BARRIERS AND STRATEGIES FOR SUSTAINED PARTICIPATION OF AFRICAN-AMERICAN MEN IN COHORT STUDIES

Background: Prostate cancer incidence is about 70% higher among African Americans compared to Whites. Factors associated with this differential remain unclear, although several studies suggest that genetic factors may play a role. Before epidemiologic research can adequately identify factors associated with this differential, we need studies to determine the feasibility of recruiting and retaining African-American men in cohort studies, especially those that collect biological and questionnaire data.

Methods: We conducted 4 focus group discussions among African-American men aged 40 to 64 years in North Carolina, and an additional group comprised of their partners, using a semi-structured interview protocol (total N=55 subjects). Data were analyzed with QRS NU*DIST to identify themes.

Results: Participants' willingness to participate in cohort studies seemed to be motivated by a perceived risk of prostate cancer. Barriers to participation included mistrust of the research community, poor knowledge of cancer-site specific heterogeneity, anticipated time commitment, and the invasive nature of disease detection procedures. To foster trust and increase disease knowledge, recommended strategies included: partnering with known civic organizations that provide education on risk factors; discussing early signs and symptoms at the point of recruitment; recruiting participants from community clusters; and providing periodic feedback on biologic samples (if collected) to reassure participants of their proper usage.

Conclusion: Observational cohort studies focused on African-American men are feasible if certain barriers to participation are addressed. (*Ethn Dis.* 2003;13:470–476)

Key Words: African-American Men, Cohort Studies, Recruitment, Retention, Strategies, Focus Group

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INTRODUCTION

Nationally, prostate cancer incidence is at least 70% higher in African-American men than in their European-American counterparts. From 1993 to 1997, African-American males had mortality rates for prostate cancer 2.4 times higher than European-American males. In parts of North Carolina and other southeastern states, this difference may be even larger.1 While disproportionately higher mortality rates have been attributed, at least in part, to differences in earlier vs later detection and the course of treatment followed,^{2,3} reasons for disparities in incidence remain unclear.

Established long-term cohort studies such as the Physicians Health Study and the Framingham Study offer the best evidence for identifying etiologic factors in the broader population, and could be used to investigate prostate cancer risk factors among African Americans. However, the numbers of African Americans included in these studies are too small to perform sub-group analyses to account for prostate cancer disparities. In case-control studies with higher numbers of African Americans,^{4–6} response

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Address correspondence and reprint requests to Cathrine Hoyo, PhD; Department of Health Education; North Carolina Central University; P. O. Box 19837; Durham, NC 27707; 919-681-2441; 919-681-6560 (fax); hoyo0001@mc.duke.edu rates as low as 41% have been reported. Low response rates, coupled with problems of establishing a temporal sequence between prostate cancer and the exposure under investigation, raise questions about the validity of results. Still unclear is whether response rates differ by race in these studies, thereby biasing conclusions that might be drawn.

A European cohort study⁷ suggests that as much as 42% (95% confidence interval 30% to 50%) of prostate cancer risk could be attributed to genetic factors, a finding that may have significant implications for African-American men. Yet, before researchers can even begin to explore the complex interplay between genetic and environmental factors, the barrier of recruiting and retaining African-American men in long-term cohort studies must be addressed. Previous studies have cited time and financial constraints,8 as well as mistrust of the research and medical community,8-13 as barriers to sustained participation. However, these factors were reported in the context of clinical^{8-10,12,13} and community trials.14 Mistrust, in particular, is likely not generalizable to observational epidemiologic studies since researchers play no role in manipulating the exposure.

Religious organizations have been shown to be effective partners in recruiting African-American women to participate in research studies^{15,16} and educational outreach initiatives. The effectiveness of using this strategy to enroll African-American men in a prostate cancer longitudinal study remains unknown. Although African-American Yet, before researchers can even begin to explore the complex interplay between genetic and environmental factors, the barrier of recruiting and retaining African-American men in long-term cohort studies must be addressed.

men report church membership at comparable rates to women, only 25% of African-American men compared to 70% of women report attending worship services regularly.¹⁵ This study reports the results of a focus group looking at barriers to, and facilitators of, sustained participation in prostate cancer research studies among African-American men, as well as strategies for minimizing these barriers.

