

The Legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?

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Financial support: This study was supported by grant R03HS013274 from the Agency for Healthcare Research and Quality and a grant from the Russell Sage Foundation, both awarded to Dr. LaVeist.

Objectives: To examine race differences in knowledge of the Tuskegee study and the relationship between knowledge of the Tuskegee study and medical system mistrust.

Methods: We conducted a telephone survey of 277 African-American and 101 white adults 18–93 years of age in Baltimore, MD. Participants responded to questions regarding mistrust of medical care, including a series of questions regarding the Tuskegee Study of Untreated Syphilis in the Negro Male (Tuskegee study).

Results: Findings show no differences by race in knowledge of or about the Tuskegee study and that knowledge of the study was not a predictor of trust of medical care. However, we find significant race differences in medical care mistrust.

Conclusions: Our results cast doubt on the proposition that the widely documented race difference in mistrust of medical care results from the Tuskegee study. Rather, race differences in mistrust likely stem from broader historical and personal experiences.

Key words: African Americans ■ Tuskegee study ■ medical mistrust ■ race differences ■ health disparities

INTRODUCTION

It is well documented that African Americans are more mistrustful of the medical care system than whites.¹⁻⁴ Mistrust may be associated with underutilization of health services, a greater likelihood of refusal to participate in clinical research, reduced proclivity to donate organs or biological material, and more concern about unwitting enrollment in potentially harmful medical experiments.²⁻⁴ The mistrust expressed by African Americans has been attributed to a number of factors, including limited access to the medical care system, a consequence of historical segregation in hospitals, and discourteous treatment and maltreatment by hospital personnel and healthcare professionals.⁵⁻⁸ The Tuskegee Study of Untreated Syphilis in the Negro Male (Tuskegee study) is among the most often cited reasons for mistrust of medical care among African Americans.^{5,9-11}

The Tuskegee study was conducted by the U.S. Public Health Service, lasted for approximately 40 years and involved the intentional deception and denial of treatment of the research subjects. The Tuskegee study represents the model example of the type of harmful experimentation feared by many African Americans.³ Several studies have assessed knowledge of the Tuskegee study among African Americans compared to whites.^{6,12,13} However, no study has explicitly assessed the relationship between knowledge of the Tuskegee study and mistrust of medical care among African Americans or racial differences in this relationship. The purpose of this study is to assess racial differences in the relationship between knowledge of the Tuskegee study and mistrust of medical care.

METHODS

Study Design and Population

During July and August of 2003, participants were surveyed as part of a cross-sectional study designed to assess mistrust of the healthcare system. We conducted a telephone survey of a random sam-

© 2005. From the Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health. Send correspondence and reprint requests for *J Natl Med Assoc.* 2005;97:951–956 to: Dr. Thomas A. LaVeist, Director, Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health, 624 N. Broadway, Room 441, Baltimore, MD 21205; phone: (410) 955-3774; fax: (410) 614-8964; e-mail: tlaveist@jhsph.edu

ple of residents of Baltimore City, MD. The data were collected as part of a larger study that focused on mistrust of the healthcare system among minorities at three sites: Washington, DC; New York City; and Baltimore. The Baltimore site focused on African Americans. This was in part due to the fact that the city has a long-standing, economically diverse, yet relatively segregated black population. This characteristic of Baltimore made sampling an economically diverse black population feasible without oversampling. In addition, each study location conducted a site-specific substudy. Baltimore was selected as the site for the Tuskegee substudy because of its large African-American population.

Data were collected using the sampling method described by Waksberg.¹⁴ We sampled households

and selected the household member age ≥ 18 who had the most recent birthday. Baltimore City has 167 telephone exchanges (first three numbers of a telephone number) within two area codes (410 and 443). The 45 exchanges that were associated exclusively with cellular phones were excluded. Another 23 exchanges were excluded because they are exclusively owned by large businesses or institutions, such as universities, large corporations, or city and state government.

