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Utilization of Health Care Services and Willingness to Participate in Future Medical Research: The Role of Race and Social Support

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Abstract

Objectives—Utilization of health care services and participation in medical research are 2 distinct yet closely related areas. The goal of this study was to investigate the similarities and differences in factors that are associated with health care service utilization and future participation in medical research, and the influence of race and social support.

Method—We used data from the Greater Pittsburgh Randomized Household Health Survey, which consisted of a weighted sample of 741 white and 277 black respondents from Allegheny County, Pennsylvania.

Results—Logistic regression analyses revealed that utilization of health care services was associated with being younger (OR, 0.98; $p < .001$), being female (OR, 1.55; $p < .05$), high self-rated health (OR poor health, 2.29; OR average health, 2.18; $p < .001$; both in comparison to high self-rated health group) and high perceived quality of health care (OR poor quality, 3.63; OR average quality, 1.79; $p < .001$; both in comparison to high perceived quality group), while future participation in medical research was associated with greater awareness of the Tuskegee Syphilis Study (none OR, 0.07; $p < .01$; only a little OR, 0.13; $p < .01$), more favorable opinions toward medical research (unfavorable OR; $p < .001$; neutral OR, 0.35; $p < .05$), and increased research incentives (free medical care OR, 1.27; $p < .05$; free transportation OR, 1.29; $p < .05$; money OR, 1.25; $p < .05$; free medication OR, 1.50; $p < .001$).

Conclusions—While utilization of health care services and willingness to participate in future research are related, the factors associated with each vary greatly. Implications for health research and policy are discussed.

Keywords

health service utilization; clinical trial; race/ethnicity; Tuskegee Syphilis Study

UTILIZATION OF HEALTH CARE SERVICES AND PARTICIPATION IN MEDICAL RESEARCH TRIALS

Two main factors that perpetuate negative health outcomes and hinder improved health care treatment include, but are not limited to, the lack of utilization of health care services and the lack of medical advancements due to low participation in clinical trials research.¹⁻³ For

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example, research has shown that individuals are less likely to use health care services due to barriers such as socioeconomic status, lack of insurance coverage, and cultural beliefs.^{2,4} Previous studies have also noted that research participants are often hard to recruit and retain in clinical trials. These low numbers may be due to issues of trust and discrimination, complexity of the regimen, randomization procedures, dislike of experimentation, and potential side effects.¹ However, even though these factors are present, positive buffers such as social support may enable individuals to seek medical services and participate in medical research. The relationship between health care service utilization and participation in medical research is critical, as recruitment for clinical research is often done within the health care setting. The goals of this study were to: (1) investigate the underlying factors that are associated with health care service utilization and the factors associated with future participation in medical research, and (2) investigate the influence of race and understand the role of social support in seeking medical care and future participation in medical research.

RACIAL DIFFERENCES

The published literature has identified numerous reasons for racial disparities, including access, insurance coverage, and mistrust of the medical system.⁵⁻⁹ Medical mistrust is an important concept to understand, especially as it relates to health care services and medical research. Historical occurrences of abuse in medical research, as well as personal experiences of discrimination within medical care and society, have been well documented, and have been highlighted as potential sources of medical mistrust. Although medical mistrust exists in multiple domains, for this study, we examined medical mistrust in the domains of seeking personal medical care, and participation in and opinions of medical research on human participants. This investigation also accounted for other factors associated with research participation, including common research incentives.

SOCIAL SUPPORT

Health care utilization and participation in clinical research may also be influenced by information obtained from an individual's social network. Social networks, according to Kahn and Antonucci, provide instrumental, informational, appraisal, and/or emotional supports.¹⁰ Informational support may be the most critical in the understanding of medical mistrust. Where an individual receives information and their trust of information from that source (both formal and informal) may increase the knowledge of how medical mistrust is perpetuated.¹¹ Based on previous research, this study examined the factors associated with utilization of health care services and willingness to participate in future medical research, with a specific focus on the influence of social support. Specifically, we hypothesized that the factors associated with individual use of health care services would differ from those associated with future participation in medical research. We also hypothesized that increased social support would facilitate both seeking health care services and willingness to participate in medical research.

