

Participation in Biomedical Research Studies and Cancer Screenings: Perceptions of Risks to Minorities Compared With Whites



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Background: This analysis was conducted to determine whether there is a difference among blacks, Hispanics, and whites in their perception of risks associated with participating in either a biomedical study or a cancer screening.

Methods: The Tuskegee Legacy Project Questionnaire, which focused on research subject participation, was administered in two different surveys (1999–2000 and 2003) in seven cities. The Cancer Screening Questionnaire was administered in 2003 in three cities.

Results: The study sample across the three surveys consisted of 1,064 blacks, 781 Hispanics, and 1,598 non-Hispanic whites. Response rates ranged from 44% to 70% by city. Logistic regression analyses, adjusted for age, sex, education, income, and city, revealed that blacks and Hispanics each self-reported that minorities, compared with whites, are more likely to be “taken advantage of” in biomedical studies and much less likely to get a “thorough and careful examination” in a cancer screening (odds ratios ranged from 3.6 to 14.2).

Conclusions: Blacks and Hispanics perceive equally high levels of risk for participating in cancer screening examinations and for volunteering to become research subjects in biomedical studies. This perception provides a strong message about the need to overtly address this critical health disparities issue.

Introduction

Two widely espoused but widely different goals within the field of health disparities are (1) to increase the number of minorities who volunteer to participate in biomedical research studies, including clinical trials, and (2) to increase the number of minorities who participate in screening programs that target the early detection of cancer.¹ The first goal will ensure that the new treatments and preventive methods work equally well for minorities, where the burden of health dis-

parities resides, in keeping with the letter as well as the spirit of the 1994 law for the Inclusion of Women and Minorities in biomedical studies.² The second goal is intended to enhance the likelihood of ensuring timely treatment and longer survival for minority persons with cancer, since again minorities disproportionately bear the health disparities burden for this deadly disease.^{3,6}

The well-established literature addressing trust/distrust issues in biomedical research has focused largely on blacks in the United States and has led to the conclusion that blacks, compared with whites, have much lower trust related to biomedical research based on surveys that have directly asked questions about “degree of trust” in their survey instruments.⁷⁻¹⁸ Other surveys that have targeted their questions not directly on the broad issue of trust per se but on the closely related, narrower topics of willingness to participate in biomedical studies and/or on fear of participation in biomedical studies have generally found that blacks reported equal willingness to participate but with higher levels of fear of participation.¹⁹⁻³⁵ More recently, there is a growing body of literature that has identified similar issues of lower trust related to biomedical services within Hispanic communities in the United States.³⁶⁻⁴⁰

While there is clear evidence that minorities have lower cancer screening rates than whites,³⁶⁻³⁸ most of

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Abbreviations used in this paper: TLP = Tuskegee Legacy Project, CSQ = Cancer Screening Questionnaire.

the published articles on factors that affect cancer screening, as reported in two literature reviews, do not assess the influence or impact of “trust” or “fear.”^{41,42} Rather, the literature on barriers that contribute to the underutilization of cancer screening examinations by minorities has postulated that blacks and Hispanics, as well as those with lower levels of formal education, are less likely to have such examinations due to an array of factors, including limited access to medical care, low income, poor knowledge and attitudes toward the screening process, lack of a regular physician, language barriers, cultural beliefs, and competing demands of day-to-day living.^{36,39-49}

A preliminary study by Miller and Hailey⁵⁰ in 1994 found that black women experience higher levels of anxiety compared with white women, and the authors suggested that the psychological barriers related to breast cancer screening for black women differ from those for white women. This line of inquiry into the role of emotion and fear as psychological factors affecting cancer screening behaviors has been reported in a recent series of articles by Consedine et al.⁵¹⁻⁵³ They concluded that the fear factor is one of the key psychological determinants for men related to prostate cancer screening⁵¹ and for women related to breast cancer screening.^{52,53} Echoing these findings, a recent report on factors affecting participation in breast cancer studies in the African American community cited “openness to risk” as a key theme.⁵⁴

Underlying the issue of trust or the concept of fear related to any activity for any individual (or within any population subgroup) is the fundamental perception of risks associated with that activity as held by that individual (or within population subgroups). We posit that this concept may underlie both research participation and the use of health services, specifically cancer screening. This report explores this heretofore unevaluated perspective, ie, that of perceived risk, as it relates to participation in biomedical research or in cancer screenings. The specific aim of this analysis was to determine whether there is a difference among blacks, Hispanics, and non-Hispanic whites in their perception of risks associated with participating in either a biomedical study or a cancer screening.

