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Black-White Differences in Willingness to Participate and Perceptions about Health Research: Results from the Population-Based HealthStreet Study

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Abstract

Health research participation of racial and ethnic minorities is significantly lower than their counterparts, impeding the testing and development of evidence based clinical and public health interventions for these populations. The purpose of this study was to determine African-Americans' (AAs) perceptions about health research, past participation in health research, and willingness to participate in health research studies compared to White adults from a large socio-economically disadvantaged population. Community members ages 18 years or older enrolled in HealthStreet, an innovative community engagement research program comprised the source of study population. A total of 7809 community members (58.6% females) participated in the study with 65.8% AAs and 34.2% Whites. AAs were statistically significantly less likely to have previously participated in a research study, be willing to volunteer for any type of health research study, or to trust research or researchers compared to Whites. AAs also desired significantly higher compensation amounts to participate compared with Whites adults. In logistic regression analysis, education, age, gender, visits to healthcare practitioners and facilities were statistically significant predictors for AAs participation in health research. Keeping in view the findings of our study, clinical and public health researchers and practitioners should use special recruitment and retention strategies to increase the participation of AAs in health research studies.

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Ethical Standards: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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Keywords

Research; Participants; Diversity; Minorities; Recruitment; Retention

Introduction

African-American (AA) adults have substantially lower rates of participation in health research studies compared to Whites. The factors for such disparity in health research participation that have commonly been cited are lack of knowledge and awareness about research studies, lower health literacy, and mistrust in researchers and the enterprise of healthcare research [1–3]. However, the available studies on AA adults' willingness to participate in and perceptions about participation in health research have several limitations [1–5]. Studies are often qualitative in nature and fail to quantify perceptions about health research in AA populations. Also, most studies focus on and recruit only AA adults, failing to compare differences between AA and White individuals. Existing studies are also limited by small sample sizes. Finally, most of the studies use convenience samples of individuals from healthcare facilities or community networks and do not capture perceptions of larger populations of AA adults. The objective of this study was to overcome such limitations, and to determine, in a large community based population whether AA individuals have unique perceptions about health research participation compared to Whites.

Methods

Sample and Procedures

The study sample included adult AAs and Whites in the HealthStreet project in Florida from 2011 to 2016. The HealthStreet model is an innovative community-engagement program to address disparities in health research participation, provide health education, and link community members with health and social services [6, 7, 8]. Community Health Workers (CHWs) identify potential participants through community outreach to local public locations. CHWs approach individuals at various venues like bus stops, laundromats, college campuses, parks, grocery stores, malls, churches, health fairs or any other local place where individuals congregate. Potential participants receive detailed explanation of HealthStreet project; those who provide written consent complete a health assessment with a CHW and are also linked with necessary health and social services in the community [6, 7]. Ethical clearance for the HealthStreet project protocols/ procedures was received from University of Florida Institutional Review Board.

Measures

The HealthStreet assessment obtained information from community members through a valid and reliable survey on health concerns and conditions, access to healthcare, healthcare utilization, and socio-demographic information [6, 7, 8]. Study participants were asked about participating in health research studies through ten questions listed on the survey. The first seven questions (yes or no answer type) began with the same stem statement “would you volunteer for a health research study”, followed by seven more specific items related to various types of research as follows: (1) “that only asked questions about your health?”; (2)

“If researchers wanted to see your medical records?”; (3) “If you had to give a blood sample?”; (4) “If you were asked to give a sample for genetic studies?”; (5) “If you might have to take medicine?”; (6) “If you were asked to stay overnight in a hospital or clinic?”; and (7) “If you might have to use medical equipment?”. The other three questions were about monetary compensation, time commitment, and interest in participating in health research within the next year. The first item (yes or no type answer) asked “would you participate in a study if you didn’t get paid?” The second question was “how much money is a fair amount of compensation for you to participate in a study that includes an hour and a half interview and a blood test”. The final intent item asked, “How interested are you in being in a research study within the next year?” A single item assessed past research participation (“have you ever participated in a health research study?”). Study participants were able to clarify doubts or questions and concerns with recruiting CHWs [6, 7, 8].

