Willingness of Minorities to Participate in Biomedical Studies: Confirmatory Findings from a Follow-Up Study Using the Tuskegee Legacy Project Questionnaire

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Objectives: The purposes of this analysis were to compare the self-reported willingness of blacks, Puerto-Rican Hispanics and whites to participate as research subjects in biomedical studies, and to determine the reliability of the Tuskegee Legacy Project Questionnaire (TLP).

Methods: The TLP Questionnaire, initially used in a four-city study in 1999–2000, was administered in a follow-up study within a random-digit-dial telephone survey to a stratified random sample of adults in three different U.S. cities: Baltimore, MD; New York City; and San Juan, PR. The questionnaire, a 60-item instrument, contains two validated scales: the Likelihood of Participation (LOP) Scale and the Guinea Pig Fear Factor (GPFF) Scale.

Results: Adjusting for age, sex, education, income and city, the LOP Scale was not statistically significantly different for the racial/ethnic groups (ANCOVA, p=87). The GPFF Scale was statistically significantly higher for blacks and Hispanics as compared to whites (adjusted ANCOVA, p<0.001).

Conclusions: The of the findings from the current three-city study, as well as from our prior four-city study, are remarkably similar and reinforce the conclusion that blacks and Hispanics self-report that, despite having a higher fear of participation, they are just as likely as whites to participate in biomedical research.

Key words: research ■ minorities ■ Tuskegee Syphilis Study ■ race/ethnicity

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INTRODUCTION

The U.S. Public Health Service (USPHS) Syphilis Study at Tuskegee (1932–1972) is arguably the most infamous biomedical research study in U.S. history.[1-5] There is widespread belief that the "legacy" of this unethical research event is that the black community has a greater reluctance to participate in clinical research studies as a result of the abuses foisted on the 399 African-American sharecroppers in Macon County, AL, who were the subjects in this 40-year USPHS study of the effects of untreated syphilis in the Negro male.[6] While a considerable amount has been written about the long-lasting effects of the USPHS Tuskegee Syphilis Study on the black community, most of this work has been from legal, historical, healthcare access or ethical perspectives.[7-20]

Between 1997–2003, the early literature on the issue of willingness of blacks to participate in biomedical studies, as compared to whites, was, understandably and typically dominated by qualitative studies that largely explored the parameters and range of issues to be studied, rather than definitively investigating the issue in depth.[21-28] Only four of those early published studies presented quantified data comparing blacks to whites on willingness to participate in biomedical research, often as related to the USPHS Tuskegee Syphilis Study.[25-28] A recent literature review article on this topic pointed out the limitations in these four early exploratory quantitative studies, e.g., all four were conducted in a single city, three only reported the findings for selected subsamples of their total number of subjects, and three only used a single question on willingness to participate as their

measure of this complex decision.[29] The one study which did report on total sample findings focused only on cancer research participation in elderly subjects and reported no difference in willingness to participate between blacks and whites.[28] Thus, the early literature provides no body of findings which could be generalized broadly. Our recently published large-scale survey on adults in four U.S. cities (Birmingham, AL; Tuskegee, AL; Hartford, CT; and San Antonio, TX), which was the first survey to use the 60-item Tuskegee Legacy Project (TLP) Questionnaire, found that blacks self-reported that they were just as likely as whites to participate in biomedical research despite having a higher fear of participation.[30]

The primary specific aim of this analysis was to compare the self-reported willingness of blacks, Puerto-Rican Hispanics and whites residing in New York City, Baltimore and San Juan to participate as research subjects in biomedical studies, as measured by the Likelihood of Participation (LOP) Scale and the Guinea Pig Fear Factor (GPFF) Scale as components of the TLP Questionnaire. The primary contrast of interest in this study is between blacks and non-Hispanic whites, with a secondary interest in clarifying if these associations generalize to Puerto-Rican Hispanics. An additional aim of this second study to use the TLP Questionnaire was to determine the reliability of both the LOP and GPFF scales of the TLP Questionnaire instrument across similar ethnic/racial groups in differing U.S. cities.

