Sociocultural variation in attitudes toward use of genetic information and participation in genetic research by race in the United States: implications for precision medicine

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ABSTRACT

Background "Precision medicine" (PM) requires researchers to identify actionable genetic risks and for clinicians to interpret genetic testing results to patients. Whether PM will equally benefit all populations or exacerbate existing disparities is uncertain.

Methods We ascertained attitudes toward genetic testing and genetic research by race in the United States using the online Amazon mTurk US workforce (n = 403 White; n = 56 African American (AA)). Generalized linear models were used to test differences in beliefs and preferences by race, adjusting for sociodemographics and prior genetic experience.

Results AA were less likely than White to believe that genetic tests should be promoted or made available. Further, AA were less likely to want genetic testing results or to participate in genetic research.

Conclusions Important dimensions that underlay PM are not universally accepted by all populations. Without clear attention to concerns, AA communities may not equally benefit from the rapidly-emerging trend in PM-centered research and clinical practice.

Keywords: genetic research, genetic testing, precision medicine, disparities, race, African-American, personalized medicine

BRIEF COMMUNICATION

INTRODUCTION

"Precision medicine" (PM) has rapidly emerged as a global priority for research and clinical care.[1,2] At its core, PM requires researchers to identify actionable genetic information and for clinicians to interpret genetic testing results to patients.[3,4] Much research remains to be completed to help guide useful, impactful clinical practice in this area.[5] Indeed, whether PM will equally benefit all populations or worsen existing disparities is uncertain.[2,6,7] Disparities may, in fact, be exacerbated in several ways, including lack of participation in the genetic research that informs PM,[8–10] and also through misunderstanding, or reluctance to want to know, genetic testing results.[11,12] To better inform the potential for addressing health disparities through PM, this study ascertained attitudes toward genetic testing and genetic research by race in a diverse US population of digital workers.

METHODS

Design

An online survey was developed and tested to ascertain attitudes toward genetic testing and genetic research, pulling elements from prior research in this area and from salient constructs of relevance to this study. The survey was first pilot tested, revised, and deployed in final form to the Amazon Mechanical Turk (mTurk) digital workforce. The mTurk digital workforce includes more than 500 000 individuals from 190 countries.[13] The mTurk digital platform is a marketplace that enables exchange of "human intelligence tasks" (tasks that are easy for people but difficult for computers) by registered workers for piece-based financial remuneration. The resulting large, global workforce created through this mechanism is increasingly used as a population for research purposes, both as assistants in research[14,15] and as a population for study.[16,17] The survey can be accessed via this link (https://s3-us-west-2.amazonaws.com/ctsi/genetic_survey_usa.html).

Recruitment

Potential global respondents were recruited by a notice posted on the mTurk human intelligence tasks landing page, inviting participation in a survey about attitudes, beliefs, and knowledge on topics related to medical care and research. Respondents completing the survey were offered compensation of $0.50.

Inclusion criteria

Potential participants were identified from the mTurk platform as age 18 and over, organized by country of residence using the mTurk Local Qualification variable (country of residence for which a potential participant's account is registered). Only mTurk respondents with a US-based account were included in this analysis. Based on self-reported race we divided the sample by White (W) (n = 403) and African-American/Black (AA) (n = 56); other races were excluded for this analysis.

Human subjects review

The University of Rochester's Research Subjects Review Board reviewed the protocol for this study and determined it to be exempt. All project personnel completed the Collaborative Institutional Training Initiative Program's Protection of Human Subjects certification.

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Variables of Interest

Genetic testing outcomes

For this analysis, we chose to focus on five genetic testing beliefs[18] that respondents indicated their agreement to using a five-point Likert scale (strongly agree to strongly disagree): (1) "The use of genetic testing among people should be promoted"; (2) "The use of genetic testing should be available for those who want to use them"; (3) "More money should be available for the development of genetic tests"; (4) "If it were easy and cheap for my health care provider to do genetic testing, I would want to know the results"; and (5) "If my health care provider knew the outcomes to my genetic testing, I would want to know the results."

Genetic research outcomes

For this analysis, we also chose to focus on three genetic research participation questions[19] with respondents indicating their likelihood using a five-point Likert scale (very likely to very unlikely): (1) "I would participate in research that used by DNA; (2) "I would allow my DNA to be shared with a private company"; (3) "I would allow my DNA to be used to create cell lines – these would allow for my DNA to be used in future studies."