METHODS

Recruitment of Participants

Focus group methods have been successfully used to generate hypotheses and uncover attitudes and opinions in marketing and health research.17 Because barriers to participation by African Americans in clinical trials used focus group interviews, and no data exist regarding participation in observational studies, this strategy was used for data collection. Several strategies were used to recruit study participants representing a broad socioeconomic cross-section of African-American men between the ages of 40 and 64 years. To reach collegeeducated African-American men who had attended Historically Black Colleges and Universities (HBCUs), flyers were distributed at a major HBCU football game and on bulletin boards at North

Table 1. Summary of focus group questions asked

Perceptions of Cancer Research Importance among African-American Men
Importance of cancer research and willingness to participate among African-American men Perceived impact of cancer research on African-American men's health Immediate and long term benefits of participating in longitudinal studies
Collection of Questionnaire and Biologic Data
Strategies and sources of recruiting African-American men Feasibility of collecting biologic specimens and conducting DNA analysis Feasibility of collecting mailed self-administered questionnaires Attitudes of periodic physical examinations to detect prostate cancer endpoint
Strategies for Sustaining Participation of African-American Men in Longitudinal Studies
Perceived effect of periodic visits or newsletters on recruitment and retention Perceived effectiveness of champion endorsers, cancer survivors, and spouses on recruitment and retention Perceived effectiveness of incentives (monetany, education, and free screening for prostate cancer)
on recruitment and retention

Carolina Central University, Durham, and North Carolina Agricultural and Technical College, Greensboro, NC. Urban non-college educated men were targeted to receive flyers, which were distributed in local barbershops, churches, and community centers in predominantly low-income, high-unemployment, African-American areas of southand north-central Durham and southeast Raleigh, NC. Men who met age eligibility requirements and who were willing to participate were asked to call a campus telephone number to schedule an interview. Because partners' beliefs may influence men's decisions to participate in research studies, female partners of men who met inclusion criteria and lived in Raleigh or Durham, NC, were also recruited and interviewed separately. Individuals who were recruited received a single Collegiate Institutional Athletic Association (CIAA) basketball tournament booklet of tickets as an incentive for participating in focus group interviews. In this manner a total of 46 African-American men and 9 African-American women were recruited.

Data Collection

Table 1 is a summary of the interview protocol used to elicit information to ascertain participants' perceptions on: the importance of etiologic studies of cancer and their willingness to partici-

pate; their attitudes towards periodic completion of risk factor questionnaires, venipuncture, and DNA analysis from blood samples; as well as strategies they would recommend for recruiting and retaining African-American male participants in long-term studies. Five focus group interviews were conducted between November 2001 and January 2002, representing: a) a fraternity, b) a church, c) a community organization, and d) a barbershop. All interviews were conducted in the evenings or weekends to ensure inclusion of the working population. A trained interviewer and HBCU alumnus moderated all interviews, which were conducted at central locations such as the Fraternal Organization Building in Kinston County, NC, university conference rooms, churches, and barbershops.

Prior to each interview session, the purpose of the discussion was reiterated and procedures explained; participants were assured of confidentiality and were told that interviews would be taped for accuracy. After signing consent forms, participants completed a short demographic sheet. Sessions lasted an average of 2 hours.

Analysis

After each interview and prior to transcription, the moderator and comoderator reviewed discussion notes

Emerging Theme	Strategy for Recruitment/Retention
1. Mistrust	Cluster identification and recruitment
Of being treated differently In use of biological data In use of questionnaire data	Partnership with known civic organizations Provision of feedback on data use Provision of data summaries
2. Lack of knowledge about endpoint under study	Education of potential participants about: Potential risk factors Signs and symptoms Early detection Education of partners and spouses Consistent update as new information is available
3. Commitment level expected in cohort studies	Send questionnaire in sections Use routine doctors' visit to collect specimens Incentives provided should be appropriate

Table 2. Barriers and strategies for recruiting and sustaining participation

and audiotapes. Two investigators independently reviewed the transcripts and notes to derive themes; a list of recurring themes was finalized by consensus. Code categories were derived for interpretive analysis using QRS NUD*IST software for qualitative data analysis. Table 2 summarizes derived themes.

RESULTS

Table 3 shows the demographic characteristics of the 46 men and 9 female partners interviewed. Male participants ranged in age from 34-79 years, with a median age of 49. Most were married (78%) and half had a college education. Most (70%) men with a college education had at least one degree from an HBCU, with a third also reporting membership in a Greek letter organization. Regular church attendance was reported by 83% of men, although three fourths (74%) reported membership in a specific congregation. Nearly all women reported regular church attendance. Half the male participants reported a family history of cancer (including prostate, breast, and leukemia) in first-degree relatives. The median age of the 9 women was similar to that of their male counterparts.

