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Factors Associated with Enrollment of African Americans into a Clinical Trial: Results from the African American Study of Kidney Disease and Hypertension

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Abstract

Recruitment of diverse populations into clinical trials remains challenging but is needed to fully understand disease processes and benefit the general public. Greater knowledge of key factors among minority populations associated with the decision to participate in clinical trials may facilitate recruitment and enhance the generalizibility of study results. Therefore, during the recruitment phase of the African American Study of Kidney Disease and Hypertension (AASK) trial, we conducted a telephone survey, using validated questions, to explore potential facilitators and barriers of research participation among eligible candidates residing in seven U.S. locations. Survey responses included a range of characteristics and perceptions among participants and non-participants and were compared using bivariate and step-wise logistic regression analyses.

One-hundred forty-one respondents (70 trial participants and 71 non-participants) completed the survey. Trial participants and non-participants were similar in multiple demographic characteristics and shared similar views on discrimination, physician mistrust, and research integrity. Key group differences were related to their perceptions of the impact of their participation. Participants associated enrollment with personal and societal health benefits, while non-participants were influenced by the health risks. In a step-wise linear regression analysis, significant positive predictors of participation were acknowledgement of health status as important in the enrollment decision (OR=4.54, p=0.006), employment (OR=3.12, p=0.05) and healthcare satisfaction (OR=2.12, p<0.01). Racially-based mistrust did not emerge as a negative predictor and subjects' decisions were not influenced by the race of the research staff.

In conclusion, these results suggest that health-related factors, and not psychosocial perceptions, have predominant influence on research participation among African Americans.

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Keywords

African Americans; subject recruitment; willingness to participate; clinical trials

INTRODUCTION

Recruitment of representative numbers of minority participants into clinical research studies, including clinical trials, remains challenging [1]. Despite the National Institutes of Health Revitalization Act of 1993 [2] which emphasized recruitment of racial and ethnic minority subjects into government-sponsored clinical research studies, and a greater recognition of this issue among private sector supporters of clinical trials, there is a paucity of information on the factors that might influence the decision to participate in clinical trials. Moreover, some of the available evidence is conflicting. For example, mistrust has been identified as an important barrier to research participation among African Americans [3–7] in some studies, whereas in others African Americans have been shown to be willing to participate in clinical research investigations [8–11] with enrollment rates similar to non-Hispanic whites [12]. A better understanding of factors that influence participation of ethnic and racial minority populations in clinical research studies may enable the development of more effective recruitment strategies, thereby enhancing the generalizability of the findings from these investigations.

The vast majority of studies to assess the willingness of African Americans to engage in research have been based on community surveys, hypothetical research questionnaires, focus groups, and among clinic populations [3,4,6–8,10,11,13–16] post-hoc analyses [12,13] and pilot surveys [6,11,15]. These extremely different approaches may be responsible for limiting our understanding of the factors that may influence an individual’s decision to participate in clinical research. As an example, evaluation of hypothetical willingness to participate has been demonstrated to be less accurate when compared to actual trial participation [17].

Although studies have focused on attitudes of African Americans toward research participation, in AIDS [17], cancer [5,6,15,18,19] and cardiovascular research [16], there remains an absence of information on what factors should be considered to enhance recruitment. A large randomized clinical trial which exclusively enrolled African Americans with chronic kidney disease, the African American Study of Kidney Disease and Hypertension (AASK), provided the opportunity to evaluate the perceptions of subjects eligible for the trial to identify those factors which either resulted in subjects enrolling or refusing to join the study.

METHODS

AASK Trial Design

The design, recruitment experience, and results of the AASK Trial have been reported previously [20–22]. Briefly, African American men and women between the ages of 18 and 70 with hypertensive kidney disease and glomerular filtration rates between 20 and 65 ml/min were eligible for the AASK trial. Screening procedures for eligibility in AASK involved an informal discussion with staff followed by a separate formal screening examination. During the screening process, eligible candidates were informed that the study involved a minimum of monthly visits, initial back-titration of current anti-hypertensive medications to confirm hypertension, administration of blinded medications, and serial measurements of glomerular filtration rates throughout the study. Upon enrollment participants were randomized to one of two levels of blood pressure control and three anti-hypertensive medication regimens. The primary outcome was the rate of decline in renal function. A total of 1094 study participants were recruited over a 42-month enrollment period at 21 clinical centers located throughout the United States. All trial-related medications and procedures were provided free of charge.

