COMMENTARY

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

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The article by Hoyo and colleagues entitled, *Barriers and Strategies for Sustained Participation of African-American Men in Cohort Studies,* used focus groups to determine the feasibility of recruiting and retaining African-American men in cohort studies, especially those collecting both biological and questionnaire data from a study conducted in the Durham, NC metropolitan area.[1] Several strategies were used to recruit study participants representing a broad educational and socio-economic cross-section of African-American men between the ages of 40 and 64, including targeting college campus sports events, local community businesses, as well as high- and low-employment geographic locations with predominantly African-American employees.[1] A total of 46 African-American men and 9 African-American women were recruited through this process.[1]

The article raises many similar issues researchers have faced while attempting to recruit and sustain participation of African Americans in clinical trials.[2] Since barriers to participation like mistrust are commonly reported in the context of clinical[3,4] and community trials,[5] Hoyo and colleagues reported the results of a focus group study regarding barriers and facilitators of sustained participation in prostate cancer research studies among African-American men.[1] Specifically, focus groups in their study addressed the following topics: strategies for minimizing barriers, the feasibility of their participation in a study collecting biological specimen and questionnaire data, feelings and perceptions of prostate cancer, as well as their risk factors, study participation and design, and sources of outreach and recruitment.[1]

Similarly, our study in the Jackson, Mississippi metropolitan area conducted a series of 10 focus groups with homogeneous groupings (6 male and 4 female) from a urology clinic patient population to investigate perceived barriers to participation, perceptions of cancer and cancer research, factors that may increase the probability of sustained participation, health awareness, social support, and coping strategies. Participants were also asked about the feasibility of their participation in a long-term follow-up study where biological specimens and interview data would be collected in regularly defined intervals.

Participants eligible for the study were African-American patients between the ages of 40–75 years who were diagnosed with prostate cancer (with an ICD-9 code of 185) within the past 10 years and seen in the local urology clinic. Female participants were partners/spouses of African-American males diagnosed with prostate cancer from the recruitment clinic. Potential participants who met the inclusion criteria were randomly selected from lists generated by the urology clinic. Those recruited to participate in the study were contacted initially by phone by clinic staff and informed of their eligibility to participate in the study. Each person contacted then received a follow-up letter and phone call to be scheduled to participate in a focus group. The spouses/partners of potential participants were contacted once the male participants had been selected and scheduled to participate in the focus group.

Similarities and differences exist between the respective focus group results from these 2 studies according to the categories addressed (Tables 1–3). In our study, we found that African Americans were more likely to participate in long-term prostate cancer studies if the recruitment source provided encouragement and followup from resources within the community, such as church supporters, gate-keepers, or key informants. Providing information, education, and periodic feedback also encouraged continued participation. Utilizing research institutions or community-based organizations that participants perceived as trustworthy, competent, credible and well known was also important to encourage participation in trials.[6] Participants stated that if prostate cancer survivors were used as recruiters they would be more encouraged to participate in research. They wanted to be kept informed of progress/outcomes from the research conducted through either newsletters or mailings. An acknowledgment of participant (geographic locale, socioeconomic status, education, occupation) diversity and a comprehensive community approach to study involvement was also important to our participants.

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Table 1. Feelings and perceptions concerning prostate cancer

Results	Mississippi	North Carolina
Fear of rectal examination	X	X
Prior participation in medical studies	X	
Lack of knowledge of risk factors and what risk means	X	X
Importance of support groups, family, and dealing with prostate cancer	X	
Fear of impotency and loss of sexual function	X	X
Overcoming stigma attached to prostate cancer within families and the community	X	
Feelings of distrust towards physicians	X	

Table 2. Study participation and design

Results	Mississippi	North Carolina
Positive attitudes toward cancer research	X	X
Insufficient knowledge about medical/clinical trial design	X	X
Offer compensation/free medical care as incentive	X	
Fully informed before consenting to participate	X	X
Fear of Tuskegee study legacy	X	
Researchers vested interest in research and participants	X	X
Participate to increase knowledge of prostate cancer (altruism)	X	X
Consent to having blood and DNA samples taken for research purposes	X	X

Hoyo and colleagues suggest that among African-American men sustained participation could be achieved by the following: recruiting within civic clusters; providing education on the end points of interest; requesting the questionnaire to be completed in sections; collecting specimens during routine doctors visits; and providing participants with periodic feedback on how biological specimens were being used.[1] Additionally, Hoyo and colleagues assert that addressing specific participant requests and needs may provide adequate assurance to ensure continued participation.[1]

