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Clinical Trial Awareness Among Racial/Ethnic Minorities in HINTS 2007: Sociodemographic, Attitudinal, and Knowledge Correlates

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Abstract

The purpose of this study was (1) to examine the association of race/ethnicity on clinical trial awareness, controlling for several sociodemographic, attitudinal, and knowledge variables, and (2) to inform future communication campaigns to increase clinical trial awareness and participation. Secondary analysis was conducted among 6,754 Hispanic, Black, and White adult respondents to the National Cancer Institute's 2007 Health Information National Trends Survey (HINTS). The dependent variable was awareness of clinical trials. Logistic regression was used to examine possible correlates of clinical trial awareness including sociodemographics, trust of sources of health information, beliefs about safety of health information, family/personal history of cancer, health seeking information, and awareness of three health agencies. Compared with Whites, Blacks and Hispanics were significantly less likely to have heard of a clinical trial. Other significant correlates of clinical trial awareness included education, income, belief that health information is safely guarded, family history of cancer, awareness of the Centers for Disease control, trust of health information from the Internet and charitable organizations, and distrust of health information from religious institutions. Blacks and Hispanics are significantly less aware of clinical trials. Campaigns that exploit unique beliefs and delivery channels for racial/ethnic subgroups should be considered.

Clinical trials are the mechanism by which new methods of screening, prevention, diagnosis, or treatment of disease are developed (National Cancer Institute [NCI], 2009). Since 1993, the National Institutes of Health (NIH) have required that all sponsored research include adequate representation of women and minority groups (NIH, 2009). While the importance

of diversity in clinical trials is well established, accrual of minorities into clinical trials remains lower than their national population representation (Baquet, Mishra, & Weinberg, 2009; Education Network to Advance Cancer Clinical Trials, 2009; Ford et al., 2008). Such underrepresentation limits our understanding of how disease processes and treatments studied in predominantly White populations may function similarly in other groups.

Key reasons for lower clinical trial participation among African Americans include distrust of health care institutions, fear of experimentation, lack of awareness of clinical trials and how to find them, and limited representation of minority investigators (Dancy, Wilbur, Talashek, Bonner, & Barnes-Boyd, 2004; Gorelick, Harris, Burnett, & Bonecutter, 1998; Roberson, 1994; Shaya, Gbarayor, Huiwen Keri, Agyeman-Duah, & Saunders, 2007). For African Americans the role of medical mistrust on clinical trial enrollment appears to be evolving. Recent studies have shown that knowledge of the Tuskegee Syphilis Study, *per se*, is not associated with clinical trial enrollment (Katz et al., 2009). A more global sense of mistrust (which we will assess) may be the driver. Alternatively, there is some evidence that minorities may be just as willing to participate in health research as their White counterparts when *provided* with a culturally appropriate opportunity or invitation (Wendler et al., 2006).

Less is known about clinical trial participation among Hispanics. In a study about willingness to participate in an HIV vaccine trial, Hispanics reported mistrust and fear of the government as reasons not to participate (Brooks, Newman, Duan, & Ortiz, 2007). Another study found that, similar to African Americans, lack of awareness and opportunities to participate may be driving lower participation more so than lack of willingness (Roberson, 1994). Although African Americans and Hispanics share similar attitudes toward participating in clinical research, Hispanics may place greater emphasis on receiving health information while African Americans expressed concerns about trust and quality of care (Calderon et al., 2006).

A previous study has reported lower rates of clinical trial awareness among Blacks and Hispanics (Brown & Moyer, 2010). The objective of this study is to examine the association of race and ethnicity on clinical trial awareness, controlling for several sociodemographic, attitudinal, and knowledge variables in the 2007 HINTS survey. A deeper understanding of the predictors of clinical trial awareness can help inform campaigns to improve clinical trial participation both in general as well as within minority groups.

Methods

HINTS Public Use Data Set

The Health Information National Trends Survey (HINTS) is a biennial, cross-sectional survey of American adults funded by the NCI. The HINTS collects nationally representative data about the public's use of general health and, more specifically, cancer-related information. The HINTS assesses how people access and use health information, how people use information technology to manage their health and health information, and how people report engaging in healthy behaviors. The survey was conducted in 2003, 2005, and 2007. Our analyses use the 2007 data, the first year clinical trial awareness was assessed (NCI, 2010b).

