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Exploring the “Legacy” of the Tuskegee Syphilis Study: A Follow-up Study From the Tuskegee Legacy Project

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Abstract

The purpose of this follow-up 2003 3-City Tuskegee Legacy Project (TLP) Study was to validate or refute our prior findings from the 1999–2000 4 City TLP Study, which found no evidence to support the widely acknowledged “legacy” of the Tuskegee Syphilis Study (TSS), ie, that blacks are reluctant to participate in biomedical studies due to their knowledge of the TSS. The TLP Questionnaire was administered in this random-digit-dial telephone survey to a stratified random sample of 1162 black, white, and Puerto Rican Hispanic adults in 3 different US cities. The findings from this current 3-City TLP Study fail to support the widely acknowledged “legacy” of the TSS, as awareness of the TSS was not statistically associated with the willingness to participate in biomedical studies. These findings, being in complete agreement with our previous findings from our 1999–2000 4-City TLP, validate those prior findings.

INTRODUCTION

The infamous Tuskegee Syphilis Study (TSS), conducted by the US Public Health Service (USPHS) from 1932–1972, is widely recognized to have foisted research abuses on 399 African American share-croppers in Macon County, Alabama, who were the subjects of this study on the effects of untreated syphilis in the Negro male.^{1–3} Today there is widespread belief that a major legacy of that unethical research study is a strong reluctance among many African Americans to participate in clinical research studies as a result of the abuses for fear of further abuses.^{4–7} The 1994 National Institutes of Health Guidelines for the Inclusion of Women and Minorities in epidemiologic and clinical studies established the national mandate to include diverse populations in all epidemiologic and clinical studies.⁸ The ultimate goal of mandating

the inclusion of diverse populations in these studies was to set a national agenda to reduce health disparities.⁹

While a considerable amount has been written about the long-lasting effects of the TSS on the black community, most of this work has been from a legal, historical, or ethical perspective.^{10–18} Although several articles have directly examined whether there is any differential participation of blacks or other minorities in biomedical studies from that of whites,^{19–26} only a few early exploratory studies have even probed the possible influence of the “legacy” of the TSS, ie, that blacks are unwilling to participate in biomedical studies due to the influence of the TSS.^{27–29} Our recent publication, based on the first indepth, multicity, direct study into the validity of the “legacy” of the TSS, conducted in 1999–2000 4-City Tuskegee Legacy Project (TLP) Study, found no evidence to support the “legacy” of the TSS as measured 28 years after its termination.³⁰

The overall primary goal of this report from the 2003 3-City TLP Study was to determine if this follow-up second multicity survey, using the same survey instrument in 3 different US cities, replicated our prior findings (from the 1999–2000 4-City TLP Study) on the question, “Does the ‘legacy’ of the Tuskegee Syphilis Study include a measurable effect on the willingness of blacks to participate in biomedical research?,” ie, does awareness of the TSS have a negative effect on the self-reported willingness of blacks to participate as research subjects in biomedical studies? In addition, the impact on Puerto Rican Hispanics was also explored in this study.

MATERIALS & METHODS

Overview

The 3-City TLP was designed to administer the TLP Questionnaire via random-digit-dial telephone interviews to a total of 900 subjects (300 blacks, 300 non-Hispanic whites, and 300 Puerto Rican Hispanics) aged 18 years and older in 3 cities (New York City, New York; Baltimore, Maryland; and San Juan, Puerto Rico). The data-collection phase was conducted in the 4-month period of September–December 2003. This study was approved by the institutional review board of New York University.

The primary research instrument was the TLP Questionnaire, a 60-item instrument that addresses a range of issues related to the recruitment of minorities into biomedical studies. Details on the history, development, and methodological decisions related to the TLP Questionnaire, as well as on the random-digit-dial process used in the administration of that questionnaire, have been described elsewhere.^{3,21–23,30} The awareness question on the TLP Questionnaire was, “Have you ever heard anything about the Tuskegee Syphilis Study?,” with possible responses being yes, no, and don’t know. The TLP Questionnaire contains the Likelihood of Participation (LOP) and the Guinea Pig Fear Factor (GPFF) scales, each of which had been validated as scales via standardized psychometric analysis techniques using data from a prior study.²¹ Each is a 100-point scoring scale, with higher scores indicating higher likelihood of participation (for the LOP scale) or higher fear of participation (for the GPFF scale).