Methods

Subjects and Participants

Data for this report were obtained by the repeated use of several key questions in three separate random-digit-dial (RDD) telephone surveys conducted using the same survey protocol between 1999 and 2003 in seven cities in the United States. Two of the surveys focused on perception of risk associated with participation as a research subject in biomedical studies, and one survey focused on perception of risk associated with having a cancer screening examination.

Survey Instrument

The Tuskegee Legacy Project (TLP) Questionnaire, a 60-item instrument, addresses a range of issues related to the recruitment of minorities into biomedical studies. It was administered via RDD telephone interviews to respondents aged 18 years and older in two separate surveys. In the 4-City TLP Study, the TLP Questionnaire was administered in 1999–2000 in four city areas: Tuskegee, Alabama; Birmingham, Alabama; Hartford, Connecticut; and San Antonio, Texas. The 3-City TLP Study was administered in 2003 in three different cities: New York, New York; Baltimore, Maryland; and San Juan, Puerto Rico. The latter three cities were also used as the sampling base for the administration of the Cancer Screening Questionnaire (CSQ), a derivative questionnaire based on the TLP Questionnaire that focused on a range of issues related to the participation of minorities in cancer screenings. The CSQ was also administered in 2003 but to a separately drawn RDD sample of respondents in the 3-City CSQ Study. Details on the history and development of the TLP Questionnaire and the CSQ, as well as justifications of the methodologic decisions both for the selection of the cities and for the data analysis, are described elsewhere.^{15,33-35,43} The 4-City TLP Study was approved by the Institutional Review Boards (IRBs) of the University of Connecticut Health Center and New York University, while the 3-City TLP Study and the 3-City CSQ Study were approved by the IRBs of the University of Puerto Rico and New York University.

4-City TLP Study Sampling Design

The RDD interviews for the 4-City TLP Study were administered by the Survey Research Unit of the University of Alabama at Birmingham (UAB). The target population consisted of noninstitutionalized persons aged 18 years or older living in households with working telephones in the four targeted cities. The RDD sample of households in each of the four cities was based on a simple random sampling of telephone numbers using the three-digit telephone exchanges for those local calling areas with partial screening for non-working or business numbers. Thirteen interviewers were trained for the survey, using full computer-assisted telephone interviewing (CATI) technology. Unresolved numbers were retired after 20 attempts. Interviewers were trained in calibration sessions and were supervised at all times and randomly electronically monitored a minimum of four times per month.

3-City CSQ and TLP Study Sampling Designs

The RDD telephone interviews for the 3-City TLP Study and the 3-City CSQ Study were administered by ORC Macro Inc (Burlington, Vermont), a US-based international opinion research corporation, using a CATI system for the data collection. The survey sample for this study was drawn from the total noninstitutionalized

adult populations (ages 18 years and over) residing in telephone-equipped dwelling units in three targeted cities. The study provided for a disproportionately 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, calibrated supervised personnel conducted the interviews using a CATI software package (CfMC Research Software & Service Bureau, San Francisco, California).

Key Survey Questions

The two key questions that form the focus of this paper were repeated on all three surveys. These questions asked respondents about perceived risks associated with participating as a research subject in a biomedical study or about perceived risks associated with participating in a cancer screening examination. These two key questions on the TLP Questionnaire, as used in both the 4-City and the 3-City surveys, asked, “Do you believe that African Americans in the United States are more likely to be ‘taken advantage of’ when they become subjects in a medical research practice compared to whites?” and “Do you believe that Hispanics in the United States are more likely to be ‘taken advantage of’ when they become subjects in a medical research practice compared to whites?” The parallel two questions on the 3-City Cancer Screening Questionnaire asked,

“Do you believe that African Americans (or Hispanics) in the United States are less likely to get a ‘thorough and careful examination’ when they take part in a cancer screening compared to whites?” While the possible responses to each of these questions during questionnaire administration ranged across a 5-point Likert scale (always, most of the time, some of the time, rarely, and never), final analyses used dichotomized responses (always/most of the time vs the other three responses) that had been determined a priori.