METHOD

For this study, we used data from the Greater Pittsburgh Randomized Household Health Survey. The study was conducted by the Center for Minority Health (CMH) at the University of Pittsburgh, Pennsylvania, via telephone interviews from May to June 2008. The telephone interviews were administered by International Communications Research (ICR), an independent research company and expert in the use of random-digit-dial telephone surveys. ICR employed a disproportionate stratified random-digit-dial design in the study.^{12,13} Eligible respondents were residents of Allegheny County who were aged 18

years and older and self-identified as black or white. Allegheny County encompasses the city of Pittsburgh and the surrounding, less-urban areas. Interviews were conducted with 1018 respondents. The overall response rate for this study was calculated as 32.5%, which is quite favorable and consistent with highly recognized, rigorous random-digit-dial research such as the California Health Interview Survey and the Pew Research Center surveys.¹⁴⁻¹⁶ The study design oversampled for blacks, and sampling weights were used to account for the stratification design and to represent the demographic characteristics (education, gender, age, and race) of Allegheny County. The final weighted sample resulted in 277 (27%) black and 741 (73%) white respondents.

Measures

Details regarding the full wording of all survey items as well as response categories can be found in the Box.

Covariates—Information on age, gender, employment status, and level of education was obtained from all participants. Gender was coded so that 1 = male and 2 = female. Age was treated as a continuous variable. Employment status was assessed through a 1-item measure asking, “Which of the following categories best describes your employment status?” Responses included: 1, employed full-time; 2, employed part-time; 3, a homemaker; 4, a student; 5, temporarily laid off; 6, receiving disability; 7, retired; and 8, unemployed. Responses were recoded so that 1 = employed full-time or part-time, 2 = other. Education was assessed through a 1-item self-report measure asking, “What is the highest degree you have received so far?” Responses were coded so 1 = none through high school diploma, 2 = some college/vocational degree, and 3 = college degree or higher.

Independent variables—Race was assessed by asking, “Do you consider yourself to be white, black or African American, Asian-American, or some other race?” Responses were coded as 1, white and 2, black or African American. Self-rated health was assessed using a 1-item measure stating, “Would you say your health is...” with responses ranging from 5, excellent, to 1, poor. Responses were recoded so that very good/excellent = 3, good = 2, fair/poor = 1. The categories are noted throughout the paper as 3 = good, 2 = average, 1 = poor. Quality of received health care was measured with 1 item, “How do you rate the quality of health care you receive? Do you think it is...” with responses ranging from 5, excellent, to 1, poor. Responses were recoded so that very good/excellent = 3, good = 2, fair/poor = 1. Racial discrimination in the medical setting was measured by 1 item asking “Have you experienced discrimination getting medical care once, 2, or 3 times, 4 or more times, or never?” Responses were recoded and ranged from 0, none, to 3, four or more times. Responses were then dichotomized so that 1 = none and 2 = 1 or more. Trust of information from friends, family, and doctor was assessed by asking: “There are many people, or groups, from whom you might get information about health or health problems. For each one of the following, please indicate how much you, personally, feel you would trust information about health that you got from that source. How about your own doctor; your friends or family; your church or religious leaders?” Each source was presented as a separate item and responses were coded so 1 = probably/definitely would not trust and 2 = probably/definitely would trust for each. Awareness of the Tuskegee Syphilis Study was assessed by asking, “How much have you heard or read about the Tuskegee Syphilis Study?” Responses were coded so the range was 1, none at all, to 4, a great deal. Incentives to participate in medical research were evaluated by asking about 4 specific types of incentives: free medical care, free transportation, \$500, and free medication. Responses to each type of incentive were coded as 1, would not have an effect; 2, less likely; and 3, more likely. Social support was assessed using the Lubben Social Network scale,¹⁷ consisting of 6 items relating to levels of support from both family (3 items) and friends (3 items) (total scale Cronbach’s α = 0.85,

friend Cronbach's $\alpha = 0.83$, family Cronbach's $\alpha = 0.86$). Respondents were asked, "How many relatives do you see or hear from at least once a month?," "How many relatives do you feel at ease with that you can talk about private matters?," and "How many relatives do you feel so close to such that you could call on them for help?" The same questions were asked relating to friends. Response categories for friend support and family support ranged from 0, none, to 5, nine or more. Scores for friend support and family support were calculated by adding scores across the 3 questions in each category. Responses for friend support and family support individually ranged from 0 to 15. Responses for total support were calculated by adding scores from both family and friend support, creating scores ranging from 0 to 30.