METHODS

Overview

This three-city research subject study was designed to administer the TLP Questionnaire via random-digit-dial (RDD) telephone interviews to a total of 900 subjects (300 blacks, 300 non-Hispanic whites and 300 Puerto-Rican Hispanics) aged ≥18 years in three cities: New York City, Baltimore and San Juan. The choice of

Table 1. Questions from the TLP Questionnaire on willingness to participate, and key questions that formed GPFF and LOP scales in the three-city research subject study

Q16. How likely are you to agree to become a participant in any kind of medical study at the present time?* [responses to Q16: VL SL NQS SUL VUL]

Q17. Would you feel the same no matter who was running the study? I'm going to read you a list of people who might run a study. For instance, how likely would you be to participate in a medical research study if it were run by:

a. your own doctor*
b. a university medical school/hospital*
c. the government*
d. a nonprofit foundation*
e. a tobacco company*
f. a drug company*
g. an insurance company* [responses to Q17a-g: VL SL NQS SUL VUL]

Q18. Each medical research study is different, so people who participate might have to do different things in different studies. How likely are you to participate in a medical study if you had to do the following:

a. give blood*
b. take IV injections*
c. do exercises*
d. be interviewed in person*
e. be interviewed by telephone*
f. have diet limited or restricted*
g. take medicine by mouth*
h. undergo major surgery*
i. undergo minor surgery* [responses to Ql8a-i: VL SL NQS SUL VUL]

LOP Scale comprised of Q16 + Q17a-g + Q18a-i [as marked in italicized boldface above with single asterisk]

Q19. There are lots of things that might make people NOT WANT to participate in medical research studies. How much would the following interfere with your taking part in a medical research study?

i) any fear you have of getting AIDS**
ii) any fear of being a 'guinea pig'**
iii) any fear of results not being private or confidential**
iv) any fear of having to pay for the research treatments**
v) lack of trust in research** [responses to Ql9i-v: totally a great deal some a little not at all]

GPFF Scale comprised of #19i–v [as marked in boldface above with double asterisks]

these three cities was based upon obtaining the desired sample size for the three ethnic/racial groups within the broader parameters set by the goals of the projects within the NYU Oral Cancer RAAHP (Research on Adolescent and Adult Health Promotion) Center, a U54 Oral Health Disparities Research Center funded by the National Institute of Dental Craniofacial Research (NIDCR) at the National Institutes of Health (NIH). The data collection phase was conducted in the four-month period of September to 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, which was slightly modified for this study by the elimination of a few questions that had proved redundant in prior use. The TLP Questionnaire addresses a range of issues related to the recruitment of minorities into biomedical studies. Details on the history and development of the TLP Questionnaire as well as the justifications of the methodologic decisions in the analysis of the TLP Questionnaire have been published elsewhere.[20,34] The TLP Questionnaire contains two identified conceptual domains of interest (the LOP domain and the GPFF domain) which had been validated as scales via standardized psychometric analysis techniques using data from our prior study.[30] As in the first study, these two scales are referred to as the LOP Scale and the GPFF Scale.

The Random-Digit-Dial Process

ORC Macro, a U.S.-based international opinion research corporation, conducted a RDD survey using a computer-assisted telephone interviewing (CATI) system for the data collection. The survey sample for this study was drawn from the total noninstitutionalized adult populations (ages ≥18) residing in telephone-equipped dwelling units in three target cities: New York City, Baltimore and San Juan. The study provided for a disproportionally allocated, stratified, random-digit sample of telephone-equipped residential households in the three targeted cities, which were sampled independently. The telephone survey followed a 10-attempt dialing protocol, in which up to 10 attempts were made unless a final disposition was obtained. Experienced, supervised personnel conducted the interviews using Computers for Marketing Corp.'s CATI software package.

Key Variables from the TLP Questionnaire

Table 1 consists of the key questions from the TLP Questionnaire, which formed the basis for this analysis. It shows both the precise wording of the four key questions and their subparts as well as the elements of those questions that were used to create the LOP Scale and the GPFF Scale. The LOP Scale was comprised of 17 variables contained within questions 16, 17a–g and 18a–i of the TLP Questionnaire, while the GPFF Scale was comprised of five variables, all contained within question 19i–v of the TLP Questionnaire (Table 1). The LOP and the GPFF scales were calculated by summing the response values for the constituent questions where VL = 5, SL = 4, NQS = 3, SUL = 2 and VUL = 1, and then each was converted, proportionally, to a 100-point scoring scale with the top score indicating higher likelihood of participation or higher fear of participation, respectively, for the LOP Scale and GPFF Scale.