The telephone interviewers, regardless of whether they were from the UAB Survey Research Unit (for the 4-City TLP Study) or from ORC Macro Inc (for the 3-City TLP and CSQ Studies), read the same question in the same manner, at the approximate midway point of the questionnaire interview. Moreover, the interviewers in all three surveys read the same choice of possible responses to the respondents: “always,” “most of the time,” “some of the time,” “rarely,” and “never” (as well as “don’t know”). For purposes of analyses, when dichotomization of the answers were used, “always” and “most of the time” were categorized together and compared with the remaining three valid answer choices (“some of the time,” “rarely,” and “never”).

Response Rate Calculations and Statistical Analyses

The reported response rates are the Council of America Survey Research Organization (CASRO) rates (ie, the percentage of completions of residential households dialed). The reported cooperation rates are the per-

Table 1. — Distribution of the 3,443 Subjects by Age, Sex, Education, and Income Within Ethnic Groups for the 4-City Tuskegee Legacy Project (TLP) Study, the 3-City Tuskegee Legacy Project (TLP) Study, and the 3-City Cancer Screening Questionnaire (CSQ) Study

	4-City TLP Study (1999–2000)			3-City TLP Study (2003)			3-City CSQ Study (2003)		
	Blacks (n = 353)	Whites (n = 623)	Hispanics (n = 157)	Blacks (n = 356)	Whites (n = 493)	Hispanics (n = 313)	Blacks (n = 355)	Whites (n = 482)	Hispanics (n = 311)
Mean age ± SD	49.1 ± 16.5	53.8 ± 17.0	41.5 ± 16.1	47.2 ± 15.5	48.4 ± 17.1	44.3 ± 15.8	45.1 ± 16.5	47.5 ± 17.0	44.0 ± 15.9
Female	47.9%	51.7%	60.5%	67.4%	63.3%	68.4%	72.4%	56.8%	69.5%
Education level									
Less than high school graduate	21.6%	11.8%	14.0%	18.1%	11.8%	21.9%	19.9%	10.6%	19.8%
High school graduate	60.5%	51.3%	61.0%	54.0%	42.2%	41.2%	59.1%	44.0%	43.3%
College graduate or greater	17.9%	36.9%	25.0%	28.0%	45.9%	37.0%	21.0%	45.4%	36.9%
Income level									
< \$20,000	42.8%	21.3%	41.7%	33.5%	20.8%	42.3%	41.5%	19.6%	39.2%
\$20,000–\$74,999	52.1%	58.4%	52.5%	57.8%	56.5%	40.7%	49.5%	59.7%	49.8%
≥ \$75,000	5.1%	20.3%	5.8%	8.7%	23.7%	8.0%	9.0%	20.6%	11.0%
Statistically Significant Contrasts* (P < .05) Within Each Study:									
Blacks vs whites	Age, education, income			Education, income			Age, sex, education, income		
Blacks vs Hispanics	Age, sex			Age, education			Education		
Hispanics vs whites	Age, sex, education, income			Age, education, income			Age, sex, education, income		
*Using <i>t</i> tests for parametric data (age) and chi-square tests for nonparametric data (sex, education level, and income level) with adjustment for multiple comparisons using the Tukey post hoc test criterion.									
Total percentages do not equal 100% in all columns due to rounding off of figures.									

centage of completed interviews once contact was made with the targeted household subject. These two rates are the universal standard methods of reporting the response and cooperation rates for RDD surveys.⁵⁵

The frequency distribution of all selected variables was examined first. Recoding of categories followed to assure that the frequency distribution was appropriate for the planned statistical analysis. Then, bivariate logistic regression analysis was conducted to examine the relationship between each independent variable and the dependent variable. Finally, the multivariate logistic regression was conducted with race as the independent variable, adjusting for age, sex, education level, income level, and city. All analyses were conducted using either SPSS v14.0 (SPSS Inc, Chicago Illinois) or SAS v9.0 (SAS Institute Inc, Cary, North Carolina) data analysis software.