Dependent variables—Seeking medical care was measured by asking, "Has there been any time over the past year when you thought you should see a health care provider but did not?" Responses were coded as 1, no, and 2, yes. Participation in medical trials was measured by asking, "In the future, if you were asked to be a subject in a medical research study, do you think that you definitely would, probably would, probably would not, or definitely would not agree to participate?" Responses were coded as 4, definitely would; 3, probably would; 2, probably would not; or 1, definitely would not. Response categories were combined so that 1 = probably and definitely would and 2 = probably and definitely would not. Attitudes toward medical research involving people was measured by asking, "If you were to describe your general attitude towards medical research involving people, would you say that you feel very favorable, somewhat favorable, somewhat unfavorable, very unfavorable—or is this something you feel neither favorable nor unfavorable about?" Responses were coded so that 1 = very/somewhat unfavorable, 2 = neutral, and 3 = very/some-what favorable. The categories throughout the paper are noted as 1, unfavorable; 2, neutral; and 3, favorable.

Analysis

Descriptive analyses were conducted using analysis of variance (ANOVA) and χ^2 tests, and hypotheses were tested using binary and multinomial logistic regression. Multinomial logistic regressions were conducted to observe the factors that were associated with health care utilization and willingness to participate in future medical research. Direct and interaction effects were examined. For all logistic regression models conducted in this study, the odds ratios, confidence intervals, Cox and Snell R^2 statistic, and χ^2 statistics were reported.

RESULTS

Racial Differences in Sample Characteristics

Descriptive information on the various measures is reported in Table 1. ANOVA and χ^2 tests revealed that significant differences existed by race in age (blacks were younger), education (blacks had lower levels of education), reports of discrimination (blacks reported more discrimination), awareness of the Tuskegee Syphilis Study (blacks reported more awareness), social support (blacks had lower levels of support), perceived quality of health care (blacks perceived worse quality), and self-rated health (blacks reported lower self-rated health). Additionally, significant differences existed by race in trust of information from church (blacks reported higher trust), the doctor (blacks reported lower trust), friends (blacks reported lower trust), willingness to participate in future medical research studies (blacks were less likely to participate), attitudes regarding research on human subjects (blacks had more neutral and unfavorable attitudes), and free medicine as a research incentive (blacks perceived it as less of an incentive).

Utilization of Health Care Services

For the binary logistic regressions, models were additive, starting with demographics for the base model (model 1) and then adding variables measuring discrimination, Tuskegee Syphilis Study awareness, self-rated health, and perceived quality of care (model 2), then adding variables measuring trust from doctor, family and friends, and church (model 3) and, finally, social support (model 4). When investigating if there was a time when an individual needed to go to the doctor but did not, lower self-rated health, lower perceived quality of care, being male, and younger age emerged as significant factors associated with higher odds of not going to the doctor when needed (Table 2). In preliminary analyses, it was evident that level of education was not significantly associated with the utilization of health care services; however, employment status was significantly associated. For this reason, education was excluded and employment status was included in the analyses presented in Table 2. Level of education and gender were removed from the analyses presented in Table 3 due to the lack of association with willingness to participate in future medical research (Table 3).

Willingness to Participate in Future Medical Research

When investigating individual willingness to participate in future medical research, model 4, which included all variables of interest, revealed that those with more awareness of the Tuskegee Syphilis Study, greater interest in research incentives of transportation, free medical care, free medications and money, and individuals with more favorable views of research involving people had higher odds of reporting that they would be willing to participate in future medical research (Table 3). Moreover, there was also a significant interaction between race and awareness of the Tuskegee Syphilis Study, revealing that at the same level of awareness, whites are more willing to participate in future research (Figure 1). Preliminary analyses revealed that the demographic variables of education, income, gender, and employment status were found to have no association with willingness to participate in future medical research and were therefore excluded from the models presented. The next section of this investigation contextualizes these results within the current literature.

DISCUSSION

This study examined the underlying factors associated with health care service utilization and the factors associated with future participation in medical research, and the influence of race and social support. This study is important because it investigated the variation in the factors associated with 2 interconnected areas of the health literature with an emphasis on race and social support. While previous studies have investigated the reasons why individuals do not participate in medical research, none, to our knowledge, have investigated these reasons side by side with reasons why individuals may not seek medical care when needed. This study contributes to the literature by uncovering the variation in factors predicting 2 intertwined areas.

