POPULATIONS AT RISK

Differences in the Patterns of Health Care System Distrust Between Blacks and Whites

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CONTEXT: Although health care-related distrust may contribute to racial disparities in health and health care in the US, current evidence about racial differences in distrust is often conflicting, largely limited to measures of physician trust, and rarely linked to multidimensional trust or distrust.

OBJECTIVE: To test the hypothesis that racial differences in health care system distrust are more closely linked to values distrust than to competence distrust.

DESIGN: Cross-sectional telephone survey.

PARTICIPANTS: Two hundred fifty-five individuals (144 black, 92 white) who had been treated in primary care practices or the emergency department of a large, urban Mid-Atlantic health system.

PRIMARY MEASURES: Race, scores on the overall health care system distrust scale and on the 2 distrust subscales, values distrust and competence distrust.

RESULTS: In univariate analysis, overall health care system distrust scores were slightly higher among blacks than whites (25.8 vs 24.1, p=.05); however, this difference was driven by racial differences in values distrust scores (15.4 vs 13.8, p=.003) rather than in competence distrust scores (10.4 vs 10.3, p=.85). After adjustment for socioeconomic status, health/psychological status, and health care access, individuals in the top quartile of values distrust were significantly more likely to be black (odds ratio=2.60, 95% confidence interval=1.03–6.58), but there was no significant association between race and competence distrust.

CONCLUSIONS: Racial differences in health care system distrust are complex with far greater differences seen in the domain of values distrust than in competence distrust. This framework may be useful for explaining the mixed results of studies of race and health care-related distrust to date, for the design of future studies exploring the causes of racial disparities in health and health care, and for the development and testing of novel strategies for reducing these disparities.

KEY WORDS: race; values distrust; competence distrust; health care system distrust.
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INTRODUCTION

Interest in health care-related distrust has grown substantially over the last 10 years for several reasons. First, it has been increasingly recognized that distrust can impede the functioning of most elements of society, including business, government, and communities.[1–3] Second, a growing body of theoretical and empirical evidence suggests that distrust may also contribute to problems with health and health care in the US, including rising health care costs, ineffective or low quality care, and poor patient outcomes.[4–9] Third, health care distrust is commonly cited as an important contributor to racial disparities in health and health care, following the argument that higher distrust among racial minorities interferes with seeking medical care and adherence with medical recommendations.[10–15]

Despite the interest in distrust as a cause of racial health and health care disparities, the available evidence about racial differences in health care-related distrust is limited and often conflicting. The majority of prior studies has focused on trust in personal physicians and generally demonstrated that relatively few people of any racial group distrust their personal physician.[10,11,16–21] Racial differences in trust in personal physicians have been inconsistent with some studies finding higher distrust among minority groups and others finding no differences in distrust.[10,11,17–21] Relatively few studies have examined racial differences in institutional or social forms of health care-related distrust, such as distrust in the health care system or health insurers, and again, results are mixed.[4,11,22–24] Using a scale of health care system distrust that we developed

previously, we found higher health care system distrust among blacks in 1 general population sample in a Northeastern city, but not in a national telephone survey.[4,22] Another study found that blacks had higher distrust of hospitals but lower distrust of insurers than whites.[11]

One potential explanation for the inconsistency in prior studies of race and distrust relates to the multidimensional nature of distrust. Following some conceptual confusion in early studies of trust,[25,26] it has become generally accepted that trust and distrust are multidimensional and composed of 2 primary domains—a domain related to technical competence and a domain related to values.[18,27,28] Whereas the technical competence domain is rarely decomposed, the values domain varies in its structure across studies with some studies focusing on a single value, generally termed fiduciary responsibility, fidelity, or agency, and other studies including additional values such as respect, honesty, caring, confidentiality, and dependability.[18,29–31] Interpersonal communication is included in some studies but appears to mostly represent underlying values of respect, honesty, and caring.[6] Despite the widespread acceptance of the multidimensional nature of trust, existing measures of health care-related trust and distrust are unidimensional and empirical studies of racial differences have been unable to examine patterns across different domains.