Results

Demographic Findings

Of the 3,443 respondents in the three surveys in these seven US cities, 30.9% were black, 22.7% were Hispanic, and 46.4% were non-Hispanic white. The 4-City TLP Study, conducted in 1999–2000, included 1,133 respondents with response rates of 70%, 65%, 50%, and 49% across the four cities of Birmingham and Tuskegee in Alabama, San Antonio in Texas, and Hartford in Connecticut, respectively. The 3-City TLP Study conducted in 2003 had 1,162 respondents, with response rates of

52% for San Juan, Puerto Rico, 51% for Baltimore, Maryland, and 44% for New York, New York. The 3-City CSQ Study, with 1,148 respondents, had response rates for these same three cities of 58%, 51%, and 45%, respectively. The Hispanic sample in the 4-City TLP Study was a mix of 75% Mexican Americans and 25% Puerto Rican Americans, while in the two 3-City Studies, the Hispanic sample was all of Puerto Rican descent. The cooperation rate (ie, number of completed interviews and number of initiated interviews) for the 4-City TLP Study was over 90% and the cooperation rate for each of the two 3-City Studies was over 82%. Table 1 shows the age, sex, education, and income distribution of the 3,443 subjects by race for each of the three studies.

Survey Findings

Fig 1 shows the unadjusted percentage of black, Hispanic, and white respondents in each of the three surveys who answered “always” or “most of the time” to the question, “Are African Americans more likely to be ‘taken advantage of’ when participating in biomedical research [or ‘less likely to get a thorough examination’ for cancer screenings] than whites?” When asked about being “taken advantage of” when participating in biomedical studies, blacks in the 4-City TLP Study were 8.2 times as likely as whites to say that blacks would “always” or “most of the time” be taken advantage of and 4.3 times as likely in the 3-City TLP Study, while His-