Data Analyses

Descriptive statistics with a report of the appropriate frequencies and means to describe the participants’ responses to the questionnaire items on health, demographic/background characteristics, and perceptions about health research studies were computed. *t* tests and Chi square (χ^2) tests were used to determine differences between AA and White study participants for study measures described above. Multiple logistic regression analysis was employed to examine associations between willingness to participate in health research studies within the next year and several predictor variables (e.g. sociodemographic and health related).

Results

Demographic and Background Characteristics of Participants

A total of 7809 African-American and White adults participated in the study (Table 1). The majority of participants were African-American (65.8%), unemployed (65.3%), females (58.6%), with health insurance (59.7%), and had a general health checkup in the past 12 months (66.3%). Most respondents rated their health as ‘excellent’ or ‘good’ (59.7%) and their average age was 44.3 years (standard error [SE] = ± 0.18). Compared to Whites, AA adults were statistically significantly less likely to be female, married, and to have seen a doctor in the last 6 months for a medical condition. In addition, AA respondents were significantly more likely to be younger, have fewer years of education, and have more children compared to Whites (Table 1).

Health Research Participation Perceptions

Majority of the study participants (> 50%) reported that they would participate in a variety of health research studies with different types of requirements from them (e.g. no compensation, being questioned about health, giving access to health records, being hospitalized, or being given medications). However, compared to Whites, AAs were statistically significantly less likely to: have been a participant in a research study in the past, volunteer for different types of health studies, participate within the next year in a research study; and trust research or researchers (Table 2). AAs (*M* = \$111) preferred significantly

higher amounts of compensation for participation in health research studies compared to Whites ($M = \$59$).

Intent to Participate in Health Research

Participants were asked about their interest in participating in any health research study within the next year. Intent to participate was categorized into a binary variable (yes = definitely, no = may be or not at all) and treated as an outcome variable in a logistic regression analysis to assess predictors for intent to participate. Among AAs, males, those who were older (> 65), had lesser education (< 12 years), were married, reported excellent or good health, or had health insurance were statistically significantly less likely to report an interest in participating in a health research study within the next year compared to their counterparts (Table 3). AA respondents who had visited a doctor for a medical reason within the past 6 months, had a general checkup in the last 12 months, went to the emergency room within the past 6 months, reported being unemployed, those who experienced food insecurity last year, and those who had participated in health research previously were significantly more likely to be interested in participating in health research within the next year. AAs who reported 'yes' for volunteering in different types of research studies were statistically significantly more likely to be interested in participating in any health research study within the next year compared to AAs who were not interested in volunteering. When asked if they would ever participate in a health research study without being paid, AAs who said "no", were statistically significantly less likely to be willing to participate in a study within the next year, compared to those who said "yes" (Table 3).

Among Whites, those who had a general doctor visit/checkup in the last 12 months or had excellent health were significantly less likely to report interest in participating in health research. However, among Whites, those who were unemployed, food insecure, had greater number of emergency room visits, or participated in health research in the past were statistically significantly more likely to be interested in participating in a health research study within the next year compared to Whites who did not share these characteristics.

Discussion

A major finding of this study was that the majority of study participants were willing to participate in health research, even though AAs had significantly lower inclination to participate than Whites did. The high level of willingness to volunteer for various types of health research studies among this socioeconomically disadvantaged population (especially, AA adults) is promising given their historical as well as current day societal experiences and perspectives [9, 10]. The majority of AAs in this study had not previously participated in any health research study, a finding consistently confirmed through several studies over the past years [2, 3, 4, 5]. This is significant because our study also found that past research participation was a strong predictor of research participation intent in the future. It could be possible that individuals who previously participated in health related research studies may have had favorable experiences with research participation or they are potentially more aware and familiar with the process [1, 2, 11]. Although we did not measure knowledge and awareness about research processes, there is evidence available on facilitators of research

participation in racial/ethnic minorities such as greater knowledge, literacy, and awareness about research processes [2, 3, 10, 11].

Our large sample and unique study design was helpful in assessing and quantifying the differences in perceptions about health research between AA and White adults in this population based study. For example, when participants were given various scenarios for participating in research, compared to White respondents, AAs were less willing to participate in health research in a variety of scenarios (e.g. medication will be administered). One widely cited reason for AAs not participating in health research is trust and this factor is accentuated when drugs, equipment, or invasive procedures are being tested [4, 5, 9]. This is also logical given our finding that AAs were statistically significantly less likely to trust health research and researchers compared with Whites, which has been widely confirmed in several studies [1, 12, 13].