Barriers to Sustained Participation

Although participants expressed the importance of taking part in etiological studies and exhibited a willingness to do so, they also reported several barriers to participation. These barriers included: mistrust of the medical and research community; lack of knowledge of the heterogeneity of cancers and their risk factors; and the failure of researchers to consult or include civic organizational structures known to the African-American community prior to conducting their studies.

Mistrust of the Research and Medical Establishment

Both partners and spouses expressed concern that African-American men might be subjected to differential treatment once they enrolled in a study, citing the Tuskegee Syphilis Study as an example with comments like, "You don't know how much of a guinea pig you are—remember Tuskegee ..." Participants' spouses and partners expressed similar fears.

"... when I hear about African-American men in a long-in [ie, longitudinal] study, I have to tell you I think about [the] Tuskegee study ... how do you help yourself to get past that?"

Participants cited other, more recent incidents of discriminatory treatment in the medical world, such as the case of Charles Drew, the developer of blood plasma who allegedly bled to death in an all-White hospital in the South in 1950 because he was Black, making remarks such as, "Even Charles Drew; ... they'd not give him a blood transfusion ..."

Participants reported even greater mistrust of the medical establishment with regard to studies involving collection of biological specimens. More specifically, they identified misuse of DNA data and the possibility that misuse of the data could affect their ability to be approved for medical insurance.

"You never know what is going to happen to records ... Blue Cross-Blue Shield may say you have a pre-existing condition."

Another articulated a mistrust of medical and police authority together, expressing a fear that researchers will "... want to see if you have committed a crime..."

Lack of Knowledge of the Heterogeneity of Chronic Diseases and Variability of "Causes"

Although most participants knew someone with some cancer, most did not recognize the heterogeneity of cancers or their risk factors. Few understood prostate cancer's pathophysiologic aspects, suspected risk factors and early detection strategies or how the disease differs from heart disease or lung cancer. Their confusion was expressed in questions such as, "what is a prostate?" and "where is it?" and, "... what does it do when it is not [making a person] sick?" Some who were aware of the relationship between cigarette smoking and lung cancer thought smoking also caused prostate cancer. "... What you consume . . . that is what basically causes cancer and that's smoking . . ."

Participants' assumption that genetic factors might interact with environmental exposures to increase prostate cancer risk varied, as expected, by educational level of participants. One participant

Characteristic	Mean (N=46)	Women (N=9)
Median age	49 years (range 34–79)	48 years (range 42–62)
Marital status	(lange 51 7 5)	(141.90 12 02)
Married	36 (78.3%)	8 (88.9%)
Divorced/single	5 (10.9%)	0
Chose not to report marital status	5 (10.9%)	1 (11.1%)
Education		
College graduate	23 (50.0%)	2 (22.2%)
Non-college graduate	17 (37.0%)	7 (77.8%)
No response	6 (13.0%)	0
College attended		
HBCU	16 (69.6%)	2 (22.2%)
Not HBCU	7 (30.4%)	0
Membership to a Greek letter organization		
Yes	15 (32.6%)	3 (33.3%)
No	30 (65.2%)	4 (44.4%)
No response	1 (2.2%)	2 (22.3%)
Membership to a Masonic organization		
Yes	10 (21.7%)	0
No	35 (76.1%)	9 (100%)
No response	1 (2.2%)	
Frequency of congregational attendance		
Most days of worship	38 (82.6%)	8 (88.9%)
Not most days of worship	5 (10.9%)	1 (11.1%)
No response	3 (6.5%)	0
Member of a congregation		
Yes	34 (73.9%)	6 (66.7%)
No	10 (21.7%)	2 (22.2%)
No response	2 (4.4%)	1 (11.1%)

thought researchers have not "been able to isolate [the gene that] . . . causes certain forms of cancer . . ."

Participants who were skeptical about participation in long-term studies tended to be those whose lack of knowledge about prostate cancer was expressed by fatalistic comments such as, "African Americans don't know what cancer is, and [don't know about early intervention] procedures . . . I truly didn't . . ." Speaking of her husband, one woman said, "His mother, his father, his sister all died of cancer. He's not going [to get screened]; he doesn't want to know." Other women echoed this response, with comments such as, "Mine is an organic person and thinks chemicals in foods [cause any cancer]."