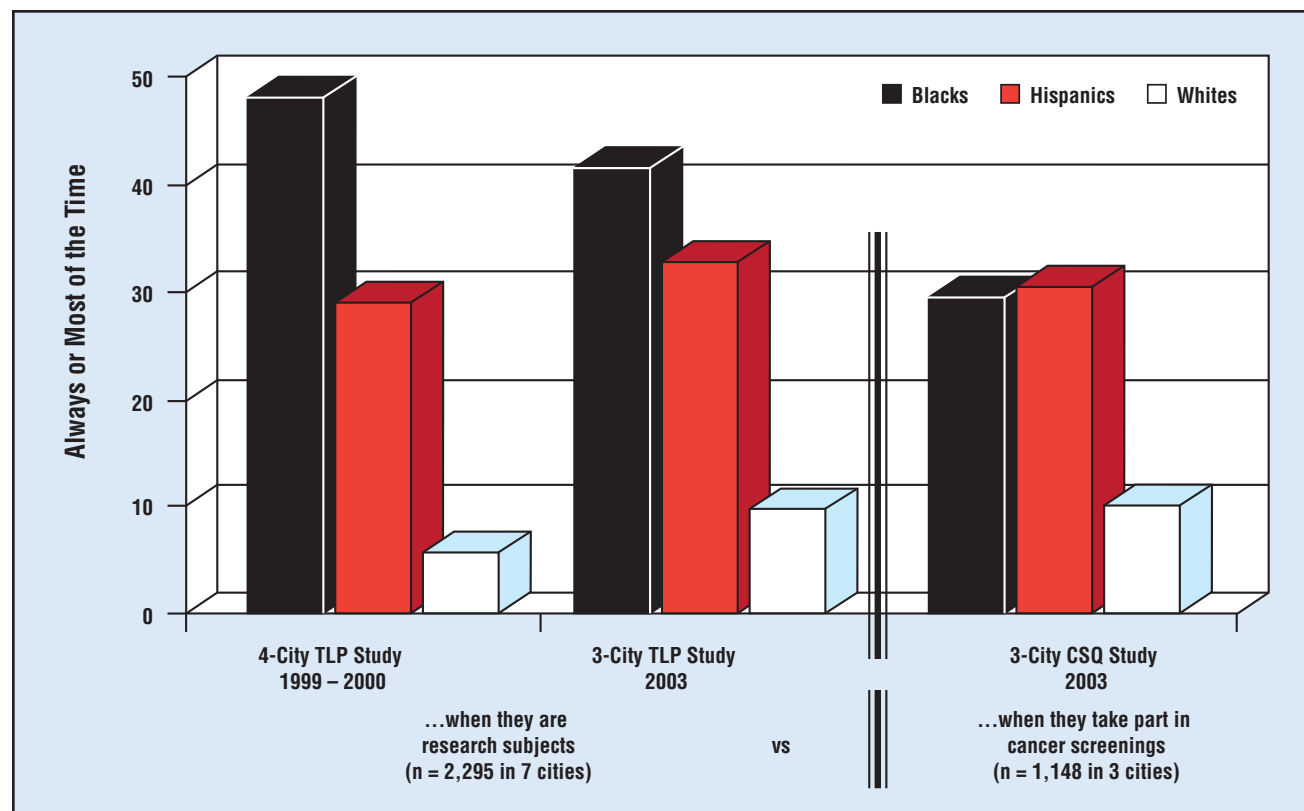


Fig 1. — “Always” and “most of the time” responses to question whether blacks in the United States are more likely to be “taken advantage of” in research studies or “less likely to get a thorough examination” in a cancer screening, compared with whites, based on unadjusted data from three separate studies.

panics were 5.0 and 3.4 as likely as whites to say that African Americans would be taken advantage of “always” or “most of the time,” respectively, in the two surveys. When asked about having a cancer screening, blacks and Hispanics were equally likely to state that African Americans would have a less thorough examination “always” or “most of the time” compared with whites (2.9 and 3.0 times as likely, respectively).

Fig 2 shows the unadjusted percentage of black, Hispanic, and white respondents who answered “always” or “most of the time” to the question, “Are Hispanics more likely to be ‘taken advantage of’ when participating in biomedical research participation [or ‘less likely to get a thorough examination’ for cancer screenings] than whites?” in each of the three surveys. Regarding being “taken advantage of” when participating in biomedical studies, both blacks and Hispanics were more likely than whites to say that Hispanics would “always” or “most of the time” be “taken advantage of” (9.4 and 6.8 times as likely in the 4-City TLP Study and 3.5 and 3.8 times as likely in the 3-City TLP Study, respectively). Regarding having a cancer screening, blacks and Hispanics were equally as likely to say that Hispanics would have a less thorough examination “always” or “most of the time” compared with whites (3.4 and 3.6 times as likely, respectively).

Multivariate analysis results for the racial/ethnic contrasts for two perceived risks questions for each of

the three surveys are shown in Table 2. Overall, chi-square analyses, adjusted for age, sex, education level, income level, and city, revealed that blacks, Hispanics, and whites in a 3-way comparison had statistically significant different response patterns of answering “always” or “most of the time” ($P < .0001$) for both questions. Table 2 shows the odds ratios (ORs) and 95% confidence intervals (CIs) for each specific question for the two-way racial/ethnic contrasts in each of the three surveys, calculated using adjusted logistic regression analyses. When minorities are compared with whites, the ORs range from 3.6 to 14.2 with accompanying CIs that always exclude the value of 1.0, ie, they are all statistically significant. Conversely, when blacks are compared with Hispanics, the ORs range from 0.6 to 1.7 with accompanying CIs that never exclude unity, ie, none of them are statistically significant.

The statistically significant findings from Table 2 are presented graphically in Fig 3 (all ORs were statistically significant except those for the two-way comparisons between blacks and Hispanics). Fig 3 shows the consistency of the OR findings that blacks and Hispanics each believe that minorities, compared with whites, are much more likely to be “taken advantage of” in biomedical studies and much less likely to get a “thorough and careful examination” in a cancer screening across the two key questions (Q31 and Q32) within each of the three studies.