Study Design

For the 2007 HINTS, data were collected both by telephone and mailed surveys. Telephone surveys were conducted using a Random Digit Dial, Computer Assisted Telephone Interview (CATI) format. Surveys lasted approximately 30 minutes. The mailed survey was sent to potential participants selected from a list of addresses from the U.S. Postal Service administrative records. All adults at each sampled address were asked to fill out the questionnaire and return it in a postage-paid envelope. Approximately 3,582 surveys were completed by mail and 4,092 were completed via telephone (NCI, 2010b). Additional details about the study procedures and measures can be found elsewhere (NCI, 2010a).

A total of 7,674 respondents were surveyed. For our analyses, we limited the sample to the 6,754 individuals who self-identified as being non-Hispanic Black/African American, non-Hispanic White, or Hispanic/Latino. Multiracial and multiethnic individuals were excluded ($n=146$). Our subsample composed 94% of the full data set.

Measures

Clinical trial awareness was the dependent variable [HS25HeardOfClinicalTrial]. Participants were asked, "Clinical trials are research studies that involve people. They are designed to test the safety and effectiveness of new treatments and to compare new treatments with the standard care that people currently get. Have you ever heard of a clinical trial?" Response options were yes and no.

Sociodemographic, Attitudinal, and Knowledge Variables

Sociodemographic variables included in our analyses were race, ethnicity, gender, age, marital status, education, and income. We collapsed income into five categories. Other variables included awareness of (yes/no) the NCI, CDC, and the American Cancer Society (ACS).

Respondents were asked to rate the degree to which they trusted health information from various sources on a 4-point Likert-type scale ranging from "a lot" to "not at all." Higher values indicated lower trust. The survey question was, "In general, how much would you trust information about health or medical topics from *each* of the following?" The response options included doctor, family or friends, newspapers or magazines, radio, the Internet, television, government health agencies, charitable organizations, and religious organization and leaders.

Other potential correlates used in our analyses included attitudes about safety of health information and scientists having access to deidentified medical information. The specific questions were (1) "In general, I think that the information I give doctors is safely guarded" [HS20InfoSafe] and (2) "Scientists doing research should be able to review my medical information if the information cannot be linked to me personally" [HS21NonlinkedInfoUsed]. Response options were strongly agree, somewhat agree, somewhat disagree, or strongly disagree. Finally, where individuals sought health information was assessed. The question asked was, "The most recent time you looked for information about health or medical topics, where did you go first" [HC02WhereSeek]

HealthInfo]. Responses included books, brochures/pamphlets, cancer organization, family, friend/coworker, doctor or health care provider, Internet, library, magazines, newspapers, telephone information number, complementary/alternative/or unconventional practitioner, television and other. We collapsed these variables into five categories: print, family/friends, doctor or health care provider, Internet, and other.

Analysis

Logistic regression was used to examine the relationship between race/ethnicity (categorized as White, Black, and Hispanic) with clinical trial awareness controlling for sociodemographic, attitudinal, and knowledge variables. We also explored potential interaction effects of all sociodemographic, attitudinal, and knowledge variables by race/ethnicity. All analyses were conducted using PASW Statistics 18.0 (formerly known as SPSS).

Results

Each of the sociodemographic variables (age, gender, education, marital status, and income) differed significantly across racial/ethnic categories (Table 1). Black and Hispanic respondents tended to be younger than Whites, and a greater percent of Black respondents were female. Black and Hispanic respondents tended to have lower educational attainment and lower income than Whites. Trust in each source of health information differed by race/ethnicity. Black and Hispanic respondents placed greater trust in information from radio, television, newspapers, and religious and charitable organizations. Whites placed greater trust in doctors. Blacks had the lowest confidence in the safety of their medical information.

In terms of where individuals seek health information, Blacks had the highest rates of using print media, whereas Whites had the highest rates of information seeking from the Internet. Blacks and Hispanics were more likely than Whites to seek information from health professionals. Whites had higher rates of personal and family history of cancer. Regarding awareness of NCI, CDC, and ACS, Whites had the highest rates and Hispanics the lowest rates for each of the three agencies. Rates of clinical trial awareness were significantly lower among Hispanics, 50.3%, and Blacks, 62.3%, than Whites, 75.8%.