The variable of age was calculated from the date of birth variable on the TLP Questionnaire. The level of education and level of income variables were collected in an ordinal listings of nine ascending categories of educational level and of 10 ascending categories of income level. They were then each collapsed into three categories for the demographic table and the multivariate analyses. To acknowledge and account for cultural differences among the cities (i.e., above and beyond simple demographic differences), the variable of "city" was included as a separate covariate in all multivariate analyses.

Table 2. Distribution of the 1,162 subjects by age, sex, education, income within racial/ethnic groups for the three-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% High-school grad/+ = 54.0% College grad/+ = 28.0%	<$20,000 = 33.5% $20–$74,999 = 57.8% ≥$75,000 = 8.7%
Whites[1,3] (n=493)	48.4 (17.1)	63.3%	< High-school grad = 11.8% High-school grad/+ = 42.2% College grad/+ = 45.9%	<$20,000 = 20.8% $20–$74,999 = 56.5% ≥$75,000 = 23.7%
Hispanics[2,3] (n=313)	44.3 (15.8)	68.4%	< High-school grad = 21.9% High-school grad/+ = 41.2% College grad/+ = 37.0%	<$20,000 = 42.3% $20-74,999 = 49.7% ≥$75,000 = 8.0%

Statistically significant contrasts: 1 for Blacks versus Whites contrast: differed on education and income (p≤0.05); 2 for Blacks versus Hispanics contrast: differed on age and education (p≤0.05); 3 for Hispanics versus Whites contrast: differed on age, education and income (p≤0.05)

Statistical Analysis

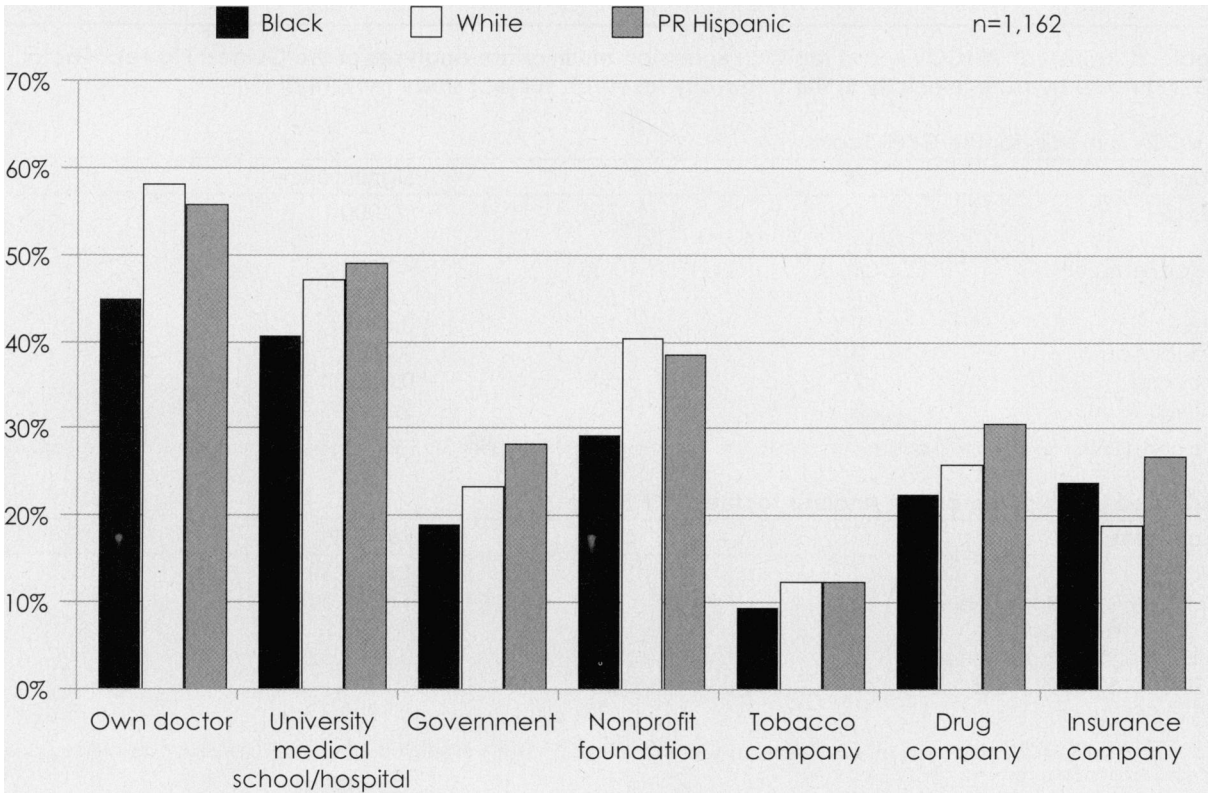
ANCOVA multivariate analyses and logistic regression analyses, which accounted for the multistage sampling techniques used in the RDD survey, were performed. ANCOVA multivariate analysis was used to determine whether the LOP Scale or the GPFF Scale scores differed across the racial/ethnic groups adjusting for key variables. The final ANCOVA multivariate analyses resulted from a two-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 alpha set at 0.05. Step 2 consisted of an ANCOVA multivariate analysis for the study sample as a whole with race/ethnicity as the independent variable with the model for any of the two dependent variables (GPFF and LOP), including only those covariates that achieved statistical significance in Step 1. Finally, for each dependent variable (GPFF and LOP) for which statistically significant findings were observed, pairwise comparisons, using the post hoc Bonferroni criterion, were conducted to explore two-way differences (i.e., blacks versus whites, blacks versus Hispanics and Hispanics versus whites).