Our findings also show the importance of sociodemographic factors among African Americans and research participation intent and perceptions about health research studies. According to our findings, lesser-educated, older, and male AAs are less likely to participate in health research studies in the near future. It could be possible that this generation of older AA males still experiences prejudice or is highly aware of the past exploitation of racial and ethnic minorities in healthcare research and healthcare systems. These differences based on age, gender, and education need additional exploration as most studies to date have focused on variables such as trust and knowledge only [2, 9, 12, 13].

Exposure to healthcare system in the recent past (e.g. ER visits and general doctor visits), having health insurance, and general health status were significant predictors of intent to participate in health research. This finding needs additional exploration as some of these variables could be interrelated [2, 4, 9, 10]. For example, those who have chronic diseases or greater emergency medical needs will more likely visit a healthcare facility and thereby, have a greater chance of being recruited onsite for health research studies open to participants. It is also postulated that socio-economically disadvantaged individuals with severe chronic diseases may volunteer for research studies as a last resort and in the anticipation of finding effective treatment or with the expectation of subsidized treatment & healthcare services [2, 4, 10]. Another factor that could play a role is monetary compensation for participation. AA participants expected higher compensation for participating in health research studies and in this study, compensation was a significant predictor of health research participation intent only in AA participants.

Trust in health researchers and research failed to significantly predict intent of research participation among AAs or Whites. This is interesting as most literature cites trust as an issue only for African American individuals in relation to research participation [1, 3, 13]. For socio-economically disadvantaged individuals to participate in health research, trust building should be a key effort, irrespective of the target audience's race/ethnicity. In addition, salient characteristics of disadvantaged groups who are less likely to participate in health research should be further explored, as they probably do not trust the healthcare research establishment irrespective of their race. We also question based on our findings- can monetary compensation override trust issues? Would higher compensation nearly coerce

people or unduly influence individuals to participate in health research studies because they are needy? What could be a reasonable amount of compensation for health research study participants? These are issues to be addressed by researchers and research enterprises worldwide [1, 3, 10, 11]. Currently, no clear guidance is available from governments and agencies across the world on the level of compensation that should be offered to research subjects to obtain a truly informed consent.

The results of this study suffer from all traditional limitations of observational and cross-sectional studies (e.g. socially desirable responses, recall bias, and self-reported data). The instrument was mostly a closed format monothematic survey, which may be a threat to validity as we may have missed important research related perceptions of participants. The study was limited to a geographic region in the United States (i.e. Florida) and the sample population for Whites was smaller than the AA population, this could limit the external validity of the findings.

Conclusion

Racial and ethnic minorities, especially AAs are significantly less likely to participate in health related research than Whites. This impedes the testing, development, implementation, and evaluation of various clinical and community based disease prevention and health promotion interventions. Our study delineates important sociodemographic characteristics of AAs that may influence their participation in health related research. Clinical and public health researchers and practitioners should use special recruitment and retention strategies to enhance the health research participation of African American adults, taking into account the findings from this study. This would also entail reduction of barriers to participation, enhancing facilitators to participation, utilizing proper venues and incentives, and developing attributes and behaviors in research teams that are seen favorably by potential racial and ethnic minority participants.

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Table 1.

