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J Aging Health 2004; 16; 78

DOI: 10.1177/0898264304268150

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Normative Health Research Experiences Among African American Elders

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Objectives: Data are meager regarding the prevalence of participation and the overall experience of African American elders in research across a variety of health-related studies. This study sought to increase our knowledge about older African Americans' participation in health research by capturing some of their normative experiences and attitudes. **Methods:** A telephone-based survey was conducted on 1,290 urban African Americans ≥ 60 years old. The assessment focused on issues of housing, neighborhoods, health, and experiences with health research. **Results:** The overall prevalence of respondents who took part in a health research project was 14%. Significant predictors included income, attitudes about fairness, perceptions of protection from harm, understanding of research as a key to improving health care, and participation in survey research. **Discussion:** Findings underscore the importance of addressing economic, educational, and trust barriers to research participation as well as the importance of conveying a sense of caring for the health of individuals and the community as a whole.

Keywords: *minority health research; African Americans in research; health disparities*

AUTHORS' NOTE: This article was supported by a grant from the National Institute on Aging to the Michigan Center for Urban African American Aging Research (#5P30AG01528).

JOURNAL OF AGING AND HEALTH, Supplement to Vol. 16 No. 5, November 2004 78S-92S

DOI: 10.1177/0898264304268150

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78S

The recruitment and retention of minority participants into health research is an area of increasing interest and research, in part because participation in health research often leads to receipt of the latest and best health care. The opposite is also true: Those with the lowest involvement in health research are the most likely to receive less than optimal health care. Indeed, the common *health disparities* term refers to the findings that many chronic health conditions are more prevalent in minority elders than in White elders. This pattern is certainly true among the minority group the Michigan Center for Urban African American Aging Research focuses its efforts toward. Across many federally funded Michigan Center grant projects is an attempt to significantly increase participation by minority elders in research as one way to help reduce health disparities.

Recruitment and retention research in African Americans is thus most often conducted around specific disease or treatment trials. A review of the published data on this topic includes samples drawn from clinical health settings. The retention rate is often calculated by comparing those who participated in research to those who either refused to participate or withdrew their participation in the research. In many studies currently under way, follow-up contact is made with those who refuse or drop out of treatment to better understand the experiences of those who do not participate in research. As valuable as this information is, it does not inform us about the broader picture of engaging African American elders into research.

The current article reviews data collected as part of a health-needs assessment in which a random sample across the entire city of Detroit was drawn. Normative data inform us about the prevalence of participation and the overall experience of African American elders in research across a wide variety of health-related studies. Clinical studies attempting to recruit African Americans are significantly affected by the invisible backdrop of these normative experiences. Do African American elders get routinely approached for research? What is the overall rate of participation in research, and what is the level of trust and satisfaction with the research experience? These are questions for which there are almost no normative data.

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HEALTH DISPARITIES OF AFRICAN AMERICAN ELDERS

Compared to Americans of European descent, at every point in their life span, African Americans have greater morbidity and mortality (Braithwaite & Taylor, 1992; Jackson, 1991; Jackson & Sellers, 1996, 2001; LaVeist, 2000; Smith & Kington, 1997a). Among African Americans, as with most racial-ethnic groups in the United States, cancer and cardiovascular disease are the two leading causes of death (LaVeist, 2000). However, because of hypertension, which afflicts one out of every three African Americans, Blacks have a 60% greater risk of death and disability from stroke and coronary disease than Whites. In particular, Black women have three times the rate of high blood pressure compared to White women (National Center for Health Statistics, 1999). Similarly, cancer incidence rates for Blacks are 6% to 10% higher than for Whites.

Mortality statistics are equally troubling. The infant mortality rate for Blacks is 20 deaths per 1,000—twice the rate that occurs among Whites (LaViest, 1992, 2000). The average life expectancy for Whites is approximately 76.8 years compared to 70.3 years for Blacks (LaVeist, 2000) with an almost 10-year difference between White (73.8) and Black men (66.1). Hypertension is particularly deadly with Black women twice as likely as White women to die of hypertensive cardiovascular disease (National Center for Health Statistics, 1999). African American overall cancer mortality rates are 20% to 40% higher than the general population (National Cancer Institute, 1986).