AASK Participation Survey Study

The AASK participation survey study was conducted as an ancillary study to the AASK trial and participation was offered to all 21 AASK sites during the AASK recruitment period. Seven AASK trial clinical centers volunteered to participate in this survey study: Case Western Reserve, Medical University of South Carolina, Meharry Medical College, University of Alabama-Birmingham, University of California – San Diego, University of Michigan, and University of Texas – Southwestern.

A sample of 330 eligible candidates from the AASK trial recruitment period was randomly selected for the AASK participation telephone survey. This sample consisted of 220 African Americans who declined enrollment in the AASK trial (non-participants) along with 110 African Americans who chose to enroll in AASK (participants). The larger pool of non-participants was selected based on predictions that this population would be more difficult to contact and less likely to participate in the survey. Subjects from the participant group were randomly selected for the survey as needed to obtain an equivalent sample size. A total of 141 subjects, 71 (32% of original sample) non-participants and 70 (64%) participants, completed telephone interviews.

The AASK participation survey was approved by The University of Michigan Health System institutional review board (IRB). Verbal consent of each participant was obtained prior to initiation of the survey; a requirement for written informed consent was waived by the IRB. Surveys were conducted at a separate time from recruitment interviews via telephone by experienced interviewers using a standardized script. Ten attempts were made to contact each respondent; if no contact was made at that point, the respondent was removed from the call list. Refusal conversion was not attempted on non-participant respondents. Given the initial refusal to participate in the AASK trial, this second refusal to participate in the survey was accepted without discussion.

Two instruments were designed by the Institute for Social Research at the University of Michigan to obtain similar information from the participant and non-participant groups. Questionnaires included a mix of both closed- and open-ended questions from the Commonwealth Fund Minority Health Survey and validated population surveys [23] and consisted of 45 questions for participants and 43 questions for the non-participants. These two comprehensive surveys were designed to ascertain demographic and socioeconomic information; reports on mood, physical and mental health status; attitudes about racism, religion, biomedical research, trust and satisfaction with health care providers and decisions regarding participation. The respondents were also provided the opportunity, through open-ended questions, to mention additional considerations important to them; all subjects were subsequently asked to choose the most important factors in their decision. Table 1 includes a sample of survey questions from the instruments used in this study.

Data Analysis

Means and standard errors were compared using unpaired Student's t-tests. Bivariate analyses were performed to compare responses of the participant and non-participant groups. Step-wise multivariate logistic regression analysis was performed to determine independent factors that predicted participation. Variables were grouped and added to the equations in the following order: demographic information (age and gender), socioeconomic status (education, employment, income), motivation (low mood scale, mastery scale, religion, health status), general perceptions (discrimination, healthcare satisfaction, importance of healthcare satisfaction in decision, research integrity, physician mistrust), and importance of health status in decision. Health status was based on the respondents' perception of his/her health at the time of recruitment. Statistical differences at $p \leq 0.05$ were considered significant..

RESULTS

Demographics/Socioeconomic Characteristics

The 70 participants and 71 non-participants were similar in age, gender, and education (Table 2). Notably, unemployment was high in both groups but was significantly higher among non-participants. Of the potential barriers to research participation related to socioeconomic factors, household income and childcare were not significantly different between groups. Transportation was noted to be a critical factor among only 4 (6%) non-participants.

Perceptions on Healthcare and Biomedical Research

Both groups had equivalent access to primary healthcare and similar levels of physician mistrust. Interestingly, participants and non-participants had equally positive views regarding medical research and agreed that people should participate in research trials (Table 2). In contrast, significantly more participants were satisfied with their healthcare, while more non-participants were reluctant to visit their physicians. Regarding respondents' willingness to participate in the AASK trial, health–related factors were highly influential for a majority of participants and less critical among non-participants (Table 4).

Sociocultural Factors

The majority of psychosocial and cultural factors which included respondents' perceptions of mood, discrimination, and coping skills (mastery scale) did not differ between the groups (Table 2). Holding strong religious beliefs was more likely to influence the decision to enroll in the trial among participants (Table 3).

Key Factors Guiding Participation among African Americans

Common responses to open-ended survey questions regarding important factors influencing participation are summarized for both participants and non-participants in Table 4. Interestingly, the majority of critical factors spontaneously generated in both groups focused on potential health effects of the research. While participants identified personal and societal health benefits from research as key reasons for enrollment, non-participants identified health risks as critical reasons to explain why they did not enroll in the trial; mistrust was not the predominant reason to refuse enrollment.

