the intervention group, those retained in the study tended to be wealthier and better educated and were more likely to be married and employed than those who dropped out. It seems probable that women of lower socioeconomic status found our intervention to be intrusive or burdensome. Among the controls, socioeconomic factors did not discriminate between those who completed the study and those who did not; loss to follow-up in this group was associated only with younger age. In conducting research of this type in low-income minority communities, special attention must be given to issues of recruitment and retention if the validity of the study is to be preserved.

Key Words. Recruitment of subjects, retention of subjects, inner-city community, longitudinal research, cancer prevention

Recruiting subjects for controlled clinical trials presents some well-known difficulties (Meinert 1986). Retaining subjects in such studies over time presents additional difficulties (Marmor, Oliveria, Donahue, et al. 1991). These problems are compounded when the study involves a preventive rather than a therapeutic intervention (Hansen, Collins, Malotte, et al. 1985), since the motivation to participate is reduced.

When the subjects for a preventive intervention trial are to be recruited from a low-income minority community, the difficulties may be further compounded, for several reasons. For individuals leading a day-to-day existence with regard to food and shelter, health care is generally important only in the presence of symptoms; preventive measures receive a low priority. Moreover, among African Americans and some other minority groups, there is the perception that they have been exploited for research purposes in the past; they may therefore be averse to serving as research subjects. This aversion may be increased by cultural, racial, or ethnic differences between the researcher and the potential subjects.

At the same time, there is a great need for prevention research in low-income minority populations, since these groups have the highest rates of morbidity and mortality from preventable illnesses. Despite the difficulties, therefore, it is important to identify effective approaches to enrolling and retaining members of these populations in studies of disease prevention and health promotion.

We present here our experiences in recruiting and retaining subjects in a longitudinal cohort study of a cancer prevention intervention in a low-income, inner-city, black community. While our success was mixed, lessons of the experience may be of use to others pursuing this type of research.

METHODS

The general design for this study has been published previously (Sung, Coates, Williams, et al. 1992). We invited African American women living

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Address correspondence and requests for reprints to Daniel S. Blumenthal, M.D., M.P.H., Professor and Chairman, Department of Community Health and Preventive Medicine, Morehouse School of Medicine, 720 Westview Drive, S.W., Atlanta, GA 30310-1495. Dr. Blumenthal is also Associate Director of the Drew-Meharry-Morehouse Consortium Cancer Center (DMMCCC). John Sung, Ph.D., M.P.H., Morehouse School of Medicine, is a Member of DMMCCC; Ralph Coates, Ph.D. is Associate Professor, School of Public Health, Emory University, and Associate Member, DMMCCC. Jackie Williams, R.N., M.Ed. was formerly a Teaching Associate, Morehouse School of Medicine, and is a Member, DMMCCC. Jonathan Liff, Ph.D., is Associate Professor, School of Public Health, Emory University, and an Associate Member, DMMCCC.

in an inner-city community in Atlanta to participate in a breast and cervical cancer prevention study. The goal of the project was to evaluate an intervention designed to educate and motivate recipients to obtain breast and cervical cancer screening annually.

The target population resided in the West End, a low-income community of about 83,000 persons (including approximately 32,000 adult women). The median family income of this area according to the 1980 census was $9,378 (Bureau of the Census 1980); in some census tracts containing public housing projects, the median family income was less than $5,000 according to the 1990 census (Bureau of the Census 1990). Nearly 45 percent of the households were headed by women.

The intervention was developed primarily by health activists who were members of the National Black Women's Health Project (NBWHP), an Atlanta-based organization that promotes self-help strategies in health for black women. Designed to be culturally sensitive, the intervention was delivered by trained lay health workers (LHWs) to women (and sometimes their families) in their homes. It consisted of two sessions held two to three weeks apart and a third ("booster") session about two months later. It included factual material and interactive discussion on breast and cervical cancer and on screening tests for these cancers, including Pap smears, clinical breast exams, breast self-exams, and mammography; it also included information on other aspects of women's health.