Multistage sampling method was adopted in this study. Multistage sampling is a complex form of cluster sampling. Instead of randomly drawing the subjects from the population, researchers randomly selected subjects from each cluster. First, city and zip code were constructed as clusters, which were considered the first stage. Then, subjects were randomly selected within the city and zip code clusters, which was the second stage.

Statistical Analysis

The analyses included the following:

1. The percentages of 3 ethnicity groups with each demographics, ie, gender, education, and income. The χ^2 test was also obtained to examine relationships between these variables. In addition, the mean age and standard deviations were also obtained for each ethnicity group.
2. Percentage of respondents who were aware of the TSS, ie, those who answered yes to "Have you ever heard of the Tuskegee Syphilis Study?," by race, sex, city, age group, education levels, and income levels in the 3-City TLP Study in 2003. In addition, χ^2 analysis was also performed.
3. Analysis of covariance (ANCOVA) was used to determine whether the LOP or the GPFF scale scores differed across the racial/ethnic groups, adjusting for key demographic variables. The final ANCOVA analyses resulted from a 2-step process. Step 1 consisted of a bivariate analysis of each independent variable (race/ethnicity, age, sex, education, income, and city) by each dependent variable with α set at .05. Step 2 consisted of ANCOVA analysis for the study sample as a whole, with race/ethnicity as the independent variable with the model for any of the 2 dependent variables (GPFF and LOP) including only those covariates that achieved statistical significance in Step 1. The survey analysis procedure analysis was used to account for the multistage sampling techniques used in the random-digit-dial survey. All analyses were performed by SAS version 9.3 (SAS Institute Inc, Cary, North Carolina)

RESULTS

In this study, the TLP Questionnaire was administered to 1162 adults (356 African Americans, 313 Puerto Rican Hispanics, and 493 non-Hispanic whites) in 3 cities: New York City, New York, Baltimore, Maryland, and San Juan, Puerto Rico and with response rates by city, of 44%, 51%, and 52%, respectively. The overall completion rate (number of completed interviews divided by number of initiated interviews) was 82.6%. Table 1 shows the age, sex, education, and income distribution of the 1162 subjects within the 3 racial/ethnic groups.

Table 2 shows the percentage of respondents who answered yes to the awareness question by race/ethnicity, sex, city, age, education level, and income level. The differences in findings were statistically significant within each of these 6 demographic variables. Blacks, males, residents of Baltimore, middle-aged subjects, more-educated subjects, and subjects with higher income were more likely to have heard of the TSS.

Table 3 shows the findings from the adjusted multivariate analyses that were conducted to determine the impact of awareness (Q37b) of the TSS on 2 dependent variables: (1) the likelihood of participation (as measured by the LOP scale), and (2) the degree of fear of participation (as measured by the GPFF scale). These adjusted multivariate analyses were only conducted (Table 3) for blacks and for whites, as too few Puerto Rican Hispanics indicated an awareness of the TSS to include them in these analyses. The analyses by race and by race within city were adjusted for age, sex, education, and income, while the analyses by city were adjusted for race as well as the other 4 potential confounders. When analyzed by race or by city, awareness of the TSS did not have a statistically significant relationship with either the likelihood of participation (as measured by the LOP scale) or the fear of participation (as measured by the GPFF scale). When analyzed by race within city, of the 4 subanalyses between awareness levels of the TSS for LOP, only one (for the whites in Baltimore) was statistically significant ($p = .005$); none of the 4 subanalyses between awareness levels for GPFF were statistically significant. Given the sample size of this study, the above analyses had the

capability of detecting a difference of approximately 0.35 standard deviations, ie, the capability to detect a small- to moderate-effect size.³¹