Demographic Characteristics of Participants

Demographics		Total N (%) 7,809 (100%)	African-Americans N (%) 5,139 (65.8)	Whites N(%) 2,670 (34.2)	Chi- square; <i>p</i> value
Employed (Yes)		2,653 (34.7)	1,753 (34.9)	900 (34.4)	0.19; 0.66
Food insecurity (Yes)		3,676 (48.1)	2,443 (48.6)	1,233 (47.1)	1.57; 0.21
Gender	Female	4,575(58.6)	2,944 (57.3)	1,631 (61.1)	10.6; 0.005
Marital status	Married	1,562 (20.4)	876 (17.4)	686 (26.1)	16.2;
	Never Married	3,689 (48.1)	2,752 (54.5)	937 (35.7)	<0.001
	Separated/ Divorced/ Widowed	2,424 (31.6)	1,420 (28.1)	1,004 (38.2)	
Insurance (Yes)		4,584 (59.7)	3,001 (59.5)	1,583 (60.2)	0.37; 0.54
Seen a doctor in last 6 months		5,130 (66.8)	3,271(64.8)	1,859 (70.7)	17.1; <0.001
Had a general checkup in last 12 months		5,091(66.3)	3,411 (67.5)	1,680 (64.0)	9.78; 0.002
Health status	Excellent	424 (13.9)	251 (13.2)	173 (15.2)	4.29; 0.23
	Good	1,391 (45.8)	879 (46.3)	512 (44.8)	
	Fair	975 (32.1)	621 (32.7)	354 (31.0)	
	Poor	250 (8.2)	147 (7.7)	103 (9.02)	
		M (±S.E)	M (±S.E)	M (±S.E)	<i>t</i>-test; <i>p</i> value
Age		44.3(0.18)	42.9(0.21)	46.9(0.31)	10.42;<.001
Education		12.8(0.03)	12.4(0.03)/5,051	13.4(0.06)	15.51;<.001
ER visits in the last 6 months		0.86(0.14)	0.93(0.21)/4,782	0.72(0.04)	0.99; 0.32
Number of children		1.94(0.22)	2.19(0.03)/5,041	1.48(0.03)	16.77; <.001
N=7809					

Note: Percent might not add to 100% due to rounding or missing values

Table 2.

Participation in Different Types of Health Research Studies

		Total N(%) 7,809 (100%)	Blacks N(%) 5,139 (65.8)	Whites N(%) 2,670 (34.2)	Chi-Square; p value
<i>Past Participation and Intent to Participate</i>					
Have you ever participated in a research study?	Yes	1,388 (18.0)	785 (15.4)	603 (22.9)	
	No	6,246 (80.9)	4,258 (83.7)	1,988 (75.5)	26.6; < .001
	Not Sure	42 (1.1)	44 (0.86)	42 (1.60)	
How likely are you to participate in a health research in the next year study	Definitely	3961 (50.7)	2455 (48.2)	1506 (56.9)	21.2; < .001
	May be	3245 (41.5)	2268 (44.6)	977 (36.9)	
	Not at all	532 (6.8)	367 (7.2)	165 (6.2)	
<i>If you were to volunteer for a health research study, would you participate in a study (Yes)?</i>					
That only asked questions about your health? If researchers wanted to see your medical records? If you had to give a blood sample? If you were asked to give a sample for genetic studies? If you might have to use medical equipment? Would you participate in a study if you didn't get paid? If you were asked to stay overnight in a hospital/clinic? If you might have to take medication? <i>Trust and Compensation</i> How much do you think is a fair amount for participation a study that lasts 1 ½ hours & involves an interview On a scale of 1 to 10, where 1 is 'Not at All' and 10 is 'Completely', how much do you trust <u>research</u> ? On a scale of 1 to 10, where 1 is 'Not at All' and 10 is 'Completely', how much do you trust <u>researchers</u> ? N=7809	Yes	7,258 (93.5)	4,740 (92.8)	2,518 (94.9)	13.3; < .001
	No	6,721 (86.6)	4,383 (85.8)	2,338 (88.2)	8.70; 0.003
	Not Sure	6,632 (85.5)	4,251 (83.2)	2,381 (89.8)	19.3; < .001
	Definitely	6,577 (84.8)	4,204 (82.4)	2,373 (89.5)	19.2; < .001
	May be	6,465 (83.4)	4,150 (81.5)	2,315 (87.3)	22.4; < .001
	Not at all	6,079 (78.6)	3,869 (76.0)	2,210 (83.5)	28.3; < .001
	Definitely	5,653 (72.9)	3,667 (71.9)	1,986 (74.9)	8.02; 0.005
	May be	4,834 (62.4)	3,041 (59.7)	1,793 (67.7)	27.8; < .001
	Not at all	M (±S.E)	M (±S.E)	M (±S.E)	t-test; p value
		93(1.99)	111(2.75)	59(2.32)	14.35; < .001
		7.82(0.13)	7.44(0.14)	8.44(0.25)	3.50; < .001
		7.94(0.15)	7.51(0.16)	8.65(0.28)	3.47; < .001