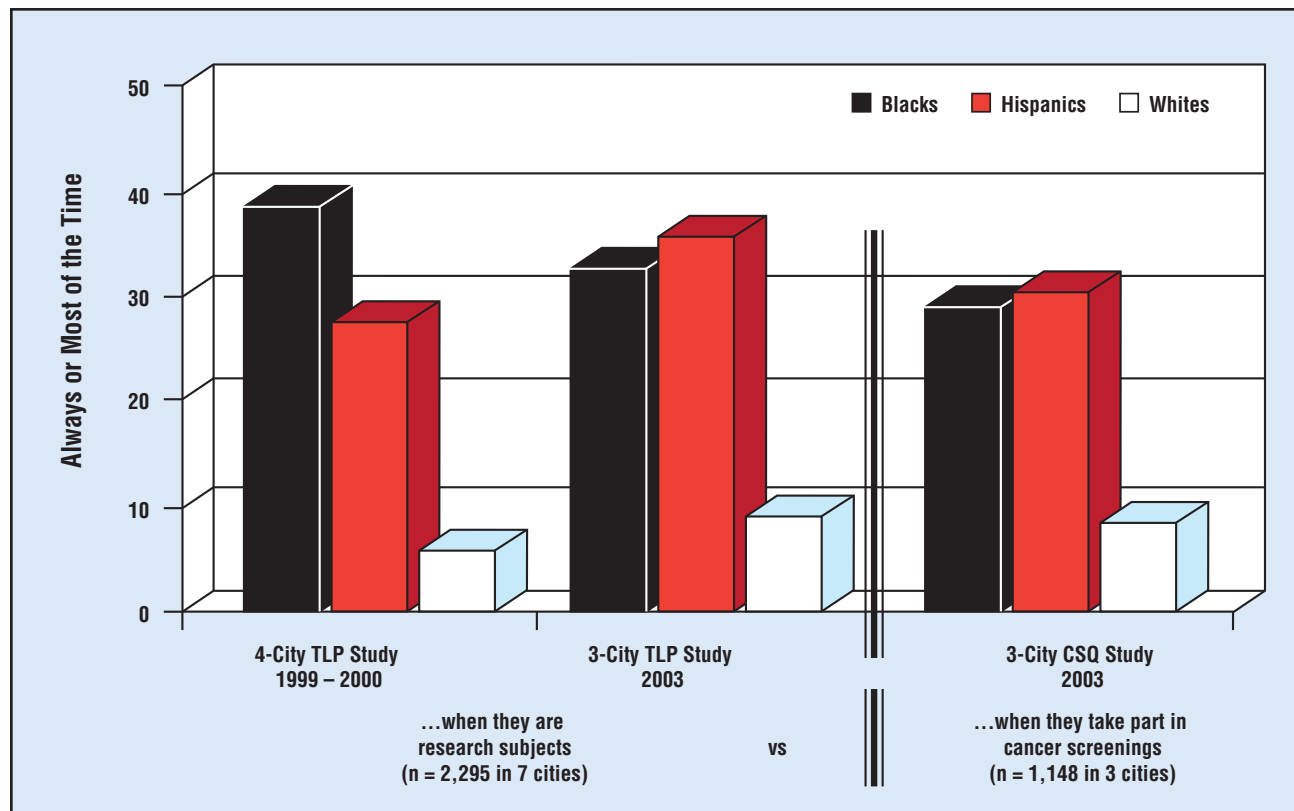


Fig 2. — “Always” and “most of the time” responses to question whether Hispanics in the United States are more likely to be “taken advantage of” in research studies or “less likely to get a thorough examination” in a cancer screening, compared with whites, based on unadjusted data from three separate studies.

Discussion

These data show overall similarities in both the direction and magnitude of the differences in “perceived risk” for both the blacks and Hispanics, compared with the perception of whites, as related to participation in

both biomedical studies and cancer screenings. In addition, within the studies that focused on perceived risks of participating in biomedical research (ie, the 1999–2000 4-City TLP Study and the 3-City TLP Study 2003), the difference in perceived risks between each minori-

Table 2. — Summary of Adjusted* Logistic Regression Analysis of Q31-32 for the 4-City Tuskegee Legacy Project (TLP) Study (1999–2000), the 3-City TLP Study (2003) and the 3-City Cancer Screening Questionnaire (CSQ) Study (2003)

Racial/Ethnic Contrasts	Q31: Are blacks more likely to be “taken advantage of” than whites ... when becoming subjects in a biomedical study?		Are blacks less likely to get a thorough examination than whites ... when participating in a cancer screening?	
	4-City TLP Study (1999–2000) OR (95% CI)	3-City TLP Study (2003) OR (95% CI)	3-City CSQ Study (2003) OR (95% CI)	
Blacks vs Whites ^a	14.2 (8.9–22.6)	5.6 (2.9–10.9)	4.1 (2.1–8.1)	
Hispanics vs Whites ^a	7.3 (3.2–16.6)	3.9 (1.5–10.5)	3.6 (1.7–7.9)	
Blacks vs Hispanics ^b	1.7 (0.8–3.4)	1.2 (0.6–2.6)	1.1 (0.5–2.4)	