Thus, African Americans, especially older Blacks, are at disproportionate risk for negative health outcomes when compared to European Americans (Smith & Kington, 1997b). A number of factors may contribute to these disparities ranging from biological dispositions (Baquet & Ringen, 1987) to dietary habits (Hargreaves, Baquet, & Gamshadzahi, 1989) to a failure to receive adequate health care (Jones & Rice, 1987; Williams & Rucker, 2000). The specific mechanisms, however, that produce these differential outcomes are less clear (LaVeist, 2000; Williams, 1999). Given the complex sociohistorical context of African Americans, it may be less useful in determining exact mechanisms to compare between racial and ethnic group outcomes than within groups. For example, Black/White comparisons may be less illuminating than the examination of various intragroup

social and cultural factors as possible sources of risk and resilience for African American men, women, and children (Dressler & Bindon, 2000; Jackson, 1991; Jackson & Sellers, 1996).

*MINORITY PARTICIPATION
IN HEALTH RESEARCH*

It is well known that African Americans are, and have been, underrepresented in biomedical research (Brown & Topcu, 2003; Jamerson, Jackson, & Stillman, 2001; Svensson, 1990). To some extent, this is the result of a selection bias on the part of researchers for recruiting European American men in recent clinical trials (e.g., heart failure and stroke prevention). In addition, perceived reluctance on the part of African Americans to agree to participate in trials may contribute to their low numbers in research. The underrepresentation of minority groups in biomedical research has substantial health care implications including increased incidence and mortality rates for some diseases when African Americans are compared to Whites. In addition, patients who participate in clinical trials often do better than those who do not, and there is uncertainty about whether treatment efficacy differs by race and ethnicity (Thomas, Quinn, Billingsley, & Caldwell, 1994).

Little is empirically known about the reasons for the lack of minority participation in health studies, although many investigators have speculated that part of the reason may be that African Americans are distrustful of medical researchers and care providers as a result of the Tuskegee Syphilis Study and other well-known health studies. In the past few years, a number of researchers have begun examining possible reasons for nonparticipation by African Americans. Issues related to trust appear to influence the decision made by African Americans on whether to participate (e.g., Corbie-Smith, 1999; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Freedman, 1998). However, other factors may also be important such as lack of information (Thomas et al., 1994), barriers to participation (Flaskerud & Nyamathi, 2000), lack of cultural understanding on the part of White researchers and study recruiters (Corbie-Smith, 1999; Flaskerud & Nyamathi, 2000; Freedman, 1998), and deep-seated fears of racism (Freimuth et al., 2001; Gamble, 1997; Thomas & Curran, 1999).

Issues involving trust are reflected, to some degree, in almost all the research focusing on African Americans' lack of participation (Corbie-Smith et al., 1999; Freedman, 1998; Freimuth et al., 2001). The mistrust reported by African Americans appears to be based not just on attitudes toward medical research and the medical establishment but also on deeper seated fears of broad-based racism (Freimuth et al., 2001; Gamble, 1997). In addition, it may be that it is not just African American patients who are distrustful but also their physicians who have, after all, been subjected to the same kinds of inequities as their patients (Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997; Swanson & Ward, 1995). Physicians have been shown to have an important role in whether a patient will agree to participate in a research project (e.g., Gorelick, Harris, Burnett, & Bonecutter, 1998; Kass, Sugarman, Faden, & SchochSpana, 1996; Robinson, Ashley, & Haynes, 1996). If African American physicians are distrustful of the system, they are less likely to provide information about and referrals to clinical trials. This adds to the impact of widely reported findings that African Americans have traditionally had less access to medical care than Whites (e.g., Blendon, Aiken, Freeman, & Corey, 1989; Gorelick et al., 1998) and that African Americans report being unaware of clinical trials (Harris, Gorelick, Samuels, & Bempong, 1996).

PURPOSE OF THE STUDY

The current study aimed to increase our knowledge about older African American participation in health research by capturing some of the normative experiences and attitudes. The following research questions were specifically posed:

1. What is the prevalence of urban African American elders participating in health research?
2. How satisfied were African American elders with their research participation?
3. How well or poorly treated did the research participants perceive themselves to be?