We selected a 1% random sample (9,899) of the remaining 99 exchanges with all possible combinations of the last four digits (0001–9999). Trained interviewers called each number, documenting those that were disconnected or not in service, those who did not speak English, those who refused and those who agreed to participate in the interview. For the telephone numbers answered by an answering machine, a message was left, and the number was called back a minimum of two times. The interviewers made contact (actually talked with an eligible respondent) with 783 people—401 completed the interview (51.2%) and 382 refused. The interviewers obtained oral consent. Respondents were compensated \$20 for their participation.

Measures

Knowledge of the Tuskegee study was assessed by six items. The first five items were multiple-choice, with one correct response for each item. These survey items assessed factual information about the Tuskegee study. The final item asked if a similar study was possible today.

Medical mistrust was assessed using the seven-item Medical Mistrust Index (MMI).^{1,15} The scale employs Likert-type response codes ranging from “strongly disagree” to “strongly agree.” Examples of items included in the mistrust scale are: “Patients have sometimes been deceived or misled by healthcare organizations” and “Healthcare organizations put the patient’s health first.” The MMI shows good reliability (Chronbach’s $\alpha = 0.76$).

Other measures used in the study were race, age, sex, education, income and insurance status. Age, education and income were analyzed as continuous variables. Race and sex were analyzed as binary variables. Insurance status categories were private, Medicaid, Medicare and uninsured. For analysis, three dummy variables were created for insurance status with private insurance as the reference group.

RESULTS

Respondent Characteristics

Table 1 shows the demographic profile of the sample, which is not unlike the distribution of demo-

Table 1. Demographic Profile of the Sample (N=401)

Variable	Percent
Age	
Younger than 25	14.9
25-34	12.1
35-44	17.4
45-54	21.7
55-64	14.4
65 or older	19.6
Sex	
Male	28.7
Female	71.3
Race	
White	25.2
Black	69.1
Other	5.7
Income	
Less than \$5,000	8.7
\$5,000-\$9,999	15.2
\$10,000-\$14,999	11.5
\$15,000-\$24,999	12.9
\$25,000-\$34,999	13.8
\$35,000-\$49,999	12.9
\$50,000-\$59,000	8.1
\$60,000 or more	16.9
Education	
Less than high school	25.6
High-school graduate	32.7
Some college	19.6
College graduate	22.1
Health Insurance	
Medicaid	21.9
Medicare	32.9
Private	50.9
Uninsured	23.9

graphic characteristics for the city of Baltimore. The sample was 69.1% African-American and 71.3% female. There was a broad age range within the sample, although 51.2% of the sample was between the ages of 25 and 54 years. Income ranged from <\$5,000 to ≥\$60,000. Most of the sample (48.3%) reported their income to be <\$25,000, although 34.8% reported an income between \$25,000 and \$59,000. The remaining 16.9% reported an income of ≥\$60,000.

Nearly one-third of the sample (32.7%) reported graduating from high school, 25.6% had less than a high-school education. The rest of the sample reported having graduated from college (22.1%) or having completed some college (19.6%) without graduating. The largest proportion of the sample reported having private health insurance (50.9%), followed by Medicare (32.9%), Medicaid (21.9%) and those reporting no health insurance (23.9%). It should be noted that due to the overlap of the private, Medicare and Medicaid categories among respondents, insurance status proportions sum to more than 100%.

We first asked respondents if they had ever heard of the Tuskegee study. Respondents who indicated they had heard of the study were asked the items that

assessed factual information about the study. Respondents who were unfamiliar with the study were read a brief description (taken from the CDC website) and then asked if they thought a study like the Tuskegee study could happen today.

Approximately two-fifths of the total sample (41.9%, n=168) had heard of the Tuskegee study. However, there were no significant race differences in awareness of the study, with similar proportions among black (41.7%, n=70) and white (44.6%, n=75) respondents reporting having heard of the Tuskegee study. Knowledge of specific aspects of the Tuskegee study was further assessed among those who were aware of the study.

