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Is There a Legacy of the U.S. Public Health Syphilis Study at Tuskegee in HIV/AIDS-Related Beliefs Among Heterosexual African Americans and Latinos?

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Is There a Legacy of the U.S. Public Health Syphilis Study at Tuskegee in HIV/AIDS-Related Beliefs Among Heterosexual African Americans and Latinos?

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The Tuskegee Syphilis Study is often cited as a major reason for low research participation rates among racial/ethnic minorities. We use data from a random-digit-dial telephone survey of 510 African Americans and 253 Latinos drawn from low income Los Angeles neighborhoods to investigate associations between knowledge of the study and endorsement of HIV/AIDS conspiracy theories. Results indicate African Americans were significantly more likely than Latinos to endorse HIV/AIDS conspiracy theories and were more aware of the study. Nevertheless, few Americans and Latinos had ever heard of Syphilis Study suggesting that awareness is not a major factor in low participation rates.

Keywords: Tuskegee Syphilis Study, AIDS conspiracy theories, African Americans, Latinos, Health beliefs

INTRODUCTION

Over the last two decades, there has been an ongoing debate on the role that the controversies surrounding the U.S. Public Health Service Tuskegee Study of Untreated Syphilis in the Negro Male has played in HIV/AIDS risk reduction efforts among racial/ethnic minorities, particularly African Americans (Dodor & West, 2011; Mays, 2011; S. B. Thomas & Quinn, 1991). To date, a handful of researchers has explored the possible influence of the legacy of the U.S. Public

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Health Service Syphilis Study at Tuskegee (SST) on African American participation in biomedical research, as measured by both survey questions and focus groups (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Freimuth et al., 2001; Katz et al., 2009; McCallum, Arekere, Green, Katz, & Rivers, 2006). Although each study is unique, there are five general questions that underlie the work (Katz & Warren, 2011).

First, are minorities more reluctant to participate in biomedical research than Whites (Durant, Legedza, Marcantonio, Freeman, & Landon, 2011; C. R. Thomas, Pinto, Roach, & Vaughn, 1994)? Some researchers (Brown & Topcu, 2003; Katz et al., 2006; Katz et al., 2007; Wendler et al., 2006) have not found support for this assumption, though others have (Bates & Harris, 2004; Shavers et al., 2002). For example, Wendler et al. (2006) reported few ethnic/racial differences in research consent rates among more than 70,000 individuals. Also, Katz and colleagues reported no appreciable differences among Blacks, Latinos, and Whites in their willingness to participate in biomedical research (Katz et al., 2006; Katz et al., 2007). Even in an older sample where many respondents were likely to be aware of the SST, older African Americans were no less likely than older Whites to be willing to participate in clinical research (Brown & Topcu, 2003). Indeed, the overwhelming majority of respondents, 73% of older African Americans and 78% of older Whites, indicated they were willing to take part in experimental clinical treatment research should they be diagnosed with cancer. Nevertheless, Shavers, Lynch, and Burmeister (2002) reported differences between African American and White Detroit area residents in their willingness to participate in medical research. In sum, the evidence is somewhat equivocal that African Americans are more unwilling to participate in biomedical research.

A second question is whether general awareness of SST affects African Americans' willingness to participate in biomedical research. Here, a number of studies have found support for this proposition. For example, a study of 179 African American and White residents of the Detroit Metropolitan area observed that general awareness of the SST influenced willingness to participate in biomedical research (Shavers, Lynch, & Burmeister, 2000). Of the 46% of African American and 34% of White respondents who knew of the SST, almost half of African Americans (49%) and 17% of Whites reported that they would not be willing to participate in medical research studies in the future. Similarly, Katz, Kegeles, et al. (2008) found that general awareness of the SST influenced willingness to participate in biomedical research differently among African Americans and Whites. Among those who knew of the SST, surprisingly, half of African Americans and 70% of Whites reported that they were less likely to participate in research as a result of what they had heard of about the SST. In addition, two qualitative studies (Bates & Harris, 2004; Scharff et al., 2010) have reported evidence of a harmful impact of the SST. Bates and Harris (2004) found that African American respondents recruited from the southeastern United States are more suspicious of the medical enterprise and express relative reluctance to participate in biomedical research. However, the authors here concluded that the SST alone was not the only factor creating concern with biomedical research participation. A second qualitative study including 70 African American participants observed that the SST awareness played an influential role in the mistrust of the health care system and, thus, was a barrier to research participation (Scharff, 2010).