Multivariate Analysis Characterizing Influential Factors among AASK Participants and Non-Participants

Using participant and non-participant responses to identify factors linked to participation, we performed a step-wise regression analysis clustering conceptually similar variables (Table 5). Based on the divergence in health-related perceptions between groups (Table 2 and Table 3), we included the importance of self-perceived health status in the decision as the final step in the model. We were able to explain a significant proportion of the variance ($R^2 = 0.42$) in respondents' decisions. Participation was strongly and independently linked with eligible candidates who admitted that their health played a significant role in their decision to enroll in the study (OR = 4.54, p=0.006). In this analysis, there were no significant negative predictors. Additional factors associated with willingness to participate included employment (OR = 3.20, p=0.05) and healthcare satisfaction (OR = 2.12, p<0.01).

Recruitment Approach and Participation

Twenty non-participants (28%) stated that recruiting staff could have done more to convince them to join the AASK trial. When asked "what kind of help" might have encouraged their participation (in an open-ended question), the most frequent response was that more information provided by the research staff initially would have been most effectual. Another interesting observation is that neither the ethnicity nor gender of the research team member influenced enrollment. Specifically, only a minority of respondents in the entire survey group answered that their decisions were influenced by the perceived race (7%) or gender (5%) of the initial recruitment contact, and these percentages did not differ between the participant and non-participant groups.

DISCUSSION

Our observations provide evidence that practical considerations, more than emotional biases, have substantial influence on whether or not African Americans choose to participate in biomedical research. During the recruitment phase of the AASK trial, a longitudinal study of blood pressure management in African Americans with hypertensive nephropathy, eligible candidates who enrolled considered their health in their decision, had positive healthcare experiences and were more likely employed compared to those who refused enrollment. In contrast, social factors, including racially-based mistrust, were not critical determinants of participation among recruited African Americans. Based on these results, greater emphasis on health education, treatment options, and potential personal and community impact of research involvement will lead to enhanced recruitment of African Americans in biomedical research.

The similarities between the participant and non-participant groups were as interesting as their differences. Non-participant and participant groups were comparable on most demographic characteristics. The average household income was similar and unemployment was high in both groups. Notably, employment, and not income, was a predictor of participation. Others have demonstrated a positive correlation between income and research participation among African Americans [6,10,18] and in other populations. In this study, transportation issues were not found to be a significant barrier among non-participants. However, other factors not addressed in this study, such as local social network, may be linked to employment and a greater chance of research involvement. Nonetheless, the responses from this population argue against employment as a *barrier* to research participation.

Psychosocial perceptions were also similar in participants and non-participants. Other studies have suggested that deep-seated, historically-based mistrust and discrimination are significant barriers to research participation [3,4,7,14,16,24,25]. As noted in other studies among African Americans [14,26], physician mistrust was relatively high among both survey groups. However, this factor along with attitudes about discrimination did not differ between groups nor influence participation. Interestingly, religion, which was strongly linked to participation in the bivariate analysis, did not remain a significant factor when other variables were considered in the multivariate analysis. Further, in contrast to observations by Moorman and colleagues [27], we found that the perceived race of research staff in the initial recruitment interaction did not affect participation. Therefore, these data provide additional evidence against the need for ethnic matching of staff and subject populations for successful recruitment of minorities in research trials [28,29].

Previous studies suggest that African Americans hold skeptical views about research [3–5, 13,14,25,30]. Our data reveal that both groups shared positive views on medical research integrity and its benefit to society. Community surveys support our findings and demonstrate that 80% of African Americans recognized the societal benefits of research [10] and over 70% were interested in research participation [10,13,18]. Moreover, several survey reports demonstrated that African Americans were equally as likely to participate in biomedical research as White Americans [8], especially when socioeconomic differences were taken into consideration [18]. In addition, a single-center assessment of actual participation rates in 13 cancer trials demonstrated that 60% of eligible African American candidates enrolled in these studies [11]. In a comprehensive analytical review of consent rates in over 70,000 eligible candidates in 20 large-scale clinical trials of various interventions, African Americans had equivalent and, in some instances, higher enrollment rates than non-Hispanic whites [12].

