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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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Abstract

Knowledge of the US Public Health Syphilis Study at Tuskegee is sometime cited as a principal reason for the relatively low participation rates seen among racial/ethnic minorities, particularly African Americans, in biomedical research. However, only a few studies have actually explored this possibility. We use data from a random digit dial telephone survey of 510 African-Americans and 253 Latinos, age 18 to 45 years, to investigate associations between knowledge of the USPHS Syphilis Study at Tuskegee and endorsement of HIV/AIDS conspiracy theories. All respondents were drawn from an area of low-income, predominantly race-segregated inner city households in Los Angeles. Results indicate that African Americans were significantly more likely than Latinos to endorse HIV/AIDS conspiracy theories. Further, African Americans were more aware of the USPHS Syphilis Study at Tuskegee (SST). Nevertheless, 72% of African Americans and 94% of Latinos reported that they have never heard of the Syphilis Study at Tuskegee. Further, while awareness of the Syphilis Study at Tuskegee was a significant predictor of endorsing HIV/AIDS conspiracy theories, results suggest that other factors may be more important in accounting for low biomedical and behavioral study participation rates.

Introduction

Over the last two decades, there has been an ongoing debate on the role that the controversies surrounding the U.S. Public Health Study of Untreated Syphilis in Negro Men has played in HIV/AIDS risk reduction efforts among racial/ethnic minorities, particularly African Americans (Thomas & Quinn, 1991; Mays, 2011, Dodor & West, 2011). To date, a handful of researchers have explored the possible influence of the legacy of the U.S. Public Health Service Syphilis Study at Tuskegee (SST) on African American participation in biomedical research, as measured by both survey questions and focus groups (Freimuth et al., 2001; Corbie-Smith et al., 1999; McCallum et al., 2006; Katz et al., 2009). Although

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each study is unique, there are five general questions that underlie the work (Katz et al., 2011).

First, are minorities more reluctant to participate in biomedical research than Whites (Thomas et al., 1994; Durant et al., 2011)? Some researchers (Brown & Topcu, 2003; Katz et al., 2006, Katz et al, 2007, Wendle, 2006) have not found support for this assumption, though others have (Bates & Harris, 2004; Shavers, 2002). For example, Wendler, Kington, Madans et al. (2005) reported few ethnic/racial differences in research consent rates among over 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, Shaverset al. (2002) has reported differences between African American and White Detroit area residents in 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 Syphilis Study at Tuskegee influenced willingness to participate in biomedical research (Shavers et al., 2000). Of the 46% of African American and 34% of White respondents who knew of 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 et al., 2008 found that general awareness of the Syphilis Study at Tuskegee influenced willingness to participate in biomedical research differently among African Americans and Whites. Among those who knew of the Syphilis Study at Tuskegee, 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 2010) have reported evidence of a harmful impact of SST. Bates and Harris (2004) found that African American respondent 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 of 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 over 1,000 respondents in 3 cities, showed no appreciable relationship between the 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 USPHS Syphilis Study at Tuskegee 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 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 4 US 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 USPHS Syphilis Study at Tuskegee. Several studies have, in fact, observed that racial/ethnic minorities and Whites vary in their general awareness of the Syphilis Study at Tuskegee. For example, Shavers et al. (2002) reported that African American (81%) were more likely than Whites (28%) to report having knowledge of the SST. Similarly, Katz et al. (2009) found that 56% of Blacks vs. 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 1) that someone like them would be used as a guinea pig without their consent (79.2% vs. 51.9%), 2) that physicians often prescribe medication in order to experiment on patients without their consent (62.8% vs. 38.4%), and 3) 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 were five times more likely to (25.2%) as compare to Whites (5.2%) to believe that most of the risks of medical research are placed on racial/ethnic minorities. Finally, Katz and colleagues (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 Syphilis Study at Tuskegee 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.

Materials and Methods

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 was 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, 2008). 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 or not 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. Over 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:

Knowledge of Syphilis Study at Tuskegee—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 7 categories described below.

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, through 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 7 of 9 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 9 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 80's and mid 90's 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 post-stratification 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 Π^2 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 Syphilis Study at Tuskegee. 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 &P;^{2}. 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 $p < 0.05$ level. This study received UCLA IRB approval.