The five lay health workers were black women drawn from the inner-city target population. Their backgrounds varied, but each had attended at least some college, and all had experience in grass roots community organizing around women's health issues. Over a ten-week period, the project staff trained them in interviewing skills, and the NBWHP trained them to deliver the intervention.

Women who agreed to participate in the study were administered a baseline questionnaire to obtain their past history of breast and cervical cancer screening and to elicit information about their knowledge of and attitudes toward cancer and cancer screening. The questionnaire required approximately 45 minutes to complete. The subjects were then randomly assigned to intervention and control groups. Six months after the completion of the interventions, all subjects were interviewed again.

RECRUITMENT

Black women aged 18 years and older with no history of cancer, hysterectomy, or breast surgery were eligible to participate in the study. Initially, subjects were recruited from the patient population of the West End Medical

Center (WEMC), a federally funded primary health care center located in the West End community. Eligible women were identified by reviewing patient registration logs and medical records. These women were contacted by letter; the letter was followed by a phone call from an LHW for the purpose of making an appointment for an interview in the home.

Subsequent recruitment efforts focused on public housing projects (both senior citizen high-rise apartment buildings and low-rise general public housing); selected businesses (beauty parlors, Laundromats, stores, and shopping areas); churches; and referrals from the National Black Women's Health Project.

Recruiting in each housing project was undertaken with the support of the housing project manager (a Housing Authority employee) and the president of the tenant association, both of whom assisted in disseminating information about the study. Following these initial efforts to inform residents of the study, lay health workers passed through the housing project distributing flyers that described the study and invited women to participate. The following day, they went door-to-door attempting to identify eligible women and recruit them as subjects. When possible, women who agreed to participate were interviewed on the spot; otherwise, return appointments were scheduled.

Recruiting in business establishments was done with the approval of the management. Women were approached directly, particularly in places where they were otherwise waiting idly, such as Laundromats and beauty parlors.

Several of the ministers in the West End community cooperated by identifying potential subjects from their congregations. This was generally done with the assistance of the church health committee, which is active in many black churches.

During the period of subject recruitment for our study, the staff of the NBWHP referred to the LHWs eligible women who were participating in the activities of the organization.

FOLLOW-UP

The LHWs undertook follow-up interviews in the subjects' homes approximately 6 months after the final intervention. At that time, it had been 12 to 18 months since the last contact with subjects in the control group.

The follow-up questionnaire was similar to the baseline questionnaire but somewhat shorter, requiring about 30 minutes to administer. When possible, subjects in both the intervention and control groups were first

contacted by phone to schedule appointments for the interviews. If a subject could not be contacted by phone, a home visit was made to conduct or schedule the interview. If the subject could not be located at her former address, a letter was sent and inquiry was made of neighbors and the "contact person" designated at the baseline interview in an attempt to locate her.

RESULTS

Over a period of three months, we contacted or attempted to contact 275 women identified from the patient registration log at WEMC. We were only successful in recruiting 55 (20.0 percent) of them to the study. We were unable to contact 132 (48.0 percent) of the women either because their phone number, their address, or both was incorrect in the patient registration log, or because they did not answer their phone despite repeated calls at different times. Of the 143 we contacted, 47 refused to participate, 4 failed repeatedly to keep appointments, and 37 were not successfully recruited for a variety of other reasons.

Because of this limited success in recruiting from the WEMC patient population, we adopted the second strategy described previously: contacting women in public housing projects, business establishments, and churches, and through the NBWHP. Many of the unsuccessful contacts, particularly in business establishments, were very brief. During this second phase of the recruitment effort, approximately 600 women were contacted. Of these, 286 agreed to participate, for a total of 341 subjects.

There was considerable attrition in the sample at follow-up. Among the 163 women in the intervention group, 97 (59.5 percent) completed the first two intervention visits; 93 (57.1 percent) completed the third (booster) visit and were successfully interviewed at follow-up. Of the 158 women in the control group, 102 (64.6 percent) completed the follow-up interview. Approximately 30 percent of the women in each group could not be found ("lost to follow-up"), while about 10 percent of the subjects in the intervention group and 4 percent of those in the control group refused the follow-up interview.