In this study, we test the hypothesis that racial differences in distrust are greater in the domain of values than the domain of technical competence. There are several reasons for this hypothesis. The history of racism in the US, and particularly in medical research and clinical care, is likely to have created deep suspicion about the motives of the US health care system.[12,32,33] Inferior communication with minority patients may also result in greater concerns about the honesty of the health care system.[34–37] Furthermore, considerable concern about the technical competence of the health care system has been documented among whites, which may equal that seen among minority groups.[38] To test this hypothesis, we use a revised scale of health care system distrust that includes separate subscales for technical competence and values congruence. The conceptual model underlying this scale defines distrust as the belief that an entity will act *against* one's interest in the future, in contrast to trust which is defined as the belief that the entity will act in one's interest in the future. It focuses on distrust, rather than the absence of trust, because distrust implies a step beyond the absence of trust and this step may be critical to racial disparities.

METHODS

We conducted a cross-sectional survey using the revised scale of health care system distrust to test the hypotheses about the relationship between the domains of values- and competence-related distrust and race.

Study Population

From our reference population of individuals over the age of 18 who had been seen at a primary care practice or emergency department with the University of Pennsylvania Health System in the past 3 years, a random sample of 845 individuals was selected. The final response rate was 48.5% based upon the AAPOR response rate formula 4.[39] Two hundred and sixty four individuals completed the interview, 118 declined participation, 49 were ineligible (unable to speak English), 192 were unable to be reached, and 222 had disconnected telephone numbers. Compared to nonresponders, responders were older (odds ratio [OR]=1.02, 95% confidence interval [CI]=1.01–1.04), more likely to be women (OR=1.71, 95%CI=1.23–2.40), and less likely to be uninsured (OR=0.35, 95%CI=0.19–0.66). Respondents and nonrespondents did not differ in race/ethnicity (p=.32). Of the 264 interviewed subjects, 28 participants did not provide information on race/ethnicity or were neither black nor white and were excluded from the study population, leaving a final sample of 236 participants.

Data Collection

Data were collected using telephone interviews with calls spread over days of the week and times of the day. The telephone interviewers were racially diverse, but no attempt was made to match respondent and interviewer race.

Measures

Health Care System Distrust. Health care system distrust was assessed using the revised 9-item scale of health care system distrust. This scale has a Cronbach's alpha of 0.85 and 2 subscales consistent with the domains of competence (4 items, Cronbach's alpha=0.75) and values (5 items, Cronbach's alpha=0.77). Items are scored from 1 to 5 with 1 corresponding to strongly disagree and 5 strongly agree.

Race/Ethnicity. Based on items from the 2000 U.S. Census survey, participants were asked first about Hispanic ethnicity and then about their racial background.

Covariates. We measured a series of variables that may confound the relationship between race and distrust, including sociodemographic characteristics, health insurance/access, and health/psychological status.

Sociodemographic Characteristics. Age, gender, educational attainment, employment, and household income were measured using items from the 2001 Behavioral Risk Factor Surveillance System questionnaire.[40] The number of people in the household was measured using a single pretested item.

Health Insurance/Access. Items from the National Health Interview Survey were used to assess whether the participant currently had health insurance, had been without health insurance in the past year, had not received care in the past year because of the cost, and had a personal doctor.[41] For participants with health insurance, items assessed whether they needed a referral for specialty care and had to choose doctor from a list, as well as whether they thought they were in an HMO.

Health/Psychological Status. Self-reported health was measured with the General Health Perceptions question that asks participants to characterize their health as excellent, very

good, good, fair, or poor.[42] Dispositional optimism was measured using the Life Orientation Test-Revised, a 6-item scale with a Cronbach's alpha of 0.78.[43] The 2-item PRIME-MD was used as a brief screening test for depressive symptoms.[44]

Statistical Analysis

Data analysis was performed using STATA 8.2. All *p* values are 2-sided. Insurance coverage was stratified in 2 complementary ways: (1) by the degree of doctor choice and need for specialist referral and (2) by payer type (no insurance, government insurance, and employer-based insurance). Univariate analyses examined scores on the overall distrust scale and each subscale both as a continuous variable and in quartiles, comparing individuals in the highest quartile of distrust with individuals in the lower 3 quartiles. Because these results were substantively the same, we chose to present the multivariate results using the highest quartile of distrust as the dependent variable to facilitate interpretation of the results. Multiple logistic regression was used to adjust the association between race and high distrust for potential confounding and effect modification. Covariates included sociodemographic factors: age (in decades), gender, educational attainment (high school or less, some college or college degree, more than college), household income (<$20K vs $20K or greater), number of people in household (one versus more than one), and having a job outside the home; health status factors: general health status (fair/poor, good, very good/excellent), depressive screen questions (0, 1, or 2 positive responses), and optimism score (as a linear term); and health care factors: not having obtained health care in the past year because of the cost, having a personal doctor, and the indicator variables for health insurance coverage. Having been uninsured in the past year and belonging to an HMO were strongly correlated with measures of insurance coverage and were not included in the final model. Separate models were constructed for the overall distrust score and each subscale score (i.e., values distrust and competence distrust).