Whenever an ANCOVA-adjusted analysis showed a statistically significant difference for LOP or GPFF scales across the racial/ethnic groups, a second step logistic regression analysis was planned to be performed across racial/ethnic groups, and an odds ratio (OR) was calculated to measure of the magnitude of this observed difference. As the LOP and GPFF scales are both continuous variables, a series of correlation analyses seeking the maximum correlation point between the respective scale score and its individual constituent items was used to determine the best dichotomization point for that scale, as required for conducting the logistic regression analysis. As a result of this maximum correlation analysis, the median score was selected as the most appropriate dichotomization cut-off point for the logistic regression analysis.

RESULTS

In this study, the TLP Questionnaire was administered to 1,162 adults (356 African Americans, 313 Puerto-Rican Hispanics and 493 non-Hispanic whites) in three cities: San Juan, Baltimore and New York City, with response rates by city, of 52%, 51% and 44%, respectively. The overall completion rate (# of completed interviews/# of initiated interviews) was 82.6%. The majority of African Americans came from New York City (54.5%) and Baltimore (41.9%), while the majority of Puerto-Rican Hispanics came from San Juan (49.8%) and New York City (47.9%); non-Hispanic whites main-

Figure 1. Percentage willing to participate in biomedical studies dependent upon "who" was running the study for blacks, whites and Puerto-Rican (PR) Hispanics in the three-city research subject study



ly came from New York City (63.7%) and Baltimore (33.3%). Table 2 shows the age, sex, education and income distribution of the 1,162 subjects within the three racial/ethnic groups.

The unadjusted analysis of question 16, a direct general "gestalt-type" inquiry on the subject's overall willingness to participate in biomedical research, revealed no statistically significant differences among blacks, Puerto-Rican Hispanics and whites (28.0%, 31.0% and 33.1%, respectively; p=0.29) regarding the percentage of each racial/ethnic group's willingness to participate (i.e., the combination of the VL + SL responses). These data show that the vast majority of whites (67%) as well as blacks (72%) and Puerto-Rican Hispanics (69%) self-reported that they did not want to participate in biomedical research projects.

Figure 1 shows the unadjusted findings on willingness to participate in biomedical studies based on questions 17a–g, which addressed the influence of who was conducting the study (Q17). The data reveal a large range in percent willing to participate depending upon who was conducting the study, with two "who" categories (your own doctor and university medical school/hospital) at the high end of the rankings with 40–58% willing and one at the low end (tobacco companies) with 10% willing. Blacks indicated they were less willing to participate than whites on six of the seven prompts in question 17 on who was conducting the study. Interestingly, the three racial/ethnic groups, while showing some differences in response to any one "who" probe, exhibited—on the whole—very similar ratings in regards to the relative ranking of who was to be trusted, as can be readily seen in Figure 1.