Confounders

The following confounders were examined for each model: gender (male/female); proxies for socioeconomic status (education (high school or less/undergraduate/graduate); owns a car (yes/no); owns a house (yes/no)); religion (Christian (yes/no); atheist (yes/no)); and ever had a genetic test (yes/no). We also examined associations with the Multidimensional Health Locus of Control[20], which addresses beliefs that the source of reinforcements for health-related behaviors is primarily internal, a matter of chance, or under the control of powerful others. There are 18 questions on a 6-point Likert scale. For the Internal, Chance, and Powerful others scales the range in responses is 6–36. The Powerful others scales can be further divided into Doctors and Others scales that has a range of 3–18.

Statistical Analysis

Frequency distributions and summary statistics were used to describe the characteristics of respondents. Generalized linear models with an identity link function[21] was used to test the difference in beliefs variables and research questions between W and AA respondents. Significant covariates were included in the model to adjust for confounding effects based on Hosmer and Lemeshow's purposeful model selection method.[22] The likelihood ratio method was used to obtain the 95% confidence interval for mean differences between W and AA respondents in each of the tested variables. SAS v 9.4 (SAS Institute Inc, Cary, NC, USA) was used for all analyses and the significance level was set at 5%.

RESULTS

Shown in Table 1, the sample for this analysis was predominantly W (n = 403, 87.8% of total sample); female (W sample 60.35%; AA sample 69.64%). There were significant differences between the W and AA respondents in terms of religion (55.41% of the W sample was Christian v. 74.07% of the AA sample; P = .0093); car ownership (W sample 82.32%; AA sample 68.52%; P = .0160); and home ownership (W sample 44.81%; AA sample 26.92%; P = .0142). For the Multidimensional Health Locus of Control scores only the Internal score differed between the samples (W mean score = 26.67; AA mean score = 28.10; P = .0977).

Table 1: Description of sample

	White (W) sample	African-American/ Black (AA) sample	
	n = 403	n = 56	
	n (%)	n (%)	P-value
Gender			0.1812
Female	239 (60.35)	39 (69.64)	
Male	157 (39.23)	17 (30.36)	
Missing	7	0	
Education			0.4350
HS or less	163 (41.16)	26 (47.27)	
Undergraduate	164 (41.41)	23 (41.82)	
Graduate	69 (17.42)	6 (10.91)	
Missing	7	1	
Christian			0.0093
Yes	215 (55.41)	40 (74.07)	
No	173 (44.59)	14 (25.93)	
Missing	15	2	
Atheist			0.0170
Yes	82 (21.13)	4 (7.41)	
No	306 (78.87)	50 (92.59)	
Missing	15	2	
Own a car			0.0160
Yes	326 (82.32)	37 (68.52)	
No	70 (17.68)	17 (31.48)	
Missing	7	2	
Owns a house			0.0142
Yes	177 (44.81)	14 (26.92)	
No	218 (55.19)	38 (73.08)	
Missing	8	4	
Ever had a genetic test			0.2459
Yes	28 (7.16)	6 (11.76)	
No	363 (92.84)	45 (88.24)	
Missing	12	5	
Multidimensional Health Locus of Control[a]	Mean (SD)	Mean (SD)	P-value[b]
Internal	26.67 (4.75)	28.10 (5.59)	0.0977
Chance	17.03 (5.44)	18.26 (5.68)	0.6434
Powerful others	19.60 (6.07)	18.37 (5.98)	0.9233
Doctors	9.25 (3.53)	10.15 (3.66)	0.6901
Others	7.90 (2.76)	8.02 (3.04)	0.3200

[a]MHLC scales for internal, chance, and powerful others has a possible range of 6–36; doctors and others scale has a possible range of 3–18.

[b]P-value for equality of variances.

Regarding genetic testing, AA respondents were significantly less likely than W respondents to indicate that use of genetic testing should be promoted and available for those who want to use them after controlling for confounders (Table 2). Further, after controlling for

Table 2: Multivariate analysis of respondent race and attitudes toward genetic testing and participation in genetic research