Table 2 shows the results of responses to the knowledge questions regarding the Tuskegee study. Most participants correctly reported when the Tuskegee study began. However, a large minority of both blacks (24.4%) and whites (31.7%) believed the study began two decades later, in the 1950s. The remaining respondents believed the study began in the 1890s (blacks: 4.9%, whites: 0%) or in the 1970s (blacks: 7.3%, whites: 2.4%).

A larger proportion of whites (46.3%) than blacks (32.5%) correctly answered when the study

Table 2. Knowledge about Tuskegee among Black and White Respondents Aware of the Tuskegee Study (n=145)

Question	Responses	Black (n=70)	White (n=75)	P Value
<i>In what decade did the study begin?</i>	1890s	4.9%	0%	0.294
	1930s	63.4%	65.9%	
	1950s	24.4%	31.7%	
	1970s	7.3%	2.4%	
<i>In what decade did the study end?</i>	1930s	6.0%	4.9%	0.421
	1950s	47.0%	41.5%	
	1970s	32.5%	46.3%	
	1980s	14.5%	7.3%	
<i>How many men were in the study?</i>	75	34.1%	12.2%	0.538
	200	28.0%	51.2%	
	600	22.0%	19.5%	
	1,000	15.9%	17.1%	
<i>Which organization conducted the study?</i>	U.S. Public Health Service	25.3%	26.8%	0.898
	Tuskegee Institute	29.1%	26.8%	
	Johns Hopkins	5.1%	2.4%	
	US Army	40.5%	43.9%	
<i>Did the researchers give the men syphilis or did they already have it?</i>	Gave it to them	75.3%	52.8%	0.019
	Already had it	24.7%	47.2%	
<i>Do you think it is possible for a study like this to occur today?*</i>	Yes	76.6%	47.2%	<0.001
	No	17.9%	43.8%	

The proportions of correct responses to items 1–5 are presented in bold; the proportion of those answering "yes" to item 6 is presented in bold; * this question was asked of the full sample (n=378)

ended. However, the majority of both black and white respondents answered incorrectly. Similar but small proportions of blacks (6.0%) and whites (4.9%) reported the study came to an end four decades early, in the 1930s. However, substantial percentages of blacks (47.0%) and whites (41.5%) believed the study ended in the 1950s. A somewhat higher proportion of blacks (14.5%) than whites (7.3%) thought the study concluded in the 1980s.

The largest proportions of both black and white respondents underestimated the size of the Tuskegee study. The most common response for blacks was that 75 men participated in the study. The majority of whites thought only 200 men were in the study. Only 19.5% of whites and 22% of blacks correctly responded that approximately 600 men participated in the study.

The Tuskegee study was conducted by the U.S. Public Health Service. The facilities of the Tuskegee Institute (now Tuskegee University) were used for some aspects of the study. Only 26.8% of whites and 25.3% of blacks knew that the U.S. Public Health Service conducted the study. More than 29% of blacks and nearly 27% of whites thought the Tuskegee Institute conducted the study. Large proportions of blacks (40.5%) and whites (43.9%) believed the U.S. Army was the organization that conducted the Tuskegee study. A small proportion of blacks (5.1%) and whites (2.4%) reported that the study was conducted by Johns Hopkins University.

Most respondents believed the men followed during the Tuskegee study were given syphilis by the study team. The vast majority of blacks (75.3%) and just over one-half of whites (52.8%) believed this, although a higher proportion of whites (47.2%) compared to blacks (24.7%) correctly indicated the men followed during the Tuskegee study "already had it [syphilis]." A substantial percentage of white respondents (47.2%) believed such a study is possible today. However, a significantly higher proportion of black respondents (76.6%) believed a similar

study could occur today.