In parallel fashion, Figure 2 shows the unadjusted findings on willingness to participate in biomedical studies based on the question that addressed the influence of "what one is asked to do in the biomedical study" (questions 18a–i). Again, a large range is exhibited depending upon "what one is asked to do" in biomedical studies and, again, the three racial/ethic groups demonstrate very similar ratings across the nine specific probes (i.e., they appear to more or less travel together "up and down" the scale of willingness to participate). Only in the two "what asked to do" categories involving blood did blacks indicate the lowest willingness to participate (i.e., for giving blood and having an IV).

Unadjusted mean GPFF Scale and LOP Scale scores for each racial/ethnic group are shown in Figure 3. While the mean GPFF Scale scores for blacks (59.8, SD ± 27.9) and for Puerto-Rican Hispanics (60.4, SD ± 26.2) were virtually equal, whites had a lower mean GPFF score (50.6, SD ± 26.8). The two-way contrasts for mean GPFF Scale scores were statistically significantly for both the blacks versus whites, and the Puerto-Rican Hispanics versus whites, contrasts ($p<0.05$). For the LOP Scale, the observed mean LOP scores for blacks, whites and Puerto-Rican Hispanics were 41.8 (± 21.1), 42.0 (± 21.2) and 49.6 (± 20.8), respectively, with no statistically significant difference between blacks and whites, but each of the contrasts between Puerto-Rican

Table 3. Adjusted* ANCOVA and logistic regression multivariate analyses of the Guinea Pig Fear Factor (GPFF) scale by race/ethnicity in the three-city research subject study (n=1,162)

ANCOVA model for the GPFF Scale

Source	df	F	Significance
Model	10	5.75	<0.0001
Race/ethnicity	2	10.53	<0.0001[a]
Age	1	1.61	0.2045
Sex	1	0.18	0.6741
Education	2	2.84	0.0588
Income	2	3.54	0.0293
City	2	1.70	0.1840

a a post hoc test revealed that both blacks and Puerto-Rican Hispanics had higher GPFF Scale scores as compared to whites ($p \leq 0.01$)

Adjusted Logistic Regression Analysis for the GPFF Scale

Variables	OR[a]	95% CI[b]
Blacks[1]	1.65	1.01–2.69
Puerto-Rican Hispanics[1]	2.68	1.58–4.54
≥ College graduate[2]	1.89	0.91–3.91
≥ High-school graduate[2]	1.71	0.86–3.38
$20,000–$74,999/year[3]	0.63	0.41–1.11
>$75,000/year[3]	0.37	0.19–0.71

a OR: odds ratio; b CI: confidence interval Reference groups: 1 Whites; 2 < High-school graduate; 3 <$20,000/year; * adjusted for age, sex, education, income and city

Hispanics and the other two racial/ethnic groups being statistically significant.