In both intervention and control groups, those who responded to the follow-up interview differed from those who did not. In the intervention group, responders (completers of the program) and nonresponders (noncompleters) were similar in age distribution; however, responders tended to have higher incomes, to be married or living as married, to be better educated, and to be employed.

In the control group, the situation was reversed: responders differed from nonresponders *primarily* in age distribution; responders tended to be older than nonresponders. However, there was no significant difference between responders and nonresponders in the control group with respect to income, marital status, education, employment, or source of recruitment. While the differences were not statistically significant, responders were somewhat more likely to have a higher income and less likely to have higher education.

DISCUSSION

Difficulties in recruiting community subjects to longitudinal studies are well known. For instance, the Framingham Study experienced a 31 percent refusal rate among those originally invited to participate (Gordon, Moore, Shurtleff, et al. 1959). To the extent that refusers do not resemble subjects, this problem threatens the external validity of the study (Hansen, Collins, Malotte, et al. 1985).

Since recruitment is difficult even when conducted in a middle-class white community, it is not surprising that we encountered significant obstacles to recruiting subjects from a low-income urban minority community. As noted earlier, health priorities in the inner-city tend to focus on obtaining treatment for acute problems, rather than on prevention. In addition, a bias against participation in research often exists among low-income minority groups that have historically been research targets, sometimes under circumstances lacking informed consent safeguards (Byman 1991). Compounding these problems is the fact that we offered potential subjects an intervention that was relatively intrusive and time-consuming.

Overall, we were able to recruit about 38 percent of the women we approached to participate in this study. Recruiting subjects from the patient registry of a community health center proved especially time-consuming and inefficient. The health center's records were subject to inaccuracies found in the records of many public health care facilities. These included addresses and phone numbers that were obsolete due to the mobility of the patient population and the frequency with which low-income persons' telephone service is disconnected; addresses and phone numbers that may have been falsified by patients to evade possible bill-collection efforts or for other reasons; and telephones that went unanswered, possibly for causes associated with unstable living situations.

We were more successful in enrolling subjects when we began recruiting directly from the community–that is, when we substituted a ***community-based*** recruitment strategy for the previous ***institution-based*** (or clinic-based) strategy.

The community-based strategy centered largely on increasing the visibility of the project in the community. This was done through the participation of LHWs and other project staff in community organizations, meetings, and activities; through the use of existing social networks, such as church groups; by working with community leaders such as ministers and tenant association presidents; and by the targeted distribution of flyers and letters.

We found that face-to-face communication whenever possible was important, rather than communication by telephone. We utilized this approach in door-to-door recruiting in housing projects as well as in recruiting women in locations where they were waiting idly, such as Laundromats and beauty salons.

Although housing projects were ultimately found to be the most productive sites in which to recruit, fear of crime limited our ability to do so. The LHWs worked in pairs in housing projects, but were still unable to work after dark in these locations.

In addition to recruitment difficulties, retaining subjects in a longitudinal study may also be difficult. Attrition represents a threat to the internal validity of the study. This may be true even when the rates of attrition are similar in the experimental and control cohorts (Greenland 1977).

Several studies have examined factors associated with retention in a longitudinal prevention project. In such a project conducted among elderly patients of a large group medical practice, attrition was associated with older age, being a woman, being unmarried, poorer health, intervention group assignment, non–single family residence, no alcohol use, and depression. Income was not associated with attrition, and race was not examined. However, persons who left the practice, moved away, or died were not counted as dropouts (Slyman, Drew, Wright, et al. 1992).

In a review of several substance abuse prevention programs for youth, Hansen, Collins, Malotte, et al. (1985) found that users of the substances in question (tobacco, alcohol, and marijuana) were more likely to drop out than nonusers.

Marmor, Oliveria, Donahue, et al. (1991) surveyed parents of subjects in the Framingham Children's Study and found that factors contributing to retention included the attitudes of the staff, feedback to the subjects,

the staff's handling of questions and problems, and association with the Framingham Heart Study.

Attrition from a longitudinal prevention study in an inner-city minority community has not been previously studied. However, attrition might be expected to be particularly pronounced in such a community, where rates of transiency and family instability are high and where, as previously noted, the motivation to participate in such research is low.