While health care service utilization and future participation in medical research are related due to the notion that if individuals are not using medical services, they have a limited chance of even being approached to participate in a clinical trial, the factors associated to each are markedly different. For example, while race did not influence when an individual went to the doctor,¹⁸ it was an important factor when examined in conjunction with medical mistrust. Instead, needed visits to a doctor were predicted by age, gender, self-rated health, and perceived quality of care. Specifically, health care services are more likely accessed by women, older adults as compared to younger adults, and those who perceive their health and quality of care as good. Medical mistrust (also referred to as *distrust in research* by Musa, Schulz, Harris, Silverman, and Thomas¹⁹) is of particular interest because of its subjectivity,

meaning that each individual has their own perceptions of medical research and health care, which may or may not coincide with others' perceptions. Musa and colleagues¹⁹ describe it as a multifaceted concept and note that it may be a product of individual experiences with discrimination, others' reports of discrimination with the health care system, and health information received from informal sources and agencies.¹⁹ Medical mistrust may manifest itself in limited visits to health care professionals and health care institutions for routine, preventive care or even necessary acute care when needed.²⁰ This, in turn, may impact an individual's health and/or perceptions of the quality of health care they receive. Likewise, the inverse may also be true.

Within the historical context, one of the most noted examples of medical abuses is the Tuskegee Syphilis Study, in which black men were denied treatment for syphilis in the name of research.²¹⁻²³ Many studies note that the legacy of the Tuskegee Syphilis Study is still an important element underlying medical mistrust.²⁴⁻²⁶ Personal experiences of discrimination, both inside and outside the medical system, have also been identified as strong reasons for individuals to harbor mistrust in the medical system.²⁷ While we did not find evidence that discrimination experienced in the medical setting was a factor, we did find that lower perceived quality of care was. It may be the case, though not investigated in this study, that lower perceptions of quality of care may be a proxy for indirect discrimination within the medical setting. If quality of care is perceived as being discriminatory, then an individual may not be likely to use services as frequently.²⁸ In the same theme, medical mistrust has also been found to influence blacks' participation in clinical research. Previous studies have noted that blacks were less likely to participate in clinical research.^{5,6,21,29} With blacks also being at a higher risk for disease conditions and discrimination due to outside factors such as socioeconomic status,³⁰⁻³² understanding the link among health care service utilization, future participation in medical research, and race is of critical importance.

The factors associated with seeking medical care are not the same factors that are associated with future participation in medical research. Rather, younger adults, whites with a great deal of awareness of the Tuskegee Syphilis Study, those with more favorable opinions of medical research, and those who are more enticed by research incentives are more willing to participate in future medical research.

Moreover, we hypothesized that there would be an association between social support and our outcomes of seeking medical care and willingness to participate in future medical research. While we did not find significant associations with social support in our models, this null finding may not be the end of the story. Supported by our descriptive analyses, Musa et al noted that blacks "reported significantly more trust than did whites in health information sources like [...] church or religious leaders, reflecting the importance of information from social networks, faith communities [...]" (p. 5).¹⁹ Because social networks are a potential source of health information, it is possible that social relations may also be a channel for medical mistrust and misinformation. Similarly, the level of engagement one has with others may also influence their feelings.³³ It may be the case that individuals who are socially isolated are also excluded from critical medical information, both positive and negative. Previous studies have noted the church as being a source of information and intervention,^{29,34,35} and others have discussed and intervened with the patient-doctor interaction.³⁶

This study, however, did not find direct support for this hypothesis, drawing us to the conclusion that while social support has the potential to buffer against negative outcomes, in the cases of seeking medical care and willingness to participate in future medical research, it simply may be that other factors (eg, research incentives) are more influential. It may be the case that individuals are more driven to participate in research when they feel that they are

receiving something tangible that is of value to them. Likewise, our measurement of social support among participants was limited to a 6-item survey measure, and therefore, future studies may find social support to be influential when using other methods and measures (eg, qualitative probes). To our knowledge, there is little research directly investigating family and friend relationships with participation in medical research. Future studies should begin to investigate the manner in which knowledge is disseminated among closely associated individuals, and the impact that such communication mechanisms have on health-related behaviors and opinions.³⁷ By reaching out to an individual's social support network, there may be greater opportunities for dispelling research myths and discussing past injustices in conjunction with current practices.

Another intriguing finding from this study was that awareness of the Tuskegee Syphilis Study was a significant predictor of participation in future medical research. These results support previous studies that have noted that the Tuskegee study remains influential in individual decision making to participate in clinical trials.^{21,22,38} Again, this finding provides important information for the health care delivery system and medical research community. Efforts are necessary to ensure that patients and research participants are aware of what research means, as well as the ethical implications of the risks and benefits of research participation. This is especially important for blacks, who, with the same awareness of Tuskegee as whites, are less likely to participate in clinical research.