The belief that a similar study could happen again is particularly germane to the issue of race differences in medical care mistrust. In Table 3, we examined the relationship among race, awareness of the Tuskegee study and the belief that a similar study could happen again. After hearing about the Tuskegee study, 63.6% of unaware whites believed a similar study could happen again today. However, a much smaller proportion of whites already aware of the Tuskegee study (37.8%) believed a similar study could happen again today. By contrast, 76.9% of unaware blacks and 87.1% of blacks already aware of the Tuskegee study believed a similar study could happen again today. These findings indicate that, for whites, being told about the Tuskegee study made a tremendous difference in their belief that a similar study could happen again. However, for blacks, being made aware of the Tuskegee study made little difference in their belief that such a study could happen again.

We also examined the relationship between race and the incidence of the belief that a similar study could happen again. The proportion of initially unaware blacks who believed a similar study could happen again was compared to the proportion for their white counterparts. This resulted in a ratio of 1.21 ($p < 0.05$), indicating blacks were 21% more likely to believe a similar study could happen again. A similar comparison was made among those who were aware of the study. This comparison produced a ratio of 2.30 ($p < 0.05$), indicating that blacks were 130% more likely to believe a similar study could happen again. Overall, blacks were more likely to believe a similar study could happen again regardless of their awareness of the Tuskegee study.

We used Ordinary Least Squares Regression analyses from SPSS 12 to analyze the relationship between race and mistrust of the medical care system using the MMI. We also examined whether knowledge of the Tuskegee study is associated with medical mistrust and whether it attenuates the relationship between race and mistrust. We specified a series of regression models.

In Model 1, we tested for an unadjusted effect of race on mistrust. There was a positive association, indicating that blacks had higher scores on the MMI and therefore higher levels of mistrust ($b = 0.100$, $p < 0.05$).

In Model 2, we added sex, education, age, income and insurance status to test for a change in the race effect. Black race remained a significant predictor of mistrust, controlling for the demographic variables and insurance status ($b = 0.166$, $p < 0.05$).

In Model 3, a binary variable indicating whether the respondent had heard of the Tuskegee study was added. Similar to our findings for the previous model, black race remained an independent predictor of

Table 3. The Relationship among Race, Awareness of Tuskegee and Belief that a Similar Study Could Happen Today (n=378)

	Can Tuskegee Happen Again?		P Value
	No	Yes	
<i>Whites (n=104)</i>			
Unaware of Tuskegee	36.4%	63.6%	<0.02
Aware of Tuskegee	62.2%	37.8%	
<i>Blacks (n=284)</i>			
Unaware of Tuskegee	23.1%	76.9%	<0.05
Aware of Tuskegee	12.9%	87.1%	

mistrust after adjusting for demographic variables and awareness of the study ($b=0.171$, $p<0.05$).

Finally, in Model 4, we computed a Tuskegee Knowledge Summary Score by summing the correct answers to the five Tuskegee study questions. Adjusting for knowledge of the Tuskegee study resulted in a small reduction in the strength of the relationship between black race and mistrust. However, the relationship remained significant ($b=0.164$, $p<0.05$). Overall, the results indicate that black race remained a significant predictor of medical care mistrust controlling for demographic variables, including income and insurance status, as well as awareness and knowledge of the Tuskegee study.

DISCUSSION

The results indicate that there was little difference between black and white respondents in knowledge of the Tuskegee study. Most people were unaware of the Tuskegee study, with only approximately two-fifths of both black and white participants indicating they had heard of it. Among those that were aware of the study, there was limited accurate knowledge of the details, including when it began and ended, the total number of participants, the organizations that conducted the study and how the subjects were infected with syphilis. These findings suggest that misinformation and incomplete information concerning the Tuskegee study are quite prevalent. Moreover, these findings emphasize that Tuskegee is not a central event in the African-American ethos; instead for some, the Tuskegee study represents another example of why the medical system cannot be trusted.