RESULTS

Over half of the 236 study participants were black. (Table 1) Participant age ranged from 22 to 75 years with a mean age of 48 years. Almost three-quarters of the participants were women. The sample was socioeconomically diverse with 12% without a high school degree, 30% with a high school degree only, and 34% with a college degree or higher. About two-thirds of participants worked outside the home; less than one-third lived alone. The proportion of participants without current health insurance was small (7%) but, over the past year, 13% had been uninsured and 10% had not received medical care because of the cost. A little over half of the participants said they currently needed a referral for specialist care or had to choose a doctor from a list.

The characteristics of our sample differed by the race of the participant (Table 1). In our sample, blacks were more likely to be female, have lower levels of educational attainment and household income, and were less likely to be employed outside the home than whites. Blacks were also more likely to be currently uninsured or to have been uninsured in the last year, to report being in an HMO or needing a referral for specialty care, and to have the government pay for their insurance than whites. However, blacks were less likely to report having to choose their doctor from a list than whites. Blacks had higher numbers of positive responses to depression

Table 1. Participant Characteristics

	Overall (*n*=236)	Blacks (*n*=144)	Whites (*n*=92)	*p* value
Mean age, y (range)	47.8 (22–75)	46.9 (22–75)	49.0 (31–69)	0.16
Female (%)	73.8	80.4	63.3	0.004
Education (%)				
Less than high school	13.3	18.3	5.5	<0.0005
High school degree	30.0	43.7	8.8	
Some college	24.5	28.9	17.6	
College degree	10.7	7.8	15.4	
Graduate school	21.5	1.4	52.8	
Household income (%)				
<$20,000	22.5	32.6	6.5	<0.0005
$20,000–$39,999	19.9	30.6	3.3	
$40,000–$59,999	14.0	13.2	15.2	
$60,000–$99,999	10.6	6.9	16.3	
>$99,999	17.0	0.7	42.4	
Missing	16.1	15.6	16.3	
Number in household (%)				
1	30.0	23.9	33.3	0.02
2	22.0	33.7	14.6	
3	15.7	14.1	16.7	
4	13.1	14.1	12.5	
5 or more	10.2	7.6	11.8	
Job outside the home (%)	64.8	59.1	73.3	0.03
Parents born in US %	84.0	85.0	82.6	0.63
Health insurance (%)				
No current insurance	7.5	11.5	1.1	0.003
Uninsured in the last year	12.8	19.7	2.2	0.0001
Have to choose doctor from a list	53.0	40.5	55.8	0.03
Need referral for specialist care	61.2	77.1	39.8	<0.0005
HMO	42.0	49.2	24.4	0.0003
Health insurance payer (%)				
Employer	72.4	54.2	86.7	<0.0005
Government	28.4	31.6	18.9	0.04
Pocket	35.2	21.8	50.5	<0.0005
Have not received medical care in the past year because of cost (%)	8.5	10.7	5.6	0.18
Have a personal doctor (%)	90.8	89.0	93.3	0.27
Depression screen score (PRIME-MD) (%)				
0	70.0	61.8	81.5	0.006
1	9.9	11.8	6.5	
2	20.1	26.4	12.0	
Optimism (mean LOT score)	14.0	14.4	13.1	0.001
Self-reported health status (%)				
Poor	7.0	9.4	3.3	<0.0005
Fair	21.1	27.5	11.1	
Good	33.3	35.5	30.0	
Very good	25.9	21.0	33.3	
Excellent	12.7	6.5	22.2	

screening questions and worse self-reported health status but higher optimism scores than whites.

The mean score on the health care system distrust scale in our sample was 25.2 with a range from 9 to 41 (Table 2). Although overall health care system distrust scores were slightly higher among blacks than whites (25.8 vs 24.1, p=.05), this difference was driven by racial differences in values distrust (15.4 vs 13.8, p=.003), not competence distrust (10.4 vs 10.3, p=.85) (Table 2). This pattern was also seen in individual items with blacks reporting higher distrust on most of the values distrust items. None of the other measured variables were associated with overall distrust or competence distrust at a p value of .05 or less. However, higher values distrust scores were also significantly associated with not having received care in the past year because of the cost (16.8 vs 14.6, p=.01) and worse health status (15.9 for fair/poor health status vs 14.2 for very good/excellent health status, p=.02).