Overall, this study represents an attempt to delineate the complex processes involved with encouraging individuals to take advantage of health care services and participate in research trials. The factors that were associated with someone seeking treatment in a medical setting were different from factors associated with participation in clinical research. The clinical setting is the common thread where individual patients both receive medical care and are recruited as subjects for participation into research studies.

Strengths and Limitations

A notable strength of this study is that it adds to the scientific literature regarding factors that influence health care utilization and future participation in medical research. While this information contributes to the scientific literature, the study has certain limitations that require acknowledgment. First, this is a cross-sectional study, therefore preventing interpretations related to causality. Second, because the study data were obtained from a survey measure, the underlying motivation for certain responses could not be addressed. Future studies regarding mistrust should include qualitative components so that nuanced individual differences can be obtained and assessed. Third, this study did not go into great depth regarding the type of social supports of individuals. While other studies delineate between social support from friends and family, and emotional vs instrumental support, this study employed a gross measure of social support. Future studies should investigate the types, quality, and sources of social support that influence individuals regarding their health. Fourth, this study did not include individual health insurance status. While education and employment status were used as a proxy for socioeconomic status, the type of insurance or level of insurance coverage should be assessed in future studies. Finally, while this study did use age as a covariate, it was an influential variable throughout this investigation. Future studies must address developmental differences in mistrust by investigating how younger and older adults perceive medical research and the health care system.

CONCLUSION

This paper makes a unique contribution to the existing literature because it highlights 2 main points: (1) the characteristics that bring people to medical care professionals are not the same characteristics that determine if people will participate in medical research; and (2)

social support was not a factor in individual usage of health care services nor when recruiting participants into medical research. For public health professionals, this study is useful as it allows for greater understanding of the profiles of those receiving medical care (and those who are not), as well as linking how those seeking medical care are affecting the pool of potential research participants. By understanding who visits health professionals as well as the role of mistrust and incentives, researchers can begin to alter their recruitment styles to be more diverse. Again, if the patients who are in the greatest amount of medical need are not seeking services, they are less likely to be approached to participate in medical research. This, in turn, affects the diversity of trials and outcomes that are generalizable to the minority populations in the greatest need of the very medical advancements made possible through research.

While the profiles of those who seek medical services differ from those who are willing to participate in future clinical medical research, public health research may benefit from seeking out individuals who are willing to participate in research outside of the medical services setting (eg, community), or likewise engaging health professionals through offering recruitment reimbursements.³⁹ This may allow for an introduction (or reintroduction) to health services for individuals who may not seek the services on their own. Likewise, public health professionals are providing services in a manner that will be conducive to the circumstances of the individual and their social network. By reaching out to community members, public health professionals will better understand the needs of their service communities and strengthen/restore the relationship between researcher and the community.

Box

Survey Measures from the Greater Pittsburgh Randomized Household Health Survey40

Construct	Survey Question(s)	Response Set
Covariates and Independent Variables		
Age	How old are you?	
Education	What is the highest degree you have received so far?	<p>Open response</p> <p>01 = GED</p> <p>02 = High school degree or diploma</p> <p>03 = Post high school vocational certificate</p> <p>04 = Some college</p> <p>05 = Bachelors degree</p> <p>06 = Associates degree</p> <p>07 = Postgraduate degree</p> <p>08 = No degree</p> <p>97 = Other</p>
Employment	Which of the following categories best describes your current employment status? Are you...?	<p>1 = Employed full-time</p> <p>2 = Employed part-time</p> <p>3 = Homemaker</p> <p>4 = Student</p> <p>5 = Temporarily laid off</p> <p>6 = Receiving disability</p> <p>7 = Retired</p> <p>8 = Unemployed</p>
Income	Which of the following income groups includes your	<p>01 = \$0 to <\$1000</p> <p>02 = \$1000 to <\$5000</p> <p>03 = \$5000 to <\$10 000</p> <p>04 = \$10 000 to <\$15 000</p> <p>05 = \$15 000 to <\$20 000</p> <p>06 = \$20 000 to <\$30 000</p> <p>07 = \$30 000 to <\$50 000</p> <p>08 = \$50 000 to <\$75 000</p> <p>09 = \$75 000 to <\$100,000</p>