Method

PARTICIPANTS

Participants were part of a citywide, telephone-based health-needs assessment for individuals aged 60 years and older in the city of Detroit. Neighborhood clusters were established by city mayor, and participants from each cluster (weighted as to population characteristics) were recruited. The assessment focused on issues of housing, neighborhoods, and health. There were, in addition, nine questions that inquired about the experiences and attitudes related to engaging in health research. The data presented here are based on a sample of 1,290 African American respondents. Ninety three percent of the sample had a personal income of less than \$20,000 per year, whereas 55% reported a household income of less than \$20,000 per year. Social Security was the main source of income for 55% of the sample, Retirement pensions (17%), supplemental security income (15%), and a job (13%) accounted for the other major sources of income. Twenty-seven percent of the sample were married at the time of the survey. Seventy-two percent of the sample owned their own homes, and 27% were renters.

RESEARCH QUESTIONS

1. Have you ever been asked to participate in health research, and by that I mean a study of problems like high blood pressure or high blood sugar?
2. Did you participate in the study?
3. What was the study about?
4. What did you have to do?
5. How satisfied were you with the study?
6. In your opinion, does health research improve care?
7. How careful are researchers to treat participants carefully?
8. How careful are researchers to protect participants from harm?
9. Would you like to be notified about future health research taking place in this city?

PROCEDURE

Data were collected through telephone interviews using random-digit dialing methods. After a brief introduction to the purpose of the study, the interviewers asked if there was any person or persons older than the age of 60 in the household. If more than one person in the household was older than the age of 60, the person with the most recent birthday was asked to participate. The interview took 30 to 60 minutes to complete.

Results

All participants completed the citywide needs assessment survey. They were then subdivided into those who had participated in health research prior to this survey and those who did not participate in health research prior to this survey. In Table 1 are the demographic comparisons between those respondents who were contacted and asked to participate in a research study and those who were not contacted. As can be seen in the table, respondents who were contacted for research were significantly younger, had higher levels of household income, more years of education, and better self-reported health. These data support the notion that the neediest of African American elders (those with less education, income, older, and in poorer health) are significantly less likely to be asked to participate in health research than are those with more education and income, those that are younger, and those that have better health. The prevalence of being asked to participate in health research was 19% for this sample.

Of the 245 persons asked to participate in a health research project, 185 (76%) agreed to participate thus indicating that a majority of people agreed at some point to participate in a health study. The overall prevalence, however, of respondents who took part in a health research project was 14%. In Table 2 are the demographic characteristics of those who, when asked to be in research, agreed to take part versus those who declined to participate in any health research. The only significant difference was in household income with those who declined reporting a lower level of household income. These data suggest that once asked to participate, age, education, and self-report of

Table 1
Demographic Characteristics of Those Contacted for Research and Those Never Contacted

	Contacted (n = 245)	Never Contacted (n = 1,045)
Age	69.8 (6.5)	72.0 (7.8)**
Income	1.6 (0.49)	1.4 (0.48)**
Education	8.9 (10)	7.0 (8.0)**
Self-reported health	3.1 (1.1)	2.9 (1.1)*

Note. Income: 1 = < \$20,000 household income, 2 = > \$20,000 household income. Education: 1 = < 5th grade; 2 = 5th-8th grade; 3 = 9th grade; 4 = 10th grade; 5 = 11th grade; 6 = 12th grade, no diploma; 7 = high school graduate or General Equivalency Diploma; 8 = some college but no degree; 9 = associate's degree; 10 = bachelor's degree; 11 = master's degree; 12 = doctorate. Health: 1 = excellent, 2 = very good, 3 = good, 4 = fair, 5 = poor.

* $p < .05$. ** $p < .005$.