After adjustment for sociodemographic characteristics, health status factors, and health care factors, high values distrust remained strongly associated with being black (p=.01) (Table 3). This association held whether the model adjusted for insurance coverage stratified by the extent of doctor choice or insurance coverage stratified by payer (data not shown). In the final model, high values distrust was also positively associated with having a household income greater than $20,000 a year, although there was no significant correlation between distrust and increasing income above $20,000 ($p$=.04). These results were very similar to adjusted analyses with values distrust as a continuous variable where the adjusted mean difference in values distrust score between blacks and whites was 2.16, 95%CI from 0.48 to 3.85.

After multivariate adjustment, there was a trend toward higher competence distrust among blacks but the confidence interval was wide (OR=1.49, 95%CI=0.62–3.43). The association between race and high overall distrust score was stronger (OR=2.20, 95%CI=0.83–5.83) but did not reach statistical significance. These measures of distrust were not significantly associated with other sociodemographic characteristics, measures of health status, or measures of health care access.

Table 2. Distrust Scores by Race

		Overall	Black	White	p value
Overall score		25.2	25.8	24.1	0.05
Values distrust score		14.8	15.4	13.8	0.003
Competence distrust score		10.4	10.4	10.3	0.85
Full scale					
1. The health care system does its best to make patients' health better.*	C	2.26	2.24	2.28	0.73
2. The health care system covers up its mistakes.	V	3.29	3.33	3.24	0.53
3. Patients receive high-quality medical care from the health care system.*	C	2.59	2.65	2.49	0.18
4. The health care system makes too many mistakes.	C	2.90	2.85	2.98	0.33
5. The health care system puts making money above patients' needs.	V	3.33	3.42	3.19	0.14
6. The health care system gives excellent medical care.*	C	2.62	2.65	2.59	0.66
7. Patients get the same medical treatment from the health care system, no matter what the patient's race or ethnicity.*	V	3.01	3.09	2.95	0.39
8. The health care system lies to make money.	V	2.45	2.63	2.20	0.002
9. The health care system experiments on patients without them knowing.	V	2.70	3.04	2.17	0.0001

C competence, V values
**Reverse scored*

Table 3. Associations with High Values Distrust

	OR (95%CI)
Black (versus white)	2.65 (1.06–6.65)
Annual household income (>$20K vs ≤$20K)	2.52 (1.02–6.63)
Female (versus male)	1.07 (0.51–2.26)
Educational attainment (versus high school or less)	
Some college	1.17 (0.53–2.57)
College degree or higher	1.88 (0.54–6.52)
Number in household (>1 vs 1)	0.70 (0.33–1.48)
Job outside the home	0.79 (0.36–1.73)
Depression screen*	0.91 (0.58–1.45)
Optimism	1.01 (0.89–1.13)
Self-reported health status (versus fair/poor)	
Good	0.93 (0.38–2.26)
Very good/excellent	0.60 (0.23–1.61)
Missed care in last year due to cost	1.47 (0.48–4.48)
Have a personal doctor (versus no personal doctor)	1.88 (0.52–6.76)
Insured, doctor choice limited	0.69 (0.10–6.60)
Insured, doctor choice not limited	0.39 (0.04–3.97)

Top quartile of distrust compared to bottom 3 quartiles.
**For each depression screen question answered positively.*

DISCUSSION

Although health care-related distrust may be an important contributor to racial disparities in health and health care in the US, the empirical data about racial differences in distrust are limited and often conflicting. In this study, we demonstrate that racial differences in distrust of the health care system arise from differences in values distrust rather than from differences in competence distrust. In addition, we demonstrate that this racial difference in values distrust is not explained by differences in socioeconomic status, health or psychological status, or health care access.

These results suggest a novel framework for understanding racial differences in distrust that may underlie the mixed results of prior studies and provide guidance for future studies in this area. In this framework, racial differences in distrust exist but are focused on concerns about values distrust rather than equal across domains. In addition to the empirical results of this study, this framework is grounded in theoretical and empirical research in social psychology demonstrating the 2 dimensions of trust (values and competence) and analyses of the impact of historical and current racism on minorities' perceptions of the health care system's values. Although our study focused on health care system distrust, this differential relationship between race and different domains of trust or

distrust may also exist for other types of health care-related trust/distrust, such as distrust of personal physicians. Because most other scales of health care trust or distrust have been found to be unidimensional in psychometric analyses, it may be reasonable to examine patterns in racial differences across items. Future studies examining race and distrust should consider the possibility that racial differences in distrust are more complex than mean differences in overall scores and ensure that measures can capture this complexity.