A multivariate model was run using clinical trial awareness as the dependent variable, and all variables in Table 1 as independent variables. Variables that were significant in the initial model were included in the final model and presented in Table 2. As shown, race/ethnicity was significantly associated with clinical trial awareness, independent of sociodemographic, attitudinal, and knowledge variables. Compared with Whites, Blacks (OR = .76; CI .61–.96) and Hispanics (OR = .62; CI .49–.78) were significantly less likely to have heard of a clinical trial.

With regard to other predictors, knowledge of clinical trials increased across strata of education and income. Agreeing that health information was safely guarded by doctors was associated with lower awareness of clinical trials. In contrast, agreeing that deidentified medical information should be reviewed by scientists doing research was associated with higher awareness. Compared with those who had not heard of the CDC, those who had were

3.4 (CI: 2.84–4.09) times more likely to have heard of a clinical trial. Trust of the Internet as a source of health information and trust in information provided by charitable organizations were associated with greater clinical trial awareness. Conversely, increased distrust of religious organizations was associated with greater awareness of clinical trials. We examined the interaction of race/ethnicity with each of the variables in Table 2, and found that none of these variables moderated the association of race/ethnicity with clinical trial awareness.

Because income data were missing for approximately 18% of the HINTS sample, we ran our logistic model excluding income. The results were virtually identical; that is, the odds ratios for the remaining variables were similar to those with income in the model.

Discussion

The key finding from our analyses was that the association of race/ethnicity with clinical trial awareness remained significant after adjustment for potential confounders. Lower awareness of clinical trials is at least a partial explanation for lower minority participation in trials. Given that the impact of race/ethnicity remained significant after adjusting for income and education, it appears this disparity is not solely an artifact of socioeconomic differences between Whites, Blacks, and Hispanics. Despite the fact that income and education did not eliminate racial/ethnic differences on clinical trial awareness, nonetheless, across the entire sample, knowledge of clinical trials was positively associated with increased education and income. And, Blacks and Hispanics in HINTS had lower levels of education and income than Whites. Thus, Socioeconomic status differences probably contribute, albeit slightly, to disparities in clinical trial awareness.

Tailored campaigns to increase clinical trial awareness and participation among minorities should consider accounting for cultural and structural factors beyond socioeconomics. The use of social media to promote clinical trials to minority audiences should also be explored. African Americans and Latinos are more likely than Whites to view government use of social media as helpful and informative, and report positive attitudes toward government engagement of social media (Smith, 2010). Additionally, the use of ethnic-targeted media to increase clinical trial awareness should be evaluated. Black newspapers have been used to deliver general cancer education in previous studies (Caburnay et al., 2008).

There is a paucity of data regarding facilitators of clinical trial awareness and enrollment among minorities; however, a number of groups are addressing this issue. For example, the National Medical Association's Project I.M.P.A.C.T. (Increase Minority Participation and Awareness of Clinical Trials) aims to increase the awareness, knowledge, and participation of African American physicians and consumers in biomedical research and clinical trials (National Medical Association, 2009). The Education Network to Advance Cancer Clinical Trials is exploring community level strategies to increase minority enrollment into phase III cancer treatment trials (Education Network to Advance Cancer Clinical Trials, 2009). Statewide collaborations have addressed infrastructure challenges that hinder full participation of minorities in clinical trials (Baquet et al., 2006). Additionally, the authors of

this paper are evaluating an academic–community partnership model to increase African American enrollment in clinical trials.

In addition to race/ethnicity, other variables were found to be associated with clinical trial awareness that may also inform message construction and channel selection. First, trust in health information from the Internet was a significant predictor of clinical trial awareness. This is understandable, as increasingly health organizations have used the Internet to promote their clinical trials. We examined whether general Internet use differed by race in HINTS, and found that Whites were significantly more likely to report Internet use, 71%, than Blacks, 56%, or Hispanics, 52%. And, Internet users were significantly more likely to report being aware of clinical trials, 81%, than nonusers, 48%. However, we reran our full model with Internet use included, and the odds of trial awareness among Blacks and Hispanics were virtually identical to the odds from the model without Internet use. Thus, lower Internet use does not appear to account for lower rates of clinical trial awareness among Blacks and Hispanics.