Construct	Survey Question(s)	Response Set
Covariates and Independent Variables		
Age	How old are you? (and only your) total income last year?	Open response 10 = ≥\$100,000
Race	Do you consider yourself to be white, black or African American, Asian American, or some other race?	1 = White 2 = Black or African American 3 = Asian American 97 = Some other race
Social support (Lubben Social Network scale [LSNS-6])	<p>1 How many relatives do you see or hear from at least once a month? Would you say...?</p> <p>2 How many relatives do you feel at ease with that you can talk about private matters? Would you say...?</p> <p>3 How many relatives do you feel close to such that you could call on them for help? Would you say...?</p> <p>4 How many of your friends do you see or hear from at least once a month? Would you say...?</p> <p>5 How many friends do you feel at ease with that you can talk about private matters? Would you say...?</p> <p>6 How many friends do you feel close to such that you could call on them for help? Would you say...?</p>	<p>0 = none</p> <p>1 = 1</p> <p>2 = 2</p> <p>3 = 3 or 4</p> <p>4 = 5-8</p> <p>5 = ≥9</p>
Tuskegee awareness	There have been news stories about a medical experiment among black men in the south that began in the 1930s. It was referred to as the Tuskegee (tus-KEE-gee) Syphilis Study. How much have you heard or read about this—would you say you have heard or read...?	<p>1 = A great deal</p> <p>2 = A moderate amount</p> <p>3 = Only or little, or</p> <p>4 = None at all</p>
Trust in medical research	<p>There are many people, or groups, from whom you might get information about health or health problems. For each one of the following, please indicate how much you, personally, feel you would trust information about health that you got from that source. How about (INSERT)? Would you say you...?</p> <p>Your own doctor</p> <p>d. Your friends or family</p> <p>e. Your church or religious leaders</p>	<p>4 = Definitely would trust</p> <p>3 = Probably would trust</p> <p>2 = Probably would not trust</p> <p>1 = Definitely would not trust</p>
Trust in medical research	If you were to describe your general attitude towards medical research involving people. Would you say that you feel very favorable, somewhat favorable, somewhat unfavorable, or very unfavorable—or is this something you feel neither favorable nor unfavorable about?	<p>5 = Very favorable</p> <p>4 = Somewhat favorable</p> <p>3 = Neither favorable nor unfavorable</p> <p>2 = Somewhat unfavorable</p>

Construct	Survey Question(s)	Response Set
Covariates and Independent Variables		
Age	How old are you?	Open response
Research Participation Incentives	Sometimes different things are offered to encourage people to participate as subjects in medical research. Please indicate whether each of the following would make you more likely or less likely to agree to participate. Would you say (INSERT ITEM) would make you more likely, less likely, or have no effect on your agreeing to participate? a. Free medical care b. Free transportation c. \$500 d. Free medicine	1 = Very unfavorable 3 = More likely 2 = Less Likely 1 = Would have no effect
Discrimination	Have you ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior in any of the following situations because of your race, ethnicity, or color? Have you experienced discrimination getting medical care once, two or three times, four or more times, or never?	1 = Once 2 = 2 or 3 times 3 = ≥4 times 4 = No/never
Health	How do you rate the quality of health care you receive? Do you think it is...?	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Health	Would you say your health is...?	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Outcome Variables		
Health	Has there been any time over the past year when you thought you should see a health care provider but you did not?	1 = No 2 = Yes
Trust in medical research	In the future, if you were asked to be a subject in a medical research study, do you think that you definitely	4 = Definitely would

Construct	Survey Question(s)	Response Set
Covariates and Independent Variables		
Age	How old are you? would, probably would, probably would not, or definitely would not agree to participate?	Open response 3 = Probably would 2 = Probably would not 1 = Definitely would not

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Figure 1.
Interaction Between Race and Awareness of the Tuskegee Syphilis Study in Predicting Participation in Medical Research

