

Distrust, Race, and Research

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Background: Investigators have voiced concerns that distrust of research and the medical community impedes successful recruitment of African Americans into clinical research.

Objectives: To examine possible differences in distrust by race and to determine to what extent other sociodemographic factors explain any racial differences in distrust.

Methods: We analyzed data from 527 African American and 382 white respondents of a national telephone survey on participation in clinical research. Our main outcome measure was a 7-item index of distrust.

Results: African American respondents were more likely than white respondents not to trust that their physicians would fully explain research participation (41.7%

vs 23.4%, $P < .01$) and to state that they believed their physicians exposed them to unnecessary risks (45.5% vs 34.8%, $P < .01$). African American respondents had a significantly higher mean distrust index score than white respondents (3.1 vs 1.8, $P < .01$). After controlling for other sociodemographic variables in a logistic regression model, race remained strongly associated with a higher distrust score (prevalence odds ratio, 4.7; 95% confidence interval, 2.9-7.7).

Conclusions: Even after controlling for markers of social class, African Americans were less trusting than white Americans. Racial differences in distrust have important implications for investigators as they engage African Americans in research.

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DISPARITIES in health, health care, and health outcomes have been documented extensively in the public health and biomedical literature. In an effort to better understand disparities in health and to improve the generalizability of research findings, federal agencies have mandated that minorities be adequately represented in all clinical research.¹ Despite awareness of the ethical and scientific underpinnings of this mandate, investigators have voiced their concerns about successfully recruiting minority groups into clinical studies.^{2,3} A widespread concern is that distrust of research and the medical community will impede successful recruitment of African Americans and other minority groups.

Distrust by African Americans is thought to stem from the history of racial discrimination and exploitation in the United States. The US Public Health Service study at Tuskegee has come to symbolize ethical misconduct in the context of clinical research.⁴⁻⁶ However, as sev-

eral authors⁷⁻⁹ have challenged, distrust in medicine and research may be rooted in experiences extending back to slavery and continuing to the present day.

Studies that have explored the effect of trust on research participation suggest that distrust may in fact be an important factor in decisions to participate in research. The data suggest that trust is an important determinant of willingness to participate¹⁰⁻¹² and that, among those who refuse participation, African Americans may be less trusting.¹³ However, these studies have been limited by having small sample sizes,^{10,11,13} focusing on attitudes about research on a particular disease,¹¹⁻¹³ or studying only minority groups, so that comparisons across races could not be made.^{11,12} In addition, because race may be a proxy for social class, if racial differences in trust exist in the general population, the role that socioeconomic features might play is not clear. We undertook this study to examine possible differences in distrust by race in a national sample of respondents. In addition, we investigated to what extent other

sociodemographic factors explained any racial differences in distrust.

METHODS

DATA SOURCE

The data for this analysis came from the first wave of a series of national surveys that examined the knowledge, attitudes, and beliefs of Americans toward physicians and participation in clinical research. The 45-minute telephone survey consisted of a series of eligibility questions, 42 questions designed to measure attitudes toward medical and public health research, and 10 demographic questions. Survey items on attitudes toward research included some questions modified from those used in subject interviews by the Advisory Committee on Human Radiation Experiments.¹⁴

STUDY POPULATION

Respondents were interviewed by telephone from February 12 through 27, 1997, by a consulting firm (Roper Starch Worldwide, New York, NY) contracted through the Institute for Minority Health Research, Rollins School of Public Health, Emory University, Atlanta, Ga. A 2-stage sampling procedure was used to select respondents for each of 2 samples, first selecting households using random-digit dialing, then selecting respondents within those households. The 2 samples comprised 500 respondents from the general US population and 500 African Americans. The general population sample was representative of all adults (ages ≥ 18 years) living in households with telephones within the 48 contiguous states and the District of Columbia (ie, 382 white, 27 African American, and 91 of other race/ethnicities). The African American sample consisted of respondents who identified themselves as African American or black, not of Hispanic origin. The samples were balanced by age within the variables of sex, educational attainment, marital status, number of adults in the household, and 4-fold census region. Refusal rates were similar for each sample, 49.1% for the African American sample and 49.6% for the general population sample. The study analysis was restricted to those respondents from either sample who classified themselves as white, not of Hispanic origin, or as African American or black, not of Hispanic origin. The numbers of respondents who classified themselves as members of other races or ethnicities were too small to make meaningful comparisons.