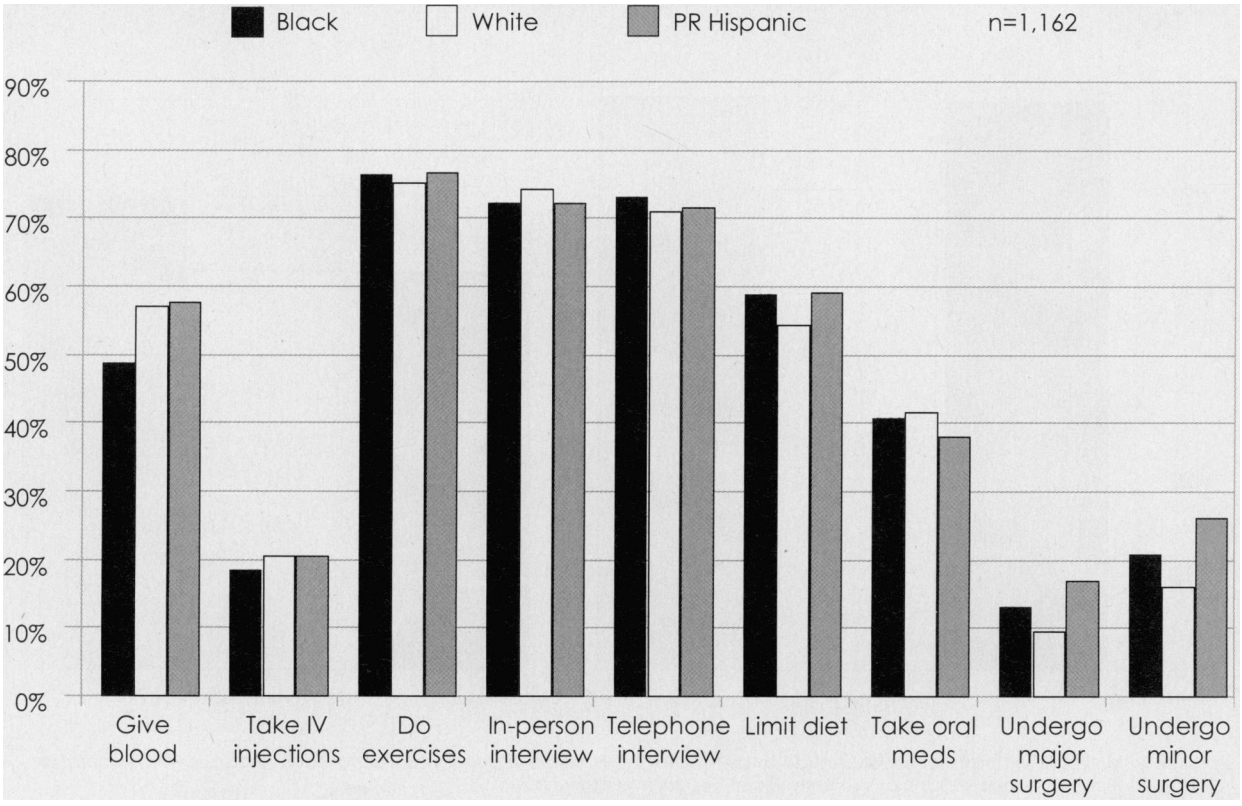
Table 3 shows both the adjusted ANCOVA and logistic regression multivariate analyses for the GPFF Scale using race/ethnicity as the independent variable. The ANCOVA model shown in the top half of Table 3 resulted from a two-step process that adjusted for age, sex, education, income and city. The adjusted results for the GPFF Scale show that the race/ethnic factor was statistically significant ($p<0.001$), as were the variables of education and income. A post hoc test of adjusted GPFF means, using the Bonferroni criterion, revealed that both blacks and Puerto-Rican Hispanics had a significantly higher GPFF Scale score as compared to whites ($P<0.0001$). Conversely, the adjusted results for the LOP Scale across the racial/ethnic groups was not statistically significant ($p=0.87$).

Given that the ANCOVA adjusted analysis showed a statistically significant difference for the GPFF Scale across the racial/ethnic groups, the bottom half of Table 3 shows the logistic regression multivariate analysis for the GPFF Scale adjusted for race, age, sex, education and income. The findings revealed that, controlling for important differences in education and income, the OR of have a GPFF Scale score above the median (indicating more fear) for blacks, as compared to whites was 1.65 (95% CI: 1.01–2.69) and for Puerto-Rican Hispanics, as compared to whites, the odds ratio was 2.65 (95% CI: 1.58–4.54).

DISCUSSION

Taking the findings from these two complex measures (LOP Scale and GPFF Scale) together for this study sample of 1,162 subjects, the final conclusion is that while both blacks and Puerto-Rican Hispanics are more likely to report a higher level of fear related to participation in biomedical studies than are whites, they are nevertheless just as likely as whites to be willing to participate in biomedical research studies, as measured by the LOP Scale. While the three racial/ethnic groups did not differ on the self-reported willingness to participate, Hispanics reported slightly (with borderline significance) higher likelihood of willingness to participate in biomedical research than did blacks. Based on these findings using the LOP, the recruitment of minority subjects for biomedical studies appears to be a fully attainable goal for most types of biomedical studies, in addition to being desirable to ensure diversity in study populations. It should be noted that the findings from this current three-city, follow-up study as presented in this report address the broad issue of willingness to participate in biomedical studies in minority popula-

Figure 2. Percentage willing to participate in biomedical studies dependent upon "what one is asked to do" for blacks, whites and Puerto-Rican (PR) Hispanics in the three-city research subject study



tions, and not do not specifically address the subissue of whether general awareness of or specific knowledge about the Tuskegee Syphilis Study as an separate independent variable had a direct influence on that willingness to participate.