DISCUSSION

The findings showed no relationship between awareness of the TSS and the self-reported likelihood of participating in biomedical studies among blacks. Of the 8 subanalyses testing the relationship between awareness levels for the LOP scale, only 1 showed a statistically significant relationship and that was for whites in the city of Baltimore. Similarly, all 8 subanalyses of the relationship between awareness levels for the GPFF scale failed to detect a single statistically significant finding. It is likely that the 1 subanalysis with a statistically significant finding (ie, that for whites in Baltimore, awareness of the TSS was associated with the LOP scale) was a spurious finding due to the direction of the finding as well as the high number of analyses conducted.

Our findings from this follow-up 2003 study in 3 different US cities support the findings from our prior 1999–2000 4-City TLP Study. Specifically, we again find that awareness of the TSS, as measured about 3 decades after the termination of that infamous study, was not associated either with a willingness to participate in biomedical research studies, as measured by the LOP scale, or with a wariness, as measured by the GPFF scale, for either blacks or whites.

Our study findings point to the need for sustained, community-based discussions of the major reasons underlying the low levels of participation in biomedical studies by African Americans. Based on our findings, detailed knowledge about the TSS or lingering fears of abuse by contemporary biomedical researchers are not the most plausible explanations. Potential explanations, all subject to verification by community-based focus groups or survey research targeted more sharply to African Americans—who vary in levels of education and income—may fall into the following general categories: lack of concrete knowledge of how biomedical research has benefited African Americans, as well as other groups, in the past; the lack of African Americans in visible leadership roles in biomedical studies; distrust of specific research institutions based upon the latter's historical relationship with their local African American communities; lack of “endorsement” of the proposed research by trusted, grass roots leaders in the community; and lack of time and energy to participate in research studies owing to demanding family or job responsibilities.^{32,33} Any one of these potential explanations, or all taken collectively, could contribute to the ongoing lower participation rates of African Americans in biomedical studies; and, to reiterate, none of these potential explanations appear to be specifically rooted in the TSS. Rather, they may be much more deeply rooted in the contemporary life circumstances of blacks in the United States, which continue to include instances of discrimination and mistreatment. In addition to building mutual trust and respect, clearer and more persuasive explanations by spokesmen for the biomedical research establishment of “how racial minorities will benefit”—in both the short- and long-term—from participating in biomedical research may well constitute our best chance to make progress on this important issue in the years ahead.

Perhaps the most unusual measure of the depth of cultural influence of this “legacy” of the USPHS Syphilis Study at Tuskegee is documented by its appearance as the core theme of a Marvel comic book 7-issue series: *Truth: Red, White and Black*. This series, written in 2003 as a presequel to the overall Captain America series, describes outrageous research abuses in experiments done on a black military unit in order to develop a safe injectable compound that would create a “super-soldier.” Once perfected via a series of unethical experiments on this “research-abused” black military unit, the injectable compound is then used safely to create Captain America, a white super-soldier of comic book fame.³⁴

Two recent studies provide clear evidence that successful recruitment and retention of minorities and women into biomedical studies are achievable goals, given that a realistic plan is used and a genuine effort extended toward this goal.^{35,36} A 2004 study on the enrollment of minorities into the national Women's Health Initiative Study reported that the targeted minority subject recruitment goals had been met and even that recruitment yields for minority groups surpassed those of white women.³⁵ In a 2006 review of 20 US studies that reported enrollment rates by race and ethnicity for more than 70 000 individuals involving a wide range of biomedical studies, only very small differences were observed in the willingness of minorities—mostly blacks and Hispanics—to participate in health research compared to non-Hispanic whites.³⁶

CONCLUSION

As these findings validate our prior findings, we conclude that our surveys in 7 US cities, conducted about 3 decades after the termination of the TSS, provide no support for the widely held belief in the “legacy” of the TSS, ie, that African Americans are more reluctant to participate in biomedical studies than whites due to awareness of the TSS.