Trust in nonprofit charitable organizations was also associated with increased clinical trial awareness. This has implications for message content and channel selection. Charitable organizations may represent a particularly useful channel through which to recruit minorities. In the HINTS study, Hispanics and Blacks were significantly more likely to place greater trust in health information from these organizations (data not shown), and many charitable organizations are utilized by minority groups. Partnerships with charitable entities may be beneficial across all race/ethnic groups as well, as they are institutions that may be seen as inherently trustworthy, given their altruistic focus. Messages delivered through this channel could exploit common values such as altruism or community responsibility as reasons to participate in clinical trials.

In contrast, those who reported greater trust in religious organizations for health information were less likely to know about clinical trials (i.e., as distrust increased, clinical trial awareness increased). This trust variable is likely a marker for religiosity. In HINTS, Blacks and Hispanics were significantly more likely to place greater trust in health information from faith organizations (data not shown). Although religiosity was not directly assessed in HINTS, other studies have shown greater religious involvement amongst Blacks and Hispanics (Johnson, Elbert-Avila, & Tulskey, 2005; Taylor, Chatters, & Jackson, 2007). More secular (i.e., less religious) individuals may place greater importance on science and therefore may be more likely to be aware of and participate in Clinical trials. Nonetheless, faith organizations may be a useful channel to promote Clinical trials, particularly if messages are consistent with religious principles and values.

There was an inverse relationship between belief that health information was safely guarded and clinical trial awareness. It is possible that those who know more about clinical trials are also more aware of the complexities of data confidentiality and the ethics of scientific research. This may in part underlie the negative correlation between perceived protection of health information and clinical trial awareness. Communications regarding the ethics and process of data confidentiality may be useful in promoting clinical trial participation.

Perhaps the most intriguing finding was that awareness of the CDC (but not the NCI or ACS) was associated with greater clinical trial awareness. A priori we assumed that knowledge of the NCI would have been the strongest predictor of the three, as NCI strongly promotes clinical trials. The CDC, however, also promotes clinical trials on their website, and this may be where many individuals learn about clinical trials. Another possible explanation for this finding is that the CDC may be the most visible agency on radio and television. Their increased exposure may be due to their sponsorship of ongoing health campaigns and their rapid response to impending epidemics. Consequently, consumers may turn to the CDC first when seeking out health information and in doing so find a reference to ClinicalTrials.gov. Collaborating with the CDC could help maximize reach of clinical trials promotions. Although the NCI heavily promotes clinical trials, the agency may reach researchers and healthcare professionals more so than the general public. Alternatively, the ACS may appeal more to lay consumers looking for general cancer information versus information on clinical trials. Additional qualitative and quantitative assessments are needed to understand the underlying bases for these associations and to suggest means for these organizations to be more effective in increasing clinical trial awareness and enrollment.

Finally, respondents who reported a family history of cancer had more knowledge of clinical trials than those who did not. Somewhat surprisingly, however, individual history of cancer was not significantly associated with clinical trial awareness. Individuals with family history of cancer may be more likely to seek information about alternative treatment for their relatives than themselves.

Strengths of this study include a large, nationally representative sample of U.S. adults and assessment of multiple potential correlates/confounds of clinical trial awareness. Perhaps the greatest limitation of HINTS is that there were no questions about past clinical trial participation or willingness to participate in future studies, only awareness of clinical trials. It is unclear how well awareness predicts actual clinical trial enrollment. Further exploration is needed to elucidate the relationship between *awareness* of a clinical trial and *willingness to enroll*, *attempt to enroll*, and *actual enrollment* into clinical trials. Additionally, assessing types of clinical trials and their correlates may be useful. Clinical trials are conducted across a diverse set of diseases and health care settings, and predictors of participation may vary by disease and setting. Another limitation of HINTS is the lack assessment of other constructs that might explain clinical trial awareness and eventual participation, such as overall medical mistrust. Finally, understanding trends in clinical trial awareness over time cannot be determined in HINTS as this question was only asked in the 2007 survey.