MEASURES

In creating the outcome variable in this analysis, we considered 12 questionnaire items that, based on face validity, examined aspects of trust important to research participation. For each of these items, *distrust* was defined as lack of agreement with a statement of trust. In an effort to create a single, parsimonious dependent measure, we conducted a principal components analysis using those 12 items. Seven of those 12 had high factor loadings (0.51-0.61) on the first factor, which accounted for 24.8% of the variance in the evaluated items. A distrust index, which ranged from 0 for the most trusting to 7 for the most distrusting, was created using the sum of the responses to the 7 component items. The dependent variable of interest, high levels of distrust, was categorized as 5 or higher (upper 10%) on the distrust index.

The main independent variable of interest was race: non-Hispanic African American vs non-Hispanic white. In addition, the variables of age (categorical), sex, educational attainment (categorical), employment status, income (categorical),

and geographic region of residence were considered as potential effect modifiers or confounders of the relationship between race and distrust.

DATA ANALYSIS

Data were analyzed using SAS version 6.12¹⁵. Because of the complex sampling strategy, analyses were weighted to account for the 2-stage stratified strategy used to generate the survey sample, such that the sample results could be used to generate national population estimates. Bivariate analyses using χ^2 tests examined the relationships between each of the covariates and race and between each of the index items and race. Stratified analyses were used to evaluate each of the covariates for potential effect modification. Covariates were considered to be effect modifiers based on the Breslow-Day test of homogeneity.¹⁶ $P < .20$ was considered suggestive of heterogeneity of the odds ratios across strata of each covariate. In the absence of effect modification, covariates were then considered as potential confounders. We created a multiple logistic regression model, which yielded adjusted prevalence odds ratios and 95% confidence intervals that assessed the independent relationship of race to distrust, while adjusting for possible confounding. In addition, as a test of the sensitivity of the results to dependent variable coding, we used other reasonable dichotomies (ie, distrust scores ≥ 3 and ≥ 4) in the logistic regression model, and a linear regression model using the distrust index was also created.

RESULTS

Of 1000 survey respondents, there were 527 African American and 382 white respondents eligible for this analysis (N=909). Among the sample, whites were more likely than African Americans to be older and employed, to have higher educational attainment and income, and to be from the Midwest and the West (**Table 1**). There were no racial differences by sex.

In the next step of the analysis, we examined bivariate comparisons between race and each questionnaire item that composed the distrust index (**Table 2**). Although most participants in each group responded trustingly to most items, African American respondents were more likely than white respondents not to trust that their physician would fully explain research participation (41.7% vs 23.4%, $P < .01$) and less likely to believe that they could freely ask their physician questions (15.2% vs 7.6%, $P < .01$). African American respondents were also more likely to disagree that their physician would not ask them to participate in research if the physician thought there was harm (37.2% vs 19.7%, $P < .01$) and more likely to state that they thought their physicians sometimes exposed them to unnecessary risks (45.5% vs 34.8%, $P < .01$). African Americans were more likely to believe that someone like them would be used as a guinea pig without his or her consent (79.2% vs 51.9%, $P < .01$), that physicians often prescribed medication as a way of experimenting on people without consent (62.8% vs 38.4%, $P < .01$), and that their physicians had given them treatment as part of an experiment without their permission (24.5% vs 8.3%, $P < .01$).

To better understand the relationship between race and distrust, we plotted race-specific distrust index scores (**Figure**). Possible scores ranged from 0 for the most trust-

Table 1. Sociodemographic Characteristics of the Study Sample*

Variable	African American (n = 527)	White (n = 382)	P Value†
Age, y			
18-29	122 (28.3)	55 (16.7)]. <.01
30-49	220 (42.9)	187 (45.2)	
50-64	98 (16.1)	77 (19.9)	
≥65	84 (12.8)	61 (18.1)	
Sex			
Male	195 (42.6)	178 (47.5)]. .14
Female	332 (57.4)	204 (52.5)	
Education			
<High school graduate	122 (26.1)	33 (12.4)]. <.01
High school graduate	187 (38.1)	128 (40.0)	
Some college	110 (23.6)	104 (24.4)	
College graduate	105 (12.3)	116 (23.2)	
Employment			
Yes	319 (56.8)	269 (65.9)]. <.01
No	207 (43.2)	111 (34.1)	
Income, \$/y			
<20 000	159 (31.1)	51 (16.1)]. <.01
20 000-29 999	87 (22.6)	62 (18.1)	
30 000-49 999	104 (22.8)	99 (30.5)	
≥50 000	107 (23.6)	135 (35.3)	
Region			
Northeast	112 (20.4)	68 (21.2)]. <.01
Midwest	72 (17.7)	105 (27.8)	
South	303 (51.5)	131 (28.8)	
West	40 (10.4)	78 (22.2)	

*Data are given as unweighted number (weighted percentage) of respondents unless otherwise indicated. Numbers of respondents vary because of unanswered questions. Some percentages do not sum to 100 because of rounding.