Table 1 describes feelings and perceptions participants had about prostate cancer, some of which were unique to our study. Many of the participants spoke of prostate cancer as curable. They felt that prostate cancer did not cause the same fear of death as did other cancers. We found that many of the male participants did not trust the physicians who treated them, especially if they were of another ethnic background. Participants also felt that their families and the community at large attached a stigma to having (prostate) cancer. In our study, the "Tuskegee" study, represented concerns of distrust for research in general. Despite feelings of deep mistrust often resulting from past experiences with healthcare professionals, most participants in both studies 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. Many were willing to participate in research studies, especially if the studies were seemingly culturally appropriate and addressed their issues and concerns. Questions about prostate cancer (causes and treatment) were asked more by participants who were not participating in support groups. In both studies, men feared the rectal examination, and lacked knowledge and understanding of risk factors for prostate cancer. Perhaps one of the biggest fears expressed by male participants in both studies was the fear of impotency and the loss of sexual function (Table 2).

Both studies had similar findings in regard to general participation in cohort studies. We found that participants involved in support groups were more informed about prostate cancer and felt positively about involvement in cohort studies. They said they would agree to participate in observational studies as well. Participants wanted to be fully informed of the study design, aim, and objectives before enrolling in the study. This suggests that it is extremely important that researchers give participants detailed explanations about the studies conducted in medical research to gain informed consent from African-American communities. Each group agreed that the researchers must have a vested interest in the participants, their opinions and the outcomes of the study. Having cohort studies conducted by African-American researchers in key roles was also another important factor in increasing participation in cohort studies (Table 2).

Suggested sources of recruitment to participate in medical trials recognized in both studies included churches, the community at large, and targeted media campaigns (Table 3). In our study participants suggested targeting younger ages by providing health and medical education in secondary and high schools. The participating spouses stated that they wanted to be actively involved in their spouse's entire treatment and healthcare process. They also stated that they would help recruit their husbands/partners into medical studies if they were in-

Table 3. Sources of recruitment and outreach

Results	Mississippi	North Carolina
Churches	X	X
Schools (secondary and high schools)		
Community-at-large (referrals, community outreach, and advocacy)	X	X
Targeted media campaign	X	X
Electronic information		X
HBCU (social groups)		X
African-American	X	
Spouse/partner involvement	X	

volved and given ample information about the study objectives and aims beforehand.

Participants from our study were recruited from a primary care urology clinic where patients were previously diagnosed with prostate cancer. These patients may be more knowledgeable than the general population and may be more willing to participate in medical studies because of their previous diagnosis. Therefore, one limitation of our study is that these findings may not be generalizable to the larger community. A strength of our study is inclusion of concerned female partners and spouses.

Informed decision making (IDM) for prostate cancer screening is now being recommended by many of the medical organizations. IDM explores both the risks and benefits of prostate cancer screening[7] and can be applied to study participation. Chan suggests a "reasonable person standard" where the physician reveals what a hypothetical and reasonable person needs to know about prostate cancer.[8] This should be done within the context of the patient rather than the doctor. We propose that IDM be extended to cohort studies.[8–10] IDM implies that the decision to screen includes the doctor, patient, and perhaps significant others. The decision to participate in research is sometimes a mutual one involving the patient, family or support network, and the medical team. However, the extent of involvement of family and friends in the decision process warrants further study. In our study, involving the partner/spouse was important.

As noted, patient knowledge about prostate cancer can vary. Socioeconomic status and education links with knowledge are well established in literature.[11–14] Blacks more often than Whites demonstrate less knowledge about race or heredity as risk factors, perception of the disease and its treatment, access to screening, and research. This may be very important since the linkage of knowledge and screening has been established and can be extrapolated to observational studies. In general, patients' lack of knowledge about prostate cancer may be a barrier to making an informed decision about study participation.

We suggest that an educational guide be developed to inform healthcare professionals, consumers, and advocacy groups about research and the barriers to participation to encourage the sustainment of African-American participants in research. Providers should then be able to provide knowledge about prostate cancer studies to give the best critical information to patients.

We also suggest the development of strategies for cohort development targeting under-served (African-American) populations. Finally, we recommend targeting community resources to encourage study participation in research and prostate cancer screening by using community representatives, gatekeepers, prostate cancer survivors, and even spouses/partners. These suggestions might be appropriate channels for other non-cancer related studies targeting African Americans.

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AUTHOR CONTRIBUTIONS

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Manuscript draft: Hughes, Sellers, Fraser, Knight
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