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Table 1Sociodemographic and psychosocial characteristics by racial/ethnic group ($N = 6,754$)

	White ($n = 5,445$)	Black ($n = 687$)	Hispanic ($n = 622$)
Age range (%) [*]			
18–34	11.9	18	30.2
35–49	22.7	25.8	30.2
50–64	33.2	36.8	24.7
65–74	16.8	12.4	10.8
75+	15.3	6.9	4.0
Gender (% Female) [*]	60.6	68.4	60.3
Education (%) [*]			
<High school	6.2	15.6	27.9
High school	24.5	26.7	27.1
Some college	29.9	32.9	26.3
College	39.4	24.8	18.6
Marital status [*]			
Married	58.8	34.1	53.9
Living as married	2.3	2.5	6.3
Divorced	11.9	17.1	10.6
Widowed	12.5	11.1	5.5
Separated	1.4	5.8	4.7
Single, never married	12.2	29.4	19.1
Income range (%) [*]			
<\$19,999	13.6	35.5	29.9
\$20,000–34,999	15.9	20.1	22.4
\$35,000–49,999	14.1	14.4	12.7
\$50,000–74,999	20.2	13.6	14.4
\$75,000+	36.3	16.4	20.6
Trust health information from... (% agree a lot)			
Doctor [*]	70.9	64.5	61.6
Family or friends [*]	13.8	12.2	14.9
Newspapers/magazines [*]	6.6	8.8	8.2
Radio [*]	2.6	5.2	4.7
Internet [*]	19.8	20.4	22.6
Television [*]	4.4	10.5	11.6
Government Agency [*]	28.5	35.1	35.4
Charitable organization [*]	8.3	13.8	14.0
Religious organization/leaders [*]	5.9	14.7	12.3
Information I give doctors is safely guarded (% strongly agree) [*]	37.5	21.7	33.0

	White (<i>n</i> = 5,445)	Black (<i>n</i> = 687)	Hispanic (<i>n</i> = 622)
Scientists doing research should be able to review nonlinked medical information (% strongly agree) *	41.4	42.8	44.6
Print	18.8	24.5	20.3
Family/friend	3.6	3.0	3.8
Health professionals	13.8	19.5	20.1
Internet	60.6	49.1	50.8
Other	3.2	3.9	4.9
Personal history of cancer (% yes) *	15.5	7.9	6.5
Family history of cancer (% yes) *	76.9	67.5	57.4
Awareness of NCI (% yes) *	84.1	77.3	68.1
Awareness of CDC (% yes) *	86.9	76.4	57
Awareness of ACS (% yes) *	95.6	89.4	79.9
Clinical trial awareness* (% yes)	75.8	62.3	50.3

* Statistically significant, $p < .001$.

Table 2Clinical trial awareness by sociodemographic, attitudinal, and knowledge correlates ($N = 5,010$)

	Odds ratio	CI
Race/ethnicity		
Black *	.76	.61–.96
Hispanic *	.62	.49–.78
White (reference)	1.0	
Education (%) *		
<High school *	.38	.28–.51
High school *	.42	.34–.51
Some college *	.60	.50–.73
College (reference)	1.0	
Income Range (%) *		
<\$19,999 *	.48	.38–.61
\$20,000 – 34,999 *	.63	.50–.80
\$35,000 – 49,999 *	.74	.58–.94
\$50,000 – 74,999 *	.78	.62–.97
\$75,000+ (reference)	1.0	
Trust health information from Internet		
A lot *	2.44	1.86–3.21
Some *	2.22	1.75–2.81
A little *	1.94	1.49–2.52
Not at all (reference)	1.0	
Trust health information from charitable organizations *		
A lot *	1.78	1.27–2.49
Some *	1.47	1.15–1.89
A little	1.07	.85–1.35
Not at all (reference)		
Trust health information from religious organization/leaders *		
A lot *	.50	.37–.69
Some *	.63	.51–.80
A little	.94	.76–1.16
Not at all (reference)	1.0	
Information I give doctors is safely guarded		
Strongly agree *	.53	.32–.87
Somewhat agree	.67	.41–1.11
Somewhat disagree	.91	.53–1.56
Strongly disagree (reference)	1.0	

Scientists doing research should be able to review nonlinked medical information

	Odds ratio	CI
Strongly agree *	1.37	1.1–1.74
Somewhat agree *	1.06	.85–1.33
Somewhat disagree	.81	.61–1.07
Strongly disagree (reference)	1.0	
Family history of cancer *	1.36	1.15–1.59
Awareness of CDC *	3.41	2.84–4.09

* Statistically significant, $p < .05$.