Table 3.**Predictors of Intent to Participate in Health Research**

Sociodemographic Characteristics		African-American OR (95%CI)	Whites OR (95%CI)
Age	65 and older	0.51 (0.36 – 0.73) *	1.02 (0.66 – 1.59)
	45–64	0.90 (0.70 – 1.15)	1.15 (0.81 – 1.64)
	25–44	0.93 (0.75 – 1.17)	1.23 (0.88 – 1.74)
	18–24	1	1
Education	< 12 years	0.83 (0.71 – 0.98) *	0.77 (0.59 – 1.01)
	12 years	1	1
Gender	Male	0.81 (0.72 – 0.93) *	0.96 (0.78 – 1.18)
	Female	1	1
Employment	Unemployed	1.72 (1.51 – 2.13) *	1.49 (1.33 – 1.69)*
	Employed (full/part time)	1	1
Children (number)	> 1	1.05 (0.88 – 1.26)	1.04 (0.80 – 1.35)
	1	1.18 (0.95 – 1.45)	1.04 (0.78 – 1.40)
	0	1	1
Marital Status	Married	0.77 (0.61 – 0.91) *	0.86 (0.64 – 1.15)
	Widowed/divorced/separated	1.01 (0.85 – 1.20)	1.23 (0.93 – 1.62)
	Never Married	1	1
Didn't have enough money to buy food at least once in the past year	Yes	2.29 (1.93 – 2.71) *	1.78 (1.58 – 1.99) *
	No	1	1
Health Related Predictors			
Health Status	Excellent	0.33 (0.21 – 0.53) *	0.44 (0.29 – 0.66) *
	Good	0.51 (0.34 – 0.78) *	0.72 (0.39 – 1.34)
	Fair	0.80 (0.46 – 1.38)	0.84 (0.48 – 1.48)
	Poor	1	1
Have health insurance	Yes	0.61(0.52 – 0.62) *	0.86 (0.77 – 1.02)
	No	1	1
Had a general doctor visit/checkup in last 12 months	Yes	1.21 (1.04 – 1.40) *	0.74 (0.60–0.93) *
	No	1	1
Seen a doctor for any reason in last 6 months	Yes	1.18 (1.06 – 1.23) *	1.08 (0.86 – 1.36)
	No	1	1
ER visits in last 6 months	> 1	2.16 (1.68 – 2.79) *	1.74 (1.38 – 2.19) *
	1	1.86 (1.57 – 2.21) *	1.30 (1.12 – 1.51) *
	0	1	1
Participation in Different Types of Health Research			
Past Participation in a Health Research Study	Yes	1.70 (1.41 – 2.05) *	1.65 (1.29 – 2.09) *

Sociodemographic Characteristics		African-American OR (95%CI)	Whites OR (95%CI)
If researchers wanted to see your medical records? If you had to give a blood sample? If you were asked to give a sample for genetic studies? If you might have to use medical equipment? If you were asked to stay overnight in a hospital/clinic? If you might have to take medication?	No	1	1
	Yes	1.34 (1.06 – 1.71) *	1.94 (1.33 – 2.82) *
	No	1	1
	Yes	2.00 (1.59 – 2.53) *	1.52 (0.98 – 2.33)
	No	1	1
	Yes	1.52 (1.22 – 1.89) *	2.15 (1.42 – 3.26) *
	No	1	1
	Yes	1.54 (1.23 – 1.91) *	1.83 (1.26 – 2.65) *
	No	1	1
	Yes	2.14 (1.79 – 2.58) *	2.51 (1.94 – 3.24) *
Trust and Compensation			
Participate without being paid	Yes	0.63 (0.54 – 0.81) *	0.85 (0.64 – 1.11)
	No	1	1
Fair amount for participation in a study that lasts about 1 ½ hours and h h involves an interview<	\$50	1.21 (1.08 – 1.36) *	1.01 (0.83 – 1.27)
	< \$50	1	1
	High	1.32 (0.96 – 1.81)	1.81 (1.16 – 2.82) *
Trust Research ^a	Low	1	1
	High	1.14 (0.83 – 1.57)	1.26 (0.81 – 1.96)
Trust Researchers ^a	High	1.14 (0.83 – 1.57)	1.26 (0.81 – 1.96)
	Low	1	1

^aMedian value used to dichotomize variable

* indicates a p value <0.05, 95% CI= Confidence intervals

OR= Odds ratio indicating odds of participating in health research studies in the next year.