Nevertheless, two other studies did not find a harmful impact of SST awareness on the willingness of African Americans to participate in biomedical research. Green et al. (2000) conducted a qualitative study in Alabama with only African American participants observing little SST impact on individual participation in clinical cancer research studies. A second qualitative study with

more than 1,000 respondents in three cities showed no appreciable relationship between SST awareness and the self-reported likelihood of participating in biomedical studies in the future among African Americans (Katz et al., 2009).

Overall, then, the findings here are mixed as well. But a preponderance of studies suggests a possible harmful impact of general SST awareness on the willingness of individuals, both African American and White, to participate in biomedical research.

A third question that arises in the context of the SST studies is whether awareness of the Presidential Apology for the SST has had a beneficial impact in reducing mistrust among African Americans. On May 16, 1997, President Bill Clinton made a public apology to the victims and their family members for the Tuskegee syphilis experiment. To date, there is only one reported study of which we are aware that has investigated the effects of this apology. Katz, Kegeles, et al. (2008) found that awareness of the Presidential Apology influenced African Americans' participation in biomedical research presumably by increasing awareness of the SST. The study, which included 1,133 adults in four U.S. cities, found that 41% of African Americans and 62% of Whites were less likely to join a biomedical study as a result of awareness of the Presidential Apology.

A fourth question underlying previous SST studies is whether there is a difference between racial/ethnic minorities and Whites in awareness of the SST. Several studies have, in fact, observed that racial/ethnic minorities and Whites vary in their general awareness of the SST. For example, Shavers et al. (2002) reported that African Americans (81%) were more likely than Whites (28%) to report having knowledge of the SST. Similarly, Katz et al. (2009) found that 56% of Blacks versus 38% of Whites were aware of the SST. Further, a qualitative study (Bates & Harris, 2004) observed a relative absence of mentions of the SST in focus groups by all other racial groups as compared to African Americans. All of these findings suggest that the SST is more salient for African Americans than for Whites.

Finally, a fifth question in previous SST studies is whether racial/ethnic minorities are more likely than Whites to believe that they will be taken advantage of if they were to participate in biomedical, HIV/AIDS trials, or cancer screenings. The answer here is unequivocally affirmative. In a quantitative study with more than 900 respondents results show that 41.7% of African Americans, compared to 23.4% of Whites, had doubts that their physician would fully explain research participation information (Corbie-Smith, Thomas, & St. George, 2002). The study also found that when compared to Whites, African Americans were more likely to report (a) that someone like them would be used as a guinea pig without their consent (79.2% vs. 51.9%), (b) that physicians often prescribe medication in order to experiment on patients without their consent (62.8% vs. 38.4%), and (c) that their physicians had given them treatment as a part of an experiment without their consent (24.5% vs. 8.3%). Similarly, Shavers and colleagues (2002) found that African Americans (25.2%) were 5 times more likely than Whites (5.2%) to believe that most of the risks of medical research are placed on racial/ethnic minorities. Finally, Katz, Kegeles, et al., (2008) observed that racial/ethnic minorities, particularly African Americans, perceived high levels of risk when participating in cancer screening examinations. Specifically, African Americans were 8.2 times more likely than Whites to report that African Americans would "always" or "most of the time" be taken advantage of when participating in cancer-related biomedical research.

These findings underscore the depth of concerns that African Americans have when contemplating possible participation in biomedical research. Although the SST is often identified as

the cause of this distress, it remains unclear what aspect of the SST experience are influential in creating distrust. In the present study, we investigate in more detail than previous studies the ways in which memories of the SST covary with current concerns and misbeliefs about HIV/AIDS. We anticipate that knowledge of the SST contributes to HIV/AIDS misbeliefs in the African American community and that these effects will be more pronounced among African Americans than Latinos.

METHODS AND MATERIALS

Source of the Data

To recruit the study population, we first created a sampling frame from low-income census tracts in a central part of Los Angeles using telephone exchanges having at least 80% of their numbers located within these tracts. From these, exchanges were selected where average household annual income, based on the U.S. Census block information, was less than $35,000 and 31% to 61% of the population within the exchange area were comprised of African Americans. From the final list of exchanges, a sample of random landline telephone numbers was drawn. Potential household cases were called a maximum of 12 times during day and evening hours at varied days of the week until final disposition.