	White (W) sample	African-American/ Black (AA) sample			
Genetic testing	Mean[a] (SD)	Mean (SD)	Difference (95% CI)	P-value	Adjusted covariates
Promote use	3.51 (0.92)	3.18 (0.84)	0.35 (0.08, 0.63)	.0125	Prior history of having a genetic test, gender, MHLC-Internal, MHLC-Chance
Available to those who want it	4.35 (0.66)	3.89 (1.00)	0.33 (0.12, 0.53)	.002	Christian, gender, MHLC-Internal
More money for development	3.72 (0.96)	3.52 (0.89)	0.22 (−0.07, 0.50)	.1335	Prior history of having a genetic test, gender, MHLC-Internal, MHLC-Doctors
If it were easy and cheap for my health care provider to do, I would want to know the results	3.85 (1.13)	3.51 (1.14)	0.48 (0.15, 0.80)	.0039	Gender, MHLC-Internal, MHLC-Doctors
If my health care provider knew the outcomes, I would want to know the results	4.10 (1.07)	3.73 (1.15)	0.46 (0.16, 0.77)	.003	Gender, MHLC-Internal
Genetic research					
I would participate in research that used my DNA	3.46 (1.32)	3.05 (1.30)	0.50 (0.13, 0.87)	.0074	Gender, MHLC-Doctors
I would allow my DNA to be shared with a private company	2.58 (1.32)	2.18 (1.29)	0.47 (0.08, 0.86)	.0176	Prior history of having a genetic test, gender, MHLC-Chance
I would allow my DNA to be used to create cell lines-these would allow for my DNA to be used in future studies	3.08 (1.35)	2.24 (1.19)	0.84 (0.46, 1.23)	<.0001	MHLC-Chance

[a]Measures use 5-point Likert scale, with higher mean equaling stronger agreement.

confounding, AA respondents were significantly less likely to want to receive the results of genetic testing, and were less likely to want to learn the test results if their providers knew them.

Regarding participation in genetic research, after controlling for confounding, AA respondents were significantly less likely than W respondents to participate in research that used their DNA, have their DNA to be shared with a private company, and allow their DNA to be used to create cell lines for future research (Table 2).

DISCUSSION

Consent to donate tissue for future genetic research purposes occurs in a socio-cultural context.[23,24] An individual's decision-making process reflects cultural influences but also community attitudes and pressures, feelings of altruism and beneficence, and perceptions of "genetic research," among other dimensions.[25] In this study, AA respondents were significantly less likely to want to know the results of genetic testing, and were generally less supportive of the promotion of genetic testing. Suggested in other studies,[26–28] the return of genetic results and action upon that information may be more challenging in populations that do not necessary support it.

Further, this study showed in a national sample that AA respondents were less likely to participate in genetic research than were W respondents. That AA populations are less likely to participate in research has been previously demonstrated,[29,30] though whether or not this reduced likelihood relates to beliefs about research[31] or access to research opportunities[32] is debated. Our study suggests that AAs and W Americans differ to the extent they wish to participate in genetic research, which, if manifested in lack of actual genetic research participation, could lead to under-representation of AAs in the corpus of research informing PM.[33]

Significantly, AA distrust in the medical system generally[34–36] and the research establishment more specifically[37–39] is well-documented and rests on a long history of research abuse and social injustice.[40] Indeed, much of this experience in fact does relate to genetic (or at least cellular) research,[41,42] as in the well-known example of Henrietta Lacks[43] and frequent abuses in genetic research in other minority populations.[44–46] Our findings differ from the Foundation for the National Institutes of Health's recently completed public opinion survey about participation in a large PM cohort study that found that opinions on the study and willingness to participate were not significantly different between racial/ethnic groups.[47] Given our findings, enthusiasm of researchers and clinicians about the potential for PM to reshape American health care, extend longevity, and improve quality of life is tempered in populations historically disadvantaged by unethical medical – and specifically genetic – research.

This study is limited in its generalizability and should be interpreted as suggestive, though consistent with similar research. The representativeness of the mTurk digital workforce is unclear. In a recent study accessing US-based mTurk workers, significantly more females (64.85%) than males (35.15%) participated,[15] similar to the gender distribution in our study. The relative overabundance of women is consistent with research on subjects recruited through the Internet and

may reflect women having greater access to computers (either at home or at work) or gender differences in motivation. Respondents participating in this study were slightly younger than the US population as a whole and the population of Internet users.[48] Further, the sample size was small, and though the study had power to detect the differences identified, a larger sample size could produce more robust results. Finally, this study ascertained general attitudes about genetic testing and participation in genetic research. Perhaps respondents would be more likely to participate in a more specific instance (eg, recruitment of cancer patients for a genetic study), as some authors have suggested.[49,50]

Important dimensions that underlay PM (eg, participation in the research informing it, allowing genetic testing that facilitates recommendations, and acting on test results) are not universally accepted by all populations. Without clear attention to their concerns, AA communities may not equally benefit from the rapidly emerging trend in PM-centered research and clinical practice. Better understanding of these dimensions could directly lead to development of more effective engagement between researchers, clinicians, and communities.

COMPETING INTERESTS

None.

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