Racial/Ethnic Contrasts	Q32: Are Hispanics more likely to be “taken advantage of” than whites ... when becoming subjects in a biomedical study?		Are Hispanics less likely to get a thorough examination than whites ... when participating in a cancer screening?	
	4-City TLP Study (1999–2000) OR (95% CI)	3-City TLP Study (2003) OR (95% CI)	3-City CSQ Study (2003) OR (95% CI)	
Blacks vs Whites ^a	12.1 (7.2–20.4)	3.9 (2.0–7.7)	3.8 (1.9–7.5)	
Hispanics vs Whites ^a	7.4 (3.1–17.3)	5.5 (2.2–14.1)	4.5 (2.1–9.4)	
Blacks vs Hispanics ^b	1.2 (0.6–2.4)	0.6 (0.3–1.2)	1.0 (0.5–2.1)	

* adjusted for age, sex, education, income, and city
^a referent group: Whites
^b referent group: Hispanics
 All statistically significant findings are in bold type.
 The adjusted 3-way analyses by race/ethnic group for both questions (Q31 and Q32) were statistically significant (χ^2 , $P < .0001$).

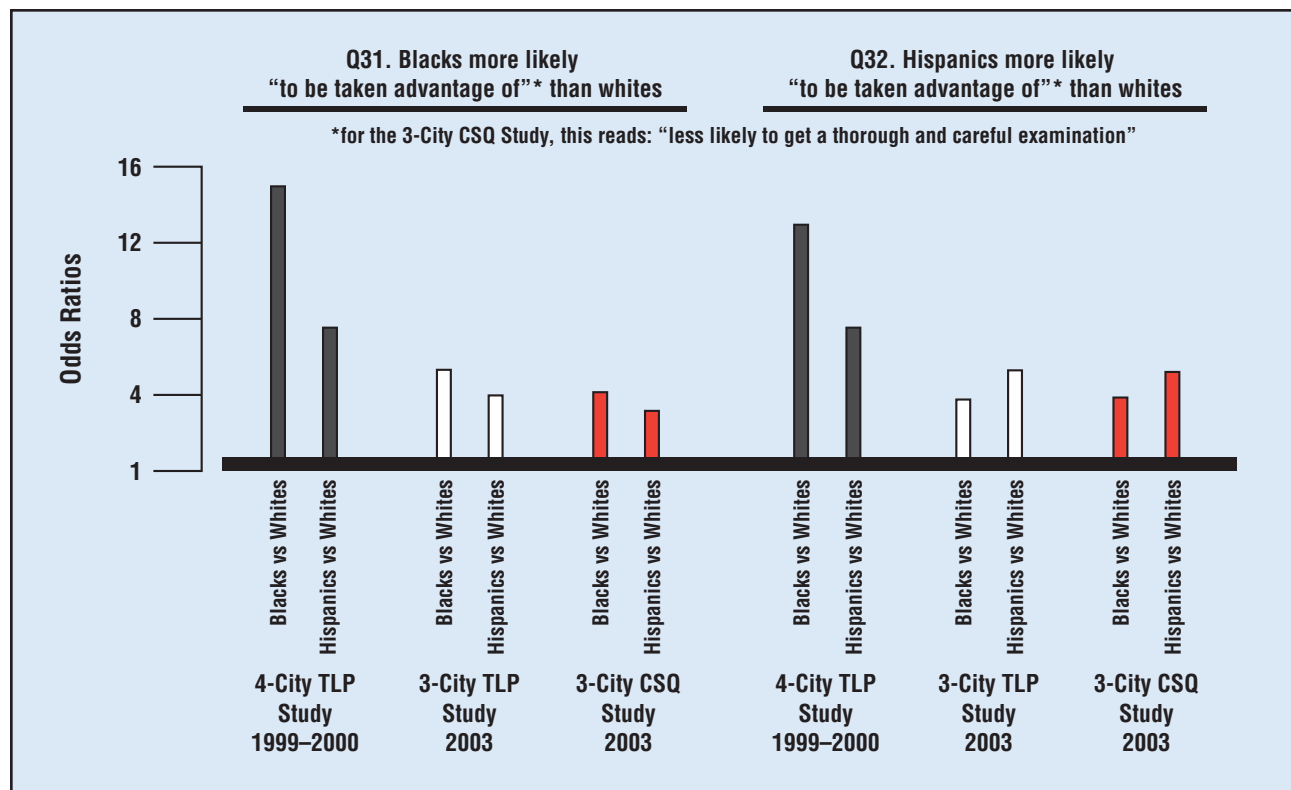


Fig 3. — Statistically significant odds ratios (ORs) for two-way racial/ethnic contrasts for the perceived risks when participating in biomedical research studies and cancer screenings in three separate studies, adjusted for age, sex, education, income, and city.

ty group vs whites was markedly and consistently higher in the earlier study. This observed 2.5-fold lowering in the odds of perceived risks for participating as research subjects for blacks vs whites in the 1999–2000 4-City TLP Study (OR = 14.2) compared with the 2003 3-City TLP Study (OR = 5.6) might be due to the temporal proximity of that 1999–2000 4-City TLP Study to the well-publicized Presidential Apology for the United States Public Health Service Tuskegee Syphilis Study as made by President Clinton in 1997.³⁴ Alternatively, this observation might be due to regional differences in the two study samples, as two-thirds of the blacks in the 4-City TLP Study came from US cities in the deep South (ie, Alabama) whereas the southernmost city in the 3-City TLP Study was Baltimore, in the Middle Atlantic state of Maryland, or might reflect the influence of both of these factors.

This dichotomous minority vs white viewpoint of “perceived risks” regarding these two types of events was most exaggerated in the comparison on research subject participation between the earlier 4-City TLP Study (1999–2000) and the later 3-City TLP Study (2003). Even putting that largest discrepancy aside, the data from the two 2003 studies show that blacks and Hispanics perceive themselves as a group to be a greater risk than whites when they participate as research subjects (ie, 4-fold or greater odds of “being taken advantage of” always or most of the time). Interestingly, this viewpoint is also held regarding participation in cancer screenings (and at the same magnitude of perceived risk, ie, about a 4-fold greater odds for blacks and Hispanics).