Table 1

Sample Demographics

Variable	Black		White		p
	(N = 277) % (N)	(N = 741) % (N)			
Age (mean, SD)	47.58 (19.08)	52.21 (18.14)			<.001 ^b
Education					<.001 ^a
≤ High school	43% (118)	34% (255)			
Some college/vocational	24% (61)	19% (137)			
≥ College degree	31% (79)	40% (295)			
Gender (male)	45% (124)	47% (349)			NS
Employment status					
Full-time/part-time	50% (137)	53% (394)			<.001 ^a
Other	50% (138)	47% (346)			
Discrimination in medical setting (yes)	22% (61)	4% (30)			<.001 ^a
Family support (mean, SD)	9.78 (3.53)	10.56 (3.18)			.001 ^b
Friend support (mean, SD)	7.99 (3.69)	9.46 (3.53)			<.001 ^b
Total support (mean, SD)	17.76 (6.17)	20.01 (5.89)			<.001 ^b
Quality of health care					
Low	19% (53)	7% (52)			
Average	29% (79)	26% (190)			
High	52% (142)	67% (492)			<.001 ^a
Self-rated health					
Low	33% (91)	19% (139)			
Average	32% (88)	29% (220)			
High	35% (96)	52% (382)			<.001 ^a
Trust info from church (would)	80% (213)	70% (478)			.001 ^a
Trust info from doctor (would)	95% (257)	98% (718)			.020 ^a
Trust info from friends (would)	81% (220)	86% (633)			.032 ^a

Variable	Black		White		p
	(N = 277)	% (N)	(N = 741)	% (N)	
Awareness of Tuskegee					
None	26% (73)		52% (387)		
Only a little	23% (62)		22% (164)		
A moderate amount	27% (74)		21% (158)		
A great deal	24% (68)		4% (28)		<.001 ^a
Attitudes about research with people					
Unfavorable	25% (70)		11% (80)		
Neutral	16% (44)		15% (109)		
Favorable	56% (156)		73% (540)		<.001 ^a
Research incentive					
Free medical care (mean, SD)	2.11 (0.95)		2.10 (0.97)		NS
Free transportation (mean, SD)	1.72 (0.90)		1.65 (0.87)		NS
\$500 (mean, SD)	2.04 (0.95)		2.02 (0.97)		NS
Free medicine (mean, SD)	1.84 (0.92)		1.98 (0.96)		.048 ^b
Is there a time you should have seen a doctor but didn't? (yes)	38% (104)		33% (243)		NS
Would you participate in research study if asked? (yes)	41% (109)		54% (377)		.001 ^a

Abbreviations: NS, not significant; SD, standard deviation.

^a Significance was calculated using χ^2 tests.

^b Significance was calculated using analysis of variance tests.

Table 2
Logistic Regression Predicting if Participants Should Have Seen a Health Care Provider but Did Not

Variables	Model 1	Model 2	Model 3	Model 4
	OR (CI)	OR (CI)	OR (CI)	OR (CI)
Race	1.12 (0.82-1.53)	0.74 (0.50-1.08)	0.72 (0.49-1.05)	0.71 (0.48-1.05)
Age	0.99 ^a (0.98-1.00)	0.98 ^b (0.97-0.99)	0.98 ^b (0.97-0.99)	0.98 ^b (0.97-0.99)
Gender	1.32 (1.00-1.74)	1.54 ^a (1.14-2.08)	1.55 ^a (1.15-2.10)	1.55 ^a (1.15-2.10)
Employment status ^d	0.74 ^c (0.55-1.00)	0.69 ^c (0.50-.96)	0.67 ^c (0.48-0.93)	0.66 ^c (0.48-0.93)
Discrimination ^e		0.82 (0.48-1.40)	0.80 (0.47-1.38)	0.80 (0.47-1.38)
Tuskegee awareness				
None at all		0.64 (0.36-1.13)	0.65 (0.37-1.15)	0.64 (0.36-1.14)
Only a little		1.09 (0.61-1.95)	1.11 (0.62-2.00)	1.10 (0.61-1.99)
A moderate amount		0.92 (0.51-1.64)	0.95 (0.53-1.70)	0.94 (0.53-1.69)
Self-rated health ^f				
Poor		2.27 ^b (1.49-3.47)	2.30 ^b (1.51-3.52)	2.29 ^b (1.50-3.50)
Average		2.22 ^b (1.56-3.16)	2.18 ^b (1.53-3.12)	2.18 ^b (1.53-3.12)
Quality of health care ^f				
Poor		3.71 ^b (2.26-6.08)	3.69 ^b (2.24-6.08)	3.63 ^b (2.18-6.03)
Average		1.81 ^b (1.30-2.53)	1.80 ^b (1.29-2.51)	1.79 ^b (1.28-2.50)
Trust info from doctor			0.97 (0.42-2.24)	0.97 (0.42-2.25)
Trust info from friends/family			0.71 (0.45-1.11)	0.71 (0.45-1.12)
Trust info from church			1.09 (0.76-1.55)	1.08 (0.76-1.55)
Total support				1.00 (0.97-1.02)
Model statistics	$R^2 = 0.03$	$R^2 = 0.11$	$R^2 = 0.12$	$R^2 = 0.12$
	$\chi^2 = 25.76$	$\chi^2 = 109.66$	$\chi^2 = 111.98$	$\chi^2 = 112.09$
	$p < .00$	$p < .000$	$p < .000$	$p < .000$

Abbreviations: CI, confidence interval; OR, odds ratio.