From each screened household, one eligible respondent was selected using "next nearest birthday" criterion (Salmon & Nichols, 1983). If the eligible respondent was unavailable or refused to be interviewed, the household was considered a refusal. The response rate (interviews/households contacted), depending on whether no-contact cases were used in the denominator, ranged from 42% to 46%; the overall cooperation rate including callbacks (interviews/interviews + refusals + persistent unavailable) was 55%, consistent with surveys of this nature (Burgard, Cochran, & Mays, 2005; Simon, Wold, Cousineau, & Fielding, 2001; National Center for Chronic Disease Prevention and Health Promotion, 2004). Final respondents included African American ($n = 510$) and Latino ($n = 253$) residents between the ages of 18 and 45 years. All respondents were heterosexual by self-report.

Data Collection and Survey Instrument

Structured telephone interviews were conducted by trained African American and Latino women either in English or Spanish. More than 70% of the Latino respondents were interviewed in Spanish, with most indicating they or their families were immigrants from Central America (39% of Latinos interviewed, unweighted $n = 97$) or Mexico (55%, unweighted $n = 138$). All African Americans were interviewed in English. Items in the questionnaire included the following.

Knowledge of SST. Respondents were asked if they had ever heard of the "Tuskegee Syphilis Experiment" or "Tuskegee Syphilis Study." Those who responded in the affirmative were then asked to describe to the interviewer what they knew about the study. Interviewers recorded verbatim the open-ended responses. These were then coded into seven categories.

Level of HIV/AIDS knowledge. Respondents were asked nine true/false questions asked about improbable or impossible HIV transmission routes (by touch, being coughed on, kissing, food sharing, mosquito bites, and toilet contact), the protective properties of two behaviors (choosing lambskin as opposed to latex condoms, douching after sex), and determination of HIV infection in others (by their appearance). These were asked in order to assess the extent to which individuals correctly rejected common misperceptions about HIV transmission. Respondents' answers were summed for total answers correct. For the current sample, Cronbach's reliability coefficient was .80. The median score was seven of nine items correctly answered.

Agreement with HIV/AIDS "conspiracy theory" beliefs. To assess agreement with HIV/AIDS "conspiracy theory" beliefs, participants were also asked to what extent they agreed or disagreed with nine statements using 5-point indices (*totally disagree, disagree somewhat, not sure, agree somewhat, agree totally*). The nine statements were chosen from stories and discussions found starting in the late 1980s and mid-1990s in African American newspapers, radio shows, television shows, and community discussion forums. Those responding that they agreed "somewhat" or "totally" with a statement were considered as endorsing the statement. We counted the number of statements agreed with to estimate the extent to which an individual endorsed HIV/AIDS conspiracy theories. Respondents were grouped into those who agreed with none, one, two or three, or four or more of the nine statements.

Data Analysis

Data were weighted to adjust for selection probability and poststratification for ethnic background. The SAS (SAS Institute Inc., Cary, NC) statistical package was used to conduct data analyses. Univariate comparisons were made using *t* tests and chi-square tests. Using stepwise logistic regression method, we evaluated the independent contributions of ethnic/racial background, age, gender, employment status, income, and marital status, as well as levels of HIV/AIDS knowledge in predicting awareness of the SST. Next, we used stepwise polychotomous regression to examine the independent contributions of ethnic/racial background, levels of HIV/AIDS knowledge, SST awareness, and the other sociodemographic characteristics to levels of agreement with common HIV conspiracy beliefs. Model fit of the regression equations was evaluated by the goodness of fit chi-square. In addition, for final polychotomous model, we conducted a score test for the proportional odds assumption. All equations reported are consistent with model fit. Statistical significance was evaluated at the $p < .05$ level. This study received University of California Los Angeles Institutional Review Board approval.

RESULTS

African Americans respondents, when compared to Latino respondents, were more likely to be female, be older, be unmarried, have higher annual incomes, and possess more accurate knowledge about HIV/AIDS, as measured by the nine-item HIV/AIDS Knowledge test (all *p*s $< .05$; see Table 1).

When asked if they had ever heard of SST, 17.4% of the weighted sample, 95% confidence interval (CI) [14.7%, 20.1%], indicated that they had (see Table 2). Among African

TABLE 1
Description of Participants in the Central Los Angeles County Health Study by Race/Ethnicity

Characteristics	*African American*[a]	*Latino*[b]
Male gender	42.1%	50.3%
M age in years (*SD*)	30.3 (6.8)	27.4 (8.9)
Married	23.0%	39.5%
Employed	62.8%	62.8%
Annual household income		
Less than $10,000	31.3%	51.4%
$10,000 to $19,999	14.5%	34.7%
$20,000 to $29,999	19.8%	8.7%
$30,000 to $39,999	16.1%	4.5%
$40,000 or more	18.3%	0.7%
Interviewed in Spanish	0.0%	71.8%
M AIDS knowledge score (*SD*)[c]	6.8 (1.8)	4.8 (3.1)

Note. All respondents were between 18 and 45 years of age.
[a]$n = 510$. [b]$n = 253$. [c]Scores ranged from zero to nine correct answers.