Table 2
Demographic Characteristics of Those Who Participated in Research Versus Those Who Chose Not to Participate in Research

	Participated (n = 185)	Did Not Participate (n = 64)
Age	69.7 (6.3)	70.1 (7.1)
Income	1.6 (0.48)	1.4 (0.50)*
Education	8.9 (9.5)	8.9 (11.4)
Self-reported health	3.1 (1.2)	3.2 (1.0)

Note. Income: 1 = < \$20,000 household income, 2 = > \$20,000 household income. Education: 1 = < 5th grade; 2 = 5th-8th grade; 3 = 9th grade; 4 = 10th grade; 5 = 11th grade; 6 = 12th grade, no diploma; 7 = high school graduate or General Equivalency Diploma; 8 = some college but no degree; 9 = associate's degree; 10 = bachelor's degree; 11 = master's degree; 12 = doctorate. Health: 1 = excellent, 2 = very good, 3 = good, 4 = fair, 5 = poor.

* $p < .05$.

health did not influence the decision of whether to participate in the health research.

In Table 3 are listed the types of studies respondents engaged in. Drug treatment studies for cancer and heart disease made up 49% of the total. The next largest categories were health surveys (23%) followed by diabetes treatment studies.

In Table 4 are listed the participants' overall research satisfaction and overall attitudes about their research participation. Fifty percent of the sample reported being very satisfied with the study they participated in, and an additional 20% stated they were satisfied. Thirteen

Table 3
Research Participation Experiences

<i>Study Types</i>	
Health survey	57 (23%)
Cancer treatment	69 (28%)
Heart disease treatment	52 (21%)
Diabetes treatment	20 (8%)
Arthritis treatment	8 (3%)
Unknown	17%

Note. Some participants were in more than one research study; thus, 185 people made up 209 participants in various studies.

Table 4
Research Participant Satisfaction and Attitudes Means and Standard Deviations

<i>Participant Responses (n = 185)</i>	
Satisfaction with study	4.0 (1.2)
Fair treatment of participants	5.3 (1.7)
Protect participants from harm	5.4 (1.7)
<i>Entire Sample Responses (N = 1,290)</i>	
Does health research improve care	0.8 (0.4)
Like to be notified of future research studies	0.73 (0.44)

Note. Satisfaction with study: 1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = somewhat satisfied, 5 = very satisfied. Fair treatment: 1 = not at all careful to treat participants fairly, 7 = very careful to treat participants fairly. Protect participants: 1 = not at all careful to protect participants from harm, 7 = very careful to protect participants from harm. Health research improves care: 0 = no, 1 = yes. Future notification of research: 0 = no, 1 = yes.

percent reported that they were either very or somewhat dissatisfied with the study. Seventy-five percent of the sample rated the researchers as very careful to treat participants fairly, whereas 14% felt that the investigators did not take care to treat participants fairly. Similarly, 75% stated that the researchers took great care to protect participants from harm, and 14% believed the researchers did not take great care to protect participants from harm. Eighty percent of the entire sample reported a belief that health research improved patient care. Similarly, 73% of the sample stated that they would like to be notified about

Table 5
Correlates of Research Satisfaction (n = 185)

Self-reported health	.11
Gender	.03
Education	.09
Age	-.08
Income	.13
Health research rating	.30*
Fair treatment rating	.22*
Protection from harm rating	.29*
Survey research (1 = yes)	.38*

* $p < .05$.

future health research taking place in the city. These results offer both optimistic and pessimistic views. Three quarters of respondents had a very satisfying experience with their research participation, whereas 14% had a dissatisfying experience and felt poorly treated by researchers. Fourteen percent is likely to be a relatively high rate of dissatisfaction, because dissatisfied participants are more likely to vocalize their unhappiness to their family, friends, and neighbors than were those who were more satisfied.

Correlational and multiple regression analyses were used to determine the best predictors of research satisfaction among the 185 participants who engaged in a health research project. In Table 5 are listed correlations between demographics, research attitudes, and research type with research satisfaction. None of the demographic variables or self-rated health was significantly correlated to satisfaction with the research. Satisfaction was correlated with participation in survey research ($r = .38, p < .05$) and with positive attitudes about health research in general and the care that researchers took to protect and treat participants fairly.

The results of the hierarchical multiple regression analyses can be found in Table 6. Overall, 17% of the satisfaction variance was accounted for, $F = 6.6, p < .0001$. Significant predictors included income, attitudes about fairness, protection from harm and perceptions of research as a key to improving health care, and participation in survey research.