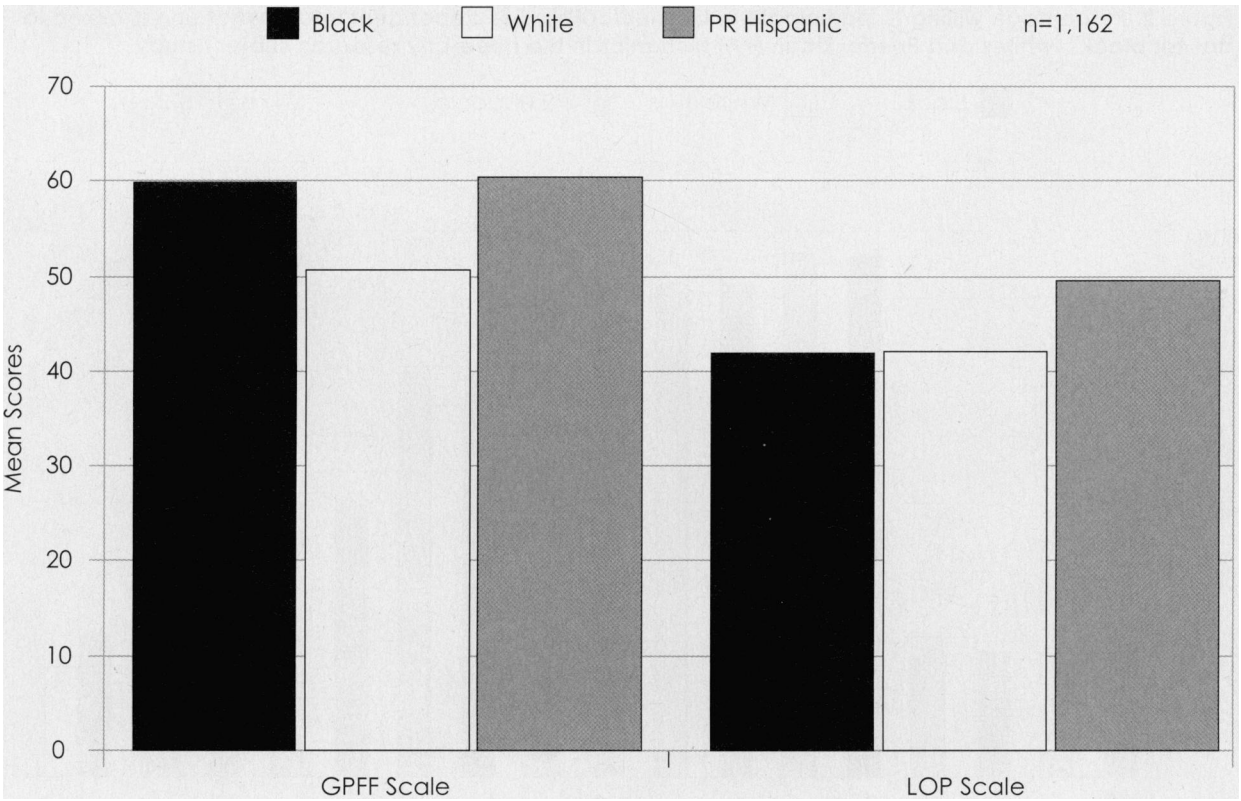
The findings of this three-city research subject study using the TLP Questionnaire agree very closely with the findings of our prior TLP Study, which administered the same TLP Questionnaire to blacks, whites and Hispanics in four other U.S. cities three years earlier (i.e., between 1999–2000).[30] In that prior four-city study, the major findings were extremely similar to those found in this three-city research subject study: 1) <33% of any of the three racial/ethnic groups indicated that they were likely to participate in biomedical studies; 2) there were no statistically significant differences on the LOP Scale among blacks, whites and Hispanics; 3) the mean LOP and GPFF Scale scores for each of the three racial/ethnic groups were nearly identical to those in this current study; and 4) the odds of blacks, as compared to whites, having a higher GPFF Scale score were 1.8 (versus a nearly identical OR of 1.7 in this current study). The findings from this current three-city research subject study also are in very close agreement with the findings from our prior four city study in regards to the pattern of responses shown in Figures 1 and 2 in this report (i.e., the percentage indicating willingness to participate dependent upon "who was conducting the study" and "what one was asked to do in a study" were nearly identical in these two studies).