TABLE 2
Awareness of the U.S. Public Health Syphilis Study at Tuskegee and Accuracy of Knowledge by Racial/Ethnic Background

Awareness of SST	*African American*[a]	*Latino*[b]
Has never heard of SST		
Male	63.3%	94.2%
Female	78.3%	93.0%
Total sample	71.9%	93.6%
Among those who had heard of study		
Describes deliberate infection of research subjects by scientists	9.9%	0.3%
Describes study the purpose of which was to harm Blacks	1.5%	0.0%
Describes an experimental study	1.4%	0.0%
Describes a natural history study	3.8%	0.0%
Reports source of information about study	2.8%	2.4%
Irrelevant response	2.2%	1.1%
Cannot remember any details about it	6..5%	2.7%

Note. Among African Americans, 143 of 510 respondents had heard of the Syphilis Study at Tuskegee (SST); among Latinos, 16 of 253.
[a]$n = 510$. [b]$n = 253$.

Americans, men were significantly more likely than women ($p < .05$) to report having heard about the SST, though the majority of African Americans denied awareness. Few Latinos knew about the SST, and the awareness rate was significantly lower than that seen among African Americans ($p < .05$), however, open-ended descriptions provided by respondents suggest that

few who reported having heard of the study knew about it with any accuracy. Twenty-six percent reported that they did not know any details of the study. Twenty-nine percent reported that scientists had injected Tuskegee participants with syphilis. This was a belief more commonly shared by African Americans. Almost 10% of African American respondents described deliberate infection of research subjects by scientists compared to less than 1% of Latino respondents. Furthermore, only 11% described a study where subjects were followed over time to watch the effects of infection; another 4% described what could be considered an experimental study.

Correlates of SST awareness included being African American, older, and male; knowing more about HIV/AIDS; and reporting higher income levels (see Table 3). Specifically, being African American as opposed to Latino was significantly associated with a 3.28 increase in odds of reporting awareness of the SST.

Agreeing with HIV/AIDS conspiracy theory statements was not uncommon in the sample (see Table 4). Indeed, 53% of the weighted sample, 95% CI [49.4%, 56.5%], indicated agreement with at least one of the nine statements. Approximately one fourth agreed that HIV/AIDS was created in a test tube by scientists. Reflecting, perhaps, the debate over Kemron (Hulton, Levin, & Freedman, 1992) occurring at the time, more than one third of African Americans agreed that a cure for HIV/AIDS existed but that the government would not import it. Almost one fourth of respondents agreed that an AIDS vaccine already exists but is being withheld.

African American men were more likely to report agreement with each HIV/AIDS conspiracy theory statement compared to African American women and Latino men and women. Although 20%, or 1 in 5, of the African American respondents agreed that HIV/AIDS is a plot to destroy the Latino community, only 8% of Latino respondents agreed with this statement.

Reporting awareness of the SST was a positive correlate of agreeing with the HIV/AIDS conspiracy theory statements (see Table 5). Other predictors included being African American, possessing lower levels of HIV/AIDS knowledge, and reporting lower income (Table 5). In particular, reporting awareness of the SST was associated with a 3.29 increase in odds of agreeing with HIV/AIDS conspiracy theories.

TABLE 3
Correlates of Awareness of Syphilis Study at Tuskegee: Results of Stepwise Logistic Regression Analyses

Correlates	*Final Adjusted Odds Ratio*	*95% Confidence Interval*	*p**
Ethnic background (African American)	3.28	[1.94, 5.57]	.001
Age (older)	1.07	[1.04, 1.10]	.001
AIDS knowledge (greater)	1.18	[1.06, 1.30]	.001
Gender (male)	1.79	[1.18, 2.72]	.002
Income (higher)	1.19	[1.02, 1.38]	.024

Note. The goodness-of-fit chi-square test for the final stepwise logistic regression model was 570.97 ($df = 711, p = 1.00$).

* p value of the improvement chi-square at each step.