Table 6
Hierarchical Multiple Regression to Predict Study Satisfaction (n = 185): Final Equation

<i>Variable</i>	<i>Beta</i>	<i>Cumulative R²</i>
Age	-.02	
Income	-.21*	
Gender	.02	
Marital status	.03	
Education	-.07	
Health	.16	
Fairness	-.08	
Harm protection	.27*	
Improve care	.23*	
Survey research	.28*	.17

* $p < .05$.

Discussion

Normative data are useful for understanding how a population experiences and perceives important events. The strength of this research was in the ability to collect normative data using a random sampling technique that included every neighborhood cluster in a major midwestern city. The responses obtained do reflect the population of interest—community-dwelling African Americans older than the age of 60 years. We were able to impose a brief set of questions onto a needs assessment study and capture some important snapshot findings of how Black elders participated and perceived health research.

In some ways, the data paint a surprisingly optimistic picture. Nearly 20% of the sample was contacted to be in a health research project, and three quarters of those contacted agreed to be in a study. Similarly, three quarters of the sample were satisfied with their participation in research and felt well treated by the researchers. Four out of five persons interviewed believed that research does improve health care delivery. There were clear deviations from this rosy and optimistic viewpoint. Older, less healthy, poorer, and less educated elders were less likely to be invited to participate in research. Thus, those with the greatest health needs were the least likely to be approached to be a research participant. Of those who did participate, 14%, a some-

what higher than expected number, were dissatisfied with their experience and felt poorly treated by the researchers.

Some health researchers may conclude that the data obtained here are optimistic as a whole. Indeed, in clinical settings, it is far more likely that 75% of potential participants would decline to participate in a research study. The normative data collected in this study went far beyond asking about participation in medical intervention research. Participants who were involved in health survey research only accounted for a quarter of the research respondents. Indeed, health survey research had the highest level of satisfaction ratings. The data also do not indicate how many projects people were asked to participate in and how many they accepted—the data here only reflect numbers that agreed to at least one health research study.

The correlates of research satisfaction are interesting and of potential utility to those engaging in minority aging research. Beliefs about research and its overall effect on health (i.e., does research improve health) and attitudes about how careful researchers were to protect participants and treat participants fairly were significantly related to research participation satisfaction. Conveying a sense of caring for the health of a community and each person comprising it is thus an integral part of the factors that can positively influence minority participant satisfaction.

One surprising finding was to see the relatively low rate of participation in diabetes treatment studies, because diabetes is one of the major health problems in African American elders. Only 8% of the study participation figures were related to investigations about diabetes. This may reflect the relative lack of congruence between the university researchers' strengths in the City of Detroit and the population's needs. Diabetes is devastating in its effects on overall functioning and other disease states. Diabetes is a significant risk factor for stroke, the leading cause of macular degeneration, and the leading cause of limb amputations. These data can call attention to the need for strengthened research in diabetes among urban African American elders.

Because this brief survey was superimposed on a needs assessment study, there are several weaknesses to the research. Generalizability of these findings is limited to urban areas where African Americans con-

stitute the majority of the city's population. There was one important difference between those who participated in research and those who did not, and that was income level. Those who declined to participate in research after being contacted were less affluent than those who agreed to participate. Researchers need to be aware then that extra efforts may be necessary to recruit the poorest African American elders. Because of time constraints, it was not possible to get in-depth reports from participants on their research experiences. In this study, we were not able to ascertain what motivates people to participate in research and what acts as deterrents to their participation. We view these factors as orthogonal. That is, the removal of barriers to research participation does not insure increased participation. Good research participation requires the removal of barriers plus the enhancement of motivators. Many health researchers have, for example, made provisions for free transportation to their study sites only to discover that this investment produced no return. Many health research centers are viewed as not community focused or community sensitive, and thus, only the removal of barriers such as transportation does not increase their minority participation in research. The present study was not able to address these issues in any fashion. Nevertheless, these normative data represent an important start to understanding the population's experience with research recruitment and retention.

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