These data, specific to perceived risks associated with either participation in cancer screenings or biomedical research, appear to echo the well-known and broader society issue of differing perceptions by blacks and whites on life in the United States.^{16-18,34} The perception of risks of life in the United States appears to be highly dependent on whether one is viewing US life through the prism provided by the perceptions of the black or Hispanic community or the prism provided by perceptions of the white community. One of the most recent well-publicized examples of the existence of these two prisms by which life in the United States is perceived was provided by the worldwide coverage of the O.J. Simpson murder trial. Following the verdict of “not guilty,” the Gallup Poll of October 5–7, 1995, reported that the majority (78%) of the black community agreed with the “not guilty” decision, while a minority (42%) of the white community agreed with that verdict.³⁶ This vast divergence in the expressed opinion of the black community and the white community of the United States as to the correctness of that verdict speaks directly to the widespread use of one or the other of these two prisms of life in the United States. The data from these three surveys reported here on perceived risks associated with participating in can-

cer screenings and biomedical studies demonstrate how deeply these two prisms reflect into other — if not all — aspects of views on life in the United States.

Conclusions

While volunteering to be a subject in a research study inherently and overtly carries clear “risks of participation” for any subject, it is more surprising that this concept of “being taken advantage of” carries over so equally into the arena of standard health care procedures, such as routine cancer screening examinations. The fact that blacks and Hispanics perceive equally high levels of risk for participating in cancer screening examinations as they do for volunteering to become research subjects in biomedical studies provides a strong message to health care providers, organizations, and systems about the need to overtly address this critical health disparities issue. Given that most cancer incidence rates disproportionately affect minorities in the United States and that most cancer mortality rates also disproportionately burden minorities, there is a clear need for all service components of the US health care system to focus on improving their cancer screening actions and cancer screening messages to the minority communities that they serve.

Disclosures

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