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Table 1

Distribution of the 1162 Subjects by Age, Sex, Education, Income Within Ethnic Group for the 3-City Research Subject Study (Unweighted)

Race/Ethnic Group	Mean Age (SD)	% Female	Education Level	Income Level
Blacks ^{1,2} (n = 356)	47.2 (15.5)	67.4%	< High school grad = 18.1%	<\$20,000 = 33.5%
			High school grad or more = 54.0%	\$20 000–\$74 999 = 57.8%
			College grad or more = 28.0%	≥\$75,000 = 8.7%
Whites ^{1,3} (n = 493)	48.4 (17.1)	63.3%	< High school grad = 11.8%	<\$20 000 = 20.8%
			High school grad or more = 42.2%	\$20 000–\$74 999 = 56.5%
			College grad or more = 45.9%	≥\$75,000 = 23.7%
Hispanics ^{2,3} (n = 313)	44.3 (15.8)	68.4%	< High school grad = 21.9%	<\$20 000 = 42.3%
			High school grad or more = 41.2%	\$20 000–\$74 999 = 49.7%
			College gradu or more = 37.0%	≥\$75 000 = 8.0%

Statistically Significant Contrasts:

¹For blacks vs whites contrast: differed on education and income ($p \leq .05$).

²For blacks vs Hispanics contrast: differed on age and education ($p \leq .05$).

³For Hispanics vs whites contrast: differed on age, education and income ($p \leq .05$).

Table 2

Percentage of Respondents Who Were Aware of the Tuskegee Syphilis Study, ie, Those Who Answered Yes to “Have You Ever Heard of the Tuskegee Syphilis Study?,” by Race, Sex, City, Age Group, Education Levels, and Income Levels in the 3-City Tuskegee Legacy Project Study in 2003

Variable	Yes to Awareness Question (n = 466)
Race/ethnicity ^a	
Blacks	56.2%
Whites	38.5%
Puerto Rican Hispanics	24.3%
Sex ^a	
Females	37.6%
Males	44.9%
City ^a	
Baltimore, MD	48.8%
New York City, NY	40.9%
San Juan, PR	21.8%
Age, y ^a	
18–29	28.1%
30–44	42.5%
45–59	46.6%
60–74	38.5%
≥74	32.5%
Education ^a	
< High school grad	25.8%
High school grad	27.2%
Some college	43.3%
College grad	50.3%
Postgrad/prof degree	56.4%
Income ^a	
<\$20 000	26.1%
\$20 000–\$34 999	35.8%
\$35 000–\$49 999	46.7%
\$50 000–\$74 999	51.5%
≥\$74 999	58.8%

^aStatistically significant for recognition probe (χ^2 , $p < 0.05$).

Table 3

Summary of Adjusted Analysis of Covariance Findings on Relationship Between Awareness of the Tuskegee Syphilis Study on Likelihood of Participation Scale and Guinea Pig Fear Factor Scale for Blacks and Whites in Baltimore and New York City in the 3-City Tuskegee Legacy Project Study in 2003

	Awareness and Likelihood of Participation Mean (n)	Guinea Pig Fear Factor Mean (n)
By race ^a		
Blacks	41.75 (355)	59.80 (355)
Whites	42.04 (493)	50.59 (489)
By city ^b		
Baltimore	41.91 (312)	54.54 (311)
New York City	41.60 (513)	54.01 (510)
By race within city ^c		
Baltimore		
Blacks	40.05 (148)	60.90 (148)
Whites	43.60 ^d (164)	48.76 (163)
New York City		
Blacks	42.60 (199)	58.96 (199)
Whites	40.97 (314)	50.84 (311)

^a Adjusted for age, sex, education, income, and city ($p = .05$).

^b Adjusted for race, age, sex, education, and income ($p = .05$).

^c Adjusted for age, sex, education, and income ($p = .05$).

^d The only statistically significant finding in this table was that among whites in Baltimore, those who were aware of the Tuskegee Syphilis Study had a higher mean Likelihood of Participation score than did those who were not aware of the Tuskegee Syphilis Study (50.4 vs 40.5, $p = .005$).