† χ^2 Test.

ing to 7 for the most distrusting. The mean score was significantly higher for African American respondents than for white respondents (3.1 vs 1.8, $P < .01$). We used a score of 5 or more distrustful responses to identify respondents with a high level of distrust.

Table 3 gives the unadjusted relationships between the sociodemographic variables and distrust. Nearly 24% of African Americans compared with about 6% of whites had scores that were 5 or higher ($P < .01$). In addition, sex, lower educational attainment, unemployment, and geographic region were associated with distrust.

In stratified analyses, none of the sociodemographic variables were found to substantially modify the relationship between race and distrust. Hence, those found to be associated with race and distrust in the bivariate analyses (ie, educational attainment, employment status, and census region) were included in the final logistic regression model (**Table 4**). In unadjusted analyses, African Americans had 5 times (odds ratio, 5.0; 95% confidence interval, 3.1-7.9) the odds of whites of having a distrust index score of 5 or higher. After controlling for other sociodemographic variables in the logistic regression model, race remained strongly associated with a higher distrust score (prevalence odds ratio, 4.7; 95% confidence interval, 2.9-7.7). This strong relationship between distrust and race was robust to dependent vari-

Table 2. Responses to Individual Items in the Distrust Index, Stratified by Race*

	African American	White
If your physician wanted you to participate in research, you trust that he or she would fully explain it to you (disagree or do not know).	41.7	23.4
Do you believe that you can freely ask your physicians any questions you want (no or do not know)?	15.2	7.6
Your physician would not ask you to participate in medical research if he or she thought it would harm you (disagree or do not know).	37.2	19.7
In deciding what treatments you will get, do you feel that your physicians always try to protect you from unnecessary risk, or do you feel that they sometimes expose you to unnecessary risk (expose to unnecessary risk or do not know)?	45.5	34.8
How likely is it that you, or people like you, might be used as guinea pigs without your consent (very likely, somewhat likely, or do not know)?	79.2	51.9
How often, if ever, do you think physicians prescribe medication as a way of experimenting on people without their knowledge or consent (very often, fairly often, or do not know)?	62.8	38.4
Do you believe that physicians have ever given you treatment as part of an experiment without your permission (yes or do not know)?	24.5	8.3

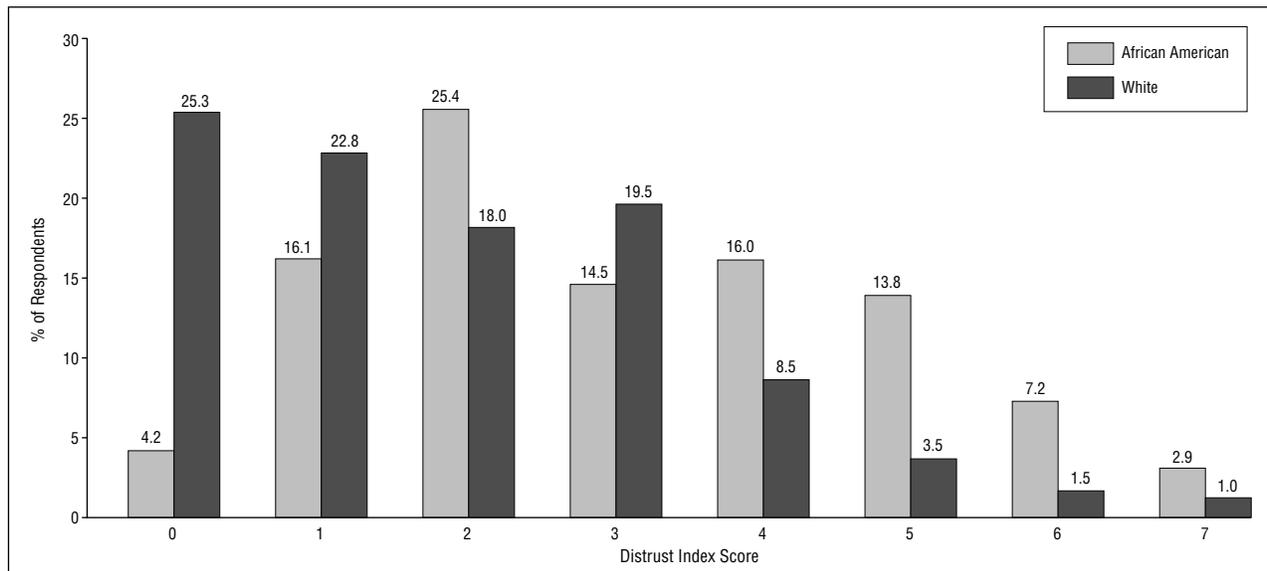
*N = 909. Data are given as percentages unless otherwise indicated. $P < .01$, χ^2 test, for all.