Level of Commitment Expected

Participants expressed concern over sustained participation and the multiple tasks expected of them during the long course of a cohort study. "If you send me a long questionnaire," said one, "I don't do that." Respondents recommended limiting questionnaire length to reduce the time burden. "I would like to complete the questionnaire, but ... will need ... one or 2 pages" Participants articulated concerns about procedures required to collect both exposure and outcome data for prostate cancer epidemiological research; among those expressed more emphatically were the following: "The Black man is not for that," said one respondent about the "intrusive ways" clinicians screen for prostate cancer. Others continued:

"... most brothers are not going to do that (ascertain a prostate cancer outcome) if the doctor say we have to do this ... He will say, *no doctor*, *I ain't going there*..."

"... I mean ... I was ashamed to tell anyone I had it [ie, a rectal exam] done ... Most men are not going to let anybody do that to them ... [It was a] fearful experience ..."

Strategies for Recruiting and Retaining Participants

To Foster Trust

Mistrust of the medical and research community, coupled with limited knowledge of the pathophysiologic aspects of prostate cancer, led participants to suggest 3 main strategies for recruiting participants to a longitudinal cohort study. First, to foster trust and alleviate fear of differential treatment, natural clusters of African Americans who participate in civic groups should be identified, with potential participants recruited from within these clusters. "Identify clusters," said one. "Determine where they gather periodically and bring to them the measurements and blood takers [interviewers and phlebotomists] ..." All men concurred that their likelihood of participation would increase if known community "gatekeepers" asked them to participate and if other persons in the community participated. "I think everyone of us would have come without incentives . . . if you get someone in the community to head it up ... I would come because someone made the call."

Participants varied, however, in their perceptions of the best "communities" or "clusters" from which to recruit. Church-goers tended to suggest recruitment through the church "... go to churches ..." with heads of congregations serving as community "gatekeepers." Alumni of HBCUs suggested fraternal organizations as recruitment clusters, while others suggested recruiting from local organizations such as local Partners Against Crime Networks.

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"Clusters could include the Omega Psi Phi, [a fraternal organization], [the] American Legion ... since they have regular meetings. I think people are genuinely interested in it [the study of prostate cancer etiology]." Women, and men involved with 2 of the 4 men's groups, suggested women's groups as clusters and potential "gatekeepers." "You have to get to the women; they will convince their husbands to participate."

Second, participants concurred that having African-American researchers in charge of a study would alleviate concerns about exploitation or misuse of data. "You know, you want people of color running the show, people you can trust . . ." and, ". . . the bottom line is that when you are looking for DNA, you want someone professional . . . it would be nice to have a person of color."

Having an HBCU or other African-American civic organizations as partners in the study, though, was equally important and, respondents thought, might ensure a more expedient dissemination of information. "... We do not necessarily want a different color [researcher] ... we want at least HBCUs to be involved so when they find out something that could help, it gets to us ..." Another expressed his view that it would be more likely for "Historically Black Colleges [to do] a study to advance the health of Black men ... the interest here is not University of North Carolina or Duke ... this is a Black HBCU." Female participants expressed similar sentiments saying, "I think if more African-American doctors were involved ... we tend to be more comfortable among our own."

Third, participants concurred that a feedback mechanism would ensure that data, especially specimens, were used as intended and that potential changes in the political climate would not change the way the data were used. "We want to know what you are going to do with it," said one. Another said, "if ... [they're] going to help find a cure ...

let them do it ... but ... [we] need feedback assurance that DNA analysis is [being used for] what it is supposed to do."

To Alleviate the Burden of Data Collection

To alleviate the burden of long etiologic questionnaires, some participants suggested completing and returning questionnaires periodically in short segments. Others recommended that blood samples could be collected during routine visits to their physicians.

"I would want to [complete the questionnaire], but will need the questionnaire short ... one or 2 pages ... just to sit down and stay focused ... keep track. I'd question that ..."

"If you send me a long questionnaire, I don't do that . . ."

"If you send me a survey and I don't know anything, you won't get it back ..."

"... if the questionnaire is long ... could you break it up? ... send it in sections, then follow up with a phone call to say how you doing ... maybe 10 pages at a time ..."

These sentiments were also shared by female partners, who recommended that they, too, be informed so they could encourage their partners to participate:

"If you send it to them, and then contact the wives or significant others, they can remind them ..."

"Educate the wife ... Black men listen to wives ... my wife gave me this with the air of 'I think you ought to do it [complete the questionnaire]."

Other responses suggested, as well, a need to additionally inform potential participants through the civic structure of African-American society, prior to mailing questionnaires.