Nearly twice as many black respondents believed that Tuskegee study research investigators infected the study participants with syphilis, and blacks—compared to whites—were much more inclined to believe a study similar to Tuskegee could happen today regardless of initial awareness of the study. These two questions relate more to the issue of trust than the others, which are more fact-based questions about a specific set of historical events. Finally, the results show that black race—but not knowledge of the Tuskegee study—was predictive of medical care mistrust, controlling for demographic variables. While there are not significant race differences in knowledge about the historical events, there are clear racial differences in trust. Put another way, trust varies by race, but it is unlikely that the Tuskegee study is a primary reason for widespread mistrust of medical care among African Americans.

The findings are supportive of the notion that historical and continuing patterns of negative

interactions with the healthcare system are likely more important determinants of medical care mistrust among African Americans than awareness or knowledge of the Tuskegee study.^{5,16} Most likely, African-American mistrust of the medical care stems from a general mistrust of societal institutions. Like a number of other American institutions, healthcare has a long history of mistreatment of African Americans. The experience of discrimination and devaluation faced by African Americans fosters an environment of skepticism and mistrust for large healthcare systems or organizations^{7,17} as well as individual providers.²

The greater level of medical care mistrust experienced by African Americans compared to whites has been implicated in lower levels of patient satisfaction with care, decreased participation in health promotion, lower participation in health research and less willingness to donate blood or cadaveric organs among African Americans.^{1,4,6,18} As long as high levels of mistrust exist among African Americans, there may be continued higher rates of underutilization of healthcare within this population. The Tuskegee study is a form of confirmation of what is already known or speculated about African-American treatment in medical systems. This continued detachment from the medical establishment will complicate efforts to eliminate racial disparities in health.

The study does have several limitations. For instance, the results may not generalize to a national sample. The refusal rate was relatively high, which could affect the generalizability of the findings. Moreover, we do not have data on respondents who refused to participate in the survey. As a result, we do not know if nonparticipation is associated with higher levels of mistrust. In addition, the analyses included only black and white participants; therefore, we cannot be sure how knowledge of the Tuskegee study may be related to medical mistrust

Table 4. Mistrust of Medical Care Regressed on Race, Knowledge of Tuskegee and Demographic Variables

	Model 1	Model 2	Model 3	Model 4
Constant	2.61	2.48	2.44	2.45
Black	0.100*	0.166*	0.171*	0.164*
Female		-0.034	-0.034	-0.031
Education		-0.034	-0.007	-0.011
Age		0.058	0.067	0.062
Income		0.066	0.087	0.080
Medicare		-0.031	-0.024	-0.027
Medicaid		0.016	0.019	0.021
Uninsured		0.043	0.050	0.047
Heard of Tuskegee			-0.092	
Tuskegee Summary				-0.078
R ² (Adj)	0.010	0.017	0.021	0.022

* $p<0.05$

in other minority groups. Although interviewers were trained and monitored, voice inconsistencies by interviewers reading the CDC script may have influenced responses, yet we have no reason to believe there were such inconsistencies. In spite of these limitations, we believe this remains a strong study and advances our understanding of race differences in mistrust of medical care.

The results suggest that it is time that we move beyond Tuskegee as a catch-all for why African Americans mistrust medical care and begin to address the root causes. Moving beyond the focus on the Tuskegee study has implications for increasing African-American participation in timely research studies and health promotion as well as potentially reducing health disparities. Addressing medical mistrust must begin with a process of engagement with African Americans on the part of medical care providers as well as researchers.^{3,4} However, once breached, trust is difficult to re-establish.

Through the implementation of policies that address the concerns over a Tuskegee-like experiment happening again, major strides have been made in insuring protection for participants in research. Moreover, an increasing number of training programs now offer cultural competency training.¹⁹ Many of these improvements may not be fully comprehended among those whom the policies were implemented to protect.^{4,20} These important strides need to be articulated and presented to communities of color to improve the ability of members to advocate for themselves. More importantly, healthcare providers, workers and staff should focus on improving the overall experience of African-American healthcare consumers.

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VOL. 97, NO. 7, JULY 2005