Given the findings between these two sets of cities, the consistency of the LOP and GPFF scales has been demonstrated across a range of U.S. cities (i.e., two northern cities, one mid-Atlantic city, two southern cities, one southwestern city and one city in Puerto Rico).

The findings of this study on willingness to participate also agrees with those of Brown and Topcu[28] in that neither study found a statistically significant difference between blacks and whites on self-reported willingness to participate as subjects in biomedical studies, even though the Brown and Topcu study was limited to older adults and was only asking about participation in cancer studies. Moreover, our findings on the GPFF Scale are in general agreement with prior studies that did present findings that clearly indicated a higher level of distrust in biomedical research among their black subjects as compared to their white subjects.[26,27,31]

Interestingly, recently published articles which have

Figure 3. Guinea Pig Fear Factor (GPFF) Scale and Likelihood of Participation (LOP) Scale scores for blacks, whites and Puerto-Rican (PR) Hispanics in the three-city research subject study



Statistically significant contrasts for unadjusted data (p≤0.05): for GPFF: blacks versus whites; Puerto-Rican Hispanics versus whites, for LOP: Puerto-Rican Hispanics versus blacks; Puerto-Rican Hispanics versus whites

directly evaluated actual enrollment rates of minorities into biomedical research studies have found that minorities (largely blacks and Hispanics) do enroll, proportionally, in clinical research at expected and targeted rates when a reasonable effort is made to enroll minority participants. A report on the enrollment of minorities into the national Women's Health Initiative Study (WHIS) stated that "the WHI achieved 93% of is targeted minority goal" and noted that "recruitment yields for [black and Hispanic] minority groups surpassed that of white women."[32] A recent review of 20 studies which reported enrollment rates by race and ethnicity for >70,000 individuals involving a wide range of biomedical studies (ranging from interview studies to drug treatment and surgical trials) reported that they "found very small differences in the willingness of minorities, most of whom were blacks and Hispanics in the United States, to participate in health research compared to non-Hispanic whites" and concluded that "racial and ethnic minorities in the United States are as willing as non-Hispanic whites to participate in health research."[33] A recent article has even summated recruitment strategies to enroll minority subjects into studies and succinctly identified barriers to research participation by minorities (and also suggests a comprehensive conceptual model describing how individuals make rational decisions about participation in biomedical research studies).[34]

The TLP Questionnaire was developed to address and understand a wide range of issues related to the recruitment and retention of blacks and other minorities in biomedical research studies. Attainment of this goal is critical in order to ensure that the findings from biomedical studies provide health data on the diverse populations of the United States, and to assist biomedical researchers to achieve compliance with 1994 NIH Guidelines for the Inclusion of Women and Minorities in clinical studies.[35]

CONCLUSION

The findings from this three-city research subject study provides independent evidence that there was: 1) no difference in self-reported willingness to participate in biomedical research, as measured by the LOP Scale in the TLP Questionnaire, among blacks, Puerto-Rican Hispanics and whites; and 2) a statistically significant difference across the three racial/ethnic groups as regards the GPFF, with the odds of having a higher fear of participation in biomedical research being statistically higher in both blacks and Puerto-Rican Hispanics, as compared to whites. In addition, comparison of the finding from this three-city study on both the LOP and GPFF scales with the four-city study conducted three years prior provides strong evidence that there is a consistency of these scales within the TLP Questionnaire over time and across differing U.S. populations.

The combination of these two main findings, from both the current three-city study and the prior four-city study, leads to the conclusion that blacks and Hispanics self-report that despite having a higher fear of participation they are just as likely as whites to participate in biomedical research. These findings, consistent in >2,200 subjects across seven U.S. cities, begin to provide a body of findings that, for the first time, can be generalized to broader U.S. populations. Further, these findings are largely in concert with the few similar early exploratory studies on self-reported participation in the literature, and with the emerging literature that has assessed actual enrollment rates in biomedical studies by race and ethnicity.

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