Health consciousness and personal health interests are strong motivators for research participation among minority groups [9,31]. In this study, the potential impact on health was the single most important factor guiding participation. As observed by others [3,9,32] and suggested by the non-participant respondents in this study, there is potential to enhance enrollment if recruiting staff spend additional effort educating eligible candidates about the targeted disease and health benefits and risks of participation. These observations, along with the positive correlation between healthcare satisfaction and participation, indicate that the motivations for joining a trial for these candidates are focused on their own health-related views and experiences and potential future benefits.

There are some limitations of this study. First, health status was assessed by respondents' self-reports which may not be consistent with medical assessments. However, "perceived" health status may be more influential in the decision-making process, although more difficult to assess in the recruitment process. Further studies may be necessary to link patients' attitudes toward their health and their medical condition(s) to further guide recruitment strategies. Second, individuals completing the survey may not have been candid in their responses. We did, however, attempt to maximize the chance for candid responses by having interviewers who were not part of the AASK study team conduct the surveys at a time separate from the screening process. Third, there may be a selection bias among those who agreed to do the survey in that those who chose not to be interviewed are more skeptical about research. Also, the race and gender of the telephone interviewer, which was not recorded, may have influenced participation in the survey study. These limitations may create greater bias among non-participants. Additionally, because of recruitment strategies employed by the AASK study teams to identify African Americans with known kidney disease, the majority of respondents in both groups had access to healthcare. Therefore, these results may not reflect the attitudes of those African Americans who have limited or no access to medical care. Finally, these results are limited to an African American population with hypertensive nephropathy. However, many of the salient factors influencing participation in the AASK study are general to treatment trials. Also, all survey respondents suffered from hypertension, a chronic disease itself, which can lead to other end-organ complications such as congestive heart failure, strokes, and heart disease. Potentially, this population has similar attitudes as other chronic diseases populations, particularly these illnesses with high burden among African Americans. Yet, further observations of African American participants and non-participants with other chronic illnesses are necessary to confirm whether these results are generalizable.

There were a number of strengths. First is the unique study design that compared the perceptions and beliefs of both those who enrolled in the clinical trial with those who did not wish to participate. Second, our sample was drawn from clinical centers located around the U.S. Third, we queried eligible participants on a wide range of factors that were believed to be important in the decision making process on whether to join a long-term and demanding clinical trial. Lastly, we conducted a telephone survey with callers distinct from clinic screening staff in order to promote candid responses.

Importantly, these results are encouraging and support the growing literature that suggests that African Americans may be best targeted by strategies that enhance communication of the personal health benefits of the research for participants. Furthermore, the findings indicate that strategies that attempt to overcome the potential barrier of mistrust, for instance race/ethnicity matching of staff and subjects, are less critical for successful recruitment of diverse populations.

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Table 1

Sample of Questions from the Survey Instruments

Survey Topic	**Survey Questions**
Health Status	How important was the state of your health in your decision to participate? Would you say very important, somewhat important, a little important, or not important?
Views on Biomedical Research	What types of people do you think should be asked to participate in medical research, people who are doing well medically, people who are not doing well medically, or both? 1. __People doing well 2. __People not doing well 3. __Both
Views on healthcare	Overall, how satisfied are you with the quality of your health care services? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?
Mastery Scale	In the past 30 days, how often did you feel confident about your ability to handle your personal problems? Would you say very often, fairly often, not too often, hardly ever or never?
Discrimination Scale	Now I'm going to ask you about a few things that might happen to you in your day-to-day life. For each one, please tell me whether it happens very often, fairly often, not too often, hardly ever, or never. a. You receive poorer service than other people at restaurants or stores. Does that happen very often, fairly often, not too often, hardly ever, or never

Table 2

Characteristics of the AASK Participation Survey Group

Variables	Participants	Non-Participants	P-value
Mean age (years)	58±10	60±11	NS
Gender (% women)	51	46	NS
Mean Education (in years)	12	12	NS
Employment (% yes)	55%	39%	<0.05
Mean Income*#	$20,001–$30,000	$20,001–$30,000	NS
Child/Adult care responsibilities	60%	52%	NS
Satisfied with your healthcare	99%	89%	< 0.05
Has primary physician	81%	80%	NS
Do not trust physicians	34%	46%	NS
Do not like to go to doctor	52%	74%	< 0.05
Should participate in research	100%	97%	NS
Medical Research treats people fairly	84%	79%	NS
Everyday discrimination scale (mean)	2.0	1.9	NS
Low Mood Scale (mean)	3.7	3.8	NS
Mastery Scale (mean)	2.9	3.0	NS

[*] Income information was collected in categories;

[#] Income information was available from 60 participants (86%) and 64 non-participants (90%). Missing data was minimal on the remaining variables.