able coding, as seen in the results of a linear model using the continuous distrust index and logistic models in which the outcomes were distrust scores 3 or higher and 4 or higher (data not shown).

COMMENT

In a national sample of respondents, we found important differences by race in aspects of trust that may be associated with willingness to participate in research. African Americans were more likely to believe that physicians would ask them to participate in harmful research or expose them to unnecessary risks. Compared with white Americans, they were also more likely to believe that their physicians would not explain research fully or would treat them as part of an experiment without their consent. Even after controlling for markers of social class, African Americans were less trusting. Although there was a clear relationship between distrust and certain socioeconomic variables, socioeconomic status had only a small confounding effect (6% change in prevalence odds ratio) on the independent relationship between race and distrust.

Trust can be seen as a complex set of overlapping domains of competence, fiduciary responsibility, disclosure, and control.^{17,18} Although there are various theoretical frameworks through which to view trust, a trust-based relationship, whether interpersonal or societal, can be thought to consist of certain elements. As Gould¹⁹ describes, persons who must choose to trust or not trust are often in a position of vulnerability. If they choose, they entrust their well-being or health to a person or institution, with the expectation of a good outcome and



Relationship between distrust index scores and race.

Table 3. Proportion of Respondents With a Distrust Index Score of 5 or Higher, by Demographic Characteristics*

Predictor	Distrust	P Value†
Race		
African American	23.8]< .01
White	5.9	
Age, y		
18-29	16.0]< .61
30-49	16.2	
50-64	18.3	
≥65	12.7	
Sex		
Male	19.3]< .02
Female	13.6	
Education		
<High school graduate	23.1]< .01
High school graduate	16.4	
Some college	14.0	
College graduate	10.6	
Employment		
Yes	12.0]< .01
No	22.6	
Income, \$/y		
<20 000	14.1]< .21
20 000-29 999	25.7	
30 000-49 999	11.6	
≥50 000	13.8	
Region		
Northeast	18.7]< .01
Midwest	7.2	
South	18.6	
West	19.0	

*N = 909. Data are given as percentage of respondents unless otherwise indicated.

† χ^2 Test.

advocacy. The distrust index in this study reflects agency and fiduciary responsibility at an interpersonal and societal level.

Methods to measure and understand the interrelated aspects and levels of trust and distrust are in their

Table 4. Adjusted Prevalence Odds Ratio (OR) and 95% Confidence Interval (CI) for the Association Between Race and Distrust, Controlling for Sociodemographic Confounders*

Predictor	OR (95% CI)
Race	
African American	4.7 (2.9-7.7)
White	Reference
Education (ordinal)	
	0.9 (0.7-1.1)
Employment	
Yes	1.7 (1.2-2.6)
No	Reference
Region	
Northeast	2.7 (1.4-5.3)
South	2.2 (1.2-4.0)
West	3.3 (1.6-6.8)
Midwest	Reference

*Each variable is adjusted for confounding by other variables using multiple logistic regression. Six observations were deleted because of missing values for 1 or more of the model variables.

infancy.²⁰ At the time of this study, there was only one published scale to measure trust. The Trust in Physician Scale, developed and validated in a homogeneous clinical population, has high internal consistency.^{21,22} However, because it primarily measures interpersonal trust in the clinical context, we did not consider the scale appropriate for this study. Subsequently, other authors have developed tools, the Primary Care Assessment Survey and the Patient Trust Scale, that have focused on interpersonal trust and the effect of payment method and managed care within the context of clinical care.^{23,24} The items that we report herein focus on other aspects of the physician-patient relationship in a different context. We believe these items more closely reflect perceptions of societal and interpersonal trust and distrust that might affect a person's willingness to participate in research.