Results

African-Americans respondents, when compared to Latino respondents, were more likely to be female, older, unmarried, to have higher annual incomes, and to possess more accurate knowledge about HIV/AIDS, as measured by the 9-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% CI: 14.7%–20.1%) indicated that they had (see Table 2). Among African Americans, men were significantly more likely than women ($p < 0.05$) 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 ($p < 0.05$), 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, 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 Syphilis Study at Tuskegee.

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 quarter agreed that

HIV/AIDS was created in a test tube by scientists. Reflecting, perhaps, the debate over Kemron (Hulton et al., 1992) occurring at the time, more than a third of African-Americans agreed that a cure for HIV/AIDS existed but that the government would not import it. Almost a quarter 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. While 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 Syphilis Study at Tuskegee 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'.

Discussion

Results of this study raise questions about the extent to which the actual Syphilis Study at Tuskegee operates in the participation behavior of African Americans in HIV/AIDS clinical trials, prevention and intervention efforts. Results of our study suggest that a focus on other factors, particularly low levels of knowledge about HIV/AIDS and what symbolically is represented by the Syphilis Study at Tuskegee, 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 American of being treated like guinea pigs in HIV/AIDS clinical trials, being taken advantage of in cancer screenings as well as during medical care noted in other studies (Corbie-Smith, Thomas & St. George, 2002; Katz et al., 2008; Shavers, Lynch & Burmeister, 2002).

Results also underscore that SST is less relevant as a driver of the lack of participation by Latinos. At the time that this data was 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 USPHS in Guatemala will have an effect on 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 which 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 USPHS 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 Syphilis Study at Tuskegee and knowledge of HIV. Overall, our findings further support prior findings (Katz et al., 2009 Shavers, Lynch & Burmeister, 2002 that underscore despite the egregiousness of the Syphilis Study at Tuskegee reasons for low participation rates by African Americans, especially African American men are far more complicated than merely looking to TSS for an explanation. It is important that we move beyond blaming the Syphilis Study at Tuskegee 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: 1)Culturally competent research training for investigators, particularly non-African Americans (Mays, 2011, Mays

2012 this issue); 2) Development of an African American bioethics perspective to guide non-African American researchers (Mays, 2012 this issue) and; 3)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 NIH 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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Table 1

Description of participants in the Central Los Angeles County Health Study by race/ethnicity

Characteristics	African-American (n = 510)	Latino (n=253)
Male gender, %	42.1%	50.3%
Mean age in years (S.D.)	30.3 (6.8)	27.4 (8.9)
Married, %	23.0%	39.5%
Employed, %	62.8%	62.8%
Annual household income, %		
under $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%
Mean AIDS Knowledge Score, (S.D.)[1]	6.8 (1.8)	4.8 (3.1)

Note. All respondents were between 18 and 45 years of age. SD = standard deviation.

[1] Scores ranged from 0 to 9 correct answers.

Table 2

Awareness of the U.S. Public Health Syphilis Study at Tuskegee SST) and accuracy of knowledge by racial/ethnic background

Awareness of TSE	African American (n = 510)	Latino (n = 253)
Has never heard of Tuskegee Study:		
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 whose purpose 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 Tuskegee Syphilis Study; among Latinos, 16 of 253.

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 value*
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 Π^2 test for the final stepwise logistic regression model was 570.97 (df = 711, p = 1.00).

*p value of the improvement Π^2 at each step.

Table 4

Percent agreeing with HIV/AIDS "Conspiracy Theory" statements by race/ethnicity and gender (weighted percents shown)

	African American		***Latinos***	
	Males (n =208)	**Females (n = 302)**	**Males (n =208)**	**Females (n = 302)**
Percent agreeing with statement:[1]				
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%
Number 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%

[1]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 value*
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)	.92	(.85,97)	.002
Income (higher)	.89	(.80,1.00)	.04

Note. Goodness-of-Fit Π^2 test for the final stepwise polychotomous logistic regression model was 1786.19 (df = 2180, p = 1.00). The Score Π^2 test for proportional odds assumption was 6.83 (df = 8, p =0.55).

*p value of the improvement Π^2 at each step.