In fact, retaining subjects in our study proved nearly as difficult as recruiting them. Of the 341 women initially enrolled, we were only able to interview 195 at the end of the project one and a half years later (102 in the control group, 93 in the intervention group). Of the 163 women in the intervention group, 65 were lost to follow-up or refused further participation before completing all three intervention visits. Those who did not complete the intervention were more likely to be poor, unmarried, high school dropouts, and unemployed. Thus, even this very personalized intervention was unable to reach the most socioeconomically disadvantaged inner-city women.

Loss to follow-up in the control group was not unexpected; during the approximately 18-month interval between the baseline and the follow-up interviews, there was no attempt by project staff to contact women in this group. Unlike the intervention group, loss to follow-up in this group was not associated with lower socioeconomic status, but was associated with younger age.

Participation in research projects does not rank high on the list of priorities for low-income inner-city residents. Interviews and individualized interventions are likely to be seen simply as impositions, even when the interviewer or the intervenor is a member of the same ethnic group and a similar social class. Moreover, the fact that the project is being conducted by well-known community organizations or institutions does not necessarily improve participation.

Nonetheless, we were able to identify some approaches to improving recruitment. Chief among these was the strategy of taking the project directly to the community rather than approaching the community through a health care institution as an intermediary. We found that attrition was greatest among women of lower socioeconomic status in the intervention group; in the control group, education and income did not discriminate between dropouts and those who completed the study. This suggests that women of lower socioeconomic status may have found our intervention to be intrusive or burdensome; retention in the study might have been greater

had the intervention taken less time or if we had recruited higher-income black women.

Our experiences demonstrate some of the difficulties associated with conducting prevention research in a low-income, minority, inner-city community. These difficulties are generally greater than those encountered in more affluent communities, and special attention must be given to them if the validity of the study is to be preserved.

REFERENCES

Bureau of the Census, U.S. Department of Commerce. 1980. "1980 Census of Population and Housing." Summary Tape File, Data Users Service Division (CD-ROM).

———. 1990. "1990 Census of Population and Housing." Summary Tape File, Data Users Service Division (CD-ROM).

Byman, B. 1991. "Out from the Shadow of Tuskegee. Fighting Racism in Medicine." *Minnesota Medicine* 74 (1): 15–20.

Gordon, T., F. E. Moore, D. Shurtleff, and T. R. Dawber. 1959. "Some Methodologic Problems in the Long-Term Study of Cardiovascular Disease: Observations on the Framingham Study." *Journal of Chronic Disease* 10 (2): 186–206

Greenland, S. 1977. "Response and Follow-up Bias in Cohort Studies." *American Journal of Epidemiology* 106 (3): 184–87.

Hansen, W. B., L. M. Collins, C. K. Malotte, C. A. Johnson, and J. E. Fielding. 1985. "Attrition in Prevention Research." *Journal of Behavioral Medicine* 89 (3): 261–75.

Marmor, J. K., S. A. Oliveria, R. P. Donahue, E. J. Garrahie, M. J. White, L. L. Moore, and R. C. Ellison. 1991. "Factors Encouraging Cohort Maintenance in a Longitudinal Study." *Journal of Clinical Epidemiology* 44 (6): 531–35.

Meinert, C. L. 1986. *Clinical Trials: Design, Conduct, and Analysis.* New York: Oxford University Press.

Slymen, D. J., J. A. Drew, B. L. Wright, J. P. Elder, and S. J. Williams. 1992. "Compliance with a 12-Month Assessment in an Elderly Cohort Participating in a Preventive Intervention Study: The San Diego Medicare Preventive Health Project." *International Journal of Epidemiology* 21 (4): 701–706.

Sung, J. F. C., R. J. Coates, J. E. Williams, J. M. Liff, R. S. Greenberg, G. A. McGrady, B. Y. Avery, and D. S. Blumenthal. 1992. "Cancer Screening Intervention among Black Women in Inner-City Atlanta. Design of a Study." *Public Health Reports* 107 (4): 381–88.