The percentages listed in this table are for variables ranked somewhat to very important. Age is presented as mean ± standard deviation. For discrimination scale: 1= every day, 2 = once a week, 3 = not too often, 4 = once or twice a year, 5 = never. For mood and mastery scales: 1 = very often, 2 = once a week, 3 = not too often, 4 = hardly ever, 5 = never.

Table 3

Critical Factors in the Enrollment Decision among Participants and Non-Participants in the AASK Participation Survey Group

Variables	Decision to Participate	Decision Not to Participate	P-value
Health status	94%	69%	< 0.01
Health benefit (or risk)[#]	96%	68%	< 0.01
Importance of healthcare satisfaction	94%	64%	< 0.01
Work schedule	80%	57%	< 0.05
Religion	70%	38%	< 0.05

[#] Indicates parallel survey item for non-participants.

Table 4

Summary of High-Ranking Variables in the Decision among Participants and Non-participants

AASK PARTICIPANTS (N=70)			
Important Variables in Decision to Participate			
Most Important	**Group %**	**Very Important**	**Group %**
Health concerns	52	Help others	81
Help others	32	Improve health	80
AASK NON-PARTICIPANTS (N=71)			
Important Variables in Decision Not to Participate			
Most Important	**Group %**	**Very Important**	**Group %**
Health concerns	37	Side-effects	53
Trust issues	21	Interfere with medications	46
		Experimented on	45
		Time concerns	37
		Helps no one	20

Table 5

Odds Ratios of the Step-wise Logistic Regression Model for Participation in AASK

		Odds Ratios (95% C.I.)				
Variable Category	**Variables**	**Step 1**	**Step 2**	**Step 3**	**Step 4**	**Step 5**
Demographic	Age	1.00 (.96 – 1.04)	1.01 (0.97–1.05)	1.03 (0.98–1.07)	1.02 (0.97–1.07)	1.01 (0.95–1.06)
	Gender	0.98 (0.23–1.73)	0.96 (0.1–1.74)	0.93 (0.12–1.73)	1.00 (0.1–1.92)	1.22 (0.24–2.20)
Socioeconomic Status	Education		1.02 (0.86–1.19)	1.03 (0.86–1.22)	1.10 (0.9–1.30	1.15 (0.94–1.37)
	Employment		1.91 (1.1–2.72)	**2.52*** **(1.63–3.40)**	**3.7*** **(2.63–4.78)**	**3.20*** **(2.08–4.32)**
	Income		0.93 (0.73–1.13)	0.95 (0.75–1.16)	0.88 (.63–1.13)	0.86 (0.6–1.12)
Motivation	Low mood Scale			0.67 (0.23–1.11)	0.61 (0.10–1.13)	0.65 (0.1–1.20)
	Mastery Scale			0.60 (0.00–1.37)	0.67 (0.0–1.56)	0.76 (0.00–1.17)
	Religion			0.61 (0.00–2.58)	0.44 (0.0–2.69)	0.77 (0.0–3.03)
	Health Status			0.99 (0.61–1.36)	0.82 (0.37–1.28)	0.88 (0.38–1.38)
General Perceptions	Everyday Discrimination Scale				1.36 (0.74–1.98)	1.24 (0.62–1.86)
	Healthcare satisfaction				2.50 (1.53–3.47)	2.13 (1.11–3.15)
	Importance of healthcare satisfaction in decision				**2.15**** **(1.61–2.68)**	**2.12**** **(1.56–2.68)**
	Research Integrity				1.27 (0.62–1.90)	1.22 0.53–1.91)
	Mistrust of doctors				0.82 (.35–1.29)	0.76 (0.26–1.26)
Health Perception	Importance of health status in decision					**4.54**** **(3.46–5.61)**
Nagelkerke R^2		**0.00**	**0.03**	**0.09**	**0.35**	**0.42**

[*] indicates p≤0.05;

[**] indicates p≤0.01; 95% C.I. confidence intervals; Analysis was performed on subjects with completed surveys without missing data elements (N=110).