TABLE 4
Percentage Agreeing With HIV/AIDS "Conspiracy" Theory Statements by Race/Ethnicity and Gender

	African American		*Latinos*	
	Male[a]	*Female*[b]	*Male*[a]	*Female*[b]
% agreeing with statement[c]				
AIDS was created by scientists in a test tube	32.1%	24.7%	20.9%	24.5%
AIDS was spread in Africa by scientists doing research	32.2%	22.3%	13.9%	14.6%
An AIDS cure exists but government will not import it	38.7%	30.7%	15.6%	13.5%
A vaccine exists that is being withheld	33.8%	26.4%	20.3%	15.5%
AIDS is a plot to destroy the Black community	34.2%	21.1%	7.2%	9.3%
AIDS is a plot to destroy the Latino community	25.8%	16.4%	8.1%	7.9%
AIDS was created to get rid of Blacks	32.6%	21.1%	10.3%	12.4%
AIDS was created to get rid of Latinos	23.0%	15.5%	8.1%	7.6%
AIDS was created to get rid of the poor	18.6%	15..8%	4..7%	4.2%
No. of statements agreed with				
None	32.0%	41.9%	58.5%	54.6%
One	17.2%	19.2%	22.6%	17.2%
Two or three	18.7%	17.4%	7.5%	21.1%
Four or more	32.1%	21.5%	11.4%	7.0%

Note. Weighted percentages are shown.
[a]$n = 208$. [b]$n = 302$. [c]Those agreeing "somewhat" or" totally" with the statement.

TABLE 5
Correlates of Agreement With HIV/AIDS "Conspiracy" Theories: Results of Stepwise Polychotomous Logistic Regression Analyses

Correlates	*Adjusted Odds Ratio*	*95% Confidence Interval*	p^*
Study at Tuskegee Awareness (yes)	3.29	[2.28, 4.76]	.001
Ethnic background (African American)	2.63	[1.91, 3.63]	.001
HIV/AIDS knowledge (greater)	0.92	[.85, .97]	.002
Income (higher)	0.89	[.80, 1.00]	.04

Note. Goodness-of-fit chi-square test for the final stepwise polychotomous logistic regression model was 1786.19 ($df = 2180, p = 1.00$). The Score chi-square test for proportional odds assumption was 6.83 ($df = 8, p = .55$).
*p value of the improvement chi-square at each step.

DISCUSSION

Results of this study raise questions about the extent to which the actual SST operates in the participation behavior of African Americans in HIV/AIDS clinical trials, prevention, and intervention efforts. Results of our study suggest a focus on other factors, particularly low levels of knowledge about HIV/AIDS and what symbolically is represented by the SST, as a method for increasing HIV/AIDS research participation. This is particularly true for African American men. One area for further research is the concern expressed by African Americans of being treated like guinea pigs in HIV/AIDS clinical trials and being taken advantage of in cancer screenings and

during medical care that is noted in other studies (Corbie-Smith et al., 2002; Katz, Wang, et al., 2008; Shavers et al., 2002).

Results also underscore that SST is less relevant as a driver of the lack of participation by Latinos. At the time that these data were collected, revelations about the syphilis study at Guatemala were not known. As Reverby (2012) in this issue points out, it remains to be seen whether Latinos in learning about the syphilis study conducted by the U.S. Public Health Service in Guatemala will have it affect their level of mistrust and participation in health research. Cacari Stone and Avila (2012) in this issue offer some insight into the importance of classification status as a potential factor in differences in attitudes about health research in the era of the Affordable Care Act. Individuals who are undocumented while able to participate in health-related research that may yield insights into solutions to health disparities will not be eligible in many states to be covered for medical care except in emergencies under the Affordable Care Act. Differences in classification status of Latino subpopulations may be a factor in the extent to which the U.S. Public Health Service syphilis study at Guatemala influences attitudes about participation in HIV/AIDS and other health-related clinical trials, intervention, and prevention research. To the best of our knowledge this is one of the few studies that examined the association between actual knowledge of the facts of the SST and knowledge of HIV. Overall, our findings further support prior findings (Katz et al., 2009; Shavers et al., 2002) that, despite the egregiousness of the SST, the reasons for low participation rates by African Americans, especially African American men, are far more complicated than merely looking to SST for an explanation. It is important that we move beyond blaming the SST when research studies fail at enrolling significant numbers of African Americans, particularly African American men (Mays, 2011). A number of areas of potential fruitful examination for solutions to the low participation rates include (a) culturally competent research training for investigators, particularly non-African Americans (Mays, 2011, 2012); (b) development of an African American bioethics perspective to guide non–African American researchers (Mays, 2012); and (c) research training in how to incorporate racial/ethnic culture into study designs to ensure relevance of research to African American populations. It is important that the National Institutes of Health and others fulfill the promises of President Clinton's 1997 Apology to train biomedical researchers to ensure that what happened at Tuskegee never happens again.

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