Interpersonal, institutional, and societal trusts are interdependent. Trust in one's physician (interpersonal

trust) is usually an iterative process, from selection by personal referrals to multiple interactions over time. Several studies^{23,25,26} have focused on the effect of managed care in disrupting these iterations, thereby undermining trust. Practices that emphasize continuity and communication are associated with higher levels of trust in physicians.^{27,28} However, trust in society, medical institutions, and medical research may be formed largely by community perceptions, public opinion, and the media.¹⁷

In recent years, we have witnessed a dramatic fall in public trust in medical establishments.^{29,30} Negative events such as violations of public trust and unethical behavior are widely disseminated. Because these instances have become more visible, they may carry greater psychological weight and adversely affect the ability to overcome distrust.²⁹ In this context, our findings are consistent with negative views about the health system held by African Americans.^{7,30-35} Fueled by current and past experiences of African Americans in the United States, negative views of medicine and the health care system may contribute significantly to the sentiments of distrust in medicine and medical institutions.

Societal trust also rests heavily on the construct of advocacy, the belief that persons and institutions will act in a manner consistent with our interests. Because the expectation of advocacy is a fundamental underpinning, trust is inherently associated with risk. Those who have less faith in this fiduciary relationship are less willing to take risks.^{36,37} Perceptions of advocacy may be particularly important for African Americans. In a study of African Americans, Sengupta and colleagues¹² found that, while perceptions of past abuses were important, the most significant contributor to distrust was concern about the motives of scientists and research institutions.

However, these results raise an important related question: Are researchers trustworthy? Unfortunately, in the setting of clinical research, violations of the fiduciary relationship have not been uncommon and are widely publicized. To protect against violations of trust and to protect potential research participants from unnecessary risk, medicine has developed a widening range of legislations and regulations.^{17,38} However, despite detailed and increasing regulations to protect research participants, a substantial portion of the population has chosen not to trust in physicians, medicine, or research.

How then can this potential barrier to successful recruitment be addressed? To counteract the distrust that has been documented in this study and to demonstrate trustworthiness, we suggest that recruitment in the African American community be thought of as an ongoing process of engagement, dialogue, and feedback. As we have noted, trust is generated and maintained through repeated interactions in a long-term relationship. Community members become skeptical, and distrust possibly reinforced, when researchers approach communities only when recruiting subjects. Ongoing community involvement is not only important in building trust but also allows the investigator an opportunity to better understand the barriers and challenges that are specific to that community. Engaging members of the target community, for example, through the mechanism of com-

munity advisory boards, can prove invaluable in the initial stages of study design, as well as in planning and evaluating recruitment strategies.³⁹⁻⁴³

Although we find these results compelling, we must acknowledge limitations. For example, it is possible that respondents who agreed to participate in this study may have believed more strongly about these topics than others who did not agree to participate. However, in trying to estimate the magnitude and direction of the potential bias, it is difficult to know if distrustful persons would have been more or less likely to participate in a telephone interview on these topics, or if persons interested in research participation would have been more likely to participate in this study. In addition, several questions remain unanswered because of the nature of these data. Although there are differences by race in aspects of trust that may be related to research participation, we cannot conclude that differences in research participation will be explained by distrust. Distrust is only one of many variables that a person may consider as he or she makes decisions about participation in research. It would be misleading and premature to suggest that distrust is the only predictor of intention to participate in research. More work is needed to determine other constructs that potential research subjects may consider and how the relative weight placed on these variables may differ by race or ethnicity. In addition, we cannot draw conclusions about the effect of interpersonal trust on societal distrust, as we do not have specific information on whether the respondents were seeing a physician regularly. It is possible that those respondents who were in a trusting relationship and therefore had higher levels of interpersonal trust may also have higher levels of societal trust. How persons integrate these 2 aspects of trust as they make decisions about health care and research participation is an important next step in understanding the implications of this research. In light of disparities in access to care by race/ethnicity, it will be important to determine whether having a regular source of care and trusted health care provider may mitigate distrust, especially among minority patients.

Despite these limitations, we believe the differences in distrust that have been documented in this study are a critical step in understanding and addressing differences in research participation. Information about safeguards that are in place to protect research subjects should be more widely disseminated in the lay community. In addition, given the magnitude of these differences in distrust, we believe that investigators trying to engage African Americans in research must focus on developing interpersonal trust with community members by actively engaging the members in all aspects of research design, development, and dissemination of findings.

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