Racial difference in values distrust may have implications for racial differences in health care and health outcomes. As noted previously, distrust has been demonstrated to decrease the frequency of transactions and increase the costs of monitoring and regulation in many segments of society.[1,2,45] Similarly, health care system distrust may lead to lower rates of effective health care and greater use of unnecessary testing and potentially even ineffective interventions. However, the empirical evidence supporting the effect of distrust on health or health care is limited. Several studies have found that lower levels of trust are associated with lower rates of preventive service use,[14,15,46] adherence with physician recommendations,[5,47–49] and changing physicians.[48,50,51] In a separate study, we recently demonstrated that our previous measure of health care system distrust is associated with worse self-reported health status (as was seen in this analysis), but we did not examine the pathways linking distrust and poor health.[4] A recent analysis of a public health survey in Sweden demonstrated a similar association between health care system distrust and poor self-reported health status and found that use of health care services explained a significant proportion of this association.[52] In the current study, the association with health status was stronger for values distrust than competence distrust. Furthermore, given the imperfect nature of health care, it is possible that some level of distrust is protective when trustworthiness is not high.[53] More studies are needed to understand the "downstream effects" of this pattern of racial differences in health care system distrust.

Although part of the appeal of studying distrust is the theoretical potential to intervene to reduce distrust and improve health care, relatively little guidance is currently available about how best to reduce distrust in general or to address racial differences in values distrust in particular. A relatively recent Cochrane review concluded that "overall there remains insufficient evidence to conclude that any intervention may increase or decrease trust in doctors."[54] Even less evidence exists about health care system trust or distrust with no published controlled studies of strategies to increase trust. Although our results are not focused on intervention development, the pattern across the items in Table 2 suggests that 2 specific beliefs—about experimentation and lying to make money—are important contributors to racial differences in distrust and that strategies that address these 2 issues may be particularly effective for reducing racial disparities in values distrust. Addressing the legacy of Tuskegee is often suggested as a method for reducing concerns about experimentation among blacks; however, current studies suggest that knowledge of Tuskegee is relatively low and not correlated with distrust or willingness to participate in research.[55,56] Educational and policy efforts targeting concerns and ethical issues with current biomedical research may be a more effective intervention strategy than targeting concerns about Tuskegee. Addressing the concern about lying to make money may require both fundamental change in current models of health care financing and leadership, as well as focused strategies to educate and inform patients about these issues.[27,57]

We found very few factors that were significantly associated with either competence or values distrust other than race. Values distrust was significantly higher among younger individuals and among individuals with higher household incomes. It is interesting to note that prior studies have found conflicting results about the association between income and distrust with some studies demonstrating higher levels of trust in physicians among patients with higher incomes,[58] others finding no association with income,[59] and others demonstrating higher levels of trust in patients with income <$20,000 a year as we found in this study.[23] Similarly, increasing age has been correlated with higher levels of trust in a provider[15] and with lower levels of trust in the medical profession in general.[59] More research is clearly needed to understand the relationship between these basic sociodemographic characteristics and patterns of health care-related trust and distrust.

This study has several limitations. The sample was restricted to the patient population of a single, urban health system in the Mid-Atlantic region and it is possible that the pattern of distrust would be different in other populations. Our sample size was adequate for testing our hypothesis about racial differences in values and competence distrust but provided only limited power for exploring other associations with distrust, including measures of health care access. Larger studies with more diverse samples are needed. Although we had a reasonable response rate, response bias remains a concern. Responders differed from nonresponders in several ways, although not in racial breakdown. Some of these differences reflect the difficulty of reaching low socioeconomic status individuals for follow-up research (e.g., higher rates of uninsurance among nonresponders) and may lead the concerns of these groups to be underrepresented in this study and other areas of clinical research. The lack of difference in race reduces the concern that the inclusion of nonresponders would have changed the primary study findings of racial differences in the patterns of distrust.

In summary, this study suggests that racial differences in health care system distrust are complex with far greater differences seen in the domain of values distrust than in competence distrust. This framework may be useful for explaining the mixed results of studies of race and health care-related distrust to date, for designing future studies exploring the causes of racial disparities in health and health care, and for the development and testing of novel strategies for reducing these disparities.

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