^a $p < .01$.

^b $p < .001$.

^c $p < .05$.

^d Comparison group for employment status is "other."

^e Comparison group for discrimination is "a great amount."

^f Comparison group for self-rated health and quality of health care is "good."

Table 3

Logistic Regression Predicting Willingness to Participate in Future Medical Research

Variables	Model 1	Model 2	Model 3	Model 4
	OR (CI)	OR (CI)	OR (CI)	OR (CI)
Race	0.51 ^a (0.36-0.70)	0.76 (0.30-1.90)	1.29 (0.49-3.40)	1.33 (0.50-3.57)
Age	0.99 ^a (0.98-1.00)	0.99 (0.98-1.00)	0.99 ^b (0.98-1.00)	0.99 (0.98-1.00)
Discrimination ^d		0.97 (0.52-1.79)	1.11 (0.59-2.10)	1.07 (0.57-2.03)
Tuskegee awareness				
None at all		0.12 ^b (0.02-0.71)	0.08 ^a (0.01-0.53)	0.07 ^a (0.01-0.44)
Only a little		0.21 ^b (0.05-0.88)	0.15 ^b (0.03-0.68)	0.13 ^a (0.03-0.58)
A moderate amount		0.58 (0.21-1.58)	0.49 (0.17-1.39)	0.43 (0.15-1.23)
Race × Tuskegee ^e		0.74 (0.51-1.08)	0.66 ^b (0.44-0.97)	0.64 ^b (0.43-0.95)
Self-rated health ^f				
Poor		0.63 ^b (0.40-0.99)	0.55 ^b (0.34-0.88)	0.54 ^b (0.34-0.82)
Average		0.95 (0.66-1.39)	0.88 (0.60-1.30)	0.88 (0.60-1.30)
Quality of health care ^f				
Poor		0.80 (0.46-1.04)	0.90 (0.51-1.58)	0.90 (0.48-1.57)
Average		0.64 ^b (0.44-0.94)	0.69 (0.47-1.02)	0.69 (0.47-1.02)
Research incentive				
Free medical care			1.27 ^b (1.03-1.56)	1.27 ^b (1.03-1.56)
Free transportation			1.27 ^b (1.03-1.57)	1.29 ^b (1.04-1.60)
\$500			1.24 ^b (1.01-1.52)	1.25 ^b (1.02-1.54)
Free medication			1.53 ^c (1.23-1.89)	1.50 ^c (1.21-1.87)
Opinion of human subject research ^g				
Unfavorable			0.25 ^c (0.15-0.42)	0.24 ^c (0.14-0.40)
Neutral			0.37 ^c (0.23-0.58)	0.35 ^c (0.22-0.55)
Trust info from doctor				0.53 (0.19-3.50)
Trust info from friends/family				1.62 (0.96-2.75)

Variables	Model 1	Model 2	Model 3	Model 4
	OR (CI)	OR (CI)	OR (CI)	OR (CI)
Trust info from church				1.29 (0.87-1.91)
Total support				0.99 (0.96-1.03)
Model statistics	$R^2 = 0.03$ $\chi^2 = 21.91$ $p = .000$	$R^2 = 0.20$ $\chi^2 = 175.88$ $p < .000$	$R^2 = 0.24$ $\chi^2 = 218.65$ $p < .000$	$R^2 = 0.25$ $\chi^2 = 227.16$ $p < .000$

Abbreviations: CI, confidence interval; OR, odds ratio.

- ^a $p < .01$.
^b $p < .05$.
^c $p < .001$.
^d Comparison group for discrimination is “a great amount.”
^e Race $\times$ Tuskegee is the interaction variable between race and awareness of the Tuskegee Syphilis Study.
^f Comparison group for self-rated health and quality of health care is “good.”
^g Comparison group for opinions of human subject research is “favorable.”