To Increase Knowledge

Respondents agreed that increased knowledge of both the study and the disease, coupled with free screening as an incentive, would increase sustained participation. "You can get a total exam," said one. "My incentive would be to insure that they got good information ... I would not need anything else." To ensure community involvement, respondents recommended recruiting educators from the same civic clusters from which participants are recruited.

There was neither consensus about whether to provide an incentive nor, if an incentive were provided, consensus about what type of incentive would be appropriate. Responses ranged from "have some kind of incentive," to "... pay for mileage . . .," to "phone cards or gas cards," to "incentive not necessary for everyone ... you can get a total exam." One suggested tailored incentives. Although a tailored incentive for every community may not be feasible, an educational campaign and a free screening could serve as both an incentive to sustain participation and a feedback mechanism to foster trust.

DISCUSSION

These data suggest that, although barriers to sustained participation in long-term observational studies exist among African-American men, sustained participation will be likely achieved if specific concerns are appropriately addressed. Barriers to participation included: mistrust of researchers and their use of data; poor knowledge of pathophysiologic aspects of many chronic diseases, including cancers and their risk factors; and the time required to provide questionnaire and biologic data. Participation in cohort studies could be facilitated by perceived personal and community risk. Among African-American men, sustained participation could be achieved by recruiting within civic clusters, providing education (particularly on the end point of interest), providing periodic feedback, and requesting the questionnaire to be comAmong African-American men, sustained participation could be achieved by recruiting within civic clusters, providing education (particularly on the end point of interest), providing periodic feedback, and requesting the questionnaire to be completed in sections.

pleted in sections. Specimens could be collected during routine doctors' visits.

Findings that mistrust of the medical and research community is a major barrier in participation in a cohort study of prostate cancer among African-American men corroborate previous findings from clinical,8,9,13 and community trials.8,10,12 Nevertheless, as reported in other studies, researchers can alleviate mistrust by recruiting individuals from community groups trusted by African-American men. In a diabetes prevention study aimed at determining barriers limiting African Americans' participation in a community exercise program, recruiting within civic structures such as women's groups fostered trust in the program and increased the likelihood of sustained participation by African Americans in the exercise group.¹⁸ Despite deep mistrust, most participants in this study were not only willing to participate in etiologic studies where questionnaire data were collected periodically, but were also willing to provide biologic specimens for DNA analysis.

As expected, our findings suggested that inadequate knowledge about the disease under study was a barrier to participation. In a community trial aimed at determining the effect of knowledge on breast self examination, Mauer,¹⁹ and Hatch,²⁰ showed that health behavior changes in a community occurred if the proposed changes were supported by a basic technical understanding of risk, and if the population were convinced that the recommended changes were efficacious. In addition, our study showed that providing participants with periodic feedback on how biological specimens are being used, may provide adequate assurance to ensure continued participation.

Although Green¹⁰ cites time constraints as a barrier to participation, respondents' recommendation to mail etiologic questionnaires in several sections and to collect specimens during a routine visit to one's family practitioner may be a viable way to alleviate this burden. Completing questionnaires in sections may increase the risk of missing data, thereby threatening the validity of study findings. However, this approach is worth testing in future longitudinal studies.

A limitation of this study is that only focus group methods were used to identify barriers and suggest solutions, hence the relative importance of each factor in influencing sustained participation remains unknown. This ambiguity, however, can be tested in longitudinal studies. Also, participants recruited for the focus group interviews were, by definition, more homogenous than other groups, representing specific segments of the African-American male population. In order to capture a wide spectrum of opinions of African Americans living in North Carolina, participants were recruited from different socioeconomic levels. However, socioeconomic heterogeneity may not have been fully achieved, as suggested by the average income of participants. Participants' median income was \$46,000, nearly double that of North Carolina African Americans, and most men (65%) were college-educated, also higher than the North Carolina average for race and age. In spite of this, since these men are community advocates, they

may have perceptions that reflect the opinions of important constituencies in the population. Also, although the recruitment strategies suggested are novel, the barriers identified in this study have been reported previously.^{8,13} Strategies in this feasibility study can be useful not only for recruiting and sustaining future participation in cohort studies, but also for recruiting population-based controls in case control studies.

CONCLUSION

In this study, identification of barriers such as time constraints and lack of knowledge about prostate cancer were expected, given the size of etiologic questionnaires and the time commitment required. These barriers can be somewhat alleviated by increasing efficiency in the data collection process. However, because researchers do not manipulate the exposure in cohort studies, mistrust as a barrier to participation was unexpected. Findings from this study suggest that recruiting African-American men using community clusters may be effective, although this strategy should be empirically tested.

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